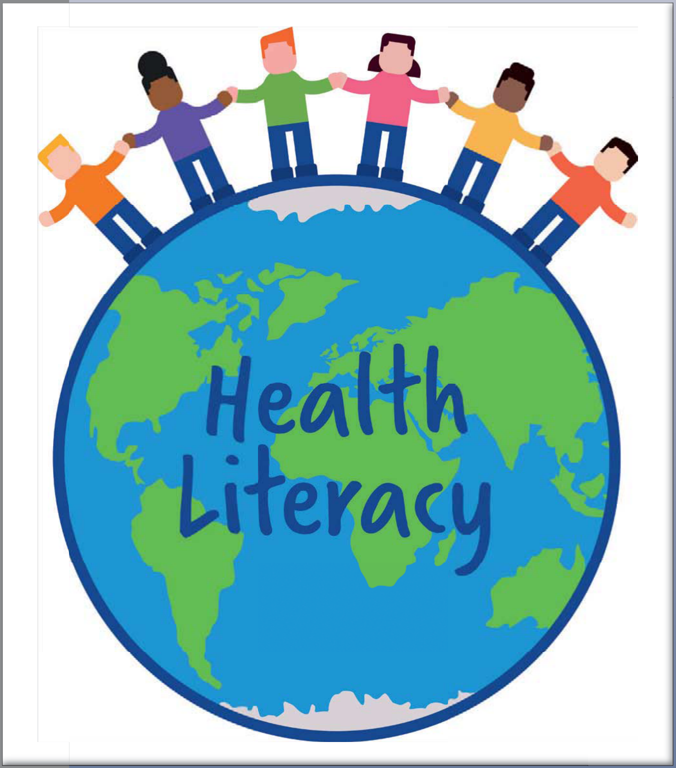
STUDIES IN HEALTH TECHNOLOGY AND INFORMATICS 269

Health Literacy in Clinical Practice and Public Health

New Initiatives and Lessons Learned at the Intersection with other Disciplines



Editors: Robert A. Logan
Elliot R. Siegel

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"Health literacy is the ultimate global currency of health and well-being. Without health literacy, medicine fails, public health fails, and people pay the cost for these failures with their lives. As this book goes to press, the world is confronted by the COVID-19 pandemic. Improving health literacy becomes increasingly important if we are to successfully confront the challenges that stress our systems of medicine and public health like never before."
(Richard H. Carmona, M.D., M.P.H., FACS, former Surgeon General of the United States, in his foreword to this book.)

Two years ago, HTI published the book *Health Literacy: New Directions in Research, Theory and Practice*. Together with that earlier volume, this book: *Health Literacy in Clinical Practice and Public Health: New Initiatives and Lessons Learned at the Intersection with other Disciplines,* strives to enumerate and expand our understanding of the multidisciplinary connections which underpin the field of health literacy. The book's balance between research and practice is a response to the feedback the editors received about the previous publication, which focused more on HL theory and research.

With reports of specific health literacy research initiatives and interventions, particularly in clinical practice and public health, the book covers contemporary health literacy research and practice and is divided into three sections. Section one explores health literacy's capacity to foster progress in clinical practice and public health; section two provides insights into health literacy initiatives and lessons learned from diverse healthcare stakeholders; and section three examines health literacy's similarities with – and differences from – related health research disciplines.

The book sets the practice and research of health literacy on an evidence-based, thoughtful, effective, efficient, and applied course.
As Dr Richard Carmona says in his foreword:
"It is enthusiastically recommended for all health and medical practitioners and researchers."

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HEALTH LITERACY IN CLINICAL PRACTICE AND PUBLIC HEALTH

Studies in Health Technology and Informatics

International health informatics is driven by developments in biomedical technologies and medical informatics research that are advancing in parallel and form one integrated world of information and communication media and result in massive amounts of health data. These components include genomics and precision medicine, machine learning, translational informatics, intelligent systems for clinicians and patients, mobile health applications, data-driven telecommunication and rehabilitative technology, sensors, intelligent home technology, EHR and patient-controlled data, and Internet of Things.

Studies in Health Technology and Informatics (HTI) series was started in 1990 in collaboration with EU programmes that preceded the Horizon 2020 to promote biomedical and health informatics research. It has developed into a highly visible global platform for the dissemination of original research in this field, containing more than 250 volumes of high-quality works from all over the world.

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In memory of Donald A.B. Lindberg M.D., 1933–2019;
Director Emeritus, U.S. National Library of Medicine.
Dr. Lindberg was a visionary leader and medical informatics pioneer. His extraordinary contributions advanced the health knowledge and understanding of patients, families, and the public worldwide.

Introduction

Elliot R. SIEGEL Ph.D., FACMI[1]
U.S. National Library of Medicine (Retired); Editorial Board Member, Studies in Health Technology and Informatics

The *Studies in Health Technology and Informatics (SHTI)* series was started in 1990, driven by developments in biomedical technologies and medical informatics research. Both were advancing simultaneously to form an integrated view of information and communications technologies that sought to manage and benefit from increasingly large amounts of health data and information available to professional and lay audiences. The latter helped spawn the multidisciplinary field of health literacy, which promotes the successful engagement with and communication of health information to patients, caregivers, and the public.

Health literacy intersects with the field of consumer health informatics (CHI) that focuses on information structures and processes which empower consumers of health information to manage their own health. The cornerstones of CHI research and practice involve fostering health information literacy; promoting consumer-friendly language; encouraging accessible and usable personal health records; and developing innovative Internet-based strategies and resources. The American Medical Informatics Association further characterizes other disciplines that transect with CHI and health literacy, which include nursing informatics, public health, health promotion, health education, library science, and communication science.

Two years ago *SHTI* published *Health literacy: new directions in research, theory and practice* [1]. The current book coupled with the earlier volume strive to enumerate and expand our understanding of the aforementioned multidisciplinary connections with reports of specific health literacy research initiatives and interventions, particularly in clinical practice and public health.

A number of these reports also advance the use of communications tools and strategies, including contemporary information and/or communications technologies and resources. While typically a secondary emphasis, the use of communications tools and strategies serve as a means for intervention or a topic of study in their own right.

Among the book's 41 submissions, thirteen papers addressed some aspects of information and communications technology and were selected for co-publication in special issues of the companion IOS Press journal *Information Services and Use* (ISU) [2–3]. In several of the latter manuscripts, the Internet occupies an outsize role, reflecting its unique strengths and weaknesses as a medium of communication and engagement, and an instrument for persuasion. For society – whether we seek it or not – the Internet mediates a shared vision of achieving the goals of a health literate and a healthy society.

In ISU's special issue, Ahmed describes the launch some 21 years ago and the continued development of *MedlinePlus.gov's* search engine and website [4]. Currently, *MedlinePlus* serves as a valued and effective resource for patient education and the promotion of health literacy in the general population.

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As a topical focus, childhood immunization is a serious public health concern that has generated considerable activity on the Internet. In the ISU special issue, Willis and colleagues note the proliferation of web-based platforms and mobile applications that disseminate credible information about immunization [5]. Christie and Ratzan explain the need for leadership and investment in digital health communication to increase vaccine coverage as a social norm throughout the world [6]. They along with Peterson and colleagues [7] also address the aspersive influences of some social media sites and online patient support groups that deliberately disseminate health *misinformation* on issues such as child immunization safety. The latter authors propose the need to inoculate information seekers with health literacy skills that enable them to successfully identify and distinguish between evidenced-based and non-evidenced based information.

Borrowing as they do from CHI and communication science, efforts to inoculate information seekers with health literacy skills is an excellent example of benefits accruing from the skill sets, strategies and tools available in related disciplines. In this era of 'fake news' that seemingly permeates all communications media – especially electronic, health literacy researchers and practitioners would do well to avail themselves of such knowledge as a means to confront this common challenge.

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Foreword

Richard H. CARMONA, M.D., M.P.H., FACS[1]

I am elated that health literacy and cultural competence are becoming a solid part of the evidence-based mainstream of public health and clinical medicine. As a young U.S. Army Special Forces soldier and medic half a century ago, some of my best training and health literacy experience resulted from living with and being immersed in the culture and language of the tribal Montagnards of Southeast Asia. From them, I learned that people are the best experts in their own lives and trying to impose a one-size-fits-all solution simply does not work.

In the decades since then - in numerous roles from soldier to physician, professor to surgeon general, father to friend - I fully realized that health literacy (HL) is the ultimate global currency of health and well-being. Without health literacy, medicine fails, public health fails, and people pay the cost for those failures with their lives. This could not be truer than in the emergence of new diseases around the world, and, in particular, the COVID-19 pandemic. As our systems of medicine and public health become increasingly stressed by growing demand, challenged by the emergence of new threats to health, and unable to respond to the needs of the public they serve, improving health literacy becomes increasingly important.

In a world that is growing increasingly complex in political, cultural, and social realities, general literacy rates vary from a low 19% in Niger to South Korea where nearly 100% of the adult population is literate. Yet, disparities remain the most critical issue - two-thirds of the world's non-literate citizens are female.

As we strive to improve HL in order to enhance the quality and length of life and reduce health care costs, 'Health literacy in clinical practice and public health: new initiatives and lessons learned at the intersection with other disciplines' is a much needed publication that clearly denotes the importance of health literacy as the most effective and cost efficient way to improve public health, prevent illness, and advance medical care.

As important as improving general literacy is, the average citizen often struggles with limited health literacy and is surrounded by public health and medical care systems that demand HL to understand and navigate needed health care. That is, both people and health systems continue to have difficulty in comprehending, synthesizing, communicating clearly, and acting on necessary scientific information to improve health and well-being. People and the health systems that surround them struggle to sustain healthy behavioral changes that are necessary to prevent or mitigate disease. Citizens and their leaders also often fail to connect the quality of their lived and natural environments with the quality of the broader public's health and well-being. An unhealthy environment produces unhealthy people just as unhealthy people produce an unhealthy environment.

As this book goes to press, illustrations of the aforementioned problems abound in the global response to COVID-19. For example, significant differences in therapeutic responses to the pandemic have emerged within and between nations despite extant evidence about the pandemic's health risks. Significant public health consequences,

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[1] 17th Surgeon General of the United States; Distinguished Professor, University of Arizona

including an overwhelmed health care system and preventable deaths, sometimes have been the result of inconsistent and delayed local, regional, and national implementation of physical distancing as well as other evidence-based protocols to thwart global pandemics.

In addition, occasional occurrences linked to COVID-19 provide a sobering reminder about the use of social media to diffuse health disinformation and misinformation, which can appeal to populations with limited health literacy. For instance, British activists have used social media to allege the COVID-19 pandemic's diffusion is accelerated by the expansion of 5G network phone services and cell phone towers. The latter allegations prolong pre-pandemic assertions that cell phone towers and services represent an omnipresent, deliberately concealed threat to public health.

The continuation of health conspiracy theories and delayed government responses each illustrate the consequences of limited health literacy and its potential to generate public and health policy indecision and confusion – in this case during a pandemic.

In the U.S., health care's stakeholders increasingly perceive health literacy as a robust field of practice. Moreover, there are organizations, researchers, practitioners, and networks working to advance health literacy that stretch around the globe. While we have experienced great advances on every continent from an idea initiated by small groups, there is much more that needs to be done. The editors of this volume have aggregated global researchers and their knowledge through 'scientific crowd sourcing' and they have significantly advanced the science of health literacy. In three major sections, global thought leaders in health literacy explore and report on their efforts to foster progress in clinical practice and public health.

Meanwhile, as preventable disease and its resulting economic burden continues to mount in the U.S. and globally, the currency of health literacy and cultural competence becomes ever more valuable. Improving health literacy in health and medical organizations, health professionals, and the public is the pathway to better health for all at reduced costs.

Similarly, the biomedical science that needs to be translated via HL principles creates an enduring challenge. Providers know how to keep many people healthy and prevent disease through simple lifestyle practices - and medical science often knows how to help people regain their health after they become ill. However, whether you live or practice in Bangladesh or Beverly Hills - successful health outcomes are derived from a culturally competent and health literate translation of biomedical and related sciences into applied care.

While all health and medical practitioners must be aware of (and incorporate) health literacy and cultural competence practices in their disciplines and daily practices, it is noteworthy that many best practices emerge in the communities where pressing social and cultural issues are best understood. Just as I learned from the Montagnards of Southeast Asia as a young medic in the U.S. Army, we cannot impose our world view and science upon people without first understanding their reality.

Although the future is bright for health literacy and its supporters, significant work remains and funders must begin to fully prioritize health literacy in their missions. We must engage more practitioners across disciplines like pharmacists, EMT's, and nurses. We must bring in commercial sectors - from grocery stores to the entertainment industry. We must expand our content distribution networks and continue to create more health literate content. Through the latter approaches, we increase the chance to diminish disease and health's economic burden as well as create healthier populations.

Health literacy can become the basis for a new partnership among the public, medical systems and professionals, and public health practitioners and systems. As those systems of health become increasingly stressed by issues like the COVID-19 pandemic, the need for all individuals, families, and communities to have the ability to make evidence-based and informed decisions becomes ever more critical in order to improve health for all at a lower cost.

On a final note, as autocrats rise and fake news and political instability trumps the truth globally, I am concerned about the unintended public health consequences of the lack of needed global coordination to reduce morbidity and mortality and improve the quality of life for millions suffering from preventable diseases and resulting economic burdens.

This new publication clearly articulates our past challenges and future opportunities while advancing the science of health literacy. Overall the book, which is enthusiastically recommended for all health and medical practitioners and researchers, sets the practice and research of health literacy on an evidence-based, common, thoughtful, effective, efficient, and applied course.

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Preface*

Robert A. LOGAN[1]
Senior staff, U.S. National Library of Medicine (retired)

1. Introduction

'Health literacy in clinical practice and public health: new initiatives and lessons learned at the intersection with other disciplines' covers contemporary health literacy research and practice and is divided into three sections. Section one explores health literacy's capacity to foster progress in clinical practice and public health. Section two provides insights into health literacy initiatives and lessons learned – from diverse health care stakeholders. Section three details health literacy's similarities with – and differences from – related health research disciplines.

The book combines chapters and reports. While the book's reports are shorter and focus on health literacy practices by diverse organizations, the chapters update readers on health literacy's diverse research contributions and address theoretical and multidisciplinary issues (where relevant). While section one contains both reports and chapters, section two is composed of reports and section three features chapters.

To avoid repetition, this preface provides an overview of the book's balance of contributions regarding health literacy (HL) research and HL practice rather than providing a summary of each contribution. The book contains a table of contents, which provides a section-by-section list of all the book's authors and chapters. In addition, each of the book's 40 contributions are discussed and many are contextualized within summaries at the end of each section. The author shared the latter responsibility with Cynthia Baur, Ph.D., the practice editor of *Health Literacy Research and Practice*.

The book's balance between health literacy research and practice is a response to the feedback the editors received about their 2017 health literacy volume, which emphasized HL theory and research. The current book's dedication to Dr. Donald A.B. Lindberg (the late, director emeritus of the U.S. National Library of Medicine – NLM) partially is derived from his January 2018 encouragement to provide more examples of health literacy practice interspersed with research developments "in the next book [1]." Both the author and Elliot Siegel, the book's co-editors, were members of Dr. Lindberg's senior staff @ NLM. Dr. Lindberg died unexpectedly in August 2019 while this book was well underway. In fact, one of the last things Dr. Lindberg did was to email the current author about the book's progress prior to the accident that led to his untimely death.

For the readers of the 2017 health literacy book (that the author and Elliot Siegel also co-edited), the differences herein are: the aforementioned balance; the inclusion of contributions devoted to HL practices from diverse organizations in reports; an extension and update of HL research; and the addition of three section summaries that provide an overview with pertinent commentary [2–3].

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* Editors note: With the exception of the foreword, all the book's contributions were submitted prior to the COVID-19 pandemic.

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2. The Book's Topics

The 21 reports that focus on health literacy practices are organized into reports about HL interventions in the U.S. such as:

- Successful child immunization programs in medically underserved Milwaukee neighborhoods [4];
- Improved self-management via health information initiatives in New York City Latino neighborhoods [5];
- Boosting clinical trial awareness and preventive colorectal cancer screening in rural Louisiana [6].

The 21 reports that focus on health literacy practices are organized into reports about interventions in other nations such as:

- Population health literacy improvements and their policy impacts in Austria [7];
- Health awareness among public employees in Malaysia [8];
- Improving childhood immunization rates and health self-management in Israel [9]
- Development of the Danish Health Literacy Network and the Dutch Health Literacy Alliance as well as HL research and other initiatives in Denmark and the Netherlands [10].

The 21 reports that focus on HL practices include programs from governmental agencies, such as:

- The benefits of audience testing to improve consumer understanding from the U.S. Food and Drug Administration [11];
- The Science Ambassador Fellowship program, HL training, tools, and action plans from the U.S. Centers for Disease Controls and Prevention [12];
- The impact of an internal HL plan to develop measures, improve the evidence base, and enhance evidence-based research and practice approaches at the U.S. Agency for Healthcare Research and Quality [13];
- The impact of the Wisconsin, Kentucky, and Massachusetts Area Health Education Centers to foster a more health literate workforce from the U.S. Health Resources and Services Administration [14];
- The origin, overview, content, and future direction of MedlinePlus.gov at the U.S. National Library of Medicine [15];
- The role of health literacy within a broader health prevention agenda at the New York State Dept. of Public Health [16];
- Improving digital health information tools for the public via the use of health literacy principles from the Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services [17].

The 21 reports that focus on HL practices include activities from non-governmental agencies, such as:

- Using HL to boost adult health learning and understanding of prescription medication labels in Wisconsin [18];
- Building health literacy organizations and coalitions in Canada, Africa, Asia, the U.S. state of Georgia, and globally with the International Health Literacy Association [19].

The 21 contributions that focus on health literacy practices include reports from corporations and HL focused organizations, such as:

- The Universal Patient Language project to boost patient understanding of drug safety information from Bristol-Myers Squibb [20];
- How public understanding, the design, and conduct of clinical trials are enhanced by incorporating health literacy principles from Health Literacy Media [21];
- Assisting Southern California parents with child health information as well as helping senior citizens prevent falls and understand aging from the Institute for Healthcare Advancement [22].

Other reports about health literacy practices include:

- Using health literacy to enhance professional career resilience (and decrease burn out) among medical students at Stony Brook University [23];
- Podcasts that discuss an array of health literacy issues and best practices, as well as introduce listeners to HL practitioners [24].

Turning now to the book's chapters, the 19 contributions that focus on HL research include a focus on clinical research, such as:

- An overview of health literacy research including how HL impacts: disease knowledge; medication knowledge and understanding; health prevention behaviors; illness and medication beliefs; as well as HL's impact on clinical health outcomes [25];
- Specific examples of HL research in pediatrics that includes HL's impact on: child and adolescent medication adherence; immunizations, injury prevention; tobacco and alcohol use; nutrition; physical activity; screen time; obesity; diabetes; and health through the life course. The chapter includes a discussion of gaps in the current literature [26];
- How HL research impacts the reduction and prevention of dental cavities and periodontal diseases as well as fosters the evolution of oral health literacy programs [27];

The 19 contributions that emphasize research include chapters that focus on HL and leadership within the health professions, such as:

- How health literacy initiatives contribute to develop the Quadruple Aim in clinical care. (The quadruple aim strives to: enhance the quality of care; advance the health of communities; reduce costs; and improve the care and experience of patients and providers) [28];
- A specific example of how to advance the quadruple aim through bidirectional clinical care. The chapter proposes a new bidirectional perspective on HL's contribution to clinical medicine [29].

The 19 contributions that emphasize research include chapters that address HL's importance from a public health perspective. These chapters note:

- How the broader acceptance of – and support for – HL in the U.S. depends on: developing an epidemiology of health literacy; agreement on standards to educate and train health professionals; providing materials and conduct organizational assessments; and more health literacy impact assessments (so

previously hidden or minimized health literacy effects from health, education, and social polices become visible and measurable) [30];
- How the international advancement of health literacy depends on interventional research that yields practical and implementable solutions which inform future policy, strategy, and priorities. The chapter also addresses the need for HL interventions within diverse community settings [31];
- How the World Health Organization's (WHO) international conferences contribute an ethical foundation for HL work and promote an agenda for the sustainable development of global health. The chapter adds the WHO's HL findings suggest some of the challenges facing HL research and practice around the world [32].

The 19 contributions that emphasize HL research include contributions which focus on health literacy law and policy, such as:
- A proposed integrated measure of health literacy, language access, and cultural competency that could improve institutional assessment, contribute to quality improvement efforts, and demonstrate a recommitment to patient and family-centeredness as well as equity in clinical care [33];
- A review of the incorporation of HL and patient understanding requirements within the diverse laws and policies that impact health care. The chapter helps healthcare providers, hospital executives, biomedical researchers, industry sponsors, and public health professionals better understand the regulatory trend towards health literacy in the U.S. and how stakeholders can use these embedded sources of authority to advocate for change in their respective areas [34].

Consistent with the book's title, the 19 chapters that emphasize HL research include contributions which focus on the interaction (and intersection) of health literacy with similar research disciplines including:
- Health literacy and health communication [35];
- Social media, health literacy, peer-to-peer communication, and public understanding [36];
- Health literacy and patient empowerment [37];
- Health literacy and health education [38];
- Health literacy and health journalism [39];
- Arts appreciation, health literacy, and clinical practice [40];
- Health literacy and health disparities. The latter chapter provides a new theoretical framework for health literacy and health disparities research [41].

Other HL research issues in the book focus on:
- The importance of improving health literacy across the lifespan. Early childhood vaccinations, alcohol intake in adolescence, and dementia care in older adults are suggested to demonstrate the need for improved health literacy across the life course. The chapter also draws on digital health data and technology and multisectoral partnerships to define the future of health literacy [42];
- How a health literacy survey in the European Union was adopted for widespread international use and fostered a new, revised HL survey instrument (HLS19),

which is planned to be partly or comprehensively administered in about 16 initially participating nations [43].

3. Lessons Learned

The diverse lessons learned about health literacy that emerge from the reports and chapters in this book include:

In clinical practice:

- Advancing health literacy is integral to quality improvements in clinical medicine
- The link between health literacy and improved patient outcomes is evidence-based within some specific areas of clinical practice, such as pediatrics and oral health
- Advancing health literacy issues within health care organizations is a strategy to address the Quadruple Aim
- Limited health literacy is associated with poorer health-related knowledge, poorer overall health status, greater rates of urgent healthcare utilization and hospitalization, and higher mortality
- Health literacy is part of a bidirectional clinical approach to improve patient care and rededicate a health care organization to patient satisfaction and empowerment
- A combined measure of cultural competence, language access, and health literacy fosters a strategic approach to quality improvement for health care organizations
- In addition to medical centers, clinics, and physician's offices, health literacy is advanced by: governments; non-governmental organizations; attorneys, courts and legislators; insurers; the pharmaceutical industry; health care for-profit and non-profit corporations/organizations, public health agencies; medical/health professional education; higher education; K-12 education; public and health professional interest organizations; as well as others
- The opportunities to elevate or adversely impact health literacy also exist in non-traditional settings such as: community interactions; mass media, social media, news media; architectural, drama and other fine arts; and in the law.
- Advancing health literacy is the responsibility of all of health care's stakeholders.

In public and global health:

- Improving individual and population health literacy is a global challenge
- Advancing population health literacy is integral to improving public health
- Health literacy is integral to an improved quality of life within communities as well as for individuals
- Health literacy has an integral role in international sustainable development and environmental practices
- Advancing an agenda to address health literacy across the life course should be a global health policy priority
- Health literacy principles and definitions are embedded in statutory, administrative/regulatory, and case law in some nations.

Impact of initiatives:

- Developing health educational initiatives for younger persons, especially in K-12 and higher education, potentially improves health literacy across the life course
- Health literacy initiatives can be used to address (among other examples): clinical trial participation; health preventive screening; K-12 health education; patient understanding of prescription labels; child and adolescent vaccination participation; diet and nutrition, exercise; tobacco, alcohol, and drug abuse; interpersonal violence; sexually transmitted diseases; depression; senior self-care; hypertension; diabetes and other chronic disease management challenges; patient health self-management; utilization of the health care delivery system; informed consent; patient adherence to medical instructions; patient awareness of disease/condition; physician/health care provider adaptation to clinical challenges; and physician/health care provider resilience to professional stress
- Health literacy initiatives can be used to counter health misinformation and disinformation from social and mass media, interpersonal, community, advertising, and governmental influences.

For HL field work:

- Sustainable health literacy interventions require providers to: be strategic; get senior leadership support; adapt to local circumstances; build partnerships; use as many health literacy techniques as necessary; prepare; test drafts or prototypes with the audience or end-users of the health information or service; and assess all initiatives using empirically grounded methods
- While HL practices often demonstrate feasibility and adoption as well as some efforts towards sustainability, HL field work frequently lacks evidence of an extended reach or transferability to other public health or clinical contexts.

Barriers:

- Although health literacy is an intermediate variable that impacts clinical outcomes and the utilization of the health care delivery system, HL is difficult to empirically distinguish among the other intermediate variables which have been associated with improved health outcomes and health care utilization
- The evidence base that links health literacy to improved public health outcomes is not as comprehensive as the clinically focused HL literature
- Some of the challenges to advance HL research include: a consensus about a health literacy definition; the development of multidimensional assessment tools; consistent use of grounded psychometric methods; and regular use of undergirding conceptual frameworks
- The barriers to advance HL research foster uncertainty about HL’s empirical grounding, which undermines public and private investment in health literacy research and initiatives
- Despite 20 years of findings that limited health literacy is a public health emergency, HL sometimes is not perceived as a comparatively urgent public health issue. Hence, health literacy improvements are rarely used as a benchmark of public health policy

- The current skepticism about health literacy's future (as a discipline) should be addressed via leadership in research measurement and HL's coordination with health policy
- Some urgent areas that require leadership are: to develop an epidemiology of health literacy; agree about standards to educate and train health professionals; furnish materials and conduct organizational assessments; and provide more health literacy impact assessments (so previously hidden or minimized health literacy effects from health, education, and social polices become more visible and measurable).

Underappreciated attributes:

- Recent findings about the individual, public health and clinical impacts of HL suggest the need for a more comprehensive approach to health literacy research and expanding its conceptual underpinnings
- One of the least appreciated attributes of health literacy is its triangular role as a predictor of individual health, as a health institutional (or structural) determinant of health, as well as a social determinant of health. Health literacy may be the rare indicator and interventional variable that operates across the individual, structural, and social dimensions of health
- Research opportunities abound to explore health literacy's interactions with similar disciplines such as: health communication; health journalism; social media; peer-to-peer communication; patient empowerment; health education; arts appreciation and clinical practice; and numeracy.
- The HLS-EU comprehensive health literacy instrument to assess health literacy in general populations (originally was developed by HL scholars in European Union nations) has been translated, validated, and administered (in whole or partially) in 36 nations across five continents. A new, revised instrument (HLS19) enables both the measurement of general health literacy as well as some specific aspects of HL

4. Geographical, Academic, and Organizational Diversity

The book's authors represent five continents and diverse nations including: Austria; Australia; Canada; Denmark; Ethiopia; Israel; Malaysia; The Netherlands; Taiwan; United Kingdom; and the United States.

Represented international colleges and universities include: Aarhus University; Chapman University; Columbia University: Duke University; Emory University; George Mason University; Harvard University; Hofstra/Northwell University; Louisiana State University-Shreveport; Maastricht University; Medical College of Wisconsin; Michigan State University; Monash University; New York University; Northwestern University; Stony Brook University; Tufts University; University of Arizona; University of Arkansas; University of California-Berkeley; University of California-Los Angeles; University of California-San Francisco; University of Georgia; University of Haifa; University of Maryland-College Park; University of Malaysia; University of Massachusetts-Amherst; University of Missouri-Columbia; University of North Carolina-Chapel Hill; University of Sydney; University of Vienna; and the University of Wisconsin-Madison.

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The editors hope 'Health literacy in clinical practice and public health: new initiatives and lessons learned at the intersection with other disciplines' attains the 2018 request to the initial author-invitees to 'create a gem.'

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Section One

Exploring Health Literacy's Capacity to Foster Progress in Clinical Practice and Public Health

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Health Literacy in Clinical Practice and Public Health
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Health Literacy and Its Impact on Health and Healthcare Outcomes

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Abstract. This chapter summarizes research that investigated relationships between health literacy (using currently accepted measures) and specific classifications of health outcomes, including healthcare utilization. To better understand the causal pathway which limited health literacy affects poorer health outcomes, the literature is presented from proximal (health knowledge) to distal (mortality) outcomes. Overall, the most consistent evidence was observed at the most proximal and distal outcomes, but less consistent evidence with intermediary outcomes, particularly self-management behaviors and clinical health outcomes. The chapter concludes with a discussion of the findings and larger implications for the causal mechanisms which health literacy impacts health outcomes.

Keywords. Health literacy, health outcomes, health knowledge, self-management behaviors, causal pathway

1. Health Literacy as an Important Determinant of Health

The relationship between basic reading skills and various health-related outcomes has long been a focus of research investigations, yet during the past three decades, this area of study has been codified and contextualized within the multidisciplinary field of health literacy. With numerous seminal reports from national and international health organizations and professional societies advocating its importance to public health, the concept of health literacy has taken on a prominent role as both a risk factor and proximal healthcare outcome. Specifically, the body of evidence that has evolved over time has highlighted how a large proportion of adults may lack the requisite capabilities to access, understand, and apply existing forms of health information to make informed decisions.

Estimates of limited health literacy are based on national functional literacy assessments, which are prevalent among many countries [1]. In the United States, the National Assessment of Adult Literacy (NAAL) in 2003 reported 14 percent of U.S. adults possessed skills in the lowest level of prose and document literacy ('below basic'),

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and 22 percent were at the lowest level for quantitative literacy [2]. These individuals could perform only the most simple and concrete tasks associated with each of these domains. However, even those with only 'basic' literacy proficiency were likely to be hindered in routine daily activities. When considering individuals with basic and below basic skills combined, as many as 34 percent to 55 percent of adults in the U.S. have limited literacy skills. Estimates were significantly higher among the elderly; 60 percent of individuals past the age of 65 have limited levels of prose and document literacy.

However, a primary determinant of any individual's ability to navigate and successfully use healthcare services is the simplicity - or more often the complexity - of a healthcare system or other pertinent entity's design and delivery of services. The expanse of literature summarizing the associations between health literacy and health outcomes has not yet accounted for healthcare system or community attributes. Rather, studies usually have operationally defined health literacy, often crudely, as an individual trait that measured by any number of assessments that capture reading fluency, numeracy, or a combination of both without taking into account the healthcare environment. While there already have been a few systematic reviews about the impact of health literacy, it would be helpful to review the associations between health literacy and specific types of health and healthcare outcomes; as with the strength and consistency within the literature. The authors suggest this approach can better guide our understanding of the causal mechanisms through which limited health literacy negatively impacts health, as well as to elucidate where more research may be needed.

The Paasche-Orlow & Wolf conceptual framework posits specific plausible pathways through which health literacy might affect health status [3]. This multidimensional framework recognizes that both patient and contextual factors inform access and utilization to health care, medical encounters, self-care activities, which ultimately lead to patient health outcomes. In contrast, the current evidence regarding health literacy's impact focuses on patient-level characteristics, which is the dimension that will underpin the research reported in this chapter. However, the authors recognize the causal associations among health literacy-health outcomes are due not only to patient-level characteristics, but to attributes within the health care delivery system.

1.1. Purpose of the Chapter

More specifically, this chapter summarizes some of the available research that has investigated relationships between health literacy (using currently accepted measures) and specific classifications of health outcomes, including healthcare utilization. The literature is presented from proximal (knowledge) to distal (mortality) outcomes.

While the chapter seeks to summarize associations between measures of health literacy and a range of health and health care outcomes, is not intended to be an exhaustive summary of the literature. Studies were eligible for inclusion in the chapter if they incorporated a validated measure of health literacy, were written in English, and reported health outcomes of adults (ages 18 years or older).

The chapter will begin with a brief overview of the widely used health literacy measures referenced throughout the chapter. A description of each measure, the scoring system and derived categories are outlined. This is followed by a summary of the available literature exploring the associations between health literacy and health outcomes is presented. Beginning with the most proximal outcomes, the relationship between health literacy and knowledge is first reviewed, knowledge is sub-divided into disease knowledge, medication knowledge and understanding, knowledge of preventive health behaviors, and illness and medication beliefs. This is followed by a review of literature documenting associations between health literacy and self-management behaviors, with studies sub-divided by disease group, including asthma and COPD, diabetes, heart failure and cardiovascular disease, and HIV. The relationship between functional health outcomes and health literacy is summarized, followed by the association between health literacy and a variety of clinical health outcomes is discussed by disease group, including asthma and COPD, diabetes and cardiovascular disease. We then review literature on health literacy and preventive health care use and the limited body of evidence on the relationship between routine healthcare use and health literacy. The relationship between urgent health care use and health literacy is discussed, with a focus on risk of hospitalization, readmission and emergency department visits. Lastly, the relationship between mortality and health literacy is reviewed. The authors conclude the chapter with a summary of each section and a discussion of the impact of findings in relation to the causal mechanisms through which limited health literacy negatively impacts health.

1.2. Health Literacy Measures

The primary health literacy measures included in this review emphasize the Rapid Estimate of Adult Literacy in Medicine (REALM), the Test of Functional Health Literacy in Adults (TOFHLA) and its short form, (S-TOFHLA), the Newest Vital Sign (NVS) and the Brief Health Literacy Screen (BHLS). Each test provides both a continuous and categorical score, and all utilize different labels for the derived categories. For the purpose of this chapter, the authors will refer to the categories as: adequate; marginal; and limited health literacy. In reviewing each of the measures the authors have included their original nomenclature.

The REALM is a word-recognition test comprised of 66 health-related words [4]. Individuals are asked to read aloud as many words as they can. Scores are based on the total number of words pronounced correctly and range from 0-66, with higher scores indicating greater health literacy. Scores are classified in terms of reading level (0-44: less than sixth grade reading level; 45-60: seventh or eighth grade reading level; 61-66: ninth grade reading level or above).

The TOHFLA and S-TOFHLA are composed of a numeracy and a literacy section [5-6]. The numeracy section assesses comprehension of actual health information materials by a series of prompts (prescription bottle, appointment slip, results from a medical test) that a patient may encounter in a healthcare setting. The reading assessment evaluates the patient's ability to read passages of healthcare materials. The assessment uses the Cloze procedure whereby every fifth to seventh word of a text is omitted and four multiple choice options are provided. Scores range from 0 to 100, with higher scores indicating higher health literacy (TOFHLA: 0-59: inadequate health literacy, 60-74: marginal health literacy; 75-100: adequate health literacy; S-TOFHLA: 0-53 inadequate; 54-66: Marginal; 67-100: Adequate). Alternatively, the reading comprehension items of the S-TOFHLA also can be administered without the numeracy items; scores range from 0 to 36, with higher scores indicating higher health literacy (inadequate: 0-16; marginal: 17-22; adequate: 23-36).

The NVS is a screening tool used to determine the risk of limited health literacy. Patients are given a copy of a nutrition label and asked six questions about how they would interpret and act on the information contained on the label. The number of correct responses is summed to produce a health literacy score ranging from 0-6. Scores are classified in terms of likelihood of limited literacy (0-1: likely limited; 2-3: possibly limited; 4-6: adequate) [7].

The BHLS includes three single-item screening questions that ask participants to self-report 1) the frequency that someone else helps them read hospital materials; 2) their difficulty understanding written information; and 3) their confidence filling out forms independently. Responses are scored on a Likert scale from 0 to 4 with total scores ranging from 0 to 12 [8].

2. Health Literacy and Knowledge

2.1. Disease Knowledge

A significant amount of research has been conducted to establish the relationship between health literacy and disease knowledge. Studies have demonstrated strong associations between health literacy and disease knowledge across a range of chronic conditions, including asthma and chronic obstructive pulmonary disease (COPD), diabetes, heart failure and HIV. Lower health literacy consistently has been associated with lower disease knowledge across a variety of measures.

Two large studies explored the relationship between health literacy and general knowledge of chronic disease [9-10]. For example, an earlier study by Gazmararian and colleagues identified a strong positive association among 653 older adults with asthma, diabetes, congestive heart failure, or hypertension [9]. Medication knowledge was assessed using knowledge questions derived from educational materials and concepts typically communicated to patients within these disease groups. In an adjusted analysis, the percentage of correct medication answers increased with scores on the S-TOFHLA across all disease groups. These findings support previous work from Williams et al. derived from 402 patients with hypertension and diabetes [10]. In the latter study, a significantly higher number of patients with adequate health literacy were able to identify a high blood pressure reading and symptoms of hypoglycemia, compared to those with inadequate literacy.

In relation to disease-specific knowledge, several studies have evaluated the associations among health literacy with diabetes, heart failure, HIV, and respiratory illnesses. Four large studies of more than 300 adults with heart failure found strong positive associations between low health literacy and lower disease knowledge, including heart-failure specific knowledge, salt knowledge, knowledge of cardiovascular risk factors, and the potential complications of diabetes and hypertension [11-14]. These findings were supported by research with adults living with HIV [15-16]. In one of the latter studies, patients with higher health literacy (as measured by the TOFHLA) were almost two times more likely to know their CD4 cell counts and viral loads. Patients with lower health literacy also were less likely to indicate they understood the meaning of these results - and were more likely to hold misconceptions about the transmission of HIV. Similar results have been found among adults with COPD and asthma, and among patients with diabetes, albeit with smaller sample sizes [17-23]. One study did not observe an association between health literacy and diabetes knowledge; however, this research was conducted with only 144 Spanish-speaking adults, which may have contributed to the findings [24].

2.2. Medication knowledge and understanding

Research also has explored the relationship between health literacy and medication-related knowledge. The findings on this topic suggest a strong association between health literacy and medication knowledge, with lower health literacy widely associated with lower medication knowledge and higher levels of misunderstanding.

In a large study of 790 hospitalized adults, Marvanova et al. used the Medication Understanding Questionnaire (MUQ) to assess knowledge of medication purpose, dose, and frequency among predominantly older adults in two U.S. academic medical centers [25]. Compared to patients with adequate health literacy, patients with marginal or inadequate health literacy had a lower odds of understanding their medications (odds ratio [OR] = 0.53; 95% confidence interval [CI], 0.34 to 0.84; p=0.0001; and OR = 0.49; 95% CI, 0.31-0.78; p=0.0001; respectively). These findings built on previous work from Davis and colleagues, where the ability to understand and demonstrate instructions found on common prescription medications was assessed among 395 patients attending primary care clinics [26]. Overall, 62.7% of patients with low literacy, and 51.3% of patients with marginal literacy, misunderstood one of more of the labels. Patients with low health literacy experienced higher rates of misunderstanding compared to those with marginal or adequate literacy. In a follow-up study, Wolf et al. classified the reasons for misunderstanding among the 374 incorrect responses [27]. Common causes for misunderstanding included: label language; complexity of instructions; implicit versus explicit dosage intervals; presence of distractors; label familiarity; and attentiveness to label instructions.

A second study from Wolf and colleagues found a similar association among patients on highly active antiretroviral therapies (HAART) [16]. For patients taking one to two HIV medications, 100% of higher literate patients could correctly identify their medications, compared to none of the lower literate patients prescribed three or more HIV medications. Findings from two additional studies supported this association, with lower health literacy associated with lower medication knowledge in a study of 100 patients [28]. In a smaller study of 79 adults at outpatient pharmacies, patients with inadequate health literacy less frequently recalled correct medication names when compared to patients with adequate functional health literacy. Correct dosages and frequencies also were reported less frequently among those with inadequate functional health literacy [29].

2.3. Knowledge of preventive health behaviors

A number of studies have examined the relationship between health literacy and knowledge of preventive health behaviors, which focused on knowledge (and awareness) of screening for colorectal and cervical cancers, as well as preventive measures such as mammograms and human papillomavirus (HPV) vaccinations [30-32]. While the findings from the latter studies reported associations between lower health literacy with lower knowledge and awareness of preventive health behavior, the overall findings were mixed.

Multiple studies explored the relationship between health literacy and knowledge of colorectal cancer (CRC) screening [33-37]. A recent study from Smith and colleagues examined comprehension of a colonoscopy preparation information leaflet among 764 older adults [36]. Health literacy (as measured by the TOFHLA) was a significant predictor of comprehension. These findings were supported in a smaller study by Agho et al., in which health literacy was found to have a positive association with self-reported knowledge and awareness of CRC [33]. These findings were supported by two previous studies of CRC screening knowledge [34-35]. While the findings predominantly identified positive associations, Guerra and colleagues observed no association between functional health literacy and colorectal cancer screening knowledge [37].

A smaller number of other studies assessed the relationship between health literacy and knowledge of prevention in relation to women's preventive health behaviors, such as mammograms, cervical cancer screening, and HPV vaccinations [31,38-39]. In a study of 529 patients attending ambulatory women's clinics, health literacy was found to be the only factor independently associated with knowledge of cervical cancer screening (AOR 2.25; 95% CI, 1.05-4.80) [31].

Nevertheless, the remaining studies have reported mixed findings. One study among low-income women found that REALM scores were associated with knowledge of the purpose of mammograms, but not with knowledge of when to have a first mammogram, or how often to seek them [40]. Similarly, a more recent study from Bynum and colleagues found some associations between health literacy (as measured by the Single Item Literacy Screener (SILS) and diverse aspects of preventive behavior knowledge [41]. The findings suggested while there were significant differences between the low and high literacy groups in relation to ever hearing of HPV or the HPV vaccine, no differences were found in relation to knowledge of HPV. These findings might be a result of the age of the sample (mean age 46 years) as public health efforts have predominantly sought to increase HPV awareness among younger women [41].

2.4. Illness and Medication Beliefs

A small body of research has explored the relationship between health literacy and illness and medication beliefs [42-45]. The findings in this area predominantly are based on two large studies among patients with respiratory illnesses, including asthma and COPD [43-44]. Federman and colleagues assessed illness and medication beliefs among 420 older adults with asthma in two large U.S. cities [43]. Patients with lower health literacy comparatively were more likely to incorrectly posit asthma's frequency - with a belief that asthma could be cured. In relation to beliefs about medications, patients with lower health literacy were more likely to be concerned about medication use as well as more likely to endorse the necessity of taking medications. In an older study from the same author, patients with inadequate literacy were more likely to hold suboptimal beliefs, including the perception that a lack of symptoms suggests no asthma - that asthma is temporary and curable - and medications work better when used periodically [42]. These associations have been supported among patients with COPD; Kale and colleagues found patients with limited health literacy were less likely to recognize the chronicity of COPD and more likely to express concern about their medications [44].

3. Health Literacy and Self-management Behaviors

The studies that examined associations between health literacy and self-management behaviors primarily have focused on respiratory conditions (e.g. asthma, COPD), diabetes, heart failure, and HIV - and frequently assessed condition-specific behaviors. Overall, inconsistent findings have been reported on a range of self-management behaviors across the studied conditions. While patient adherence to prescribed medication regimens was commonly assessed, findings have been inconsistent and largely depend on the manner in which medication adherence was assessed.

3.1. Asthma and COPD

The studies that focused on asthma and COPD predominantly have assessed the relationship between health literacy and inhaler techniques and medication adherence. The majority of studies observed positive associations between health literacy (HL) and the number of steps completed correctly when using an inhaler [18,46-48]. However, one study among hospitalized patients with asthma and COPD did not observe an association between health literacy and inhaler techniques - and observed high rates of misuse among both HL groups [49]. Among the studies that examined medication adherence, the self-reporting of adherence was associated with health literacy [46,48]. HL also predicted adherence in unadjusted analyses when adherence was measured via electronic monitoring. But when adjusted for age, sex, and race, the association was no longer significant (p=0.07) [50]. Trigger avoidance also was examined in one study with unexpected findings; individuals with low health literacy were: more likely to avoid animals with fur; have someone else clean their house or apartment; and less likely to use allergy covers [46].

3.2. Diabetes

The studies among individuals with diabetes primarily have assessed the relationship between health literacy and diabetes self-care, as measured by the Summary of Diabetes Self-Care Activities measure (SDSCA), and medication adherence. Overall, the studies that evaluated diabetes self-care activities did not observe a significant association with health literacy; however, these studies reported relatively small sample sizes (n <150) [19-20,22,51]. In a larger study conducted among 459 Korean adults, health literacy exerted a direct effect on diabetes self-care activities [52].

Similarly, there have been mixed findings about health literacy and medication adherence among patients with diabetes. For example, the studies that included the Morisky medical adherence scale did not observe an association between HL and antidiabetic medication adherence [19,53]. Conversely, studies that assessed medication adherence via pharmacy records found significantly more patients (with poor adherence to insulin medication) comparatively reported problems learning about their medical condition because of difficulty understanding written information (a single item self-report measure of health literacy) [54]. Additionally, among individuals with diabetes who were newly prescribed antidepressants, limited health literacy was associated with larger gaps in pill supply and inadequate use of antidepressant therapy [55].

3.3. Heart Failure and Cardiovascular Disease

The studies among individuals with heart failure have examined self-care activities specific to health failure management and medication adherence. Overall, no consistent associations were observed between health literacy (as measured by the short or long form TOFHLA) and heart failure self-management behaviors [14,56-57]. In one study among 1549 older adults, the odds of low refill adherence in cardiovascular disease (CVD)-related medications were lower among limited compared to adequate health literacy. Yet, this relationship was no longer statistically significant in multivariate analyses [57].

3.4. HIV

Among patients with HIV, self-management behaviors were assessed in the form of adherence to antiretroviral (ARV) medications. Overall, a significant association was found among health literacy, as measured by the REALM and TOFHLA, and ARV medication adherence across a variety of adherence thresholds (80%, 85%, 90%, 100%) [58-59]. Medication adherence was measured via self-reporting and unannounced pill counts [58]. While one study observed a reverse trend, individuals with the lowest level of literacy had higher odds of adherence, this association was no longer statistically significant in adjusted models (AOR 1.93, 95% CI, 0.86 to 4.31) [60].

4. Functional Health Outcomes

A small number of studies have investigated the relationship between health literacy and functional health outcomes [61-63]. For the purposes of this review, functional health was operationalized as assessments that measured the degree to which an individual was able to function normally and to carry out daily activities, and included measures of activities of daily living, physical functioning, and physical fitness [64]. The studies that assessed functional health outcomes primarily have been conducted among samples of older adults [62-63]. Overall, the findings in this area suggest a predominantly significant association between health literacy and functional health outcomes.

In a seminal study, a sample of 2923 Medicare managed care enrollees were interviewed; the respondents with low or marginal health literacy comparatively experienced worse physical function, had more difficulties with activities of daily living, and reported more limitations in physical activity [65]. Relatedly, among 529 older adults, health literacy, as measured by the NVS, was associated with poorer physical function in multivariable analyses, and participants with marginal or low health literacy were more likely to experience a meaningful decline in comparative physical function during a three-year period [66]. These findings were supported by Mottus and colleagues, who examined the relationship between health literacy and physical health among 730 community-dwelling older adults in Scotland [62]. The study included three measures of health literacy - the REALM, S-TOFHLA, and the NVS. Lower scores on all measures of health literacy were associated with worse physical fitness scores including walk time, lung function, and grip strength. In adjusted analyses, lower health literacy (as measured by the REALM and S-TOFHLA) was associated with poorer physical fitness.

5. Clinical Health Outcomes

The studies that examined the associations between health literacy and clinical health outcomes have included respiratory conditions (e.g. asthma, COPD), CVD (e.g. heart failure, hypertension), and diabetes, and focused on condition-specific outcomes. Overall, most of the research has reported inconsistent findings regarding the relationship between health literacy and respiratory outcomes. A few studies have examined CVD clinical outcomes. The only consistent findings reported significant associations between lower health literacy and uncontrolled blood pressure. Otherwise, numerous studies have examined the relationship between low health literacy and poor glycemic control, and the aggregate findings are mixed. More specific findings are provided below.

5.1. Asthma and COPD

Inconsistent results were observed related to health literacy, asthma, and COPD outcomes. Among a sample of predominantly African American adults, health literacy (as measured by the STOFHLA) was predictive of both asthma control and asthma quality of life in fully adjusted models [50]. This association was supported in a similar study of adults with asthma in which health literacy (as measured using the TOFHLA) was associated with asthma control and asthma quality of life in unadjusted analysis. However, the relationship was not maintained when adjusted for asthma severity, self-efficacy, age, education, and depressive symptoms [67]. Among a sample of 452 elderly adults with asthma, limited health literacy (as measured by the STOFHLA) was not associated with asthma control or quality of life in adjusted analyses [68]. A study of patients with COPD found limited health literacy was associated with worse respiratory quality of life, and greater COPD severity [69]. In this case, health literacy was measured using the Brief Health Literacy Screener, although tertiles were used to create cut-points. Two studies also examined associations with lung function, as measured by the forced expiratory volume in one second (FEV_1), albeit with inconsistent findings. One study did not observe a significant association with FEV_1 in unadjusted or adjusted models, while another study of elderly adults with asthma found low health literacy was associated with FEV_1 <70%, an indication of poor lung function [68].

5.2. Diabetes

Numerous studies have examined the association between health literacy and glycemic control. One study among 408 diverse low-income patients found limited health literacy was associated with two-fold greater odds of very poor glycemic control (>9.5%). The study additionally found for each one-point decrement in STOFHLA score, the HbA1c value increased by 0.02 [70]. Conversely, among a sample of 1000 individuals with diabetes, health literacy was not associated with glycemic control [71]. Yet, 83% of the study's sample demonstrated adequate health literacy and was almost exclusively white [71]. Among other smaller studies (sample sizes <150), most did not observe an association between health literacy and glycemic control [19-21,72]. Yet, in a study of 68 individuals with diabetes, health literacy (as measured by the REALM) was associated with participants most recent HbA1c value in adjusted analyses [23].

5.3. Cardiovascular Disease

Despite extensive research on associations between health literacy and cardiovascular healthcare utilization, there has been significantly less assessment of the association between health literacy and clinical outcomes associated with CVD, including health failure quality of life and blood pressure. Lower health literacy consistently has been reported to be associated with uncontrolled blood pressure in a variety of settings (hospitalization, outpatient ambulatory care clinic) (as measured using the REALM, BHLS and STOFHLA) - albeit with a variety of cut-points for adequate health literacy

[13,73-74]. Among a sample of 600 patients with heart failure, higher STOFHLA scores were associated with heart failure quality of life; those with adequate literacy had better heart failure quality of life scores compared to those with low literacy [14].

6. Preventive Health Care Use

The research regarding the relationship between health literacy and use of preventive health care services has focused on cancer screening, including colorectal cancer and cervical cancer [39]. A smaller number of studies have focused on a range of preventive health care services, including mammograms and immunizations. While the germane findings suggest a trend towards an association between lower health literacy and lower use of preventive health care services, the comparability of studies has been hampered by measurement and study design flaws [39].

Oldach and colleagues summarized the associations between health literacy and various forms of cancer screening in a systematic review [39]. Ten articles with 14 comparisons of health literacy and cancer screening were included in the final review, including studies of colorectal, breast, cervical, and prostate cancer.

The overall findings were mixed; seven analyses found a significant positive relationship between health literacy and cancer screening, one analysis found a significant negative relationship, and the remaining six found no association of significance. Meanwhile, significant positive associations were found between higher health literacy and higher use of preventive services among all types of cancer screening [40,75-76]. The majority of studies in this review included breast and cervical cancer screening, with higher levels of health literacy associated with higher rates of pap smears and mammograms [40,75-76].

Focusing on colon cancer, a positive relationship between health literacy and colorectal cancer screening was identified in a large, nationally representative study [75]. Significant findings in this case were reported only among adults aged 65 and older [75]. The research was partially corroborated in a similar study of 3087 U.K. participants where adequate health literacy was associated with improved odds of participating in a publicly available colorectal cancer screening program [30].

While three studies within the systematic review found no association between CRC screening and health literacy, this may stem from a variety of factors within the studies, including small sample sizes, a predominantly Spanish speaking sample, and the diverse health literacy measures the study's employed [34,77-78]. Among the aforementioned studies, some age-related differences were found be associated with the impact of health literacy on cancer screening. In a large nationally representative study from White et al., higher health literacy was associated with a higher likelihood of having had a pap smear or colon cancer screening within the previous year [75]. In relation to pap smears, this finding was only significant for women younger than 40, while the colon cancer screening was significantly impacted by health literacy levels among adults 65 years and older. Both of these findings reflect age-related differences in cervical and colon cancer risks and their respective preventive efforts.

7. Routine Health Care Use

Limited research has assessed the relationship between health literacy and routine health care use - and has reported mixed findings [79]. The data from a large study from Baker and colleagues explored the effect of health literacy on the use of outpatient physician services among 3260 Medicare managed care enrollees age 65 and older [79]. Health literacy was measured using the S-TOFHLA. The findings suggested little or no independent association between health literacy and the number of outpatient physician visits attended within the previous year. However, these findings were contradicted in a recent, smaller study of adult Latinos at risk for diabetes [24]. In the latter case, lower health literacy was associated with greater healthcare service utilization, as measured using a revised version of the Immigrant Use of Health Care Scale. In summary, there is insignificant evidence to draw conclusions about the relationship between health literacy and routine health care use.

8. Urgent Health Care Use

A number of studies have explored the relationship between health literacy and urgent healthcare utilization [80-81]. The literature in this area has focused on patients with heart failure, respiratory illnesses, and on older adults. Despite variation in the population studied and in the measurement of health literacy, the findings consistently linked lower health literacy with an increased use of urgent healthcare utilization. Patients with lower health literacy have been found to be at an increased risk for hospitalization, readmission, and a higher number of emergency department visits.

Associations between health literacy and urgent healthcare utilization among patients with heart failure have been reported in three recent studies [80-82]. Fabbri and colleagues explored the relationship between health literacy and a number of health outcomes among 2487 community-dwelling older adults with heart failure [80]. Using the 3-item BHLS, approximately 10% of patients were identified as having low health literacy (score <8). In adjusted analyses, these patients were found to be 1.3 times more likely to be hospitalized, compared to patients with adequate health literacy (HR=1.30; 95% CI, 1.02-1.66). These findings support research by Bailey et al., which reported patients with above basic literacy had a 12% lower risk of 30-day admission compared to those with inadequate health literacy [81]. This risk was reflected in the incidence rate of readmission for these patients, which was found to be 16% higher among patients with below basic literacy. The findings were based on claims of 7733 Medicare patients hospitalized for acute myocardial infarction. Similarly, a smaller study added a 30% increased risk of hospitalization among patients with low HL [82]. Nevertheless, Peterson and colleagues did not find an association between health literacy and all-cause hospitalization in adjusted models [83]. Notably in the latter study, health literacy was measured using the BHLS (limited health literacy <10).

Among patients with asthma or COPD, the findings suggest an inverse relationship between health literacy and urgent healthcare utilization, with lower health literacy significantly associated with increased emergency department visits and hospitalization [68]. In a recent study from Federman and colleagues of 452 older adults with asthma, patients with lower health literacy (as measured using the STOFHLA) experienced a greater likelihood of asthma-related emergency department visits and hospitalizations [68]. These findings have been supported in studies across the U.S. and Australia among adults with COPD and asthma. Patients with low HL were more likely to report hospitalizations and had higher odds of COPD-related emergency healthcare utilization in the previous year [69,84]. Earlier research from Mancuso did not find associations between health literacy and emergency department utilization in adjusted models [67].

The relationship between health literacy and urgent healthcare utilization also has been reported among adults who use the emergency department (ED) as well as patients with multiple sclerosis [85-87]. In two recent studies of adults presenting to the ED in the U.S., patients with limited health literacy had comparatively more potentially preventable hospital admissions and a higher risk of hospital admissions (in a prior six month period) [86-87]. These findings were supported in a study from Baker and colleagues, in which the odds ratio of hospitalization for patients with inadequate health literacy was 1.69 [88]. Furthermore, among patients who had been hospitalized within the previous year, inadequate health literacy comparatively was associated with a three-fold greater odds of hospital admission [88].

9. Mortality

Overall, the research examining the association between health literacy and mortality has found significant, consistent inverse associations. Studies have primarily been conducted among older populations and individuals with heart failure. Overall, there are three large studies examining health literacy and mortality, and each used different measures of health literacy. Among a sample of older Medicare patients, those with inadequate health literacy (as measured by the S-TOFHLA) had comparatively higher mortality rates when controlling for cognitive function (HR 1.27, 95% CI, 1.03 to 1.57) [89] and baseline measure of socio-demographics, disease, physical functioning and lifestyle (HR 1.52, 95% CI, 1.26 to 1.83) [90]. Similarly, (using the REALM to assess health literacy) significant associations were found between limited health literacy and mortality among a sample of white and African American Medicare beneficiaries (HR 1.75, 95% CI,1.27 to 2.41) [91]. In addition, (in a sample of older British adults adjusted for cognitive function, socio-demographics, and health status), participants with low health literacy comparatively had higher risk of mortality (HR 1.26, 95% CI, 1.02 to 1.55). Among the studies conducted among patients with heart failure, the BHLS was used to assess health literacy. In all three studies, limited health literacy was associated with increased risk of mortality in adjusted analyses [80,83,92]. Interestingly, all three studies used different cut-points for the BHLS. Similar results were found among a sample of individuals with end stage renal disease [93].

10. Summary

This chapter summarizes existing literature exploring the relationship between health literacy and health outcomes from proximal (health knowledge) to distal (mortality), in order to better explore the causal mechanisms through which limited health literacy negatively impacts health outcomes. Interestingly, the authors found the most consistent evidence for the causal pathway at the most proximal and distal outcomes, but less consistent evidence with intermediary outcomes, particularly self-management behaviors and clinical health outcomes. Our findings are consistent with the 2011 systematic review of health literacy and health outcomes, which also found low health literacy was associated with poorer health-related knowledge, poorer overall health status, greater rates of urgent healthcare utilization and hospitalization, and higher mortality [94].

It is not surprising that strong consistent associations were observed between health literacy and health knowledge. While a variety of definitions regarding health literacy exist, the most commonly cited defines health literacy as: "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [95-96]. This definition conceptualizes health literacy largely as a cognitive skill set and is therefore likely to be closely associated with the acquisition of health-related knowledge.

Further along the causal pathway are intermediary outcomes such as engaging in daily self-management behaviors. The authors' findings suggest less consistent associations between health literacy and daily self-management behaviors, including medication adherence and condition-specific behaviors. The authors posit while knowledge is one critical component of carrying out self-management behaviors, motivation, time and resources to follow-through with these behaviors are additional, critical components. Thus, while health literacy may influence health outcomes through the acquisition of health knowledge and subsequent health behaviors, the relationship between HL and health behaviors is likely influenced by other factors. While the role of extrinsic factors are addressed within the Paasche-Orlow and Wolf conceptual model, few studies have explicitly tested the degree to which individual factors versus external or system factors contribute to individual health outcomes [3]. Furthermore, extrinsic factors may be more relevant to intermediary outcomes such as self-management behaviors and may not impact the acquisition of knowledge to the same degree. In turn, the authors strongly suggest the relative impact of contextual factors on the relationship between health literacy and intermediary outcomes should be further studied.

Moving further in the causal pathway towards the more distal outcomes, health literacy was strongly and consistently associated with hospitalization and mortality. These associations may be due to the cumulative effect of living with limited health literacy over a lifetime. The impact of health literacy on health behaviors may not be as significant at any single time point, but rather accumulate over time, ultimately resulting in greater rates of hospitalization and mortality. The cross-sectional nature of the majority of investigations on health literacy hinders exploration of any potential cumulative effect. The authors suggest conceptualizing methods to capture health literacy's cumulative effect on health outcomes may help advance the understanding of its causal effect and should guide future studies.

Relatedly, an additional consideration may be the manner by which health outcomes are measured. Knowledge, hospitalization, and mortality all can be measured objectively, while self-management behaviors are assessed via patient self-report of engaging in specific behaviors. These outcomes are more likely to be impacted by social desirability bias and individuals may over report the frequency they engage in a behavior [97]. It also is plausible that individuals may overestimate how often they engage in routine self-management behaviors and may unintentionally over report. In addition, recent investigations have examined differential item functioning by health literacy level; this process quantifies whether group membership affects the relationship that a questionnaire item has to the concept it measures. Investigators found individuals with limited health literacy respond differently to questions about depression and anxiety than people with adequate health literacy. While the overall impact of differential item functioning on total scores was minimal, some items within the measure were too complex for people with limited health literacy, and inadvertently may contribute to measurement bias [98].

A variety of assessments exist to assess health literacy. Despite no single, common measure, the authors summarized literature that used one of the four most utilized assessments. Although understanding differences in associations was outside of the scope of this review, the authors observed substantial variability in scoring the BHLS while completing our review. There was variability in the number of and which of the three items are used to construct a score, as well as differing cutpoints to classify individuals as limited health literacy. While the BHLS has substantial advantages for administration and collection of health literacy data, the authors recommend future research prespecify thresholds in advance and provide justification for the scoring utilized.

During the past two decades a sizeable body of literature has developed to assess the relationship between health literacy and health outcomes. Much of the research has been implemented in older adult populations or among individuals with specific health conditions. To broaden our understanding of health literacy, and any potential cumulative effect on health outcomes, additional research is needed among younger adult populations. Additional research in younger populations may provide much needed evidence towards the causal pathway, as adults acquire new chronic conditions as they age resulting in the need to acquire new health-related knowledge and engage in new self-management behaviors to maintain health outcomes. The latter provides a unique opportunity to explore the acquisition of health behaviors and health-related knowledge in relation to health literacy. A younger population also may be more malleable than older adults, who may have already established behaviors or may have established poor health that is difficult to surmount. This review also found most extant research has been conducted in very specific disease contexts, most notably diabetes, asthma, and cardiovascular disease. As multimorbidity is increasingly common and people approach disease management holistically, rather than each condition individually, a better understanding of how individuals manage all of their chronic conditions will be warranted [99-101].

In conclusion, limited health literacy is a significant barrier to the acquisition of health-related knowledge and is likely a contributor to poorer self-management behaviors and clinical health outcomes - and culminates to greater urgent healthcare utilization and greater rates of mortality. A substantial body of literature has examined health literacy's impact on health outcomes during the past two decades. In order to advance the field, research studies should seek to conduct longitudinal research studies among younger adult populations in order to better understand health literacy's cumulative effect and how it is impacted by extrinsic factors in order to better elucidate the causal mechanisms through which it impacts health outcomes.

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The Intersections Between Social Determinants of Health, Health Literacy, and Health Disparities

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Abstract This chapter synthesizes what is known about the relationship between social disadvantage and measures of low health literacy (LHL), and reviews the research examining whether LHL is an explanatory factor connecting social disadvantage, health outcomes, and health disparities. Written from a U.S. perspective, the chapter then offers a novel conceptual framework that presents how the social determinants of health might interact with LHL to result in health disparities. The framework articulates relationships that reflect public health pathways and healthcare pathways, which include their related health literacies. In addition, the chapter highlights as an exemplar one important potential causal mechanism in the healthcare pathway by exploring the communication model in outpatient care, as communication has been very well-studied with respect to both health disparities and HL. The chapter then, provides two examples of HL interventions aligned with the conceptual framework, one of which addresses the health care literacy pathway, and the other addresses the public health literacy pathway. The chapter continues with a number of cautionary statements based on the inherent limitations of current HL research, including problems and concerns specific to the attribution of HL as an explanatory factor for extant socioeconomic and racial/ethnic health disparities. The chapter closes with recommendations regarding future research directions.

Keywords: health disparities, health literacy, social ecological model, public health, race and ethnicity, communication, measurement, discrimination, health policy

1. Introduction

This chapter attempts to synthesize what is known about the relationship between social disadvantage and measures of low health literacy (LHL), and to review the research examining whether LHL is an explanatory factor connecting social disadvantage, health outcomes, and health disparities. Written from a U.S. perspective, the chapter also offers a novel conceptual framework that presents how the social determinants of health might interact with LHL to result in health disparities. The latter articulates relationships that reflect public health pathways (e.g. the socio-ecological model, differential exposures and life course perspectives) and healthcare pathways (including health literate healthcare organizations), which include their related health literacies. In addition, the

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chapter focuses on one important potential causal mechanism in the healthcare pathway by exploring the communication model in outpatient care; communication has been well-studied with respect to both health disparities and HL. The chapter then provides two examples of HL interventions aligned with the conceptual framework that address the health care literacy and public health literacy pathways. The chapter continues with a number of cautionary statements based on the inherent limitations of current HL research, including problems and concerns specific to the attribution of HL as an explanatory factor for extant socioeconomic and racial/ethnic health disparities. The chapter closes with recommendations regarding future directions.

2. Operational Definitions of Terms

Social Determinants of Health: The complex, integrated, and overlapping social structures and economic systems that are responsible for most health inequities. These social structures and economic systems include the social environment, physical environment, health services, as well as structural and societal factors. Social determinants of health are shaped by the current and historic distribution of money, power, and resources throughout local communities, nations, and the world [1]. This chapter primarily discusses the social determinants of low income/poverty, low educational attainment, racial/ethnic minority status, and linguistic isolation.

Health Equity: A set of conditions in which all people have the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of their social position or other socially determined circumstance [2].

Health Disparity: A type of difference in health that is closely linked with social or economic disadvantage. Health disparities negatively affect groups of people who have systematically experienced greater social or economic obstacles to health. These obstacles stem from characteristics historically linked to discrimination or exclusion such as race or ethnicity, religion, socioeconomic status, gender, mental health, sexual orientation, indigenous status or geographic location. Other characteristics include cognitive, sensory, or physical disability [3].

Vulnerable Populations: Subgroups of the larger population that, because of social, economic, political, structural, geographic and historical forces, are exposed to a *greater risk of risks,* and are thereby at a disadvantage with respect to their health and health care [4]. Vulnerable populations are exposed to contextual conditions that distinguish them from the rest of the population.

Socio-Ecological Model of Health: Identifies factors affecting behavior and also provides guidance for developing successful programs through social environments. Social ecological models emphasize multiple levels of influence (such as individual, interpersonal, organizational, community and public policy) and the idea that behaviors both shape and are shaped by their surrounding social environment. The principles of socio-ecological models are consistent with social cognitive theory, which suggest that creating an environment conducive to change is important to facilitate the adoption of healthy behaviors.

Mediator Variable: A major goal of health disparities research is to identify and intervene upon modifiable risk factors or exposures that help explain the observed associations between social factors and adverse health outcomes. A mediating variable is one that partially or completely explains the relationship between an independent variable (e.g. an exposure or a risk factor) to a dependent variable (such as a health outcome). Analyses of mediation can allow researchers to move beyond merely asking

"*Does* this risk factor/exposure lead to worse health?" to asking "*How* does this risk factor/exposure lead to worse health?" Statistical methods that incorporate analysis of mediators show promise with respect to identifying evidence-based targets for interventions to reduce health disparities.

3. Limited Health Literacy and Social Disadvantage

It is estimated that one-third to one half of the U.S. adult population has LHL, which is defined by the U.S. Institute of Medicine as a limited capacity to obtain, process, and understand the basic health information and services needed to make informed health decisions [5]. While LHL affects individuals across the spectrum of socio-demographics, LHL disproportionally affects vulnerable populations [6]. These include: the elderly; the disabled; people of lower socioeconomic status; ethnic minorities; those with limited English proficiency, and persons with limited education [7].

The most comprehensive assessment of variation in HL skills across different social groups occurred in 2003 as part of the National Assessment of Adult Literacy (NAAL) [7]. Assessments were carried out in person; individuals had to be age 16 or over and be able to speak English or Spanish fluently. Results of the NAAL (reported in figures 1-4) suggested significant differences in the distribution of HL skills by: race and ethnicity; educational attainment; income; and language spoken before starting school. A more recent study using data from the 2013 Health Information National Trends Survey confirmed these findings [8].

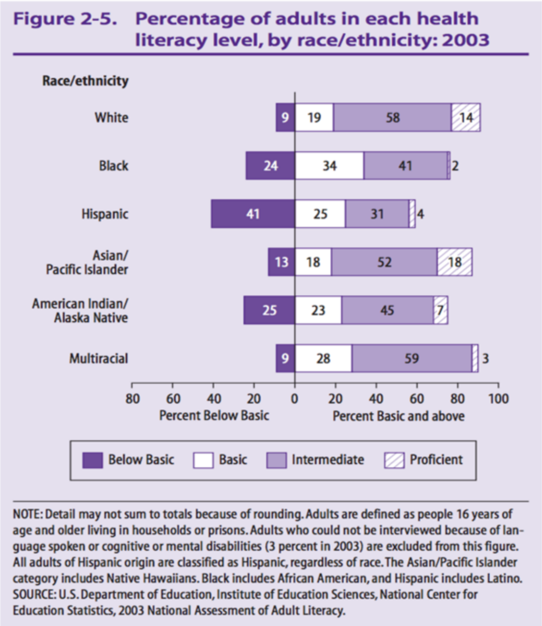
Figure 2-5. Percentage of adults in each health literacy level, by race/ethnicity: 2003

NOTE: Detail may not sum to totals because of rounding. Adults are defined as people 16 years of age and older living in households or prisons. Adults who could not be interviewed because of language spoken or cognitive or mental disabilities (3 percent in 2003) are excluded from this figure. All adults of Hispanic origin are classified as Hispanic, regardless of race. The Asian/Pacific Islander category includes Native Hawaiians. Black includes African American, and Hispanic includes Latino.
SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy.

Figure 1.

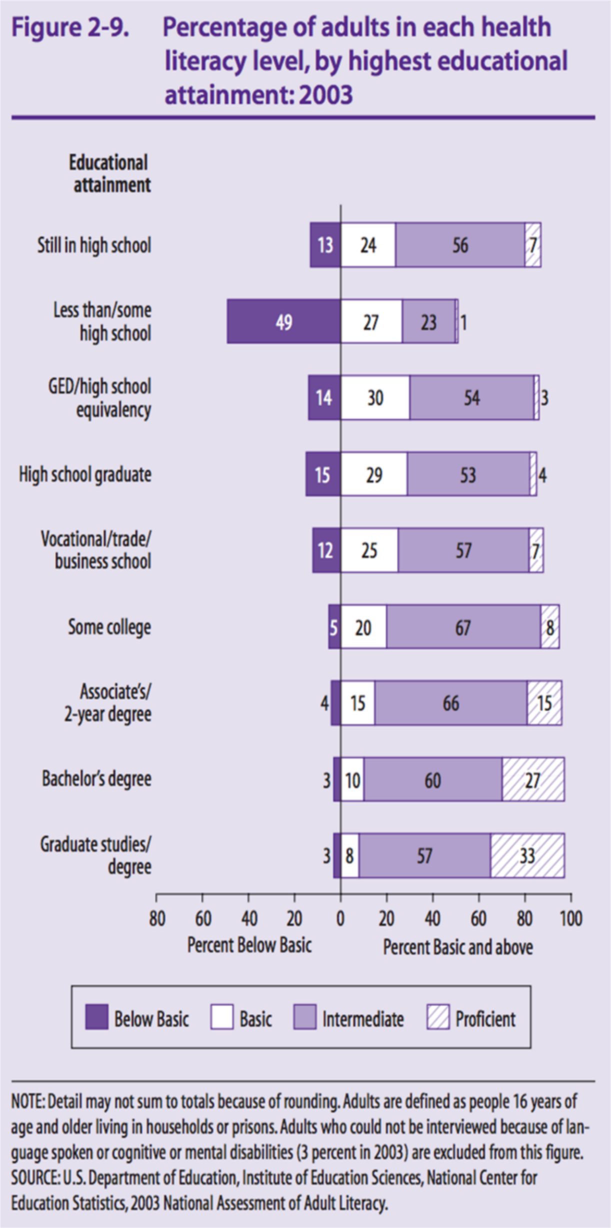

Figure 2-9. Percentage of adults in each health literacy level, by highest educational attainment: 2003

NOTE: Detail may not sum to totals because of rounding. Adults are defined as people 16 years of age and older living in households or prisons. Adults who could not be interviewed because of language spoken or cognitive or mental disabilities (3 percent in 2003) are excluded from this figure.
SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy.

Figure 2.

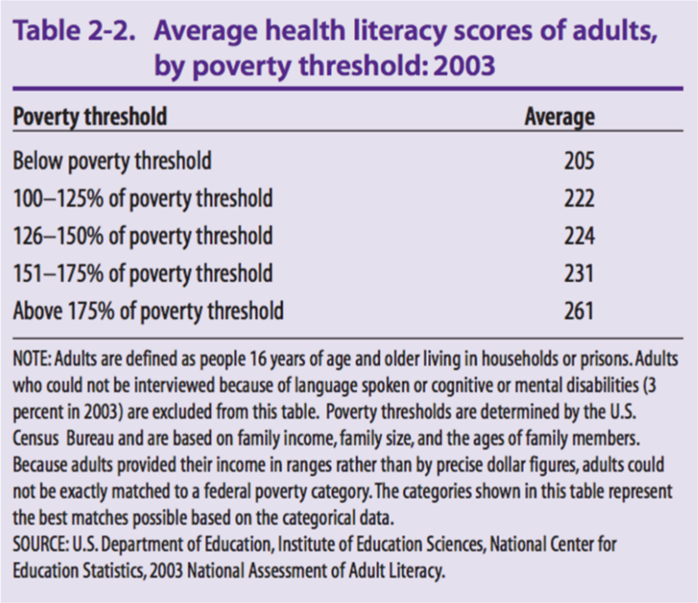

Table 2-2. Average health literacy scores of adults, by poverty threshold: 2003

Poverty threshold	Average
Below poverty threshold	205
100–125% of poverty threshold	222
126–150% of poverty threshold	224
151–175% of poverty threshold	231
Above 175% of poverty threshold	261

NOTE: Adults are defined as people 16 years of age and older living in households or prisons. Adults who could not be interviewed because of language spoken or cognitive or mental disabilities (3 percent in 2003) are excluded from this table. Poverty thresholds are determined by the U.S. Census Bureau and are based on family income, family size, and the ages of family members. Because adults provided their income in ranges rather than by precise dollar figures, adults could not be exactly matched to a federal poverty category. The categories shown in this table represent the best matches possible based on the categorical data.
SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy.

Figure 3.

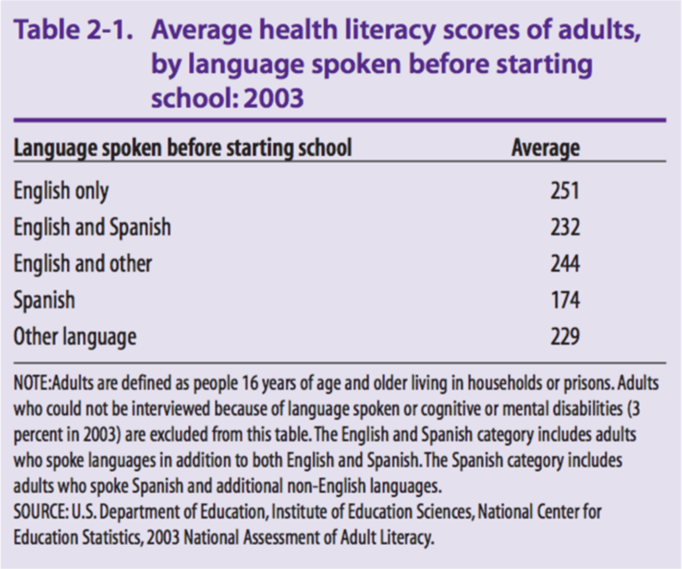

Table 2-1. Average health literacy scores of adults, by language spoken before starting school: 2003

Language spoken before starting school	Average
English only	251
English and Spanish	232
English and other	244
Spanish	174
Other language	229

NOTE: Adults are defined as people 16 years of age and older living in households or prisons. Adults who could not be interviewed because of language spoken or cognitive or mental disabilities (3 percent in 2003) are excluded from this table. The English and Spanish category includes adults who spoke languages in addition to both English and Spanish. The Spanish category includes adults who spoke Spanish and additional non-English languages.
SOURCE: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy.

Figure 4.

LHL should not be considered a ‘diagnosis,’ but rather a common pathway, marker for (or manifestation of) a number of life circumstances, including but not restricted to limited access to education, access to poor quality education, limited English proficiency, learning differences and disabilities, and cognitive impairment. Patients with LHL are more likely to have poor health, higher rates of chronic disease, and a nearly twofold higher mortality rate as compared to patients with adequate HL [9].

Compared to those with adequate HL, persons with LHL also are more likely to experience disparities in health and health care access - and have lower rates of receiving screening and preventive services. Patients with LHL exhibit patterns of utilization of care reflecting a greater degree of unmet needs, such as excess emergency room visits and hospitalizations, even when comorbid conditions and health insurance status are statistically held constant. Patients with LHL are more likely to have poorer knowledge of their disease processes, medication regimens, and exhibit worse medication adherence and inadequate skills and methods for managing their disease [9-10]. LHL also has a negative effect on doctor-patient communication. Patients with LHL more often use a passive communication style with their physician, are less likely to engage in shared decision-making, and are more likely to report that interactions with their physician are not helpful or empowering. It has been estimated that LHL leads to excess health expenditures of greater than $100 billion annually [11].

4. Evidence Connecting Health Literacy with Health Disparities

The problem of health disparities experienced within vulnerable populations is largely one of differential exposures and associated behaviors that eliminates some of the ‘shame and blame’ often associated with the higher burden of disease among socially disadvantaged people. As such, social vulnerability is not necessarily an attribute that is intrinsic to individuals or sub-populations; instead vulnerability status is determined by how society and its institutions are constructed. LHL is tightly and simultaneously linked to a number of social determinants of health. Some investigators and health policy experts have even considered LHL itself to be a social determinant of health. The high burden of LHL among vulnerable populations has led many to believe that LHL is a contributor to both health and healthcare disparities. In turn, an ensuing question is: might health literacy (HL) partially explain the health disparities associated with the social determinants of health? While the issue is of paramount importance, relatively little collaborative research has provided an empirically rigorous answer [12].

In public health practice in the U.S., vulnerable groups are often considered to be of (a) certain races and ethnic minorities, (b) low income, (c) those with a high school diploma or less, and (d) immigrants and those with limited English proficiency. Recent research, including a systematic review, focuses on (a) and (c) with respect to the question of whether HL explains some of the relationships between social circumstances and health outcomes [13]. In addition, the extant research is varied with regard to health-related outcomes and the HL assessments used. In general, multivariable modeling has been used in an attempt to determine independent effects of predictors and mediating variables on specific health outcomes. Some evidence has reported a mediating function of HL on health outcomes across racial/ethnic and educational disparities. Some evidence suggests the potential effect of HL and numeracy on racial/ethnic disparities in health behaviors and knowledge. In all research with positive associations, the effect of the mediation was partial; HL did not fully explain broader relationships.

More specific research about: health disparities related to educational attainment; health disparities related to race/ethnicity; health disparities between ethnic and linguistic sub-groups; prospective studies; and a public health perspective are outlined below.

4.1. Health Disparities Related to Educational Attainment

While a number of cross-sectional studies have explored HL as a meditating factor in the relationships between socioeconomic disparities and health outcomes, the following research specifically evaluates the relationship among HL, other variables, and educational attainment. An assessment by Bennett and colleagues (of nearly 3,000 adults over age 65 who participated in the NAAL) found HL mediated the relationship between educational attainment and self-rated health, receipt of flu vaccines, receipt of mammograms, and dental care [14-15].

A study by Howard and colleagues (of more than 3,000 seniors who participated in the Prudential Study) found HL explained the relationship between education and physical and mental health scores, but not preventive care use, such as flu vaccine, mammograms, and dental care [16]. A study by Yin and colleagues (of parents who participated in NAAL) found HL mediated the relationship between educational attainment and HL-related tasks regarding child health, dosing medications, and pediatrician appointments.

Sentell and Halpin studied 24,000 participants in the NAAL (performed in the 1990s) and found HL mediated the relationship between education and the presence of chronic illness and a health condition that limited ability to function in society [17]. Similarly, in a study of more than 14,000 persons with diabetes in a large, pre-paid integrated health plan, Sarkar and colleagues found HL mediated the relationship between educational attainment and patient's use of an electronic patient portal, which was associated with better health outcomes [18]. Finally, Schillinger and colleagues studied a diverse sample of more than 400 public hospital patients with diabetes and found HL mediated the relationship between education and hemoglobin A1c (a measure of diabetes control) [19].

4.2. Health Disparities Related to Race/Ethnicity

As to whether HL explains racial and ethnic disparities in health outcomes, a number of cross-sectional studies - some already mentioned, some additional - have looked at the explanatory power of HL with respect to black/white differences in health outcomes; few studies have assessed other racial or ethnic differences. Bennett and colleagues (2009) found HL mediated the relationship between race and self-rated health and flu vaccine receipt, but not mammography or dental care [15]. Howard and colleagues (2006) found HL mediated the relationship between race and mental health but not physical health and not the receipt of preventive care [16].

Sentell and Halpin found HL mediated the relationship between race and long-term illness and a limiting health condition, just as HL did with education [17]. In a study of 373 parents, Bailey and colleagues found HL mediated the relationship between race and misunderstandings about liquid medication dosing [20]. Osborn and colleagues found diabetes-related numeracy mediated the relationship between race and Hemoglobin A1c (a measure of blood sugar control), an effect seen primarily in diabetes patients who used insulin [21]. In patients with prostate cancer, Wolf and colleagues found HL mediated the relationship between race and the level of prostate-specific-antigen (PSA) at the time of presentation with prostate cancer [22]. Osborn and colleagues found HL mediated the relationship between HL and diabetes medication adherence [23]. Another study suggested that, while HL reduced the effect of race/ethnicity in African Americans and Hispanics on asthma quality of life and asthma control (and for African Americans only on emergency department visits), differences between African Americans and whites for asthma-related hospitalizations remained [24]. Finally, a study of more than 225 mostly black and white patients demonstrated HL mediated the relationship between race and a measure of patient activation [25].

4.3. Health Disparities between Ethnic and Linguistic Sub-Groups

Relatively few studies have explored the effects of HL in health disparities experienced by Hispanic or Asian sub-groups, and still fewer have examined HL's role in explaining health disparities associated with limited English proficiency (LEP). A study comparing Spanish to English speakers in an emergency department suggested only the former were less likely to keep up follow-up appointments if they had LHL [26]. A study of Asian Americans found LHL was not significantly associated with meeting colorectal cancer screening guidelines, but LEP was [27]. However, the combination of LEP and LHL had synergistic effects among Asians. A large study that featured diverse participants found LHL was only significantly related to health status in whites and 'other races,' but not within any Asian group. However, the study found the highest odds of poor health status occurred among Chinese, Vietnamese, Hispanics and 'other races' with LHL and LEP [28]. Similar synergistic effects were observed on patient-reported interpersonal communication outcomes in a large sample of English and Spanish speaking primary care patients [29]. LHL and LEP each was associated with worse communication within the receptive, expressive, and interactive domains of interpersonal communication, while the combination was associated with the worst communication.

4.4. Prospective Studies

Only five prospective studies have examined the question of HL as a mediator of health disparities. In a longitudinal cohort study with 342 black, Hispanic and white adults with persistent asthma, HL mediated the relationship between race/ethnicity and asthma-related hospitalizations and ED visits [30]. In a before and after trial, Volandes et al. found HL mediated the relationship between race and changes in advanced care preferences [31]. After viewing a video, patient preferences, particularly among those with low HL, changed to preferring less aggressive care. Otherwise, an experiment of the differential effects of race/ethnicity (black vs. white) and HL that studied response to a telephone-based osteoarthritis self-management support intervention) found a significant interaction between HL and race/ethnicity on change in pain; non-whites with low HL had the highest improvement in pain in the intervention compared to the usual care group [32]. Finally, a natural experiment (involving more than 8,000 ethnically diverse patients with diabetes to enhance medication adherence, implementation of an intervention to promote mail-order pharmacy use that was not tailored for patients with LHL) reported a differential uptake of the intervention that further disadvantaged LHL patients, especially among Latino, and lower income subgroups [33]. A trial of literacy-appropriate, easy-to-understand video narratives and testimonials (presented in English and Spanish to encourage advance care planning demonstrated improvements across HL levels) yielded additional benefits for Spanish speakers, although the interaction between study arms and language was not statistically significant [34].

4.5. A Public Health Perspective

In reviewing this literature, it is important to note that many studies applied clinical epidemiologic approaches to address the larger question whether LHL can explain health disparities by either exploring the interactions among HL and a particular social determinant (e.g. race, education) on health outcomes, or performing formal meditational analyses. In so doing, investigators attempted to answer whether HL had differential effects on health outcomes based on an individual's race or educational attainment.

Yet from a public health perspective (given the disproportionately high prevalence of LHL among vulnerable populations), these types of analytic approaches may be overly reductionist. Insofar as LHL is more prevalent in socially disadvantaged populations, and insofar as LHL appears to be an explanatory factor in the development of illness or its complications across populations, interventions to effectively address LHL are likely to result in a reduction in health disparities. Yet, the effect may be because LHL is equally distributed across the U.S. population more than the unique explanatory power of LHL.

In turn, figure 5 in section five describes a novel conceptual framework that integrates a social-ecological model with the more traditional causal frameworks associated with HL. The proposed conceptual model synthesizes research from multiple disciplines (such as clinical epidemiology; health services research; anthropology; health communication science; and public health) to better explain the potential pathways by which the social determinants of health, HL, and health disparities interact. The framework, and its explication, elucidate pathways and its associated factors additionally provide potential targets for intervention in the effort to reduce health disparities.

5. Conceptual Framework for the Relationships Between Social Determinants of Health, Health Literacy and Health Disparities

Figure 5 suggests there are two predominant pathways through which social determinants of health and social disadvantage can interact with LHL to result in health disparities. The first is the public health pathway (on the left of Figure 5) that suggests the structural factors that reflect the (mal) distribution of health-promoting resources and unhealthy life course exposures across the *general population* in the U.S. The second is the healthcare pathway (on the right of Figure 5) that suggests the organizational factors that reflect the responsiveness of health systems to the needs of *clinical populations* in the U.S. - with respect to access to and quality of care. Differences in resources and exposures in public health and community settings, as well as differences in access and quality in clinical settings, both foster consequences that contribute to worse health outcomes and health disparities. Several of the constructs and variables within Figure 5 are introduced below.

5.1. Social Determinants of Health

This box (and construct) is the starting point for all pathways and reflects the unequal distribution of health-promoting resources and unhealthy life course exposures resulting from differences in social status, often instigated, reinforced, or perpetuated by social policy and practice. This construct focuses on sub-populations of low income/poverty status; low educational attainment; racial and ethnic minority populations subject to marginalization or oppression; and those with LEP/linguistic isolation.

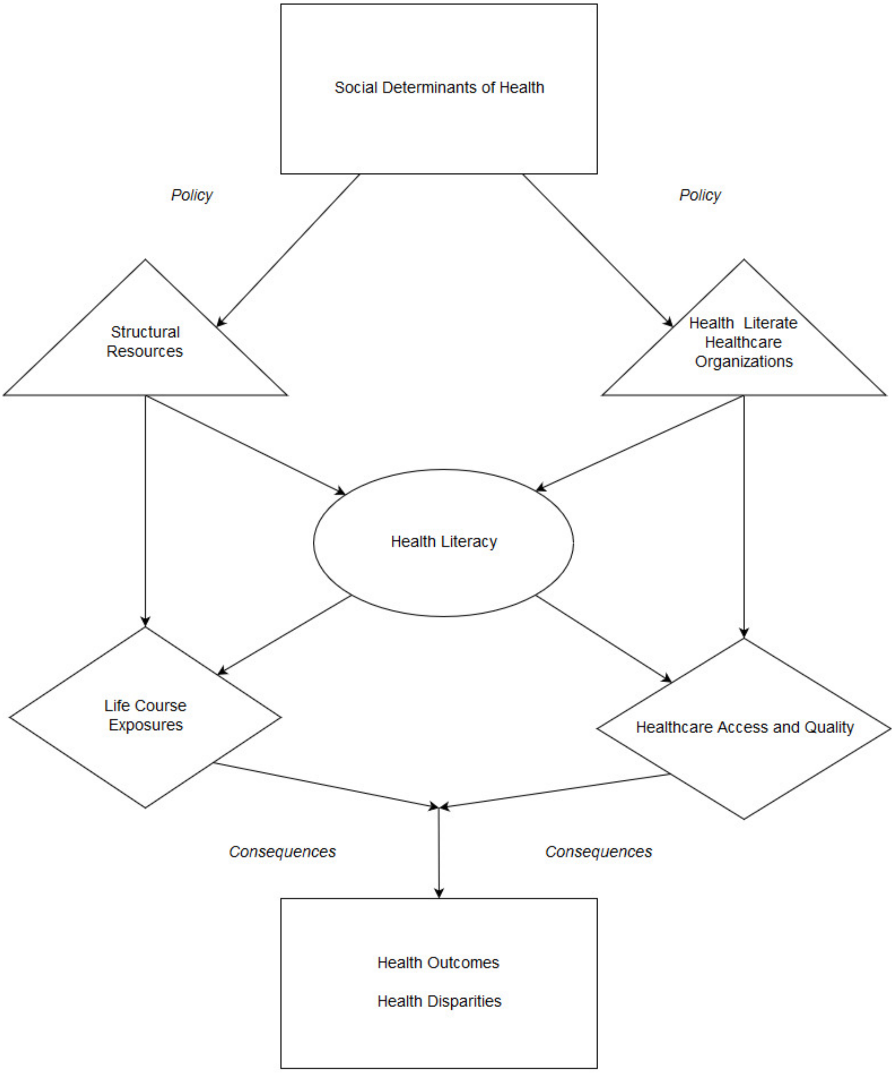

Figure 5: Conceptual Framework for the Pathways that Connect Social Determinants of Health, Health Literacy and Health Disparities. Pathways on the right represent healthcare pathways; those on the left represent public health pathways

5.2. Structural Resources and Life Course Exposures

The triangle and diamond represent the factors within the public health pathway protective to health with those that jeopardize health, which often shape health behaviors. These factors - so-called ‘structural determinants’ - flow from institutional, local, state and federal policies, and generate facts on the ground that can profoundly affect individuals, families, neighborhoods, etc. The balance between health-promoting resources and risk exposures over the life course are a major determinant of the health of individuals and communities. Some of these structural factors include: air quality/pollution; safe and green spaces for physical activity and recreation; features of the built environment and associated zoning regulations; transportation infrastructure; housing/segregation; the retail food environment/food deserts; commercial marketing environments (such as advertisements on billboards for unhealthy products); employment opportunities and occupational hazards; community stress and trauma; presence or absence of public health-promoting regulations; social support; social cohesion; and social investment.

5.3. Related Health Literacy Domains

Within the public health pathway, HL is depicted as both a product of the social determinants of health as well as a potential asset that can positively influence the balance between health-promoting resources and unhealthy risk exposures, and/or mitigate the ill effects of unhealthy exposures. Health exposures include: environmental HL; occupational HL; nutritional HL; mental HL; and the larger construct of 'public health' literacy. Public HL can be an attribute of an individual, a community, or an entire population. Public HL refers to the degree to which individuals and groups can obtain, process, understand, evaluate, and act upon information needed to make public health decisions that benefit the community [35]. Public HL aims to engage more stakeholders in public health efforts and address determinants of health. It requires an understanding of conceptual foundations related to the socio-ecological model of health, critical skills, and a civic orientation. While advocacy and policy change are its currency, improving the health of the public is its ultimate objective.

5.4. The Consequences

The depiction of the (mal) distribution of resources and exposures between populations, compounded by a disproportionately high rate of LHL of the types described above among vulnerable populations, has real consequences for health behavior and health status. These include higher rates of chronic diseases, such as: obesity, type 2 diabetes, cardiovascular disease and stroke, and asthma; cancer; mental health problems related to trauma, toxic stress and PTSD, substance use disorders, and depression; and disability.

5.5 Health Literate Healthcare Organizations

The depicted triangle represents the next step in the healthcare pathway connecting social determinants of health, HL, and health disparities. Schillinger, Keller and Brach defined health literate health care organizations (HLHCOs) as those that ensure HL is deeply and explicitly integrated into all of their activities - and HL informs both strategic and operational planning [36]. Appropriate measures to evaluate specific HL initiatives are developed and used. More importantly, the measurement of overall organizational performance assesses success with vulnerable populations. However, because of inadequacies and bias in health policy, healthcare financing, healthcare regulation, health professions training, healthcare innovation and healthcare practice, there is significant variation in the degree U.S. healthcare systems are responsive to the needs of socioeconomically and ethnically diverse patients with varying levels of HL. As such, the extent to which health systems demonstrate the attributes of HLHCOs reflects a structural determinant of health.

5.6. Healthcare Access and Quality

The depiction in Figure 5 underscores a flaw within the U.S. healthcare system where the patients who maximally benefit from health care often have the greatest capacity and resources, including but not limited to HL. In contrast, the healthcare system's weaknesses are undergirded by issues related to *access to care*, including: incomplete and/or unequal health insurance coverage; unnecessary barriers to obtaining public insurance; overly complex health insurance practices; insufficient provider workforce for specific (underserved) populations; lack of a diverse healthcare workforce; under-valuing or under-resourcing primary care; and segregation of healthcare (including an obligatory over-reliance on overextended safety net health systems among vulnerable populations). There are additional features within many U.S. health systems that further undermine the *quality of care* and are particularly salient for disparity populations and patients with LHL. These include: inadequate preparation and training of the clinical workforce and associated poor provider performance (especially with respect to interpersonal processes of care); insufficient caregiver involvement and support; lack of ethnic and linguistic diversity in the workforce; lack of involvement of vulnerable populations in the design of healthcare services and its associated innovations; lack of peer and lay health educator models; lack of HL-appropriate digital health/e-health innovations; lack of resources and integrated interventions to assess and address social needs; fragmentation of healthcare; lack of inter-visit communication; incomplete trust in provider; and insufficient or inappropriate policies, regulatory standards, oversight, measurement and/or incentives to reduce disparities and promote healthcare equity [37-38].

5.7. Related Health Literacy Domains

Within the depicted healthcare pathway, HL is a product of HLHCOs as well as a potential asset that can positively influence the balance between HL-related demands healthcare systems place on patients and the HL-related skills of patients and families. The latter can mitigate the effects of receiving care in systems that are unresponsive to the needs of persons with LHL. Much has been studied and written about the patient-related HL skills required to optimally function within U.S. healthcare settings. These skills include communicative HL capabilities, such as: speaking; listening; reading and, increasingly, writing (e.g. secure messages in electronic patient portals) of health–related content; quantitative skills; e.g. health numeracy; and health insurance literacy - e.g. the ability to navigate bureaucratic procedures and advocate for oneself [39].

5.8. The Consequences

Overall, the lack of evolution and diffusion of the model of HLHCOs, combined with the fragmentation, overextension, and under-resourcing characteristic of many safety net healthcare systems (further compounded by a disproportionately high rate of LHL of the types described above among vulnerable patients), yields consequences for healthcare disparities - with respect to access, processes of care, and outcomes. The latter include: late presenting to medical attention - often with more advanced disease; demonstrating more missed appointments; poorer self-management skills; lesser degrees of patient activation; sub-optimal clinician-patient communication; less shared decision-making; lower trust; worse quality of care; and greater rates of medical error and patient safety events. The consequences of the depicted healthcare pathway, together with the public health pathway (which leads vulnerable populations to be even more reliant on healthcare because of a higher burden of disease) includes greater complication rates, worse health outcomes, higher costs of care and utilization of services, and greater premature morbidity and mortality.

6. Limited Health Literacy and Disparities in the Clinic Encounter: A Focus on the Communication Model

While a comprehensive framework for social determinants of health, HL and health disparities is presented in Figure 5, much of the HL research interested in understanding the contribution of LHL to healthcare disparities has focused on health communication issues. As a result, health communication is underscored in the healthcare pathway within Figure 6. Building on prior research, Schillinger and colleagues have described a model of communication within clinic settings, using the chronic disease management exemplar in ways that provide insights into HL and the emergence of healthcare disparities [39-40]. The model in Figure 6 shows how communication barriers such as limited HL (which are more common among populations subject to health and healthcare disparities) can impair the development of *shared meaning* along the path to achieving optimal health and wellbeing. More specifically, the pathway is: Patient HL and provider communication skills→ Effective elicitation and explanation→ Patient-provider concordance→ Shared meaning → Trust and therapeutic alliance → Appropriate clinical decision-making → Optimal treatment adherence → Health and well-being.

The model in Figure 6 identifies the co-creation of ‘shared meaning’ as the most proximal, desired visit outcome [41]. This outcome attempts to achieve patient-clinician agreement in two domains: (a) *elicitation domains*, in which clinicians assess disease state and symptom burden and uncover barriers to adherence (including social vulnerabilities and resilience factors, as well as treatment-related preferences and value);

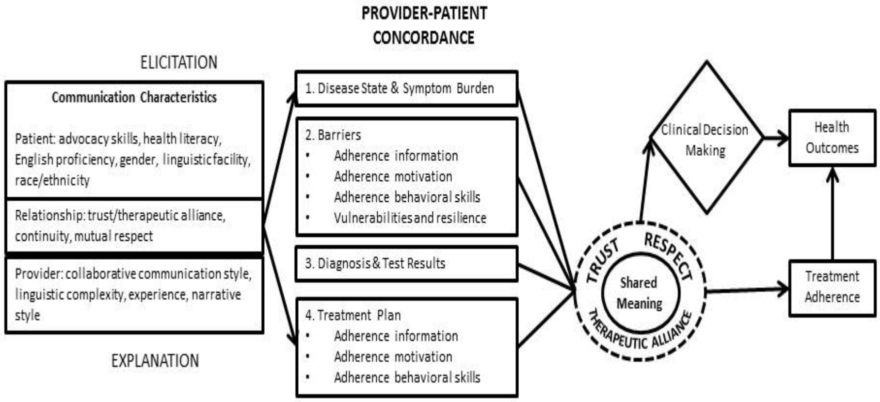

Figure 6. Model for successful communication with vulnerable patients in the outpatient clinical encounter. (From: Schillinger D, et al. The Next Frontier in Communication and the ECLIPPSE Study: Bridging the Linguistic Divide in Secure Messaging. *J Diabetes Res* 2017)

and (b) *explanatory domains*, in which clinicians convey diagnoses and results and discuss treatment plans.

Achieving shared meaning within these domains requires that each party within a dyad employs a combination of communication skills and a commitment to the relational aspects of communication that are mutually reinforcing. Showing authentic interest in the patient as a whole person (e.g. noting you are curious about him or her beyond symptoms or illnesses) and coaching a patient into telling his or her story promotes disclosure of barriers and narrows social distance while fostering trust and a more therapeutic alliance with the patient, a more intermediate outcome.

In what is considered a benevolent cycle, the depicted therapeutic alliance engenders greater degrees of shared meaning - and greater degrees of shared meaning can enhance a therapeutic alliance. The interplay between the use of narrative approaches, the co-creation of shared meaning, and the deepening of the therapeutic alliance can improve clinical decision-making and resource acquisition, promote adherence, and enhance overall health – the more distal outcome. A collateral benefit is such relationship-centered care not only appears to reduce health disparities but also can enhance clinician well-being and serve as both a preventive measure against, and a tonic to, clinician burn-out [42].

7. Examples of HL Interventions Relevant to Health Disparities Reduction

The chapter now provides examples from the author's practice-based intervention research to illustrate how the conceptual framework described in Figure 5 and Figure 6 inform the understanding of how the social determinants of health interact with HL to generate health disparities - as well as provide some insights regarding HL interventions.

The first example is related to the healthcare pathway noted in Figure 6. Schillinger, Bhandari, and Machtinger assessed the management of a common cardiac arrhythmia - atrial fibrillation - that is more prevalent in populations of low income and limited education [43-45]. Since this condition can foster clots to form in the heart and travel to the brain - resulting in a stroke -- it requires patients strictly adhere to an often complex medication regimen to thin the blood (an anticoagulant medication). Accurate anticoagulant control is critical to prevent stroke (a therapeutic effect) or prevent bleeding (a side effect). The investigators initially showed anticoagulant medication miscommunication was common; both LHL and Hispanic ethnicity were predictors of medication discordance and resultant poor anticoagulant control. However, enabling patients to communicate the anticoagulant regimen using a visual aid improved medication regimen concordance when compared to verbal communication. A subsequent intervention study involving patients in poor anticoagulant control suggested the use of a visual aid, when combined with a simple HL practice (one round of the teach-back method), when compared to usual care, was associated with a more rapid achievement of anticoagulant control, an effect observed only with those who misunderstood their regimen at baseline.

The second example relates to the public health pathway in Figure 5 and describes a public HL campaign to prevent type 2 diabetes (T2D) [46-47]. Once known as adult-onset diabetes, T2D is a significant epidemic that now affects children at alarming rates. During the last decade, T2D rates have tripled in American Indian youth, doubled in African American, and increased by 25-50% in Asian Pacific Islanders and Hispanic youth, and pre-diabetes rates have more than doubled across all ethnic groups. Public discourse predominantly frames T2D as a medical or individual behavioral problem, impeding progress on prevention. Steering attention to social and environmental forces can enable prevention efforts to gain traction.

The Bigger Picture campaign (TBP, thebiggerpictureproject.org) is a youth-generated campaign in the San Francisco Bay Area in which talented low-income youth and youth of color transform themselves from being *targets* of metabolic risk to *agents of change* by shifting conversations about T2D towards 'the bigger picture;' its social and environmental drivers. TBP merges the arts (spoken word) with public health to fuse youth's understandings of T2D with their lived experiences. Poets powerfully advocate for positive social change to eliminate T2D in young people and in communities of color by crafting messages aligned with values held closely by adolescents. The messages resonate with teen peers and effect change, especially *social justice* and *defiance against the social order*.

TBP's gifted artists and dynamic influencers create content that can motivate their peers to 'take a stand against injustice,' eliciting righteous anger and activation for civic engagement. Engaging in healthy behaviors, such as not consuming soda or junk food, or advocating for local policy change to make the healthy choice the easy choice, become ways to rebel against oppressive societal practices and structural forces that undermine health.

Moreover, TBP has observed impressive gains in both individual nutritional literacy and public HL - with youth showing a new understanding of 'how health happens' (e.g. the socio-ecological model) and a commitment to join the fight against T2D. TBP has won health and media/film awards; its efficacy is well-documented and its reach impressive (~2 million views); and its unique approach to fostering a culture of health among low-income youth, youth of color, and their stakeholders has contributed to local public health efforts to reduce health disparities. The latter efforts include the passage of a tax on sugar-sweetened beverages and an initiative to promote water consumption by installing filtered water stations in low-income communities.

8. Caveats Regarding Health Literacy as an Explanatory Factor in Health Disparities

To back up, the scientific endeavor combines unbiased experimentation with objective observations of the natural world to accumulate knowledge so as to approximate truth. However, while medicine is largely seen as a force for good, clinical science has a deeply checkered record of, at times, using its tools and its authority to promote or perpetuate inhumane policies and practices ranging from unethical research and medical practices which have harmed lower income and minority populations, to "racial hygiene" and race-based genocide.

When examining the question of whether and how HL affects health, researchers need to be mindful that literacy represents a resource which, for minority subgroups, historically has been withheld as a means to oppress, or has been measured and then used to judge groups as inferior or ineligible to participate as citizens as an alternate means to oppress [48]. There are several related challenges in HL research that researchers, policymakers and practitioners must be aware of that temper confidence in the validity of the research and its synthesis just presented, which encourage additional, complementary research to better approximate truth. The specific challenges of measurement and attribution are discussed in the remainder of this section.

To begin, there are diverse challenges associated with research measurement [49]. How best to measure patient HL - and whether or not HL measures are detecting true differences in capacities and skills in marginalized populations - can be problematic and controversial. A recent review of all HL research measures found that at least 51 unique measures have been created and employed, including a number in Spanish, with virtually all requiring paper and pencil responses, with individual measures requiring up to one hour to administer. Of the 51, 26 measured general HL, 15 measured disease or content-specific HL, and 10 measured specific sub-populations [50].

As previously described, health disparities are produced and perpetuated by multilevel forces operating at the individual, family, health system, community, and public policy levels that mutually reinforce each other to produce injustice and perpetuate inequity. Since conventional literacy assessments are bounded by cultural and linguistic assumptions derived from the dominant, majority population, more research is needed to assess patient HL in a comprehensive, holistic, and unbiased manner, and to expand the assessment of reliability and validity across sub-groups of interest in order to avoid misattributing health disparities solely to limited HL.

A clear, but by no means isolated example of this challenge is the use of HL measures that require proper pronunciation of medical terms to assess HL, such as the REALM (Rapid Estimate of Adult Literacy in Medicine). It is not hard to imagine that a measure in which a white researcher from a Northeast US institution scores a patient's HL by determining whether a patient has read and pronounced a medical term correctly may lead to biased measurement. This is especially true if the subject is, for example, a black patient born in the southern U.S. whose pronunciation of some words in the English language may differ from that of the dominant or 'mainstream' linguistic culture, be that in medicine or any other field that involves both language and a pre-existing knowledge base [48]. The problem of cultural hegemony in literacy assessment, and the untoward downstream effects of related mis-measurement, is well elucidated in the social psychology field [51].

A second research challenge is attribution. The critique here is both general to social epidemiology and specific to HL research. For example, do the observations that LHL is more common is marginalized populations, and that in some cases observed social disparities in health outcomes appear to be (statistically) 'explained' by LHL suggest that the mediational relationship represents a causal pathway? There are alternative hypothesized mechanisms by which LHL may be associated with healthcare quality and health outcomes in research exploring the causes of health disparities among vulnerable population that are not causal [52]. These mechanisms include:

a) *Confounds*: LHL may simply be a marker for, or a result of socio-demographic and behavioral factors or life course exposures or experiences that by themselves directly or indirectly lead to morbidity and mortality. While most studies attempt to account for confounds using multivariable analytic methods, it is widely recognized that socio-economic variables obtained at one point in time (such as income) only incompletely capture income over the life course, or that income does not equate with assets and wealth. As such, residual confounding is not only possible, but is almost certain to exist. Similarly, while variables such as race or immigration status are often collected, these measures do not begin to capture the experience of being black or an immigrant in the U.S.

b) *Reverse or cyclical causation*: LHL may be a consequence of high disease burden or poor disease control, and thus associated with worse health trajectories (cyclical effect). In addition, individuals with longstanding T2D that is poorly controlled have been shown to experience worse cognitive function as a complication of the disease. In turn, this may contribute to the downward trajectory in self-management due to poor understanding - but it may be captured as LHL within a HL assessment, all occurring in a patient whose clinical course has already been largely determined.

c) *Attention bias*: What we choose to measure and what we choose not to measure inevitably influences inferences regarding cause and effect. LHL may affect outcomes through a demand-capacity mismatch, with the healthcare system placing inappropriate communication demands on patients; or communication resources are poorly distributed for the population with the greatest needs. The latter hypothesis suggests changes at the health system level provide intervention targets to mitigate health disparities related to LHL. While greater attention is finally being paid to the communication attributes of clinicians and healthcare organizations as they relate to patient HL, there has been little work to operationalize a measure of clinician or systems responsiveness to the needs of population with LHL [53]. This has hindered progress in reducing HL and racial and ethnic disparities in healthcare [49].

d) *Attribution bias*: Finally, insofar as literacy skills – be they HL or otherwise – reflect a resource that results from privilege and power, the absence of literacy reflects a particular manifestation of oppression and marginalization, be it historical or ongoing. Following this argument, those with LHL have inexorably been exposed to other forms of systematic deprivation - including forms of inter-generational oppression that are difficult or impossible to measure at the individual level. In this case, LHL - despite consistently demonstrating statistically significant meditational relationships - presents itself as an overly simplistic, stereotype-laden, and potentially dangerously false explanation for observed health disparities.

9. Conclusions and Future Directions

Limited HL is more common in populations who are socially disadvantaged, and there is a growing body of research to suggest that LHL may be an explanatory factor in pathways that generate health disparities. To better understand the potential mechanisms whereby LHL can mediate health disparities resulting from the social determinants of health, this chapter presents a novel conceptual framework that can inform research, policy, and practice for those interested in promoting health equity in the U.S.

The framework describes two primary pathways that generate consequences for health outcomes. The first operates through multi-level factors related to the unequal distribution of resources and exposures, and their related environmental and public health literacies. The second operates through underdeveloped institutional capacities of the health care systems, and related individual communicative literacies of the patients that rely on these systems. Both pathways emerge within a complex society characterized by competing forces that reflect both a history of marginalization and oppression of vulnerable sub-groups as well as a tradition of civic engagement and advocacy for progressive change that is the foundation of democracy. HL research - both descriptive and interventional - while still in its infancy, represents a progressive force whose objective and early achievements help reverse deeply ingrained policies, structures, and practices that create, perpetuate, or even amplify health disparities.

Nevertheless, when it comes to shedding light on the fundamental causes of health disparities, articulating mechanisms leading to health disparities, and intervening to promote health equity, HL research needs to evolve in at least six ways to achieve its promise. First, future research should focus on developing alternative HL measures that are not subject to bias and mismeasurement in marginalized populations - and should attend to ensuring the reliability and validity of these measures across population subgroups. Second, more attention needs to be paid to comprehensively measure confounding variables, with a particular emphasis to avoid attribution bias. Third, since most HL research has focused on patients' HL deficits; more work needs to operationalize a measure of clinician or systems' responsiveness to the needs of populations with LHL, including the communication attributes of clinicians and healthcare organizations.

Fourth, descriptive research must be designed and powered to enable the simultaneous disentanglement of socioeconomic status, race/ethnicity (representative of *all* major ethnic subgroups) and limited English proficiency from HL, and to enable valid and informative meditational analyses, with a particular emphasis on longitudinal studies. Fifth, investment in interventional research must increase to: (a) ensure an ability to stratify effectiveness results by socio-demographic characteristics as well as by HL level; (b) enable exploration of interaction effects; and (c) include public HL interventions. Relatedly, a lack of differential effectiveness should not prevent the dissemination, uptake, and adoption of HL-appropriate interventions; rather, given the disproportionate burden of LHL in vulnerable populations, such interventions should be seen as an important means to reduce health disparities.

Finally, while making significant advances during the last twenty years, the field of HL research in the U.S. has involved a relative paucity of investigators from under-represented minority (URM) groups, groups that otherwise are very active in the field of health disparities research. This may be due, in part, to the inherent assumptions, biases and limitations that HL research to date suffers from, as described above. While there is a growing body of community-based participatory research in the field of HL, there remains a critical need to extend and enhance HL research by including the experience, voices, and intellectual capacity of a multidisciplinary cohort of URM researchers. Only by expanding inclusivity in this way will the field of HL be able to be optimally harnessed to reduce health and healthcare disparities.

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How Health Literacy Develops the ‘Four Aims’ of Better Health Care

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Abstract. The chapter’s audience and purpose are twofold. First, the chapter introduces the ‘Quadruple Aim’ to policy makers and provides a general overview of health literacy strategies and tools to meet the Quadruple Aim to enhance care delivery while reducing costs.

Second, the chapter identifies gaps in health literacy related research and encourages a research agenda to further the evidence base of health literacy to reduce cost, enhance quality, increase access, improve satisfaction, and achieve health equity

Keywords. Health literacy, Quadruple Aim, health care quality

1. Introduction

The Quadruple Aim framework is an extension of the Triple Aim [2] in health care and focuses on: 1) enhancing the quality of care; 2) improving the health of communities; 3) reducing costs; and importantly 4) improving the care and experience of patients and providers [1]. Health literacy is a vital component to achieve the Quadruple Aim. Specifically, health literacy is especially important for people who experience medication errors, higher rates of hospitalization and emergency room use, poorer health outcomes, as well as increased illness and early death [3]. The sections below provide a evidence-based business case from an updated review of the peer reviewed literature as well as searches and requests for promising practices from the grey literature and non-peer reviewed reports [4-5].

Section 2 focuses on health literacy interventions and initatives to improve the patient expericne and specifically focuses on quality of care and satisfaction. Section 3 turns attention to the impact of public health literacy interventions on population health. Reducing total and per capita costs of health care are central in Section 4. Section 5 highlights the dearth of health literacy evidence related to improving the experience of providers. Section 6 notes the current policy challenges to integrate health literacy into the healthcare system. However, the movement to value-based reimbursement and patient-centered care, discussed in Section 7, are opportunities to integrate health literacy into the structure of healthcare delivery. Section 8 highlights

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the current research gaps to strengthen the case for health literacy. Section 9 concludes with a discussion of the implication for health literacy to assit the health system to meet the Quadruple Aims.

2. Improving Patient Experience - Quadruple Aim #1

Health literacy has a long-recognized role in patient safety and is widely endorsed through initiatives (in the U.S.) by the Institute for Healthcare Improvement and the National Patient Safety Foundation, the Centers for Disease Control, the American Medical Association, the Joint Commission, the Department of Health and Human Services, and the Agency for Healthcare Research and Quality [4]. Despite widespread recognition, when one examines the literature for specific studies linked to medical errors, there is extensive research only in one area and broad gaps in all of the others.

2.1 Quality of Care

Numerous studies have examined the role health literacy plays in medication adherence and dosing errors [5–9]. Even employing simple health literacy universal precautions can make an impact, such as listing specific times to take doses, using milligram as the standard unit for liquid medication, and using oral syringes over cups for small doses [10]. A systematic review of the use of pictograms to assist caregivers in dosing liquid medication found limited but clear evidence that integrating pictograms into verbal or text-based instructions reduced dosing errors and enhanced comprehension and recall of instructions, while improving adherence [11].

Similarly, the use of patient-centered medication labels are suggested to improve adherence for those with limited health literacy [12]. The U.S. Veterans Administration developed and adopted a patient-centered medication label format in an attempt to improve the quality of care for its more than nine million veterans [13]. Widespread implementation of patient-centered medication label standards in the U.S. state of Wisconsin was found to increase adherence (Medication Possession Ratios and Pill Daily Counts) in Medicaid populations [14].

2.2 Patient Satisfaction

Limited health literacy is associated with reduced patient satisfaction [15]. In contrast, interventions addressing health literacy improve patient satisfaction in medication adherence and management, hypertension management, obtaining informed consent, eye health education, and maternal health education [16]. Shared-decision making models also continue to show promise in improving patient satisfaction within health care settings [17].

Using video materials to improve patient knowledge and expectations has been found to enhance patient satisfaction for individuals receiving radiation therapy and recent stroke survivors [18]. In a comprehensive study of nearly 100,000 Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) surveys employing commercially developed and implemented video programs, 100% of hospitals had a higher aggregate HCAHPS Top Box percentage. To backup, the HCAHPS contains 21 questions on the care a patient receives at a hospital. There are four response choices for each question: Never, Sometimes, Usually, and Always. The

'Always' choice is the most positive survey response. In other words, the Top-Box means a higher percentage of patients selected the most positive survey response or literally the 'top box' choice which is 'Always.' The comprehensive study also reported: 69% of aggregate Top Box answers were 4% higher or more; 86% of hospitals had a higher 'doctor communication' dimension scores; 62% of hospitals had higher 'discharge information' dimension scores; and 59% of hospitals had higher 'nurse communication' dimension scores [19].

In addition to video, use of web-based applications can enhance patient satisfaction, such as employing automated illustrations for cardiovascular education [20] and using web-based interventions enabling diabetes patients to better track glucose levels, communicate directly with health providers, and interact with other individuals with diabetes [21]. Satisfaction can be enhanced by coupling these with telephone-based education and support services [22].

Moreover to improve patient satisfaction, health literacy interventions do not have to be extensive or expensive to develop and implement. Even following simple health literacy universal precautions like rewording Magnetic Resonance Imaging (MRI) reports, standardizing emergency room instructions, employing audio-recorded messages, and encouraging patients to bring a family member or friend with them to the visit enhance patient satisfaction [23-26].

Increased patient satisfaction also translates into increased revenue. An analysis conducted by Accenture found the hospitals that offer a superior patient experience experience 50% higher hospital margins [27].

3. Improve the Health of Populations - Quadruple Aim #2

Studies are starting to examine the impact of public health literacy interventions on behavior change. For example, an initiative using education classes, a teach-back call, and interactive voice response calls led to reductions in drinking sugar-sweetened beverages, which resulted in small but significant decreases in Body Mass Index (BMI) [28]. Health literacy also has been associated with increased physical activity among Latinos and with parents' preferences for rotavirus vaccination, which suggests health literacy plays a role in addressing these and many current and future public (or population) health challenges [29-32].

There is additional evidence that community based interventions which focus on the combination of health literacy, self-efficacy, sense of empowerment, self-esteem, or social support influence socially therapeutic health behaviors. For instance, health literacy based instruction for adult learners increased their knowledge about health issues and self-efficacy [33]. Other studies suggest health literacy and self-efficacy play a critical role in: preventive health screening, intention to take an HIV test; smoking cessation; and diabetes management [34-40]. In addition, interventions to increase health literacy that use existing social support resources improve patient-provider communication [41-42].

4. Reducing Total and Per Capita Costs of Health Care - Quadruple Aim #3

There are potential cost savings to address health literacy from a societal standpoint. An early U.S. systematic review by Eichler et.al. reported a range of an additional 3%

to 5% in total health costs derived from limited health literacy for the U.S. health care system and a range of $143 to $7,798 of additional expenditures for individual patients with low/limited health literacy compared to those with adequate health literacy [43]. More specifically, in 2017 the U.S. was estimated to spend $3.5 trillion on total health expenditures [44]. Translating Eichler and colleagues reported savings into current U.S. healthcare dollars reflects a potential cost savings of $105 to $175 billion a year.

Others have estimated limited health literacy costs the U.S. economy between $106 to $238 billion annually in direct health costs and between $1.6 to $3.6 trillion each year in indirect costs such as savings that could be derived from healthy eating, exercising, smoking cessation, etc. [45]. A three year retrospective service utilization study of nearly 93,000 U.S. veterans found veterans with limited health literacy cost the system $143 million more compared to veterans with adequate health literacy [46].

Other research suggests health literacy's potential to save costs in public health and health care delivery. For example, public health savings have been documented using the quality-adjusted life year (QALY) measures – that use preference-based measurements of health-related quality of life to provide an assessment of the overall burden of diseases associated with both mortality and morbidity [47]. A computer-delivered intervention targeting HIV medication adherence found a net cost savings per user and per QALY for high health utilizers [48].

A National Academy of Sciences, Engineering, and Medicine report suggested diverse ways health literacy can potentially reduce health care costs including: underuse of preventive and other services; inefficient access to health services (such as unnecessary emergency department (ED) visits and preventable hospitalizations); medication errors and mismanagement of chronic conditions; patient noncompliance due to not understanding care instructions; and inappropriate health services. In addition, some tailored health literacy health care delivery interventions have been found to be cost effective such as: using cell phones to deliver health education via text messaging; a multi-pronged intervention targeting colorectal cancer screenings involving health literacy training for physicians and establishing a feedback loop to monitor patient compliance; a pharmacist intervention for those with heart failure to increase cardiovascular medication compliance; and a community health worker-led cancer screening intervention among Korean women [49-52].

5. Improve the Provider Experience - Quadruple Aim #4

Perhaps due to the recent addition of 'improving the experience of providers' to the Triple Aim (which fostered the Quadruple Aim), the direct relationship between health literacy and provider satisfaction only is supported by preliminary evidence.

One study suggests orthopedic surgeons were more satisfied with patient visits when patients received a video and written information describing treatment alternatives for hip and knee osteoarthritis and developed a structured list of questions for their surgeon in consultation with a health coach [53]. Another study found higher provider satisfaction rates for bowel preparation prior to a colonoscopy when patients received a patient-centered educational video versus traditional print materials [54]. More research is needed to examine the links among becoming a health literate organization and provider satisfaction in communicating with patients, which simultaneously impacts patient understanding, as well as provider overall job satisfaction, and burnout. An initiative regarding provider satisfaction is covered in a report in this book.

6. Current Challenges to Integrate Health Literate Care Delivery

There are several potential challenges from a diverse perspectives that need to be acknowledged and contemplated to strengthen the integration of health literacy in health care delivery, and address the quadruple aims.

Pardoxically, the U.S.' volume-based reimbursement and traditional fee-for-service payments for health services do not incentivize evidence-based health literacy practices, at the same time that some value based reimbursements (e.g., the Medicare Access and CHIP Reauthorization Act of 2015) for health literacy practices are provided. Until there is a complete transition to value-based purchasing, existing reimbursement incentives are a barrier to the integration of health literacy principles into practice and will continue to undermine the policy and business case for health literacy.

Consumer information in health care also is not as transparent as in other consumer based industries. While an attribute of a health literate organization directs that a hospital/clinic: "communicates clearly what health plans cover and what individuals will have to pay for service," out-of-pocket costs for health care services are rarely communicated in the U.S. before they are delivered [55]. As Duesenberry explained: "economics is all about how people make choices. Sociology is all about why they don't have any choices to make [56]." Health literacy is a similar paradox because patients/caregivers are expected to be empowered to use health literacy skills once learned, yet health consumers are confined by complex health systems, structures, policies, and procedures that limit choice and restrict equitable information exchange necessary to navigate the health care and insurance marketplaces. Until there is a movement toward cost and quality transparency, the implementation of comprehensive health literacy practices will be challenging and frustrating.

While there is evidence regarding short-term outcomes that support the effectiveness of specific health literacy interventions to date there are no large scale longitudinal studies that assess long-term outcomes related to cost, quality, satisfaction, and impacts of broad based health literacy initiatives and interventions.

The U.S. legal profession also has not embraced the health literacy movement and can be a barrier in health care. For example, patient consent forms for procedures in health care that are crafted with health literacy in mind are often rejected by the health system legal team. This same dynamic is at play in hospitals, health plans, and state agencies (such as Medicaid divisions) across the United States.

7. Current Opportunities in Care Delivery to Address the Quadruple Aim

Although current U.S. fee-for-service reimbursement system is a disincentive to address health literacy, reimbursement penalties are beginning to restructure the incentive system. In October 2014, the U.S. Centers for Medicare and Medicade (CMS) began reducing Medicare payments for hospitals that ranked in the lowest quartile regarding hospital-acquired conditions (HACs) [57]. In 2011, 21 states already had nonpayment penalties for HACs and section 2702 of the U.S. Affordable Care Act prohibits the federal government from providing payments to states for HACs and other provider-preventable conditions as of July 2012 [58].

In October 2017, CMS increased penalties for 30-day readmissions by reducing Medicare payments to facilities whose readmission ratios exceed the national average. This reflects CMS continuing commitment "to increasingly shift Medicare payments from volume to value" with an underlying goal to link half of all Medicare payments to value-based reimbursement by 2019 [59]. These new reimbursement structures place more risk on hospitals and providers and truly incentivize the integration of health literacy to provide enhanced patient supports to ensure people have the understanding and access to home and community resources (to impact patient recovery). As more insurers follow suit, there will be increasing financial pressure to integrate health literacy practices to enhance profit margins. Hospitals also are being compelled to reduce Medicaid readmissions due to payment reforms, such as accountable care organizations, other alternative payment models, and through regulatory actions from state governments that require hospitals to demonstrate reductions in avoidable admissions and readmissions [60].

In addition, many U.S. state Medicaid programs are starting to implement payment mechanisms that incentivize more continuity and efficiency in care delivery. Specifically, 22 states have implemented Medicaid payments through health home models, 26 states have Medicaid payments through medical homes, and 12 implemented delivery system reform incentive payment programs [61]. Bundled and global payment mechanisms shift some financial responsibility and risk to the provider. In turn, the integration of health literacy universal precautions into practice can assist providers if these strategies reduce risk - and improving patient health becomes more directly associated with improved margins.

In addition, the shift towards value-based purchasing will strengthen in the next few years in the U.S. as the Medicare Access and CHIP Reauthorization Act (MACRA) replaces the sustainable growth rate formula and establishes "a new payment framework for rewarding health care providers for giving better care and not more care" [62]. MACRA began implementation in 2015 and by 2021, physician Medicare payments will be more aligned to quality and performance measures.

In short, MACRA may launch an era of more private-sector attention to inefficiencies in physician payment, which may trigger a 'disruptive innovation' in health care delivery [63]. Under MACRA, providers will be paid only through two mechanisms: Merit- based Incentive Payment System (MIPS) and Alternative Payment Models (APMs). Addressing health literacy is a strategic way to increase payments under these systems.

8. Strengthening the Case - Research Gaps

Health literacy research and practice in the United States primarily focuses on clinical interventions at the same time affiliated areas such as quality of care, patient safety, cost, outcomes, medication adherence or medication errors, health equity, and health disparities research and practice operate in silos - and do not integrate health literacy efforts.

Similarly, health literacy funding often does not include stipulations to examine and study health equity, so there is little incentive to collaborate with professionals and conduct research across some of the aforementioned domains. However, a 2009 review of health literacy and child health promotion research and practice recommended and discussed cross-domain interventions that included targeting all areas of care, from patient care, health system characteristics, educational systems like pre-school and K-12 curriculum, and community based approaches like home visiting programs, after school programs, etc. [64].

To date, studies only have examined the short-term impact of specific health literacy practices. Hence, longitudinal studies of broad-based health literacy activities are needed to broadly assess the savings from long-term outcomes and behavior change. The latter is especially needed in innovative programs that propose a paradigm shift in health education, such as more integration of the medical curriculum normally targeted for medical students within elementary and secondary education [65]. More upstream approaches potentially foster a greater return on investment once implemented and fully evaluated.

Along with incentivizing cross-domain collaborations among health care organizations and systems, policies must encourage improvement in health care professional competencies that include knowledge about community resources, everyday lived experience, and community partners. A comprehensive approach is critical to integrate the appropriate professional and community resources that meet the needs of the U.S.' diverse population.

9. Conclusions

Health care is a business and health literacy is a tool that can be used to reduce costs and improve value. When health systems and those who work in health care use health literate methods, it fosters an understanding about what patients should do to make better decisions to manage their health.

Health literacy also is a vital tool to enhance public and population health. Value based reimbursement will shift the focus to preventive care in the U.S., which will increase the need to strengthen health literate public health education and support. Hence, health literacy is not simply the right thing to do for the patient and the community. Health literacy also is the right thing to do to control costs and improve quality. The business model to provide health care is shifting from one where we make money by using more health care to one in which providers profit by keeping people in better health and out of the healthcare system.

Overall, health literacy is a vital tool to aid in this movement, achieve health equity, and help attain all of the quadruple aims.

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Achieving the Quadruple Aim Through Bidirectional Care

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Abstract. This chapter discusses the notion of 'bidirectional health literacy' between the patient/care partner and the care team, and its impact on the quadruple aim: the care experience, population health, engagement, and the cost of care. It provides a brief historical perspective of the quadruple aim along with its relationships to value and health literacy. It overviews the responsibilities of health care organizations and highlights best practices, such as bidirectional care opportunities in patient-centered medical homes, with a focus on improving provider and care team communication.

The chapter's aim is to provide a new bidirectional perspective on health literacy. It illuminates for readers that the focus of health literacy should not just be about patients' understanding of and engagement in their own health and health care, but instead, a partnership where care teams become equally 'literate' about the patient/care partner, by learning what they value, the contextual and social determinants that impact their ability to engage in self-care, and by demonstrating cultural humility in all of their care efforts. Various models that support bidirectional literacy and care are provided.

Keywords. Quadruple Aim; Health literacy; Bidirectional care; Interpersonal health communication; Partnership-based healthcare.

1. Introduction

The purpose of this chapter is to provide a unique perspective on addressing the U.S.-based quadruple aim, specifically, better population health, improved care experience, reduced cost of care, and healthcare team engagement via the inclusion of an expanded perspective on health literacy and bidirectional care [1-2]. The latter incorporates a unique approach that equally values the patient's and the care team's understanding of perspectives, values, and contextual factors critical to the delivery of better care. By becoming "literate" about the crucial components that directly impact patients' ability to engage and share in decision making, the care team is better able to partner with patients and meaningfully foster health literacy, person-centric health decisions, and patient self-management.

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This chapter is written for health care leaders, administrators, educators, care providers and staff, quality/performance improvement teams, patients/care partners, and students in order to promote awareness of the importance and value of shared responsibility in advancing a health literacy partnership. It will begin with a synopsis of the quadruple aim, its relationship to health literacy and to value, and a brief snapshot of the evolving culture of care in the U.S. Next, health stakeholder responsibility, activation, and engagement will be explored, followed by a discussion of considerations and contemporary approaches employed across the U.S. health care continuum that foster a bidirectional model.

2. Overview of the Quadruple Aim

Quality, performance improvement, best outcomes, and increasing value in the delivery of health care are now central foci of patient and provider decision-making, insurance design, and payment policies [3-6]. The Affordable Care Act references 'value' in seven different sections. The U.S. Institute of Medicine's (IOM) publications To Err is Human: Building a Safer Health System (2000) and Crossing the Quality Chasm: A New Health System for the 21st Century (2001), provided a critical foundation that advanced these foci.

The IOM and subsequent efforts focused national attention on quality, patient safety, and the necessities of performance improvement to achieve best outcomes and 'value.' The Quality Chasm report recommended a systematic approach to identify priority areas for quality improvements. In 2003, an IOM Committee was formed to develop a report, 'Priority Areas for National Action: Transforming Health Care Quality' [7]. This committee was more attentive (or prioritized) diverse ways to improve the delivery of therapeutic approaches to illness and disease instead of research and innovation to improve best practices. Figure 1 summarizes the committee's patient-oriented approach that identified four domains of care: staying healthy (preventive care); acute care; living with illness/disability (chronic care); and end of life care (palliative care). Overlapping these domains were cross cutting system interventions, such as care coordination and communication. Perhaps today the report's authors would add: patient satisfaction and patient reported outcomes; patient and family engagement; and self-management.

However, the IOM committee added, a future transformation of the health care system in either a patient-centered or best practice direction was impossible in the absence of a health literate population [7]. In turn, the IOM committee identified 20 priority areas for improvement in health care quality - and added some accompanying health literacy initiatives. For instance, the IOM committee noted health system interventions were reliant on the knowledge and use of health literate principles, which was seen as necessary to foster cross cutting system interventions [8-9]. Indeed, the first two priorities identified by the IOM committee areas were care coordination and self-management/health literacy. A review of the remaining 18 priority areas to transform health care (as recommended by the IOM committee) suggests all their recommendations were grounded in improved health literate communication and enhanced population health literacy [7].

Subsequently, Don Berwick and colleagues introduced the concept of the Triple Aim [1]. The Triple Aim sought to: improve the health of populations; enhance the patient experience of care; and reduce the per capita cost of care. The Triple Aim was built on the foundation of earlier IOM publications, "To Err Is Human" and "Crossing the Quality Chasm" [8-9].

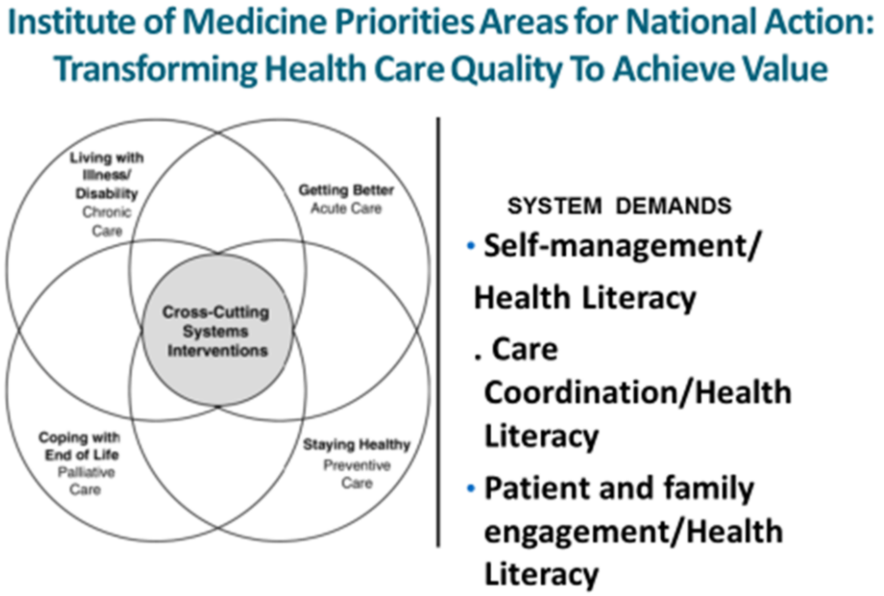


Figure 1. Adapted From: Institute of Medicine (U.S.) Committee On Identifying Priority Areas For Quality Improvement: Adams K, Corrigan, JM, Editors. Washington DC: National Academies Press (US); 2003. [7]

A fourth aim (proposed in 2014) focused attention on provider well-being; the fourth aim seeks to enhance the work life of health care providers, clinicians and staff [2]. The associations among the fourth aim with clinician burnout, communication, and health literacy are well grounded and will be discussed in this chapter. As Bodenheimer and Sinsky succinctly noted, “care of the patient requires care of the provider” [2].

3. How the Quadruple Aims Are Tied to Health Literacy

Health literacy is operationally defined as the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [8]. In this context, improved health literacy occurs when the demands and complexities of the health care delivery system are aligned with individual skills and abilities.

Yet, improved health literacy also requires a bidirectionality between patient/family and a provider team. Health literacy is needed by patients and families to navigate a very complex health care system. Health literacy is needed by patients and families to understand discharge instructions both from the hospital and outpatient facilities, to understand prescription labels, medication reconciliation, physician and nurse instructions, appointment times, consent forms, preventive care, and to ask, ‘What is best for me?’

Clear health literate bidirectional communication by a provider team is foundational to develop increased abilities to navigate acute and chronic illnesses, achieve best outcomes, and assure trust. Clinicians additionally require an understanding of a patient’s values, perspectives, and context to engage meaningfully and elicit trust.

Yet, the decreasing numbers of U.S. primary care physicians suggests there are operant frustrations with the status quo of applied medical care among contemporary clinicians. The Association of American Medical Colleges' '2018 Update on the Complexities of Physician Supply and Demand: Projections from 2016 to 2030' suggests there will be a primary care shortage between 14,800 and 49,000 physicians by 2030 [11]. While the expanding roles of advanced practice registered nurses and physician assistants may offset some of the impact of the anticipated physician shortage, a Rand Corporation study in 2013 found widespread physician job dissatisfaction because the pressures of non-patient responsibilities and administrative tasks often undermine a provider's ability to achieve to focus on patient-centered care [12]. The inability to optimize population health and outcomes due to the current and projected shortages (enhanced in certain rural and underserved areas), and the impact on provider satisfaction, has contributed to the expansion of the Triple Aim to the Quadruple Aim.

3.1 Quadruple Aim, Value, and Health Literacy

Embedded in the Quadruple Aim is the concept of value. As U.S. health care moves from volume to a value-based healthcare system, hospital, integrated delivery network, and provider compensation are increasingly based on health outcomes. In turn, value is defined as the ratio of outcomes to cost, or the cost effectiveness ratio.

In reality, healthcare value also is a measure of the perceived benefit, by the patient (or payer), of the services rendered. As Porter attests, "Value…neither an abstract ideal nor a code word for cost reduction…should define the framework for performance improvement in health care. Value should always be defined around the customer, and in a well-functioning health care system, the creation of value for patients should determine the rewards for all other actors in the system" [13, p.2477].

However, it is difficult to perceive value, appreciate bidirectionality, or address any of the admirable quadruple aims (including physicians' job frustrations) without health literate communication. Without improved health literacy it is difficult for patients to judge the affordability and necessity of the service(s), its value, or cost effectiveness ratio. Without improved health literacy it is difficult for patients to assess comparative methods of value, such as: a 5-star rating system, patient reported outcomes, patient satisfaction scores, or understand HospitalCompare.Gov, and various other public reporting methodologies. While each of these options are designed to provide key metrics that enhance the patient experience, improve population health, the health of communities, and reduce costs (the triple aim), they are difficult for patients to contextualize without corresponding institutional efforts to improve health literacy.

Having health literate healthcare organizations benefits the 77 million Americans who have limited health literacy, and the majority of Americans who have difficulty understanding and using currently available health information and health services [14]. Health literacy improves patient outcomes as well as patient experience since patients would receive some appropriate tools to better define the value received versus the cost expended.

Moreover, a recent paper and report from the National Academies of Science, Engineering and Medicine (NASEM) adds how health literacy initiatives, coupled with improved population health literacy, contribute to the advancement of each of the quadruple aims across the U.S. health care delivery system. The NASEM paper suggests there is a business case for health literacy strategies because the latter favorably impact the revenue cycle of health systems, ambulatory clinics, and clinical services [15]. In addition, the paper reviews an array of evidence that suggests health literacy interventions are associated with better health outcomes and a higher quality of care. The paper adds improved health literacy is associated with improved utilization of the health care delivery system, which suggests patients and their families obtain the tools needed to optimize care (which saves money for clinical institutions and improves patient satisfaction). In short, the NASEM paper suggests improved health literacy is associated with the advancement of the triple aim.

While the NASEM paper acknowledges “more research is clearly needed to examine the link between becoming a health literate organization and provider satisfaction in communicating with patients, ensuring patient understanding, and overall job satisfaction,” its authors note preliminary findings suggest an association between health literacy improvements and physicians’ work satisfaction [15, p.20]. The latter suggests there is evidence to support the hypothesis that health literacy interventions provide tools and strategies to address all of the quadruple aim’s dimensions.

On the other hand, the NASEM paper does not discuss the importance of bidirectionality in clinical care, which will be addressed in section 6 of this chapter.

4. Literature Focused on Patient Involvement and Eventual Quadruple Aim Outcomes

In addition to the literature that notes health literacy’s association with achieving the quadruple aim, a related body of evidence focuses on the associations between greater patient involvement through information sharing and decision-making with better health outcomes [16]. The latter literature introduces the importance of bidirectionality and better health, which will be briefly reviewed in this section and discussed more extensively in section 5.

The extant literature suggests a framework where at one end is a ‘paternalistic doctor,’ and at the other the ‘informed patient’, and in between is a ‘shared’ approach where control is mutual or exchanged thus leading to a ‘negotiated plan’ [17]. Taylor suggests the latter fosters an informed and shared decision-making clinical/healthcare culture within health care organizations and clinical practices [17].

The literature similarly suggests patients, who are active participants in managing their health and health care, experience improved disease/condition (and overall health) outcomes compared to passive care recipients. Greater patient involvement through information sharing and decision-making additionally is associated with better health outcomes [16].

In the best sense of bidirectionality, shared decision-making is a process in which the healthcare team and patients work together to clarify treatment, management or self-management support goals, share information about options and preferred outcomes - with the aim to mutually agree on the best course of action. Shared decision-making is the principal mechanism to ensure patients get “the care they need and no less, the care they want and no more,” resulting in the essential of patient-centered care delivery [18-19].

Yet, survey data suggests patient interest in shared decision-making is not always uniform [20]. For example, Hibbard found patients with chronic conditions seek to be more active partners in care more than patients with non-chronic conditions [20].

In keeping with the theme of this chapter, the authors suggest a greater understanding of the need for shared decision-making (and its therapeutic impacts) is undergirded by health literacy initiatives at multi-levels inside of the health care delivery system as well as some other settings (such as formal and informal education and targeted community interventions).

The Patient-Centered Medical Home (PCMH), a care delivery model initiated in 2010, may provide a model to advance bidirectional care delivery and enhance patient understanding of the need for shared decision-making. The goal of PCMHs is to create an environment that fosters partnership between individual patients, and personal physicians [21]. PCMH is defined as a team-based model of care, where the aim is to equalize decision-making processes by engaging and empowering patients. The latter approach contrasts with the current provider-driven, fee-for-service primary care infrastructure [17].

Meanwhile, within the PCHM model, the responsibility to improve health literacy is shared in a bidirectional relationship between the healthcare team and the patient. Hence, PCMH fosters a stronger, integrated and mutual sharing of knowledge.

PCMH efforts also may help advance the idea that patients bring important expertise to the table and are equal members of the team who can offer critical knowledge in improving care and the care environment [22]. If PCMH integrates a health literacy dimension as one of the foundations to advance bidirectional interactions, then, the authors suggest the aggregate result may address many areas of the quadruple aim.

At the same time, while patient empowerment and health literacy have been studied independently, they rarely have been assessed simultaneously or empirically associated together with health outcomes [23]. Other issues that need assessment include the individual factors that can affect a patient's motivation, willingness, and ability to engage, including patient knowledge and attitudes, their beliefs about their role in the treatment plan, their experience with the health care system, their self-efficacy, and their functional status [24]. The shared decision-making process also is heavily influenced by patient perceptions of provider trustworthiness. Patients who lack trust are more likely to report low or non-engagement with the health care team and the shared decision-making process [25]. Yet, the process to create or improve patient trust needs additional research.

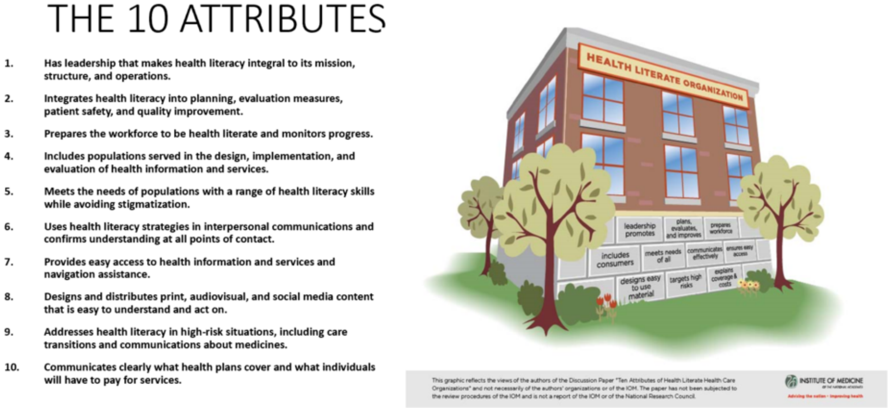
Regardless of the limited evidence in selected areas, it seems clear that the advancement of the quadruple aim requires bidirectional approaches and innovative strategies such as the PCMH, and the integration of dimensions such as health literacy, patient empowerment, and trust in physicians.

5. Health Literacy Responsibilities of Health Care Organizations

The balance (or bidirectionality) between patient and provider sharing within the PCMH indirectly suggests there are initiatives traditional health care organizations can contribute to take some of the health literacy burdens off patients, caregivers, and families. In a 2012 paper, Brach outlined ten broad attributes of a health literate organization, which are explained in Figure 2 [26]. The authors suggest these attributes are pillars for a health care organization to adopt in order to create an environment that enables patients and the health workers to be engaged in bidirectional communication, learning and partnership.

The attributes also indicate a clinical center's workforce needs to be mobilized in order to create an effective, transformational patient-centered health literate environment.

Meanwhile, the authors suggest health literacy is cross-cutting and must be deeply embedded in every aspect of a health care system at all levels, from the housekeeping department, to the surgeons in the operating room, caregivers in the emergency department, and at executive/management levels. There must be an unwavering agreement among public and health care leaders that anyone who interacts with patients, families or communities via oral or written communication must have a basic competency in health literate principles [27]. The workforce should also have the tools to: 1) improve access to accurate and appropriate health information, 2) facilitate shared decision-making, and 3) partner with patients to improve health outcomes [28].



THE 10 ATTRIBUTES

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.

This graphic reflects the views of the authors of the Discussion Paper "Ten Attributes of Health Literate Health Care Organizations" and not necessarily of the authors' organizations or of the IOM. The paper has not been subjected to the review procedures of the IOM and is not a report of the IOM or of the National Research Council.

Figure 2. The 10 attributes of a health literate organization

In addition, the commitment to health literacy efforts within health care organizations provides points of engagement for clinicians - and creates initiatives that potentially counter some of the barriers that foster provider dissatisfaction.

6. Moving to a Bidirectional Model

Historically, care teams' health literacy efforts have sought to advance patient, caregiver, and family knowledge and understanding of health conditions and prescribed treatments. A second and third generation of previously noted health literacy initiatives and research focus on shared provider/patient responsibilities as well as the underlying attributes for specific efforts by health care organizations [15,26,29].

However, as health care stakeholders strive to achieve the quadruple aim and evolve from a paternalistic to a patient-centered health care system, the authors suggest a comprehensive bidirectional approach first necessitates increased attention among physicians to health's social determinants - and for clinicians to be more 'literate' about the diverse external influences that impact the health and well-being of patients.

While it is widely recognized that medical care is responsible for 10 - 20% of population health outcomes, 80% is associated with health behaviors as well as underlying environmental, social, and economic factors. The environmental, social, and economic dimensions often are referred to as the social determinants of health (SDOH) [31].

In this section, authors suggest a care team's 'literacy' (regarding how social determinants impact the lives of individual patients and caregivers) is foundational to comprehensive bidirectional interaction and better care. The authors suggest comprehensive bidirectional care is accomplished through communication that enables a care team's clear understanding of patient perspectives, values, and preferences as well the contextual and social factors (that impact a patient's ability to engage in their own care).

Previously, the Institute of Medicine (IOM) noted physician support for shared decision-making and a respect for a patient's 'voice' were crucial antecedents to high quality care [9]. Ten years later, the IOM added physician listening was a key factor to achieve patient-anchored care [31]. The IOM added interactions between individual patients and care team members should always begin with "uninterrupted attention to the patient's voice on issues, perspectives, goals, and preferences" [31, p.235]. Listening to patients is a critical element of patient-centeredness, which results in more satisfied patients and better clinical outcome [32-33]. Yet despite two decades of reports, the concept of patient listening as a requisite of patient-centered care has not been conceptually embraced or widely applied in contemporary U.S. healthcare.

Interactive provider/patient communication is challenging and easily sabotaged by a range of barriers, including false assumptions about patient perspectives among physicians. For example, Kennedy and colleagues found providers underestimated patients' perspectives about their health conditions and patient interest in shared health responsibilities [34]. Contrary to providers' perspectives, patients widely supported bidirectional communication [34].

Similarly, Street and Haidet suggest the chasm between provider perception and actual patient beliefs widens when patients are African American, Hispanic, or a different race than the physician [35]. Interestingly, physicians' perceptions are more accurate among the patients who query and engage clinicians in discussion [35].

Weiner noted the effort to advance better provider-patient interpersonal communication was hampered by a range of challenges to empirically assess patient-provider clinical encounters and standardize measurement tools [36]. The authors acknowledge there are a dearth of tools and standardization of methods that health care organizations and providers can use to assess patient/provider interpersonal health communication, which are impediments to progress.

6.1 Contextualizing Care

However, the challenges surrounding listening to patients and attending to the SDOH have fostered several creative suggestions, which the authors will summarize. For example, Weiner and colleagues were among the first to suggest the concept of 'contextualizing care,' where providers listen and probe for clues of contextual factors in a patient's life that could be relevant to his or her health and care [37]. They also noted the number of missed contextual factors by physicians in interpersonal health encounters was measurable and the ensuing findings could be linked to patient outcomes [37].

More specifically, Weiner and colleagues used audio recordings of actual patient encounters to measure clinician identification of contextual factors, including their use of probing vs. listening, and whether care planning was altered accordingly [37]. The results were 41% of relevant contextual factors were missed by the attending physicians. In addition, the authors evaluated outcome data and found when contextual factors were taken into account in a care plan there was a 71% improvement in care outcomes, compared with a 46% improvement when care was not contextualized ($p = 0.002$). A meta-analysis of this and similar research added contextual factors were more prone to be integrated into care plans if identified by a clinician instead of spontaneously raised by patients [38].

There is emerging evidence that care team expertise in interpersonal health communication, including contextualizing care, also has a meaningful impact on reducing healthcare expenditures. Schwartz and collaborators combined retrospective cost analysis by a secondary analysis of contextualizing care measurement study [39]. This 2012 study identified 399 validated contextual errors that occurred across 111 internal medicine visits and ascertained the error-associated cost of care to be $174,000 then, reviewed the same patient cases but used a standard medical records quality review. This approach revealed an error-related cost of $8,745, a gross underestimate due to the missing patient context in the patient record. In response to the contextualizing care literature, Stojan and colleagues issued a call to action for a mandate by accreditation, healthcare, and professional organizations that would require on-going professional training in communication proficiency, using direct observation of care [40].

6.2 Integrating Health Literacy and Cultural Competence and the Construct of Cultural Humility

However, the authors suggest any advancements in contextualized care depend on the further integration of health literacy and culturally competent care efforts as strategies and markers of bidirectional care and attention to SDOHs.

For example, the National Committee for Quality Assurance suggests cultural competency is a strategy to improve health care quality and equity as well as the ability of health care team members to provide responsive, respectful care to populations of all races, ethnicities, cultures, and language capacities [41]. Shepherd and colleagues described cultural competency in practice as: having knowledge about different customs and practices and communicating through interpreters. However, they did not focus on awareness of social biases, scanning for imbalances of power, or implicit bias. Further,
envisioned cultural competency was an endpoint instead of one of the markers of provider contextualization [42].

As a potential marker of SDOH contextualization and bidirectional care, the work of Shepherd et.al. induces that cultural competence may be an inadequate indicator [42]. In addition, health literacy and cultural competence are separate research constructs that often are assessed independently. So, in order to comprehensively define cultural competence's contribution to contextualization, its underpinnings as a construct may need some reconsideration.

In turn, the authors suggest the construct of cultural competence might be redefined as 'cultural humility.' Cultural humility fosters provider 'literacy' through an on-going process of learning and self-reflection. Rather than a focus solely on knowledge and language access, the construct of cultural humility: "promotes interpersonal sensitivity; requires an attitude of openness and egolessness; involves supportive interaction; entails maintaining an interpersonal stance that is other-oriented; and necessitates learning from differences" [43, para.5]. Hence, cultural humility is suggested as a future construct to furthering clinician contextualization and bidirectionality.

While not using the term 'cultural humility,' Lie and colleagues infused health literacy and cultural competence into their case-based learning, which provides a start for the integration of the two constructs, which also would provide a more comprehensive approach and measure of physician contextualization [44].

6.3 The Patient Explanatory Model

A comprehensive framework of contextualization and bidirectional initiatives additionally should include the patient explanatory model, which provides an alternative, empirically evaluated framework to assess patient needs. Kleinman suggests the patient explanatory model enables a provider to become more knowledgeable about patient beliefs regarding their health conditions [45].

In the patient explanatory model, a provider asks standardized, targeted questions (i.e., What do you think caused your problem? Why do you think it started when it did? What do you think your sickness does to you? etc.). Ensuring interpersonal communication builds trust and is an important tool for facilitating cross-cultural communication, ensuring patient understanding and identifying areas of conflict that will need to be negotiated [46]. With the exception of cultural humility, the patient exploratory model (and approach) provides a window into understanding a patient's health literacy, other contextual factors, SDOH, and barriers to improved health, while fostering provider/care team 'literacy' or knowledge about their patients.

6.4 Administrative Approaches in a Bidirectional Model

Thinking more administratively, a strategy to foster more comprehensive bidirectional care in health care institutions is to embrace a team-based care approach - where each member is empowered and working at the top of their license or job description [2,47]. Some evidence suggests high functioning and engaged teams communicate well, have more time with patients, and better patient outcomes, with greater satisfaction among providers, staff, and patients [21,27,48-50]. Demonstration projects additionally suggest clinical practices that utilize a 'shared-care model,' where care responsibilities are distributed across the team, experience greater efficiency, better quality of care, lower costs, and higher staff satisfaction [51].

Team based approaches thrive when clinical organizations better utilize their 'First Line Staff' (FLS). FLS, like patients and families, are uniquely knowledgeable about the challenges in their particular care environments as well as in potential solutions. Empowering the first line staff to utilize tools, such as human-centered design, empowering leadership model strategies, and shared governance, helps the FLS co-create improvement strategies, determine how their work is accomplished, and participate in institutional decisions. The latter strategies increase staff engagement and have been associated with a range of improved clinical outcomes and enhanced patient and staff satisfaction [48,52].

6.5 Partnership-Based Health Care Model

The principle to empower clinical teams and providers is part of the Partnership-Based Health Care model suggested by Eisler and Potter [53]. Eisler and Potter note: "power is not used as *power over* employees, but to *empower employees*," which stimulates the perception of self-efficacy as well as team function, collaboration, and innovation [53, p.174]. The authors suggest the application of this partnership-based healthcare concept across all relationships, including those with patients and communities.

The Partnership-Based Care Model contrasts with a domination-based community model. A partnership model includes diverse community representation from conception to implementation and completion - and recognizes the critical intelligence of and key role community members play in the design and execution of successful initiatives. Under the model, clinical administrative leadership also focuses on fostering "engagement, inclusivity, and empowerment of those with less power" [53, p.257]. Via the latter approach, care teams undergo continuous learning about their patients, and communities become increasingly 'literate' since hallmarks of partnership include deep listening, empathy, and understanding of the perspective of one's partner(s).

In addition to the Partnership-Based Health Care model, a concept called Relationship-Centered Care (RCC) expands upon the patient-centered care approach. Schoenthaler recognized that “addressing SDOH will require a cultural shift within health care” [54, p.810]. They proposed utilizing RCC as a framework and have developed questions and communication strategies to establish trust and minimize shame through communicating respect, inviting patients to discuss their needs, normalizing the topic, focusing on patient strengths, utilizing bi-directional communication, etc.

7. Conclusion

To backup, Koloroutis and Trout remind us that being ill puts an individual in a “non-ordinary” state, where one feels vulnerable, fearful, anxious, and in pain, and thus what one wants more than anything is to feel that one matters to their providers and caregivers [55]. “Being in a non-ordinary state heightens a person’s need for human connection” [55, p.54]. In our data-driven, value-based care system, the focus has moved away from that caring connection to analytics and health information technology.

The bidirectional models discussed in section 6 humanize healthcare, promote empathy for the patient’s perspective and experience of illness, recognize the human experience of the practitioner, and emphasize self-awareness, partnership, and shared decision-making [56]. The discussed approaches provide important and promising tools for care teams to become more knowledgeable about patients and what matters to them. In other words, to become “literate” about those they serve.

Finally, bidirectional approaches are seen as comprehensive strategies that help achieve the quadruple aim. The chapter suggests bidirectional strategies provide thoughtful approaches to improve the quality of care, performance improvements, best patient outcomes, increase value in the delivery of health care, and improve the work life of the care team.

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Health Literacy: An Essential Element of Health Care Professionalism and Resilience

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Abstract. This report discusses the importance of incorporating health literacy into health care professionalism and resilience. It defines health care management professionalism and its subcomponents. The report addresses the need for an improved definition of health care management professionalism. The inclusion of health literacy is not only important to the improved definition, but also to health care management education competencies.

The report builds on the move towards competency-based education as a strategy to address health literacy in the areas of professionalism and ethics for healthcare professionals. This could lead to building healthcare systems with healthcare professionals who encompass high levels of professionalism as well as incorporating tools to combat burnout and increasing resilience.

Keywords. Health literacy, health care professionalism, health care management, resilience, burnout

1. Introduction

Health care professionalism remains at the forefront of discussions related to sustaining the delivery of person-centered, high quality care to patients. In addition, thought leaders in the field are now suggesting the benefits of health care professionalism include combating burnout and improving resilience of health care professionals as they navigate the U.S. health care environment. This report focuses on the health care delivery challenges in the U.S. The authors also aim to initiate a dialogue about similar issues in other countries with similar or different health care delivery systems.

This is a challenging time for U.S. health care managers and executives as they navigate a complex and dynamic health care environment. Health care organizations continue to face many external factors brought about by rapidly changing political, financial, demographic, and technological influences. These factors may include threats of increased mergers, additional public reporting, changes in the insurance industry, impact of social determinants of health upon outcomes, data security, declining reimbursement, consolidation of physician practices, and a consumer driven culture.

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In addition, many internal aspects influence health care managers, professionals and the organizations they lead as they strive to provide the ultimate goals of safe, cost effective, quality health care and services for increasingly diverse patient populations. Being able to successfully manage these innumerable challenges requires a partnership between effective leadership and productive clinicians [1].

Unfortunately, health care leaders often partner with clinicians who experience stress and burnout. Burnout is often used to describe a state of fatigue and frustration brought about by a commitment to a way of life, or relationship that has not produced an expected reward [2]. In fact, U.S. physician satisfaction regarding work-life balance has been reported at extremely low levels and burnout among them has been reported at 50 percent or more [3].

However, burnout is not limited to physicians as all members of the health care workforce can experience its impact. Although research regarding burnout among other health care providers and staff is preliminary, the stress of working in the health care industry is far reaching and burnout is a widespread concern impacting the healthcare professions [4,5].

The success of a health care organization also is dependent upon how stressful events are addressed on both a personal and team-based level. Morrow et al propose “focusing on overall improvement of the environment for all staff to optimize wellness and resiliency” to ultimately decrease burnout [4,p.293;6]. Meanwhile, resilience is the internal ability of a system to adapt its functioning before, during, or after changes and disturbances so it can sustain operational efficiency after major disasters, or even in times of extreme stress [6].

The importance of competency in professionalism and ethics extends beyond the traditional healthcare provider-patient relationship. To provide an environment in which healthcare providers are supported in their goals of providing high-quality care in a professional environment, healthcare managers and professionals must become competent in the realms of professionalism and ethics. This report: defines health care management professionalism and its subcomponents; operationalizes the healthcare management professionalism competency; presents a case study; and concludes with a potential to incorporate health literacy tools which can combat burnout and increase resilience for health care professionals.

2. Health Care Management Professionalism Definition

To facilitate competency attainment in professionalism and ethics in healthcare management and administration education, an examination of the healthcare management professionalism definition and the components included in this important definition are necessary. The literature and discussions focused on the crucial components of health management professionalism and ethics regularly overlook the importance of health literacy. The authors suggest it is essential to recognize the incorporation of health literacy as a vital component of the healthcare management professionalism competency definition.

Importantly, an understanding of health literacy and its impact upon health care organizations can serve as a tool for all healthcare administrators to better understand the healthcare environment in which they practice as well as the necessary elements needed to provide safe, equitable care for all. In turn, the authors suggest health literacy should be included as an achievable and measurable sub-competency in support of the critical goal of promoting competence in healthcare management professionalism. With a sound, inclusive healthcare professionalism competency definition in place, educators in the field will be well-positioned to operationalize the agreed upon health literacy sub-competencies by developing sound assessment methods and attainment measures to ensure and promote improved competence in healthcare management professionalism.

3. Health Care Management Professionalism Competency

In general, healthcare managers and professionals often believe they are sufficiently "competent" in the area of health management professionalism and ethics. Historically, such an assessment has been made of individuals without robust quantitative data to support the ascribed position. Although the definition of healthcare management professionalism and ethics remains amorphous, a definition is becoming more enunciated as part of the healthcare management field's movement toward competency-based education and assessment.

The movement toward competency-based education has facilitated an opportunity within the healthcare management education field to delve into the definitions of critical competencies. One of the most critical competencies identified for healthcare managers has been and remains the competency of "professionalism and ethics." The latter competency seems to have a legitimate place in an effort to promote the delivery of high-quality patient care -- as care delivered in a professional and ethical manner is likely to result in improved practice and resulting patient satisfaction. Simultaneously, professional and ethical behavior builds recognition of healthcare management as a distinct "profession." The benefits of educating healthcare professionals to gain competence in professionalism and ethics suggests parallel benefits, such as improved outcomes for patients and simultaneous improvement in professional well-being, which deters burnout.

Yet, one challenge to facilitate competency attainment within this realm is the lack of an agreed upon definition of healthcare management professionalism and ethics. Without an agreed upon definition, it is difficult to determine what should be assessed and the appropriateness of an assessment.

More promisingly, the Commission on Accreditation of Healthcare Management Education (CAHME) provides a resource for guidance. Currently, CAHME addresses competency attainment related to professionalism and ethics using a number of non-systematic approaches. While flexibility is one benefit of CAHME's accreditation process, additional standardization within the professionalism and ethics domains would serve the profession well. Without an agreed upon definition or set of minimum standards for professionalism and ethics, it is difficult to uniformly assess competency attainment in this critical area. The authors suggest a standardized definition or guideline should be an essential starting point in an effort to meaningfully contribute to the attainment of professionalism and ethics competencies.

Still, facilitating the competency attainment of professional and ethical healthcare managers remains an ongoing challenge for healthcare management educators. As noted above, the growing acceptance of competency-based education has allowed the transformation of focus to grow from purely an assessment of substantive knowledge and skills to recognition of the importance of behavioral development in the area of professionalism and ethics. However, the way in which educators implement this complicated competency remains unsettled.

A recent study by Meacham, Thompson, and Hall found healthcare management programs address issues of professionalism in diverse ways including the development of courses, dedicated effort to preparing résumés and cover letters, seminars, and practice-based internships [7]. Similarly, topics related to ethics and ethical decision making have been integrated into healthcare management programs primarily through the use of case studies and practicums. The prior research is scarce about competency-based education that targets the development of professionalism in healthcare management. The preponderance of the prior literature on professionalism describes current applications of professional development, competency model development, and the importance of competency attainment for graduate students [8-10].

To provide more clarity on this issue, CAHME added to this competency development discussion in 2013 with then-new accreditation standards [11]. CAHME's standards placed a new emphasis on the attainment of competencies among master's-level students and focused on developing four domains: (a) III.A.3 a program curriculum to develop students' competencies in communications and interpersonal effectiveness; (b) III.A.4 a program curriculum to develop students' competencies in critical thinking, analysis, and problem solving; (c) III.A.5 a program curriculum to develop students' competencies in management and leadership; and (d) III.A.6 a program curriculum to develop students' competencies in professionalism and ethics [11].

To assess desired competencies, programs seeking CAHME accreditation complete a Self-Study document consisting of a series of questions about the program, which is reviewed during the accreditation process. To engage in this review, graduate programs initially requested further guidance on definitions of terms such as "professionalism and ethics" to ensure they were measuring students appropriately. Their inquiries suggested the definition of healthcare management professionalism and ethics was not necessarily straightforward.

To assist in moving educators' ability to assess competencies forward, CAHME eventually provided guidance to define III.A.6. (professionalism and ethics) to include the domains of "Accountability," "Acting with Integrity," "Achievement Orientation," "Ethical-Decision Making," "Professionalism," "Lifelong Learning," and "Self-Confidence." The definition of each of these terms can be informed by the literature as well as related healthcare management education guidance documents.

Nevertheless, the aforementioned organizations as well as experts in the field have not overtly recognized the importance of incorporating "health literacy" into the definition of health management professionalism and ethics. As a result, the following discussion outlines how health literacy fosters provider competency and how health literacy constructively impacts evolving definitions and assessment methods related to healthcare management professionalism and ethics.

The authors suggest that incorporating health literacy as an essential element of health care management competencies will assist health care managers and leaders in the ability to have meaningful interactions with patients, health care professionals, and all health care staff. When health care organizations are committed to being health literate, everyone benefits from clear communication that is easy to understand [12].

Fortunately, Brach et al identify ten attributes of a health literate health care organization, which strives to help people navigate, understand, and use information and services to take better care of their health [12]. Brach et al's first attribute is a leadership focus to make health literacy integral to a health care organization's mission, structure, and operations [12]. Brach et al's suggestions to meet the latter attribute are not prescriptive and are adaptable for diverse health care organizations. Their specific suggestions include: making clear and effective communication a priority across all departments, levels and channels; fostering a culture that values patient/consumer perspectives and two-way interactions; provide incentives for health literacy improvement; and allocating fiscal and human resources needed to meet the organizational health literacy goals [12].

Assuming it is best to inculcate these ideas early in a health care manager's career, recent efforts have attempted to integrate health literacy within the education of sub-competencies expected of healthcare management students. The next section describes the implementation of an ongoing initiative in a university in the Northeastern U.S.

4. Case Study

A foundational introduction of health literacy was provided within the Stony Brook University, Master of Health Administration introductory course in Professionalism and Ethics through assigned readings and reflections. This effort was supplemented by an incorporation of health literacy knowledge into subsequent healthcare management professionalism case study assignments accompanied by robust classroom discussions.

In the summer between their first and second year course work, Stony Brook graduate students participated in two health management practicum and seminar courses. The practicum placements provided practical, real-world management and administrative experience.

The goals of these courses were for students to demonstrate an understanding of the application of their theoretical and conceptual knowledge to realistic and unique management challenges. In addition, Stony Brook students were encouraged to assess how health organizational cultures and structures can be redesigned to respectfully accommodate diverse populations. A focus on clear communication in health care organizations was discussed, as well as how miscommunication can negatively affect patient care and outcomes. Some assigned readings about health care management and health literacy formed the foundation for reflection, discussion and analyses of student experiences during faculty led seminars and synchronous learning.

Several examples of inculcating sub-competencies during this coursework included effective patient communication as well as how body language, facial expression and tone of voice impacted the content being communicated. During discussions to enhance interpersonal understanding, a sub-competency was incorporated to better appreciate cultural, ethnic and social preferences. The latter sub-competency also included actively using diversity and multicultural approaches to create a welcoming environment within a health care organization. Within the sub-competency of strategic orientation, the ten attributes of a health literate health care organization were included in an effort to further expose and educate the students about the integral role health literacy plays in developing the mission, culture, structure and outcomes of health care organizations [12].

Student achievement in these interwoven health literacy sub-competencies were evaluated. The assessments included hypothetical-reflective writing assignments where Stony Brook students (asked to assume the role of a future health care management professional) responded to questions about ethical and professional challenges. Other assessments included interactive group discussions and faculty led synchronous discussions. In addition, health literacy sub-competencies were evaluated from interactive discussion board posts coupled with reflective writing assignments based on each student's "real-world" practicum field experience.

In turn, the case study suggests a health literacy focus within the curriculum enhanced pedagogical efforts to facilitate meaningful competency development within a health management professionalism curriculum. For instance, a class focus on the benefits of clear communication to enhance patient care triggered discussion and student learning relevant to the domains of "accountability" and "acting with integrity," as outlined in the CAHME standards related to professionalism [11]. A discussion of health management professionalism through the lens of health literacy also enabled students to appreciate the importance of clear communication and how the implementation of latter skills boosted provider-to-patient "accountability." An improved student understanding of the meaning of clear patient communication additionally suggested how providers can "act with integrity" within routine patient care.

Overall, the Stony Brook case study suggests the field of health literacy creates opportunities for similar, meaningful student learning opportunities as they evolve from beginner, to intermediate, to advanced levels of competency attainment. There are constructive lessons learned by the integration of health literacy sub-competencies into the overall healthcare management professional competencies. Similarly, the case study suggests healthcare management students absorb the concepts of healthcare professionalism at a more diverse, deeper level when health literacy is incorporated into competency learning and assessment. The breadth of health literacy examples infused in the health management curriculum provides an asset by which students can carry tangible tools away from their learning experiences. Moreover, the inclusion of health literacy enables students to become upstanding healthcare professionals with foundational organizational tools, and strategies that can assist with combating burnout and promote resilience.

In the future, to assist with the program's sustainability, the assigned readings, reflective writing assignments, group sessions, faculty–led synchronous discussions and case study assignments will be incorporated annually. This ensures Stony Brook healthcare management students have the opportunity to learn about health literacy as a critical dimension of healthcare professionalism.

5. Conclusion

Bringing health literacy to the forefront in healthcare management education shines new light on the health literacy and healthcare management fields. This Stony Brook case study suggests the fields are integral components of each another and serve as a model to revise competency development among healthcare management professional educators.

The overall importance to develop healthcare management professionals with high levels of professionalism competence remains an undisputed goal in the U.S. The employment of U.S. medical and health care services managers is projected to grow by 20 percent from 2016 to 2026 [13]. Concurrently, a demographic transformation will continue to evolve in terms of health care administrators, provides, and patients. As the latter occurs, health care management professionals with an understanding of the importance of health literacy will be better prepared to align health care services to meet the needs of the U.S.' increasingly diverse patient population [14].

Health care leadership is "the ability to effectively and ethically influence others for the benefit of individual patients and populations" and should focus on enhancing clinical outcomes, while also improving clinician well-being by promoting workplace engagement and decreased burnout [15]. Incorporating health literacy into the healthcare management professionalism competency provides a novel opportunity to not only enhance healthcare professionals' health literacy knowledge and competence, but it also contains the potential to incorporate tools to combat burnout and increase resilience for health care professionals.

This report suggests while health literacy research and practice are missing from discussions about medical ethics and professionalism, their integration creates a rising tide that lifts all boats. The issues raised within this report provide research and leadership opportunities for the fields of medicine, nursing, public health, as well as health literacy students and other health care professionals. The authors hope this report contributes to an ongoing discussion about health literacy, medical ethics, and provider professionalism in the U.S. and other nations.

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Health Literacy and Pediatric Health

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Abstract. The chapters and reports in this book explore a wide variety of topics related to how health literacy can impact clinical practice and public health. While health literacy is relevant to healthcare issues across populations, it has unique implications in the field of pediatrics, where parents and other caregivers are responsible for managing their child's healthcare. Younger children have varying roles and involvement; over time, as children reach adolescence, they have an increasing understanding of and participation in their healthcare. This chapter will review the epidemiology of health literacy in parents, adolescents, and children, and how this compares to the general adult population. It will highlight unique considerations regarding health literacy and pediatric health. The chapter will then focus on the impact of health literacy and relevant health literacy-informed interventions on pediatric health. Finally, the chapter will discuss gaps in the literature and future directions.

Keywords. Health literacy, pediatrics

1. Introduction: Background and Epidemiology of Health Literacy in Parents, Adolescents, and Children

1.1. Health Literacy in Parents Compared to the General Population

The 2003 National Assessment of Adult Literacy (NAAL) found 36% of adults have basic or below basic health literacy [1]. Yin and colleagues performed a cross sectional study using a nationally representative sample of U.S. parents from the NAAL [2]. They found overall rates of basic or below basic literacy (referred to as "low health literacy") were slightly lower than in the general adult population at 28.7%; only 15.1% of parents had proficient health literacy levels. In adjusted analyses, non-parents had 1.5 times the odds of basic or below basic health literacy compared to parents.

The authors postulate this difference might stem from non-parental limited interaction with the health care system compared to parents who have to manage their child's medical issues and seek medical care for their children. It is estimated more than 21 million parents in the United States have low health literacy [2].

Several studies have examined health literacy among specific populations of parents. Anywhere from 14% to 63% of parents in the pediatric emergency department (ED) have

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low or marginal health literacy levels, depending on the population and health literacy assessment used [3–9]. One study found 61% of parents of children with sickle cell disease recruited from the ED had low health literacy compared to only 32.5% of those recruited from a medical clinic [9]. The higher proportions of limited health literacy observed in the ED may be explained by the fact that anxiety and stress, which may be high in the ED, can affect an individual's ability to process health information [10]. In addition, parents with lower health literacy may have a poorer understanding of illness severity [6]. One systematic review found up to 65% of parents of children with special health care needs had low or marginal health literacy [11].

1.2. Health Literacy in Children and Adolescents Compared to the General Population

Fewer studies have assessed health literacy in children and adolescents; measurement of health literacy can be a barrier in these groups. Recent work has focused on validation or adaptation of existing health literacy measures or the creation of new measures for adolescents and children [12–15]. The reliability and validity of health literacy measures in children and adolescent has been found to be variable [16]. Further complicating health literacy-related research in children and adolescents is many studies have measured reading ability or general literacy as a proxy for health literacy, making comparisons to the adult population more difficult [17].

Adolescent and child health literacy levels vary depending on the measure used and the assessed population. Studies utilizing the Newest Vital Sign (NVS) have found varying levels of limited health literacy in adolescents, ranging from 19-51.5% when adult scoring guidelines are used [12,18–20]. Younger children perform more poorly on health literacy evaluations, which is unsurprising given a child's developmental level and assessments designed for adult populations [21-23]. One study found children between seven and nine years old had a median NVS score of one, whereas those who were 10 to 17 years old had a median NVS score of three [22]. Another study found a median NVS score of 0 in children seven to 13 years old [23]. These findings suggest health literacy assessment results should be interpreted with caution for younger children. Use of health literacy assessments specifically designed for adolescents and children may provide more valuable information [15].

1.3 Factors Associated with Low Health Literacy in Parents of Children

A nationally representative study of U.S. parents by Yin et. al. assessed some of the demographic factors independently associated with low health literacy [2]. For example, parents without a high school education had 8.5 times the adjusted odds of low health literacy compared to those who were more educated. Parents whose families were below the poverty threshold also were more likely to have low health literacy, even after controlling for other factors. The parents with limited English proficiency had more than 18 times the odds of low health literacy compared to those who understood English well. Black and Hispanic parents had higher adjusted odds (3.9 and 2.3 times, respectively) of low health literacy compared to white parents [2].

1.4. Factors Associated with Low Health Literacy in Children and Adolescents

While the health literacy of adolescents and children has not been assessed comprehensively in the U.S., a study in Iran found adolescents whose parents have lower education levels and lower income were more likely to have low health literacy in unadjusted analyses [24].

1.5. Costs

Although studies have not specifically assessed the total costs of low health literacy in pediatrics, adult research suggests the additional costs associated with low health literacy contribute 3% to 5% of total annual health care costs. On an individual level, low health literacy may lead to between $143 and $7,798 per year in additional expenditures compared to those with adequate health literacy [25]. Given that children represent ~23% of the U.S. population, the overall health literacy-related contributions to costs in the pediatric population are likely to be substantial [26].

2. Health Literacy in Pediatrics: Unique Considerations

While the epidemiology of health literacy is similar in parents compared to the overall adult population, there are several unique aspects related to the care of children that are likely impacted by health literacy. This section will review the implications of a caregiver acting as a child's proxy, how health literacy can develop throughout childhood, and how medical instructions differ for children vs. adult patients.

2.1. Parents as Child's Proxy

As other sections in this book describe, an adult's health literacy has substantial impacts on his or her own health knowledge, behaviors, and outcomes. Children, however, may be developmentally unable to understand and act on certain aspects of health information. A parent must often act as a child's proxy, with the parent's health literacy playing a valuable role. At home, parents must act on a variety of different types of medical instructions, including medication, appointments, as well as signs and symptoms to monitor [27]. Even in an inpatient setting, children rely on their parents to be involved in their care, provide support, and advocate for them [28-29].

At the same time, a medical team appreciates parental involvement [28-29]. In a hospital, parents play a critical role to ensure proper monitoring and treatment and sometimes are the first to observe important clinical changes; parents also participate in decision-making on behalf of their child [30]. Parents have unique knowledge and experiences related to taking care of their children and add a perspective a medical team cannot provide [29]. Outcomes are improved when parents are more involved; for example, children whose parents stay with them while hospitalized experience a shorter length of stay [31].

2.2. Health Literacy Across the Age Spectrum and Family Health Literacy

2.2.1. Development of Health Literacy Skills Over Time

Whereas parents often act as a child's proxy in medical care and decision making, children can start to understand health-related concepts and acquire skills that can lead towards the development of health literacy skills as early as three years old [32]. The following section will discuss the development of health literacy skills over time.

While there has been limited study of how health literacy skills develop over time, it is thought these skills may begin to emerge in children as young as three to five years old. While children in this age group are reliant on their parents to address health-related issues, children can begin to incorporate and understand information, but often in a concrete way [32]. For example, qualitative work suggests children in this age group want a medical team to talk to them (in addition to their parents) during medical encounters and seek to learn about their condition [33]. When dealing with stressful and painful procedures such as venipuncture, young children often appreciate having enough information and time in order to process a situation and become engaged [34].

Further health literacy skills begin to develop between seven and 11 years of age. Bhagat and colleagues found eight to 11-year-olds began to develop functional health literacy as they became able to read and interpret some information from a nutritional label. Children in this age group also start to develop critical thinking and become involved in some of their own health decisions (e.g., perceptions of how healthy foods have an impact on whether or not they will eat them) [35]. Some of the skills required to complete the NVS assessment, such as subtracting two digit numbers, could be performed by a seven to eight-year-old, whereas nine to 10-year-olds should have slightly more complex numeracy skills such as working with fractions and percentages [23]. While nine to 10-year-olds are introduced to nutrition labels in school, 10 to 11-year-olds learn how to analyze these labels for nutritional content [23].

As children enter and progress through adolescence, they gain more critical thinking skills and are able to think more abstractly, which enables them to develop their health literacy skills (and facilitates their ability to become involved in their own health care [36-37]. One study of adolescents with inflammatory bowel disease found most 12-14 year-olds attained skills and knowledge related to their medications, treatment adherence, and nutrition.

However, understanding the need for a new healthcare provider when entering adulthood, and insurance were not grasped well until adolescents were more than 18 years old [38]. One study of adolescents with cancer and their families found there is a wide range (from 12 to 18 years old) in which teenagers would be capable of making medical decisions – with a mean age of 14 or 15 [39]. Adolescents with sickle cell disease also share responsibility with parents in disease management and take more of an active role over time. Adolescents often defer to their parents when symptoms are not well-controlled and when the care regimen is complicated. While some adolescents are more independent, some parents need to work to engage an adolescent in taking over responsibility for care management [40].

The studies in this section discussed findings related to a variety of pediatric conditions and situations. One may postulate how this would apply to the development of health literacy skills in a child with a common pediatric condition, such as asthma. While children as young as three to five years old may want the process of getting a nebulizer treatment explained to them, they would not be able to administer the nebulizer on their own or probably understand the underlying concept of asthma. A child who is seven to eight years old may have the basic math skills to understand how frequently their asthma medication is given. Children who are nine to 10 years old may begin to read medication labels, understand their medication names, and locate different types of information (e.g., dose and frequency) on an asthma medication label.

The skills of understanding different concentrations and strengths of asthma medications and their side effects may develop when a child is closer to 10 to 11 years old. The age at which adolescents with asthma would be able to manage their own care also would vary depending on the individual. Whereas younger adolescents (e.g., 12 to 14 years old) may be able to administer their own asthma medications, the skills related to navigating the health care system such as filling out insurance forms and making an appointment with an adult asthma provider, may not develop until closer to 18 years old or later.

2.2.2. Parent and Child Health Literacy Within a Family and Impact on Outcomes

While most studies focus on a parent or a child's interaction with the healthcare system, few have examined the whole family. One study examined adolescent cancer survivors, their parents, and siblings. Parents usually were involved in and attended appointments. While there was a range of adolescent participation in decision-making with most major decisions being made by the oncologist or the parents adolescents tended to be more involved post treatment. Social or lifestyle decisions were made by parents or shared between parents and adolescents; often the most conflict arose in the post-treatment phase [39].

There is a dearth of research that assesses child and parent health literacy together within the same study. While one study found a moderate correlation between NVS scores in parents and their children, others have found limited agreement [21,23,41]. Even fewer studies have assessed the impact of a parent's *and* a child's health literacy on a child's health outcomes. For example, one study examined the association between reading ability in children with Type 1 diabetes compared to their parents and glycemic control; the study found associations between parent, but not child, reading ability and hemoglobin A1C level [42]. This comparison was limited by the fact reading ability was used as a proxy for health literacy.

2.3. Comparison of Physician Instructions for Pediatric and Adult Patients

A unique feature with implications for health literacy in pediatrics is the type of medical instructions that must be followed for children. This section will outline differences between pediatric and adult instructions from a health literacy perspective.

2.3.1. Medication Instructions

One of the most challenging aspects of children's health is administering liquid medications, which can be more complex than the tablets and capsules typically given to adult patients. More than 40% of parents make liquid medication dosing errors in low literacy populations [3].

Liquid medications can be difficult to dose, in part due to parental confusion regarding how to use the diverse types of dosing tools. Use of dosing cups leads to more than four times the adjusted odds of dosing errors compared to syringes [43]. The size of the dosing tool also matters. Use of a dosing tool most closely matched in size to the prescribed medication dose is associated with fewer errors probably because it is akin to a pre-emptive strike that eliminates the possibility of providing additional medicine [44].

The type of units utilized as part of medication instructions also can affect dosing accuracy. Instructions with milliliters (mL) dosing lead to fewer dosing errors compared to instructions that include teaspoon units [44]. Parents who reported use of teaspoon or tablespoon units were twice as likely to make a dosing error compared to those who used mL-only units in one study [45]. Use of metric units only (e.g., mL-only) is recommended by the American Academy of Pediatrics [46]. There also is a gap regarding provider counseling and prescribing practices compared to best practices. Although primary care providers (PCPs) recognize that mL-only is the safest option, significantly fewer report they would write prescriptions using mL-only units, in part due to concerns that parents prefer to dose in teaspoons [47].

Medication label and packaging information additionally can be confusing for liquid medications. One study systematically examined packaging for non-prescription medications. While all companies included active ingredient information in the Drug Facts panel, this information was highlighted using a colored background in only 20% of cases. Nearly 20% of principal display panels did not include active ingredient information, and many utilized a small font to depict active ingredients. Zero medication bottles and only 2.6% of medication boxes utilized pictographic instructions [48].

U.S. national guidelines were instituted to address some of the challenges associated with liquid medication instructions and labeling; examples included having a tabular format for dosing instructions, using mL only units, using leading zeroes and avoiding trailing zeroes, and provision of an appropriate dosing tool [49,50]. These changes, along with recommendations to utilize a single concentration of liquid acetaminophen, was associated with a 19% decrease in acetaminophen medication error exposures reported to the U.S. National Poison Data System [51].

2.3.2. Other Instructions

Several other types of instructions provide distinct challenges to parents. Parents may not be able to recognize subtle symptoms developing in their children, so they may wait too long to act on instructions, such as when to start as-needed medications or seek medical care [52]. Parents can overestimate how well controlled their child's asthma is, leading to non-adherence; and parents also have difficulty identifying signs and symptoms in children with asthma [53-54]. Finally, parents need to understand when children are permitted to return to school following an acute illness, although parent understanding of school return instructions has not been well studied [27].

2.4. Barriers Unique to Pediatrics

While medical instructions by themselves can be confusing for families to understand, other barriers may make it additionally difficult to implement these instructions. Many barriers are relevant to the health care of both children and adults, such as financial reasons, lack of insurance, or poor access to care or transportation, but there are several barriers that are unique to a child's health care [55-59].

For example, the health of a child often is the responsibility of multiple caregivers. The caregiver who is present for provider counseling may not care for the child at home. In turn, those absent at a clinical encounter are reliant on another caregiver to forward key information, and there may be a greater reliance on instructions in written and/or audiovisual form [60]. In addition, parents may disagree about the need for certain treatments or have a differing understanding of how to execute care plans [52]. Schools also can complicate the care of children with conditions such as asthma. For instance, school nurses may not be aware of a child's asthma history and may not have access to the proper prescription medications or orders indicating how children should take them [61].

Under the latter scenario, it often is helpful when an older child becomes more involved in his or her own care. Collaboration between the parent and child in managing diabetes care, as opposed to the parent taking a more controlling approach, is associated with better regimen adherence and diabetes control [62]. Family cohesiveness also is associated with treatment adherence in children with diabetes [63].

A parent's job and other responsibilities may serve as barriers to adhering to a child's care plans. For example, missing work to take a child to an appointment may pose a challenge to parents [55,57]. While parents are at work, children are often taken care of at daycare centers and by other non-family members without the assurance that child care centers adhere to medical instructions [52]. Having multiple caregivers, inside or outside of the home, may make it difficult to track a child's progress, such as their nutritional and fluid intake (which is important in the setting of or immediately following an acute illness) [64]. Parents also may have to take care of other children in the home, or may need to make arrangements to have someone else do so [55,57]. The child or siblings may have to miss school, not only during an acute illness, but for subsequent follow-up appointments [55,59].

3. Parent, Adolescent, and Child Health Literacy & Impact on Pediatric Health

This section describes the associations between parent/child health literacy and knowledge, behaviors, and outcomes across areas of preventive care, acute care, and chronic disease. Since many of the studies discussed do not adjust for other variables when examining associations with health literacy; this section specifically highlights those studies in which other variables are evaluated within analyses. Relevant health literacy-informed interventions will be discussed for individual areas for which they have been developed, although the principles from these interventions may be applicable to multiple different types of conditions and situations.

3.1. Prevention

3.1.1. Injury Prevention

Low parent health literacy has been associated with poor injury prevention knowledge and behaviors even after controlling for other variables. Low parent health literacy is associated with poor knowledge of first aid related to choking and burns, as well as with having a fire escape plan [65]. Parents with low health literacy have ~3.5 times the adjusted odds of not having a working smoke detector [65]. Parents with low health literacy are less likely to have discussions about guns or have guns properly stored (unloaded or locked in a safe place) [65]. Low parent health literacy is associated with allowing a child to play alone near water, harmful household products and matches/lighters being within reach of a child, and setting a hot water heater at too high of a temperature [65].

Another study examined the impact of parental health literacy on the effectiveness of an ED-based intervention in which parents in the intervention group received a personalized safety report. Receipt of the intervention and higher health literacy were associated with better knowledge related to poison storage and smoke alarm use [66].

3.1.2. Tobacco and Alcohol Use

Studies have examined the associations between parent and adolescent health literacy and tobacco and alcohol use. One study found adolescent males with lower reading ability smoke more cigarettes per week [67]. Another study of 11 to 12-year-olds found low literacy (not health literacy) was associated with increased smoking in boys and girls and higher levels of alcohol use in boys [68]. While one U.S. study did not find a relationship between adolescent health literacy and alcohol use in adjusted analyses, this relationship has been established in some nations [69]. A study of 12 to 24-year-olds in Ghana found those with low functional health literacy had higher levels of alcohol intake and smoking [70]. A study in 10 to 16-year-old children in Guatemala found lower health literacy was associated with higher lifetime alcohol use in adjusted analyses [71]. Children whose parents have lower health literacy are more likely to have higher levels of salivary nicotine and exposure to higher air nicotine levels in the home in adjusted analyses [72].

One study compared smoking-related outcomes in adolescents taking part in one of three arms of a cluster randomized trial: no intervention; a game housed on a mobile phone or tablet focusing on tobacco; and a website with similar information as in the game. The adolescents randomly assigned to the game experienced changes in smoking outcome expectations and attitudes towards smoking; no changes were observed in the other two groups or for any of the groups regarding the primary outcome of anti-smoking self-efficacy [73]. Similar smartphone and tablet-based games also may lead to improved outcomes in adolescents in other areas and should be a focus of future interventions.

3.1.3. Promotion of Healthy Habits: Nutrition, Physical Activity, and Screen Time

Another research focus is the association between health literacy and nutrition-related knowledge and behaviors. Parents with lower numeracy levels have less ability to estimate portion sizes correctly or understand growth charts even after controlling for other variables [74]. Rates of exclusive breastfeeding are lower among mothers with lower health literacy [75]. Mothers with lower health literacy have approximately twice the adjusted odds of bottle propping and immediately feeding their children when they cry [76]. Parents with low health literacy also are less likely to use healthy weight-related behaviors for their children, such as increasing fruits and vegetables and decreasing fat in adjusted analyses [77]. Lower health literacy levels in adolescents are associated with more unhealthy diets (including consumption of soda, energy drinks, and fast food) in adjusted analyses [78].

Lower health literacy is associated with less optimal physical activity-related behaviors even after adjusting for other variables. Adolescents with lower perceived health literacy are less likely to participate in sports activities [79]. Infants whose parents have lower health literacy have three times the odds of inadequate tummy time [76].

Children whose parents have limited health literacy are more likely to have a television in their bedroom and watch >2 hours of television each day [65,80]. Lower parent health literacy also is associated with infant television-watching [76].

One randomized controlled trial sought to improve nutrition and activity-related outcomes in low-income Hispanic families. The intervention included nutrition and breastfeeding counseling, support groups timed with well child visits, and plain language handouts that included images and action-oriented instructions. Infant activity, including unrestrained floor time, was more likely in infants whose parents had higher health literacy levels as well as participants in the intervention group [81].

3.1.4. Immunizations

While parents with higher health literacy typically exhibit more positive preventive health behaviors, this relationship has not been found to be consistent for vaccination completion. One study found parents with adequate health literacy were less likely to have children who were vaccinated; parents with higher health literacy were more likely to have anti-vaccine attitudes and perceive informal information sources that oppose vaccines as more reliable [82]. Another study found no relationship between parent health literacy and child vaccination status [83].

Vaccines have been an area of focus for health literacy-informed interventions. One study compared an informational pamphlet for the polio vaccine designed by the U.S. Centers for Disease Control and Prevention with a pamphlet designed from a health literacy perspective (which included graphics, was written in question and answer format, and utilized bullets and bolding). Parents preferred the health literacy-informed pamphlet and believed it was easier to read [84]. Comprehension levels were slightly higher with the health literacy-informed pamphlet although comprehension levels were still low overall [84].

The American Academy of Pediatrics offers several resources to aid providers in communicating with families about immunizations including an immunization schedule for adolescents designed using health literacy principles (e.g., plain language, visual aids, adequate white space) [85]. The topic of health literacy and vaccination attitudes and behaviors is discussed elsewhere in this book.

3.1.5. Other Outcomes

Among adolescents and young adult females attending a reproductive health clinic, those with lower health literacy had a lower understanding of written information related to chlamydia in adjusted analyses; health literacy was not associated with high risk sexual behaviors [86].

Women receiving prenatal care with higher health literacy levels are more likely to understand information related to prenatal screening tests [87].

3.2. Acute Care

3.2.1. Medications

In acute illness settings, parents and adolescents with lower health literacy have poorer medication-related behaviors and outcomes. Although medication management related to short-course medications are discussed in the acute care section of this chapter, many of these principles can be applied to chronic medication use.

Parents with low health literacy have difficulty understanding over-the-counter medication labels (three times adjusted odds more than those with higher health literacy) [2]. Parents with lower numeracy skills are more likely to report they would use over-the-counter cold medications in a child less than two years old in adjusted analyses [88].

Parents with low health literacy are more likely than those with adequate health to exhibit worse medication dosing-related behaviors even after controlling for other variables. Parents with low health literacy have more than twice the odds of making a large dosing error (>40% deviation from the prescribed dose) [89]. The latter errors are more pronounced in parents with both low health literacy and limited English proficiency [90]. Parents with lower health literacy are more likely to prefer to use teaspoon units as opposed to mL in medication dosing instructions [91]. Low parent health literacy is associated with use of non-standardized dosing instruments (e.g., kitchen tablespoons and teaspoons), lack of knowledge of weight-based dosing, and poor understanding of active ingredients [92,93].

Fewer studies have assessed adolescent health literacy and medication-related outcomes. Adolescents and young adults with lower health literacy have less understanding of the active ingredient information for medications in adjusted analyses [94]. Another study found no association between an adolescent's health literacy and self-reported medication adherence. Because adolescents were questioned about overall medication adherence as opposed to adherence related to a specific illness or medication course, it was suspected the low medication adherence might be related to adolescents' lack of understanding of the questions being asked [95].

Interventions that aim to improve acute care medication-related outcomes utilize a variety of health literacy-informed communication strategies. Medication labels and instructions with pictographic instructions are associated with lower dosing error rates compared to labels/instructions that are text only [44,96]. Similarly, demonstrating how to dose liquid medications decreases the likelihood of liquid medication dosing errors [97]. One intervention utilized several health literacy principles, including low literacy pictographic medication instruction sheets (visually depicting the liquid medication dose) in addition to teachback/showback, dosing demonstration, and the provision of a dosing tool. The parents randomly assigned to receive this intervention were less likely to make medication dosing errors (intervention vs control: 5% vs. 48% for daily short course medications, 16% vs. 40% for as-needed medications) [3].

3.2.2. Health Care Utilization and Perception of Illness Severity

Parents with low health literacy are more likely to bring their children to the ED overall, and also present increased odds to bring their child for ED visits, which are considered to be non-urgent in adjusted analyses [98]. Children who are two years old and older are also more likely to have a non-urgent ED visit for a febrile illness if their parents have low health literacy even after controlling for other variables [4].

Health care utilization may be more frequent for children of parents with lower health literacy given their worse understanding of illness severity. Parents with lower health literacy perceive their child to be more sick compared to parents with adequate health literacy [6,99]. Parents with low health literacy also may be more likely to have ED visits given a poor understanding of the reasoning for their child's illness, preference to seek answers immediately, and less understanding of how to fully navigate the healthcare system [6].

Several interventions have focused on reducing unnecessary ED visits. One health literacy-informed intervention focused on the use of a children's health aid book, written at the third through fifth grade reading level, with information on common pediatric illnesses; parents were educated and tested on how to use the book. In this study, post-intervention, rates of ED use decreased by 30%. The intervention also led to a 13% reduction in parents reporting they would go to the ED first if their child was sick [100]. Another study utilizing a low literacy booklet on non-urgent care of children also reduced pediatric ED use [101]. A different study compared the use of a condensed summary of Bright Futures materials with these materials combined with educational text messages in a population primarily with low health literacy. Parents who received the text messages were less likely to bring their children to the ED for both urgent and non-urgent reasons

[102].

3.2.3. Other Outcomes

Several other health literacy-informed acute care interventions have been developed. One study found use of pictographic instructions with plain language explanations (broken down into explicit and actionable steps) were associated with better parental understanding of how to prepare oral rehydration solution [103].

Other studies in the pediatric ED used video instructions to explain concepts. One study utilized videos with content written at the eighth grade level or below; use of these videos compared to standard instructions led to improved comprehension of fever and closed head injury instructions [104]. Video instructions also have been shown to improve comprehension of ED instructions related to lacerations and sprains [105], as well as fever and vomiting/diarrhea [106].

3.3. Chronic Disease

3.3.1. Asthma

Several studies have examined the associations between parent health literacy and asthma knowledge, behaviors, and outcomes. Parents with low health literacy have less knowledge related to asthma in general, as well as worse knowledge specific to treatment, medications, and triggers [107–109]. Low parent health literacy also is associated with poorer self-efficacy, higher perceived need for asthma medications, and greater levels of worry about asthma in adjusted analyses [110-111]. Parents with low health literacy are less likely to bring their child to an asthma specialist [108]. Low parent health literacy also is associated with difficulty categorizing their child's level of asthma control or determining the appropriate course of action utilizing an asthma action plan [112]. Children whose parents have low health literacy have worse parent-and-provider-reported asthma control and more missed school days [107, 109]. Asthma-related ED visits (as high as 1.7 times adjusted odds) and hospitalization rates (greater than a 4-fold adjusted incidence rate ratio) are greater in children whose parents have lower health literacy [108-109, 113].

Lower adolescent health literacy also is associated with worse asthma outcomes. Adolescents with lower health literacy are more likely to have been hospitalized for asthma and have worse quality of life in adjusted analyses [114]. Another study of adolescents with undiagnosed asthma found those with lower health literacy had worse asthma knowledge and self-efficacy after controlling for other variables [115].

Asthma-related outcomes and behaviors have been the target of health literacy-informed interventions. One study examined the impact of a low literacy asthma action plan, which utilized photographs, pictographic instructions, and plain language as part of hypothetical asthma counseling scenarios. Physicians who utilized the low literacy asthma action plan provided richer and more detailed counseling [116]. Parents who were counseled using the low literacy plan evidenced a better understanding of spacer use and medications children should take when well and sick [117]. Another study examined the asthma knowledge among parents who took children to the ED and received video or written educational materials. Parents with low health literacy displayed improved knowledge regardless of the type of education they received [108]. However, for parents with adequate health literacy, knowledge scores only improved in those who received video education [108]. A different study focused on inhaler technique in children seven to 17 years old. Children showed a nurse how they used an inhaler and then viewed a tailored video providing feedback on correct and incorrect steps. Observed inhaler technique improved immediately after watching the video and was sustained after one month [118].

3.3.2. Obesity and Body Weight

Several studies have assessed the associations between health literacy and a child's weight. One study found low parental numeracy was associated with having either underweight or overweight children in adjusted analyses [74]. Limited health literacy in adolescents and children also is associated within an increased body mass index (BMI) [20,119]. While one study found no associations between parent health literacy and adolescent obesity as well as child NVS scores and child obesity, a weak association was found between low parent NVS score and child obesity [120]. Parents with low numeracy also have difficulty interpreting growth charts [74].

Obesity-related outcomes have been the target of some health literacy-informed interventions. One quasi-experimental study utilized small group classes where: a shame free environment was established; workbooks written at a 5th grade level with understandability and acceptability were provided and new behaviors, and teachback all were demonstrated. The intervention fostered improvements in child BMI-z-score [121]. Another study utilized a cluster randomized trial design to assess the impact of an intervention that included age-specific, low literacy informational booklets and tangible tools (e.g., snack bowls and placemats illustrating appropriate portion sizes). The primary care physician at intervention sites also received training in health communication strategies including teachback. Compared to the control group, BMI-z-scores in the intervention group were lower at 6, 12, and 18-months but not at 24-months of age [122].

3.3.3. Diabetes

Diabetes-related knowledge and behaviors have been linked to low parent health literacy. Parents with low health literacy have difficulty understanding diabetes jargon, prefer diabetes education that utilizes plain language, and desire key information to be repeated and broken down [123]. Among adolescents with diabetes and complex insulin regimens, low parent health literacy (reading comprehension score in particular) is associated with poorer adolescent and parent diabetes management (using a measure which assessed proper insulin administration, diet, blood glucose monitoring, and response to symptoms) after adjusting for other variables [124].

Parent health literacy has variable associations with child diabetes outcomes. Higher hemoglobin A1C levels in children have been noted in parents with lower numeracy and NVS scores; the NVS has a substantial numeracy component [125-127]. However, reading ability is not associated with diabetes control [42,125].

3.3.4. Human Immunodeficiency Virus

Many of the pediatric studies related to health literacy and human immunodeficiency virus (HIV) have focused on adolescents. Health literacy is associated with receiving medical care in adolescents with HIV in adjusted analyses [128]. While adult studies have found a relationship between health literacy and HIV medication adherence, this relationship is not present in adolescents [128,129]. Health literacy was not associated with viral load, CD4 count, ED visits, or hospitalizations in adolescents with HIV [128].

One study of parents found those with lower HIV-specific health literacy experienced higher rates of liquid zidovudine dosing errors after adjusting for other variables [130].

One pilot intervention focused on improving an HIV outreach coordinator's awareness and use of health literacy principles such as teachback using educational videos and factsheets, along with a teaching plan that was to be used with adolescents (which included information on healthcare system navigation). The coordinator conducted four educational sessions with the enrolled adolescents. Adolescent medication knowledge test scores and a measure of health navigation significantly increased post-intervention [131].

3.3.5. Sickle Cell Disease

The impact of health literacy is variable in the setting of pediatric sickle cell disease. Parents with lower health literacy have lower disease-specific knowledge about sickle cell disease [132]. One study examined appointment attendance in patients with sickle cell disease. Whereas adults in this study with lower health literacy had higher rates of missing their own clinic appointments in adjusted analyses, parent health literacy was not associated with appointment attendance for their children [133]. Although a study of parents of children with sickle cell disease found those parents with lower health literacy gave pain medication less frequently than prescribed, health literacy was not associated with medication knowledge assessments, dosing errors, or ED use [9].

3.3.6. Other Chronic Conditions

Parent health literacy is associated with behaviors and outcomes for several other conditions even after accounting for other variables. Parents with low health literacy are less likely to adhere to epilepsy medication regimens; their children have increased seizure frequency [134]. Among parents whose children have glaucoma, lower parent health literacy is associated with poor adherence to prescription eye drops [135]. In pediatric patients with nephrotic syndrome, lower parent health literacy is associated with lower odds of remission and higher risk of first relapse [136].

4. Promising Areas of Research and Future Directions

This section will outline promising research opportunities and future directions for the field of health literacy in pediatrics.

4.1. Development of Health Literacy Throughout the Life Course

Recent work has focused on the development of the health literacy skills of children, with an emphasis on health literacy-related education in schools. One program designed for U.S. children in third through eighth grade used a multimodal approach with a variety of hands-on activities and guest medical lecturers, with lessons focusing on developing literacy skills, including reading food labels, communicating with health care providers, and making healthy choices. Knowledge consistently increased and was retained after children received the intervention, and students enjoyed the experience [137]. Another intervention for high school students used interactive activities along with videos and educational content; example activities included a role play navigating a full doctor's appointment (e.g., checking in, making appointments, talking with the doctor) and practice assessing whether specific illnesses/injuries should lead to an ED, urgent care, or a primary care physician visit using hypothetical scenarios. Knowledge scores increased after the intervention; students and teachers gave the intervention positive feedback [138]. Another study found the use of a comprehensive health text book fostered improvements in health-related knowledge (e.g., smoking, nutrition, physical activity) and skills (e.g., accessing information, goal setting) in middle and high school students [139].

However, not all curricula were positively received. One educational program was designed for high school students to teach them basic health information and develop skills which would allow them to think critically about making health decisions. Students did not find the program helpful and cited the content was repetitive, passively delivered, and insufficiently individualized [140]. Instead, students preferred to be more active participants in the learning process [140]. School-based interventions which utilize hands-on and interactive activities that encourage active learning, are likely to be more effective and better received than interventions that involve passive learning through lectures alone [141].

While current research has focused on child and adolescent development of health literacy skills in the classroom, a few interventions have targeted the parent or family in the development of a child's health literacy. As children obtain most of their health habits and information (such as unhealthy eating behaviors) from their parents, more research is needed to determine whether interventions targeting parents can influence the development of a child's health literacy skills [35,142].

4.2. Technology-Based Interventions

Several novel interventions have combined a health literacy approach with technology in order to improve adolescent outcomes. One study of adolescents and young adults with kidney transplants utilized a computerized teachback method, which entailed showing the patient relevant videos (e.g., basic kidney transplant information, medication purpose), quizzing the patient about video content, discussing quiz results with the provider, and a corrected quiz given to the patient. The study found a significant increase in knowledge of medication name and purpose three months after the intervention compared to baseline. Patients also were satisfied with and found the computer program easy to navigate [143]. Social media provide another potential platform to increase adolescent health literacy skills; pilot work suggests increases in scores on oral health literacy assessments in adolescents receiving education via Facebook and YouTube [144].

Recent studies also have utilized technology-based interventions based on health literacy principles to improve knowledge in parents. One pilot intervention included text messaging reminders in addition to a short video that explained Early Intervention (EI) and child development; the video used plain language, action-oriented instructions, a summary of important messages using bullet points, and visual aids. Parents in the intervention group had improved knowledge of EI topics and developmental delay compared to the control group. While there was no difference in actual EI evaluations by study arm, there was a non-significant trend towards a higher percentage of EI evaluations for those parents with lower health literacy [145]. Recent work suggests most parents, regardless of health literacy level, seek to communicate with providers using the internet and via texting, providing a potential avenue for future intervention [146].

4.3 Inpatient Pediatrics

While many pediatric health literacy-informed interventions have targeted the ED and ambulatory venues, recent work has begun to focus on inpatient settings. The goal of one inpatient health literacy-informed intervention was to decrease adverse events; the intervention utilized a structured framework for family-centered rounds including use of plain language and teachback, written summaries of what was discussed on rounds, and role play and computer modules to support provider training. The intervention led to a 38% decrease in preventable adverse events, an increase in parent report in understanding of the plan and written updates, and an increase in parent read back of the plan [147].

Unaka and colleagues utilized quality improvement methodologies (cycles included implementation of an electronic health record-based discharge instruction template, education, and individualized feedback) to improve the readability of inpatient discharge instructions; instructions written at the seventh grade level or lower increased from 13 to 98% [148].

While studies have addressed some areas in which health literacy may impact a child or adolescent's inpatient admission or discharge, there are gaps and areas for future research. While recent work seeks to improve the readability of pediatric discharge instructions, fewer studies have examined additional important aspects such as understandability, actionability, and presence of key content [148]. A systematic review of the literature noted several important gaps related to parental management of their child's discharge instructions. Health literacy is rarely measured in parents on acute care inpatient units, which makes it difficult to assess its impact on discharge plan comprehension and adherence [27]. While interventions have been designed to target medication dosing and adherence as well as post-discharge appointments, other domains of care (e.g., medication side effects, activity restrictions, return precautions) are understudied, and few interventions target more than one domain of care [27]. Finally, more research is needed regarding children who are medically complex, have multiple caregivers and are responsible for managing their health care needs, Additional research should examine how to best design and test interventions targeting multiple caregivers and those with more challenging discharge plans [149].

5. Conclusions

While much of the research on health literacy has focused on adults, this chapter outlines some of the issues unique to children. Studies of the development of health literacy in children and adolescents are limited, as are studies of how health literacy within a family impacts a child's health. As much of the research in this field has focused on parents, health literacy researchers should expand their work to investigate the impact low child and adolescent health literacy may have on a child's knowledge, behaviors, and outcomes. Researchers also must develop and validate developmentally appropriate health literacy measures that can be used in children and adolescents in order to be able to complete studies within these groups. Understanding the costs associated with low health literacy in pediatric patients and their parents additionally would be helpful. Moreover, much of the extant literature focuses on the impact of health literacy on knowledge, behavior, and outcomes for a limited number of diagnoses and domains of care, such as medications. An expansion to additional care domains helps further elucidate the impact of health literacy on child health-related issues. Finally, research focused on technology-based, health literacy-informed interventions in pediatrics are beginning to emerge and provide promising areas for future research.

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The Evolving Role of Health Literacy in Improving Oral Health

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Abstract. This chapter provides a review of the evolution of oral health literacy including its impact on oral health outcomes, the current status of oral health literacy initiatives and future research needs. Using the Healthy People 2010 definition, the chapter describes opportunities needed to improve oral health literacy among health providers as well as individuals/patients, communities and policy-makers. Studies of the two most prevalent dental diseases—dental caries and periodontal diseases – reveal that increasing the oral health literacy of the public and health care providers can play a major role in reducing these diseases. Increasing oral health literacy by creating access to accurate knowledge and supporting use of science-based preventive measures is essential. A major part of the chapter describes oral health literacy's influence in the integration of dental and medical care. The chapter provides an extensive list of research needed to further our understanding of the impact of oral health literacy on health disparities and the health of the population.

Keywords. Oral health literacy, Oral health disparities, Health literacy, Dental and medical integrated care.

1. Introduction

Oral health is integral to overall health; a person cannot be healthy without good oral health, according to the U.S. Surgeon General's Report on Oral Health [1]. Despite these famous words, oral health has not improved for many Americans in the last two decades.

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Although research has demonstrated many oral diseases and conditions can be prevented using readily available evidence-based interventions, prevention has remained out of reach for the most vulnerable populations. In part, the latter occurs because the knowledge from these interventions (and how to benefit from them) is not uniformly shared with the public and policy makers by health professionals. When it is shared, it is not always easy to access, understand, and take appropriate action.

The purpose of this chapter is to provide a history of oral health literacy, an overview and update of ongoing research, and provide recommendations for future scholarship. The chapter is organized into nine other sections that provide: some background information about oral diseases; a review of the knowledge about oral diseases; milestones in the development of oral health literacy; the scope of oral health literacy; measuring the oral health literacy of individuals; assessing provider health literacy and use of communication techniques; health literacy and the environments where patients receive dental care; oral health literacy's influence in the integration of dental and medical care; and some conclusions and recommendations.

2. Background Information about Oral Diseases

Oral diseases are chronic diseases and their prevention is similar to preventing other chronic diseases. An individual, or caregiver, must know, understand, and be able to practice recommended preventive measures.

Unfortunately, individuals (especially persons with low educational attainment) tend to not practice recommended preventive procedures, which may be derived from a lack of exposure to good oral health information and practices. Certainly, it is difficult for persons to make informed oral health decisions without prior knowledge, the skills to find oral health information, and sufficient digital skills reinforced by a limited access to the internet.

Yet as Bloom warned, "primary prevention can be no better than the knowledge, skills and values of its practitioners" [2]. To help patients, health care providers also need to stay abreast of current research findings and share resulting information in a manner that patients can understand and apply. Policy-makers additionally require appropriate knowledge and understanding to make appropriate decisions concerning oral health.

Despite decades of research substantiating evidence-based oral disease prevention, there is a pressing need for the structured and effective transfer of current findings (knowledge and programs) to appropriate user groups including patients, health providers, and policy makers. To achieve oral and craniofacial health and well-being, there is a parallel need to increase health literacy to offset related oral health disparities and inequalities.

3. Knowledge About Oral Diseases and Conditions and their Prevention

The major oral diseases consist of dental caries (tooth decay), periodontal disease [gum disease], oral and oropharyngeal cancers (cancers of the mouth and pharynx), craniofacial birth defects, and intentional and unintentional orofacial injuries (tooth intrusion or avulsion from sports, automobile facial injuries and broken jaws). These diseases and conditions, if not prevented and treated, compromise general health and well-being and are often associated with other systemic, traumatic, or preventable conditions.

Dental caries remains one of the most prevalent childhood diseases. For 2015-2016, the prevalence of total dental caries (restored and untreated lesions) for 2-5-year-old Americans was 45.8% and prevalence increased with age [3]. In 2011-2012 among adults ages 20-64, 91% had dental caries (restored and untreated) and 27% had untreated decay.

Untreated tooth decay was higher for U.S. Hispanics (36%) and non-Hispanic blacks (42%) compared with whites [4]. In 2011-2014, 25% of U.S. adults age 19 and older, or 57.6 million people, had untreated caries [5].

The enduring status of dental caries suggests a mismatch among what has been demonstrated by research to prevent tooth decay, what health providers communicate to and provide patients and policy makers, and what the public and policy makers know and practice. For example, in addition to regular brushing and flossing, dental caries can be prevented with the appropriate use of fluorides and the application of pit and fissure sealants [1].

In contrast, in recent surveys 70% of Americans suggest only brushing and flossing are needed to prevent dental caries (only 7% correctly answered fluoride) [6]. In the U.S. state of Maryland, 770 adults were asked in a phone survey if they had ever heard of fluoride. While nearly all said yes (97.9%), only about 4% recognized fluoride's role in preventing dental caries. The Maryland respondents also did not practice recommended procedures to use fluoride toothpaste and drink tap water with fluoride [7].

The public knows even less about dental sealants, a thin plastic coating applied to the chewing surfaces of teeth to prevent decay. Among parents of children younger than 18, a 2019 national study suggests only 55% had knowledge of dental sealants [8]. Although dental sealants have existed for decades, they are only available through a dental provider laying the sole burden for information transfer to the dental team.

In addition, when the public is asked the best way to prevent dental caries, most respond: 'brush your teeth twice a day, floss, and see a dentist' [6]. Yet, the public's incorrect response is understandable since the latter solution is emphasized in dental product advertisements and educational messages within magazines and other public literature.

Meanwhile, the early stages of the majority of periodontal diseases (gum diseases) can be prevented by routinely practicing oral hygiene measures of brushing and flossing teeth to remove and disrupt dental plaque. The latest data find 42% of U.S. adults after age 30 have periodontitis (a moderate form of periodontal disease) and 7.8% have severe periodontitis [9]. A review of the last two national surveys added there are significant income disparities among patients with periodontitis [10]. Still, a patient study in California and Maryland demonstrated demographically diverse populations recognized at least one cause of periodontal disease [11]. The public's understanding of causes of chronic diseases are noteworthy because of the reciprocal nature of periodontal disease and diabetes [12].

The American Cancer Society also estimates in 2019, 53,000 adults will be diagnosed with mouth or oropharyngeal cancers and 10,860 will die from one of these cancers [13]. Oral and oral-pharyngeal cancers can be prevented by not using tobacco products, reducing alcohol intake, practicing safe sex, and being appropriately vaccinated for HPV.

Unfortunately, HPV-related oropharyngeal cancers have increased rapidly in recent years. Although the new HPV vaccine (Gardasil9®) prevents five cancers, it has a low uptake among U.S. adolescents, which requires further education for providers, the public, and policy makers [14]. Also, many U.S. adults report they have never had an oral cancer examination [15].

Interestingly, the latter may stem from a lack of recognition as well as provider uncommunicativeness. Patients may not know the examination of the sides of and underneath their tongue by a dentist or dental hygienist is part of an oral cancer screening because the latter often is unexplained. Health care providers need to be more assertive in explaining the reason for the examination they give to increase patient' knowledge of oral diseases.

The primary cause of craniofacial injuries are motor vehicle collisions, falls, sporting activities, and assaults. The use of seat belts and child car seats are a primary way to prevent head injuries related to traffic accidents. However, not all states have mandatory seat belt and or child restraint laws [16]. While the use of bicycle helmets has reduced head injury by 48% and face injury by 23%, many U.S. states still do not have or do not enforce helmet laws for bicyclists [17]. Although the use of mouth guards decreases chances of oral-facial injuries by 55%, mouth guards are not required and not used widely [18]. Craniofacial birth defects, such as cleft lip and cleft palate, have benefited from the recommendation to increase folic acid during pregnancy [19].

4. Milestones in the Development of Oral Health Literacy

The concept of health literacy (as opposed to oral health literacy) gained visibility when Healthy People 2010, released in January 2000, devoted a chapter to health communication that contained three health literacy objectives [20]. Concomitantly, the first time 'oral health literacy' was defined occurred in the oral health chapter within Healthy People 2010. The definition paralleled health literacy: "The degree to which individuals have the capacity to obtain, process and understand basic oral health information and services needed to make appropriate health decisions" [21].

In June 2000, 'Oral Health in America: A Report of the Surgeon General' was released, highlighting the importance of and need for increasing oral health literacy and its role in oral health promotion [1]. Besides the specific mention of the term 'oral health literacy,' the U.S. Surgeon General's report suggested oral health could be ameliorated through improved knowledge, understanding, and skills of both the public and health care providers. The Surgeon General's report reinforced that the challenge of oral health literacy is evidenced by what both the public and health care providers do not know and practice to prevent dental caries, gingivitis, oral cancers, and craniofacial injuries [1].

Inherent in the definition of oral health literacy is a premise that oral health outcomes improve when individuals have better access to both health information and enhanced self-management skills regarding dental health information and care. However, the focus frequently has been on the patient's or the public's access to health information and individual skills and capacities. Conversely, the degree to which individuals gain capacity often depends on how, where, and whom provides oral health information. The participation of health care providers, teachers, policy-makers, media, social services workers, insurance plans, dental practice administrators and others who need access to health information in an understandable manner is needed to communicate key health information to others [20].

Health literacy also includes much more than the ability to read. Other skills necessary to improve national health literacy include competence in numeracy (to understand concepts such as dosage of medicines) as well as written and oral communication skills, such as listening and comprehension.

Prior research suggests individuals with low levels of health literacy are less likely to use preventive measures, such as early childhood immunizations, flu vaccines, mammograms, and preventive dental visits [22]. Persons with limited health literacy also are more prone to use the emergency room and to experience comparatively deficient health outcomes - especially in the case of chronic diseases, such as cardiovascular diseases, diabetes, and oral diseases [23]. In addition, individuals with lower levels of oral health literacy tend to have higher rates of severe dental caries, are less likely to use preventive regimens, are more likely to fail dental appointments, have fewer dental visits, and have a lower oral health quality of life [7,24-28].

Similarly, when parents do not understand the importance and required care of their child's primary teeth and do not understand they can prevent early childhood caries (ECC), parents are unlikely to seek out and follow evidence-based recommendations for oral home care as well as professional services for preventive and restorative dental care. Concomitantly, if policy makers fail to understand the intimate role of oral health in general health and well-being, they are unlikely to support coverage for oral health services in the U.S.' public insurance programs, such as Medicaid. (Of note, in the U.S. Medicaid does not cover adult dental care in the majority of states, and dental care in Medicare essentially is omitted. The 2010 U.S. Affordable Care Act increased dental benefits for children but not for adults) [5].

A more direct focus on oral health literacy was highlighted in the U.S. Surgeon General's 'National Call to Action to Promote Oral Health,' which was released in 2003 [29]. The Call described five specific actions and numerous sub-actions needed to address the Surgeon General report's 'national framework for oral health.' Figure 1 below shows action # 1 and the sub-actions specifically related to health literacy. While the latter 'framework' was published in 2003, the proposed actions provide guidance for continuing activities and are pivotal to address current needs as well as those raised in the 2000 Surgeon General's report. The timing of the National Call to Action to Promote Oral Health coincided with several major reports on health literacy.

Health literacy received wide visibility in the 2003 simultaneous release of the Institute of Medicine's (IOM) report, 'Health Literacy: A Prescription to End Confusion' and the Agency for Health Care Research and Quality's (AHRQ) 'Literacy and Health Outcomes' [23,30]. While dentistry or oral health was barely mentioned in the IOM report and not included in the evidence-based review conducted by AHRQ, these reports reached a broad audience and stimulated subsequent action by the U.S. federal government in oral health initiatives. For example, in 2003 the National Institutes of Health (NIH) issued a program announcement (PA) for research on health literacy. The National Institute of Dental and Craniofacial Research (NIDCR) was one of the participating institutes in this PA. Since its initiation, numerous grants have been awarded, many in connection with oral health, including investigating the role of health literacy in decreasing early childhood caries (ECC). While NIH's PA is no longer active, most institutes recognize the importance of culturally competent communication in improving health and both accept and fund applications that include research regarding health literacy.

Implementation strategies to change perceptions needed to change perceptions are needed at local, state, regional and national levels for all population groups. All stakeholders should work together and use data in order to:

Change public perceptions:

- ➢ Enhance oral health literacy.
- ➢ Develop messages that are culturally sensitive and linguistically competent.
- ➢ Enhance knowledge of the value of regular, professional oral health care.
- ➢ Increase the understanding of how the signs and symptoms of oral infections can indicate general health status and act as markers for other diseases.

Change policymakers' perceptions:

- ➢ Inform policymakers and administrators at local, state, and federal levels of the results of oral health research and programs and of the oral health status of their constituencies.
- ➢ Develop concise and relevant messages for policymakers.
- ➢ Document the health and quality-of-life outcomes that result from the inclusion (or exclusion) of oral health services in programs and reimbursement schedules.

Change health providers' perceptions:

- ➢ Review and update health professional educational curricula and continuing education courses to include content on oral health and the associations between oral health and general health.
- ➢ Train health care providers to conduct oral screenings as part of routine physical examinations and make appropriate referrals.
- ➢ Promote interdisciplinary training of medical, oral health, and allied health professional personnel in counseling patients about how to reduce risk factors common to oral and general health.
- ➢ Encourage oral health providers to refer patients to other health specialists as warranted by examinations and history. Similarly, encourage medical and surgical providers to refer patients for oral health care when medical or surgical treatments that may have an impact on oral health are planned.

Figure 1. Action 1. Change Perceptions of Oral Health from A National Call to Action [29]
Adapted from: U. S. Department of Health and Human Services. A National Call to Action to Promote Oral Health. Rockville, MD: US. Department of Health and Human Services, Public Health Service, Centers for Disease Control and Prevention and the National Institutes of Health, National Institute of Dental and Craniofacial Research. NIH Publication No. 03-5303, May 2003

NIDCR supported the first ever workshop on oral health literacy in 2004. The NIDCR-sponsored research agenda workshop included numerous dental researchers as well as researchers in health literacy, cognition, communications, and adult education. The workshop produced a rich research agenda for oral health literacy and was published in the *Journal of Public Health Dentistry* [31]. The workshop also served to educate dental researchers regarding the impact of health literacy on oral health outcomes as well as inform non-dental researchers about the connection between oral and general health. One of the workshop's recommendations was to develop instruments to evaluate the oral health literacy of individuals similar to those available to assess general health literacy. Diverse quantitative instruments to evaluate oral health literacy have been published and will be discussed later in this chapter.

While a research agenda on oral health literacy continues to be pursued, there have been numerous efforts to inform dental practitioners, educators, and researchers about the importance of oral health literacy. An extensive overview of oral health literacy was included in the 2011 Institute of Medicine (IOM) report, 'Advancing Oral Heath in America' [32]. This report's purpose was to update the Surgeon General's Report of 2000 and to recommend strategies to improve the oral health of more Americans. In 2013, the IOM's Roundtable on Health Literacy published the proceedings of a workshop on 'Oral Health Literacy' [33]. Although most of the initial U.S. National Academies' Health Literacy Roundtable's workshops did not include dental related contributions due to the lack of oral health expertise of the membership, currently there are two dentist-members and workshops routinely include relevant oral health content.

Other efforts include the publication of research findings and symposia as well as workshops on oral health literacy from diverse meetings. For example, symposia on oral health and literacy have been included in the annual sessions of nearly all major U.S. dental organizations, including the American Association for Dental Research, American Public Health Association, Hispanic Dental Association, American Dental Association, Academy of General Dentistry and the American Association of Public Health Dentistry.

Some U.S. professional organizations also have taken formal actions. For instance, the U.S. Academy of General Dentistry established a Memorandum of Understanding with the U.S. Department of Health and Human Services to address oral health literacy in the Healthy People 2010 objectives. The American Dental Association (ADA) established a National Advisory Committee on Health Literacy in Dentistry, which is now part of the ADA's Council on Advocacy for Access and Prevention (CAAP). The ADA's advisory committee recommends providing sessions on oral health literacy at their annual sessions; and sponsors national surveys about knowledge, opinions, and practices among dental practitioners and students; as well as explaining health literacy techniques to improve health information leaflets. The ADA also developed a patient and general population guide to dental health that includes easy-to-understand educational messages in print and video format [34].

5. The Scope of Oral Health Literacy

Although oral health literacy has similarities to other health literacy disease areas, such as diabetes and cancer, oral health literacy has some distinctive characteristics. While oral health literacy requires knowledge of oral and craniofacial disease - or condition-specific prevention and management at multiple levels from the individual to the community - it also requires an understanding of the overall role of these tissues and structures to overall health and well-being. The accessibility of the mouth and face provides visibility to signs and symptoms of other conditions. In this manner, the mouth and face serve as a sentinel marker of conditions that undergird health and well-being.

It is these additional characteristics that embed oral health literacy as a 'content and function' area and create the need for a more comprehensive 'systems' approach to an oral health literacy research agenda. The latter approach also aligns with the proposed role of health literacy in the Healthy People 2030 Initiative. The Framework for Healthy People 2030 envisions "a society in which all people can achieve their full potential for health and well-being across the lifespan." The Framework's foundational principles and overarching goals highlight that achieving this vision requires "eliminating health disparities, achieving health equity and attaining health literacy" [35].

Acknowledging that health literacy has been part of the Healthy People initiative since 2010, the HHS Secretary's Advisory Committee on the National Health Promotion and Disease Prevention Objectives for 2030 suggests health literacy should better align individual skills and community initiatives with the multidimensional factors that impact people's ability to find, understand, and use health information.

The HHS Advisory Committee describes health literacy as a process and includes the definition that "health literacy occurs when a society provides accurate health information and services that people can easily find, understand and use to inform their decisions and actions." The term 'society' is intended to capture the diversity of stakeholders that provide and are sources of health information and services: such as health care providers, health care facilities and associated organizations (such as health insurance and professional and community groups), as well as mass and social media. Individuals, families and communities comprise the levels and groups of 'people' whose skills and capacities need to be addressed. To improve health literacy, "interventions that target the complex factors that contribute to or mediate health literacy are needed." Building on potential intervention points suggested in the health literacy framework in the 2004 IOM report, the HHS Advisory Committee identified examples such as improving the basic quality of health information and materials, enhancing the communication skills and knowledge of health professionals, and advancing some characteristics of health care and public health practices, facilities, and systems. The alignment between society's actions and peoples' abilities is perceived as a "key to eliminating health disparities and achieving health equity."

Yet, to achieve fair and just information and services available for most Americans, and particularly for vulnerable populations, efforts to attain oral health literacy must extend to assess and address the existing, aforementioned gaps. In that regard, a systems approach to oral and craniofacial health and well-being should be considered.

6. Measuring the Oral Health Literacy of Individuals

Health literacy is a complex construct that means different things to different people and is dependent upon multiple factors. These factors include an individual's ability (patient and providers) and the responsiveness of the health care delivery system. Figure 2 shows the interactions and roles within the health care system, which makes it challenging to comprehensively assess and plan health literacy initiatives.

However, the instruments to measure oral health literacy have focused almost exclusively on individuals or patients and often parallel those developed for use in medicine. For example, the Rapid Estimate of Adult Literacy in Dentistry (REALD) and the Test of Functional Health Literacy in Dentistry (ToFHLiD) are oral health versions of the REALM and TOFHLA [36-38]. The REALM and TOFHLA are two widely known and used instruments to measure laypeople's recognition of medical words and comprehension of print health information.

The existing instruments that focus on word recognition and reading ability have been criticized because of their narrow focus and failure to assess domains that are critical to patient care, such as numeracy (which impacts appropriate medication use), and consumer misunderstanding of (or access to) the health care delivery system. On the other hand, some early assessment efforts in dentistry established a foundation upon which broader instruments have emerged.

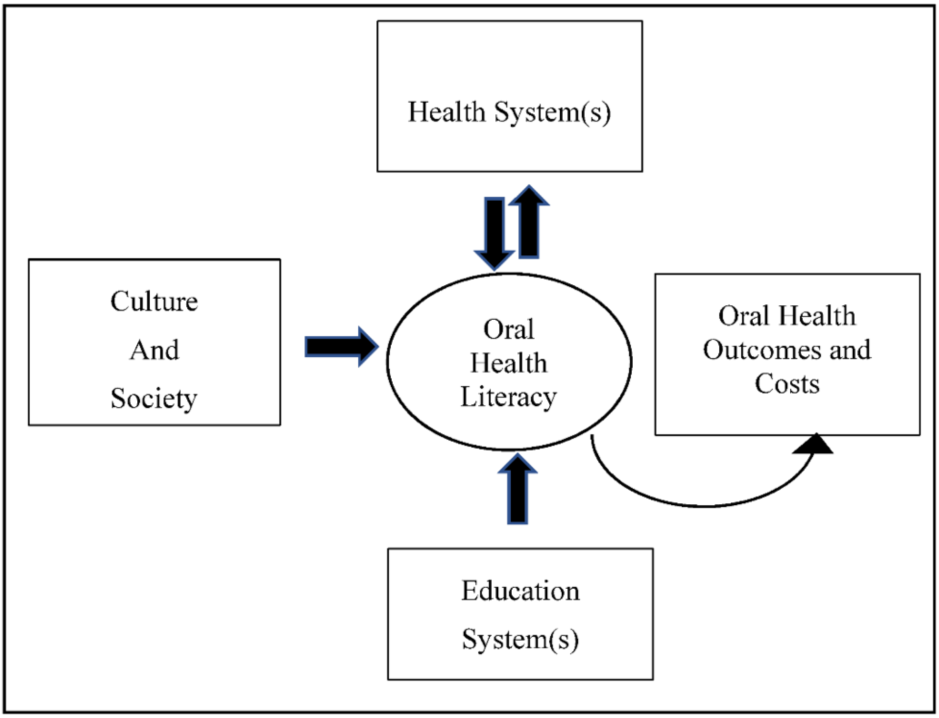


Figure 2. Potential Sites for Interventions.
Adapted from: IOM Health Literacy A Prescription to End Confusion 2003.

For example, Dickson-Swift and colleagues conducted a scoping review of oral health literacy measurement in which they identified 14 different measures used in 32 publications. The majority of measures used either were based on the REALD or ToFHLiD. The authors suggested this prior work relied heavily on word recognition and reading skills, and infrequently assessed numeracy [38]. Macek and colleagues additionally developed a Comprehensive Measure of Oral Health Knowledge (CMOHK) scale to explore conceptual and oral health knowledge among Baltimore adults [39]. Their findings enabled collaborate with additional investigators to develop the Multi-Site Oral Health Literacy Research Study (MOHLRS) [40]. Macek et.al. conducted interviews among adult patients in dental school clinics in Maryland and California and included the use of CMOHK as well as questions concerning patient self-efficacy, dental beliefs and attitudes, and their use of dental care.

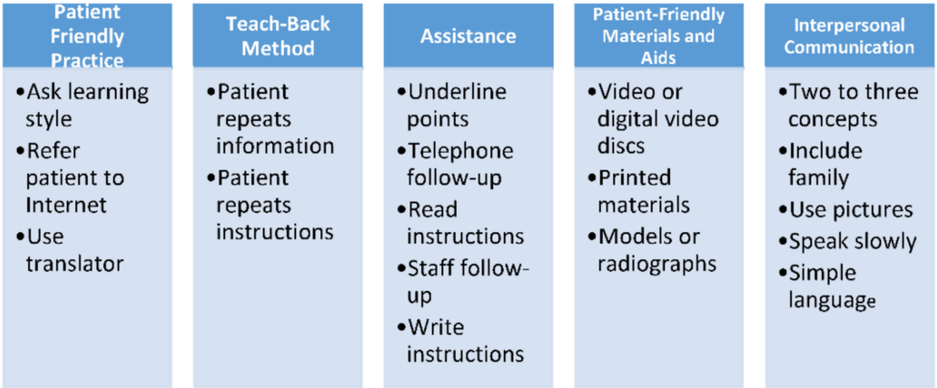
Macek et.al. found 18% of 909 participants had low conceptual knowledge and CMOHK scores were significantly associated with REALM, TOFHLA, and participant confidence to complete forms. A subsequent analysis led to the development of a combined word recognition (the REALMD-20) and comprehension (the CMOHK), into the MOLAR-K, which combined an individual’s word recognition with their knowledge of specific dental problems [11]. The inclusion of variables that operationalized the social determinants of health additionally provided some new dimensions, such as how transportation difficulties are associated with patient oral health literacy.

Sistani et al. developed the Oral Health Literacy Adults Questionnaire (OHL-AQ) which is based on four domains: reading comprehension; numeracy; listening; and decision making [41]. The authors suggested their instrument can be used in either population or clinical settings because it is relatively short. Jones et al. also developed the Health Literacy in Dentistry scale (HeLD) based on the HeLMS, which is used in medicine [42-43]. The HeLD includes the following domains: communication; access; receptivity; understanding; utilization; support; and economic barriers. The latter instrument can be used across adult demographic groups including persons in marginalized populations.

In summary, although there are different operational definitions of oral health literacy and multiple approaches to measure it within diverse populations and sample sizes, there is no shortage of available, multidimensional instruments. However, it remains difficult if not impossible to compare oral health literacy results because currently they are derived from instruments with different construct domains and psychometric properties.

7. Assessing Provider Health Literacy and Use of Communication Techniques

Although the assessment of the health literacy of health care providers has been limited, the American Medical Association (AMA) developed an instrument consisting of 18 recommended communication techniques. The AMA surveyed physicians, nurses, and pharmacists to determine which of the techniques they used on a routine basis and to identify what techniques were most effective [44]. Figure 3 describes the content in AMA's survey instrument.



Patient Friendly Practice	Teach-Back Method	Assistance	Patient-Friendly Materials and Aids	Interpersonal Communication
•Ask learning style •Refer patient to Internet •Use translator	•Patient repeats information •Patient repeats instructions	•Underline points •Telephone follow-up •Read instructions •Staff follow-up •Write instructions	•Video or digital video discs •Printed materials •Models or radiographs	•Two to three concepts •Include family •Use pictures •Speak slowly •Simple language

Figure 3. Content of American Medical Association's Recommended Communication Techniques

Rozier and colleagues modified the AMA survey to conduct a national survey of practicing dentists [45]. The primary outcome variable was the number of routinely used techniques among the 18 possibilities suggested in the AMA survey. While dentists reported routinely using an average of seven of the 18 techniques, less than a quarter of respondents used teach back, which was suggested as the most important.

Rozier et.al. noted one of the robust predictors to use communication techniques was a dentist's outcome expectancy. Outcome expectancy includes one's confidence in performing a task and one's belief the action will result in intended outcomes. In an interesting finding, dentists with a high outcome expectancy used 50 percent more communication techniques compared to peers with a low outcome expectancy.

With some modification, Horowitz et al. used Rozier et. al.'s survey instrument to assess Maryland dental hygienists and dentists' use of the 18 communication techniques, and evaluated their knowledge, understanding, and use of dental caries preventive regimens [46-47]. The participants (Maryland general dentists) reported using a mean of 7.9 of the techniques on a routine basis while pediatric dentists reported using 8.4. The Maryland dentists who took a communications course outside of dental school were more likely to use more communication techniques. Similarly, Maryland dental hygienists who took a communications course outside of dental hygiene school were more likely to use a higher number of communication techniques. Maryland hygienists also reported routinely using slightly fewer (7.0) communication techniques than dentists.

Regarding their knowledge, understanding, and reported practices of caries prevention, many Maryland dentists and dental hygienists also do not have a good understanding of how to prevent caries and often fail to recommend dental sealants [48-49].

While the latter surveys provide useful self-reported information about which communication techniques are used, there has been far less research regarding dentist and dental hygienist interpersonal patient communication practices. Using the Consumer Assessment of Healthcare Providers and Systems (CAHPS) developed by the U.S. Agency for Health Research and Quality's (AHRQ), Horowitz et al. assessed the communication skills and practices of dental providers among Maryland adults with small children [50]. Women and persons with higher education levels were more favorable about the communication practices of their dental providers. When children were insured by Medicaid, the group with the most advanced dental diseases were less likely to respond favorably about their provider's interpersonal communication practices. The same group suggested they were less likely to feel respected by a dental professional and believed they did not spend sufficient time providing dental care or counsel.

8. Health Literacy and the Environments Where Patients Receive Dental Care

Similarly, another line of research suggests the broader dental health care system is not user friendly - or is not providing a health literate environment for patients [51]. The latter research is conceptually derived from Rudd et al., who previously noted a need to evaluate and address dimensions related to user friendliness as a component of health literate, patient-centered health care facilities [52]. Some tools to assess the friendliness as an indicator of patient-centered care within health institutions also are provided within AHRQ's Universal Precautions, which is now in its second edition [53].

Although user friendliness is infrequently assessed within dental care settings, Horowitz et. al. noted considerable variation among relevant indicators within Maryland-based community based dental clinics [51]. For example, considerable differences were found among clinics regarding the provision and content of educational materials, overall facilities and operations. Providers who had taken a communications course were more likely to use recommended communications techniques, which serve as indicators of institutional caring and friendliness towards patients. Some of the assessed indicators included: signage outside and inside the facility; educational print materials on dental caries and consent forms; websites; whether or not a live person answered the phone; surveys of dental providers regarding their use of recommended communication techniques; and interviews with patients regarding health provider's communication skills. Overall, the findings suggest a need for additional research in a promising area that assesses the degree dental clinics need to improve in the communication techniques that demonstrate a friendly, patient centered outlook on sharing knowledge with patients.

9. Oral Health Literacy's Influence in the Integration of Dental and Medical Care

Turning now to a growing awareness to integrate medical and dental care, there is an evolving consensus that a lack of integration leads to: "incomplete, inaccurate, inefficient and inadequate treatment of both medical and dental disease" [54-55]. This section introduces a few programs and an overview of national efforts where initiatives to integrate oral health and primary care include some health literacy principles.

For example, a study of integration efforts (that included health literacy initiatives) in Boston successfully reduced the incidence of early childhood caries [56]. The study compared a three-pronged intervention to enhance provider and patient oral health literacy in one pediatric outpatient practice at a medical center versus usual care at a comparison pediatric outpatient site. At the intervention site, providers received a one-hour training in communication skills and anticipatory guidance to cover counsel parents about ECC risk. An electronic medical record was edited to include ECC-related topics for providers to cover and document during parent counseling, and an educational brochure was developed for providers to distribute to parents/caregivers about child oral health. After the three-prong intervention, provider ECC knowledge and provision of ECC counseling comparatively increased and the ECC incidence decreased.

9.1 Grace Health

A second example of clinical and system-level effort to boost oral and health care - with some application of health literacy principles – is occurring at Grace Health, a federally qualified health center with both medical and dental clinics in Battle Creek, Michigan [57]. The program uses dental hygienists to provide oral health education and preventive services for women during pregnancy, who are patients in Grace's (OB-GYN) facility.

The overall intent is to use health literacy and interpersonal interventions to prevent maternal periodontal disease, which is a risk factor for adverse pregnancy outcomes such as low birth weight, preterm birth and preeclampsia [58]. Additionally, children whose mothers have untreated dental caries have an increased risk of caries [59]. To backup, dental care is safe during pregnancy and is recommended by the American College of Obstetricians and Gynecologists [60].

The Grace Health program involves a variety of interpersonal and health literacy-based efforts to ensure the Center's patients receive recommended dental care. For example, a hygienist might serve as a patient navigator to help them get to a clinic, introduce them to a dental team, and provide a 'warm hand-off.' In later trimesters, the dental hygienist might discuss oral hygiene, the dietary factors that affect mothers' and children's oral health, and how to care for an infant's oral health. The Grace Health program recently expanded so hygienists now see new mothers and their children in the

Pediatrics department. During well-child visits, hygienists provide additional education, oral health screenings, caries risk assessment, preventive services and referral to the dental clinic as needed.

While assessment results are not yet available, the Grace Health effort represents the type of research opportunities that emerge when oral health and primary care are provided concurrently.

9.2 Integration of Primary Oral Health Services into Primary Care: Into the Mouths of Babes

A more applied example of utilizing integration of oral health and primary care to provide patient friendly oral health literate messages is to provide primary oral health services (POHS) during medical pediatric well-child visits [54]. The latter model has gained popularity in pediatrics since its introduction in the late 1990s because it can ease barriers to oral health information and care faced by low-income families who may not recognize the link between bottle-feeding and Early Childhood Caries or the need for oral health services before age 2 [61].

All U.S. state Medicaid programs and many private insurance companies now reimburse for POHS provided in primary care settings. Oral health screening, risk assessment, counseling and fluoride varnish are considered essential services during well-child visits; but were rarely received by low income families at a higher risk of dental decay [62]. North Carolina was one of the first states to implement such a program, Into the Mouths of Babes (IMB) via Medicaid began in the late 1990s and was implemented statewide in 2001 [63, 64]. IMB promoted these health literate messages' early entry into the dental care system and exposure to oral health messages for children in greatest need, reduced the need for caries treatment services by dentists, helped prevent hospitalizations for ECC, helped control dental costs, and complimented other social service programs [54,57,65-67].

9.3 Nation-wide Adoption and Implementation of POHS in Pediatrics

While an increasing number of U.S. medical providers are providing primary oral health services (POHS), adoption rates vary by state and remain significantly below recommended levels. In 2012, fewer than 30% of pediatricians in a national survey reported routinely (>75% of patients) performing oral screenings and risk assessments on children birth to three years of age [68]. In the same survey, fewer than 8% reported routinely applying fluoride varnish. Dental referrals fall further short of recommendations for a set of complex reasons [69]. Successful dental referrals by primary care require the completion of a number of steps that frequently fail to be initiated within a medical office and face substantial barriers that prevent their completion if initiated. Estimates from a study by Sengupta et al. suggest only about six child patients out of every 100 in an FQHC with a dental referral end up with a visit [70]. Meanwhile, effective dental referral networks are critical to the success of pediatrics because many patients exhibit treatment needs early in life, which require the intervention of dental professionals.

In general, the effective integration of medicine and dentistry provides an opportunity with a requirement that appropriate health literacy/communication principles and policies be applied when providing POHS. In one POHS-based study, providers incorporated a wide variety of recommended oral health content into visits and integrated general health and oral health messages [71-72]. While medical providers used limited jargon and uncomplicated language, more effective techniques such as teach-back method were less applied [70-71]. Overall, recent studies suggest while providers deliver the content recommend by the American Academy of Pediatrics during IMB visits, they avoid using some effective communication techniques - and patient outcomes remain unknown.

In short, the success of integrated oral health and primary care programs partially may be linked to increased provider adoption of more health literacy/patient communication principles.

9.4 A National Perspective on the Use of Health Literacy Principles Within Programs that Seek to Better Integrate Oral Health and Primary Care

Recently, the National Academies of Sciences, Engineering, and Medicine's (NASEM) Roundtable on Health Literacy commissioned a paper on integrating oral health, primary care, and health literacy [54]. The Roundtable's paper identified U.S. oral health integration programs and examined the characteristics of the program, the type of providers involved, some outcomes, and the health literacy techniques needed to implement integration.

The Roundtable's paper explained there are examples of integration of oral/primary health care at six levels throughout the U.S. and noted some of the health literacy techniques that are used during the provision of integrated oral health care. Figure 4 describes the areas of integration are: clinical; professional; organization; system; functional; and normative.

The integration of health literacy or programmatic efforts in each area are summarized below.

At the clinical level, the Roundtable paper describes direct patient services have been coordinated across multiple providers within different professional disciplines and places. For care to take place efficiently and effectively, some health literacy techniques have included: clear communication among providers; case management or coordination by clinical assistants or patient navigators; and follow-up on all referrals. Information about the patient's medical or dental home also have been built into shared medical-dental patient records.

At the professional level, the integration of health literacy techniques has included: clear communication to develop a shared vision of culturally appropriate care across the professions; development of clinical guidelines and training for all non-dental professionals on how to perform an oral health assessment; and rules on communication of all services provided.

At the organizational level, care integration has required leadership to develop programs that meet patients' needs; assure all health professionals agree with the plan; the development of appropriate metrics for the care to be provided; the creation of a referral network with appropriate guidelines; and cultural competency training for all involved providers and staff.

At the system level, care integration hypothetically aligns the care provided by all providers with all of the health care system's levels. Some appropriate health literacy techniques include: working with the community organizations to determine their needs; and developing public-private partnerships to initiate programs such as food-assistance or transportation (to bring patients for care).

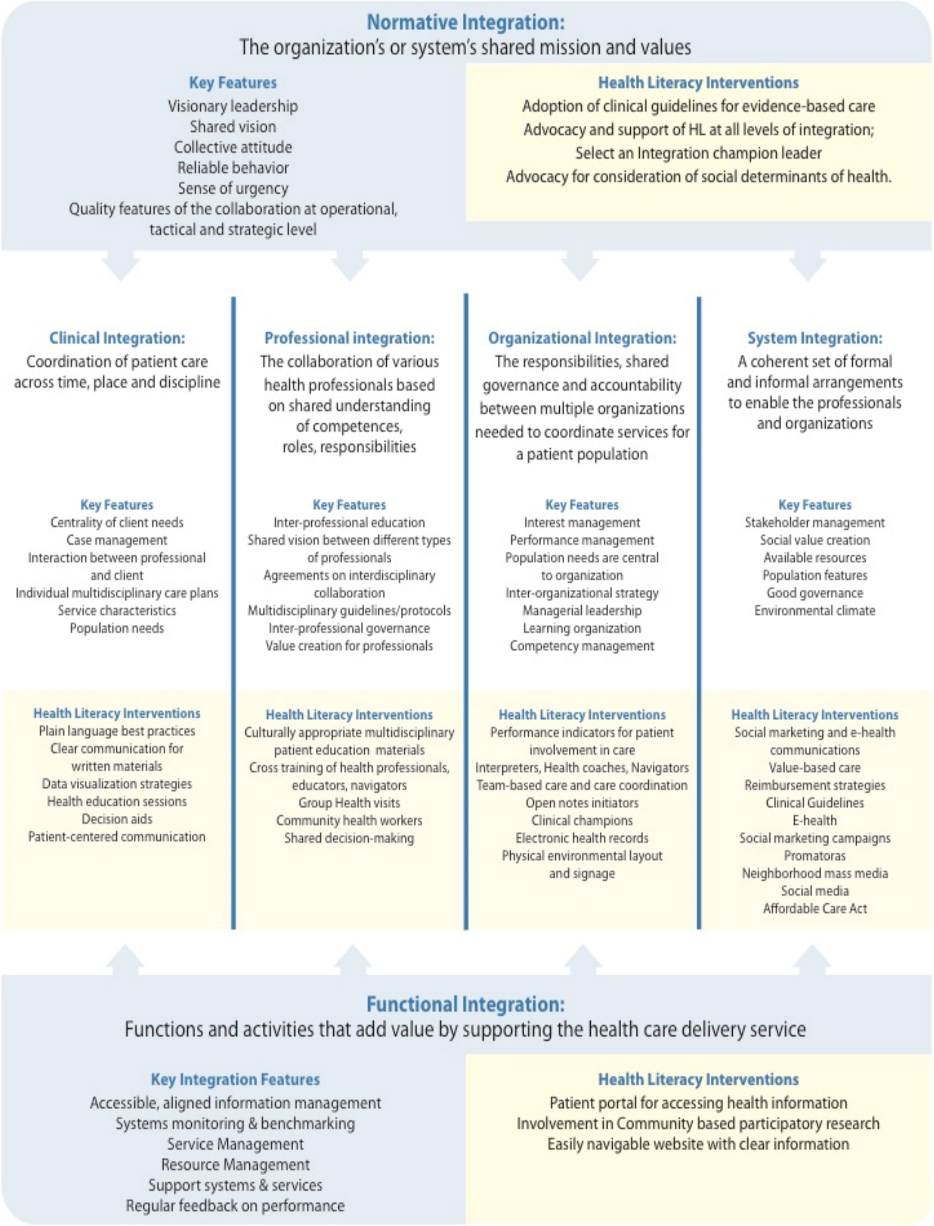


Figure 4. Normative Integration: The Organization's or System's Mission and Values

The two additional levels of integration described in the Roundtable's report are more supportive and less operational.

At the functional level, care integration recognizes that most medical and dental electronic health records are not integrated. Hence, efforts at the functional level seek to develop integrated electronic record systems and clinical decision tools to systematize and cue health care providers on new rules within the organization of care. These efforts may include the development of monitoring and feedback systems, which provides anticipatory guidance for providers.

At the normative level, care integration reflects a recognized need to have visionary leadership at the highest level of health care organizations to embrace health literacy in order to improve the nation's oral health. Health literate techniques can include developing dental home initiatives, creating a sense of urgency about the community's need for improved oral health, and building quality features at all levels of the organization [55].

Overall, the diverse levels of health literacy into care integration reflect six separate areas of opportunity for research and the additional challenge of a multilevel approach to integration and assessment.

10. Conclusions

Health literacy is now an acknowledged pathway to improve health and is on the national agenda. The future of improvements in oral health is acknowledged to be tied to health literacy. Considering that health literacy, and especially oral health literacy, is a relatively new concept, impressive gains have been made since they were first introduced in 2000. Yet, our work remains better identified than completed.

The oral health literacy action agenda has defined an immediate need to accelerate and expand the training of the U.S.' health care workforce, enhance the capacity of health care delivery systems to support oral health literacy and the integration of dental and medical care, better integrate oral health literacy services into the community and patient training and education activities, and to address these and other oral health literacy issues using a research approach. The enduring gaps in dental provider professional training, dental provider continuing education, and dental provider involvement need to be addressed. This includes training in communication, determining which messages about which disease or condition are best suited for which age and socioeconomic groups in what environments, and identifying which members of the provider team are best suited to provide health literate messages. Beyond the dental workforce, there is a need to continue the oral health training of other health professionals. The assessment of the influence of oral health literacy on the integration of dental and medical care is ripe for study. In addition, guidelines and best practices on communication techniques with implementation tools for both dental and medical providers need to be developed and assessed. Of note, this includes the education of health care systems administrators and staff, the alignment of medical electronic health record technologies and tailored use of their components, such as after visit summaries, studies of referral practices, and the effects of the overall health care environment on appropriate and effective use of health services.

Research should continue on measurement of individual (person/patient, provider, payer, policy-maker) and population/community health literacy using the expanded definition of health literacy. Finally, assessment of the impact of health literacy related policies need to be addressed.

It is clear from the lack of diffusion about known, effective, evidence-based oral health prevention services for common oral diseases, such as dental caries and periodontal disease, that there is much to be done. It is the public's right to know about their disease or condition and their options for appropriate care and the health provider's responsibility to provide enabling information. Taking action to enhance oral health literacy has an essential, important and integral role in decreasing inequities and improving the oral health of the population.

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Advancing Health Literacy Interventions

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Abstract. The past 25 years has seen extraordinary growth in interest in health literacy among researchers, policy-makers and practitioners. This interest has been underpinned by academic debate about the concept, definition, and measurement of health literacy, and further strengthened by a growing volume of research that has investigated the relationship between health literacy and a wide range of health and social outcomes. A smaller but growing number of studies report on interventions to address the practical challenges of low health literacy in clinical settings - and describe approaches to improving health literacy in different clinical and community populations. This chapter examines the evolution of the concept of health literacy and its practical implications for health literacy interventions. The chapter, then, provides an updated overview of reported interventions and existing strengths and weaknesses. It concludes with recommendations on interventional research that provides practical and implementable solutions which can inform future policy, strategy, and priorities.

Keywords. Health literacy, interventions, risk, asset

1. Introduction – Health Literacy as a National Priority

The past 25 years have evidenced extraordinary growth in interest in health literacy among researchers, policy-makers and practitioners. This interest has been underpinned by debate about the concept, definition, and measurement of health literacy, and further strengthened by a growing volume of research that has investigated the relationship between health literacy and a wide range of health and social outcomes. This body of work has improved the understanding of health literacy as a distinctive concept that has an impact on health decisions, behaviours, and outcomes and is independent of other social variables [1].

As professional and academic interest has grown, countries as diverse as the United States (U.S.), China, Germany, and Australia have adopted national strategies and plans to improve health literacy in their populations [2]. Each of the existing national policies and strategies has different origins and processes that reflect the diverse political and health system contexts in which they have been developed. Most represent a response (at least in part) to perceived deficiencies in the quality of patient communication and patient engagement in the health care system.

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The responses of governments have ranged from structured guidelines and standards for health care organisations (such as in Australia), to practical actions (such as the specified demonstration projects identified in the China strategy) through to more aspirational statements, such as those reflected in the U.S.

Most present health literacy as a universal challenge (applying to all patients and/or communities) - with some also identifying groups who are higher priorities. All recognise the importance of professional education in improving the quality of health communications within the health care system. Most existing policies and strategies also recognise the responsiveness of the health system to variations in the health literacy of patients' needs to be improved. These make clear that organisational change is required, with the necessary action expressed in different forms, such as 'embedding health literacy into systems' (Australia), and 'promoting changes in the health care system' (U.S.).

The very existence of these national health literacy policies and national strategies indicates governments in significantly different parts of the world have recognised the need to respond to the personal and societal challenges represented by inadequate health literacy in populations. There are many positives in these current examples: the public acknowledgement of the challenge to improve health literacy; the priority given to the health system; and the stimulus to improve the education and training of front-line staff in the health system (and beyond). That said, there is significant variability in linking resources to specific strategies and actions, and in the systems for monitoring progress, and accountability for progress [2].

This lack of specificity may reflect uncertainties as to the best approaches to address health literacy in populations. In turn, this reflects deficiencies in the volume, quality, and consistency of current evidence to support the choice of different actions and priorities. This disconnect between the scale and nature of the problem, the policy response, and the availability of evidence from interventional research remains a concern. Without focussed attention, this paucity of evidence may pose a risk to the long-term commitment of governments to improve health literacy in populations.

Though the volume of published research on health literacy continues to increase rapidly, the proportion of research reporting on interventions remains stubbornly low. The past 20 years has seen relatively minor growth in the number of studies describing practical approaches to addressing health literacy in different clinical and community populations. Reviews of the evidence emerging from this work have indicated modest but consistent progress in achieving positive outcomes from different interventions, but not yet the compelling evidence needed to sustain political and professional interest.

This chapter examines the evolution of the concept of health literacy and its practical implications for health literacy interventions. The chapter, then, provides an updated overview of reported interventions and existing strengths and weaknesses. It concludes with recommendations on interventional research that provides practical and implementable solutions which can inform future policy, strategy, and priorities.

2. Defining Health Literacy

Numerous definitions of health literacy exist [3]. Whilst there are important differences in emphasis, almost all definitions of health literacy in common use have the same core elements describing the skills that enable individuals to obtain, understand, and use information to make decisions, and take actions that will have an impact on health status. These are an observable set of skills that will vary from individual to individual.

The differences in skills have been categorised as *functional*, *interactive,* and *critical health literacy* [4]. Such a classification is derived from mainstream literacy studies and has the advantage of signaling the impact that differences in skill levels may have on health-related decisions and actions. *Functional health literacy* describes basic-level skills that are sufficient for individuals to obtain relevant health information (for example, on health risks and on how to use the health system), and to be able to apply this knowledge to a range of prescribed activities. Individuals with these basic health literacy skills are generally able to respond well to education and communication that is directed to clearly defined goals and specific contexts, such as medication adherence, participation in prevention activities, and some behavioural change.

Interactive health literacy describes more advanced literacy skills that enable individuals to extract health information and derive meaning from different forms of communication; to apply new information to changing circumstances; and to engage in interactions with others to extend available information and make decisions. Individuals with these more advanced health literacy skills are well positioned to adapt to changes in context. These skills enable people to respond more productively to education and communication that is focused on the development of personal skills -and improving one's capacity to act independently on new information. Correspondingly, individuals with higher level skills are better able to discriminate between different sources of information - and respond to health communication and education that is more interactive and accessible through structured communication channels (for example, school health education, mobile apps, interactive websites).

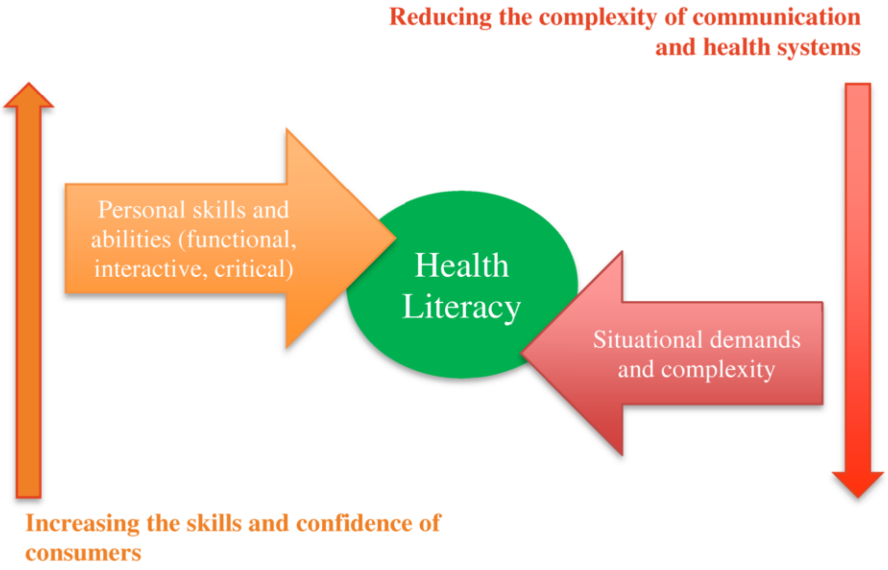
Critical health literacy describes the most advanced literacy skills that can be applied to critically assess information from a wide range of sources, and information relating to a greater range of health determinants. Individuals with these most advanced skills can obtain and use information to exert greater control over life events and situations that impact health. This may include not only information on personal health risks, but also the social, economic, and environmental determinants of health. This type of health literacy can be more obviously linked to population benefits alongside benefits to the individual.

Understanding health literacy as a set of observable skills that can be developed through structured communication has important implications for the way in which we can respond to the challenge of limited health literacy in populations. This is discussed in greater detail in the following sections.

The past decade also has seen a much improved understanding of the impact of the context in which people are required to use their health literacy skills and capabilities. Research in clinical settings has consistently exposed that even a person with a high level of observable health literacy skills may experience real challenges in applying them in an environment (like a hospital) or in interacting with a person (like a physician) that they find unfamiliar and intimidating.

In 2010, Parker and Ratzan proposed a health literacy framework which makes explicit the extent to which health literacy is mediated by the situational demands and complexities that are placed on people [5]. Figure 1, adapted from Parker's and Ratzan's original framework, summarizes this dynamic interaction and indicates the implications for intervention. In the Parker and Ratzan framework, health literacy can be understood as the application of personal skills that are mediated by the environment in which these skills are to be applied. Figure 1 illustrates if health literacy is understood as an observable set of skills, this necessarily focuses intervention efforts on improving individuals' skills and capacities through educational intervention. Recognising the impact of situational demands and complexities focusses attention on simplifying communication and reducing organisational complexities. Both represent important methods to address the challenges posed by limited health literacy in the health system and in the community.

Figure 1. Improving health literacy: Enhancing personal skills and reducing system complexity. Adapted from: Parker R, Ratzan S. Health literacy: a second decade of distinction for Americans. J Health Commun. 2010;15(2): 20–33.



3. Improving Health Literacy

The categorisation of functional, interactive, and critical health literacy distinguishes between communication and education that is *task-based* - designed to develop specific skills to manage prescribed activities (medication adherence, behaviour change); and interventions that are skills based – designed to develop generic, transferable skills that equip people to make a range of more autonomous decisions relating to their health and to adapt to changing circumstances.

Functional health literacy aligns more closely to the immediate and necessary goals of clinical care and some public health priorities. In this context, health literacy is commonly used to describe a set of individual literacy capacities that act as a mediating factor in health and clinical decision making [6]. Health literacy may be seen more as a static patient characteristic – a *risk* that needs to be managed in the process of providing clinical care. The implications of this are clinicians need to modify the way they communicate with patients to respond to lower levels of health literacy, and where possible, reduce the organizational demands and complexity faced by patients within a clinical environment. In such circumstances, people need the knowledge and skills required to achieve outcomes that are primarily determined by those providing health care. Health and patient education often are correspondingly task-based and goal directed, and do not always require significant interactive communication.

The concepts of interactive and critical health literacy connect more closely to contemporary models of health promotion and patient enablement. In this case, health literacy has been viewed as a personal and population *asset* offering a route to greater autonomy and control over health decision-making [7-9]. It is through this focus on skills development, shared-decision-making, and empowerment that the concept of health literacy potentially has a fundamentally distinctive influence on the purpose and methodologies of health and patient education.

Correspondingly, health literacy skills can be developed through tailored information, communication, and education. Improvements in health literacy can be assessed through the measurement of changes to both the specific knowledge required by an individual at a point of decision-making, and the more generic transferable skills that enable well-informed and more autonomous health decision-making. Differences in communication methods, media, and content will foster different learning outcomes and associated behavioural and health outcomes.

Individual responses to information and education will be moderated by the environment in which they occur. Understanding this has led to interventions and related research that focus on reducing the situational demands and complexities experienced by patients and the public in their endeavour to ‘obtain, understand, and use’ health information. This includes attention to health professional education, as well as interventions to reduce the organisational complexity often faced by people using health services or seeking health information. In the former case, there are examples of sustained efforts to better prepare frontline workers for the variability in health literacy among patients, and to promote practical techniques, methods, and media to simplify communication. This is discussed further in the following section.

4. Interventions to Manage Health Care Risk - Reducing the Complexity of Communication and Health Systems

To date, the majority of reported health literacy interventions have been in clinical settings. Although there are exceptions, the plurality of published interventions have focused on improving communication with patients with a goal of supporting task-directed, functional health literacy.

Generally, such interventions are intended to mitigate the effects of low health literacy on patients’ (and carers’) ability to understand medical conditions and respond correctly to advice and instructions relating to their health care - supporting functional health literacy rather than developing transferable interactive and critical health literacy skills.

More specifically, communication is directed to help patients more successfully manage common clinical challenges, such as medication adherence, self-management of chronic conditions, and hospital discharge instructions. As the number of reported intervention studies has increased, there have been some helpful reviews [10-12]. In aggregate, these reviews provide broadly consistent evidence that the comprehension of health information and advice among individuals with low health literacy can be improved through modifications to communication and other mixed-strategy interventions, and improved comprehension leads to better patient outcomes and enhanced health system use.

For example, these reviews (and the individual projects that they draw upon) provide practical, clear, and consistent guidance on how to reduce the literacy demands of written materials by using pictograms and other devices for more effective communication along with practical techniques to improve face-to-face communication, including and especially "teach-back" [11-12]. These improvements are associated with better health outcomes that include: changes to identifiable risks for chronic disease (and among those with established disease); reduced reported disease severity; as well as fewer unplanned emergency department visits and hospitalisations [11]. These reviews also identified the potential utility of different communication formats (e.g. illustrated text; spoken animations) for adults with lower health literacy [10]. As this evidence grows, the case for adopting universal precautions in health care communication has progressively strengthened [13].

Taken as a whole, these studies have provided consistent and compelling evidence of the benefits to patient safety and health care quality of purposeful interventions to improve communication with patients, and their carers who interact with health care professionals. The best available evidence demonstrates the need to put into practice what we already know to be effective, whilst continuing to investigate new and alternative approaches to health communication. This includes continued attention to provide information in a format that is tailored to the individual needs of patients, including and especially the use of digital platforms for some.

Despite evident progress, the constraints on patient communication experienced by many frontline healthcare professionals often mean more effective communication materials and methods are difficult to use in practice. The current challenge is less about *what* to do, and more about *how* to get effective practice systematically established in everyday clinical care.

In response, there are an increasing number of programs to develop the health literacy-related skills of frontline healthcare professionals both in initial education and as a part of continuing professional development. A 2011 review of published papers on health literacy programs for practicing health professionals (mostly from the U.S.) found diverse health literacy curricula have developed [14-15]. Yet, few health literacy programs for health professionals have published evaluations - and those that have feature unique outcome measures and have often been trialled with small samples [14]. While the findings of these evaluative studies are limited, they are consistent with previous research on communication training for health professionals. The research suggests promise in delivering positive educational outcomes, although none reported whether this leads to improved professional practice, and enhanced patient-centered outcomes.

The absence of widely accepted guidelines for the content or structure of health literacy curricula for health professionals has led to increased efforts to standardise training internationally. For example, Coleman, Hudson and Maine used a consensus project to develop a comprehensive list of 32 health literacy and clear communication practices and 62 underlying educational competencies (knowledge, skills and attitudes) for U.S. health professionals [16]. This list has been replicated with similar results in the field of nursing and among a European expert panel [17-18]. A Q-sort consensus method also identified eight top-rated items, which can be considered a minimum or 'core' set of practices to be embedded within training for health professionals (e.g. 'routinely uses a teachback technique'; 'consistently avoids using medical jargon'). While this work has helped to advance the direction of training efforts, Coleman et al. acknowledge many of the recommended practices and educational competencies identified in these consensus studies are supported primarily by expert opinion without empirical evidence regarding their effectiveness [16]. Questions about the differential impacts of alternative intervention and teaching methods, and optimal program duration also remain unanswered.

In addition to the valuable initiatives for the existing workforce, there are important efforts to improve health literacy education for healthcare professionals in training. In a systematic review evaluating the impact of health literacy training for a wide range of health professions students, Saunders, Palesy and Lewis [19] reported overwhelmingly positive results, including increases in students' knowledge and self-rated abilities as well as confidence. Although the level of detail regarding the interventions was often deficient, most reported programs appeared to focus on communication for functional health literacy, though some also included elements designed to support more interactive and critical engagement with patients and members of the public. Saunders et al. add most studies included some best practice training methods, such as integrative approaches to health literacy knowledge and skill acquisition through multiple training episodes, group work, and learning through practical, hands-on activities that enhance thinking and problem-solving capabilities [19]. However, the authors go on to recommend progressive changes to teaching methodologies that reflect the 'real-world' interactions between health care providers and patients - and note the need for increased rigour and reliability in evaluation methods and longer-term assessment [19].

Overall, current published interventions to improve the health literacy knowledge and skills of health care providers suggest great potential to improve health care practice through improved communication skills - to reduce the 'complexity' of communication in ways that account for the significant variation in health literacy among patients. While the past decade may be viewed as largely experimental, the learning from these experiences needs to be consolidated and normalised within standard health professional curricula and continuing professional development. Although many government and non-government agencies in several countries produce health professional education materials for use with practicing health professionals (e.g. Centers for Disease Control and Prevention - U.S.; NHS The Health Literacy Place - Scotland; Teachback.org – Australia), a systematic response is lacking in most health care systems, and the 'normalisation' of health literacy education represents the next challenge for professional educators and health literacy advocates. Such systemic responses are needed to ensure professional education on health literacy reaches all who are involved in communication with patients, careers, and members of the public - including those in administrative roles.

Alongside efforts to improve the communication skills of health care professionals, increasing attention has been given to interventions designed to more directly reduce the organisational complexity of health systems. Research in this emerging area of *organisational health literacy* explores the features of health-literate organisations as well as the barriers preventing these features from being addressed [20-21]. A range of models and practical strategies have been proposed to help create health-literate organisations that deliver practical strategies to reduce the demands and complexities faced by people engaging with health care institutions and health professionals (e.g. [20,22-23]). These proposals range from improved systems to make appointments, communicate with patients throughout their health care 'journey', to changes to wayfinding in health care facilities.

In a systematic review of strategies to develop health literate organisations, Lloyd et al. found relatively few studies that examined the process and immediate impact of organisational change [24]. All seven of the included studies adapted health literacy tools for use in their health service. Four studies conducted environmental scans to identify where organisational health literacy needed to be improved - using either Harvard University's *Health Literacy Environment of Hospitals and Health Centres* toolkit or the *First Impressions and A Walking Interview* packet. Two studies adapted the U.S. Agency for Healthcare Research and Quality's health literacy tools for pharmacies, and one incorporated the Brief Health Literacy Screening tool into the electronic record at a large academic medical centre in the U.S. However, despite the tools providing feedback on current organisational performance, the authors of the systematic review note none of the tools resulted in sustained organisational change. In other words, the tools highlighted the problems but failed to provide solutions to ensure organisation-wide improvements in patients' access to quality care or improved health literacy.

Notably though, since the publication of the Lloyd et al. review, research has emerged on organisation-wide approaches to provide services and information in ways that promote equitable access and engagement [24]. For example, Mastroianni et al. implemented and evaluated an organisation-wide, evidence-based Health Literacy Framework within a regional health service in New South Wales, Australia [25-26]. A core component of the Framework is a coordinated, whole-of-organisation system with standardised processes and tools for staff to prepare, review, and store plain-language, locally developed, written patient information. The process is supported by an interactive Patient information Portal intranet site and a Patient Information Coordinator who manages the process and supports staff to develop resources. Governance structures require staff to use the above standardized processes to develop patient information and education materials, and a Health Literacy Ambassador program trains staff to be health literacy champions and lead their teams on partnering with patients to develop plain-language materials. Pre-post evaluations suggest this organisation-wide approach improved the understandability and actionability of patient information materials across the health service [25]. Although similar efforts are likely occurring elsewhere in the form of service and quality improvement initiatives, the formal evaluation and publication of the above findings demonstrate how organisational health literacy interventions can be advanced through shared learning and dissemination of good practice.

Although the evidence to guide approaches to health literacy in health care systems has matured and expanded in the past decade, it remains in an early stage. We currently lack compelling evidence about the practicalities of implementation, and the effectiveness of organisational changes to create a less complex experience for patients, and to support frontline health professionals in the delivery of effective communication practices [20]. For the future, getting more healthcare organisations to commit to change will require continued development of practical implementation methods, and improved evidence of effectiveness.

5. Interventions to Improve Health Literacy in the Community - Increasing the Skills and Confidence of Consumers

Whilst some health literacy interventions in health care settings undoubtedly aim to develop health literacy skills that have an application beyond the immediate needs of patients, the majority of reported studies understandably focus on the development and application of specific skills with immediate functionality - recognizing that poor health literacy is a *risk* to effective clinical care. As suggested in the definition above, health literacy also can be understood and developed as a personal and population *asset* [7-9].

In this context, the focus of interventions shifts from responding to immediate functional needs to the development of transferable skills that enable people to engage in more interactive and critical ways with health information. The goal here is to support people to obtain and use information to address more immediate health decisions and also develop more advanced health literacy skills. The latter better equips people to interpret different forms of health communication - and to adapt to the contextual changes in which health information is used to make choices and decisions about health. It is through the latter lens that the concept of health literacy potentially augurs a distinctive influence on the purpose and methodologies of community health education and communication.

The research on health literacy interventions with community (non-clinical) populations is not yet as common as those for clinical populations within the published literature. Still, the number is growing and a small number of reviews have attempted to summarise the current state of knowledge, lessons learned and future directions [27-28]. These reviews offer useful guidance on current practice and future directions for research and program development.

A review by Baur et al. identifies some important and emerging themes in research with communities [27]. The review identified 74 papers reporting on community-based interventions where health literacy was either a factor in determining the selection of the study population, a specific measurement item in the evaluation, and/or health literacy outcomes were reported. The Baur et al. review took a broad definition of community as meaning “interventions that intentionally brought together people to participate in an intervention that addressed health literacy” [27]. The review included a high proportion of papers that reported on interventions related to health conditions (e.g. mental health, cancer, diabetes) and health services use (e.g. medications use, screening uptake).

The Baur et al. review identified several emerging research themes [27]. These included several constructive examples of the extent to which researchers are engaging meaningfully with communities to design interventions. Indeed, the latter is described as a reason why so many of the reported interventions were highly specific to populations and/or localities and as a consequence. Conversely, Baur et al. caution that tailored community studies might be challenging to reproduce in other settings [27]. The review additionally identified several ways in which the concept of health literacy informed the intervention design or evaluation including: the use of health literacy as a way of defining a population (as ‘low health literate’) as an important measurement to analyse and understand intervention outcomes; as the basis for designing programs or materials; and as a way to describe changes in knowledge, self-efficacy, skills or behaviours that the authors note are related to health literacy. As is often the case in systematic reviews of this type, the Baur et al. review draws attention to significant methodological weaknesses in a high proportion of reported studies, which is not an uncommon problem in complex, community-based health interventions [27].

In contrast, Nutbeam et al. identified only seven studies that met more restrictive inclusion criteria where the intervention was explicitly designed to improve health literacy in a community population (non-clinical; no existing condition) and the evaluation included and reported on a well-defined measure of health literacy [28]. Nutbeam et al. also excluded several reported interventions to address mental health literacy [28].

The Nutbeam et al. review closely examined health literacy outcomes from the interventions and suggested most were directed to the development of interactive and/or critical health literacy skills [28]. This finding is less evident within the Baur et al. review where a high proportion of included studies appear to have knowledge-improvement outcomes as the main health literacy outcome [27]. Meanwhile in the Nutbeam et al. review, the educational methods varied from formal classes, home visiting, and study circles, through multi-media and eHealth/online interventions [28]. Most interventions were targeted at populations and in settings that have a higher proportion of individuals with lower health literacy.

The Nutbeam et al. systematic review also noted the parallels between modern concepts of health literacy and how health education has evolved in past decades [28]. Many health education efforts have been and continue to be characterised by their emphasis on the transmission of information. These interventions are mostly based on the well-established knowledge/attitudes/behaviour (KAB) conceptual framework. This framework, at its simplest, posits a direct connection between knowledge acquisition and subsequent behaviour change. Over time it has become clear that health education that is focused only on goal-directed transmission of information (developing functional health literacy) has not achieved the results that had been expected in terms of sustained impact on health behaviour.

During recent decades, health education has been considerably strengthened by the development of more sophisticated, theory-informed interventions [29-30]. The latter theories are focused on the transmission of information supplemented by the development of personal and social skills that fit with contemporary concepts of interactive and critical health literacy. These contemporary programs additionally integrate the social context of behavioural decisions and enable people to develop the transferable personal and social skills required to make health-related decisions at different times and in different contexts across the life course [31].

The Nutbeam et al. review highlights a danger of conflating traditional health education interventions, based on the KAB framework, with interventions designed to improve health literacy; KAB framed interventions do not always reflect the skills-directed methods and learning theories that are required to develop interactive and critical health literacy [28]. The review additionally warns proxy measures that are limited to knowledge improvement sometimes repurpose ‘health literacy’ as a convenient, contemporary label to update health education interventions, which actually represent more traditional and less progressive initiatives.

Taken as a whole these reviews provide consistent if not yet compelling evidence of the feasibility and potential effectiveness of health literacy interventions conducted with communities, and within community settings. Whilst there is undoubtedly some re-badging of traditional knowledge-based health education, there is a growing body of evidence that suggests it is possible to work with community groups to develop transferable health literacy skills which have both immediate application, and enable people to engage in more interactive and critical ways with information about their health in a wide variety of situations. It is clear from the reviews that more work needs to be done in the development of replicable interventions, improved measurement of health literacy, and use of more robust evaluation methodologies.

6. Conclusions

The concept and rhetoric relating to health literacy has excited the interest of public health researchers, practitioners, and policy makers. The latter fostered a decade of unparalleled policy development, resource investment, and practical activity to advance understanding and practice in health literacy. Despite recent progress, there is a danger that the policy and practice interest could exceed the quantity and quality of evidence to support it. This chapter provides a reminder that despite significant advances in our knowledge and understanding of health literacy, the volume of evaluated interventions in clinical and community settings remains relatively low.

The reasons for a limited health literacy evidence-base are not hard to identify. For example, intervention research is often complex and messy. Its findings are frequently equivocal and contestable in their interpretation. The need to create a manageable environment for research often leads to narrowly defined interventions with highly specified populations - often making it difficult to generalise the ensuing results.

Despite the latter challenges, there is a clear need for interventional research to move health literacy forward; the interest and attractive rhetoric surrounding health literacy needs to be tested more often and more systematically through intervention experimentation in a wide range of populations using valid and reliable measurement tools. This work is more established and more immediately capable of advancement within clinical populations. We have learned a great deal about effective communication methods, and how to build staff capacity to use these methods in the health care system.

Despite this evident progress in our understanding of effective communication methods, the organisational constraints experienced by many frontline healthcare professionals often mean that more effective communication materials and methods are difficult to use in practice. As noted earlier, the current challenge is becoming less about *what* to do, and more about *how* to get effective practice systematically established in everyday clinical care. Although progress in professional education appears to be promising, this needs to be consolidated and normalised within standard health professional curricula and continuing professional development.

The existence of persistent organisational constraints additionally will necessitate a change in research orientation, requiring us not only to examine ways to change professional practice, but also the organisational structures that limit the application of communication methods that are known to be most effective. This latter challenge is a translational research challenge that necessitates a better understanding of the processes for the dissemination, implementation, and scaling up of promising interventions within clinical settings [32]. While the evolving concept of a ‘health literate organisation’ offers some promise in this regard, it remains largely untested.

Interventions to improve health literacy in community settings also remain significantly underdeveloped. The paucity of intervention studies that clearly reflect the ‘skills-directed’ methods at the heart of the health literacy concept, and the continuing challenge of are a cause for concern in measurement (see [33-34] for an overview).

Overall, the evidence to support the implementation of national policies and programs, and the intervention tools required by community practitioners are not emerging as quickly as needed. This should be addressed as a matter of priority by research funding agencies.

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What Must Health Literacy Stakeholders Do to Build a Public Health and Population Health Agenda?

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Abstract. This chapter argues that although the health literacy field has many frameworks and conceptual models, it lacks core components necessary to address health literacy as both a pressing public health and population health matter. Health literacy stakeholders need to develop three sets of activities that can provide the infrastructure for large-scale health literacy improvement. First, the field needs an 'epidemiology of health literacy' so we have a sustained and robust mechanism to collect and report data on multiple health literacy dimensions. Second, stakeholders should agree on standards to educate and train health professionals; develop health materials; and conduct organizational assessments. Third, the field should adopt a Health Literacy in all Policies stance and prepare to conduct health literacy impact assessments so previously hidden or minimized health literacy effects from health, education, and social polices become visible and measurable.

Keywords. Public health, population health, epidemiology, standards, policy

1. Introduction

Limited health literacy has been recognized as both a high priority clinical and public health problem in the U.S. and many other countries for at least two decades [1-4]. National and regional surveys in the U.S., European Union, and Asia, to name a few, document the hundreds of millions of adults who are challenged to understand and use everyday health information and materials and navigate healthcare systems [5-7]. The number of adults with limited health literacy is so overwhelming and widely distributed around the world that if health literacy were an infectious disease, we would have declared a pandemic many times over.

Twenty years have passed since the U.S. Department of Health and Human Services elevated health literacy to the U.S. public health agenda with a national health literacy objective in Healthy People 2010 [1]. It has been almost as long since acting U.S. Surgeon General Kenneth Moritsugu presided over a Surgeon General's Workshop in which "…participants unanimously agreed that enough data exist to substantiate limited health literacy as a major public health problem in America." [8] Since then, additional articles, reports, surveys, and national action plans make the case that improving or

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increasing health literacy should be a primary public health concern and 'public health literacy' is an important area for action. An annual conference in the U.S. presents the latest health literacy research, and the National Academies of Sciences, Engineering, and Medicine Roundtable on Health Literacy has considered a wide range of health literacy issues in more than 35 public workshops [9-10]. NIH reports it has invested more than *$500 million* in health literacy related research [11].

Despite this continuous, high-level attention and knowledge-building work to document the problem and NIH's research investments, the population-level measures, surveillance systems, interventions, evaluations, and policy proposals that characterize other high-priority public health issues (such as obesity prevention or pandemic preparedness) are absent in the health literacy space. While health literacy is a field with many insights for public and population health research and practice, health literacy's influence on health policy reforms and population-based interventions often is absent. For example, the Robert Wood Johnson Foundation (the main resource for private sector funding to improve health and health care in the U.S.) does not explicitly acknowledge health literacy as a critical component of its signature Culture of Health initiative to "provide everyone in America a fair and just opportunity for health and well-being." [12]

Given the strong intellectual and research foundation for health literacy as a core public health concern with significant population health consequences, what must the health literacy field do next to be taken seriously in public and population health work?

This chapter outlines available frameworks to guide a public and population health approach and suggests three actions that health literacy stakeholders can take to ensure our future work matches the scale of health literacy problems, not only in the U.S. but around the world. The frameworks are drawn from both public health and health literacy publications and are briefly discussed in section two.

As the first action, health literacy stakeholders must educate and persuade policymakers and funders to invest in multi-level, continuous surveillance and reporting on the full range of health literacy factors. Currently, we lack routine data on individual, provider, organizational, and community health literacy factors. Section three of this chapter suggests that a health literacy surveillance and reporting system will create an 'epidemiology of health literacy' that can be used to inform policy, programs, and interventions for short and long-term improvements.

Second, stakeholders must agree on and follow guidelines and standards for professional health literacy education and training; development of health messages, materials, products, and services; and the conduct of health literacy organizational assessments. This chapter's section four makes the case for why consensus guidelines and standards are necessary and highlights key consequences of not building consensus.

And, third, stakeholders must become savvy about policymaking and develop a health literacy policy agenda and implementation plan. Suggested health literacy policies and a 'health literacy in all policies' approach are addressed in section five.

2. Relevant Public Health and Health Literacy Frameworks for a Public Health and Population-based Approach

Health literacy researchers have been laying the foundations for a public/population health focus in an explosion of published frameworks that expand health literacy beyond descriptions of consumers' and patients' lack of knowledge and literacy and numeracy skills. The overarching goal of this abundant conceptual work is to move health literacy from the hospital and clinic into other domains of health-related information, decisions, and actions. Many of the frameworks' authors suggest health literacy is a public health issue and its surveillance requires approaches similar to other public health issues.

Examples of recent frameworks include McCormack and colleagues' 'health literacy social ecological model' to broaden patient-focused interventions into multi-level interventions beyond the clinic [13]. Sørensen et. al. used literature review results to propose a synthesized definition and an 'integrated model of health literacy' with medical and public health components [14]. Schillinger also uses a social ecological approach to examine pathways by which social determinants interact with low health literacy to create and perpetuate disparities [15]. The Australian-based team of Osborne and colleagues published both a framework and questionnaire to collect group and population-level data that provide insights about the availability, quality, and usefulness of health information and services in a local area, region, or country [16-17].

Moreover, the public health field has multiple frameworks that can be adapted to inform a population-based approach to health literacy. The 10 Essential Public Health Services model lays out a progression of steps from quantifying the problem to implementing, evaluating, and refining solutions [18]. The model shows how data, community engagement, partnerships and policies, evaluations, and course corrections work together to support an evidence-based public health approach. The Essential Services model also is not topic specific and has the benefits of awareness and acceptance among a wide range of public health leaders and practitioners. The U.S. Centers for Disease Control and Prevention's (CDC) Knowledge to Action framework provides another example of how to take a data-driven approach to public health action. The framework shows how different types of evidence need to be produced, interpreted, and applied to change organizational and professional practices that eventually become a new professional norm [19].

The new Healthy People 2030 framework is an established public health initiative that opens space for a necessary shift in how health literacy is addressed at the population level [20]. The Healthy People 2030 framework includes a set of foundational principles, one of which is: "achieving health and well-being requires eliminating health disparities, achieving health equity, and *attaining health literacy*" (emphasis added). In addition, the federal advisory committee to the U.S. Department of Health and Human Services recommended a new health literacy description: "Health literacy occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions." [21] The latter description aligns with the *U.S. National Action Plan to Improve Health Literacy* that describes health literacy as a society-wide problem based in organizational and professional deficiencies, such as weak public educational systems and complex, jargon-filled health information, that require multi-sector actions [22]. Before Healthy People 2020 recognized health literacy as a social determinant of health, the IOM health literacy report and the National Action Plan positioned health literacy as a social phenomenon affected by many different factors operating on individual or multiple levels [22-23].

Transformations in U.S. healthcare services delivery and payment generate a new focus on population health and offer an additional pathway to a public/population health approach to health literacy. As policy reforms shift incentives for hospitals to think broadly about the communities they serve and bolster the role of primary care and prevention as the first line in healthier communities, health literacy has a lot to offer.

However, in their review of the U.S. Patient Protection and Affordable Care Act (ACA), McKinney and Rikard report the ACA had few explicit health literacy requirements and even the modest requirements have not been well implemented [24]. In contrast, there are some extant best practices. For example, the U.S. Centers for Medicare and Medicaid (CMS) Center for Medicare and Medicaid Innovation (CMMI) has stimulated many new opportunities to directly and indirectly address health literacy issues at both the patient and population levels. CMMI manages a portfolio of payment and service delivery innovation programs and projects that allow states to try new healthcare models. The U.S. Medicaid program has a demonstration project called Delivery System Reform Incentive Payment (DSRIP). The federal Medicaid program provides funds to state Medicaid programs for projects to improve the quality of care and patient outcomes, reduce the cost of care, and move toward value-based purchasing [25].

In New York state, the Medicaid funding enabled multiple New York healthcare providers to include health literacy and cultural competence assessment, training, and evaluation as a system-level innovation [26]. Maryland (a U.S. state with a Medicare program waiver) is trying an integrated primary care program that expands patient services, provides care coordination, and asks community members to provide ongoing feedback about healthcare operations [27]. Although nested in clinical services, these innovation models suggest ways to provide population-focused care using health literacy principles and techniques.

This cursory summary identifies many diverse frameworks and models that could support a public health and population-based health literacy approach. Still, none has emerged as the dominant framework or model, and it is likely the healthcare-based models may have the most long-term traction and visibility because they connect to how health care services are delivered and paid for. While the health literacy field debates definitions, concepts and pathways, current stakeholders can and should begin work on universal building blocks essential to whichever framework or model emerges. The building blocks are a comprehensive data system; guidelines and standards; and a policy mindset that ensures health literacy is central to health reform and ‘health in all policies’ developments that are discussed in the chapter’s following sections.

3. An Epidemiology of Health Literacy

A popular policy motto is what gets measured, gets done. As a result, an epidemiology of health literacy is needed to provide the type of data that will enable the field to measure and ‘get things done’ on a population-level scale.

The health literacy field lacks the most important tool for population health: a surveillance system.

In public health, ‘surveillance,’ or collecting and reporting data on suspected and confirmed public health problems, is a core assessment function, and surveillance is often called *the* essential function because data are supposed to inform decision making [28]. In public health, data are not intended to be inanimate numbers; data should drive corresponding actions. Although inconsistent, governmental attention and funding often follow the data; based on data, problems determined to have a significant enough public health effect often become federal, state, and local organizational priorities and are more likely to receive resources. Surveillance is a significant and influential enough activity that it is worth quoting Dr. Stephen Thacker, one of the U.S. Center for Disease Control and Prevention's (CDC) epidemiology icons, and his colleagues at length:

> Public health surveillance is the systematic, ongoing collection, management, analysis, and interpretation of data followed by the dissemination of these data to public health programs to stimulate public health action. The best recognized use of public health surveillance data is the detection of epidemics and other health problems in a community, but there are many other uses that are critical to public health practice. These data are used to estimate the scope and magnitude of a problem, including the geographic and demographic distribution of health events that will facilitate public health planning. Surveillance data also can be used to detect changes in health practices, monitor changes in infectious and environmental agents, evaluate control measures, and describe the natural history of a health event in a community that will generate hypotheses and stimulate applied research. In short, public health surveillance is the foundation for decision making in public health and empowers decision makers to lead and manage more effectively by providing timely, useful evidence [28].

Examples of specific activities informed by surveillance data include community health needs assessments (required of non-profit hospitals to maintain tax exempt status), community indicators, and organizational, county, and state performance dashboards. These data applications shape perceptions of the health of communities and inform critical resource allocations. When a topic or issue affecting a community's health is not represented in data that are used to characterize the community, then for all intents and purposes, the problem is invisible when decisionmakers look for evidence to determine and justify priorities. Community members may raise issues and relay personal experiences during public meetings or when communicating directly with officials, but these become the anecdotes, not the data, of public and private decision making.

This chapter suggests as long as a health literacy surveillance system (that can support health literacy epidemiology) is missing, then health literacy will suffer the fate of other anecdotal issues: routinely acknowledged and mentioned in public discussions and reports but infrequently prioritized and funded as a serious population health and organizational performance matter. One of the primary reasons is after more than two decades of measurement trial and error, the health literacy field has not settled on a standardized measurement system at any level: individual; interpersonal; organizational; socio-cultural; policy; or population. Consequently, the field lacks a surveillance system to monitor and report, and ultimately draw attention and resources. The lack of data resulted in the U.S. Department of Health and Human Services dropping the health literacy objective from the proposed Healthy People 2030 objectives.

The Healthy People 2010 and Healthy People 2020 health literacy objectives relied on different data sources, undercutting the opportunity to establish a 20-year trendline. Healthy People 2010 used the U.S. Department of Education's 2003 household survey of individuals' health literacy skills with written materials to collect and report one-time data [1]. These data - that nine of 10 English-speaking adults have less than proficient health literacy skills - have become the benchmark consensus number to characterize the health literacy challenge in the U.S. However, health literacy stakeholders have yet to repeat this study and track health literacy skills over time. While the U.S. Department of Education's most recent adult literacy and numeracy study confirms that in 2016 adults' general literacy and numeracy skills were similar to results collected in 2003, health literacy stakeholders lack comparative health literacy-specific results over time [29].

As of 2020, the U.S. has three existing measurement options that could form the basis of a partial surveillance system. However, none of these option can produce data that fully aligns with the new Healthy People 2030 health literacy concept of social responsibility to ensure information and services access for all. Yet, implementing one or more options nationwide could initiate a process to build a robust surveillance system that eventually aligns with the Healthy People 2030 concept. The three options are: 1) population surveys that allow individuals to self-report on health literacy; 2) patient surveys that ask participants to report on their experiences with healthcare providers and service delivery organizations; and 3) organizational data that healthcare facilities and health departments report to accrediting bodies, such as the Joint Communication or the Public Health Accreditation Board, or payer organizations, such as the federal Centers for Medicare and Medicaid Services. This third option is discussed at the end of section four as part of organizational health literacy standards.

Although the health literacy field has examples of how to do population surveys or skills assessments, none has emerged as the preferred, affordable, and sustainable option that could contribute to a surveillance system. Researchers have developed many different surveys administered to individuals to characterize a variety of health literacy-related factors. The widely differing survey approaches demonstrate a variety of health literacy characteristics or outcomes that researchers have considered. Some researchers have been interested in performance-based assessments that capture individuals' skills in action; other researchers focus on questions that ask individuals to report perceptions and experiences.

The only U.S. representative population survey with primary data collection that measured adults' literacy and numeracy skills was the 2003 U.S. Department of Education's National Assessment of Adult Literacy (NAAL) [6]. The NAAL included enough health-related questions to create a health literacy scale with its own results. Researchers presented study participants with everyday health materials and asked them to answer questions that required a range of literacy and numeracy-based skills. The 2003 study is the only time the latter scale was used for two reasons. First, it was a household survey that was expensive and time-consuming to design and conduct. Second, the health literacy scale required having enough health materials and questions so responses could be analyzed and reported separately. Consequently, no other organization has been willing or able to repeat the NAAL health literacy scale. The subsequent adult literacy surveys conducted by Organisation for Economic Cooperation and Development (OECD) countries (which includes the U.S.) contain some health questions embedded in their surveys, but these are not designed for separate analysis or reporting of health question responses [29].

Other population surveys have asked respondents to self-report on their attitudes, confidence, experience, and comfort with a range of health literacy issues, tasks, and services. For example, the European Union (EU) sponsored the European Health Literacy Survey Questionnaire, a subjective, perception-based 47-item survey administered in person to about 1000 citizens in eight EU countries [30]. The survey's creators suggest their process validated the survey for use in multiple EU countries, although they acknowledge the survey's initial use did not have sufficient representation and sample size to characterize an 'average' EU citizen.

In Australia, Richard Osborne and team developed the Health Literacy Questionnaire (HLQ) as part of a broader approach called Ophelia (OPtimising HEalth LIteracy and Access) [16]. The HLQ is given to respondents who answer questions about different health literacy domains, such as access to information and navigating the healthcare system. The authors describe the HLQ as a tool to 'assess the needs and challenges of a wide range of people and organizations' [17]. In addition to Australia, the HLQ has been used in countries with different health system environments and cultures, such as Denmark [31].

In the U.S., the Behavioral Risk Factor Surveillance System Survey (BRFSS) is a state-based annual telephone survey of individuals who self-report chronic disease and personal health behaviors. In 2016, states had an option to add three standardized health literacy questions, and seventeen states with a total respondent pool of more than 100,000 people used these questions. An analysis found that the self-reported responses were overly optimistic and not useful for prevalence estimates of low health literacy [32]. The U.S. also has a survey system to collect patient feedback on experiences with healthcare services. Individuals who receive healthcare services in a prior 12-month period are eligible for the Medical Expenditure Panel Survey (MEPS), a federal Agency for Healthcare Research and Quality survey that includes questions about people's perceptions of (and experiences with) healthcare providers' information, and communication practices [33]. One use of MEPS's responses partially operationalizes the Healthy People health literacy and health communication objectives [34]. Yet, because MEPS samples only respondents who have received healthcare services in the prior 12 months, the data describe a subset of the U.S. population and exclude people who may have health literacy challenges and avoid the healthcare system, find healthcare unaffordable, or choose to deal with health issues *outside* the formal system of hospitals and doctors' offices.

4. Routine Use of Consensus Health Literacy Standards

Professional fields use standards to educate, communicate, and evaluate acceptable and unacceptable practices to those people who work in the field as well as to others, such as customers, policymakers, and the public at large, who depend on professionals and their organizations to follow the standards. Most health literacy domains currently operate without a common set of recognized standards or even consensus guidelines, which leaves professionals and organizations considerable latitude to define their own 'health literacy practices.' The result is a variable range of practices and techniques labeled 'health literacy' as well as inconsistent and possibly lower quality products and services that are difficult to interpret, compare, contrast, and evaluate.

Key domains without accepted professional education and evaluation standards include health literacy or communication training for patient communication; health material development; and organizational health literacy assessments. For example, although 'teach-back' is a widely recommended technique to help clinicians communicate clearly with patients, there is no single protocol for what the teach-back method is, how to train someone in teach-back, nor assurance that someone claiming to have been trained in teach-back has achieved basic competency, let alone proficiency or mastery. Another example concerns health materials that are purported to have been developed using health literacy or plain language techniques, which can refer to any of a large number of techniques from many different sources. Health material developers can use a formal, tested tool such as the CDC Clear Communication Index [35]; a personal list of favorite plain language tips; or no tool at all, and still claim the material was developed according to health literacy techniques.

A final example refers to the organizational health literacy assessment tools that have emerged. A healthcare facility that wants to assess its ‘health literacy readiness’ can choose from the Health Literacy Universal Precautions Toolkit; the Ten Attributes of a Health Literate Health Care Organization; HLE2: The Health Literacy Environment of Hospitals and Health Clinics; ENLIVEN; and C-CAT, to name some of the best known [36-40]. However, facilities do not have authoritative guidance to educate and help them choose among these tools and interpret the results. Which tool might be best for a given situation and facility and how assessment factors, process, and results differ often are not known, even with the availability of the Health Literacy Toolshed [41].

If the inconsistencies and variations in professional education and training, health material development practices, and organizational assessments were small-scale and not important, then different practices might be tolerable. A provider who is a poor communicator or a few patients who don’t understand their diagnosis would be unfortunate and manageable. However, health literacy is both a population and system-level matter. When so few physicians, dentists, nurses, or pharmacists receive continuous standards-based communication training, then millions of patients visiting any one of thousands of healthcare facilities are at risk for having a provider who can’t communicate clearly.

The same is true for health materials. A few poorly written brochures in a corner rack might not do much harm. But a government agency’s poorly written and presented web pages on how to prepare for a natural disaster or infectious disease outbreak present a threat to thousands or millions who might not understand necessary preventive actions.

Standards by themselves are not a guarantee of high quality results or useful public information about products and services. Standards must be part of a transparent process that shows the intended beneficiaries how the standards were applied and results determined. In the few areas where health literacy standards do exist, a lack of transparency in process and results limits what the public knows about how well organizations meet the standards. Consequently, the public who is supposed to benefit from these health literacy focused-actions may experience little to no benefit in practice.

Organizational accreditation is a notable area in which health literacy standards exist but have had limited public transparency, which leaves the public without much insight into how organizations meet standards. The Joint Commission has healthcare facility accreditation standards, and the Public Health Accreditation Board (PHAB) has standards for public health departments [42-44]. Both accrediting organizations recognize health literacy in their standards. Procedurally, The Joint Commission’s and PHAB’s process to review organizational compliance with health literacy standards is similar. An organization seeking initial accreditation or re-accreditation submits an application with supporting evidence that explains how the organization meets the standards. A review team reviews the application and conducts a “survey” or site visit to confirm the supplied information and collect additional information. The team has considerable latitude in what they ask and the information they collect during the visits, and given the number of topics covered by an accreditation review, the review team and the organization under review may not discuss health literacy nor confirm the organization's claims about its health literacy activities. The review criteria and the findings about a specific organization or even aggregated data on multiple organizations are not public information, unless the organization undergoing review chooses to make the information public. While the presence or absence of an accreditation seal in an organization's materials, such as its website, is the primary signal to the public that an organization overall meets standards, the public would not have information on what the organization is doing to address health literacy and how well it meets health literacy-specific standards.

One example that combines standards and public reporting of data is U.S. Medicare's Hospital Compare program [45]. These hospital-specific standards provide insights into some aspects of organizational health literacy and are available through the free public website, Hospital Compare. The program is intended to promote informed consumers and patients and hospital competition on quality and other factors. Hospitals that seek reimbursement from the federal Medicare program report data on a wide-range of quality measures that include measures of how well hospital staff communicate with and inform patients. Examples of quality measures include 'patients who report their doctors always communicated well' and 'patients who strongly agree they understood their care when they left the hospital.' A person interested in how well a single hospital meets the quality measures or wants to compare hospitals can review data on the website. Studies show application of health literacy techniques can make quality data more understandable and useful to consumers and patients [46-48].

5. A Health Literacy Policy and 'Health Literacy in All Polices' Approach

An essential ingredient of every community's public health work should be policy development and enforcement of public health laws and regulations, according to the 10 Essential Public Health Services Model (CDC) [18]. This model links data gathering and analysis to public health action and oversight in a continuous loop of information, insight, and improvement to safeguard the public's health.

As public health stakeholders' understanding of social determinants, population health, and policy to create large-scale change has evolved, an additional model of 'Health in all Policies' has emerged. The U.S. Centers for Disease Control and Prevention suggests: "Health in All Policies (HiAP) is a collaborative approach that integrates and articulates health considerations into policymaking across sectors to improve the health of all communities and people. HiAP recognizes that health is created by a multitude of factors beyond healthcare and, in many cases, beyond the scope of traditional public health activities" [49].

Public health experts and non-experts can use HiAP to discover previously invisible or unintended health considerations or consequences that might be at work in a proposed policy change in a seemingly unrelated area, such as a policy decision to widen a public road or regulate the cost of digital services. HiAP also allows public health experts to advocate to include public health considerations in policies traditionally outside the public health sphere, such as economic or housing development.

The ten essential services and HiAP models suggest promising opportunities for the health literacy field to learn from and integrate with public health and population health work. To do so, health literacy stakeholders need to become savvy about policymaking and policymakers. Health literacy stakeholders need to know who local, state, and federal policymakers are and what their priorities are. Which committees do they sit on, and what resources do they control or influence? Do policymakers have a history of supporting the status quo in healthcare, or have they demonstrated an openness to experimentation and change? What types of employer-based insurance plans do they have in their districts and what are the alternatives?

Health literacy stakeholders should assume policymakers know little to nothing about health literacy and why it's relevant to the healthcare issues their constituents face. Stakeholders can develop and offer plain language, district and state-focused health literacy background information, talking points, and testimony to share with policymakers' staff and key constituent groups.

Stakeholders also need to discuss and converge on key policy goals and actions at local, regional, and national levels. To begin a dialogue about a health literacy policy agenda, the 2019 Health Literacy in Action conference in College Park, Maryland provided a half-day program on health literacy and health policymaking where together policymakers and stakeholders considered health policies with significant health literacy dimensions. More specifically, the participants discussed the Maryland Primary Care Program launched in January 2019, with a stated intent to create a strong patient-centered focus across the state. The program includes extended hours and services to help identify and address undiagnosed and poorly managed chronic conditions and social factors that undermine patients' health. While the Maryland program was not created as part of a 'health literacy policy' nor does it explicitly address health literacy issues, the reality is a patient-centric program can also be a health literacy improvement program, when designed and implemented with health literacy insights.

Two fundamental questions health literacy stakeholders working at any policy level should consider are: how do we persuade politicians and government agencies to support laws, regulations, and funding that directly and indirectly improve health literacy? Which policies will create the most productive conditions to achieve health literacy goals?

Examples of policies the health literacy field should consider include:

- Plain language laws such as the U.S. Plain Writing Act of 2010. The law's intent is to require federal executive branch agencies to use plain language in public communications; however, the law does not include penalties or consequences if the agencies do not implement it at all or only partially. Based on report cards from the non-profit Center for Plain Language, federal agencies have been uneven in the law's implementation and evaluation. Health literacy stakeholders can learn from the federal experience and strategize about how to improve the federal law as well as consider the pros and cons of enhancing existing state-level plain language laws or regulations and proposing new ones. Should every state have a plain language law or regulation that covers information for health and well-being? Which organizations, professionals, activities, or public information products would the law or regulation cover? Only government agencies? All healthcare service organizations? Which types of public information and services? Which plain language standards would be used? How might we evaluate the effects on public access to and understanding of health information and services?

- Recommended or required health literacy education and training for healthcare providers and staff. U.S. physicians are supposed to demonstrate good communication practices during clinical skill exams as a requirement for a medical license in the state where they will practice medicine. However, this exam is not connected to any specific educational content or skills, and medical schools can choose what they expose their students to. New policies could expand the clinical disciplines with health literacy training and answer questions such as, which providers must be educated and trained in health literacy? What type of education or training? What is the minimum level of competency that a provider must demonstrate? How will monitoring and reporting of the curriculum and results occur? What about facility staff who have a lot of public or patient interaction but aren't licensed in the way a clinical provider is?
- Recommended or required 'health literacy impact assessments' for all health policy initiatives that impact consumers, patients, families, or caregivers and their ability to access information and services for health and well-being. A health literacy assessment could be modeled on 'environmental impact assessments' that evaluate the anticipated environmental effects of a proposed project. The findings would be public in the form of an assessment report. A health literacy impact assessment would evaluate the anticipated effects of a proposed project on the ability of participants to find and use the information and services they need for health and well-being. The approach would affect policies that are explicitly about health as well as policies about other topics or issues that contain health literacy dimensions. For instance, a health literacy impact assessment could provide data on how a hypothetical cut in public libraries' funding would reduce hours and resources and negatively affect a community's health literacy. A health literacy perspective, then, potentially provides new data and illuminates the impact of a city, county, or state funding plan, which additionally reinforces the inherent value of HL-based assessments.

Although not all health literacy problems may fit well with a policy solution, a public health approach to health literacy must include policy development and enforcement to create sustainable change on a sizeable scale. Policies can be changed or reversed, of course, which is why building public support for key policies and their continuation remains essential. Initial and continued plain language explanations of the benefits and values of health literacy policies can build public understanding and ongoing support.

6. Conclusion

This chapter has reviewed several existing frameworks and actions that can guide a public and population health approach to health literacy. Although no single framework has emerged as the dominant one, as a body of work they suggest three important areas for action related to data, standards, and policy. Health literacy stakeholders must become advocates for and participants in new systems of data collection and reporting, standards-setting, and policy development if the field is to expand its scope to population health concerns.

The chapter proposes that an epidemiology of health literacy approach could provide the necessary surveillance system and ongoing data needed for population health. Such a system would allow researchers and policymakers to track health literacy issues at the individual, provider, organization, and community levels. The data can inform decisions about policies, programs, and interventions intended to deliver population health benefits. As noted, the U.S. has only one set of primary data about adult health literacy skills that is now more than fifteen years old, and lacks national data on provider, organization, or community health literacy issues. Without sustained investments in multi-level, continuous data collection and reporting, stakeholders do not have a means to generate enough compelling evidence for health literacy as a public health priority, which can undermine the ability to get attention and resources.

Guidelines and standards are essential elements of professional practice, and the chapter argues for a consensus-based set of standards that can guide product and service development and evaluation. Although proliferation of guidelines and standards may be appropriate for early-stage development of a field, health literacy practice is suffering from a lack of transparency and consistency in how guidelines and standards are being used. One significant consequence is often a lack of clarity and credibility when a person or organization claims that a message, material, product, or service meets 'health literacy standards.' If health literacy stakeholders can come together around 'gold standards' for messages, materials, products, and services, then it is possible to provide the public with credible assurance about how health literacy insights and techniques are applied. The use of 'gold standards' also should result in overall higher quality of any given message, material, product, or service, thereby increasing their intended effects.

Finally, the chapter described the critical role that policymaking plays in advancing a public and population health approach to health literacy. The creation, monitoring and enforcement of policies is an essential public health function, and policies can be explicitly about health literacy issues, such as policies to recommend or require health providers to be educated in health literacy, or implicitly such as when they concern how patient care is delivered. The opportunity is to use policymaking to establish basic expectations and investments in health literacy improvement and make policymaking more effective in other areas by considering previously invisible or unintended consequences for health literacy. A 'health literacy impact assessment' can raise awareness and understanding of these consequences. Furthermore, building public support for health literacy policies can help ensure their longevity, even when other priorities change.

Many new professional opportunities would be created if the recommended actions in this chapter are taken. Even though health literacy is a multidisciplinary research and practice space, it has attracted few trained professionals in the sciences of epidemiology, guidelines and standards setting, or policymaking. Beyond the basic science work, there are program planning and implementation, dissemination, and evaluation opportunities. Since the launch of the first Healthy People health literacy objective, the process to establish health literacy as a national public health issue is now 20 years old. In turn, an educated and trained workforce that can provide data, standards, and policies will sustain and transform health literacy into a more credible and effective population health initiative.

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Improving Immunization and Health Literacy Through a Community-Based Approach

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Abstract. This report illustrates the importance of capacity-building to advance immunization literacy through a community-based participatory research (CPBR) approach to decrease child health immunization disparities. The research project utilizes culturally-tailored immunization and technology literacy modalities for dissemination in targeted low-income neighborhoods. The results suggest successful outcomes are dependent upon contributions and engagement of community members in all project processes, ensuring community buy-in and cultural relevance. The latter approach is time-intensive due in part to the need to build broad-based community partnerships, which can result in a promising approach to foster broader population impact.

Keywords. Health literacy, immunization, technology, community based participatory research, health disparities

1. Introduction

Advancements in the utilization of immunizations have been recognized as one of the top 10 achievements in public health [1]. However, some populations have not benefitted equitably from this achievement. In fact, in the U.S. city of Milwaukee, WI., immunization coverage rates have been documented to be as low as 45% for the four doses of diphtheria-tetanus-pertussis, three doses of polio, one dose of measles-mumps-rubella, three doses of Hepatitis B, three doses of haemophilus influenzae, one dose of Varicella, and four doses of pneumococcal vaccine, commonly referred to as the 4:3:1:3:3:1:4 antigens. These vaccines-antigens will be referenced as the age-appropriate vaccinations for children between the ages of 19-35 months for the remaining of this report [2].

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The U.S. federal government's Healthy People 2020 targeted goal for childhood immunizations in the 19-35 month age cohort is 80% [3]. In Milwaukee, the percentage of children living in households below the U.S. poverty threshold is 42.1%, and children in low-income (<200% Federal Poverty Level) households is 69% [4]. Milwaukee is a city of about 595,000 people located in the Midwestern region of the U.S.

The CHIMC (Community Health Improvement in Milwaukee's Children) Project was established in 2005, guided by community-based participatory research (CBPR) principles, to address immunization disparities in Milwaukee, while following a Knowledge-To-Action Framework [5-6]. The CBPR approach promotes a collaborative effort between community partners, community agency leaders and researchers, with community members involved in topic selection, research/program design, intervention, evaluation and dissemination of findings [7]. The community representatives' voices and roles in the CBPR processes and interventions sought to foster beneficial skill development and positive outcomes for intervention neighborhoods and was sponsored by the U.S. National Institute on Minority Health and Health Disparities and the Pfizer Foundation during a 12-year period.

Phase I of CHIMC encompassed a pilot (2005-08), which focused on community buy-in, awareness of the scope of the health disparities, and agreement regarding the research approach. In addition, partners agreed upon an infrastructure to cultivate co-learning and power-sharing to address health disparities within two primarily Black mail zip codes in Milwaukee. Phase II (2008-13) incorporated the intervention phase of research that sought to increase immunizations in four target zip codes by enhancing the impacted populations' awareness of the safety and efficacy of immunizations. During this period, a web-based toolkit and interactive eLearning Café were developed along with customized immunization messages. Phase III (2008-13) was a dissemination phase, where tools developed during previous phases were expanded to 10 adjacent zip codes for use by parents, caregivers, and childcare agency staff members. The CHIMC dissemination tools to enhance immunization literacy were adapted into a culturally-relevant Spanish-version and disseminated within two predominately Hispanic zip codes from 2013-2017. The report's following sections will discuss adaptations and dissemination of immunization information using different modalities within two vulnerable populations in Milwaukee. Immunization outcomes and lessons learned from these CBPR efforts to expand immunization literacy levels are described below.

2. Methods/Assessment

CBPR principles **(see Table 1)** guided the approach and development of health literacy materials within the CHIMC Project by focusing on community perceptions and input to facilitate partners' engagement and co-ownership from multiple sectors in Milwaukee. CHIMC's infrastructure consisted of the Community Forward Team

Table 1. Community-Based Participatory Research Principles [7]

Recognize community as a unit	Build on community strengths	Facilitate collaborative equitable partnership: *power-sharing*
Foster co-learning and capacity building	Balance knowledge generation with actions	Focus on local relevant public health problems
Build a cyclic and iterative process	Disseminate findings to all partners	Involve long-term process and sustainability

CFT), two workgroups, a steering committee, and the executive committee. CFT members were community members recruited from multiple family resource centers collectively administered under the United Neighborhood Centers of Milwaukee, a charitable organization. These agencies predominantly serve and reside within the CHIMC 12 targeted zip codes.

CFT members worked vigorously with academic and community partners within CHIMC's structural and operational components. Active engagement was accomplished through monthly meetings with the executive committee and participation by two workgroups: (1) communication strategies and tactics; and (2) dissemination and evaluation. Workgroups consisted of community members and academic partners in shared roles as co-chairs, with a membership ratio of two community members to one academic partner. Workgroups developed policies and outreach procedures and assisted in the development of evaluation instruments to ensure cultural relevancy. The day-to-day execution of the project was guided by the Executive Committee consisting of members from the Steering Committee. The Steering Committee fostered reporting from the workgroups for ratification and consensus building. For example, the CHIMC Team developed a tagline to communicate their involvement with the Project: "*Take Control-IMMUNIZE!*" (TCI!). Consistent with principles of CBPR, all project members mutually benefited from co-learning, collaboration, and equitable power sharing.

CHIMC used the CBPR approach to advance immunization health literacy in a central area of Milwaukee through the creation of co-learning opportunities. CHIMC partners planned and implemented 11 training workshops with topics that included: healthcare navigation; public health issues; biostatistics; technology education; community health assessment; and grant writing. The trainings provided bidirectional knowledge exchanges between community and academic partners.

Trainings were evaluated using a self-report satisfaction scale rated up to 100%; members of the CHIMC team ratings ranged from 82% to 100% for the various topics listed above. CHIMC partners improved their capacity building as a result of these trainings with community members, which advanced beyond immunization health areas to broader health disparities concerns, such as the social determinants of health and advocating for system changes.

The training curricula were inclusive of institutional review board (IRB) requirements and ultimately, provided essential steps in research skill development and knowledge exchange among the project's partners. Training workshops were geared towards community building, community assessment, research methodology, statistical analysis, youth empowerment, and mentoring across cultural groups (predominantly Black and Hispanic) as well as fostering bi-directional training and learning opportunities between community and research members.

CFT members and other training attendees acknowledged the professional development and individual capacity-building that occurred as a result of these trainings. Academic partners benefitted from community members sharing their community-relevant experiences and community historical knowledge. Collectively, CHIMC's workgroups propelled the project forward and ensured continuous communication and equitable representation from community members, representatives of local community-based organizations, and academic partners. The workgroups were instrumental to the project's ability to successfully employ technology platforms that planned culturally-tailored dissemination strategies and tactics to meet the goal to eliminate Milwaukee's immunization disparities.

CHIMC inclusion/exclusion criteria and baseline data collection were as follows: parents/caregivers had to live within the targeted zip codes and have at least one child less than four years old living in the household. Participants were able to enroll siblings older than four for tracking of their vaccine status. The primary exclusion criteria included households that: a) did not have a child in household who was less than four years old; or b) lived outside of the targeted geographic areas.

3. Immunization Knowledge Enhancement Opportunities

The CHIMC Project applied several modalities to enhance immunization health literacy. These modalities were utilized at different phases throughout the project and included: 1) a CHIMC website inclusive of a Toolkit and Interactive eLearning Café; 2) a social marketing campaign; and 3) implementing an intervention grounded in the theory of planned behavior. The three selected modalities are summarized below. Data from participation in the modalities are summarized as contributing to a therapeutic change in the enrollee's immunization status in section four below.

3.1. CHIMC Website

A culturally-tailored, website platform was created by the research team and CFT members (https://www.chimcmke.org/).

The website was divided into five sections: 1) Homepage: included the description of CHIMC; 2) Parent toolkit (description below); 3) The history of CHIMC: included information on the phases of CHIMC; 4) Faces of CHIMC: provided biographies of CHIMC project staff; and 5) CHIMC eLearning Café (description provided below). CFT members played an integral role in designing and refining the website so it was culturally and linguistically relevant (in English and Spanish). CFT members also were integral to teach parents/caregivers how to navigate the website, thus increasing parents'/caregivers' information technology literacy.

The parent toolkit was embedded within the web platform, which enabled parents/caregivers to have multiple opportunities to enhance their immunization awareness through diverse information sources. The toolkit included six components: (1) recommended immunization schedules in a parent/caregiver-friendly infogram; (2) how to look up your child's immunization records on the Wisconsin Immunization Registry (WIR), which is the U.S. State of Wisconsin's immunization internet database where healthcare professionals record and track immunizations. The guidance included step-by-step video directions on how to use the WIR. (3) Milwaukee clinical sites of low-income populations, which included a map of clinics and information, and links to transportation assistance. (4) A health care appointment checklist: provided a list of required and optional items families should bring to their child(ren)'s routine health care appointments; (5) Links to reputable, evidence-based immunization websites, such as information from the U.S. Centers for Disease Controls and Prevention; and (6) frequently asked questions on immunizations including benefits, risks, side effects, cost, etc.

3.2. eLearning Café

An interactive web-based platform enabled parent/caregiver to educate themselves about immunizations, with data stored in REDCap (a database management system). This online, interactive eLearning Café was offered in English and Spanish versions and provided an immunization educational module with four sections: introduction; vaccines for children zero-four years old; catch-up vaccines; and vaccines for persons 10-18 years old. The eLearning Café consisted of a 15-item pre-knowledge assessment (true/false/don't know format) to assess parents'/caregivers' baseline immunization knowledge. Post-knowledge evaluations were embedded within each module of the eLearning Café.

After parents/caregivers consented to participate in the study and prior to completing the eLearning Café, parents were invited to complete an assessment. This assessment consisted of 38-item questionnaire separated into five domains: (1) immunization attitudes, values, and beliefs; (2) perceived discrimination; (3) general self-efficacy; (4) immunization-related self-efficacy; and (5) social support. During the first dissemination phase, which occurred with a predominately Black cohort, data for enrollees was assessed based on eLearning Café completion status (completed, incomplete or no eLearning) to compare if there were baseline differences for demographic, socioeconomic or knowledge-based factors. If significant differences were found between demographic groups, the results could have skewed eventual findings and influenced the data interpretation regarding enrollees' immunization gaps.

3.3. Social Marketing Campaign

In order to increase community awareness and behavioral intent around childhood immunizations, a social marketing campaign was launched in the intervention phase of the CHIMC project [8]. This social marketing campaign included walking billboards, radio announcements, and a Facebook page. Assessment of the effectiveness of the social marketing campaign occurred via a determination of CHIMC message recognition rate through community intercept interviews.

3.4. Using the Theory of Planned Behavior

Four focus groups were conducted with parents/caregivers to assess for barriers and facilitators to immunization completion in children ≤4 years old, as suggested by the theory of planned health behavior [9]. Small groups of eight-twelve parents/caregivers received education to build specific skills and knowledge through observational learning. According to Montano, the integrated behavior model (IBM) suggests a person's intention to perform a behavior is influenced by their attitude (experiential and instrumental) toward the behavior, perceived norms (injunctive and descriptive), and personal agency (self-efficacy and perceived control) [9].

3.5. Website analytics

Website analytics were conducted using R Google Analytics package for sessions entered, page views, interactions, and referrals sources. A Facebook page was developed and analyzed for page visits, audience reach, posts and engagement as likes, comments, and shares.

In order to obtain objective measurements of the impact of the CHIMC project on child and youth immunization rates, documented immunization data was obtained at baseline and quarterly through project completion from the Wisconsin Immunization Registry (WIR). Immunization status analysis for children/youth included up-to-date

(UTD), Not UTD (NUTD), and Late UTD (LUTD) for age-appropriate antigen series. The CHIMC Team forwarded quarterly reminders to parents/caregivers for each child/youth enrolled with a NUTD status.

4. Outcomes of the Milwaukee CHIMC Initiative

A total of 1,651 parents/caregivers were enrolled in the CHIMC Project during the dissemination phases (n=1,335 Black cohort, n=316 Hispanic cohort. Overall, 69% self-reported as Black; 17% self-reported as Hispanic; 14% self-reported as other race/ethnic groups which is inclusive of Caucasians, Hmong, Multiracial, etc.). More than half of the enrollees (n= 863, 52%) participated in the eLearning Café. Enrollees were predominantly female (>90%). The range of enrollees who lived in households with income less than or equal to 200% of the federal poverty threshold ranged from 76% - Hispanics to 85% - Blacks. Enrollees unemployed at enrollment ranged from 55% for Blacks to 65% for Hispanics. The self-reported educational attainment of enrollees at or below a high school degree/GED was 57% for Blacks and 78% for Hispanics. Mothers (>90%) were the primary decision-maker for children getting immunizations.

4.1. CHIMC Interactive Website and Parent Toolkit

Site-wide statistics suggested that more than 80% of users accessed the CHIMC-TCI! website using a personal computer such as a desktop or laptop, while less than 20% used a smartphone or tablet. The primary website referral occurred when enrollees directly typed in the URL address or accessed via Google. Other major referral sources included Facebook, Bing, and project participants. The earliest spike in utilization occurred during fall months, consistent with school entry. The home page received the most Internet hits, followed by the 'look up your child's immunizations record page' within the parental toolkit. The Facebook page, including training newsblast, had the highest reach and likes, followed by the community recruitment page.

4.2. CHIMC Project Overall Impact on Immunization Rates

As a result of the CHIMC project, parents/caregivers improved their immunization and technology literacy, leading to behavior change evidenced by statistically significant increases in immunization rates for targeted children ages zero-to-four years. In the first dissemination phase with the predominately Black cohort, at enrollment, a larger percentage of parents reported their youngest child (0-4 years old) was UTD (82%, n=1,096), as compared with WIR-verified UTD status (71%, n=948). Following completion of the modalities to improve health immunization literacy described previously, there was a statistically significant increase in WIR-verified UTD immunization status for all child age groups from baseline to project completion (age-cohorts and n's): 6-18 months pre: 68% (334) - post: 75% (452); 19-35 months pre: 63% (322) - post: 70% (536); and 36-59 months pre: 62% (414) - post: 86% (577).

During the second dissemination phase with a predominately Hispanic cohort, parents were offered the options to complete the eLearning Café in Spanish or English on the website. Baseline reported parental perceptions of their child's 0-4 years UTD status was higher for the Spanish-version (97%) versus the English-version (86%), which were both higher than WIR-verified UTD status (75%). Unlike the predominately Black cohort, increases in the predominantly Hispanic cohort WIR-verified child UTD status from baseline to project completion were not statistically significant. The difference in significance could be due to a smaller sample size for children ages 19 to 35 months within the Hispanic (n=82) compared to the Black cohort (n=427). Additionally, there was a shorter follow-up time period for the Hispanic compared with the Black cohort (14 months versus 8 months). UTD immunization status for Hispanic children in the age cohort of 19-35 months increased by 2% (pre: 75% (n=52) - post: 77% (n=82) from baseline which was three quarters post enrollment. However, if compared to the 2014 immunization baseline for the Hispanic children in the same zip codes, immunization rates trended positive for UTD status increasing above the baselines of 63% and 70% for the 53215 and 53204 zip codes, for ages 6-18 mos. and 19-35 months, respectively.

4.3. Ancillary Benefit in Older Sibling for HPV Impact

In an ancillary analysis of Black adolescent (13 to 17-year-old) siblings (n=118) of the original 19 to 35-month child cohort from the first dissemination phase, adolescent's HPV-UTD immunization status increased from 30 (25%) at enrollment to 54 (46%) at study completion [p=0.004] [10]. Moreover, a statistically significant larger proportion of adolescents became HPV-UTD in the study cohort (20%) compared to the City of Milwaukee [14%, p=0.042] and the State of Wisconsin [14%, p=0.046]. The increase in youth immunization rates is evidence of increased parental/caregiver immunization literacy, as the focus of the intervention was on the younger children, and not on youth. The materials parents/caregivers received in the various immunization health literacy modalities included information on youth age-appropriate vaccines. A similar comparison was been done for the Hispanic cohort because of smaller enrollment numbers.

4.4. Social Marketing Campaign

A social marketing campaign resulted in a successful dissemination of the tagline message "*Take Control-IMMUNIZE!* (TCI!)" to the broader community beyond enrollees. A secondary study evaluated community awareness of childhood immunizations and the intent to immunize children using the "*Take Control-IMMUNIZE!"* social marketing campaign. Parents/caregivers had an 85% recognition rate of the CHIMC message among a random cohort of persons participating in intercept interviews within the targeted zip codes. Almost half of those who saw the "*Take Control-IMMUNIZE!"* message reported the message motivated them to act, which included getting their children immunized. Overall, these findings suggest social marketing may be an avenue to increase immunization messaging across diverse communities in urban areas [8].

4.5. Using the Theory of Planned Behavior

The theory of planned behavior undergirded the exploration of parents'/caregivers' attitudes and barriers to immunize their children. Building on these ideas, parents'/caregivers' perceptions were explored along with education on how to access immunization records. Modeling and rehearsing effective health care navigation strategies resulted in effective behavior change as evidenced by increased immunization rates. The major themes derived from parent/caregiver focus groups included: (1) parents believed both they and their community were responsible for their children's immunizations and overall health; (2) there were positive views regarding the CHIMC logo and messaging; (3) the CHIMC logo was associated with positive individual and community health; and (4) enrollees suggested their community should have a multi-level approach to promoting immunization rates. Parents/caregivers suggested slogans such as, "*Health Begins with You*" and "*Save the World, One Immunization at a Time.*"

5. Sustainability and Dissemination

Part of the success of the CHIMC project has been its sustainability, which was enhanced by establishing community-wide immunization collaborations, including the Immunize Milwaukee! Coalition, and the Milwaukee Succeeds Immunization Network. Immunize Milwaukee! is a non-profit, independent, community coalition that seeks to improve immunization rates in the Milwaukee metropolitan area [11]. The Milwaukee Succeeds Immunization Network seeks to improve and sustain vaccination rates for younger children (ages 19-35 months) within Milwaukee [12]. The impact of both groups stems from a diverse membership that reflects organizations which represent different demographic sectors within Milwaukee. Both groups seek to build consensus toward common goals and agendas and emphasize providing recognition and progress to accomplish therapeutic social goals.

In addition, the academic-community partnerships that started during this project opened the door for subsequent research projects that addressed other health-related issues. Essentially, the capacity building and professional development of the CFT members empowered them to become engaged in additional health and community-engaged efforts beyond the CHIMC Project. A sample of 11 CFTs suggested each were engaged in multiple other community-health promotion service and leadership activities. The ensuring activities were organized broadly within three categories: (a) health disparities issues; (b) local social determinants of health; and (c) systems impact.

Subsequent dissemination about immunization (and related disparities issues) also has occurred on a local, national, and international level through media outlets, publications, abstracts, posters, and presentations at meetings [6,10,13,14].

6. Lessons Learned

The four core lessons learned through the CHIMC project were: (1) The CBPR approach, with a focus on integrating community engagement and broad community-based partnerships, was foundational to the project's success; (2) bidirectional learning occurred for both the community and the researchers; (3) while technology facilitated the dissemination of health literacy messages, the integration of data across platforms is a barrier for sustained implementation by local organizations; and (4) improved health literacy empowered families/caregivers and advanced a broader population impact that eclipsed its original goal – to increase antigens immunizations. These lessons and their broader implications are introduced below.

6.1. Lesson One

The community-based participatory research (CBPR) approach, with a focus on integrating community engagement and broad community-based partnerships, was foundational to the project's success. The guiding principles of CBPR fostered processes of shared ownership by community leaders within health, social services and public health systems for community health improvement and health promotion among significantly impacted populations.

The CHIMC Project facilitated partnership through all phases of the research, incorporating partners from multiple sectors including: community residents; public health professionals; academic researchers; community leaders/agency representatives; and medical practitioners. Having sustained the partnership for more than a decade, the Milwaukee project illustrated the CBPR principle to sustain long-term community commitments. Partnership stakeholders also were involved in multiple areas and dimensions of decision-making throughout the project including: web content; recruitment material; data collection tools; eLearning Café; and other project domains. This level of involvement suggests the CBPR fostered high-level engagement at multiple sectors of the community. In addition, a high-level engagement, while time-intensive, was the key to the Milwaukee project's success. For students and health literacy researchers, the Milwaukee project's results suggest there are no substitutes for intense time commitments and transparency in order to build trust and rapport with community partners.

Community Forward Teams (CFTs) significantly contributed to success of the CHIMC project and influenced community-relevant health literacy by involvement in the Milwaukee project's decisions about intervention design, implementation, evaluation, and dissemination. CFTs guided word choices to ensure relevance to the targeted populations. CFT involvement in outreach, recruitment, and implementation bolstered the project's success in meeting enrollment goals; CFTs even participated in the interpretation of the project's findings. In fact, during the first dissemination phase, CFTs facilitated surpassing the original target enrollment goal by 5-11%, enrolling a total of 1,651 parents/caregivers instead of the original goal of 1,500. Given their knowledge and relationship with the community, CFTs opened doors to the targeted communities, providing unique access points.

6.2. Lesson Two

Capacity building is bidirectional and occurs for both the community and the researchers.

The CBPR approach resulted in bidirectional learning that benefitted both the project's researchers and community members (CFTs). As a result of diverse projects, CFT members improved individual health literacy at the same time the investigators expanded their understanding of community health literacy knowledge and health disparities issues. This bidirectional learning environment was intentionally cultivated by the project team. One of the key principles of CPBR is to facilitate co-learning, collaboration, equitable power sharing and capacity building among all partners, which was implemented throughout the Milwaukee project.

For example, the training topics for capacity building were selected via input from academic partners and CFTs. Fifty-eight percent of the subsequent trainings were conducted by an academic expert; 33% of trainings were conducted by community experts; and two trainings were conducted by nationally recognized community/academic experts.

Overall, the approach enhanced collaboration and skill-building by building on the strengths and resources of an entire community. For researchers and partners interested in health literacy, the project's findings suggest learning is bidirectional and investigators need to strive to advance the strengths of all involved community participants. While researchers bring individual and public health expertise, the project's findings suggest research findings and intervention programs are more effective and relevant to enrollees as a result of community engagement. Power-sharing and valuing each partner's contribution to research agendas and interventions are critical elements of an intervention's success.

6.3. Lesson Three

Technology can facilitate dissemination of health literacy messages, but integration of data across platforms remains a challenge for implementation by local organizations.

Health information technology can be quite useful to boost the dissemination efficacy of health literacy messages (e.g. Toolkit and on-site eLearning Café). The CHIMC project established neighborhood locations to gain access to targeted populations using key community entry points that were familiar to families within the selected intervention zones. The web-based platform of the Toolkit and eLearning Café at neighborhood locations enabled the rapid extension of the reach of the CHIMC Project's immunization literacy message.

However, the project's investigators found the need to update health information technology required significant investments of resources, especially personnel. In addition, the integration of multiple data platforms was challenging for the staff, community, as well as project partners. More research is still needed about how technology can be integrated across diverse platforms and be tailored to diverse community organizations.

6.4. Lesson Four

Improved health literacy empowers families/caregivers and can result in a broader population impact.

The evolution of the Milwaukee project's success from its early dissemination phase to completion - within its Black cohort - suggests educational efforts prompted improvements in community education and population health literacy. The result of community-based efforts to improve population literacy among enrollees also is evidenced by unanticipated findings, such as improved human papilloma virus immunization rates among adolescent siblings within the project's Black cohort. While there was not a statistically significant increase in child up-to-date immunization rates resulting from the subsequent Hispanic dissemination phase, these results might have been confounded by a shorter intervention time frame and a smaller, enrolled cohort. Regardless, the predominately Hispanic cohort experienced a 10% to 22% increase in up-to-date immunization status that initially had baseline rates of 63-70%.

Finally, the Milwaukee community-based project demonstrated the effectiveness and value of engaging impacted neighborhoods in sustained community-developed interventions and dissemination -- that included educational efforts which boosted individual and population health literacy and eventually, increased immunizations within vulnerable populations.

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Promoting Latino Self-Management Through Use of Information Visualizations: A Case Study in New York City

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Abstract. Social determinants of health, including low health literacy and limited English proficiency, and other factors place Latinos at high risk for health disparities related to chronic diseases. Such diseases require self-management skills as well as medical management. Well-designed visualizations are suitable for visualizing data related to self-management because they can help narrow the comprehension gap between individuals with low and high levels of health literacy by leveraging existing visual analysis skills while reducing the demand on literacy and numeracy competencies. Use of information visualizations also supports a common visual representation across languages to address limited English proficiency. This report illustrates the use of information visualizations for communication related to self-management through research-based case examples and summarizes key lessons from studies with Latinos in New York City.

Keywords. Health literacy, information visualization, self-management, Latino, health equity

1. Introduction

About one-third of New York City residents is Latino. Although most are U.S. born, some neighborhoods have many immigrants. One such neighborhood is Washington Heights/Inwood in Northern Manhattan which has the largest population of Dominicans outside of the Dominican Republic.

New York City's community profile data provide documentation about the social determinants of health [1]. Seventy-two percent of the residents of Washington

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Heights/Inwood are Latino, 47% were born outside the U.S., and 37% have limited English proficiency. The high school graduation rate of 68% is lower than New York City overall and 29% have less than a high school education. In Washington Heights/Inwood, 20% of residents live in poverty, 12% are unemployed, 53% are rent burdened (i.e., paying >30% of their income for rent), and incarceration rates are higher than the rest of Manhattan. Only one-third of renters live in housing without maintenance defects and 28% have cockroaches. Of relevance to a healthy food environment, the ratio of supermarkets to bodegas is 1:13 with the latter offering less healthy food. While these and other social determinants negatively influence health, 80% of Washington Heights and Inwood rate their neighbors as willing to help them - and 35% of the roads have bike lanes.

In terms of maternal-child health, the teen pregnancy rate is 23.3% with rates of late or no prenatal care and preterm births, 6.1% and 7.3%, respectively. The childhood obesity rate is 24%; and 23% of adults report no physical activity in the last 30 days. Fourteen percent of Washington Heights/Inwood residents are without health insurance and 17% are without needed medical care. The rate of avoidable hospitalizations among adults in Washington Heights and Inwood is higher than the citywide rate while the rate of adult psychiatric hospitalization is lower. Adult residents experience high rates of obesity (26%), diabetes (13%), hypertension (28%) and there are 31.1 new HIV diagnoses per 100,000 residents. The three leading causes of premature death are cancer, heart disease, and drug-related. Although community statistics for Alzheimer's Disease and Related Dementias (ADRD) are not available in New York City's profiles, studies document higher rates among Latinos accompanied by high levels of care burden [2].

These stark statistics reflect the context of our program of Latino health disparities research that is informed by the socioecological model [3]. The purpose of this report is to illustrate the use of information visualizations for communication related to self-management through research-based case examples and to summarize key lessons learned from studies with Latinos in New York City. Self-management is a critical component of prevention and management of chronic diseases including hypertension and diabetes and related lifestyle factors. Self-management skills also are essential for ADRD caregivers as they manage the health of their family member with ADRD as well as their own health. While not specific to Latinos, the authors also address familial hypercholesterolemia, a biomarker finding of relevance to Latinos that requires self-management.

2. Information Visualizations as a Strategy for Communication

Information visualization comprises a set of approaches that vary in objective from abstract data exploration to presentation of information through infographics of varying levels of complexity [4]. The focus of this report is on the latter. The use of information visualizations as a communication strategy for the authors research with Latinos was motivated by multiple factors. First, we conducted community-based research through the Community Engagement Resource of the Irving Institute for Clinical and Translation Research that revealed research participants wished to receive individual and aggregate results and results should be presented in a comprehensible and actionable manner. Second, as part the Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) project, the authors surveyed almost 6,000 Latinos in our community, most with limited health literacy, and wanted to return the research results to help improve the health of the community (as well as to enhance the trust between the community and academic researchers) [5-6]. Third, well-designed visualizations can help narrow comprehension gaps among individuals with low and high levels of health literacy by leveraging existing visual analysis skills while reducing the demand on literacy and numeracy competencies [7]. Fourth, many participants in the authors' research studies prefer to communicate in Spanish - and use of infographics enables a common visual representation across languages with textual components in the language of choice.

The design of infographics is inherently an interdisciplinary process and our teams include domain experts in health (nursing, medicine, public health) with backgrounds in fields with a strong visualization component including informatics, data science, art, theatrical design, and fashion design. We employ an iterative, five phase hybrid participatory approach to infographic design and evaluation that combines activities among the design experts with the intended users of the infographics [8]. Briefly, the five phases contain these strategies:

Phase 1: Defining the intended audience and purpose is informed by a taxonomy of infographic purposes and consideration of visualization components that match the purposes [9]. For each project, the authors characterize the intended viewers from their sociodemographic perspective as well as their information and communication needs [9-11].

Phase 2: Understanding the data is critical to an efficient design process as well as the identification of design opportunities and challenges [12]. It involves three major components: (a) determining the meaning of the variable to be visualized; (b) identifying the possible and likely values; and (c) understanding how values are interpreted.

Phase 3: Participatory design is an iterative process and may be implemented through a variety of approaches. Most typically, the authors use either group or individual design sessions with the intended users of the infographics and begin with some initial prototype designs to stimulate conversation about designs [8, 13]. We refine the designs between sessions as needed and typically gather intended user perceptions about the comprehensibility, preferences, and actionability of the infographic.

Phase 4: Automation is fundamental to tailoring infographics to user characteristics and data values at scale. Consequently, the authors created the Electronic Tailored Infographics for Community Engagement, Education, and Empowerment (EnTICE^3) software framework [14]. We also developed a style guide, a type of structured communication tool, to facilitate communication between the infographic designer and the software programmer [15].

Phase 5: Evaluation is tied to the purpose of the infographic and the iterative design process [8]. Any infographic should adhere to heuristics for good visual design and health-literate communication practices - and be comprehensible to its intended user. The former is the purview of the experts in the design process and may occur through a variety of formal and informal strategies with individuals (e.g., think aloud protocols, heuristic evaluation checklists) or groups (e.g., design studio) of experts. The latter relates to the intended users (e.g., research participants, patients, clinicians) of the infographic and may be assessed through gist comprehension approaches or more experimental strategies. Since the major focus of the authors research is self-management, actionability is another key aspect of our evaluation approach with Latinos, i.e., we want to know if the infographic will motivate the user to take positive action (e.g., increase physical activity level). During the design process, this is frequently captured through intent to take action. Additional studies are needed to determine if the infographic actually results in a self-management behavior (e.g., adhere to HIV medication) and subsequent outcome (e.g., reduced viral load).

3. Case Examples with Information Visualizations

In this report, the authors illustrate the use of information visualizations to promote self-management by introducing three research projects: (a) the Washington Heights/Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) project; (b) the New York City Hispanic Dementia Caregiver Research Program (NHiRP), and (c) the Precision in Symptom Self-Management (PriSSM) Center.

One aspect of the WICER project was a community survey of almost 6,000 Latinos [5, 6]. As part of our ongoing community engagement strategies, the authors wanted to return research data to survey participants. Because the majority of the sample had low health literacy, we decided to use information visualizations (i.e., infographics) and applied a hybrid participatory design approach to create the infographics [8-9, 13]. We conducted 16 of 21 design sessions with survey participants in Spanish. Infographic designs were refined between sessions based on gist comprehension, acceptability, and perceived actionability of the infographics [13]. Given that the clinical focus of the WICER project was hypertension, [16] most infographics focused on high blood pressure and its risks (Figure 1) as well as intervention targets for lifestyle modification including obesity (Figure 2) and low physical activity (Figure 3).

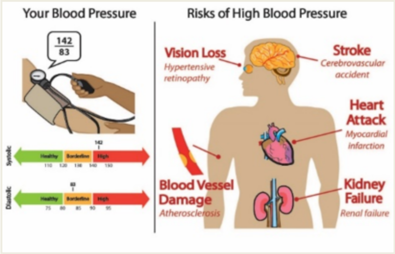

Figure 1. Hypertension Infographic

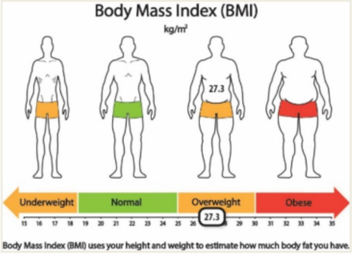

Figure 2. BMI Infographic

For NHiRP, the authors primary focus was to design infographics to help dementia caregivers understand their symptoms, caregiving burden, and health status in order to motivate and support self-management strategies. The latter is particularly important given that individuals who provide care for those with dementia have caregiving demands that exceed other chronic conditions - and tend to be older with existing comorbidity issues (and often ignore their own health needs) [17-18]. A infographics-caregiving focus is especially important among Hispanics who are 1.5 times as likely to have dementia compared to non-Hispanic Whites [19]. The iterative participatory design processes for NHiRP included a graphic designer in the design sessions with dementia caregivers. Figure 4 displays the infographic for caregiver psychological distress based on the responses to the Kessler Psychological Distress Scale [20].

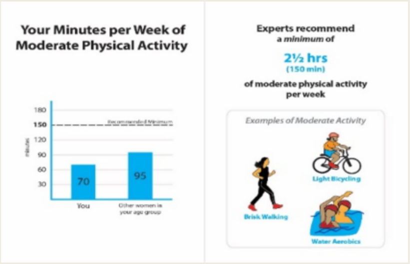

Figure 3. Physical Activity Infographic

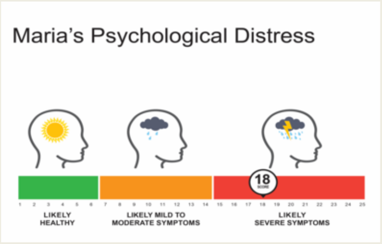

Figure 4. Caregiver Psychological Distress

One component of the PriSSM Center is a Visualization Design Studio - in which visualization experts and other researchers convene to create and evaluate information visualizations for various purposes including return of research data to participants, patient-provider communication, mobile health apps, clinical dashboards, and publication of research results. In terms of the first purpose, the authors extended design work beyond the self-reported data reflected in the WICER project and NHiRP to genomic data including Ancestry Informative Markers and common and rare variants. This included a prototype of multi-media experiential visualizations to motivate action related to familial hypercholesterolemia, a treatable condition that is passed down through families [21].

Designed specifically for Latinos with limited health literacy and limited English proficiency, Woolen's novel prototype focuses on communicating risk as a feeling rather than a probability by leveraging vicarious learning via real patient experience materials (e.g., quotes, videos) and empathy with an emotive relational agent (Figure 5). The authors compared the prototype to standard methods of communicating genetic risk using a mixed-methods approach. The findings suggested participants had difficulty correctly processing standard methods of communicating risk information, such as risk numbers, even when supported by visual aids. Comprehension alone did not result in intent to take action.

In contrast, the multi-media experiential visualizations affected an emotional response, which dually influenced perceived ease of understanding and motivation to take action on the information. While clear aesthetic design increased participant confidence in their understanding, emotionally connecting with the visualizations appeared to play a key role in participant engagement with the information.

4. Key Lessons

The authors learned some key lessons across the five phases of our iterative hybrid participatory design approach for infographic design and evaluation. Effective design requires not only an in-depth understanding of the intended audience and purpose of the infographic, but also an understanding of the possible and actual data values. For example, on a scale for assessing the mental functioning of a person with ADRD compared to ten years prior, it is not relevant (and may be disheartening) to display a valid score indicating marked improvement because current ADRD treatments may slow the transition to less function without restoring function.

Figure 5. Relational Agent for Multi-Media Experiential Visualizations

Although methods vary according to study purpose, participatory design with the intended users of the infographics is a core component across our studies with Latinos. This has been essential to tease out design features that work from those which do not. For example, while number lines with red/green (e.g., systolic blood pressure, anxiety) or red/orange/green (e.g., body mass index) reference ranges have been perceived as comprehensible and actionable, several other features have received mixed reactions [13]. Icon arrays, with the exception of star ratings for overall health, have been interpreted inaccurately – most typically due to a literal interpretation of an icon designed to display a more general concept, (e.g., carrot for vegetable consumption, sneakers for physical activity). Consequently, the authors now use simple bar graphs to present these measures. Moreover, participatory design supports discovery of cultural nuances that are essential to interpretability as well as actionability.

In terms of automation, it can be difficult for an infographic designer to communicate to the programmer the exact specifications to create a tailored infographics without a formal structure. The creation of a style guide facilitates the communication through specification of the necessary features, range and type of data values, and an example of the desired output [15].

While essential, evaluation can be difficult with individuals with limited health literacy. In one study, the authors developed and implemented an elegant experimental protocol in which individuals were asked a set of questions related to two similar sets of information – one displayed as an infographic and the other as text [22]. However, many participants found the evaluation task overwhelming and tended to focus on their subjective impressions rather than on the information displayed in the protocol. Consequently, we adopted more qualitative approaches that support probing for additional information from participants if needed.

5. Conclusion

Information visualizations are a key strategy for communicating with Latinos across levels of health literacy. Although, the authors have generated some principles from our research studies that we re-apply across projects, participatory design with the intended user(s) remains a crucial strategy to create visualizations which are perceived as understandable, engaging and actionable for self-management purposes. In addition, interdisciplinary research teams possessing the knowledge and skills to design, implement, and evaluate information visualizations are needed to produce effective designs that are health literate and culturally appropriate. Moreover, there is a need for information visualization toolkits that support individuals with less specialized knowledge and skills in design and evaluation, who possess expertise within communities of interest to apply the best practices and resources developed by others. The latter is particularly important for Latinos and other racial and ethnic minorities at high risk for health disparities.

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Health Literacy Out Loud Podcasts: Audio Interviews About Health Literacy, Health Communication, and Health from Many Points of View

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Abstract. This report introduces Health Literacy Out Loud (HLOL) podcasts, which have covered many aspects of health literacy, health communication, and health care from diverse perspectives since 2008. The report includes excerpts from select HLOL podcasts. Each includes a link to listen and learn more. Section two highlights health literacy pioneers including conversations with Len and Ceci Doak, Archie Willard, and Rima Rudd. Section three looks at two of the most common health communication strategies, the written and spoken word. Section four brings in other aspects of communication including cultural aspects of food and nutrition, disability, and health education in a remote South African village. Section five looks more generally at the production of HLOL podcasts.

Keywords. Podcast, health literacy

1. Introduction

Why does health literacy matter? Who says so? And most importantly, how can I help?

Health Literacy Out Loud (HLOL) podcasts help answer these and other fundamental questions via hundreds of audio interviews with experts about many aspects of health literacy, health communication, and health care from diverse perspectives. Helen Osborne of Health Literacy Consulting in Natick, MA USA has produced and hosted the HLOL podcast series since 2008.

HLOL podcasts are designed to be educational, engaging, and inspiring—as if listeners were overhearing important yet informal conversations with guests who have worthy information to share. Each podcast is about 20-25 minutes long, focusing on just one topic. All podcasts have corresponding HLOL webpages that include the guest's brief biography, their photo or illustration, and often a list of more ways to learn. Most HLOL podcasts also have written transcripts.

HLOL podcasts are available for free, worldwide in English. Listeners can access, download, or subscribe from the HLOL website (www.healthliteracyoutloud.com or www.healthliteracyoutloud.org) and through popular podcast sources including iTunes, Google Play, and Stitcher Radio.

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It's impossible to know specifically who listens to HLOL. But by looking at download and subscriber statistics (especially from www.libsyn.com and www.feedburner.com) and through emails and in-person comments, HLOL seems to have a loyal, albeit small, listening audience. It is assumed that podcast listeners are similar to those attending health literacy conferences and include clinicians, public health specialists, health educators, professors, students, literacy teachers, librarians, and others eager to learn ways of communicating health information more clearly.

Likewise, HLOL guests (those being interviewed) are equally diverse not only in terms of their professions but also backgrounds, levels of education, and life experiences. Their stories provide a wealth of how-to content along with context about why doing so matters. From health literacy pioneers (those there at the start) to innovators today, HLOL podcasts use the spoken word to amplify why health literacy matters and offer possibilities that lie ahead.

This report includes excerpts from select HLOL podcasts. Each includes a link to listen and learn more. Section two highlights health literacy pioneers including conversations with Len and Ceci Doak, Archie Willard, and Rima Rudd. Section three looks at two of the most common health communication strategies, the written and spoken word. Section four brings in other aspects of communication including cultural aspects of food and nutrition, disability, and health education in a remote South African village. Section five looks more generally at the production of HLOL podcasts.

2. Podcasts about Health Literacy's Pioneers

2.1. Len and Ceci Doak Discuss Health Literacy's Past, Present, and Future

Cecelia (Ceci) and Leonard (Len) Doak were a husband and wife team who, for more than 30 years, helped shape the body of work now referred to as health literacy. Their book, *Teaching Patients with Low Literacy Skills*, workshops, and articles inspired advocates everywhere to improve health understanding. (Book available at https://www.hsph.harvard.edu/healthliteracy/resources/teaching-patients-with-low-literacy-skills/) Osborne joins many peers who regard Len and Ceci as the founders of health literacy. Of note, Len Doak died in 2012.

In this podcast, Osborne asked how their work began.

- Ceci Doak: I was in continuing education for physicians and allied health personnel way at the other end of the continuum from literacy. When I met Len and he told me he was a volunteer tutoring people who couldn't read and write, I said, "My heavens! How do people with low literacy skills understand medical advice? What happens when they go to the doctor?"
- Len Doak: I said, "Often, they don't understand. They may pretend to understand to avoid embarrassment." Of course, that helps fuel the belief of many doctors and nurses, "We don't have any of those low-literate people in our practice."
- Ceci Doak: That's where we started.

This podcast is available at: http://www.healthliteracyoutloud.com/2009/03/23/hlol-13-len-ceci-doak-discuss-health-literacys-past-present-and-future/

2.2. Archie Willard Talks about Struggling to Read

Archie Willard was an ardent and articulate advocate for health literacy. He chaired health literacy workshops and participated in health literacy programs and panels run by organizations including Iowa Health System, American Medical Association, and The Joint Commission. In addition, Willard was a guest speaker at health literacy conferences across the U.S. Yet Willard did not learn to read until he was 54 years old. He died in 2017.

Osborne asked Willard what it was like to be a struggling reader in healthcare settings.

- Archie Willard: When a person does not have strong reading skills, you go into a doctor's office, a clinic or a hospital, there's always paperwork there automatically handed to you. Someone has it and says, "Fill these things out." You actually take a step back in your mind. You have fear of, "How am I going to spell this word? Am I going to be able to write?"
- Helen Osborne: Are you talking about that health history that you get when you go to a new provider? Are you talking about forms or booklets? Or is it all of the above?
- Archie Willard: All of the above.

This podcast is available at: http://www.healthliteracyoutloud.com/2008/10/20/archie-willard-what-its-like-to-be-a-struggling-reader/

2.3. Rima Rudd Discusses the Health Literacy Burden in Healthcare

Dr. Rima Rudd is a senior lecturer on society, human development and health at the Harvard University T.H. Chan School of Public Health. Rudd's work centers on health communication and the design and evaluation of public health programs. Rudd is widely recognized as a leader in health literacy, helping to shape both the research and practice agenda worldwide.

In this podcast, Rudd shared an everyday example about why word choices matter.

> "I remember when dentists used to talk about your gums and gum disease. Then suddenly, my dentist was talking to me about tissue. I was able to make that translation, knowing that he meant gum for tissue. But that is also a word that has to do with blowing our nose.
>
> "That's just one simple example of how words have very different meanings. As professional groups try to fancy up their language, we're stepping away from the language of everyday talk. I think that we have to be respectful of the everyday words that people use in common discourse. At least be aware that when we use a word that has a specialized meaning, we ought to explain ourselves. We ought to make sure that we're on the same page."

This podcast is available at: https://healthliteracy.com/2009/05/04/dr-rima-rudd-talks-about-the-health-literacy-burden-in-healthcare-hlol-15/.

3. Podcasts about Health Communication

Health communication happens in many ways. Effective strategies include written words, spoken words, graphics, music, humor, videos, drama, poetry, and multiple forms of technology. To communicate effectively, practitioners need to match the form of communication to the needs of those they are trying to reach. Here are two examples from HLOL, one about the written word and the other about the spoken word.

3.1. Plain Language: It's About Smartening Up, Not Dumbing Down

Karen Schriver PhD is President of KSA Communication Design and Research, a Pittsburgh-based consultancy focused on making information clear, compelling, and usable. Schriver helps organizations draw on the latest empirical research so they can write and design more effective people-centered communications. She is a former professor of rhetoric and information design at Carnegie Mellon University. Schriver's book, *Dynamics in Document Design: Creating Texts for Readers* (out of print) has been cited as a landmark in its field.

In this podcast Schriver discussed the history of plain language and its current acceptance. Here are some lightly edited excerpts:

- Karen Schriver: Plain language has to do with communications in which the wording, structure and design are so clear that people can find what they need, understand what they find and use that information in ways that they want to. It's very oriented toward the reader, consumer, citizen or patient--the person to whom someone or an organization may be writing. The real goal is to help that person achieve their goals and to do that through clear writing and clear visual design.
- Helen Osborne: Your paper looked at 75 years of this. Is plain language finally catching on?
- Karen Schriver: I have to say yes. Over the past 75 years, we've moved in enormous ways not only to include ideas about word choice, sentence style, structure of our sentences and so on but also look at whole texts, paragraphs, quantitative displays, visuals, tables and charts, everything that goes into the mix of making a good communication today.
- Helen Osborne: I sometimes hear from people a skepticism about using [plain language]. While I hate that term, sometimes someone might say, "Isn't this dumbing down?" Am I the only one who gets pushback about plain language?
- Karen Schriver: Absolutely not. I think that it's really part of the legacy of the history of plain language. That pushback is coming from a place where people think that plain language is really only about substituting easy words for hard words. It makes people think that if you just make the hard words go away, then that results in a text that is less sophisticated, maybe unprofessional or not smart-sounding. They think that you're taking away the intellectual integrity of their text. There are at least two problems with that. [And then she describes and refutes these objections.]

This podcast is available at: http://www.healthliteracyoutloud.com/2018/10/01/plain-language-its-about-smartening-up-not-dumbing-down-hlol-179/

3.2. Talking about Interactive Health Literacy & Oral Communication

Donald Rubin, Ph.D. is an Emeritus Professor of Speech Communication, of Language & Literacy Education, and Linguistics at the University of Georgia. He also is a senior researcher at Georgia's Center for Health and Risk Communication. Much of Rubin's work focuses on assessment, training, and analysis of oral communication, including listenability.

In this podcast Dr. Rubin highlights the importance of listening, making clear the power of silence.

- Don Rubin: Silence, for a physician or other healthcare providers trying to elicit information from a patient or customer, is one of the most powerful tools. There is a saying that nature abhors a vacuum. A conversation abhors silence. We all have a natural inclination to want to fill that space when we're face-to-face with somebody. We find it very uncomfortable. In fact, a pause over two seconds long is a pretty noticeable pause. If we stretch that pause out to 10 seconds [followed by an actual 10-second pause on this podcast], that's pretty uncomfortable.
- Helen Osborne: Boy, did I want to interrupt you and say something!
- Don Rubin: You showed great self-control. If a physician or any kind of healthcare provider is interested in eliciting information from a patient or customer, imposing those kinds of silent pauses is a very powerful tool. It's probably even more powerful than asking direct questions. A lot of times, patients are not very well prepared to answer questions. They may answer them in very vague ways. When they're confronted with silence, they will open up and do whatever they need to fill that silence.

This podcast is available at: http://www.healthliteracyoutloud.com/2010/04/13/hlol-35-talking-about-interactive-health-literacy-oral-communication/

4. Podcasts about Health from Many Points of View

How do we communicate about health in ways that are respectful and culturally relevant? What about special needs of those we communicate with? And what lessons can we learn from health educators around the world? HLOL podcasts address these and a myriad of other health policy and strategy questions. Here are three examples.

4.1. Communicating About Food in Culturally Sensitive Ways

Janet Ohene-Frempong is a plain language and cross-cultural communications consultant with more than 25 years of experience in consumer communication. She brings to this work a passion for health literacy and background as a registered dietician.

In this podcast, Ohene-Frempong discussed the U.S. Department of Agriculture's visual "My Plate" (https://www.choosemyplate.gov) that aims to show the proper proportion of various food groups. Ohene-Frempong shares why the 'My Plate' visual may not be equally useful for Americans with diverse cultural backgrounds.

> "I looked at MyPlate and thought that this is not the way I eat. It's not the way I feed my family. I've got a large family and we're multicultural. My question was, 'How do we translate this across cultures where we're not just baking and broiling, but we're actually stewing foods and serving them as mixtures, sort of combination foods, over rice, with plantains or with yams?'
>
> "Trying to separate food out on a plate is not what our food looks like in this house. We eat mostly a West-African cuisine and it's not a meat, starch and vegetable type of look on the plate. Even though that's what it basically is, it certainly doesn't look like that. It's stews and soups."

This podcast is available at: http://www.healthliteracyoutloud.com/2017/02/01/communicating-about-food-in-culturally-sensitive-ways-hlol-159/

4.2. Health Literacy and Hearing Loss

Michael McKee MD, MPH, is a family medicine physician and an Assistant Professor, Department of Family Medicine, University of Michigan. McKee's clinical work and research focuses on health care access, health literacy, and health communication with disadvantaged populations including those who are Deaf or hard of hearing. McKee has a professional interest in this topic as well as personal experience. He has profound hearing loss.

Here are some edited excerpts about what McKee shared on the podcast:

> "One of the challenges that I see, not only for individuals with hearing loss, but for other language groups, is that information is frequently inaccessible. These individuals may lack some health knowledge that we take for granted. We frequently talk about the concept of 'water cooler talk,' where you get your water or coffee and you hear miscellaneous conversations taking place. These people miss it.
>
> "The same thing happens when you talk at family get-togethers. Somebody may actually talk about another family member having a health problem, high cholesterol or heart disease, and these are things that can be missed or misinterpreted. They frequently will come back to the clinical setting and may not have that information, which is really critical health information, in my opinion."

This podcast is available at: http://www.healthliteracyoutloud.com/2015/03/10/health-literacy-and-hearing-loss-hlol-130/

4.3. Selina Maphorogo Discusses Community Health Education in South Africa

On a trip to northern South Africa, Osborne had the privilege to speak with Selina Maphorogo, a community health worker. Maphorogo retired from the Elim Care Group Project, where she worked with health professionals, volunteers and community leaders to help eradicate trachoma, a blinding eye disease. Maphorogo was recognized for her outstanding community work. In 1996, she received the South African Community Builder of the Year award, and in 1997, she was a finalist for the Nelson Mandela Award for Health and Human Rights.

Osborne recorded this podcast at Maphorogo's home in South Africa's Lempopo Province. Maphorogo shared many stories about educating the community about trachoma. In this snippet, she talks about using music and song:

> "Putting the health words in their songs and beating drums culturally. They can dance. People will flock and come to the place where music is being played and singing and dancing is going on. Everybody would listen to the song and know what they are saying. When they stopped singing and give health education, then they know. They know exactly how to prevent trachoma disease."

This podcast is available at: http://www.healthliteracyoutloud.com/2009/08/26/hlol-20-selina-maphorogo-talks-about-community-health-education-in-south-africa/

5. Making Podcasts Happen

5.1. Technology and Logistics

Nearly all of Osborne's podcast interviews are done by phone. Osborne uses Skype, recording software, and a high-quality microphone (rather than the computer's built-in one). She asks that guests use a corded landline to speak with her. If that is not an option then a cordless phone, cell phone, or Skype will do.

Although possible to manage all podcast logistics alone, Osborne prefers to work with a team that includes a podcast editor, web master, graphic designer, and transcription service. To her, the benefits of this experienced team more than offset its costs as this team's combined skills produce a professional-quality podcast.

5.2. Finding Great Guests

Osborne selects all podcast guests and then works closely with each to make their podcast happen.

She finds guests in a myriad of ways. Sometimes the guest is someone Osborne knows, knows of, or has heard speak at a conference. Other times the guest is author of an interesting research paper, article, or book. And occasionally Osborne finds guests serendipitously, such as when the salesperson at a local computer store (after hearing she was a podcaster) suggested Osborne interview his physician who treats lesbian, gay, bisexual, transgender, and queer (LGBTQ) youth. But Osborne rarely interviews those she doesn't know who "pitch" stories on their topic. That's because they frequently have a product or service they want to sell.

Some of HLOL's guests are familiar to many listeners, such as a former U.S. Surgeon General or a well-known television medical reporter. Others are people Osborne would like you to meet—such as a poet, counselor at a homeless shelter, and patient or family member. Whatever their background and accomplishments, all HLOL guests have interesting stories to share.

Osborne's favorite guests are enthusiastic about their message, good story tellers, and readily show their humility and humanity. Conversely, Osborne declines to interview those who are unwilling to engage in a back-and-forth conversation or do not value podcasts as a legitimate and worthy form of communication.

5.3. Reaping the Benefits from Podcasts

Osborne is frequently asked why she podcasts given that all episodes are available for free. After all, it not only costs Osborne to produce HLOL but she also does not make money directly from them. Osborne's answer lies in her appreciation of the series' benefits for listeners, guests, and herself.

Listeners worldwide get to learn from subject-matter experts, hearing directly what to do and why. They can also read transcripts and click webpage links to learn more. Unlike watching a video or reading a book, people can listen to podcasts while doing something else such as exercising, commuting, or doing household chores. Another benefit is that podcasts are easy to share and use as a focus for discussion such as in a class or staff meeting. This can help garner support and interest from people not already familiar with health literacy.

Guests tell Osborne they enjoy the experience of being interviewed and sometimes make new connections as a result. One guest said she was asked to speak at two conferences after someone heard her HLOL interview. A physician-guest said she now uses a communication technique she first heard about on a different HLOL podcast.

What are the benefits for Osborne as a podcast producer and host? Osborne has gained valuable skills as an interviewer and made connections with people she would not otherwise meet. HLOL also is a way for Osborne to stay up-to-date on topics she finds especially interesting and intriguing. And with each podcast, Osborne lives out her fantasy of being the "Terry Gross of Health Literacy." (Ms. Gross is a celebrated interviewer who hosts and co-produces 'Fresh Air,' available on many U.S. National Public Radio stations, https://www.npr.org/programs/fresh-air/).

Indeed, Health Literacy Out Loud podcasts bring context, content, and benefits to all.

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Health Literacy Measurement in General and Other Populations: Further Initiatives and Lessons Learned in Europe (and Beyond)

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Abstract. This chapter provides an overview of health literacy measurement initiatives with a focus on the European Health Literacy Survey (HLS-EU) - describing where measuring population health literacy started, where it currently is, and providing an outlook to the upcoming European HL survey. In the first part of the chapter, the methodology and the main results of the initial HLS-EU study from 2011 will be introduced. In the second part the worldwide impact of the HLS-EU study will be mapped. Many publications and studies used the HLS-EU instruments in the original or few in an adapted way to measure comprehensive health literacy - in many different settings and in diverse countries. Finally, the chapter ends with an outlook to the M-POHL and HLS19 initiatives of WHO-Europe which are intended to advance HLS-EU as well as the measurement of population and organizational health literacy in a more coordinated, standardized, and institutionalized manner.

Keywords: Health Literacy; Health Literacy Survey Europe (HLS-EU); Measurement; Population Health Literacy; M-POHL; HLS19.

1. Introduction

Measuring health literacy started in the U.S. by assessing mostly patients´ health literacy, using different short tests of functional health literacy (e,g, TOFHLA, REALM, NVS) [1]. Later on, a few studies used the latter tests on general populations. But concerning general populations and for matters of public health, a broader understanding of health literacy and correspondingly more comprehensive instruments for measurement were preferable. The latter challenge was advanced by researchers who aggregated items related to health issues from the available pre-2003 general large-scale adult literacy tests and constructed the Health Activities Literacy Study (HALS). HALS contained 191 heath related items and provided a comprehensive measurement instrument [2]).

HALS included health activities for five dimensions: health promotion; health protection; disease prevention; health care; and maintenance and health systems navigation. Although HALS was utilized in the first decade of this century to samples in the: U.S. (data collection 2003); Canada (data collection 2003); and in few European

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countries (data collection 2003 in Italy, Norway; Switzerland), it was not administered again [3-6].

The measurement of health literacy of general populations began in Europe when Ilona Kickbusch and Don Nutbeam recognized the potential of health literacy for health promotion and public health, in addition to its importance for clinical healthcare [7-13]. After 2004, Kickbusch advocated for health literacy within the European Health Forum Gastein and was successful in initiating a new study (the HLS-CH) in Switzerland in 2006 [14-16]. The HLS-CH did not use HALS since participant interviews took significant time and the latter instrument was not suitable for telephone interviews (CATI).

Instead, a new, mainly self-reporting instrument was developed, which was rather comprehensive and took less time (about 30-minutes in a telephone interview). HLS-CH represented a multidimensional instrument that contained 127 questions about 30 competences with diverse response formats that measured participant knowledge, behaviours/skills, motivation, and attitudes. As a result, HLS-CH provided a profile for different dimensions of health literacy rather than one general measure for health literacy (as the HALS offered). The approach underlying the HLS-CH for measuring health literacy was ‘closer to the public health asset model than the clinical risk factor one’ [15]. As aforementioned, the instrument first was applied by CATI to a randomly selected sample of n= 1250 respondents from a resident population 15+ years in Switzerland in 2006.

Between the proponents of ‘objective’ performance-based tests and those of ‘subjective’ perception-based instruments, a debate persists about how to best measure health literacy (HL). But most of the existing tests - besides HALS - measure a narrow understanding of functional health literary and not HL’s interactive and critical aspects [12]. Of course, it can be argued that a test instrument is preferable if decisions about the assessed individual participants are based on the results of the evaluation. But to measure population health literacy for public health, it is more important to assess a comprehensive concept of health literacy, which is accomplished more efficiently by a self-reporting perception-based instrument.

HLS-CH’s results also stimulated a Swiss public and political debate regarding health policy. This suggested health literacy was more accepted as a bona fide public health issue once evidence-based data on distributions and associations of health literacy within the general population became available – similar to what occurred in the U.S., Canada, and Australia.

This chapter will first introduce the methodology and main results of the initial 2011 HLS-EU study in some European nations. The chapter then provides an overview of the subsequent publications in diverse nations that used the HLS-EU’s instruments from 2012-2019 to measure health literacy, which is supplemented by Table 1. Finally, the chapter describes the M-POHL and HLS19 initiatives of WHO-Europe which are intended to advance HLS-EU as well as the measurement of population and organizational health literacy in a more coordinated, standardized, and institutionalized manner.

2. The Original HLS-EU Study

The experiences of measuring population health literacy in Switzerland (and the health policy debate the HLS-CH study created) stimulated interest to measure population health literacy in some of European Union's member states. While representatives of the European Commission became convinced of the relevance to invest in the assessment of population health literacy in 2006, it took three years until a research consortium was established and a research proposal was developed, accepted, and supported by the Executive Agency for Health and Consumers (EAHC) of the European Union (EU). So, the execution of a new, regional study, called the HLS-EU, began in 2009.

Due to financial restrictions from the European Commission only eight European countries took part in the initial HLS-EU, which required a certain proportion of the research budget to be funded via national resources. The initial participating countries were: Austria; Bulgaria; Germany (just its largest province North Rhine Westphalia); Greece; Ireland; the Netherlands; Poland; and Spain.

The initial HLS-EU project had five objectives:

- adapt a model instrument for measuring health literacy in Europe;
- generate first-time data on health literacy in European countries, providing indicators for national and EU monitoring;
- make comparative assessment of health literacy in European countries;
- create National Advisory Bodies in countries participating in the survey and document different valorisation strategies following national structures and priorities;
- establish a European Health Literacy Network.

Since the HLS-CH instrument was not considered optimal to measure population health literacy in other EU member states, the project initially developed a conceptual and generic model and definition of comprehensive HL, via a literature review of 17 HL definitions and 12 models.

The definition according to the HLS-EU Consortium was:

"Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course" [17].

The HLS-EU definition and conceptual model covered various aspects of health literacy in a modern 'health society,' including clinical, medical, patient, and public health aspects [13,18-22]. The HLS-EU HL definition also sought to proactively encompass finding/accessing, understanding, evaluating/appraising and personally using/applying information or information management competencies within a contemporary 'information society', 'knowledge society,' 'multi-option society,' and ′health society.' The HLS-EU's definition additionally was consistent with Nutbeam's suggestion for HL measures to assess a person's ability to

- gain access to age and context specific information from a variety of different sources,
- discriminate between sources of information,
- understand and personalize health information that has been obtained,
- appropriately apply relevant health information for personal benefit [13, p.2076].

In addition, the HLS-EU definition also was consistent with the aforementioned typology of functional, interactive, and critical HL. Functional health literacy refers to understanding; interactive health literacy to find/access; and critical health literacy is the ability to evaluate/appraise information to form decisions to maintain and improve one's health and quality of life [12]. Within the definition, HL is seen as more than knowledge (which has a short half-life) and cognitive skills. HL also is envisioned as an emotional resource to motivate health-relevant actions. In turn, health literacy is understood as adequately fulfilling a compliant or adherent patient's role in healthcare as well as a resource to act in a health way within diverse roles, settings, and systems pertinent to everyday life. The description of the HLS-EU definition and model partly is further explained by Pelikan et al. [23].

Based on its expanded conceptual model and definition, the first objective of HLS-EU (to adapt a model instrument to measure health literacy in Europe) was accomplished. The conceptual model and definition enabled the construction of a matrix of four stages of information management (access/find/obtain, understand, appraise/judge/evaluate and apply/use information relevant to health) for three areas of health related tasks (healthcare, disease prevention and health promotion) [23, p. 39, table 1].

The task to develop an instrument to measure health literacy then, was to operationalize for each of the 12 cells of the matrix that represented the intersection of the matrix's dimensions. To enable the calculation of one general index and also of four sub-indices for columns and three for rows (and 12 sub-sub-indices for the cells of the health literacy matrix), a unified format for the items was developed. All items were formulated as questions and not as rhetorical statements, since the former can more easily and directly be answered by respondents.

For answer categories, a Likert scale of just four symmetrical categories (very easy, fairly easy, fairly difficult and difficult) was chosen to avoid a nebulous middle category and allow for meaningful dichotomization in subsequent statistical analysis. These categories were ordered from very easy to very difficult to avoid a bias for overstating difficulty. Following HALS and a few other instruments, the items related to health-related information management tasks by asking respondents to report the assumed difficulty of the latter tasks. By asking respondents to judge the difficulty of concrete tasks, the instrument represented the relational interpretation of health literacy, because assumed difficulty is the result of the fit of personal competences with the situational demands under which they need to be executed [24]. Thus, the instrument measured the interaction or fit of personal health literacy competences and situational health literacy demands, which needed to be taken into account when interpreting results. Differing by the cell of the health literacy matrix, between 3 to 5 questions - all in all n=47 - were formulated, partly by using existing validated questions and partly by constructing new ones. The causal generic health literacy model's indicators for possible determinants and consequences of health literacy also were included into the questionnaire, which in total had n=86 items [23, p. 41, figure 1].

The data collection took place in summer of 2011 by an international agency utilizing Eurobarometer standards by Computer Assisted Personal Interviewing (CAPI) and Paper Assisted Personal Interviewing (PAPI) within eight participating European countries for probability samples of n=1000 representative EU citizens within these countries 15+ years of age [23].

The HLS-EU health literacy data could be analyzed in two ways. First, distributions of the n=47 single items could be reported, which was important especially for health policy because the distributions demonstrated the concrete HL tasks where people have specific difficulties (which indicated where public policy interventions were needed). The results suggested there was a wide variation of HL challenges when comparing survey items as well as countries [25].

Second, the HLS-EU enabled indices, or an index for general comprehensive health literacy as well as sub-indices and sub-sub-indices for specific HL aspects. In addition, levels of health literacy (inadequate, problematic, adequate and excellent health literacy) were defined for the general index as well as for the sub-indices [23,25]. Indices fostered a more economical way to analyze associations of health literacy with relevant correlates.

Compared to the HALS comprehensive test measure, the HLS-EU-Q47 was an economical instrument. However, it still took about ten minutes for an HLS-EU-Q47 interview, which was perceived as a lengthy implementation. As a result, two short forms of the instrument to measure HL were constructed: the HLS-EU-Q16 (about three minutes); and the HLS-EU-Q6 (about one to two minutes) scales. The latter were constructed using Rasch modelling and fulfilled Rasch homogeneity criteria [23,26-27].

Turning to the findings, the international benchmarking of the distributions of the four health literacy levels received the most attention. These showed about one out of two European citizens have limited, i.e. inadequate or problematic, health literacy and that this proportion varied among countries, from one out of three for the Netherlands to two out of three in Bulgaria. The initial HLS-EU results lead to specific health policy measures to improve health literacy in some countries, especially in Austria and Germany [23, p. 44, figure 2].

A social gradient for health literacy was shown for all participating countries, which varied in strength by nation [23,25]. The strongest HL predictors were: financial deprivation; NVS scores; self-assessed social status; education; age; and gender [23, p. 45, table 2]. The consequences or correlates of health literacy were collected and analyzed mostly for three aspects: health behaviors or health risks; self-assessed health status; and use of professional health care services. Four indicators were measured for health behaviors or health risks: the frequency of physical activity (with strongest significant bivariate association also in a multiple regression model); body-mass index (BMI); alcohol consumption (significant slight associations); and smoking behavior (no or inconsistent associations).

Three indicators were measured for health status: self-assessed health with an item of SF 36; number of chronic diseases; and the existence of disease related restrictions. In all three indicators there were significant associations with HL; the more robust was for self-assessed health followed by number of chronic diseases and disease related restrictions. In a multivariate regression model with different social determinants of self-assessed health, HL was the third strongest predictor following long-term illness and age. Overall, the findings suggested comprehensive HL could be understood as an independent, direct social determinant of self-assessed health, even when other relevant social determinants were controlled for [23, p.47, table 3,28].

Four indicators were used to measure disease behaviors or the use of professional health care services: emergency units; hospitals; physicians; and other health care professionals. The associations of HL with all four indicators were significant and were strongest for visits to doctors. In a multivariate regression model, HL was the third strongest predictor of physicians´ visits following age and gender.

In summary, the results of the original HLS-EU demonstrated that HL matters for health and health care by confirming the distributions and associations of HL found earlier in Anglo-Saxon countries among patients, now within the general populations of eight European countries. This overall finding catapulted HL on the public health agenda of some participating countries and within WHO-Europe, who used the model, definition, and results of HLS-EU for its publication The Solid Facts – Health Literacy [29].

3. Follow Up Studies Using HLS-EU Instruments and Design in Europe and Beyond

In order to identify peer reviewed publications on the use of the HLS-EU measurement instruments for this chapter, the databases PubMed and Scopus were searched in November 2019 using the search term 'HLS-EU' for article titles, abstracts, and keywords. In order to identify additional studies using the HLS-EU questionnaire, a full paper search of the n=304 papers in which the article 'Sørensen, K et al 'Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU)' was cited was performed using the Scopus database [30]. Other known additional reports and publications were included. Most of the publications were in English or German, but a few were published in other languages, which included an English abstract. Overall, about n=130 publications using HLS-EU-Q instruments from 2012-2019 were identified and additionally are listed in Table 1.

These publications were assigned to the following types of studies: national general population studies using the HLS-EU-Q47 or the HLS-EU-Q16; methodological (validation) studies; studies on specific population groups (adolescents/students, elderly, migrants, other); and patient studies using the HLS-EU-Q47, the HLS-EU-Q16 or the HLS-EU-Q6. The studies were regionally assigned to the following categories: the eight EU member states of the original HLS-EU study; other EU member states; further WHO-Europe member states; and nations in Africa, the Americas, and Asia.

The regional distribution of the different types of publications based on HLS-EU included six publications that provided comparative results for all eight countries (the HLS-EU-Q47 on general populations); and one study that used the data for an experimental analysis from an ecological perspective [23,25,28,30-33].

Comparing the eight participating nations, most publications occurred in Germany. These publications focused on Germany's: general population (the HLS-EU-Q47); insured persons and within regular health monitoring (HLS-EU-Q16); youth (HLS-EU-Q16); a qualitative methodological study on youth (HLS-EU-Q47); aging (HLS-EU-Q47, adapted HL measures (HLS-EU-Q47 and HLS-EU-Q16); migrants (an adapted HLS-EU measure on migrants); and mothers of new-born children (HLS-EU-Q16) [34-49, 153]. A number of studies also focused on patients, using the HLS-EU-Q47; or using the HLS-EU-Q16 [50-58,157].

In Spain, the author' search identified seven publications, which were focused on the general population in Catalonia (HLS-EU-Q16); patients (HLS-EU-Q47 and HLS-EU16); a validation of the HLS-EU-Q16 Spanish version for a sample within the Valencia region; and a specific adapted version to evaluate a mobile app from a sample within Spain's immigrant population [59-64,154].

In Austria, the authors' search found four publications, which focused an enlarged general population sample (HLS-EU-Q47); youth (HLS-EU-Q47); a validation of HLS-EU-Q16 on a sample of adolescents; and a critical methods study with the HLS-EU-Q16 [26,65-67]. In Greece, the authors' search identified four studies that included: nutrition literacy (HLS-EU-Q47); a measure on nutrition literacy among general population samples in Attica; and carers to dementia patients (HLS-EU-Q16) [68-71]. In Ireland, publications included a population survey (HLS-EU-Q47) and the use of HLS-EU-Q47 among patients [72-74].

Table 1. An overview on use of HLS-EU instruments in published studies 2012-2019

Country	**General populations**	**Methods, validations**	**Youth / students**	**Aged / seniors**	**Migrants / refugees / asylum seekers**	**Other sub-populations**	**Patients**
HLS-EU-TOTAL	**Q47:** [23], [25], [30-32]	**Q47:** [28]					
Austria	**Q47:** [65]	**Q16:** [67]	**Q47 > Q16:** [26] **Q16:** [66]				
Bulgaria			**Q47 adapted:** [79]				
Germany	**Q47:** [34-37]		**Q47:** [39-40], [43] **Q16:** [41-42]	**Q47:** [44-45] **Q47/16 adapted:** [46] **Q16:** [47]	**Q adapted:** [48]	**Q16:** mothers of newborn [49]	**Q47:** [50-51] **Q16**: [52-58], [157]
Greece	**Q47:** [68]					**Q16:** parents in pedriatic surgery consultations [71] **Q16:** carers of dementia patients [70]	**Q47:** [69]
Ireland	**Q47:** [72]						**Q47:** [73-74]
Netherlands	**Q47:** [75]	**Q47:** [77], **Q16:** [76]					
Poland				**Q47:** [78]			
Spain	**Q16:** Catalonia [59]	**Q16:** [64]			**Q16:** [154]		**Q47:** [60-62], **Q16:** [63]
OTHER EU							
Belgium	**Q16:** health insured [89-90]					**Q16:** doctors predictions of patients HL [91]	**Q6:** [92]
Czech Rep	**Q47:** [80]						**Q47:** [81]
Denmark							**Q16:** [94-96]
Finland				**Q16:** [97-98]			
France		**Q16, Q6:** [99]					
Hungary	**Q47:** [82]						
Italy	**Q47:** [83]	**Q16, Q6:** [84]					
Lithuania			**Q47:** [100]				
Malta	**Q16:** [93]						

Country	**General populations**	**Methods, validations**	**Youth / students**	**Aged / seniors**	**Migrants / refugees / asylum seekers**	**Other sub-populations**	**Patients**
Portugal	**Q47:** [85-86], just a parish [87]						**Q47**: [88]
Sweden		**Q16:** [103]			**Q16:** [101-102]		
OTHER WHO-EU							
Israel	**Q16:** [114-115]			**Q16 > Q13**: [116]			
Kazakhstan	**Q47:** [104]						**Q47:** [105]
Kosovo				**Q47> Q25:** [106]			
Norway		**Q47:** [107], **Q12**: [108]					
Serbia							**Q47:** [130]
Switzerland	**Q47:** [109]	**Q47:** food literacy [112]				**Q47:** employees [110] **Q16:** food literacy & workplace population [113]	**Q6:** [111]
Turkey		**Q47:** [117], **Q16:** [118]	**Q47:** nursing students [127]	**Q47:** [129]		**Q47:** caregivers of palliative patients [123], factory workers [128]	**Q47:** [119-122], [124-126]
AFRICA							
Ghana	**Q16:** Ashanti region [131]		**Q16:** [155]				
Egypt							**Q16:** [132]
AMERICAS							
Brasilia			**Q47:** students and lecturers [133]				
Mexico							**Q47:** [134]
ASIA							
Asia 6	**Q47:** [140]	**Q12:** [156]					
China							**Q16:** [145]
Indonesia		**Q16 & HLS-EU-SQ10-IDN:** [143]	**Q16:** [142]				

Country	General populations	Methods, validations	Youth / students	Aged / seniors	Migrants / refugees / asylum seekers	Other sub-populations	Patients
Japan	**Q47:** [146]			**Q16:** [147]		**Q47:** HL between family members [148]	
Malaysia			**Q47:** [144]				
Samoa		**Q47:** [149]					
Sri Lanka						**Q47:** school teachers [150]	
Taiwan	**Q47:** [135]	**Q47 > Q12:** [158] Rasch model [139]		**Q47:** [138]		**Q47:** women [136-137]	
Vietnam		**Q47 > Q12:** [141]					

In the Netherlands the publications included: one article on the original Dutch HLS-EU consortium general population data (HLS-EU-Q47) and two contributions regarding methodological issues [75-77]. In Poland publications included: an article on general population data analyzing health literacy and health among the elderly (HLS-EU-Q47) [78]. One Bulgarian study focused on medical university students (adapted HLS-EU-Q47) [79].

Thus, the impact of the original HLS-EU in stimulating HL research was considerably diverse among the eight participating countries. Moreover, the diverse publications and results based on HLS-EU study, coupled with the revisions in HL models and definitions, and their inclusion within the World Health Organization's 2013 report: 'The solid Facts – Health Literacy,' was recognized by researchers and public health experts in other countries, who subsequently began to administer the HLS-EU instruments.

Eventually, some member states of the European Union (who did not participate in the original instrument) translated and used HLS-EU for national studies. National population and other studies based on the Q47 were done in four countries. Two studies in the Czech Republic included: a general population study (HLS-EU-Q47); and a study on patients undergoing treatment for alcohol abuse (HLS-EU-Q47) [80-81]. A general population HL study occurred in Hungary (HLS-EU-Q47) [82]. A general population study also occurred in Italy (HLS-EU-Q47) as well as a validation study of the HLS-EU-Q16 and the HLS-EU-Q6 in Italian, which was derived from a sample in Florence [83-84]. Four studies in Portugal included a national general population study (HLS-EU-Q47), and patients in a cardiac rehabilitation program (HLS-EU-Q47) [85-88].

In two other EU member states national studies on general populations were administered with the HLS-EU-Q16 in addition to a few more specific studies. Four studies in Belgium focused on members of a Belgian health insurance fund (HLS-EU-16); the information sources for a large sample of members of a Belgian health insurance fund (HLS-EU-16); a comparison of patients with their general practitioner's predictions about HL (HLS-EU-Q16); and a study of diabetes patients [89-92]. A general population study in Malta additionally was derived from HLS-EU-Q16 [93].

In some European Union member states, the authors' search found only a few specific studies were derived from HLS-EU's instruments. For example, three studies in Denmark focused on people with type 2 diabetes (HLS-EU-Q16); patients with chronic retinal disease; and patients who were invitees for colorectal cancer screening [94-96]. Two studies in Finland focused on: older patients and active aging (HLS-EU-Q16); and 75-year-old Finnish men and women (HLS-EU-Q16) [97-98]. One HL study in France, which recruited patients in waiting rooms of general practitioners in the Paris area, was a validation of the HLS-EU-Q16 and HLS-EU-6 in the French language [99]. One study of university students in Lithuania was derived from HLS-EU-Q47 [100]. Three studies in Sweden included: the distribution and correlates of HL of refugees (HLS-EU-Q16) and a study protocol on a validation of Swedish and Arabic versions of eHEALS and HLS-EU-Q16 [101-103].

In four other countries of WHO-Europe the HLS-EU-Q47 was used in national studies of general populations and in few more specific areas. In Kazakhstan the focus was on general populations (HLS-EU-Q47) and outpatient department users (HLS-EU-Q47) [104-105]. In Kosovo an adapted 25 item instrument based on the HLS-EU-Q47 was used in a nationwide survey of adults aged 65+ [106]. In Norway two validation studies focused either on people with type 2 diabetes using Rasch modelling and confirmatory factor analysis one (HLS-EU-Q47) or on a sample on individuals aged 16 and over also via Rasch modelling and confirmatory factor analysis (developing a HLS-Q12 short version of the HLS-EU-Q47) [107-108]. In Switzerland a national survey for the general population and a study on a sample of employees for a preventive intervention trial each used HLS-EU-Q47 [109-110]. The HLS-EU-Q6 was used on a study of multi-morbidity patients in primary care; the HLS-EU-Q47 was used in a study that developed and evaluated a short food literacy questionnaire (SFLQ); and 16 items measuring health promotion literacy within the HLS-EU-Q47 were used in a study about the relationship of HL and food literacy (with salt awareness) among a workplace population [111-113]. In Israel two studies published results based on HLS-EU-Q16 that addressed HL's associations with correlates from a national survey of adults. One study focused on the associations among HL, health behavior, socio-economic indicators and self-assessed health; another focused on internal locus of control as a mediator between HL and self-perceived health. Another Israeli study adapted a 13-item version of the HLS-EU-Q16 to assess a small sample of elderly adults 65+ [114-116].

In Turkey two validation studies of the HLS-EU-Q47 occurred in addition to eight studies using the HLS-EU-Q47 to assess different patient groups; such as nursing students, factory workers, and older adults 65+ [117-129]. One Serbian study used the HLS-EU-Q47 to assess HL in patients with heart failure [130].

Researchers in two African countries also used HLS-EU instruments. The HLS-EU-Q16 was used in a study of the general population in Ghana's Ashanti region, and on undergraduates [131,155]. The Q16 also was used to assess HL of outpatient attendees in Egypt [132]. Similarly, two countries in the Americas utilized the HLS-EU's instruments. In Brazil a study of university students and lecturers validated a Portuguese version of the HLS-EU-Q47; and in Mexico the Spanish version of the HLS-EU-Q47 was used to assess associations of HL and health outcomes among type 2 diabetes patients [133-134].

Thanks to the initiative of Taiwanese researchers and the formation of the Asian Health Literacy Association (AHLA), some Asian countries measured population health literacy by creating Asian versions of the HLS-EU-Q47. The first study of a national general population occurred in Taiwan, followed by studies on specific segments of the

Taiwanese population, such as women and seniors in specific communities, as well as a validation study of the HLS-EU-Q47 based on Rasch modelling for a sample of stroke patients [135-139]. A sample of patients from a community general hospital was used to develop and validate a short form of the HLS-EU-Q47, the HL-SF12 by using confirmatory factor analysis [158].

Based on the Taiwanese population study, a comparative study of the general populations of six Asian countries (Indonesia, Kazakhstan, Malaysia, Myanmar, Taiwan and Vietnam) validated the Q47 for these six countries and indigenous languages [140]. The short form HL-SF, validated first in a Taiwanese sample, additionally was validated among the six participating Asian countries [141,156]. In Indonesia the HLS-EU-Q16 was used to measure the association of HL and media use among high school students. A new short form, the HLS-EU-SQ10-IDN, was developed using a population-based data set from Indonesia-Semarang and compared with the HLS-EU-Q16 and HLS-SF12. In Malaysia the influence of attachment to parents and peers and HL was researched on a sample of adolescents aged 15 to 17 using HLS-EU-Q47. A further validation of the HLS-SF12 in Vietnamese rural areas also was published [141-144].

Outside of the AHLA consortium, respective publications occurred in China - where two mainland Mandarin Chinese versions using HLS-EU-Q16 were applied in a study of patients with congenital heart disease [145]. While a Japanese version of the HLS-EU-Q47 was administered to a national sample of adults recruited through an Internet research service company, the HLS-EU-Q16 was utilized in a sample of older adults; and the HLS-EU-Q47 was used to assess HL levels among family members [146-148]. In Samoa semi-structured qualitative interviews within focus groups were applied exploring HL in relation to non-communicable diseases, and in Sri Lanka a culturally adapted Sinhalese version of the HLS-EU-Q47 was used in an HL study among school teachers [149-150].

Overall, the international diffusion of different types of publications that used HLS-EU instruments through November 2019 demonstrated a steady increase of annual publications from 2012 to 2019. This diffusion also exhibited that the HLS-EU instruments, which initially were developed and validated for eight member states of the European Union in the HLS-EU study, were adopted by researchers in other EU and WHO-Europe member states as well as in Asian countries - with a few participating countries in Africa and the Americas. The instruments that were developed to measure comprehensive HL for general population surveys also were applied to more specific sub-populations such as the elderly, adolescents, students, migrants, refugees, and a few other specific groups, as well as to some specific patient groups. While in the original HLS-EU study data collection was executed by personal interviews (CATI or CAPI), follow up studies also used telephone interviews, self-administered questionnaires, and internet-based questionnaires, which demonstrated the instrument's adaptability for diverse data collection. A few countries also used study designs that linked survey data with existing administrative health information.

While the original HLS-EU study used the long form of HLS-EU-Q47, two short forms based on Rasch modelling HLS-EU-Q16 and HLS-EU-Q6 were developed. Subsequently, the latter short forms were used in follow up studies and two additional short forms evolved, the HLS-FS12 that was validated in some Asian countries, based on confirmatory factor analysis, and the HLS-Q12-(NOR) which was validated in Norway in Norwegian (using Rasch modelling and confirmatory factor analysis). In the future, another HLS-Q12 will be available, which has been validated using data from the original HLS-EU study and more countries, based on Rasch modelling. This will be administered in some countries via the ongoing Health Literacy Survey 2019 (HLS19) of the World Health Organization's action network: Measuring Population and Organizational Health Literacy (M-POHL). A few international publications also featured specific adaptations of the HLS-EU instruments.

In the original HLS-EU study, the HLS-EU-Q47 (coupled with the New Vital Sign Test -NVS) was used to compare the results of the perception-based HLS-EU-Q47 with a short performance-based test for functional HL. Some of the follow up studies mostly within general populations also adopted the latter approach.

The HLS-EU-Q86, including the HLS-EU-Q47 for measuring comprehensive HL, originally was developed in English and has been translated and validated in: Bulgarian; Dutch; German; Greek; Polish; and Spanish. The HLS-EU-Q47 (partly also the HLS-EU-Q86) later was translated into: Albanian; Czech; Danish; French (in Switzerland); Hungarian; Italian (in Switzerland & Italy); Norwegian; Portuguese and within the WHO-Europe region into Turkish (Turkey). Furthermore, the HLS-EU- Q16 was translated into: French and Flemish (Belgium); Maltese (Malta); Swedish and Arabic for migrant studies (Sweden); Serbo-Croation and Turkish (Austria), and within the WHO-Europe region into Arabic, Hebrew, and Russian (Israel).

In Asia the HLS-EU-Q86 (respectively the HLS-EU-Q47) that originally was translated into and validated for Taiwan was later adopted into: Indonesian; Japanese; Kazakh; Malay; Myanmar/Burmese; Traditional Mandarin; and Vietnamese. Accordingly, the instruments of the HLS-EU study are now available in many more languages and have been evaluated for reliability and validity in studies within many participating countries. In some countries further correlates of HL than embedded in HLS-EU have been advanced.

The results of the HLS-EU study - concerning the distributions and associations of HL in general populations in principle - have been confirmed by follow up studies in more countries. While some general trends in results exist, there also is some variation in the results among the diverse nations who utilized HLS-EU. A detailed analysis and comparison of the results among these countries will be provided in a follow up publication.

All in all, the existing, aggregate, international publications (discussed above and listed in Table 1) demonstrate the HLS-EU instruments to measure comprehensive HL are well suited for HL research and public health purposes among general populations and specific sub-populations as well as within health care contexts. As a result of the HLS-EU's widespread adoption and success, WHO-Europe decided to support regular standardized measurement of populations as well as organizational health literacy by initiating a new, specific action network.

4. M-POHL and HLS19 as a Consequence of HLS-EU

The World Health Organization (WHO)-Europe in 2013 first recommended regular measurement of HL within its publication: 'The Solid Facts – Health Literacy.' WHO-Europe's recommendation suggested: "surveys of health literacy and the health literacy–friendliness of systems should be conducted.... A first important step has been the European Health Literacy Survey, which should be extended to more countries of the European Union and of the WHO European Region and repeated at regular intervals" [29, p. 11]. "The European Health Literacy Survey should be sustained, have dedicated funding, be applied to more countries and be conducted at regular intervals through the continued support of the European Union, the WHO and countries" [29, p. 71].

WHO-Europe also recommended the assessment of organizational HL: "Existing measures of health literacy are still too oriented towards the individual and must be expanded to include the collective level (including communities) and to assess the literacy friendliness of materials, organizations and environments." [29, p. 71].

While there was a four-year delay for the latter recommendation to be implemented by WHO-Europe within its European Health Information Initiative (EHII), the Action Network Measuring population and Organizational Health Literacy (M-POHL) began in 2017. M-POHL was conceptually advanced at a kickoff meeting with 19 participating countries in Vienna in February 2018, which adopted The Vienna Statement on the measurement of population and organizational health literacy in Europe [151]. HLS19, a revised, accompanying health literacy survey that is discussed below, will be the first project for the implementation of the latter efforts.

M-POHL's six ambitious aims are to: support HL by strengthening the collaboration between research and policy; address the personal HL among general populations and patients; institutionalize regular, high-quality internationally comparative population HL surveys; address HL-friendliness of systems and organizations; support collection and analysis of data on organizational HL (HL-friendly structures and processes); and foster evidence-informed policy and practice.

The action network M-POHL represents a joint collaboration among researchers and policy experts mostly from the ministries of health within the participating countries. This degree of collaboration is intended to ensure that HL research is relevant to health policy from its initiation - and the participants are responsible for the data that eventually may support the implementation of efforts to improve health literacy evidenced by the subsequent findings. The adapted procedures and financing for HLS19 practices already have been successfully applied in WHO′s Health Behaviour in School-aged Children project (HBSC).

Participation in M-POHL and HLS19 is open to all countries within the WHO-European Region. Participating nations have to agree to the aims and mission of M-POHL, nominate a research and a policy representative, and participate in M-POHL meetings (two per year). Already 28 member states of WHO-Europe participate in M-POHL: AT, BE, BG, CH, CZ, DK, DE, EL, FR, HU, IE, IL, IT, KZ, LU, NL, NO, PL, PT, RO, RU, ES, SE, SI, SK, TK, UA, UK and M-POHL welcomes more participants. Countries from the WHO-European region can join in any time. Nations are encouraged to participate in M-POHL projects, such as HLS19. At the time of this writing, if countries manage to appoint a national research centre, find funding and prepare data as late as June 2020 – their participation is possible in the next European HL survey, HLS19.

M-POHL's first project is the Health Literacy Survey 2019 (HLS19). While the core of HLS19 is based on HLS-EU's conceptual and generic model, definition, design and instrument, the revised survey contains grounded developments and additions. In terms of survey design, in HLS 19 the samples will be representative for resident populations aged 18+. While the minimum sample size is n=1000, many nations will assess larger samples to facilitate a comparative assessment of regional differences within countries.

The data collection in HLS 19 will be done either by personal, telephone, or internet-based procedures, which will complicate comparisons and benchmarking, but also will test more procedures to improve future survey waves. Concerning the core instrument for measuring health literacy, the wording within HLS-EU-Q47's items has been carefully reviewed and improved. But not all countries will use the full Q47 instrument to be able to add new optional packages. At minimum, participating countries will be asked to use the newly developed HLS-Q12 Rasch scale or 22 items of the Q47, which enables comparisons with studies that previously used the HLS-EU-Q16 or HLS-EU-Q6 short scales. A few countries also will use the NVS test.

As far as measurement of correlates of health literacy is concerned, HLS19 contains 30 standard mandatory correlate items and 18 optional correlates, which have been somewhat improved via the inclusion of more items from international health surveys. Participating nations also can add a few items to their survey, which are of importance to health policy issues within a respective country.

The most innovative feature of HLS19 is the availability of standardized optional packages regarding specific relevant or new aspects of health literacy, which subsets of participating countries can select. Specific aspects of health literacy within each of the sub-packages are measured by the same item format as HLS-EU-Q47, which enables an optimal comparison of single items, indices, and scales. There will be a package on digital health (10 HL items and six specific correlates on use of digital media). There are two packages on communication (11 items or a short form of just six items) and health care navigation (12 items). The ongoing international debate about immunization is embedded via an optional package that measures the vaccination items already included in the HLS-EU-Q47 and adds 10 specific correlates on attitudes on and experiences with vaccination. Another optional package contains 18 specific correlate items that enables an assessment of health literacy regarding health care costs and health economics.

In summary, HLS19 will be applied in some countries where HLS-EU provides an established research baseline. Among other nations, HLS19 represents the first baseline to regularly measure personal health literacy in general populations in the future. There will be a comparable core of HLS19 for all participating countries and optional packages that will be executed by subsets of these countries.

HLS19 is not limited to the member states of the European Union, but in principle the participants encompass the 53 member states of WHO-Europe. Thus, at least double the number of countries that participated in HLS-EU will join the first wave to measure population health literacy utilizing HLS19. In addition, there will be continued cooperation with the Asian Health Literacy Association (AHLA) to use the design and instrument of HLS19 in Asian member countries of AHLA, as was the case with HLS-EU. And M-POHL is open to cooperation with other WHO regions around the world to make use of its approach and instruments to measure population HL in diverse settings.

Overall, when HLS19 is well under way, M-POHL will initiate its next project, which will assess organizational health literacy. The anticipated organizational HL instrument will be based on an International Self-Assessment Tool for Organizational Health Literacy (Responsiveness) of Hospitals (OHL-Hos) developed by an International Working Group Health Promoting Hospitals and Health Literate Health Care Organizations (Working Group HPH & HLO) [152].

Finally, the development, advancement, and diffusion of HLS-EU (and its diverse accompanying instruments) established a foundation for health literacy research that will be advanced by M-POHL and HLS19 in Europe and around the world.

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Health Literacy in Austria: Interventions and Research

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Abstract. This report provides an overview of Austria's approaches to improve population health literacy (HL). The report suggests: a) research can trigger health policy responses to improve HL; b) linking HL improvement to other reform agendas can boost effectiveness, and c) coordination is required for continuously and systematically working towards better HL. Examples of strategic thematic approaches and interventions - especially in the fields of communication in healthcare, health information products, and organizational HL responsiveness - are provided, and Austria's role in preparing the next European HL survey, HLS19, is briefly described.

Keywords. Health literacy, health targets, communication in healthcare, health information criteria, organizational health literacy

1. Background and Introduction

In Austria, the uptake of the concept of health literacy (HL) goes back to the early 2000s and was characterized by close cooperation between researchers and policy makers from the beginning. The European project 'Migrant Friendly Hospitals' (2002-2005), supported by the Austrian Ministry of Health (MOH) and led by an Austrian research institute, embedded health literacy within its module on migrant-friendly information and training for mother and child care [1]. At about the same time, in 2006, HL pioneer Ilona Kickbusch initiated the first national HL study in a European country – in Switzerland [2].

Austrian researchers supported Kickbusch and advocated for HL within the influential policy and research-oriented European Health Forum Gastein, an annual event in Austria [3]. The debates created by the discussions and the results of the Swiss

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study helped convince the European Commission of health literacy's potential contribution to a broader European health agenda. The latter enabled Austrian, German, and Swiss researchers to initiate a consortium and submit a funding proposal for the initial, comparative European HL survey in 2006. In 2009, eight European countries set out to participate in the resulting European Health Literacy Survey (HLS-EU). An Austrian research institute became responsible for HLS-EU's data analysis and reporting.

On the policy side, the strong involvement of Austrian researchers in European efforts initially was reflected in the Austrian Social Security Association's 'Health Master Plan' (Masterplan Gesundheit), which was the first policy document in Austria to call for the 'strengthening of individual health literacy' [4].

In 2011 the Austrian Ministry of Foreign Affairs' National Action Plan for Integration ('Nationaler Aktionsplan für Integration') also recommended, amongst other initiatives, to improve the HL of migrants, especially in relation to the nation's healthcare delivery system.

So, when the preliminary results of the HLS-EU study became available in 2011-12, there was some recognition of the relevance of health literacy among decision-makers in health policy and public health [5].

However, the awareness of HL in Austria increased significantly when the initial HLS-EU survey found that limited HL in Austria was far from a minority problem and impacted 56.4% of all Austrians. The comparative dispersion of limited HL in Austria was worse than the international average of 47.6%, and closer to Eastern-European Bulgaria (62.1%) than to the Western-European Netherlands (28.7%) [5-6]. Austria's limited HL also was found to be predominant amongst older and chronically ill people [5-6]. Overall, limited HL among chronically ill and older Austrians increased the comparative likelihood they might not adequately benefit from the healthcare they received. In addition, the HLS-EU data found a social gradient for HL (although this appeared a bit lower for Austria than for other countries), which suggested HL was associated with health inequities within populations [5-6].

The HLS-EU data, which came as a shock to Austrian health authorities, were widely communicated amongst health systems experts and decision-makers and received very high profile mass media coverage. Austria's low level of HL also was quickly interpreted as a national policy challenge since a growing body of additional evidence suggested HL was significantly associated with health outcomes, health status, as well as with the usage and outcomes within healthcare delivery services [7].

It was a welcome coincidence that the release of the HLS-EU data occurred at the same time as the launch of two parallel, fundamental health reform processes in Austria. These included public health-oriented, intersectoral, determinant-driven national health targets as well as the introduction of a 'management by targets' approach (https://gesundheitsziele-oesterreich.at/english-summary/). The developments opened windows of opportunity that were a catalyst to HL's sudden prominence within Austria's national political agenda, especially in the health sector (while other sectors remain only loosely involved), which resulted in some commitments to specific activities and interventions.

For example, of the ten public health-oriented Austrian national health targets that were approved by the Austrian Council of Ministers in 2012, target #3 was dedicated to improving the health literacy of the Austrian population. A working group with representatives from different policy fields, social security, expert organizations and NGOs was set up to develop a set of three sub-targets and match interventions to achieve better national HL. The sub-targets focused on improving organizational health literacy in healthcare as well as other sectors; on enhancing personal health literacy, and on embedding HL in the service and production sectors of Austria's economic system [8]. The development of these sub-targets followed a systematic process that identified other social determinants that plausibly were related to HL improvements. As a result, HL interventions were carried out in different sectors – healthcare, community settings, education, extracurricular youth work, and others.

Within the narrower world of the healthcare system, the principle partners of Austria's complex healthcare system – the Ministry of Health, the Austrian provinces or Länder, and Austria Social Security (Sozialversicherung) – collaborated in the so-called 'management by targets' process. During the next four-to-five years, the partners adopted common goals and matching interventions.

Starting in 2013, the partners agreed on a general focus on HL and, initially, on four areas of interventions. First, the partners agreed to improve the quality of communication and information in healthcare by developing a national health information website (www.gesundheit.gv.at) and a national strategy to improve the quality of communication in healthcare. Second, the partners supported the HL interventions already initiated by the health target processes. More specifically, the partners agreed to implement a national coordination structure for HL in Austria and support the initial foundation and funding of the Austrian Health Literacy Alliance (https://oepgk.at). Third, the partners agreed to better utilize Austria's electronic patient record system to improve HL; and to participate in future European HL surveys.

Interestingly, the initial four fields of activity have been supplemented during the second period of Austria's reform strategy (2017-2021). The improvement of organizational HL was added as a new topic, and there are current attempts to systematically add HL to the professional competencies of healthcare professionals and services, which already has been successful for nurses and within primary healthcare regulations.

2. Health Literacy Capacities and Interventions in Austria: Key Strategies and Examples

The comprehensive definition of HL by Sørensen et. al. which was adopted by WHO´s 'The Solid Facts – Health Literacy,' is widely accepted as the basis for HL activities in Austria [9-10]. Accordingly, HL relates to accessing, understanding, appraising and applying information on treatment, prevention and health promotion throughout the life course. Since HL builds on literacy, basic education is essential. As a result, Austrian activities to improve HL conceptually have embraced several sectors – including care, health promotion, and prevention – as well as education.

It is clear that capacity building, especially a competent coordination structure, is required to continuously and systematically work within such a comprehensive concept. In Austria, a national coordination structure began in 2015 and was modelled partially on a Canadian concept. The coordination plan was further developed by representatives of the MoH, social security, and representatives from Austria's provinces [11].

The 'management by targets' reform process enabled cooperation among the latter partners and fostered their participation in a subsequent joint decision to implement the so-called Austrian Health Literacy Alliance (Österreichische Plattform Gesundheitskompetenz – ÖPGK). However, the complexity of collaboration also required a steering structure. The strategic 'core group,' which is chaired by the Austrian

MoH, consists of representatives from different ministries, the Austrian provinces, social security, and representatives of practice organizations that implement HL activities. Since all these partners have their specific (and partly competing or even conflicting) agendas, it became challenging to agree on a host organization for the alliance, which eventually was placed at the tax-funded Austrian Health Promotion Fund. The latter means that the Fund's board of trustees need to be continuously convinced of the importance of annual investments in the coordination structure.

Despite ongoing funding insecurities, the Austrian Health Literacy Alliance has evolved to become the driver of HL innovation in Austria. The Alliance organizes an annual national HL conference (that attracts about 300 delegates annually), encourages the implementation of HL measures by a membership process for organizations active in HL (with about 40 members in June 2019), and has currently five thematic program lines. These include (in historic development order): (1) improving the quality of communication in healthcare; (2) enhancing the quality of written and audio-visual health information products; (3) advancing organizational HL responsiveness in healthcare and other sectors; (4) HL measurement; and (5) empowerment of citizens and patients. The focus in all activity areas is to improve the knowledge, skills, and competences of the health professionals who either shape HL conditions via professional decision, or interact with patients (consumers) in professional encounters.

The Alliance's first three programs will be discussed consecutively within the report's next three subsections.

2.1 Improve the Quality of Healthcare Communication

To backup, Austrian patients find it challenging to understand medication leaflets, to assess the advantages and disadvantages of treatment options, to assess whether they should obtain a second opinion from another doctor, or to understand what their physician tells them. Based on a pioneering paper, some national activities to improve the quality of communication in healthcare, or the first of the five aforementioned program lines, started in 2015 [12]. Within the 'management by targets' approach, representatives of the MoH, of social security, and of the Austrian provinces jointly developed a comprehensive intervention model that recommended action in four areas [13]. These included:

(1) Human resource development for healthcare professionals – When it comes to face-to-face communication in Austrian healthcare, there is still a considerable gap between classroom and workplace learning. While the curricula regarding communication skills in medical schools have improved, when students leave to practice they lack continuous support and encouragement from health professional peers. In response, strategies were launched to offer continuous professional education and on-site training for communication for health professionals during all phases of their career. One step in this direction was a pilot train-the-trainer certificate program that was conducted from January 2018 to May 2019 in close collaboration with EACH: International Association for Communication in Healthcare (www.each.eu), and funded by Austrian social security. The program is intended to be the starting point for a country-wide network of highly professional communication trainers for the healthcare field.

(2) Empower patients and families – Because of the asymmetry of power between patients and families and healthcare professionals, patients need to be empowered to enhance interpersonal healthcare communication. As one activity to meet this goal, the Austrian HL Alliance and a number of institutions and organizations across the country

recently started an Austrian version and regional adaptations of the 'Ask me 3' initiative, sensitizing patients and healthcare professionals alike to encourage questions from patients. This initiative became the starting point for a thematic program line to empower more citizens and patients through the Austrian HL alliance. Some social security organizations also are administering HL training courses for patients, teaching them amongst others how to prepare for a medical encounter.

(3) Organizational development – High-quality communication in healthcare requires organizational support. Pilot activities currently are supported by the Austrian HL Alliance's program line to develop more health-literate organizations which is described later in this report.

(4) Health systems development for patient-centred healthcare communication – Despite the clear evidence of its effectiveness, high-quality communication in healthcare is still widely regarded as a nice-to-have rather than a must-have [12,14,15]. In the medium and longer term, legal frameworks and funding mechanisms will need to be adapted to make communication more attractive to healthcare providers. But this will require a shift in the culture of healthcare.

2.2 Enhance the Quality of Written and Audio-visual Health Information Products

According to the HLS-EU study, Austrians find it challenging to deal with written health-related information. For example, it is difficult for some Austrians to assess whether media coverage about diseases or health risks is trustworthy as well as to understand the information on food packages [16].

As the availability of good-quality, understandable health information is a HL precondition, the Austrian HL Alliance edited and published a set of 15 national criteria for high quality written and audio-visual health information. The criteria were based on a German gold standard for public health information, which was further developed into a manual by a working group of the Austrian HL Alliance [17].

The Alliance's manual addresses publishers, financers, writers, and disseminators of health information products [18]. Amongst others, the criteria demand that health information is: evidence-based; presented in clear language (with understandable pictures and graphics); equitably informs about the potential benefits and harms of treatment or other health interventions, is transparent about any conflicts of interest; and clearly informs about the sources of health information as well as the institutional publisher. Last but not least, the Alliance's manual encourages the development of health information in participation with the target group's representatives to ensure ensuing products are more understandable and meaningful to the users.

The Austrian HL Alliance encourages organizations to use the latter criteria to develop their own organizational guidelines around health information products, explain how they will adopt the criteria, and develop more and more transparent communication approaches. The organizations that do so receive a recognition from the Austrian HL Alliance. Currently, there are no formal requirements for the quality of health information products in Austria, so the commitment of organizations to higher quality health information is voluntary.

As a next step, the Austrian HL Alliance will start activities to help health professionals, citizens, and patients identify quality health information by preparing and publishing checklists that help users assess the quality and trustworthiness of health information products.

2.3 Advance Organizational HL Responsiveness in Healthcare and Other Sectors

A third activity area of the Austrian HL Alliance provides support for the development of organizational HL in healthcare as well as other sectors. Related activities build on the 'Vienna Concept of Health-Literate Hospitals and Healthcare Organizations (V-HLO),' which provides a set of standards and sub-standards in a self assessment tool of HL organizational responsiveness [19-20]. V-HLO builds on and operationalizes the U.S. Institute of Medicine´s (IOM) 'Ten Attributes of Health Literate Health Care Organizations' [21].

The Austrian Social Security Association, one of the partners of the Austrian HL Alliance, adapted the tool for their own organizations and advocates its broader usage. Based on the original tool, a working group of the Austrian HL Alliance developed a short form of the self-assessment tool and manual [22-23]. An adaption of the tool for primary care settings is currently under development in collaboration with the Swiss Careum Stiftung and the Swiss city of Zürich. The intent of these activities is to sensitize different types of organizations about their own role to improve HL by providing supportive conditions. For example, healthcare organizations are asked to facilitate access to good-quality health information, invest in personnel development to improve the quality of communication, and ensure higher patient communication standards are pursued.

Meanwhile, the approach has been adopted in settings outside the healthcare field. The standards and guidelines were adapted for communal settings and for extra-curricular youth work organizations [24-25]. The latter now can receive gold, silver, or bronze level certificates for their organizational HL activities (from the Austrian umbrella organization of extra curricular youth work settings) on the basis of a self-assessment. Developments around health-literate public administration have just begun.

To further support developments within and across its program lines, the Austrian HL Alliance has started to build working groups and sub-networks for its activity areas. While these sub-networks have operated separately, a more structured exchange across activity areas is envisioned. A proposed approach to improve the dissemination and organizational uptake of the activities of the Austrian HL Alliance would develop a certification and recognition approach across all activity areas of the Austrian HL Alliance.

3. Austria's Role in Advancing HL Research in Europe and Internationally

Austria's strong tradition in HL research has supported science, policy, and practice developments in Austria and partly beyond since the early 2000s. Austria's role in health literacy measure in Austria and resulting influence in other nations is described below.

After Austria's initial participation in HLS-EU, several related studies took place. In 2013, a study about the HL of Austrian 15-year-olds was derived from the HLS-EU questionnaire and sponsored by the Austrian Social Security Association. The data were amongst others used to develop a short form to measure HL (the HLS-EU-Q16). The intent was to include this short form within other survey tools, such as the international Health Behaviour in School-Aged Children (HBSC) Survey [26-27].

To enable comparison of HL levels between Austrian provinces, financial support from the Austrian Health Promotion Fund (FGÖ) and Merck, Sharp and Dohme (MSD) enhanced the sample sizes within Austrian regions, which resulted in a more detailed analysis of HL results across Austria [16]. And, since the Austrian sample for HLS-EU only included EU citizens, a study on the HL of migrants from two non-EU countries (Turkey and former Yugoslavia) was sponsored by the Austrian Health Promotion Fund, the Austrian Social Security Association, and MSD. While the latter qualitative and quantitative study with data collection in 2014 used the HLS-EU-Q16, it added a set of twelve specific HL questions for people with migrational backgrounds, and some other relevant questions to migrant populations [27-28].

Austria's research activities around the concept of Organizational Health Literacy (OHL), which were funded by the MoH and an Austrian research society, also have received international recognition. Today, the V-HLO conceptual model is seen as one of two multidimensional OHL frameworks [29]. The tool has been translated into English, French, Italian and Mandarin, and piloted in different countries. An international working group of the Health Promoting Hospitals and Health Services (HPH) network, which is chaired by Austrian researchers, developed an international version of the tool, which will be tested in different national contexts.

A specific area that is supported both by policy and research in Austria is the advancement of HL measurement in Europe. The impact the data derived from the HLS-EU had in Austria as well as in some other participating nations suggests that data can have sufficient power to inspire evidence-informed policy and practice and facilitate social change [30-32]. In fact, WHO Europe's publication 'Health Literacy – the Solid Facts' advocates the establishment of internationally comparative, ongoing HL surveys in Europe [10].

In light of the many activities to improve HL that have taken place in Austria since the publication of the initial HLS-EU survey, the use of HL national and international data can facilitate the identification of strategic priorities and thematic foci for national action. Data seem important to draw the attention of politicians in the sense of 'What doesn't get measured doesn't get done.'

As a first step to prepare future surveys of population HL, the HLS-EU index of population HL was embedded within Austria's national monitoring framework on health system outcomes. Similarly, Austria had a strong interest to get other European countries to jointly measure HL because comparative population data enable cross-country analyses of HL's determinants and effects which are more compelling. Following a letter of leading HLS-EU researchers to the MoHs of German-speaking countries, a HL coalition was established amongst these countries under Austria's lead.

In its attempts to support a new European survey, the latter coalition consulted with WHO Europe and established an action network under the umbrella of the European Health Information Initiative (EHII) of WHO-Europe. After approval from WHO Europe, a resulting proposal was presented to all WHO-European member states during the 67th WHO Regional Committee Meeting in Budapest, Hungary in September 2017. With the consent of member states, the kick-off meeting of the so-called 'WHO Action Network on Measuring Population and Organizational HL' (M-POHL) (https://m-pohl.net/) was held in February 2018 in Vienna with representatives from 19 countries.

The participants agreed that M-POHL's main objectives should be to support regular measurements of population as well as organizational HL and to use the results to support evidence-based policy and practice [33]. Austria was appointed to chair the network and began to prepare M-POHL's first project, the next European HL survey HLS_{19}.

The M-POHL now has 25 participating countries; 13 nations provided letters of intent to participate in the HLS_{19} survey, and the Austrian Public Health Institute was appointed as international coordination centre for HLS_{19}. Since the Vienna meeting in 2018, M-POHL has hosted two more network meetings mostly dedicated to prepare the

HLS19 survey. The latter survey will build on HLS-EU by using a standard short form of the survey tool for all participating countries, and complement it with optional packages on new topics (digital HL, communication and navigation in healthcare), and permit a few country-specific items. Data collection for HLS19 is expected to start in late autumn 2019, and a next comparative report on population HL in Europe is planned to be available in 2021.

A unique feature of M-POHL is its collaborative foundation. M-POHL brings together health researchers, health policy makers, and health administrators. The countries typically participate with a research and a policy or administrative representative which enables dialogue between these perspectives. The recent experiences of M-POHL's international participants suggest they find continuous collaboration is extremely valuable. The latter increases a broader understanding of HL, supports HL's momentum, and assists the planning of specific HL activities and interventions in respective countries.

4. Discussion and Conclusion

Austria's recent history suggests that HL research (especially if it receives a high professional and public profile via speciality and other mass media) can influence politicians, governmental and non-governmental officials, expert and public opinion, and resulting policy initiatives. The resulting momentum expedited Austria's health literacy's socio-professional diffusion, which is surprising since health literacy represents the type of complex, innovative public health concept that rarely is embraced expeditiously within heterogeneous societies [34].

The extent of HL success in Austria is evidenced by the fact it began as part of an ongoing reform agenda within the 'health target' and 'management by targets' approach just a few years ago. Yet, HL research and initiatives survived the transition into Austria's new governments and political leadership. In fact, the last Austrian government (from 2017-19) included a goal to improve HL within its national administrative agenda.

HL also has been diffused within Austria' regulatory/legal policies. For example, the act that regulates the professional competences of nurses now includes HL as a professional core competence. And the General Social Security Act now includes activities to improve HL as a strategy for optional health insurance services. In addition, health educational institutions have developed curricula to improve the HL knowledge and skills of future healthcare professionals, which advances HL's inclusion within Austria's long range professional developmental efforts.

Yet, despite the efforts of the Austrian HL Alliance to include stakeholders across sectors, the majority of discussions and interventions occur within healthcare, and within this sector, the focus is to improve patient treatment. The role of education to shape HL preconditions, and the role of business in relation to workers' HL and to support health-literate consumer decisions (e.g. by providing understandable food labels), currently are less discussed. Hence, the wider potential of HL for health promotion and prevention await to be tapped. Although emerging evidence suggests co-benefits of investments in HL for other sectors, it remains difficult to find entry points that are significant enough to motivate other sectors to include HL into their core strategic or reform processes, which has worked well within the healthcare sector [35].

While the current 'hype' regarding HL triggered pioneer and pilot activities, long-term strategic and sustainable implementation will require coordination capacities and financing strategies as well as formal regulations to support institutions to systematically orient their daily routines towards HL. The quality criteria and standards developed by the Austrian HL Alliance - for communication in healthcare, health information products, and organizational HL responsiveness - could provide a basis to advance regulatory policy.

Finally, in order to maintain public investment and momentum, it will be important to demonstrate that the activities of the Austrian HL Alliance provide efficacious outreach to Austria's citizens and migrant populations and favorably impact the nation's health outcomes. The availability of new, comparative HL population data in Austria and the successful tradition of cooperation between research and policy augurs well for HL's future in Austria and might help inspire health literacy activities in other nations in the future.

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Work in Progress: A Report on Health Literacy in Denmark and the Netherlands

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Abstract. This report focuses on the development of health literacy in two European countries, Denmark and the Netherlands. Denmark is part of the Nordic region, while the Netherlands is situated in the Western part of Europe. The report includes examples on Danish and Dutch health literacy research and lessons learned from practice. In Denmark, supported by health literacy research, health literacy developments have been advanced within some areas of practice. Health literacy advocacy initiatives promoted by the Danish Health Literacy Network and the Danish Society of Public Health provide promising perspectives for the future of health literacy in Denmark. In the Netherlands, the Dutch Health Literacy Alliance, researchers, and other relevant stakeholders are actively integrating health literacy in research and practice – both clinically and in communities. The vibrant Dutch health literacy community advocates for further national health literacy efforts to achieve governmental support.

Keywords: Health literacy, Denmark, the Netherlands

1. Introduction

This report focuses on the development of health literacy in two European countries, Denmark and the Netherlands. Denmark is part of the Nordic region, while the Netherlands is situated in the Western part of Europe. Although similar in geographical size, their populations differ significantly. Denmark has a population of 6.3 million inhabitants compared to 17 million in the Netherlands.

The health systems also are different as the Danish system is primarily tax-based via the so-called Beveridge model, while Dutch financing is based on the Bismarck model through a social insurance system. Historically, the Netherlands is one of the front runners in the European health literacy field with activities that began almost two decades ago. The Danish health literacy community evolved more slowly.

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The report includes examples on Danish and Dutch health literacy research and lessons learned from practice.

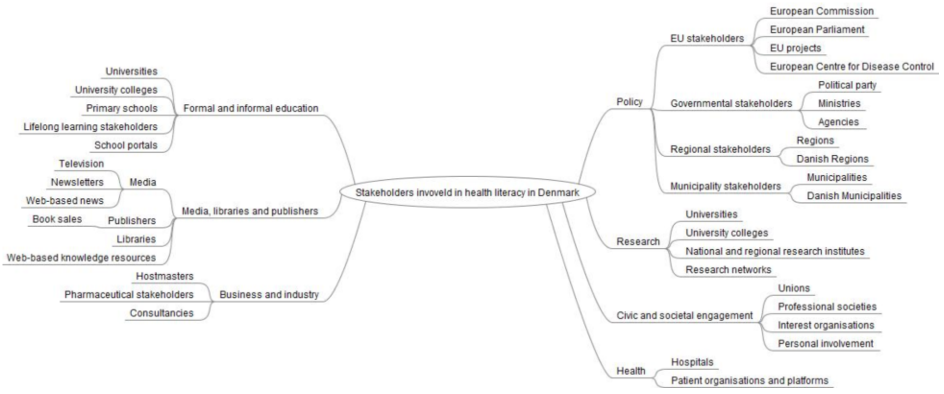
2. Denmark

Health literacy is gaining momentum in Denmark after a comparatively slow start. Although a status report was provided by the Danish Health Agency in 2009, health literacy did not really catch on within the Danish health system until recently. One of the reasons was the challenge to translate the term ‘health literacy’ into the Danish language [1]. In Danish, health literacy can be translated to ‘Sundhedskompetence,’ which is now a commonly used term.

The initial suggestions to advance health literacy in Denmark focused on research [2-3]. An Internet mapping study in 2013 suggested health literacy’s integration had begun in the diverse areas outlined in Table 1. Health literacy activities included these arenas [4]:

- Denmark’s policy arena, which was dominated by municipalities and regional governments, who applied health literacy in guidelines and local interventions as part of their health prevention and promotion efforts. Various ministries also were represented as well as international policymakers, such as the European Commission and the European Centre of Disease Control.
- Participation in Denmark’s educational arena included stakeholders in primary schools, secondary schools, university colleges, universities, and institutions working on lifelong learning.
- Denmark’s research arena was represented by all five universities as well as several university colleges and national research institutions.
- Denmark’s communication arena included stakeholders from national and local newsletters, television, web services, and blogs.
- Denmark’s arena for capacity building was characterized by diverse stakeholders including the trade unions for doctors, nurses, physiotherapists, and engineers as well as the Danish Society of Public Health.

Table 1: Stakeholders involved in health literacy in Denmark [4].



- Denmark's arena of civic engagement suggested some health literacy stakeholders were involved in some non-governmental organizations, especially patient organizations.
- Denmark's business participation included the pharmaceutical industry and smaller consultancies.
- Finally, Denmark's healthcare service health literacy participation included a few hospitals active in relation to quality of care, immigrant health, patient education, adherence and compliance.

2.1. The Nordic Health Literacy Network

The lack of data and inconsistent stakeholder commitment encouraged Danish health literacy stakeholders to join the Nordic Health Literacy Network. The Nordic Network began in 2012 to facilitate a health literacy knowledge exchange across Nordic countries and work with international colleagues. The Nordic Network hosted several meetings in Norway, Sweden, and Denmark during its first five years.

More recently, the Network mostly has been active in European health literacy activities, such as the 2nd European Health Literacy Conference that took place in Aarhus, Denmark in 2014 and the establishment of the WHO action network on Measuring Population and Organizational Health Literacy (M-POHL: https://m-pohl.net/). Denmark is slated to be part of the next European Health Literacy Survey coordinated by M-POHL called HLS19. Danish and Norwegian colleagues also developed two of seven WHO National Health Literacy Demonstration Projects (NHLDPs), which address HL needs in the European region.

2.2. The Danish Health Literacy Network

The Danish Health Literacy Network was launched in 2016 for professionals engaged in policy, research, and practice. The Danish Health Literacy Network hosts bi-annual membership meetings across the country and the first national conference will occur in spring 2020.

In terms of agenda setting, the Danish Health Literacy Network's recent project is a joint initiative launched in 2019 with the Danish Society of Public Health. Through a participatory process including members and designated key health stakeholders, a policy brief was developed with eight recommendations about how to improve health literacy as a path towards health equity [5]. All the Network's recommendations can be integrated within current health strategies, including ongoing efforts to achieve the U.N. Global Goals for Sustainable Development.

More specifically, the Network's eight recommendations are to:

1. Integrate health literacy in Danish health policies and strategies. Given the increasing complexity of health information, health literacy directly or indirectly needs to be addressed by all Danish national and local health policies and strategies.
2. Develop health literacy throughout the life course. Health literacy should be integrated into and across sectors inside and outside the health care delivery system to ensure HL needs are met throughout all life course stages.
3. Include health literacy in health education curricula. Health literacy should be prioritized and integrated into educational curricula in pre- and postgraduate training of healthcare professionals.

4. Integrate health literacy at organizational levels. Organizational health literacy responsiveness should be developed at all levels in the Danish healthcare system – municipal, regional and national as well as in private and voluntary organizations.
5. Integrate health literacy into partnerships and co-creation processes. In cross-sectional collaborations and partnerships, health literacy builds bridges between different stakeholders and fosters a common ground for communication and reference.
6. Measure and monitor health literacy using local and national data. Routine analysis of individual health literacy and organizational health literacy responsiveness should be implemented nationally and locally among the general and vulnerable populations. Digital health literacy also should be assessed where appropriate.
7. Develop, test, and evaluate health literacy interventions. More interventions with a focus on health literacy should be developed, tested, and assessed in different contexts and settings. Interventions should foster dynamic interactions between practice and research.
8. Consider health literacy principles within all forms of health communication in Denmark. All verbal, written, and digital health communication should consider potential differences in people's health literacy needs [5].

2.3. Research

To date, Denmark's health literacy research has focused on measurements and interventions. For example, the first study from Denmark was a population-based assessment of dimensions of health literacy related to understanding health information, which engaged healthcare providers to use the Health Literacy Questionnaire (HLQ) [6]. The latter study was followed by an evaluation of health literacy in people with long-term health conditions (diabetes, cardiovascular disease, chronic obstructive pulmonary disease, musculoskeletal disorders, cancer and mental disorders) [7]. The immediate findings were compared to levels in the general population to note associations among health literacy, socioeconomic characteristics, and comorbidity within each long-term condition group [7]. Meanwhile, a team validated the Test of Functional Health Literacy in Adults' (TOFHLA's) adaptation to Danish health care settings and culture. The use of TOFHLA to measure HL was seen as acceptable among Danish patients with chronic obstructive pulmonary disease (COPD) as well as a case group example [8].

A study additionally assessed the level of health literacy among Danish students who attended one of the four full university health programmes and investigated the association of health literacy with sociodemographic backgrounds. Student health literacy levels were measured using HLQ [9]. Kayser and colleagues also tested the HLQ for eHealth consumer use and developed the eHealth Literacy Questionnaire (eHLQ), which is a multi-dimensional tool based on a well-defined a priori eHLF framework. The questionnaire is designed to be used to understand and evaluate health consumer interactions with digital health services [10]. In two recent studies, Aaby et al. suggested large diversity in Denmark's population health literacy profiles [11]. Similarly, Svendsen and colleagues found diverse population-wide health literacy among Danish citizens using the HLS-EU-Q [12]. They also included patients with heart disease for comparative purposes [12].

2.4. Educational Interventions

Danish schools have been identified as central settings for health literacy interventions. For example, an educational programme, IMOVE, advances student health literacy by focusing on physical activity. IMOVE contributed to the development of functional health literacy in Denmark by suggesting health literacy could be boosted by encouraging participant awareness of everyday physical activities, which included step numbers [13]. Furthermore, intervention projects have been launched at organizational and community levels based on the OPHELIA approach [14].

In recent years, some universities and university colleges have started to integrate health literacy as part of their capacity building and education programmes in the form of lectures, modules, thesis topics, etc. Thus, health literacy is taught at university level at Aarhus University and Copenhagen University to health professionals in the schools of public health science. In addition, some nursing schools have integrated health literacy within their educational efforts. The Global Health Literacy Academy also offers courses and workshops on health literacy. It is expected that the educational efforts will increase in the future due to the increased awareness of the importance of health literacy in research, policy, and practice.

3. The Netherlands

The first comparative national study of health literacy in seven European nations (HLS-EU) found the lowest percentage of inhabitants with inadequate or problematic health literacy (28.7%) was in the Netherlands [15]. The findings, which were published in 2012, proved to be both a blessing and a curse. For example, Dutch researchers, professionals, and policy makers were pleased with their nation's achievement. From a public health perspective, health literacy in the Netherlands was superior to six other European countries. However, the appreciation of success resulted in no official measures taken by the Dutch national government to either improve the level of health literacy or to set targets for a more tailored care system. In fact, between 2012-2018, the Netherland's Minister of Health, Welfare and Sport perceived that policy initiatives as well as interventions to target limited health literacy were the sole responsibility of non-governmental stakeholders.

In contrast, lower health literacy scores on the HLS-EU in Austria and Germany created a sense of urgency, which led to national support for new research, care innovations, and policy initiatives. In 2018, a new survey suggested the level of limited health literacy in the Dutch population was much higher than found in 2012 - 36.4% [16]. Of the persons surveyed, 9.5% had inadequate and 26.9% problematic health literacy. Similar to other countries, there is a social gradient in the Netherlands with regard to health literacy: 54,7% of lower educated persons have limited health literacy, compared to 27.2% among those with higher educational levels [16].

Perhaps as a result of the revised limited health literacy estimates, the attention to health literacy (in Dutch 'Gezondheidsvaardigheden') is growing both in terms of policy and recent initiatives from Dutch healthcare organizations. Although the Dutch national government still has no official policy with respect to health literacy, the topic is sometimes being integrated in other efforts, such as efforts to improve patient shared decision making. In addition, some smaller grants have been awarded for research and networking. Moreover, a conceptual change in the Netherlands has shifted the focus of health literacy initiatives from literacy or cognitive skills to the motivation, confidence, and skills for citizens to put health related knowledge into practice ('the capacity to act') [17]. The latter shift in focus is partially linked to recent research that suggests knowledge alone is insufficient to persuade persons to take a more active patient role and/or change one's lifestyle [18].

3.1. Dutch Health Literacy Alliance

A nationally based initiative began in 2010 with the establishment of the Dutch Health Literacy Alliance ('Alliantie Gezondheidsvaardigheden'). The Dutch Health Literacy Alliance represents a network of organizations, institutions, companies, and individuals. The Alliance was started by a group of healthcare providers and researchers who sought to draw attention to the problem of limited health literacy. The Alliance's priorities include agenda setting and networking and it now contains 80 partner organizations. Several Dutch NGO's have hosted the Alliance including Pharos (Dutch Centre of Expertise on Health Disparities). The Alliance has a website, organizes semi-annual network meetings and there are three active working groups devoted to research, education, as well as patient experiences and participation [19].

3.2. Research

In the years around and following the HLS-EU assessment, several Dutch researchers developed an interest in health literacy. Initially, since most health literacy studies were conducted in the U.S., the question arose whether the measurement instruments developed within an American context were empirically valid and reliable in the Netherlands. Accordingly, several measurement instruments were translated and validated in Dutch including: the Rapid Estimate of Adult Literacy in Medicine (REALM), Set of Brief Screening Questions (SBSQ); Functional Communicative and Critical Health Literacy (FCCHL); Newest Vital Sign (NVS); and the Health Literacy Questionnaire (HLQ) [19-21].

Once these instruments were translated and validated, the next generation of Dutch research focused on: the association between health literacy and health outcomes; provider choice and healthcare use; seeking and use of health information preferences for and participation in screening activities; shared decision making; and health self-management [22-32]. The results of these studies were consistent with research from the U.S. and other countries: Dutch participants with limited health literacy in general have worse outcomes and are less active throughout the trajectory from health prevention through clinical care. Since more elaborate health literacy measurements instruments were used in Dutch research, it became clear that functional health literacy explains only some of the disparities between limited and other health literacy populations - and communicative and critical skills also are important.

Intervention studies, which focus on the development, implementation, and evaluation of interventions (in healthcare and prevention), also have begun in the Netherlands. Some interventions have been developed and implemented on a small scale [33-34]. These interventions target mostly the micro-level (patient-provider, personal use of eHealth) or the meso-level (improving a healthcare organization, and the broader training of health providers and staff).

Since there is no governmental or other central policy regarding health literacy in the Netherlands, health literacy initiatives are not necessarily coordinated, and project insights are not always shared. Since some interventions are not thoroughly evaluated, it is difficult for other Dutch health literacy professionals and policymakers to determine which interventions are (cost)-effective within specific circumstances. Hence, in 2018, the Dutch Ministry of Health, Welfare and Sport and the Netherlands Organization for Health Research and Development invested in the draft of a coherent research agenda on health literacy, specifically aimed to improve research about health care services for persons with limited health literacy [34]. The ensuing research agenda covers challenges at the micro- (patient-provider), meso- (organization) and macro-level (society). However, at present the funding for a more comprehensive health literacy research agenda is unavailable in the Netherlands.

3.3. Other Interventions

Most of the health literacy activities and interventions that are developed and initiated in Holland are in the domain of healthcare (rather than schools or in the workplace). In the international HEALIT4EU study, which was commissioned by the European Commission in 2015, all interventions on a national or regional level in European countries were inventoried. At that time, nine examples of programs and activities were found in the Netherlands [34].

More recent surveys of tools and methods suggest additional interventions are used routinely in some Dutch healthcare contexts [33-34]. For example, a health literacy toolkit was developed by the National Association of General Practitioners (LHV), for use by Dutch general practitioners and practice nurses. The toolkit provides information that helps providers improve their communication with patients with limited health literacy skills. The toolkit helps with medical admittance, medical consultations, medication prescriptions, and patient referrals. The toolkit includes tips to increase the accessibility of health care practices. Pharos also invests in various projects that improve healthcare provision to patients and caregivers with limited health literacy, such as the use of the ‘teach back’ method for providers.

In addition, a recent survey of healthcare providers in the Netherlands suggests 41% do not adapt their communication style to the needs of patients with limited health literacy [34]. And 50% do not adapt written, oral or digital information to assist persons with different levels of health literacy. The principle reasons why providers do not tailor health care are:

- Lack of time
- Unfamiliarity with limited health literacy
- Lack of personal responsibility
- Problem is not considered to be relevant
- Unaware of strategies and support for communication and information
- Lack of appropriate strategies and support
- Do not know how to apply strategies and support [33].

Since many strategies and tools already exist for patients with limited health literacy, the last three reasons provide a foundation to advance the education of providers and pay more attention to the tailored dissemination of health materials using internationally derived methods. More positively, some Dutch healthcare providers recommend the following five strategies: the teach back method; use of visual aids; more provider or organizational time; involve family or friends in the consultation and care; and the use of plain language [35]. The teach back method especially seems promising as it is a generic strategy that can be used in many settings and situations within the Netherlands [35].

As aforementioned, most health literacy interventions in the Netherlands currently are not systematically evaluated. The ensuing knowledge gap provides an important national challenge since Dutch healthcare managers and insurers seek to implement and pay only for evidence-based interventions. As a result, a gradual shift to intervention research and assessment is the key to further implementation and to foster better quality of care for persons with limited health literacy in Holland.

3.4. Educational Interventions

In the Netherlands, the topic of health literacy is not yet structurally integrated in the basis curriculum of health professionals. However, there is an increasing number of initiatives (theses, research internships) and lectures at Universities of applied sciences (a.o. Fontys Hogeschool, Hogeschool Utrecht) and academic universities (a.o. University of Amsterdam, Free University Amsterdam, Maastricht University). Maastricht University further hosts a yearly summer school on health literacy and has an endowed professor of ‘health literacy and patient participation’. Several Ph.D. students are in the process of doing research and writing a thesis on aspects of health literacy.

A working group within the Dutch Health Literacy Alliance also initiated an effort to advance health literacy in Dutch higher and other education. The working group suggests areas of attention for educators and ten learning goals regarding health literacy for health care professionals are targeted for diverse educational levels.

However, most current, Dutch health literacy educational activities focus on postgraduate professional education. As a part of further training and continuing education, many professional groups as well as health care institutions integrate health literacy in the programs of their symposia and congresses.

4. Conclusion

This report describes health literacy developments in Denmark and the Netherlands and highlights some contrasts between two countries in two adjacent European regions.

While Denmark had a comparatively slow start, health literacy developments were advanced within some areas of clinical practice, which were later supported by clinical research. Nationally, a new policy brief has raised awareness about health literacy among Danish decision-makers and the Ministry of Health is supporting Denmark´s participation in the next wave of the European Health Literacy Survey. The latter developments suggest a new era of national governmental interest and support, which may provide more focus on health literacy, health equity, and sustainability research and practice. It is especially hoped that the eight recommendations from The Danish Health Literacy Network (outlined in section 2.2 above) will generate a new range of national health literacy activities and actions.

In contrast, the comparatively favorable data from the 2012 European Health Literacy Survey fostered paradoxical governmental inattention to health literacy in the Netherlands. After 2012, the Dutch national government’s engagement in the health literacy was comparatively weak - perhaps because senior officials interpreted the European Health Literacy Survey findings as confirmation of prior policies that did not directly support comprehensive health literacy initiatives. However, more recent population data from the Netherlands suggests more than 30% of the population has limited health literacy. Hence, the Dutch Health Literacy Alliance, researchers, and other relevant stakeholders are advocating the importance of a national health literacy effort with accompanying support for governmentally supported health literacy strategies throughout the Netherlands.

In closing, as the 21st century enters its third decade, there is a critical mass of dedicated health literacy stakeholders in Denmark and the Netherlands, who support the expansion of health literacy research and practice. Dutch and Danish stakeholders also are internationally oriented and readily share their views and experience, which supports both the further development of health literacy within their own countries as well as in Europe and more globally.

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Health Literacy Research in Malaysia: Health Literacy and Other Aging Challenges Among Malaysian Public Employees

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Abstract. This report focuses on a study that addresses the role of health literacy in the challenges surrounding aging. The study was conducted among n=533 public employees ages 40 to 60 years old in Johor state, Malaysia. The validated Malay version of World Health Organization Quality of Life Instrument (WHOQOL-BREF) and the Short-Form Health Literacy Instrument (HLS-SF12) were used to assess perceived quality of life and general health literacy respectively. The WHOQOL-BREF comprises 26 items with six outcomes and the HLS-SF12 consists 12 items. This study provides an overview of participant quality of life, which was operationalized as a precondition of active aging. The participants' preconditions related to active aging were worrisome as 28% perceived their quality of life as poor and 34% were dissatisfied with their health. More positively, health literacy was found to be a significant determinant that may enable active aging.

Keywords. Health Literacy, Active aging, Ability for active aging, Older adult, Quality of life

1. Introduction

Low health literacy is associated with limited ability of medical decision-making, unhealthy life-styles, and poorer health outcomes. According to Malaysia's National Health and Morbidity Survey 2015, only 6.6% of Malaysian adults aged ≥18 have an adequate level of health literacy [1]. Findings from the study conducted among parents of Malaysian adolescents suggest about 60% of the participants have limited health

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literacy [2]. According to a systematic review, from 1985 to 2017, only 12 papers were published regarding health literacy research in Malaysia [3].

The latter underlines the need to expand health literacy research and practice in Malaysia as well as assess if the concept of health literacy can be used effectively to improve long term population health outcomes. In this report, the authors report some primary findings from recent Malaysian research, which suggests the role of health literacy among other challenges surrounding aging. This is the summarized finding of the thesis of the second author. The first and third authors were the supervisors of the doctoral research project, which has not been published.

1.1. Background

Malaysia is projected to become an aging nation in 2030. The total number of older persons in Malaysia in 2010 was 2.19 million, which represents 7.9 percent of the total population. It is estimated the percentage of older persons in Malaysia will increase to nearly 15 percent by 2030 [4]. In addition, the total age dependency ratio is expected to increase from 47.8 percent to 49.5 percent from 2010 to 2040 [5].

Aging population is a global challenge due to associations among aging, increased risk of morbidity and disability, increased healthcare demands, and the need for long-term care. The Malaysian government includes aging issues in its national agenda with a goal to sustain the quality of life among the nation's older populations. The Malaysian government's policy is consistent with the concept of active aging provided by the World Health Organization (WHO). The WHO finds active aging is the process of optimizing the opportunity of health, participation, and security in order to enhance the quality of life as people age [6].

However, little is known about the underlying preconditions among middle-age populations that impact active aging's future. For example, there is no data on health literacy status among Malaysia's pre-elders as well as the role of health literacy in active aging. Hence, the objective of a Malaysian study of public employees was to assess their level of health literacy and perceptions about their health status. Participant perceptions of quality of life and health satisfaction were seen as surrogate measures of the preconditions that impact active aging.

2. The Study's Methods

This study involved a non-professional group of Malaysian public sector employees in the Kluang district, Johor state. The non-professional group included: technicians; clerical support; services and sales workers; skilled agricultural, forestry and fishery workers; craft and related trades workers; and plant and machine operators [7]. Participation in the study was voluntary. Participants aged 40-60 years were invited and provided written consent.

The age group (40 to 60 years) was chosen because this subpopulation will contribute to Malaysia's elderly population in 2030. A sample size was estimated based on a pilot study with n=60 participants, which was conducted in March 2017. The estimated sample size (n=480) was inflated to n=672 participants to enable a 40 percent non-response rate and was rounded to n=700 participants. The research obtained approval from the Medical Ethics Committee at the University of Malaya.

A list of 74 public sector departments was obtained from the Kluang District Office. One of the research team members attended monthly district meetings where all heads of public sector departments and/or their representatives were present. Meeting attendees were briefed about the overview and implications of the study. Out of 74 departments, five armed forces departments were excluded since their nature and employee benefits were different than other public employees. Among the remaining departments, 12 claimed there was no qualified employee to participate, and 11 departments declined or failed to provide a list of eligible employees.

A list of 1,559 eligible participants were received from 46 public sector departments. A computer-based random sampling selected n=700 participants. The selected participants were approached through their respective departments. A departmental representative provided a questionnaire package in sealed envelopes to selected participants, and then collected feedback in one or two weeks. The questionnaire package consisted of a letter of invitation to participate in the study, an information sheet about the study, a consent form, and a questionnaire booklet. A pen and extra envelope also were provided in the package. Then the research team set an appointment date with the representative of the department to collect the questionnaires in the sealed envelopes. The participants were given a small gift as a token of appreciation for their time to participate in the study. Data collection occurred from April 1- November 30, 2017. The response rate of the study was 76%; n=533 participants returned the completed questionnaires.

The World Health Organization Quality of Life Instrument (WHOQOL-BREF) was used to assess the health status of the study population, as precondition of active aging [8]. The WHOQOL-BREF is widely used across the globe, is available in many languages, and was used with permission. The Malay version was validated among healthy adults and persons with chronic disease whose ages ranged from 20 and 70 years old. The psychometric property of the Malay instrument was found to be satisfactory [9].

The WHOQOL-BREF questionnaire contains 26 items with six outcomes. Within it are two stand-alone questions to measure an individual's overall perception of quality of life (QOL) and satisfaction of health (HS). The remaining 24 items are combined to measure participants self-perceived quality of life in four domains: physical health (DOM1: seven items), psychological health (DOM2: six items), social relationship (DOM3: three items) and environment domain (DOM4: eight items). A five-point Likert scale is used to score each item, where the higher the number the higher the rating. The terms used in the WHOQOL-BREF are provided in the Appendix A.

The scores for the two stand-alone questions ranged from one to five where a higher score indicated higher perceived quality of life and health satisfaction. The domain scores ranged from 0 to 100. Initially, the raw score for each domain was obtained by adding the individual item score. Next, the mean score for each domain was calculated and multiplied by four to transform the domain score into a range between four and 20. Then, a second transformation was done to convert the score to a 0 - 100 scale by subtracting the domain score in the first transformation by four, then multiplying by 100 and dividing it by 16. Appendix B provides more information about this process.

The general health literacy among study participants were assessed by a validated Malay version of the 12-item European Health Literacy Survey Questionnaire (HLS-SF12), which has been validated in six Asian countries [10-12]. The HLS-SF12 was selected because it is concise and enables comparisons among Asian countries. The HLS-SF12 employs a four-point Likert scale that assesses perceived difficulty, where 1 = very difficult, 2 = difficult, 3 = easy, and 4 = very easy, as shown in Appendix C. Three health literacy indices (the scores for healthcare (HC), disease prevention (DP) and health promotion (HP)) are constructed as a General Health Literacy Index (ranged between 0 and 50) and it was calculated using the following formula:

$$\text{GEN-HL Index} = (M - 1)x\left(\frac{50}{3}\right)$$

Where:
M = mean of all items in the tool;
1 = minimum possible value of the mean;
3 = range of the mean;
50 = chosen maximum value for the index score.

The GEN-HL Index score was then categorized into four groups: inadequate (0- 25), problematic (> 25- 33), sufficient (> 33- 42) and excellent (> 42- 50).

3. The Study's Findings

The mean age of the respondents was 50.2 (± 5.9) years. The proportion of male and female participants was almost equal, with women accounting for 52.8 percent of the total. The majority of the participants were Malay (96.2 percent), followed by Indian and Chinese at 2.8 and 0.6 percent, respectively. In a further analysis, ethnicity was categorized into two groups: 'Malay' and 'Non-Malay.' Altogether, 90.4 percent of participants were married followed by single, (3.4) percent and separated/divorced or widows/widowers were 3.1 percent each. Marital status also was categorized into two groups for further analysis, into 'has partner' for those who are married and 'no partner' for the others.

In term of socio-economic background, 63.6 percent completed secondary school. The largest group of participants are in the 'technician and associates professional group' (35.2 percent), followed by the 'clerical workers' at 31.0 percent. The remaining three MASCO occupation types – 'services and sales workers', 'skilled workers' and 'unskilled or general workers' – the percentage of participants who fall under these groups was 17.3 percent, 10.4 percent and 6.1 percent, respectively. For univariate and multivariate analyses, these three groups were combined to form 'services workers' category. The collapsed services worker category consisted 33.8 percent of the total number of participants.

The mean salary (± SD) of the participants was RM3575.70 (± 1189.20). In further analysis, the mean monthly salary was categorized into two groups using the Malaysian bottom 40 (B40) household income as a cut-off point. The B40 mean salary is less than RM3900.00. The majority of the participants (65.5 percent) earn a monthly salary of less than RM3900, which is a cut-off point for bottom 40% income group known as B40 [13]. Not surprisingly, only 32.5 percent of the participants expressed high financial confidence for post-retirement and the majority (62.9 percent) reported only moderate confidence for post-retirement.

The participants were asked whether they are aware of the term 'active aging' as well what active aging entails. Altogether, 77.1 percent of the participants admitted they had never heard the term 'active aging' and only 14% of the participants understood the concept of active aging.

Table 1. Perceived quality of life among participants (n = 532)

Dependent variable	Score	n (%)	n (%) or mean ± SD
1. Quality of life (QOL)	1	1 (0.2)	Poor QOL 143 (27.2)
	2	2 (0.4)	
	3	140 (26.6)	
	4	293 (55.6)	Good QOL 384 (72.8)
	5	91 (17.2)	
2. Health satisfaction	1	1 (0.2)	Dissatisfied with health 180 (34.2)
	2	11 (2.1)	
	3	168 (31.9)	
	4	296 (56.1)	Satisfied with health 347 (65.8)
	5	51 (9.7)	
3. Physical health domain			70.9 ± 12.2
4. Psychological domain			71.5 ± 11.8
5. Social relationships domain			74.4 ± 14.6
6. Environment domain			68.5 ± 12.0

Table 1 suggests 27.2 and 34.2 percent of the respondents self-reported a poor quality of life and health dissatisfaction. The mean and S.D. of the perceived quality of life in for domains were 70.9 (12.2), 71.5 (11.8), 74.4 (14.6) and 68.5 (12.0) for the physical health, psychological, social relationships and environment domains respectively.

Turning to health literacy, the majority of the participants (45.7%) had sufficient health literacy, 11.3 percent had excellent health literacy and the remainder had limited health literacy (8 percent inadequate and 35 percent problematic health literacy). There were positive and significant associations of health literacy with all six quality of life six outcomes. There is a significant discrepancy of health literacy status between the current study and findings from the Malaysia National Health and Morbidity Survey in 2015, which found only 6.6% of the study population had adequate health literacy

The result of the multivariable logistic regression analyses showed that sufficient health literacy (AOR 4.32, 95% CI 1.93, 9.67), and excellent health literacy (AOR 5.92, 95% CI 1.92, 18.23) were significantly associated with a perceived good quality of life. Similarly, sufficient health literacy (AOR 2.68, 95% CI 1.25, 5.76), and excellent health literacy (AOR 6.71, 95% CI 2.20, 20.49) were significantly associated with health satisfaction, when adjusted for other variables within the model.

The associations among health literacy and the four quality of life domains were identified via multiple linear regression analyses and presented in Table 2.

Table 2. Association of health literacy and four domains of quality of life

Health Literacy	**Physical health** (n=479) B (95% CI)	**Psychological health** (n=452) B (95% CI)	**Social relationships** (n=404) B (95% CI)	**Environment** (n=414) B (95% CI)
Sufficient vs Inadequate	3.18 (0.90, 5.46)**	4.02 (1.84, 6.19)***	5.48 (2.67, 8.29)***	5.61 (3.46, 7.76)***
Excellent vs Inadequate	4.88 (1.32, 4.83)**	7.29 (3.87, 10.71)***	7.39 (3.04, 11.74)**	10.28 (6.90, 13.66)***

B = Unstandardized coefficient; **p-value < 0.01, ***p-value < 0.001

4. A Summary of the Findings and Their Implications

The awareness of active aging is low among Malaysian public employees. While the topic of active aging frequently is discussed among Malaysian policy makers, the diffusion of this concept to citizens has not occurred. In fairness, Malaysia's population is younger than some nations, so the nation's future aging issues may have attracted the interest of the general population because of their indirect experience.

Based on analyses of the responses to the WHOQOL-BREF questionnaire, the quality of life among the study population was worrisome since 28% of participants perceived the quality life as poor and 34% were dissatisfied with their health.

Health literacy was found to be significantly associated with all six outcomes of quality of life. Health literacy was divided into four categories; inadequate was the lowest level of health literacy and excellent was the highest level. Compared to the inadequate health literacy group, the participants in the sufficient and excellent health literacy groups self-reported a good quality of life and were satisfied with their health status. Similarly, excellent and sufficient literacy resulted in a significantly higher mean score for self-reported quality of life in all four domains. Overall, these results suggest higher health literacy may impact the quality of life of Malaysia's older adults [14].

Health literacy levels among Malaysian adults were measured using the Newest Vital Sign tool (NVS) in the Malaysia National Health and Morbidity Survey in 2015. The NVS contains a specially designed ice cream nutritional label which tests functional health literacy. The NVS is designed as a quick screening test for limited health literacy among patients in primary care settings [15]. In contrast, the current study measured health literacy via the HLS-SF12 questionnaire, which is designed to assess the ability to access, understand, process, and use information relevant to health care, disease prevention, and health promotion [10]. While the NVS focuses on measuring individual skills and ability, the HLS-SF12 assesses the perceived difficulty of relevant health tasks. While both instruments are designed for general population research, the HLS-SF12 is a conceptually broader measure of health literacy. The latter may explain the differences in findings about health literacy among the survey respondents within the current and prior study. In terms of reliability, the findings about general population health literacy levels in the current study are similar to an assessment of Malaysia parents of adolescents, where HLS-EU-Q47 (an instrument similar to the HLS-SF12) was used [2].

Otherwise, the survey is among the first to focus on the quality of life of older Malaysians. The study provides a surrogate measure of the preconditions of aging actively. The findings also suggest an association among health literacy with the quality of life among older Malaysians.

In terms of limitations, the research utilizes a cross-sectional study design. Hence, it provides quantitative associations rather than an empirically grounded causal relationship between health literacy (exposure) and quality of life (outcome). The study involved only employees from the public sector that may not reflect Malaysia's broader middle-aged population. Although the findings from this study cannot be inferred to the employee population in Malaysia, its results are more generalizable to a non-professional group of public employees throughout the country.

Despite its limitations, this study provides an opportunity for future longitudinal studies to assess the changes in the quality of life of Malaysian adults who are more than 60 years old. Since the study's participants are public employees, it also may be easier to follow them in future longitudinal studies.

5. Possible sustainability

The authors suggest a similar study should be conducted in the private sector since 8.7 million persons are working in the formal private sector in Malaysia. It also would be beneficial if the study could be extended to self-employed population so a comprehensive picture of Malaysia's future older population can be obtained.

The development of a longitudinal study which include self-employed, public and private employee is recommended. The current cohort should be followed up at five-year intervals as they age. This approach would provide more robust evidence about the role of health literacy in the aging process of Malaysia's adult population. Since 43% of future older adults had limited health literacy, interventions to improve health literacy should be applied as part of a new Malaysian agenda to improve active aging.

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Health Literacy in Israel – From Measurement to Intervention: Two Case Studies

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Abstract. This report focuses on opportunities, challenges and outcomes of health literacy related interventions in Israel, based on health literacy measurement. The importance of a system's and community approaches are discussed, as is cultural appropriateness. Two case studies are highlighted – the first on childhood immunization and the second on self-management of chronic health situations. In the second example, a combination of community, media, digital, and face-to-face interventions comprise a broad approach to intervention. The impact and some findings are presented, including conclusions derived from each initiative.

Keywords. Health literacy, immunization, digital health literacy, vaccination, diabetes, chronic care, universal healthcare, health promotion

1. Introduction

Health literacy is directly related to both healthcare and public health and is operationally defined as: "the development of the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" [1].

The basic principles upon which health literacy is based long have been issues of concern in both patient care and public health within Israel's health system. As a country whose population is comprised of a cultural mosaic, the issue of cultural appropriateness and competence have been deeply rooted in health literacy interventions. In order to provide universal healthcare (which was sanctioned by the National Health Insurance Law of 1994), there is wide access to community, primary health care services. The latter provides a plethora of opportunities for local health literacy interventions. Finally, as Israel has, in the past decade, been coined a 'Start-up Nation,' digital health currently is at the forefront of health system innovation, which fosters the need to assess and promote digital health literacy, while ensuring existing health disparities are not exacerbated [2].

The initial health literacy research in Israel was underpinned by the Hebrew Health Literacy Test, which validated the S-TOEFL for local use [3]. The Media Health Literacy

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(MHL) model and test also was developed and validated among adolescents in Israel and predicted health risk behaviors and identified populations at risk for low MHL [4].

In addition, the Israel National Health Literacy Survey, based on the HLS-Euro Survey, suggested the country's population was 'likely sufficient' (69%). In contrast, the projected national problematic and inadequate health literacy was more than 30%. The association of health literacy with other social determinants of health – suggested by the Survey's findings – enabled comparisons with other countries in Europe and Asia, as well as the association of health literacy with Israel's quality of life [5-6]. Additional analysis of the data suggests individual locus-of control is associated with health literacy in Israel [7]. Concurrently, the scope of e-health literacy was assessed in Israel and validated compared to broader population health literacy [8].

Israel also has partnered with international stakeholders for strategic projects, such as the Diabetes Literacy Project supported by the European Commission, and the Health Literacy of Children and Adolescents (HLCA) project from Germany [9-10].

In addition to research findings derived from population measures of health literacy, Israel's other related activities include a range of interventions. In this report, the authors discuss the impact of health literacy interventions in Israel's public health and healthcare systems via two case studies. One case study assesses vaccine hesitancy and the other is a range of initiatives to promote type 2 diabetes patient self-management.

2. Case Study 1: Promoting Childhood Vaccination

2.1. Health Literacy, Vaccination, and Vaccination Hesitancy

Health literacy is generally associated with better health and health promoting behaviors, such as cancer screening, healthy eating, and other behaviors [11-14] Several studies suggest individuals with higher levels of health literacy also tend to have higher levels of vaccination coverage for themselves as well as their children [15].

More recently, however, the existence of pockets of Israeli parents that do not accept recommended vaccination schedules has risen; these parents report a 'vaccine hesitancy.' 'Vaccine hesitancy' is operationally defined as a situation in which parents decide to partially vaccinate their children. Among other decisions, parents may decide to permit their child to receive a portion of the recommended vaccines (while rejecting others), or delay the age of a child's immunization, or categorically refuse to participate. In addition, parents may comply with the entire recommended list of vaccinations, while expressing concern regarding immunization safety [16].

Ultimately, vaccine hesitancy increases the diseases preventable by vaccinations, such as measles, which fosters an increased need to understand why parents decide to diverge from medical recommendations and protocols [17]. From a public policy perspective, the maintenance of high levels of vaccine coverage (in Israel or other nations) is desirable because it averts a decline in herd immunity, which in turn prevents a reoccurrence of diseases that otherwise might be on the verge of extinction.

While many studies have associated factors such as individual knowledge, beliefs, and attitudes with vaccine compliance, these do not comprehensively explain the rise and persistence of vaccine hesitancy. Otherwise, the public decision-making regarding the uptake of vaccination is not straightforward, and the information needed to make informed decisions is complex. The comprehension of the illness and the vaccine requires functional literacy and numeracy skills as well as critical literacy and evaluation capabilities to seek accurate information, including the appropriate use of digital sources. The quantity of available health information (especially on the internet) increases the need for critical and evaluation health literacy skills, which potentially can challenge or promote more evidence-based vaccination decisions.

Meanwhile, health literacy could be one of the underlying variables that influences vaccine hesitancy, which correspondingly suggests the need for more in-depth study and analysis. In a systematic review, Lorini et.al. identified nine studies that assessed the relationships between vaccine hesitancy and health literacy [15]. All the identified studies were fairly recent (2008-2017), most were conducted in the U.S. (six), with only one study performed in a low-income country. Eight out of the nine studies were cross sectional, and only one was a prospective study. The studies assessed different aged populations and types of vaccines.

Most importantly, the studies' findings varied considerably. Some studies found a positive association between health literacy and vaccination, others found no association and some found a negative association. Despite this inconsistency, Lorini et. al. concluded "the relationship between health literacy and vaccinations seems to be driven by risk perceptions and by the likelihood of getting sick or suffering from complications in the short term. When these possibilities are high, health literacy positively predicts vaccination uptake; when they are low, health literacy negatively predicts vaccination uptake or shows no effect [15]."

2.2. A Study of Infant Vaccination and Health Literacy in Israel

The authors' Israel study may serve as a case study of parents' decision-making regarding vaccination of young children within a developed country with a good healthcare system, high life expectancy, and a highly educated population [16]. In an aforementioned study, the authors showed in Israel, general health literacy is high compared to other European countries, as 69% were found to have 'likely sufficient' health literacy [5]. Yet, health literacy in Israel is not automatically associated with desired health behaviors. Some of the results suggested Israelis with high levels of health literacy do not always choose to adopt behaviors that enhance better health or are consistent with the publicized goals of public health interventions.

To backup, Israel has a developed system of Mother and Child Health Clinics (MCHC). More than 95% of infants are registered at these clinics, so patient and treatment access to vaccination campaigns is higher than in some nations.

The authors' study was a stratified case-control study with a retrospective cohort. Participants were recruited from a sampling framework of infants born in 2009 and registered at the MCHCs, these were divided into two groups. The first group included children whose parents had not completed at least one of three childhood vaccinations by the age of two, these vaccines included: hepatitis B vaccination (HBV-3), diphtheria-tetanus, pertussis (DTaP-4), and vaccinations against mumps, measles and rubella (MMP-1). The second group was a control group that had received all these vaccines as recommended by age two.

Each group was randomly sampled and a telephone interview was conducted. In total, the authors interviewed n=422 parents whose infants were not fully vaccinated and n=309 parents whose infants were fully vaccinated. A questionnaire was developed that assessed health literacy based on a diabetes health literacy measure which was adapted to measure vaccine health literacy [18]. The measure included functional, communicative, and critical health literacy, which represent the three types of health literacy defined by Nutbeam [19]. In addition, the questionnaire included measures of participant knowledge, beliefs, and attitudes towards vaccinations and demographic characteristics.

The authors used path analysis to test a theoretical model. Overall, parents in the group that did not fully vaccinate their children were more likely to have a higher level of education and a higher income. While there was no difference in functional health literacy between the two groups of parents, communicative and critical health literacy were higher among parents in the group that did not fully vaccinate their children.

In the path analysis (taking into account all the variables associated with vaccinating the children) two pathways could be identified – a direct pathway between communicative health literacy and vaccinations, and an indirect pathway between functional and critical health literacy. There were some mediating variables, such as attitudes and the perceived reliability of informal sources regarding vaccines. For example, parents who did not comply with recommended childhood vaccinations tended to search for additional information on the internet and to base their decisions on this information.

It is possible that a high degree of functional health literacy provided Israeli parents with more access to multiple health information sources, which eclipsed the basic information that is often accessed. Yet, expanded access also fostered more exposure to the information opposing vaccinations, which could have influenced parental attitudes – and lead to a reduced compliance with the vaccination protocol.

Similarly, Meppelink et. al. suggest people with higher levels of health literacy are more prone to confirmation bias when looking for information on the internet [20]. Confirmation bias also suggests people who search for information on the internet will confirm their beliefs and attitudes and are less open to new ideas.

Although prior literature suggests critical health literacy is the most sophisticated level of health literacy, it is additionally possible that Israeli parents (with higher levels of critical health literacy) actively sought information about vaccinations and then, deliberately refrained from complying with a vaccination protocol [21]. A consequence of having a health-literate public is some of the population can display vaccine hesitancy and decide not to vaccinate their children – based on a perceived capability to make health decisions autonomously, albeit contrary to medical recommendations.

Overall, the authors did not find a positive association between knowledge and vaccinations, which suggests among the participants, knowledge seeking was not associated with compliance with vaccine recommendations. In fact, lower parental abilities to seek, understand and be critical about health information prompted higher levels of adherence to recommended vaccinations for infants.

Although improved health literacy may not have a similar effect on health behaviours among all populations, ages, and socio-economic levels, the findings call for further research to understand the exact pathway in which health literacy impacts behaviours. The findings additionally suggest the need to assess the degree health literacy is associated with numeracy, or the specific ability to distinguish the evidence basis of medical recommendations.

In addition, the study suggests high health literacy may not automatically foster public health compliance as people lose trust in medical recommendations and believe they can make their own health decisions, while simultaneously misunderstanding the validity of evidence-based health information.

2.3. Practical Implications for Applied Intervention

The implications of the latter study are important, as Israel, like many other Western countries, was recently challenged with a measles outbreak. In 2018, measles outbreaks occurred in areas where specific communities had not vaccinated their children, mainly due to either religious beliefs or, alternatively, as a result of vaccination opposition that permeated social media in secular, high socio-economic-status areas [22]. Intensive, culturally appropriate health education and promotion efforts were launched by Israel's Ministry of Health (MoH) in partnership with religious leaders, the HMOs/primary health care system, and medical professional organizations and the mass media. While the MoH declared the measles outbreak 'under control' weeks after the outbreak began, in the process, Israel's healthcare system became increasingly aware of the significance of reliable and appropriate sources of health information, as perceived by the public [23].

3. Case Study 2: Promoting Self-Management Among People with Chronic Disease

3.1. Background – The Scope of Chronic Disease in Israel

As in most Organisation for Economic Co-operation and Development (OECD) countries, Israel's prevalence of chronic disease is increasing, mainly due to rapid changes in lifestyles, and an increasingly aging population. Of greatest concern is Type 2 diabetes, which occurs among 9% of Israeli adults over the age of 18. Type 2 diabetes is higher among the Israeli Arab community and among adults from the Ethiopian immigrant community [24]. The aforementioned Israel National Health Literacy Survey suggests the lower the health literacy, the higher the prevalence of chronic disease. Hence, improving health literacy is a consideration in chronic disease prevention and health policy efforts as is empowering individual self-management [5].

3.2. Intervention Methods

The findings of a European study on Diabetes Literacy – in which Israel took part through Clalit Health Services (Israel's largest, non-profit, public healthcare institution) – suggested group, individual counselling, on-line, and peer counselling interventions could be effective for diabetes self-management (DSME) [25]. In turn, the latter study's conclusions fostered efforts to provide new diabetes self-management programs/interventions within diverse Israeli population settings. The following discussion introduces some recently implemented diabetes self-management interventions in Israel on a national and/or local or experimental basis. Since the research is in progress, only a few intervention outcome measures are provided. The programs within a large type 2 diabetes self-management initiative include: individual counseling/coaching; group workshops facilitated by interdisciplinary teams; peer education; digital information prescriptions; and grounded text messages.

3.2.1. Individual Counselling/Coaching – C.H.A.N.G.E.-D. (**C**oaching ***f***or Health and **N**ew **G**oals for **E**mpowerment)

Individual coaching and counseling are among several other promising methods to promote healthy lifestyles and self-care practices among people with type 2 diabetes. An intervention model to empower individuals through health literacy and health behavior change was developed by Clalit and implemented in Arab and Jewish communities in the north of Israel.

The objective was to assess an innovative communication program that promoted changes in lifestyle, medication adherence, and health outcomes. The study's population, a representative sample of n=502 Jewish and Arab adults with uncontrolled diabetes (type 2), was recruited from the primary care registry of Israel's largest health service organization. Fifteen health professionals were identified and trained in health coaching. They provided 20 coaching sessions for individuals and spouses/significant others. The primary conclusion from the feasibility study was the introduction of a health-promoting coach within a multiplicity of DSME methods offers promise to encourage people with chronic conditions to adopt health promoting behaviors.

3.2.2. Group Workshops Facilitated by Inter-Disciplinary Team

Israel's Ministry of Health has invested in diabetes coaching interventions for primary health care services since 2012. Patients with diabetes are invited to a six to eight weekly session workshops in which they receive instructions from an inter-disciplinary team composed of a physician, nurses, dieticians, physical education coach/physiotherapists, and social workers/psychologists. Workshops are available in Hebrew, Arabic, and Russian. Several thousand people annually participate in the program.

The initial evaluation data from Clalit Health Services suggests participation in the workshop is significantly associated with improved diabetes self-management and significantly improved glycemic control among the participants.

3.2.3. Peer Education

Part of a broad intervention program focuses on peer education and support, which are seen as effective strategies to enhance self-management among people with chronic conditions and more specifically for adults with diabetes [26-27]. The intervention's methods enable communication among the participants in equal terms and the sharing of valuable experience gained from everyday practice, which promotes empowerment and a sense of belonging to a common community.

A prototype, peer led program for people with diabetes was developed, piloted, and evaluated in the city of Ashdod in Israel. A 12-session program for peer leaders was developed by a multi-disciplinary health team along with a group of people with diabetes, followed by intense peer training and implementation among small groups of people with diabetes from Clalit's primary community clinics. Each group was facilitated by two peer leaders with diabetes, with supervision offered by a health behaviour specialist. The pilot included sessions on emotional coping with diabetes, nutrition, physical activity, self-care practices, organizing medication, communication with the health care team and accessing sources of information.

The findings from qualitative research methods suggested overall high satisfaction from participants in addition to a significantly improved sense of empowerment. The peer leaders additionally reported a high motivation to continue to contribute to the pilot months after the end of the intervention's initially predetermined closing date.

3.2.4. Digital Information Prescriptions

Information prescriptions for people with newly diagnosed diabetes also have been developed by Clalit, and automatically sent to an individual's home computer through e-mail. The information prescriptions contain information about self-care, demonstration and motivational videos, and modeling with regard to navigating the health care delivery system. In developing the special initiative, formative evaluation was conducted among providers and among people with diabetes. A subsequent applied evaluation is planned to assess the acceptability of the initiative and its contribution to patient self-management.

3.2.5. Text Messages Based on the Transtheoretical Model for Change

While text messages have been used to influence a variety of health behaviors, integrating text messages for people with diabetes (as an integral part of their primary health care) was seen by Clalit and colleagues as an especially desirable strategy to advance self-management [28]. Thus, Clalit partnered with *Otzma, a* non-governmental voluntary health organization, to develop and test a text message tool to promote healthy lifestyle and self-care among people with diabetes.

An original bank of 150 clear language messages was developed in Hebrew, based on the Transtheoretical Model for Behavior Change [29]. For each of the stages of change in the transtheoretical model, brief motivational messages were developed for the following topics: nutrition, physical activity, smoking cessation, adherence to medication, medical follow-up, and footcare. Following a needs evaluation for each participant, messages were sent daily in the first stage of the intervention period (three months), and every other day for the next three months. The intervention group (n=50) was compared to a control group (n=30), regarding health outcomes. The findings suggest the change in HbA1C measure for glycemic control was significantly better (p=.05) within the intervention compared to the control group.

4. Conclusions and Lessons Learned

The two provided case studies demonstrate the importance to assess health literacy as a strategy to address population health needs. While the impact of increased health literacy differ between the two case studies, each suggests there are important associations between population health literacy and health outcomes. In both cases, health literacy needs were taken into consideration to plan health education and health promotion interventions – acting locally and planning nationally. As evidenced in the case study to promote self-management among people with diabetes, diverse interventions are needed to address the complexity of the Israeli population and their health challenges. The results of the latter studies and initiatives will form a basis upon which a national action plan for Israel on health literacy will be developed, under the auspices of the National Council on Health Promotion of the Israel Ministry of Health. Overall, the lessons learned from Israel's current health literacy interventions hopefully will be helpful to decision-makers, practitioners, and researchers from around the globe, who seek to meet similar challenges in the public health and healthcare arenas.

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Summary and Comments About Section One

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Abstract: Section one addresses health literacy's capacity to foster progress in clinical care and public health. Section one (and this summary) are divided into five subsections: an introduction; health literacy interventions/activities and clinical practice; health literacy interventions/activities and public health; international health literacy activities; and a concluding discussion of health literacy's three current platforms and health literacy's distinctive impact on health.

1. Introduction

Section one addresses health literacy's capacity to foster progress in clinical care and public health. Section one (and this summary) are divided into five subsections: the current introduction; health literacy interventions/activities and clinical practice; health literacy interventions/activities and public health; international health literacy activities; and a concluding discussion of health literacy's three current platforms and health literacy's distinctive impact on health.

This summary thematically intersperses the section's eight reports and nine chapters. Throughout section one, the book's chapters are longer and often focus on research areas. Reports are shorter and provide specific examples of initiatives based on the broader issues discussed in chapters. Some reports cover a specific health literacy research project and some cover specific initiatives. Reports and chapters both address health literacy's impact on clinical care and public health. The summaries provided below follow the order of publication within section one.

2. Health Literacy Interventions/Activities and Clinical Practice

The second of section one's five subsections provides six chapters and one report about health literacy (HL) interventions/activities and clinical practice.

In a summary of research literature, O'Conor, Moore, and Wolf note the associations among health literacy measures on a range of individual health and health organizational outcomes [1].

O'Conor, Moore, and Wolf's review includes evidence of modest associations among: health literacy and clinical outcomes; health literacy and functional health outcomes; health literacy and knowledge; health literacy and self-management; health literacy and functional health outcomes; HL and clinical health outcomes; health literacy and preventive, routine, and urgent care use; as well as health literacy and mortality risk [1]. The authors' division into eight areas identifies the range of evidence that associates

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health literacy with clinical outcomes and health care utilization. The literature review's scope also focuses on five widely used HL instruments and includes research about the impact of health literacy levels on population health outcomes as well as HL intervention studies [1].

Regardless of the area of inquiry, O'Conor, Moore, and Wolf suggest the current depth of health literacy research varies and should be characterized as a mixed evidence-base [1]. Although O'Conor, Moore, and Wolf suggest the evidence about health literacy's therapeutic impact is expanding, there is insufficient corroboration to make unqualified assertions about the contributions of health literacy to improved individual health, disease outcomes, health prevention, improved health organizational utilization, and population health [1]. Instead, O'Conor, Moore, and Wolf's find limited health literacy is associated with poorer health-related knowledge, poorer overall health status, greater rates of urgent healthcare utilization and hospitalization, and higher mortality. The authors also suggest health literacy might be best described as one of the intermediate variables (among other health determinants) that impact individual health, clinical practice, and health care utilization [1].

Health literacy's more specific role as a potentially mediating or moderating factor in addressing health disparities is discussed in a chapter by Schillinger [2]. Schillinger reviews the research that addresses the relationships between limited health literacy and health disparities (from a population health perspective). Schillinger suggests limited health literacy may have a mediating influence on health disparities and health literacy may be a marker of health's social determinants. Schillinger provides some examples of successful health literacy interventions and suggests the latter are a viable approach to address community-based health disparities [2].

Schillinger also reviews some of the measurement challenges to assess the degree that limited health literacy is one among other social determinants of health, which include social-economic status and racial/ethnic health disparities.

Schillinger also proposes a health literacy-framed clinical interpersonal communication model. In addition, Schillinger provides a novel conceptual framework that encompasses clinical, institutional, and public health dimensions of health care delivery that is mindful of health literacy and health disparities.

Four other chapters (and one report) in the first subsection focus on health literacy's role to address specific clinical challenges. For example, Rickard and Hudson suggest health literacy research and practice interventions help U.S. health systems and clinics address the widely advanced quadruple aims to improve health care [3-5]. More specifically, Rikard and Hudson explain the extant evidence suggests health literacy interventions can: improve population health; enhance patient care experience (including care quality and satisfaction); reduce health care costs; and improve the professional life of health care providers, clinicians, and staff (which respectively represent the four aims) [3]. Similar to O'Conor, Moore, and Wolf, Rickard and Hudson find the evidence that health literacy favorably impacts all four aims is more promising than conclusive. Rickard and Hudson identify research gaps and suggest the importance of future research to better establish health literacy's contributions to improved clinical care [1,3].

Besides HL, Hudson and Rickard discuss some of the other barriers to address the quadruple aim in U.S. clinical settings include: a lack of price and quality transparency; no central health agency; a confusing system of reimbursement regulations; and ongoing legal challenges, such as litigation to block implementation of the Affordable Care Act [3].

In a chapter that expands on Rickard and Hudson's contribution, Andresen et al. provide examples of how health literacy interventions can be integrated into broad efforts to address the quadruple aim within clinical settings [6]. Andresen et al. specifically suggest a bidirectional health literate approach (as part of a clinical care continuum) may provide a foundation to address all four of the quadruple aims [6].

Andresen et al. explain a bidirectional health literate approach equally values a patient's and members of his/her health care team's understanding of perspectives, values, as well as contextual factors that are critical to the delivery of overall better care [6]. The authors outline the responsibilities of care teams, patients, and health care administration and discuss the importance to recognize the conceptual similarities between health literacy and patient activation efforts in medical centers. Andresen et al. identify a few of the clinical centers in the U.S. and other nations that have adapted this model of clinical care. Incidentally, there may be some synergy between Andresen et al.'s bidirectional health literate approach and the model of clinical communication that Schillinger proposes in his chapter [2,6].

In an example of a recent effort to address *one* of the quadruple aims (improving the quality of work and life for health care professionals), Parnell and Agris describe health literacy efforts with medical students in New York [7]. In their report, Parnell and Agris note provider burnout undermines the quality of work life for health care professionals with repercussions that impact the quality of patient care within some health care institutions [7]. Parnell and Agris conclude health literacy efforts for future health care providers may be part of initial efforts to build resilience to burnout and address health professional career satisfaction among younger health care professionals [7].

In one of two chapters that focus on the impact of health literacy interventions within a clinical specialty, Glick, Yin, and Dreyer note the influence of health literacy interventions within pediatrics [8]. Glick, Yin and Dreyer suggest health literacy initiatives have a role in pediatric injury prevention, such as choking, burns, firearm safety, water safety, and chemicals/matches within a child's reach [8]. They explain health literacy initiatives potentially address a range of health challenges for infants, toddlers, and adolescents, such as understanding nutrition and food labels, to tobacco, alcohol, and drug use; and physical activities [8]. Health literacy initiatives also are seen as useful to help mothers with prenatal screening; breastfeeding; obesogenic feeding behaviors; preparing for and responding to childhood behavioral problems; and understanding a family's medical insurance status [8].

Similarly, Horowitz et al. provide some evidence that health literacy interventions are a therapeutic tool to enhance pediatric and adult oral health [9]. Horowitz suggests health literacy interventions have a modifying impact on patient tooth and gum decay, periodontal diseases, and oral cancers [9].

Albeit in a more defined specialty context, Horowitz et al. reinforce O'Conor, Moore and Wolf's findings that -- as an intermediate variable -- health literacy has a modifying impact on individual health as well as clinical practice, and is linked to health organizational improvements [1,9].

3. Health Literacy Interventions/Activities and Public Health, Population Health

The third of section one's five subsections is divided into three reports and three chapters that explore: a) health literacy interventions in public health and b) efforts in Western Europe to measure population health literacy.

Two of the chapters and two of the reports in this subsection focus on health literacy-public health interventions in contrast to clinical medicine. One chapter focuses on Western European efforts to better assess population health literacy.

While Nutbeam and Muscat provide international examples of how health literacy interventions therapeutically impact clinical medicine, their chapter emphasizes research about health literacy and public health [10]. In turn, Nutbeam and Muscat describe health literacy research efforts in clinical settings and in community populations within several nations [10]. Nutbeam and Muscat suggest some of the lessons learned from international research and discuss some current knowledge gaps that provide potential careers for health literacy researchers on diverse continents [10].

Importantly, Nutbeam and Muscat suggest the evidence about HL's efficacy provided by health literacy researchers is not keeping pace with expectations of policy makers and front-line health professionals [10].

In an accompanying chapter, Baur also discusses health literacy initiatives in public health and explains HL's future adoption depends on a consensus about a HL definition; the development of multidimensional assessment tools; the consistent use of grounded psychometric methods; and regular use of underlying conceptual frameworks [11]. Baur proposes an epidemiology of health literacy approach is needed in the U.S. to provide a surveillance system and ongoing data needed for population health [11]. Baur suggests the HL epidemiological system would allow U.S. researchers and policymakers to track health literacy issues at the individual, provider, organization, and community levels [11]. The ensuing data could inform decisions about policies, programs, and interventions intended to deliver population health benefits [11].

Meanwhile, two reports about the impact of health literacy on public health illustrate the role of health literacy initiatives to improve health outcomes among vulnerable populations within two U.S. cities. Both reports suggest the role of health information technology tools to provide health literacy interventions. A third report in the second subsection suggests the role of health information technology tool to advance interest in the health literacy field among practitioners.

In a 12-year community engagement study, Willis et al. suggest health literacy related interventions therapeutically impacted the use of preventive health services among vulnerable populations [12]. Willis et al. explain a campaign with community participation yielded significant increases in child immunizations in Milwaukee, WI. Willis et al. also describe some advantages and challenges to use health information technology (such as internet-based health information services) as part of a community engagement, health literacy, preventive services project [12].

Similarly, Bakken and Arcia report community participation to create information visualizations of chronic disease seemed to be effective strategy to address varying health literacy levels among Latino populations in New York City [13]. Bakken and Arcia explain participatory design (with the project's participants) helped create appealing, engaging, and understandable health information regarding the prevention of chronic diseases. Specifically, Bakken and Arcia suggest the importance of participatory design in visualizations as part of initiatives to improve patient self-management and prevention of chronic diseases and life-style factors including: obesity; low levels of physical activity; diabetes; hypertension; and Alzheimer's Disease and related dementias [13]. More broadly, Bakken and Arcia note the importance of utilizing health information technology as part of health literacy initiatives to reduce health disparities within vulnerable, urban populations [13].

In the subsection's (and the book's) only manuscript devoted to an information technology tool, Osborne explains how podcasts identify leaders in the field of health literacy in order to inspire practitioners. In her report, Osborne suggests podcasts help health literacy researchers and practitioners by providing a convenient mass medium to keep people professionally engaged and au courant [14].

Meanwhile, one of the chapters in the third subsection focuses on recent efforts to better assess health literacy levels among general populations, or HL as a contributor to population health.

In a review of innovative efforts that originated in the European Union, Pelikan et al. describe the development of HLS-EU, which evolved to provide a generalizable baseline to assess population health literacy levels in multiple languages within diverse nations on four continents [15]. The authors provide an overview of the prior history and development of HLS-EU and its new successor, HLS19. Pelikan et al. note both the HLS-EU and HLS19 are comprehensive instruments designed to assess general population literacy as well as a more targeted array of behavioral attributes that have been associated with health literacy [15].

4. Health Literacy Initiatives in Six European Nations as well as Asia and the Middle East

The fourth subsection in section one contains four reports that summarize the impact of diverse health literacy initiatives in Europe, Asia, and the Middle East. Two reports focus on health literacy interventions in Austria, Denmark and the Netherlands. Two reports focus on diverse heath literacy interventions in Malaysia and Israel.

Dietscher et al. describe an array of health literacy activities in Austria, which include the creation of the Austrian Health Literacy Alliance [16]. Dietscher et al. explain the Austrian Health Literacy Alliance: administers a national strategy to improve health communication; sets 15 national criteria for quality health information; and establishes initiatives to improve the responsiveness of healthcare organizations to health literacy patient/caregiver needs [16]. Dietscher et al. also describe Austria's role in founding and coordinating the European Network on Measuring Population and Organizational Health Literacy (M-POHL).

Sorensen et al. note the development health literacy research and other efforts in Denmark and the Netherlands [17]. The report adds research and other HL activities are expanding in the Netherlands thanks to the Dutch Health Literacy Alliance, which is a network of organizations, institutions, companies, and individuals. Similarly, the authors report the growth of health literacy activities in Denmark has been influenced by the Danish Health Literacy Network [17]. The report also notes some differences in progress in support for HL research and initiatives within Denmark and the Netherlands [17].

While health literacy activities and research are just beginning in Malaysia, Su et al. describe a recent health literacy-oriented assessment of the health status of middle-aged, non-professional, public Malaysian employees [18]. Su et al. report the findings suggest most of the latter respondents were average to above average candidates for 'active aging,' or represented a potentially healthy cohort of senior citizens. The Malaysian respondents also self-reported a good quality of life and modest satisfaction with their current health status. However, Su et al. add their data suggest initiatives are needed to address persons with limited health literacy among Malaysia's middle-aged and senior populations [18].

A report by Levin-Zamir and Baron-Epel describes a range of Israeli health literacy activities including: a program to assist with childhood immunizations and a diverse intervention to improve patient self-management and glycemic control of type 2 diabetes [19]. Levin-Zamir and Baron-Epel note improved patient and public awareness impacted health outcomes in both cases [19].

In aggregate, the international projects described in the section's reports suggest recent health literacy initiatives have addressed patient challenges, population health, and public health issues. Moreover, section one and the rest of the book highlight health literacy initiatives on five continents.

5. Conclusion: Learning from Section One

The conclusion provides an overview of the section's primary lessons, discusses health literacy's three platforms of research and practice, and suggests HL's overall impact may stem from its distinctive characteristics including its importance as a social and a structural determinant of health.

First, section one's eight reports and nine chapters suggest health literacy research and practice is simultaneously diverse, vigorous, global, promising, and qualified.

The chapter by Pelikan and two reports from Su et al., and Dietscher et al. underscore informing interventions via population measures that assess the public's understanding of health and medicine on a national (or more generalizable) scale [15-16,18]. The demographic insights from the latter research provide a starting point to initiate improvements in the communication of health from providers to patients, health care institutions to patients, health care institutions to providers, and health care institutions and providers to health policy makers. Dietscher et al. note how the latter initiatives have occurred in Austria [16].

Further, some manuscripts suggest mounting but mixed evidence that health literacy interventions therapeutically impact specific areas of clinical practice, improve the utilization of the health care delivery system, and represent an appropriate strategy to address health disparities and improve public health [1-2,8-9,10-13]. For example, O'Conor, Moore, and Wolf explain extant research suggests health literacy interventions can favorably impact clinical outcomes and impact a more efficient patient utilization of the health care delivery system [1]. Their conclusions are reinforced partially by Glick, Yin, and Dreyer and Horowitz et al. within their chapters [8-9]. Focusing on HL and public health, Schillinger adds there is emerging evidence that health literacy is associated with other social determinants of health - and health literacy-based initiatives provide a viable strategy to address population health disparities [2].

Yet, O'Conor, Moore, and Wolf suggest health literacy is an intermediate variable that is difficult to empirically distinguish among the other intermediate variables which have been associated with health outcomes and health care utilization [1]. Schillinger explains it is difficult to answer whether HL has differential effects on health outcomes based on an individual's race, educational attainment, or other demographic characteristics often associated with the social determinants of health and health disparities [2]. Consequently, there seems to be insufficient extant evidence to assert health literacy is a uniquely robust variable, or a comparatively distinctive predictor of health outcomes and health care utilization as well as social determinants.

Several other chapters itemize some of the barriers to advance HL research including a lack of a consensus about a health literacy definition, one dimensional assessment tools, and research without an underlying conceptual framework [1-2,10]. In the editors' previous health literacy book, Nguyen et al. and Pleasant and Sorensen explained the field of health literacy is hampered by research methods that often are not undergirded by state-of-the-art psychometric properties [20-21]. Importantly, the latter deters the aggregation of findings within meta analyses and fosters uncertainty about the empirical reliability and validity of the field's major findings.

Nutbeam and Muscat add the ensuing uncertainty surrounding health literacy's empirical foundation may be testing the patience of providers and health policy makers, who have the capacity to advance HL and practice to address national health issues [10]. In turn, Nutbeam and Muscat (and a chapter from Smith and Carbone in section three of the book) suggest a sense of urgency for research that distinguishes the impact of HL on chronic and acute health outcomes as well as health care utilization - and identifies the comparative influence of HL (among health's other social determinants) [10,22]. Furthermore, Schillinger explains the research that the comparative influence of HL among health's other determinants is undergirded by confounds that may undermine the validity of the overall findings [2].

In aggregate, the implication is the field's momentum may be stalling and its disciplinary influence (as an epidemiological, evidence based clinical marker) may be in jeopardy even though health literacy research and practice is a nascent discipline.

However, the suggestion here is the discipline's operant conceptual expansion and its comparatively pragmatic utility within public health/clinical care research and practice may be as important to health literacy's future as the status of HL's predictive capacity as a health marker. Although it is important to identify barriers to quantitative progress, the book's chapters also indirectly suggest health literacy is conceptually expanding within three (maybe more) platforms that denotes conceptual progress within the field (even if two of the three platforms are not comparatively undergirded by an evidence base compared to the first). In addition, HL has unique and underappreciated attributes as a strategy to address diverse healthcare issues, which provides a bright future for researchers and practitioners.

Turning to HL's conceptual expansion, the chapters and reports in section one suggest the disciplinary scope of health literacy currently contain at least three different platforms of research and practice, which represent a notable, recent multidimensional conceptual expansion. Some of the research noted by O'Conor et al., Glick et al. and Horowitz et al. suggest a focus on the individual skills and capabilities needed to navigate the health care delivery system, use preventive services, reduce health risks, and improve specific health outcomes within HL research and practice, which are representative of the first platform [1,8-9]. Some of the research identified by Andresen et al. Rikard and Hudson, suggest an operant, second platform of health literacy research and practice focuses on the capabilities of health care institutions to adjust to the needs of patients, families, and providers [3,6]. A third HL platform, identified by Schillinger, partially envisions health literacy as a possible marker and strategy to advance social progress by helping to mediate health's social determinants and impact on health disparities [2].

The impetus of the first platform - that is based on how individual knowledge impacts outcomes and utilization in clinical practice settings - is associated (in several of the book's chapters) with a pioneering 2004 report about health literacy from the U.S. National Academies of Sciences, Engineering, and Medicine's health literacy roundtable [23]. The momentum for the second platform is associated (in several of the book's chapters) with a report from the U.S. Agency for Healthcare Research and Quality about the attributes of health literate organizations [1,3,5,10,24]. An inspiration for the third platform may be the World Health Organization's reports and declarations throughout the past four decades. which are detailed in a chapter from Pleasant, O'Leary, and Carmona in section three of the book [25].

Similarly, in the editors' 2017 HL book, Sorensen and Pleasant indirectly added current health literacy definitions are grounded in: an individual understanding of health; a health care institutional understanding of interpersonal and organizational health communication; and a broader understanding among all health stakeholders of the contributions of health literacy to address disparities and advance social progress [21].

To backup, it is important to appreciate the three aforementioned platforms as part of an expanding conceptual framework, which is proposed by Schillinger [2]. Schillinger's new conceptual framework incorporates all three platforms and augments them with clinical, institutional, and public health issues pertinent to health literacy and quality of care [2]. Although the first (individual skills/clinically based) platform can claim more seniority and a better-grounded evidence-base, Schillinger begs the broader question that the overall construct validity of health literacy should be perceived through a more multidimensional framework [2]. While the second and third platforms may not have an equivalent evidence base, they expand the conceptual frameworks under which HL researchers and practitioners seek to make disciplinary contributions and foster a broader construct with an improved chance of construct and face validity.

Elsewhere, the author previously noted one of the less appreciated attributes of health literacy is its triangular role as a predictor of individual health, as a health institutional (or structural) determinant of health, as well as a social determinant of health, which are incorporated (among other dimensions) within Schillinger's conceptual model [26, 2]. To reiterate here, health literacy is a rare construct and interventional variable that is flexibly applicable across the dimensions of health care and public health. In contrast, most structural determinants of health refer only to institutional care issues, and most social determinants of health do not directly refer to institutional/structural issues [26].

For example, the literature about health's social determinants, such as age, education, income, gender, race/ethnicity, employment, residential neighborhood environmental quality, parental educational levels, rarely purports these variables represent structural determinants of health. Similarly, the literature about the structural determinants of health, such as readmission rates, safety of care, hospital acquired conditions, rarely purports these variables represent social determinants of health. From a health intervention strategic perspective, most of the social and structural determinants of health often seem to be in separate lanes with little interactivity or cross-over capacity.

Hence, one of health literacy's core assets is it identifies a rare (albeit partial) marker across a spectrum of issues within health care delivery and care dimensions. One of health literacy's enduring characteristics seems to be its interoperability and efficiency as an indicator of health outcomes, health care utilization, improvements within the health care delivery system, and public health. Besides the extent of the evidence that associates health literacy with health outcomes, health care utilization and social determinants, HL's overall impact may its distinctive characteristic as a rare indicator and interventional variable that operates across the individual, structural, and social dimensions of health.

Health literacy's crossover characteristics especially stand out in the efficient planning of health interventions within health care institutions, as well as community settings – with Schillinger's caveats in mind [2]. Health literacy initiatives not only have the potential to address the social variables that undermine health, the same initiatives have the capacity to help health care institutions at all levels improve their quality of care and outcomes. In the U.S. and many nations, the need for health care institutions to demonstrate high quality medical services and the need for public health agencies to address social (or both) sometimes can be addressed simultaneously via thoughtful health literacy initiatives.

Moreover, the aforementioned three platforms of health literacy research and practice may not define the field's disciplinary boundaries. One of the current book's contributions is to identify health literacy role in interdisciplinary/multidisciplinary scholarship, which is further discussed in section three.

Yet, section one strongly suggests the vitality of the health literacy field and its potential for a wide range of research and practice interventions by researchers and practitioners. While there are mixed findings and important barriers to research progress, there are reasons for optimism about health literacy's crossover attributes and as a viable strategy for a range of efficient health care interventions.

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Section Two

Health Literacy Initiatives and Lessons Learned – from Diverse Health Care Stakeholders Initiatives and Lessons Learned – from Diverse Health Care Stakeholders

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Health Literacy in Clinical Practice and Public Health
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Health Literacy Research in Rural Areas

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Abstract. This report discusses successful approaches to conducting health literacy-directed studies with community clinics and agencies in rural areas of Louisiana. Some lessons learned from two studies in isolated rural areas with a history of health, educational, and economic disparities are presented. The first is a qualitative study eliciting patients', providers' and community members' understanding, access and acceptance of clincial trials. The second is an overview of health literacy interventions that build on each other to improve annual colorectal cancer screening in rural commuity clinics. The results suggest rural providers and patients are interested in participating in clinical trials. To increase participation in clinical trials in rural areas, academic researchers need to develop ongoing "bi-directional" working relationships with rural clinics and agencies. The support of primary care providers trusted by patients is essential. Plain language and culturally appropriate patient education material developed with the input of patients and providers and on-going telephone outreach are effective in increasing initial colon cancer screening among low-income rural patients. More intensive strategies are needed to sustain annual screening. Implementation of health literacy research strategies may help address barriers to understanding and access to appropriate studies and preventive health services.

Keywords. Health literacy, rural clinical trials, rural research disparities, rural colon cancer screening promotion.

1. Introduction

Disparities exist in recruitment, retention and trust in clinical trials among individuals with limited health literacy, low socioeconomic status, as well as those who belong to racial and ethnic minorities and people living in rural areas. Participation of underrepresented populations in clinical trials is critical to improvement of health outcomes, healthcare delivery, and scientific innovation [1]. Despite well-known health disparities in rural areas, few studies are conducted among rural populations [2-3]. In the past five years less than 3% of the National Cancer Institute's Cancer Control and Population Sciences trials have focused on rural populations [4]. The U.S. Department of Health and the U.S. National Institutes of Health are calling for health programs and research to address health care disparities in rural areas [4-6].

Rural residents suffer significant health inequities and encounter tangible and perceptual barriers to preventive services, health care, and health research which often

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are overlooked [7]. Rural adults tend to be older, poorer, under-insured and have lower literacy compared to adults in urban areas [8-10]. Individuals in rural areas also have higher rates of poor health behavior; they are more likely to smoke, have severe obesity, be physically inactive and are less likely be screened for colon or cervical cancer [11-12].

Systemic factors that contribute to increasing rural/ urban disparities in chronic illness and premature mortality include higher rural poverty rates across all races and ethnicities, distance to primary care, lower rates of preventive care, lack of public transportation, scarce community services, and persistent shortage of healthcare providers, particularly specialists [13-15, 9].

The greater understanding of barriers and facilitators of rural populations to participate in preventive care and clinical trials can better inform future studies [16-17, 3]. In looking at barriers though a health literacy lens, rural residents and providers have limited understanding and access to preventive services and medical research. The implementation of health literacy research strategies may help address barriers to understanding and access to appropriate studies and preventive health services.

The first study of two studies from the current authors illustrates a collaboration among rural and inner-city U.S. Federally Qualified Health Centers (FQHCs) and Council on Aging sites to assess the barriers and facilitators to rural population understanding, access and participation in clinical trials. The second study is a collaboration with rural FQHCs in a health literacy directed study to improve understanding, access, and completion of annual colorectal cancer screening.

2. Health Literacy Approaches to Establishing Collaboration in Rural Clinics and Agencies

In conducting studies in rural areas, it is important for urban-based academic researchers to establish relationships with rural clinic administrators, providers, and if appropriate, agency heads. The study protocol must be developed collaboratively, fit into the rural site's operational procedures and culture and be acceptable to administrators, providers and patients. The sites where we have found good partners are FQHCs and Council on Aging Agencies.

FQHCs are government-supported clinics with a mandate to provide primary care services to vulnerable populations (by socioeconomic status, racial/ethnic minorities) regardless of insurance status. These clinics are strategically located in areas designated as medically underserved by the U.S. Department of Health and Human Services. FQHCs currently serve more than 22 million low income individuals across the country [18]. The U.S. National Council on Aging is a nonprofit advocacy and service organization that partners with government and community organizations to improve the health and economic security of adults age 50 and over, 70% are women and three-fourths spend an average of three hours a week at a center. Currently, there are more than 11,000 sites throughout the US; by 2020 they will serve more than 10 million older adults [19].

3. Barriers and Facilitators to Participation in Clinical Trials

Diverse participation of underrepresented groups in clinical trials biobanks is needed to identify the most effective treatments for diverse groups [1]. A qualitative study (conducted by the authors to explore barriers and facilitators to enrolling underrepresented populations in clinical trials and biobanking) involved 19 focus groups and seven telephone interviews in urban and rural areas of Louisiana to: 1) identify awareness, understanding, trust acceptance and access to clinical trials and biobanking among minority and rural adults; and 2) elicit clear, culturally appropriate language and recruitment strategies [20]. Of 121 participants, 30 were safety-net healthcare providers, 28 were primary care or oncology clinic patients, and 58 were participants in Council on Aging, or social or faith-based groups. Patients and community participants were predominately female (92%) and members of racial and ethnic minority groups, 72% were African American, 11% Hispanic; 22% lived in rural areas. Louisiana (LA) is a state in the southern region of the U.S.

The barriers to participation in clinical trials identified in rural areas included: limited knowledge about clinical trials and biobanks; lack of information on appropriate studies; and access to participation [20]. Additional barriers included: lack of public transportation and inconvenience of getting to an urban academic center; as well as mistrust and privacy concerns about clinical trials and biobanking. Patients and community participants were concerned about who would see the information, how it would be used, and if the disclosure would impact health benefits or insurance. Few patients or Council on Aging participants also had been asked to participate in a clinical trial; rural providers and administrators did not have relationships with academic researchers; and no prior structure existed to include rural patients in appropriate trials.

Some facilitators included: participant altruism; high interest in medical research) particularly studies that might benefit them or their families); and increased awareness of medical research and genomic studies because of television advertising. Participants suggested they sought easy to understand, culturally appropriate information; local access to studies; and most importantly the input of a trusted provider. As some participants said, 'I always want to know what doc thinks.'

4. Suggestions for Clear Messages and Feasible Recruitment Strategies

Rural patients and Council on Aging participants did not understand the terms 'clinical trials', or 'biobanking.' They suggested using plain language terms such as *study or medical research. Participants said:' everyone understands what a study is.'*

Meanwhile, 'genomics' sounded intimidating, *scary*. To explain biobanking, participants suggested a concrete explicit explanation: '*your blood or tissue will be stored in a bank.*' Rural participants wanted to know where the bank was. Genomics researchers also were advised to limit detailed or scientific messages or materials and to provide brief, to-the-point explanation using everyday terms. Rural providers and patients liked the idea of a mobile health van that could come to their clinic for study visits. The providers felt this would improve access to trials and biobanking.

All rural primary care providers were interested in having clinical trial options available for their patients but said they did not have time to search for available trials. None of the participating primary care providers had looked for clinical trials appropriate for his or her patients on the internet. They also lacked relationships with academic physicians and researchers.

To increase the participation of rural and minority patients, providers suggested on site in-services or webinars to give them information about the clinical trials available for their patients and biobanking. For specific studies, they requested brief plain language information with talking points and a card they could give patients with a name and number to call for more information. Findings from this pilot study can help inform the development of education materials and strategies to increase participation of underrepresented groups in clinical trial and biobanking.

5. Improving Access, Understanding and Completion of Colonoscopy Screening Tests

Colorectal Cancer (CRC) mortality is 16% higher in rural areas than in cites [12, 21]. The disparity is largely because rural individuals are less likely to obtain CRC screening, which increases the time for diagnoses and treatment. A colonoscopy is not feasible in many rural areas because of a dearth of colonoscopy services and specialists [12]. Without insurance the cost of colonoscopy also would be prohibitive, which the case in Louisiana when these two studies were conducted. Also, during this time, rural FQHCs in LA did not use electronic health records. Below, the authors discuss two studies that built on each other to improve understanding, access, and use of annual colorectal cancer screening

The Health Literacy and Cancer Screening Project (National Cancer Institute R01*)* *(*n=961*)* and Interventions to Overcome Disparities in CRC Screening (American Cancer Society) (n=620) were randomized controlled trials conducted in predominantly rural FQHCs (n=10 Clinics). Most of the study participants were African Americans (66% and 67%) and 40% and 56% had low health literacy levels (reading below a night grade level) [22-25]. The baseline screening rates in rural clinics in both studies ranged from two to five percent.

6. Health Literacy Barriers and Facilitators Identified CRC Screening

At baseline in both studies, almost all rural patients suggested they had heard of CRC and the majority reported positive beliefs about CRC screening. More than 90% reported they would want to know if they had colon cancer [23, 24, 26-28]. Patients with low literacy were significantly less likely to know of CRC tests, believed it was helpful to find CRC early, and had completed a Fecal Occult Blood Test (FOBT). Of concern, the authors found two thirds of patients had never received a physician recommendation for CRC screening or been given an FOBT. At baseline, patients who reported they had been given an FOBT kit were significantly more likely to report they had previously completed CRC screening even after controlling for age, race, and literacy [27].

By using teach back in preliminary focus groups (to confirm patient understanding of FOBT test instructions and confidence in acting on these instructions), the authors quickly discovered most participants needed easier to read CRC materials, Fecal Immunochemical Test (FIT) instructions, and a confirmation of understanding. The current instructions for FIT and Colonoscopy tests were written on a 9th-10th grade level, were unnecessarily complicated and not formatted for reading ease [28]. In contrast, the simplified FIT screening instructions developed with rural patients were written on a fifth-grade level, were organized from the perspective of the patient, and formatted for reading ease.

7. Health Literacy Interventions to Overcome Disparities in CRC Screening

The first rural CRC study conducted by the authors was a three-arm strategy with patients randomized to: 1) enhanced usual care receiving a recommendation and a FOBT kit; 2) a literacy-directed arm that received literacy and culturally appropriate CRC education and simplified FOBT instructions, from a research assistant who used teach back to confirm understanding; and 3) a nurse arm that received the same literacy and culturally appropriate education and materials from a study nurse - and received a follow-up call from the nurse. Patients who received the simplified materials with teach back were more likely to complete the FIT. Year one FOBT screening rates respectively by arm were: 39%, 57% and 61% [24]. In year 2, when all patients were mailed a letter and a FOBT, rates dropped (14% in usual care; 19% with additional mailed simplified instructions only; and 31% with added nurse follow-up phone call [29]. The results suggest the literacy appropriate education was effective. Although a follow-up motivational call by the nurse was helpful, higher screening rates were not sustained. The strategy also was not cost effective because the nurse arm was expensive and not economically/logistically feasible for low income rural clinics.

The second study was designed based from findings and lessons learned from the first intervention. All the enrolled patients were given the FIT with simplified instructions as well as simplified face-to-face education and FIT instructions combined with teach back. In the second study, patients were randomized and received an automated follow-up call or a personal call if they did not return their FIT within a month - and again if they did not return the FIT in two months. Both calls were health literacy as well as culturally appropriate for low income rural patients.

Year one CRC completion rates were 67% for those receiving a personal call by a prevention counselor and 69% for those receiving an automated call [22]. In year two, where patients were mailed a letter and FIT kit, 39% of patients who received personal call and 38% who received an automated call completed screening. This indicated that a follow-up reminder call is helpful, and the cost-effective automated call was just as effective as a personal call to prompt both initial and repeat annual CRC screening. Repeat screening results indicated more effective cost-effective approaches are needed to sustain CRC screening in low income clinics.

These studies help inform what is feasible and effective in rural FQHCs and what is needed to improve initial and long-term screening rates. It also is feasible for a rural clinic staff member to work part time as a study screening coordinator. The research suggests rural clinical staff members are effective providers of patient health literate, appropriate education and, simplified test instructions with teach back. While the authors' health literacy education and materials and provision of FIT kits improved the initial CRC screening in low income rural patients, challenges remain in keeping patients activated for repeat follow-up annual tests.

8. Three Lessons Learned about Conducting Research in Rural FQHCs

- Providers and patients are interested in participating in clinical trials. To increase participation, academic researchers need to develop ongoing "bi-directional" working relationships with CEOs and medical and clerical staff. The support of a primary care physician is essential.
- Rural clinics. providers, and patients are more experienced with services rather than research. Hence, frequent on-site quality checks serve as a boost to confirm a clinic's adherence to a study protocol. Some attention to the service orientation of an entire clinic is essential to generate participation (and needs to be repeated annually with a briefing about the research's preliminary findings).
- The research needs to ideally benefit patients as well as clinic providers, administrators, and the researchers. Clinics, and if possible, study personal need to be incentivized or be clear about research benefits.

9. Recommendations

Academic researchers need to reach out to rural clinics and establish a trusting relationship. Studies need to be developed collaboratively with providers, patients, and researchers. To improve understanding and acceptance, rural patients and providers need to be involved in development of materials, messages, and education. The implementation of health literacy research strategies may help address unique barriers to understanding and access as well as the acceptance of preventive health services within rural areas.

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Health Literacy Initiatives and Lessons Learned with NGOs: Wisconsin Health Literacy

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Abstract. This report discusses necessary steps to help ensure successful community-based health literacy interventions using adult learning principles. Two workshop topics are covered: one on the flu and the other on the safe and effective use of opioids. Successful implementation includes conducting a needs assessment, developing project content, identifying target audiences, building strong community partners, implementing the workshops, and evaluating outcomes. The report also features the importance of patient-centered prescription medication labels to improve patient understanding, safety, and adherence. Results from a case study suggest redesigned labels that are patient-centered are easier to understand and improve adherence.

Keywords: Health literacy, community-based workshops, patient-centered labels, adherence, patient safety

1. Introduction

For more than 33 years, Wisconsin Literacy, Inc. (WLI) has provided services to its coalition of local literacy agencies, now n=75 throughout the state. WLI represents more than 17,000 adult learners and approximately 3,400 professionally trained volunteer/tutors and employed teachers.

WLI's work focuses on four areas: 1) building capacity of its member agencies; 2) advocating for literacy; 3) preparing adults in worker readiness and career pathways; and 4) improving how health information is communicated through its division, Wisconsin Health Literacy (WHL).

Wisconsin is located in the north central U.S. and has an increasingly demographically diverse population of about 5.8 million. The state contains a mix of rural, suburban, and urban geographic areas.

Wisconsin Health Literacy (WHL), was created in 2010 as a division of WLI with

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its own vision, mission, director, website, and social media presence. WHL's vision is for all people to understand health information and services, which is fulfilled by promoting clear communication among those who give and receive healthcare. WHL manages national health literacy summits, responds to requests for health literacy training for health care professionals, facilitates presentations, and directs health literacy interventions to support WLI member agencies' adult learners and other vulnerable populations.

WHL hosts a biennial Health Literacy Summit, which is considered one of the top national health literacy conferences in the U.S., and draws in expert speakers and attendees from all across the state, nation, and even internationally. Approximately 300 people attend. While topics are varied, they all focus on how the audience may better incorporate health literacy into their everyday communications. Past Summit support has been provided by public, private, and government funding.

WHL has established itself as the state's go-to resource regarding health literacy and as such, has provided several hundred presentations from either WHL's staff or the division's medical advisor, Paul Smith M.D. Long-standing organizational partnerships developed by WHL support its expertise and ability to accomplish complex health literacy projects with a broad reach.

One of WHL's areas of expertise is to promote proper medication use and patient understanding of a prescription label. WHL successfully implemented two phases of a Medication Label Project to develop patient-centered prescription medication labels. Currently, WHL is engaged in a third, three-year phase. The long-range goal of the Medication Label Project is for 20-25% of Wisconsin pharmacies to adopt more patient-centered prescription labels by December 2020.

Working closely with consumers and the community, WHL also has designed and implemented several health workshops on safe medication use, safe opioid use, the flu virus, and other topics to help adult learners, seniors, immigrants, refugees, and other vulnerable populations.

This report is divided into two sections that separately discuss WHL's aforementioned Medication Label Project and two of WHL's community-based workshops.

2. WHL's Community-based Workshops

This section provides two examples of WHL's community-based workshops: Let's Talk About the Flu and Let's Talk About Pain Medicines. Both community-based projects involve a one-hour hands-on workshop, which is provided to diverse populations. A workbook and incentives are provided to the participants. An instructor script was developed for the facilitator to follow. All workshop materials are written following health literacy principles so the participants can understand the information being provided [1].

More specifically, the Let's Talk About the Flu (LTAF) workshops focus on the following topics: defining the flu; tips for avoiding the spread of the flu; what to do if you do get the flu; and the importance of the flu vaccine. In contrast, the Let's Talk About Pain Medicines (LTAPM) project focuses on the safe and effective use of prescription opioids and addresses the following topics: identifying the differences between prescription opioid medicines and other pain medicines; how to safely store and get rid of unused medicines; how to read and understand label directions and special instructions that may come with opioid medication; understanding terms such as ‘tolerance,’ ‘dependence,’ and ‘addiction;’ understanding what naloxone can do to stop an overdose; and when it is advisable to call a pharmacist or provider.

In both types of community workshops, WHL strives to follow the same format from inception to completion. WHL suggests the following six steps help ensure successful programs: a needs assessment; developing project content; identifying target audiences; building strong community partners; implementing the workshops; and an outcomes evaluation. A brief introduction of the implementation of each step within the LTAF and LTAPM workshops is provided immediately below.

2.1. Needs Assessment

Wisconsin Health Literacy identifies the pressing health topics local communities seek to address as a prelude to develop content that eventually is delivered in an easy-to-understand format. For example, the cumulative rate of flu related hospitalizations has doubled in Wisconsin between 2014 and 2018 from 67.3 per 100,000 to 125.7 per 100,000 [2]. Regarding the opioid epidemic, in 2016, opioid overdoses accounted for more deaths (825) than car accidents in Wisconsin (600) [3]. In addition to researching diverse health topics, WHL collaborates with community partners to confirm if proposed topics match local concerns.

2.2. Develop Program Content

After completing a needs assessment, WHL’s staff assess and determine the most important topics that need to be covered. The staff works collaboratively with experts in the field, as well as with community members to create a programmatic focus. For example, in the Let’s Talk About Pain Medicines workshop, WHL’s medical advisor suggested a discussion about the definitions of the words ‘tolerance,’ ‘dependence,’ and ‘addiction’ because prior experience suggested some patients could not differentiate among these terms. For the LTAPM workshop, a pharmacist also reviewed the content for accuracy and clarity. At least one health professional reviews all WHL workshop materials prior to public release.

Health literacy principles also play a key role in developing materials to ensure participants can understand and act on the information [1]. These principles include: using adequate white space; photos that reinforce the message; larger font sizes; and writing materials in plain language.

Additionally, WHL’s experience suggests it is important to test workshop materials and related content with the target audience. In the LTAPM project, WHL staff planned to use a stock photo image within a workbook that illustrated a young adult looking at two prescription bottles. The photo was intended to convey a young woman who finds unused opioids at home and contemplates an inappropriate use. However, focus group testing found the photo suggested the medications were harmless. Based on the feedback, WHL switched images to communicate the intended message.

WHL also has learned to integrate adult learning principles to enhance audience participation throughout the workshop. For example, WHL uses cards in an interactive experience to discern how the participants review a workshop. The cards contain questions and answers and participants break into small groups in which one person reads the questions out loud and others decide if they wish to provide a consensus response.

In addition, WHL provides translated materials whenever possible. While WHL serves adults who speak diverse languages - and uses an interpreter in workshops if necessary - WHL has found the inclusion of translated materials is helpful. The latter can be challenging when a language is not commonly spoken or when participants, especially elderly refugees, do not know how to read and write in their native language. Still, the effort is a suggested strategy to foster understanding.

2.3. Identify the Target Audience

WHL identifies the target audience for a project after completing a needs assessment. Once a target audience is identified, it becomes vital to promote a workshop specifically for this group. To accomplish this, WHL relies on a strong network of community partnerships

2.4. Identify and Build Strong Community Partnerships

Although WHL's office is located in Madison, its reach is statewide. To provide outreach beyond its county, WHL uses statewide partnerships such as: literacy members; senior organizations; groups who serve English Language Learners; libraries; and places of worship. The latter organizations have established participants and members who provide a *de facto* cohort for recruitment. Both WHL and its partners find workshop participants learn best when they are in familiar, trusted settings.

In addition, WHL suggests providing a stipend to community partners. The stipend can be used to cover potential costs, such as staff time needed for recruiting, refreshments, and other potential costs. WHL also creates publicity, such as flyers and newsletter articles, to make it as easy as possible for community partners to promote workshops.

WHL also suggests it is important to be flexible and work within a community partner's organizational parameters. For example, sometimes partners like to host workshops in the evenings or on weekends, instead of during 9-5 work day hours. It additionally is important to follow through on all commitments to build and maintain a relationship, which enables future collaborations

2.5. Implementing the Workshop

A few days prior to the workshop date, WHL's staff confirm all logistics, such as the date, time, and anticipated number of participants. As with any presentation, the WHL staff, or a selected facilitator, practice the timing and delivery of presentations. WHL has developed a dedicated group of external facilitators, including local physicians, in different areas of Wisconsin.

WHL suggests facilitators need to be supported by: choosing nearby locations for workshops; following through on travel and presentation details; and ensuring a staff member from the partner organization can assist during the workshop. The latter person helps distribute and collect workshop materials, as well as assists those workshop attendees who have problems seeing or reading materials.

WHL also suggests incentives should be provided to participants to attend a workshop. For example, attendees to the Let's Talk About the Flu workshops received a coupon for a free flu vaccination at a chain of Wisconsin drug stores. At the Let's Talk About Pain Medicines workshops, participants receive a drug de-activation kit. As aforementioned, WHL provides a facilitator to assist with attendee comprehension and an interpreter is provided, if needed.

In addition, WHL suggests workshops should be maximally interactive and foster an atmosphere where participants feel valued, are welcome to ask questions, and make comments. WHL suggests the best way to foster an interactive experience is to greet all workshop participants with a smile when they first enter the meeting room. This simple act of kindness is widely appreciated - and it helps participants relax and better enjoy what they will learn at a workshop.

2.6. Outcomes Assessments

WHL evaluates all of its workshops (and other projects). In community workshops, anonymous pre-and post-tests assess participant knowledge gain, and quality control (i.e., Is WHL presenting the information in the best way so participants can understand the content?)

To facilitate a workshop assessment, WHL strives to write questions in plain language and revises any questions that confuse participants. Interestingly, it seems to help when a facilitator reads assessment questions to all attendees. The latter strategy is especially helpful when working with persons who are less familiar or learning the primary language used in the workshop. Hence in Wisconsin, the strategy is designed to reduce stigma and anxiety for English language learners and other adult learners.

3. Adopting Patient-Centered Prescription Medication Labels in Wisconsin (referred herein as the "Medication Label Project")

WHL's second project, referred to as the Medication Label Project, seeks to improve patient understanding of drug information.

The effort addresses an array of challenges for Wisconsin and American patients. For example, 7,000 Americans die annually from misunderstanding their prescription labels [4]. In the U.S. there also are 3.6 million hospital visits, 700,000 emergency room visits, and 117,000 hospitalizations annually due to injuries related to adverse drug events from medication misuse [5-6].

While prescription medication labels provide a potentially critical line of defense against medication errors and adverse drug events, current labels can employ complex language, provide unclear administration times, use small font sizes, and feature confusing layouts [6-11]. While prescription labels especially are confusing for persons with limited health literacy, a study suggests 46% of patients across all literacy levels misunderstood at least one medication dosage instruction [11].

Currently, there are no mandated standards for patient-centered prescription medication labels in the U.S. However, the United States Pharmacopeia (USP), an organization whose mission is "to improve global health through public standards and related programs that help ensure the quality, safety, and benefit of medicines and foods," has a set of evidence-based standards for patient-centered labels (USP Chapter 17 standards) [12].

The USP Chapter 17 standards couple instructions for use with other patient information. The standards suggest a patient's name, the medication's name, and its strength, as well as the directions for use, should be listed at the top of the label in a prominent position. The standards suggest the instructions for use should be written in plain language and formatted to improve readability. The standards also suggest information should be more specific than 'take twice daily,' which can be open to consumer interpretation. In addition, the standards encourage using a patient's preferred language when feasible and addressing visual impairment issues [12].

As mentioned, the USP's Chapter 17 standards are not mandatory. In fact, when one state (Utah's Board of Pharmacy) tried to standardize adoption, the Board chose voluntary compliance after membership resistance [13].

Following a more moderate path, WHL decided to encourage Wisconsin pharmacies to embrace the USP standards by using them to redesign prescription labels. The Medication Label Project was conceived in 2013 and is scheduled to end in 2020.

WHL's Medication Label Project is grounded in the Diffusion of Innovations Theory, which identifies and utilizes a few peer opinion leaders to overcome anticipated inertia and a resistance to change [14]. The goal is for sufficient Wisconsin pharmacies to reach a tipping point where the adoption of self-imposed patient-centered labels becomes a normative, statewide pharmacy best practice.

WHL's Medication Label Project has advanced through three separate phases, which are introduced immediately below.

3.1. Phase 1

The first of three phases began in 2014 and was funded by the Wisconsin Partnership Program at the University of Wisconsin-Madison. During this phase, WHL sought to explore the barriers and facilitators to implement USP's standards in Wisconsin. WHL staff interviewed pharmacists, pharmacy managers, physicians, and pharmacy software vendors in Wisconsin to determine if implementing the USP standards would be feasible. The findings from these interviews were encouraging. Although many interviewees were unaware of the USP standards, most were interested in implementing the standards after they learned about them.

The results led to the next phase of the project and were published in a white paper, 'Adopting an Easy-to-Read Medication Label in Wisconsin' [15].

3.2. Phase 2

The second phase began in 2016 and involved a two-year pilot project working with a select group of pharmacies to implement new labels using the USP Chapter 17 standards. WHL collaborated with the Medical College of Wisconsin with funding provided by the College's Advancing a Healthier Wisconsin Endowment. A WHL staff member worked directly with pharmacists to redesign the labels as part of this phase.

Since WHL perceived stakeholder input would be essential to ensure the success of the prescription labeling project, WHL created two advisory groups. The first, a Project Advisory Council, consisted of pharmacies, providers, researchers, and IT software specialists. The Council met quarterly to help guide the project. The second, a Patient Advisory Council, provided access for patient suggestions. The patient group also met quarterly to review materials and project activities to ensure they were easy for patients of all literacy levels to understand. The age, race, gender, geographic location, and literacy levels within the Patient Advisory Council were deliberately diverse.

To reinforce patient feedback, WHL initiated additional focus groups and added some interviews of Wisconsin adults who served as surrogate patients. WHL asked interviewees what they did and did not like about prescription labels and asked participants to review the label changes made by the pharmacists during the pilot phase of this project. In addition to providing feedback about the label redesign, some contributors provided occasional insights about counterproductive patient beliefs. For instance, some participants posited generic medicines were not as therapeutic as brand name medicines and therefore, were prescribed only for persons who were medically uninsured or living in poverty.

In Phase 2, WHL also sought input from members of the Pharmacy Society of Wisconsin, a statewide, professional pharmacy organization. Surveys were sent to these members to ascertain their awareness of USP standards. The results found while 59% of respondents were not familiar with the standards, 85% were in favor of adopting them after receiving an explanation about their use [16].

Finally, to seek other stakeholder input, WHL created an online survey called, 'Vote for Your Favorite Label.' The survey enabled participants to select a preference between two drug labels. Participants answered a few questions relating to a label and shared anecdotal comments about their experiences with prescription labels (or the experiences of their loved ones). Among the responses, one participant reported an elderly female relative swallowed three times the medication she was supposed to take after reading a prescription label that said, 'Take 1 ½ tablet twice a day.' While the relative was supposed to just take a ½ tablet twice a day, she thought the '1' in front of the '1/2' meant she should take 1.5 tablets twice a day.

Three pharmacy organizations in Wisconsin were recruited to participate in the second pilot. They included: a community pharmacy serving low income residents in city of Milwaukee; a pharmacy that served the southern and eastern parts of Wisconsin, and a university health system in south central Wisconsin. Due to ownership acquisitions and mergers at one of the pharmacy organizations, two additional pharmacies were formed and joined the project. Each pharmacy organization used a different software vendor which resulted in somewhat different processes to redesign the labels. The diversity among the pharmacies enriched the project and all participants agreed the effort was worthwhile and beneficial for patients. By the end of phase two, five pharmacy organizations with a total of approximately 67 pharmacies had redesigned their labels [16]. Hence, as a result of the second phase, about 1.8 million prescriptions with redesigned labels were dispensed annually in Wisconsin [16].

In addition to the 67 additional pharmacy sites implementing label changes, both patients and project-participant pharmacists completed post-implementation surveys. The patient surveys suggested participants overwhelmingly supported access to easy-to-read-and-understand prescription labels [16]. Most patients liked the redesigned labels better or at least as much as the previous labels [16]. Most patients added the redesigned labels were easier to understand [16]. Participants appreciated a larger font size and the placement of the most important information at the front and center of prescription medication labels [16].

The pharmacist and pharmacy staff surveys also were supportive. About 84% of respondents were aware of their pharmacy's label changes and anticipated that the improved labels would enhance patient adherence and yield fewer medication errors [16]. The pharmacy-derived surveys also suggested patients were perceived as more likely to benefit from the medications they are taking [16].

Although the clinical efficacy of patient-centered labels was not one of the project's outcome variables, the Medication Possession Ratio (MPR) of a group of de-identified pilot pharmacy patients was assessed. The MPR provides a way to determine adherence based on whether patients refill their prescriptions as they should. The results found MPR significantly improved for asthma medicines, blood pressure medicines, and birth control pills after the label redesign ($p<0.001$) [17].

3.3. Phase 3

The third phase of the Medication Label Project began in January 2018 and is scheduled to be completed in December 2020. Wisconsin Health Literacy will continue to recruit and partner with pharmacies across the state to implement patient-centered labels using the USP Chapter 17 standards. Similar to phase two, phase three is funded by an Advancing a Healthier Wisconsin endowment from the Medical College of Wisconsin.

Similar to phase two, phase three has a Project Advisory Council and Patient Advisory Group (made up of different members than phase two). Yet, in phase three, two advisory groups were added: an Academic Advisory Council, comprised of national experts who have engaged in research surrounding patient-centered labels, and a Sig Improvement Task Force (SITF).

A ‘sig’ is another name for directions for use on a prescription label, which phase two suggested can be a barrier to patient understanding. Improving a sig is a complex process because diverse stakeholders are involved such as: health care providers; pharmacists; pharmaceutical manufacturers; and software vendors [16]. The SITF attempts to reach a consensus and develop recommendations to help pharmacies improve their directions for use, which meet the USP standards.

As part of phase three, WHL will develop a set of resources for pharmacies who are interested in continuing to redesign their labels following the completion of the Medication Labeling project. These in-development resources include an Implementation Guide, translation resources, and a Label Champion Group, consisting of prior partner pharmacists who provide guidance and answer questions as new pharmacies redesign medication labels.

WHL is pleased with the national interest the latter resources received. The project team presented at various national conferences, including the North American Primary Care Research Group (NAPCRG) conference in Chicago in November 2018. The abstract of the latter presentation was selected as one of the conference committee’s top three submissions (out of 1,300). Subsequently, the presentation was selected for a 2018 NAPCRG Pearl Award. The Pearl Awards are selected each year by the Community Clinician Advisory Group and represent studies that potentially impact clinical practice.

WHL set its target goal of 25% of participating pharmacies in Wisconsin following the diffusion of innovation theory, hoping it will have signed up sufficient innovators, early adopters, and early majority to reach a tipping point where the label reaches a broader adoption by the late majority and laggards [14]. With more than a year left in Phase III, WHL already has almost 17% of Wisconsin pharmacies who have or are implementing the patient-centered labels and is on pace to surpass its goal by December 2020.

4. Conclusion

The common theme throughout all of WHL work is to know an audience and engage them in the development, from conception to completion, through post-completion to create meaningful, digestible, and actionable content. With strong community partners and engaged consumers, the label redesign initiatives have promoted changes among Wisconsin pharmacies and helped individuals better understand their health.

For practitioners, the implications of these two WHL activities include the importance of using community and other partners, as well as focus groups to help guide the projects. Additionally, when implementing community-based workshops, applying adult learning principles is crucial. For researchers, it would be of interest to study the long-term outcomes of these projects to see if there are associations (assessed pre-post interventions) among increased knowledge, changed behaviors, and/or improved health outcomes.

Overall, regional and local organizations across the United States are now, more than ever, in a strong position to launch and sustain health literacy interventions. There is broad professional development support within the field of health literacy through several different platforms, including Wisconsin Health Literacy, which have provided consultation, resource sharing, and training to organizations interested in advancing health literacy projects and coalitions within their own state, region, or organization. Professional communities of practice such as the International Health Literacy Association (IHLA), the Health Literacy Regional Network (HLRN), and the National Health Literacy Discussion listserv hosted by the Institute for Healthcare Advancement (IHA) each provide learning and networking opportunities for organizations to learn from the endeavors of others in the field and enjoy regular and frequent communication.

Adult literacy organizations that work as part of larger community collaborations (which address health, workforce development, and language learning for immigrants and refugees) also are well suited to share their teaching experiences, knowledge of adult learning theory, and their trusted relationships with local populations in need of services. Through community collaboration models, adult literacy organizations can help adult learners access, understand, communicate, and act on important health information and services. At the same time, these organizations can support new and sustained projects by partnering and seeking the financial support of local stakeholders vested in improving health outcomes within their communities.

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Building Health Literacy Coalitions and NGOs

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Abstract. This report describes several health literacy initiatives by non-governmental organizations (NGOs). Specifically, the authors discuss the vision, history, and establishment of the International Health Literacy Association and similar regional organizations, as examples of collaboration across professional and geographic boundaries to advance health literacy research and practice. The authors provide some observations to build future health literacy initiatives by NGOs around the world.

Keywords. Health literacy, health literacy organizations, health literacy collaborations

1. Background

Coalitions represent groups of people representing diverse organizations, factions, or constituencies who agree to work together in order to achieve a common goal. Coalitions are created and maintained to solve overarching problems identified by a broad range of stakeholders. A body of research called Coalition Action Theory characterizes coalition utility and how they mature in three phases: formation, maintenance, and institutionalization [1].

A partnership with multidisciplinary agencies and groups is crucial to the development, implementation, and maintenance of health literacy programs and can achieve more than any one individual organization alone. Learning, networking, and open communication are important features of effective collaborations. Other determinants of a coalition's success include motivation, capacity, barriers, and resources [2].

The International Health Literacy Associations (IHLA), Canadian Health Literacy and Patient Education Network (CHLPEN), Asian Health Literacy Association (AHLA), African Health Literacy Association (AfHLA), and the Georgia Alliance for Health Literacy (GAHL) represent a few examples of health literacy coalitions from around the

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world, which strive to promote public health and improve access to health information and quality healthcare. The latter non-governmental organizations (NGOs) will be discussed consecutively in this report.

2. The International Health Literacy Association (IHLA)

IHLA is a non-profit, member-based organization dedicated to the development of the health literacy field and those working to improve health and reduce health disparities. IHLA's mission is to promote health literate individuals, organizations, communities, and societies throughout the world. IHLA's website address is: http://www.i-hla.org

The organization serves members who identify themselves as health literacy professionals as well as those engaged in health literacy work representing diverse sectors, disciplines, and specialties. The growing numbers of health professionals and educators implementing health literacy practices (as well as clinician researchers, academic investigators, and students conducting health literacy research) create the need for a peer-mediated health literacy professional association. Although health literacy is emerging as a special interest within a range of health professional groups, a focused health literacy association is needed to self-determine professional norms, values, and perspectives. IHLA's members recognize an international, peer-run organization is essential to establish a recognized and flourishing field of health literacy research and practice.

IHLA was incorporated May 2017 and currently has more than 680 members from 64 countries. To date IHLA has accomplished the following:

- Formed an internationally representative advisory group
- Approved an organizational constitution and bylaws
- Incorporated in the U.S. as not-for-profit organization
- Created a website to share information and engage members
- Established a member data base and distributed a member newsletter
- Instituted globally representative Standing Committees tasked with shaping and running the organization
- Launched 14 member-initiated Interest Groups tasked with driving organizational content
- Announced and is in the process of planning the first IHLA Global Health Literacy Summit 2020 in Taiwan

3. Canadian Health Literacy and Patient Education Network (CHLPEN)

CHLPEN is an informal group that discusses health literacy initiatives and resources across Canada. CHLPEN was formed in 2012 with the goal of linking those involved in patient education and health literacy across Canada. Currently, there are more than 180 members. The group does not have a website.

In the time CHLPEN has been active, the key achievements of the group include:

- Linking health literacy practitioners and researchers across Canada. Healthcare in Canada is administered by province. CHLPEN helped create cross-provincial discussion among health literacy researchers and practitioners, which provided an important link between health literacy initiatives across the country.
- Promoting health literacy professional development. CHLPEN provides a venue to share upcoming educational initiatives, health literacy resources, calls for proposals, webinars, and other initiatives. CHLPEN is a unique cross-Canadian venue tied to health literacy that reaches both researchers and practitioners.
- Supporting Ontario-specific opportunities. CHLPEN has members across Canada, with the greatest number of members in Ontario. Through provincial partnerships with University Health Network (UHC), CHLPEN has offered a series of webinars on health-literacy related topics and a full-day gathering of health literacy practitioners from across the province.

4. African Health Literacy Association (AfHLA)

AfHLA was established on June 26, 2017 in Addis Ababa, Ethiopia. AfHLA has 116 members from 16 African countries.

Initially, health literacy in Africa was linked to broader national literacy movements, which promoted education and health in nations throughout the continent and was described as "health education meeting minimal standards for all school grade levels."

The understanding of health literacy has evolved from this initial concept. Despite differences among current definitions in African countries, health literacy is commonly envisioned as helping the public understand medical and public health information, which is seen to improve individual and public health.

Conceptually, African nations tend to gravitate towards a public health-oriented concept of health literacy instead of a focus on provider-patient interactions. African health literacy initiatives tend to be associated with community-based efforts that are supported by educational leaders, religious and independent charities, and government public health officials.

To date AfHLA has accomplished the following:

- Supported health literacy training with IHLA's assistance
- Advocated for health literacy improvements in several African nations
- Urged members to sign up for international listservs that provide health literacy information
- Created a plan to increase members from 16 to 200 and from 16 to 40 nations by the end of 2019
- Created teams to publish articles and support the publication of African-generated health literacy research and practice
- Has plans to host a regional conference in 2021
- Developed an AfHLA website to be launched by the end of 2019.

5. Asian Health Literacy Association (AHLA)

AHLA began in 2013 and is an independent, multinational, nongovernmental organization that seeks to support health literacy across Asia from research, educational, and policy perspectives. AHLA seeks to promote dialogue among researchers, public officials, health care organizations, as well as experts in health and education, corporations, and the mass media to encourage health literacy interventions in health educational and health services' settings. AHLA's website address is: https://www.ahla-asia.org

AHLA promotes health literacy as an effective approach to improve healthcare quality and reduce health disparities among communities, groups, and nations. AHLA seeks to improve health communication among patients, patient organizations, caregivers, health service providers, administrative agencies, policy makers, and media practitioners to promote health literacy, which results in more efficient health systems that help prevent clinical and public health risks.

AHLA's accomplishments to date include the following:

- AHLA will host its seventh annual international conference in 2019. The 2019 conference will be hosted by Thu Duc Hospital in Ho Chi Minh, Vietnam.
- Conference locations include: Vietnam, Taiwan, and Malaysia. Normally, more than 15 Asian countries participate in AHLA's annual meetings. AHLA Members include organizations from 22 nations.
- AHLA conference themes have included: health literacy and population health; health literacy and smart universal healthcare; health literacy and the quality of hospital services; health literacy and healthcare efficiency; health literacy and better health care. Conferences include presentations about health literacy research and professional practice.
- AHLA sponsors special health literacy programs where researchers and practitioners collaborate with the World Health Organization and work on Diabetes Literacy issues.
- AHLA is the co-sponsor of the initial IHLA Health Literacy Global Summit in Taiwan in fall 2020.
- AHLA's website provides links to health literacy publications from 12 different Asian nations

6. Georgia Alliance for Health Literacy (GAHL)

The Georgia Alliance for Health Literacy (GAHL) was initiated in October 2012, organizing small invitational meetings among representatives of healthcare payers, industry, research, and government. Within a year GAHL had adopted by-laws and elected officers. In the fall of 2014, GAHL incorporated as a not-for-profit organization and underwent a strategic planning process. GAHL is an all-volunteer organization located in the U.S. state of Georgia.

Unlike many state and local health literacy agencies, GAHL is not housed at a university or a health department, nor does it have any paid staff. Overall, GAHL is a true grass roots organization.

GAHL boasts an informal ‘membership’ roster of 120 diverse health and communication practitioners. Participants include an eclectic mix of public and hospital librarians, physician and nurse educators, health policy advocates, patient and caregiver navigators of various credentials, clinicians, health communicators, journalists, public health personnel, and researchers.

Sample activities and accomplishments of GAHL include the following:

- GAHL holds quarterly meetings that attract 30-40 attendees. Recent meeting themes addressed health literacy and adult basic education, health messaging for expectant mothers, and health literacy regarding adaptive technologies.
- GAHL educates the public about the importance of health literacy at community venues, such as book festivals and health fairs, and via workshops.
- GAHL campaigns to help patients optimize communication and comprehension during their medical appointments. Based on procedures developed through a NIH grant to the University of Georgia, GAHL created a “lunch and learn” workshop on patient question-asking.
- GAHL also campaigns to improve health literacy practices among providers and healthcare organizations. GAHL created a fact sheet about teach-back and distributed it to Georgia health professional educators and professional associations.
- Most recently, GAHL has devoted considerable energy to applying health literacy best practices to quelling the epidemic of opioid abuse in Georgia.

7. Lessons Learned

The collective experiences of the aforementioned health literacy organizations suggest at least ten observations, which are presented to assist similar health literacy coalitions thrive in the future. These observations are:

1. There are continents, regions, and nations throughout the world that may not have health literacy organizations. Although IHLA represents all geographic areas, local, national, and national organizations are catalysts for health literacy research and practice initiatives.
2. Health literacy research and practice occurs globally and thrives on collaboration and the diffusion of best practices and research findings. Professionals in nations where health literacy research is most established should engage in outreach efforts to encourage health literacy efforts in nations where health literacy research and practice is emerging.
3. It is important for health literacy organizations to be involved in setting professional standards and expectations for health literacy professionals, educators, and researchers.
4. While internet-based teleconferences help sustain regional and international health literacy organizations, it is important for members to meet periodically in person.
5. Health literacy organizations need to be mindful of the challenges to working across cultures and the need for translation into multiple languages. The current reliance on English and the lack of access to digital services and information in languages other than English is a barrier to dissemination and collaboration in some parts of the world.

6. A variety of sources is needed to raise the necessary funds for health literacy organizations to thrive. These sources include: private donations and contributions (including corporate and medical organizational grants); membership fees; government and non-governmental contracts and grants; other support from government and foundations; international aid; fee for services; and revenues from meetings.
7. It is important for health literacy organizations to collaborate with other international agencies and organizations that seek to improve public health and reduce health disparities. For example, AHLA has existing collaborations with the World Health Organization.
8. It is important for health literacy organizations to embrace the common standards and principles used by societies of health care professionals, which focus on educational values and professional development. Some common standards and principles include: professional ethics; conflict of interest; cultural competence; cultural inclusion; addressing health disparities; multicultural cooperation and engagement; peer review processes; data sharing; open access to health literacy literature and publication; providing access to clinical information and data; and outreach to communities, policy makers, patients/caregivers, providers, and other health care professionals.
9. It is important for health literacy organizations to raise the standards and practices of health literacy practitioners and researchers, to educate members about best practices, and engage in the timely diffusion of professional information.
10. Building coalitions among like-minded service organizations, governmental agencies, and healthcare providers is critical and must include community-based organizations to ensure that health literacy services and advocacy reach the people most in need.

Finally, health literacy organizations would benefit from following the aforementioned principles of coalition building: optimal inclusion of members and ideas; respect for differing opinions and values; consistent efforts to support multicultural dialogue about health literacy; and support for health literacy's diffusion across multidisciplinary domains including public health, clinical practice, health communication, and other related areas.

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The Universal Patient Language: A Set of Resources and Tools to Design Patient Communications That Support Better Health Literacy

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Abstract. Recently, pharmaceutical companies have increased their focus on engaging with patients, following trends toward patient centricity and delivering services around individual drugs. Meanwhile, the U.S. Food and Drug Administration has released draft guidance on disclosing risk information in consumer-directed materials that recommends against verbatim presentations of the risk-related sections within prescribing information, as this may be of limited value to consumers who lack medical or scientific training.

In this context, Bristol-Myers Squibb set out to build an organizational capability to communicate complex health topics to patients called the *Universal Patient Language*™, or UPL. In this report, the authors explore health literacy considerations within the pharmaceutical industry; introduce the UPL; explain how human-centered service design methods were deployed to build the UPL; and present two UPL case studies.

Keywords. Health care communications, health literacy, human-centered design, patient communications, service design, Universal Patient Language, UPL

1. Introduction

Historically, the U.S. pharmaceutical industry did not focus on communicating with patients; the industry status quo emphasized prescribers as key customers [1]. Since the industry's primary audience usually was highly trained medical professionals, a concern for health literacy was not normative. In fact, the U.S. Food and Drug Administration (FDA) once noted that drug advertisements aimed at patients typically re-used information originally written for health care providers [2].

More recently, pharmaceutical companies have expanded their focus to include patient communications, following a broad trend toward patient centricity [3]. Simultaneously, there has been an increased emphasis on going 'beyond the pill' as the industry looks at delivering services around individual drugs [4]. Meanwhile, the FDA

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has released draft guidance for the U.S. pharmaceutical industry on disclosing risk information in consumer-directed materials. The FDA's 2015 draft guidance states ('PI' refers to prescribing information or a drug label):

> FDA strongly recommends against the use of the traditional approach to fulfill the brief summary requirement in consumer-directed advertisements, an approach in which risk-related sections of the PI are presented verbatim, often in small font. Because the target audience of the PI is health care providers, it is written in highly technical medical terminology, which is potentially of limited value to consumers who may not have the medical or scientific background to understand this information [5].

Within this context, Bristol-Myers Squibb (BMS) set out to build an organizational capability to communicate complex health topics to patients - going above and beyond industry standards. The capability came to be known as the *Universal Patient Language*™, or UPL. In this report, the authors will:

- explore health literacy considerations within the pharmaceutical industry;
- introduce the components of the UPL;
- explain how human-centered service design methods of co-creation, prototyping, and systems thinking were deployed to build the UPL; and
- present two UPL case studies and their outcomes.

2. Health Literacy and Patient Communications in the Pharmaceutical Industry

Similar to all pharmaceutical companies, BMS regularly produces communications about complex healthcare topics for lay audiences. Given modern advances in medical science, these communications may seem complex, especially for audiences who lack specialist medical training. Broad, society-wide trends toward patient-centered care and the availability of information online means patients often attempt to parse this information independently, in addition to consulting with their healthcare teams. Unfortunately, patients with limited levels of health literacy may struggle with comprehension, and low health literacy levels are associated with poor health outcomes. Only 12% of adults in the U.S. have proficient health literacy levels, and even patients with high levels of health literacy sometimes find health information overwhelming [6-7].

2.1 What BMS Learned in Co-Design Sessions

In co-design sessions focused on clinical trials, BMS learned prospective study participants sometimes conflated a clinical trial treatment with an approved one and might be unaware that a study drug's efficacy could be an open question. Thus, BMS realized the company needed to be more mindful of health literacy when considering what information should be included in informed consent forms. Before BMS could tackle explaining more sophisticated topics like trial design or the risks of participating in a specific trial, the organization needed to explain the concept of a clinical trial more generally.

Similarly, in co-design sessions focused on drug safety information, BMS asked patients what they understood from traditional presentations of the data, which typically list common side effects with no information about how frequently side effects were observed in clinical trials. While many patients assumed side effects were seen in more than half of clinical trial participants, in most cases the actual incidence was substantially lower - under 10%. As a result, BMS learned, by including natural frequencies or percentages relating to side effects (when available), a revised disclosure could help patients better understand risks. Of course, in providing percentages BMS assumed a certain level of reader numeracy, so BMS needed to know how to present numerical data in a way that would be more easily understood by patients and their caregivers.

2.2 Regulatory Considerations

As a manufacturer of medicines, BMS also is heavily regulated regarding its public communications in the U.S. For instance, when communicating about approved drugs, BMS has a responsibility to stay within the approved prescribing information (PI), sometimes referred to as the label [8]. Labels are sophisticated, negotiated documents based on the results of complex trials. Although they are not written for the layperson, labels nonetheless capture information that patients want and need to know, such as the risks and benefits of a therapy [9]. BMS's challenge is to give patients the general background information to help them understand its products while clarifying the relatively narrow indications outlined in the drug's label.

When considering communications in research and development, it is important to recognize a clinical trial often is not a static, centrally controlled process. For example, clinical trials conducted by BMS will update informed consent forms throughout the study as new risks are uncovered or new samples need to be collected. Meanwhile, a BMS trial might be recruiting and obtaining consent from participants at hundreds of sites around the world, each with a separate ethical review process, required language, standards, and constraints. Hence, for BMS as a manufacturer, being mindful of health literacy in clinical trial communications is a matter of creating documents that are easier to understand and collaborating with other study sites to offer tools and templates that may help others improve and create consistency across their communications materials.

While informed consent and drug safety information provide only two examples, overall, BMS must be mindful of health literacy whenever it communicates with patients and caregivers about its medicine - whether while a drug is still in development, through promotional materials on a product website, over the phone in a patient support program, or in a printed brochure providing education on a broader disease state. Consequently, BMS decided to invest in an organizational capability to help employees communicate about complex topics to patients. The project was dubbed the *Universal Patient Language*™, or UPL.

3. The *Universal Patient Language*™

BMS's Universal Patient Language (UPL) is a set of tools and resources that provide guidance on communicating with patients. The UPL is not designed for use by patients—rather, the target users are people who create patient communications, whether they are marketers, clinical scientists, or others who produce information for patients. The UPL has three broad components: **principles**, **tools**, and **stewardship (Figure 1).**

Figure 1. Components of the UPL

3.1 Principles

The principles provide overarching guidance, distilling the UPL down to seven foundational imperatives to create patient communications:

1. **Enable Patient Learning**: Equip patients with the knowledge they need to understand complex topics.
2. **Share Qualified, Quantified Data**: Present complete, relevant, and unbiased data in context.
3. **Design for Digital First**: Consider how patients want to navigate and engage with information.
4. **Demonstrate Empathy for Patients and Caregivers**: Acknowledge the experiences of patients and their caregivers and establish an emotional connection.
5. **Use Plain Language**: Explain complex topics in a straightforward and accurate way.
6. **Communicate Visually**: Visualize complex information to make it more digestible.
7. **Format Materials for Understanding**: Design layouts that are purposeful and can be easily navigated.

3.2 Tools

The UPL's tools are used to apply the guiding principles in the tactical creation of communications. The toolset is extensive and diverse, encompassing guidance documents with tips and suggestions to apply UPL principles; build assets that can be used directly to make materials; and provide assessment tools to help people evaluate their communications. Some tools are quite specific to the work BMS does, such as templates for informed consent forms and drug safety information. Others are more generally applicable to anyone who creates patient communications. The toolset includes:

- A **graphic assets library** that provides a starting collection of visuals that can be reused to support and strengthen patient understanding
- The **UPL rules**, which provide detailed guidance on how each of the principles can be applied in practice

- A **style guide** that offers detailed guidance on a UPL "look and feel," covering everything from size of type and layout to the style of visuals and writing tone
- A collection of **thought starters** that outlines key challenges and evidence regarding how to explain diverse healthcare topics such as biological processes, data, and even health-related financial information
- A **reflection guide** that provides questions that can be used to self-assess how well a finished communication aligns with UPL principles
- A **patient impact measurement framework** that provides initial guidance on testing the effectiveness of a communication created by following the UPL.

3.3. Stewardship

Of course, in any large organization, it would be insufficient to simply create the aforementioned resources. In turn, BMS invested significant effort in creating supporting materials to help its employees find, use, and update the UPL. Several UPL training courses have been delivered internally at BMS for different audiences, from legal and regulatory teams, to marketers, to the company's advertising agency partners. The learning objectives of each course are tailored to different audiences at BMS according to role. There also is a digital repository for the UPL itself, and 'case files' showcase both final deliverables and interim work products from internal UPL projects.

In sum, the UPL is a rich repository of resources related to patient communications, ranging from the high level (principles), to the tactical (images that can be copied and pasted), to the pedagogical (hands-on training). How BMS developed the UPL materials and assessed their effectiveness is explained in the next section.

4. Building the UPL with Human-Centered Service Design

From the outset, BMS used human-centered service design to build the UPL. As with any human-centered design project, this meant that understanding and designing for people's unmet needs was of paramount importance. However, since the UPL project was grounded in a *service* paradigm, the lens was wider. BMS considered how BMS and its patients fit into the broader healthcare ecosystem and how they participate in interactions in which complex healthcare information is communicated.

Tactically, BMS used three specific service design methods to build the Universal Patient Language: systems thinking; co-creation; and prototyping.

4.1 Systems Thinking

Patients do not encounter BMS's communications in a vacuum. Doctors, nurses, and other allied health professionals all have important roles to play, alongside patients, caregivers, and other stakeholders, such as clinical trial coordinators and health insurers. BMS sought contributions from all of these perspectives. During the five years BMS developed and grew the UPL, it engaged with 161 healthcare providers (physicians, nurses, pharmacists), 233 patients, 81 caregivers, and 79 other stakeholders representing everyone from social workers and pharmacists to advocacy groups and insurance companies.

After exposure to these diverse perspectives, BMS began to perceive patient experience and communication more multidimensionally. For instance, regarding drug safety information, different information is more or less relevant depending on where patients are in their health journey. If a patient is working with their healthcare team to decide on a treatment option, the risks of side effects may be more salient. Yet, if a patient is already taking the medication, he or she might be more aware of foods or other medicines that are contraindicated. Thinking about drug communication as part of a system with many players enables BMS to include features in its design that otherwise might not have come to mind.

Finally, BMS also wanted to seek other external perspectives and have them inform its work. Specifically, BMS wanted to leverage best practices and established expertise in communicating about complex medical topics. For this, BMS turned to experts in biomedical communications and medical illustration.

The Association of Medical Illustrators (AMI) was founded in 1945; its mission is to "further the use of visual media to advance life sciences, medicine, and healthcare through a worldwide network of specialized interdisciplinary professionals" [10]. BMS welcomed multiple AMI members to UPL co-design sessions so that they could inform its work with their expertise in areas like risk communication, data visualization, and use of plain language. In addition, all of BMS's UPL communications were created by individuals with graduate degrees in biomedical communications -- trained in both medical science and visual design. Their skill and expertise, combined with the perspectives of patients, caregivers, doctors, nurses, and other stakeholders, were integral to UPL's development.

4.2 Co-creation

The entire UPL was co-created in 29 hands-on design sessions with the stakeholders outlined above. In recent years, 'co-creation' and 'co-design' have become buzzwords, meaning different things to diverse people. BMS's approach was different from a focus group (where most of the time is spent talking) or market testing (where participants are asked to provide opinions on a handful of completed options). Instead, BMS's co-creation sessions typically lasted about eight hours over two days. With the support of design facilitators, participants collaborated on curated, hands-on activities to build prototypes of new communications that addressed priorities.

Crucially, a variety of BMS participants also played an active role in building these prototypes. Thus, the sessions were not an exercise in producing a platonic ideal from the patients' perspective. Rather, co-creation was a pragmatic, iterative process to find the sweet spot where the prototypes were achieving BMS's business objectives (including legal and regulatory compliance) while also addressing the unmet needs of a variety of stakeholders: patients, caregivers, physicians, and extended healthcare teams.

4.3 Prototyping

Traditionally, prototyping is associated with large-scale industrial design. For example, an auto manufacturer or aerospace company builds a series of new car or aircraft prototypes prior to mass production. While it might seem strange to think of prototyping within the context of patient communications, BMS suggests the same principles apply.

Especially in the pharmaceutical industry where there is significant administrative overhead with every publicly released communication, prototyping enables BMS to explore many more ideas and see which ones will resonate with patients. In fact, during the course of its UPL work, BMS produced hundreds of prototypes, ranging from large-scale ones built in co-creation with markers, glue, and scissors to more refined prototypes that were validated with patients in one-on-one feedback sessions. The process of soliciting feedback on prototypes for further iteration provided BMS with thousands of opportunities to understand patient perspectives and incorporate them into finished materials.

BMS's prototyping mindset extended beyond the creation of individual patient materials to how BMS created and improved the UPL. Hypothetically, a straightforward way to craft the UPL would be initially to invest significant time to build the principles, tools, and training, and then to use these resources to create BMS's patient communications. However, BMS took a prototyping approach and flipped the order of operations upside down.

BMS spent about a month co-creating an initial prototype of the UPL principles with a diverse set of subject matter experts both inside and outside BMS. With those principles in hand, BMS immediately turned its attention to individual patient communications, beginning with drug safety information. Day-to-day, BMS's focus was on a specific patient communication with a specific purpose. Then, periodically, BMS would step back and generalize its findings, creating new UPL tools and refining existing ones based on what worked in practice. This explains why BMS refers to the UPL as a living prototype - always ready, never finished. Each time BMS builds a new patient communication, it learns something new that can be used to further refine the UPL's resources. Hence, the UPL's resources become a distillation of the lessons learned from co-design with patients, caregivers, doctors, nurses, and other stakeholders.

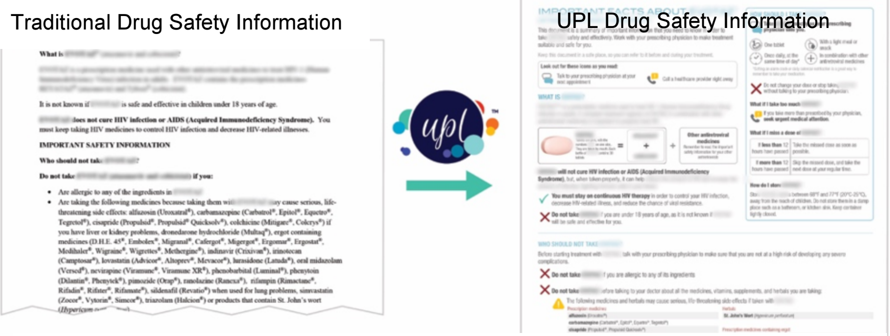
To put this another way, BMS's confidence in the UPL and its constituent resources is driven by the quantity and quality of interactions BMS experienced with people representing many diverse perspectives in healthcare. It also is grounded in real communication pieces that both leverage and inform the UPL.

5. Applying the UPL to Patient Communications

Overall, BMS has undertaken more than 25 UPL projects, resulting in dozens of new patient-facing materials, ranging from brochures to websites to call center scripts. BMS has applied the UPL to a broad array of topics, including clinical trials, drug safety information, how a drug works, health insurance, and broad disease-state education that is not tied to any one product.

UPL's first application was to redesign how BMS communicates drug safety information. Before and during treatment, patients need to understand the treatment's risks, benefits, drug interactions, as well as other important information on how to take the medicine. Traditionally, drug safety information is developed within a fixed, text-only template working within specific FDA guidance. The goal was to redesign drug safety information to make it more inviting for patients to read and potentially easier to understand. Drug safety information was particularly attractive to address and envisage because once approved it is reused in a variety of contexts.

Looking at the traditional drug safety information compared to the UPL version, the contrast is striking **(Figure 2)**.



Traditional Drug Safety Information

What is [redacted]**?**

[redacted]

It is not known if [redacted] is safe and effective in children under 18 years of age.

[redacted] **does not cure HIV infection or AIDS (Acquired Immunodeficiency Syndrome).** You must keep taking HIV medicines to control HIV infection and decrease HIV-related illnesses.

IMPORTANT SAFETY INFORMATION

Who should not tak[redacted]**?**

Do not take [redacted] **if you:**

- Are allergic to any of the ingredients in [redacted]
- Are taking the following medicines because taking them wi[redacted]ay cause serious, life-threatening side effects: alfazosin (Uroxatral®), carbamazepine (Carbatrol®, Epitol®, Equetro®, Tegretol®), cisapride (Propulsid®, Propulsid® Quicksolv®), colchicine (Mitigare®, Colcrys®) if you have liver or kidney problems, dronedarone hydrochloride (Multaq®), ergot containing medicines (D.H.E. 45®, Embolex®, Migranal®, Cafergot®, Migergot®, Ergomar®, Ergostat®, Medihaler®, Wigraine®, Wigrettes®, Methergine®), indinavir (Crixivan®), irinotecan (Camptosar®), lovastatin (Advicor®, Altoprev®, Mevacor®), lurasidone (Latuda®), oral midazolam (Versed®), nevirapine (Viramune®, Viramune XR®), phenobarbital (Luminal®), phenytoin (Dilantin®, Phenytek®), pimozide (Orap®), ranolazine (Ranexa®), rifampin (Rimactane®, Rifadin®, Rifater®, Rifamate®), sildenafil (Revatio®) when used for lung problems, simvastatin (Zocor®, Vytorin®, Simcor®), triazolam (Halcion®) or products that contain St. John's wort (*Hypericum*

UPL Drug Safety Information

Figure 2. Traditional drug safety information vs UPL drug safety information

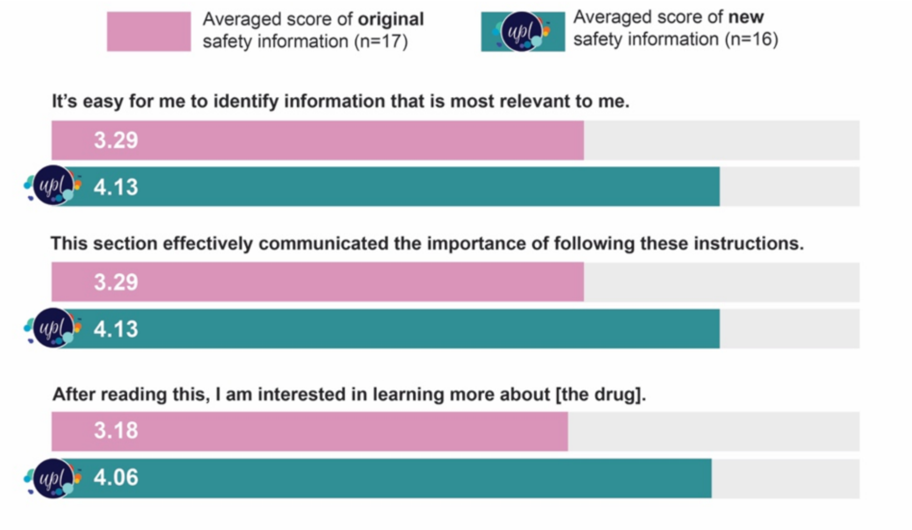
The UPL design in Figure 2 reflects dozens of design decisions that align to the UPL principles. The example suggests:

- To **communicate visually,** BMS incorporated icons to help patients navigate their way around the document and included an image of the actual pill because that is something patients told BMS in co-creation they wanted to see.
- To **demonstrate empathy for patients and caregivers,** each of the subheadings was re-phrased as a question. BMS learned in co-creation that these were questions patients wanted to ask about their medicine, either before or during treatment.
- To **format materials for understanding**, BMS changed the layout of the document, using tables to make it easier for patients to find the information most relevant to them.
- To **share qualified, quantified data**, BMS added percentages and natural frequencies showing how often side effects were observed during clinical trials.

BMS evaluated the UPL drug safety information for one specific product, conducting two small-scale studies with patients. First, BMS conducted qualitative interviews with 10 patients who were drug candidates but did not necessarily have any experience with the medicine. From these interviews, BMS learned patients appreciated seeing the information clearly broken down and found the use of color and bolding very helpful.

BMS also conducted a survey with 33 patients, who were asked to evaluate statements on a 5-point Likert scale (1 = strongly disagree; 5 = strongly agree). Seventeen respondents were shown the traditional format, and 16 were shown the new UPL format for drug safety information. On average, respondents found that the UPL version: made it easier to identify the most relevant information (3.29 vs. 4.13); more effectively communicated the importance of following the instructions (3.29 vs. 4.13); and made the respondents more interested in learning about the drug (3.18 vs. 4.06) **(see Table 1).**

Table 1. Survey results of 33 participants shown traditional format vs new UPL format



Another application of the UPL was to reconsider the promotional materials that explained how one particular drug works. BMS's traditional explanation for how the drug works was quite complicated. It used words patients found difficult to understand and did not resonate with patient knowledge or experience. The UPL version was a complete redesign, following UPL principles and leveraging the UPL toolset **(Figure 3)**:

- To **use plain language**, BMS greatly simplified the story, removing references to many elements within the immune system's cascade, such as 'macrophage,' 'cytokines,' and 'antigen-presenting cells.' In co-creation, patients told BMS those terms were so foreign that they diminished their interest in the topic. BMS worked with the patients to craft a new story that focused on the actions of T cells.
- To **communicate visually**, BMS used a visual analogy of a cell phone or wi-fi signal to represent the complicated idea of immune cascades. This visual analogy was actually created by the patients in co-creation, because they felt it helped communicate the key idea of parts of the immune system signaling other parts.
- To **enable patient learning**, BMS provided a labelled illustration of a joint to visually identify clinical jargon and demonstrate the immune response to inflamed joints.

How [redacted] works

In order to understand how [redacted] works, it's helpful to take a closer look at some of the cells of the immune system that are particularly important to the inflammation that happens in rheumatoid arthritis (RA).

Work with your rheumatologist to find the right treatment for you.

The Science Behind [redacted]

T cells play a key role in your immune system, and are particularly important in the chain of events that are believed to lead to the inflammation in RA.

In RA, your immune system confuses some of your own cells as foreign invaders, and T cells may be mistakenly **activated**.

Activated T cells send signals to the other inflammatory cells of the immune system, calling them into action.

These other inflammatory cells send out **signals** of their own. These **signals** are thought to be linked to inflammation in RA.

Please see the glossary on pages 15-18 to learn more about the key terms from this section.

[redacted] **works by targeting a source of RA early in the inflammation process**

[redacted] is a biologic DMARD (disease-modifying antirheumatic drug) that works early in the chain of events leading to inflammation in RA. It works by getting in the way of T cell activation, reducing the amount of signals that can be sent.

Many other DMARDs work by getting in the way of the signals that have been sent to wake up other inflammatory cells in the immune system.

Anti-inflammatories decrease inflammation.

Selected Important Safety Information
[redacted] **can cause serious side effects including:**

Allergic reactions. Allergic reactions can happen to people who use [redacted]. Call your healthcare provider or get emergency medical help right away if you have any symptoms of an allergic reaction, which may include hives; swollen face, eyelids, lips, or tongue; or trouble breathing.

Figure 3. UPL redesign of how a drug works

To further understand the impact of the UPL version that explains how the drug works, BMS conducted video interviews with 13 rheumatoid arthritis patients (who had experience with the specific drug). BMS showed all participants the traditional and UPL explanations (alternating the order in which it was shown to counter a first-seen bias). Eleven of the 13 interviewed patients (~85%) found the UPL version was more useful and generated additional confidence to engage with healthcare providers about the management of their treatment. Twelve of 13 patients (~92%) said the UPL version was easier to understand than the prior version. Although the evaluation was limited by a small sample size (and the fact the participants already were familiar with the specific drug), the participants clearly favored the UPL-generated version.

From a business perspective, the UPL's benefits also were evident. After updating the brand's website to include a variety of UPL materials (not just the explanation of how the drug works), the number of site visitors who took a follow-on action on the site (such as clicking a link) jumped from 9% to 38%. Internal teams also report that UPL materials are more in demand than the previous materials.

6. Conclusion

As the healthcare landscape becomes more patient-centric, the U.S. pharmaceutical industry is devoting more effort to enhance patient communications and a patient's overall experience as a health consumer. Health literacy becomes increasingly relevant for the pharmaceutical industry as these trends continue.

For BMS, the Universal Patient Language (UPL) is one important way to incorporate health literacy into patient-facing communications. The UPL is a set of resources - comprising principles, tools, and stewardship - that help communicate complex topics to patients. BMS built the UPL using human-centered service design, collaborating repeatedly with patients, caregivers, physicians, nurses, allied health care providers, and experts in biomedical communication and medical illustration. BMS has created dozens of UPL patient communications internally.

BMS's small-scale evaluation studies suggest patients respond well to UPL-generated materials and find them more inviting. Although some UPL materials for clinical trials have been used in translation around the world, most UPL work has occurred in the U.S. The adoption of the UPL for different countries, cultures, healthcare systems, and languages provides diverse opportunities for future exploration and implementation.

As BMS developed the UPL, it began to appreciate that many of the UPL's elements are not specific to BMS or the pharmaceutical industry. While some aspects are proprietary, BMS publicly released a significant portion of the UPL, which is available at www.UPL.org. BMS believes the UPL materials on the website can be useful to anyone who works in health literacy or who creates patient communications.

BMS recommends the UPL's use by health literacy practitioners and hopes it contributes to enhanced health communications from health care organizations to patients, caregivers, consumers, and health professionals.

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How Health Literacy Can Enhance the Design and Conduct of Clinical Trials from Consent to Conclusion

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Abstract. Health literacy research and interventions have provided multiple tools to improve communication between professionals and patients in clinical contexts for many years. Despite the reality that many patients participate in clinical trials in conjunction with standard medical care, only recently have efforts extended to address and improve the health literacy of both clinical trial researchers and participants. To date, the primary focus of health literacy activities in clinical trials has centered on communicating trial results to trial participants. This report describes the opportunities and strategies necessary to layer health literacy activities across the clinical trial process from consent to conclusion.

Keywords. Health literacy, clinical trials, plain language, science communication.

1. Overview of Health Literacy in Clinical Trials

Health literacy initiatives initially focused on patients and caregivers who did not understand medical professionals. More recently, health literacy has started to address how medical and public health professionals fail to clearly communicate with people in clinical contexts.

However, the authors believe health literacy has a larger role to play in health and well-being. One important area the authors seek to expand is to introduce health literacy within the institutions and practices of scientific research, especially clinical trials, to enhance the public's understanding and engagement in science and clinical trials.

Clinical trials face a host of significant communication challenges. These challenges are often found in the deeper meaning of words like diversity, recruitment, informed, consent, retention, engagement, participation, equity, evidence, and reporting. The words and actions each word represents can undermine a successful clinical trial. As a result, health literacy has a great and largely untapped potential to renew and reaffirm the power of clinical trials to advance health and well-being in practical, equitable, and ethical ways.

Health Literacy Media (HLM) believes health literacy can make a positive and productive difference to clinical trials in terms of:

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- Recruitment
- Diversity
- Informed consent
- Retention
- Engagement
- Equity
- Results, including communication of results to participants
- Evaluation
- Overall efficiency and effectiveness

More broadly, whether patients enroll in a clinical trial or are engaged in general healthcare on a broader level, diverse issues often converge to define the challenges in the relationships between medical professionals, health research, health systems, science, and society. In 1966, more than 75 percent of Americans had great confidence in medical leaders, which has declined to around 34 percent [1]. Today's health and medical systems face a crisis in confidence they are not prepared to effectively respond to - and frequently are not fully aware of the breadth and depth of the calamity. The crisis is caused by the relatively narrow focus of professional training coupled with the significant financial pressures health care systems face and a resulting pressure on medical staff - all within an uncertain health economic and policy context.

In response, HLM uses health literacy as a mechanism to improve communication about and within health and medicine in order to rebuild public support for medicine, medical professionals, medical research, science, clinical trials, and health systems. In order to succeed, this effort must address a range of activities from research to sick care to prevention. HLM believes health literacy can inform and foster a necessary transformation to a healthier and more productive relationship between generally non-scientific publics and the people and institutions within health and medicine. Eventually, a shift can reverse the ongoing erosion of the public trust in the leaders of health, medical, and health care systems.

Clinical trials provide one of the most challenging contexts and case studies in which to apply the evidence-based strategy and practices of health literacy. All too often, health care professionals hear about a clinical trial being misunderstood by its participants, the press, or the public. For example, a lack of significant findings (statistically and/or clinically) in a clinical trial is often interpreted as a failure. Instead, the lack of statistical or clinically meaningful findings adds to knowledge, specifically regarding what not to pursue among specific study populations. This is just one small, yet important, example of the public misunderstanding of the processes and goals of clinical trials. HLM suggests the misunderstandings are due, in part, to how people and institutions who manage clinical trials talk about their own efforts and goals - especially during the recruitment process.

To improve public understanding, governments around the world are simultaneously working to implement new approaches, guidelines, and rules with the ultimate goal to increase the relevance and use of clinical trials.

While a well-established approach to communicate clinical trials to the public is the National Library of Medicine's website ClinicalTrials.gov, its information and data are not targeted toward lay audiences. Deborah Zarin M.D., the former director of ClinicalTrials.gov, acknowledged ClinicalTrials.gov information is provided so: "the results can be understood by an *educated reader of the medical literature"* [3]. However, the audiences many health care agencies need to reach are rarely the educated readers of medical literature. To put this another way, the diffusion of health literacy and numeracy skills (the understanding of quantitative information) is limited - especially within underserved geographic areas and populations [4-12]. Moreover, health literacy-based misunderstandings occur among well-educated people. Recent research suggests physiological shock impacts cognition regardless of a person's educational or health literacy levels when they are faced with serious medical diagnoses and diseases [13].

Despite all these potential barriers, clinical trial participants want to learn, and have the right to learn, the results of clinical trials – especially when they directly participated in that trial [14-15]. Providing those results in a health literate manner can increase participants' feelings of value and improve the likelihood they will participate in future trials [16-17].

Thus, there is an unprecedented urgency to address the public understanding of science, specifically clinical trials. Health communication companies with a focus on health literacy, such as HLM, are uniquely positioned to lead efforts to integrate best evidence health literacy and plain language practices into the clinical trial process. While HLM is based in the United States, we work around the world.

Advances in international policy that mandate the creation of readable and usable clinical trial summaries are driving HLM's efforts in the public communication of clinical trial information. The work reported here is based on only one program in HLM's portfolio, the *Clearly Communicating Clinical Trials* program, and only details initial experiences in applying health literacy principles to public communication of clinical trial information. The remaining sections of this report will briefly: 1) contextualize the international policy that served as the impetus for HLM's focus on plain language clinical trial summaries; 2) discuss the potential impact of health literacy on the clinical trial process; and 3) provide one program example and key initial learnings.

2. European Medicines Agency Mandate to Create Readable and Usable Clinical Trial Summaries of 2017

The currency of the issue of health literacy in clinical trial communication partially stems from a European Medicines Agency (EMA) 536/2014 regulation, and its further clarification published in a 2017 consultation document. The EMA regulations outline the need for sponsors of clinical trials to produce so-called 'plain language' summaries of clinical trials [18-20]. The stated purpose of plain language clinical trial summaries is to provide clear information that people can use when making health decisions. More practically, the newly required summaries are discussed as a hopefully effective way to report on what occurred within a clinical trial to the participants.

In turn, the EMA's attempt to bring the reporting of clinical trial results into a more public space (based on both regulatory and ethical reasons), opens the door for trial participants and the lay public to enter a complex scientific communication sphere that historically has required medical background knowledge, familiarity with common research practices, a large clinical vocabulary, as well as the skills and access to learn, and apply the meaning of newly encountered clinical and scientific jargon.

3. How Health Literacy Can Impact Clinical Trials

As previously mentioned, health literacy can enhance every stage in the process of designing, conducting, and reporting on a clinical trial. To explain how this occurs, the authors will first introduce exactly what health literacy is - and what it is not.

While there are many current definitions of health literacy, in practice there is some agreement that health literacy helps everyone (e.g. the public at large and health and medical professionals) better communicate complex information about health and wellbeing in a way that elevates mutual understanding and encourages informed decision-making [2]. Hypothetically, better health literacy nurtures more informed consent among participants to join clinical trials as well as fosters a dialogue about the mutual goals of participants (and other stakeholders) when a new medical drug or technology is introduced.

Health literacy is not is a panacea, however. Health literacy requires hard work, close attention to detail, a plan to move from knowledge acquisition to action, and - most importantly - direct and honest engagement with each desired audience. Except for recruitment, informed consent, and recent public clinical trial summaries, the testing and improvement of the actual communication processes and content with clinical trial participants largely has been neglected, unnoticed, and underappreciated. The vast amount of what should be continual communication between clinical trial staff and participants has largely focused on one-way communication that often fails to make sure people arrive for their appointments on time and to report any adverse events they may have experienced, let alone seeking more information about experiences, preferences, and well-being.

At the heart of health literacy is a new-found respect for the expertise that people have in their own lives. While participants may not be research scientists, physicians, nurses, public health experts, molecular scientists, geneticists, or biologists, participants know their life better than any of these experts. Embracing that reality can shift communication efforts to bring a new level of awareness and respect of the important role participants should play in clinical trial processes.

Using the EMA guidelines, some health organizations have started to adopt plain language principles - to help participants understand exactly what did (or did not) occur within a clinical trial. While this is an important first step, it is incomplete. Patient understanding does not mean trust is established and trust alone does not always result in desired patient action. On the other hand, health literacy can target and produce informed understanding, trust, and therapeutic behavioral change. The challenge is how to best implement health literacy practices in clinical trial settings as well as the venues that report trial findings.

4. An Opportunity of Health literacy in Clinical Trials: The Example of Result Summaries

Health literacy strives to explain health conditions and health care concepts in language that most people can understand and use. While this seems straightforward, biopharma companies are more accustomed to communicating directly with providers rather than patients. As a result, biopharma firms are understandably wary about how to engage in patient and public communication in a respectful and non-promotional way. Yet, some of the communication gaps in past practices now need to be addressed, as biopharma companies (who are engaged in EMA-oversight clinical trials) are required to communicate clinical trial results within public summaries.

To date, some companies have recognized the need for health literate clinical trial result summaries, which is a step in the right direction. Yet, obtaining a shared understanding of clinical trial results is only a small piece of health literacy. To be truly health literate, clinical trial information also has to move beyond plain language - and contain a context that an audience can relate to, rather than simply using words that meet an arbitrary reading level guideline (such as 5th or 8th grade levels).

Consequently, a health literate approach to communicating the results of a clinical trial is a process that, ideally, begins at a drug's protocol development and continues throughout the entire clinical trial process, culminating in the delivery of a summary of results. HLM suggests a comprehensive effort should include:

- The evidence-based best practices of plain language in the choice of language(s) to reach the desired level of reading ease and preferred language of the audience
- The evidence-based best practices of health literacy to substitute plain for scientific language to improve readers' skills, vocabulary, and knowledge. This extends the content beyond a simple reporting of data to assure that data are relevant and useful to people's lives.
- Continual input and revisions from multiple perspectives - from clinical trial staff to participants to plain language and health literacy experts. This includes:
  - A process that produces summaries tailored to the content and context of each clinical trial.
  - An active review process engaging members of the intended audiences, especially people with the condition or disease focused on in the result summary.
  - The latter should occur before publication in order to assure effectiveness and usability.
- An evaluation of the effects of the summary upon the desired audiences and upon all the other audiences involved in a clinical trial process and the reporting of its results.

While the authors are using result summaries as the primary example, health literate attributes are critically important within other aspects of the clinical trial process from protocol development to recruitment, informed consent, and the reporting of results. When this entire process is conducted rigorously from day one of a clinical trial, result summaries will often - but not always - include:

- Visual explanations of complex concepts, using charts, tables, and drawings
- Analogies people can relate to based on their everyday lives
- Clear language that explains complex science in accurate and understandable ways to help teach people the words they need to use to successfully communicate with medical staff
- Publications tailored to the diverse channels that people use in their lives (e.g. social media, internet, print, and video)
- A clinical trial staff that is prepared to communicate the trial's results directly to participants.

Successful, comprehensive public and patient communication also recognizes the value of tailoring content to audiences, which contrasts with the use of templates to communicate to the public. Tailoring is operationally defined as the process of personalizing messages for individuals and audiences based on their beliefs, traits, or abilities [21]. Tailoring can help weave context throughout materials. While a template approach to communication assumes all clinical trial results can fit within the same template, the effectiveness of tailoring lies in its ability to create potentially greater relevance to each intended audience [22].

Yet, the EMA guidelines have been widely used to create templates for the diverse sections a trial result summary should contain. Unfortunately, some communicators have taken those guidelines too literally and assume the order in which information is presented must follow the order they are listed in within the guidelines. In addition, strict adherence to template styles can result in a confusing focus on outcomes. For example, early phase 2 studies largely report data on safety without outcomes, while later phase studies largely report outcomes and also safety. Thus, a template that prioritizes outcomes would not be appropriate for a study largely focused on safety and vice versa. Conversely, a tailored approach - if taken too far - could mean each result summary would begin with a blank page, require extensive research of the target audience in advance, and quickly become a labor-intensive process that would outstrip the resources dedicated to creating the summary.

To remedy, HLM suggests a balanced approach, whereby a template may be used to create the initial draft of a clinical trial summary, which can then be tailored through a user testing process. Thus, HLM developed a clinical trial summary template built on the principles of: patient-centered communication; plain language; health literacy; logical idea structure; and an explanation of background knowledge to clearly explain the need and desired outcomes of a clinical trial. HLM then used a focus group to test the clinical trial summary template to create a more tailored clinical trial communication. Focus groups are considered to be a standard to assess an audience's preferences and their understanding of documents.

In this early development stage of HLM's clinical trial summary development process, two audience groups were identified and focus groups were conducted to develop and test a clinical trial result summary template [23-24]. One group was recruited from an adult literacy education program and included adults with low literacy. The second group of participants was recruited from people who had the condition the template draft focused upon (breast cancer). In addition to testing the template, overall, the focus groups helped HLM identify and better understand the impact of language that might be unfamiliar to people who are more and less experienced with a particular medical condition. In addition, the focus groups suggested lay audiences appreciated more background information about a disease, as they may have less knowledge about medical conditions and treatments. This contrasted with breast cancer patients, who sometimes preferred more detail about treatments, side effects, and results than members of the general public [25]. Both lay audiences and people who are more directly impacted by a disease/illness sought additional context about what the results mean for patients as they consider treatment or other medical decisions. Thus, the value of tailoring became as apparent as the value of a template approach in an early, formative research process.

5. Key Guidelines to Creating a Clinical Trial Summary Based on HLM's Research and Experience

Fundamentally, all successful communication of complex information shares similar characteristics regardless of the specific content or audience - therein lies HLM's development and use of templates. Yet, all audiences for the communication of complex information are not the same – therein lies HLM's development and use of a research-based approach to engage audiences directly and tailor information to their needs within a template.

HLM suggests there are several principles to produce a usable and effective clinical trial summary. More specifically, HLM suggests:

- Above all, stay true to the science
  - In very practical terms, this means to never include any information that is not contained within the core reports produced by the clinical trial team.
- Quickly relay the main point of the study and any findings
  - State the main need for and findings of the study up front. This produces a flow of information that is generally the reverse order of a traditional journal and regulatory reporting in which the outcomes are often found near the end of an article or report.
- Frame the findings in a useful way for the main audiences
  - This can mean presenting information based as an answer to the main questions people have. Those questions are often used as headers for each 'chunk' of information within a summary.
  - Describe who participated in a clinical trial in as clear and complete a style as the original scientific documents.
- Highlight the necessary cautions to using scientific information within an informed decision-making process
  - Be clear that a health care decision should not be based on the findings of a single clinical trial and consulting health care professionals is always a vital part of an informed decision-making process.

In practice, HLM's approach and suggested principles are based upon effective methods to create clinical trial summaries. HLM acknowledges their suggested approach is not simple, and requires skilled personnel, health literacy training, and a meaningful investment of their time and energy.

For instance, HLM suggests a clinical trial summary creation process begin with a thorough review of the documentation available about the clinical trial as well as becoming familiar with the condition that each clinical trial focuses upon. Built into this process should be an opportunity to directly discuss with the scientific team the understandings and questions about the clinical trial. The latter direct communication, while invaluable, also can identify different approaches and perceptions of the value of communicating scientific information, and how information should be communicated between the writing of a summary and the researchers who designed and conducted the entire clinical trial.

HLM notes an enduring paradigm within science fosters a communication approach that sometimes is at odds with communicating directly with non-scientific audiences. For example, the use of scientific jargon has several underlying components, which frequently include:

- The language, especially the vocabulary, unique to a particular trade, profession, or group
- Unclear or meaningless (to certain audiences) talk or writing
- A discussion section or writing that people do not understand
- Language that is characterized by uncommon or pretentious vocabulary and convoluted syntax that is often vague in meaning.

While jargon enables scientists to more efficiently communicate with each other as they develop a shared understanding of jargon-derived meanings, the public rarely shares similar insights. The resulting gaps produce a choice about communication priorities that HLM suggests should be resolved on the basis of developing public understanding. Ultimately, the culture and needs of the audience must be prioritized to produce an understandable and usable clinical trial summary. The latter approach additionally favorably shifts the culture of science toward public engagement and away from a perspective that separates science from society.

6. Wrapping Up

So, why does this all matter? Especially, why should this matter to an industry whose main goal is to create successful and profitable new approaches to medicine?

Clinical trials should not occur without honest and sincere public engagement. If done well, clinical trial summaries offer opportunities to engage the public and patients in new ways and helps create a more efficient clinical trial process. Overall, clinical trial summaries can help the pharmaceutical industry, researchers, clinical practitioners, hospitals and clinics, as well as government and non-governmental health agencies:

- Show respect to trial participants
- Help health care providers keep up with research advances
- Show how clinical trial participation can lead to better medical solutions
- Help people quickly learn more about new medical conditions, and what to do about it
- Help people develop the critical questions they need to make decisions about their health.

Public clinical trial summaries also present an opportunity to create information from a perspective that can engage and involve people in their own medical care, while creating goodwill and a better understanding of the companies, agencies, and scientists who conduct medical research.

The authors believe that health literacy offers significant potential to improve and advance clinical trials when health literacy strategies are used throughout the entire clinical trial process. The latter can occur at every phase of a clinical trial to produce the best possible outcomes for companies, providers, and patients.

For all audiences, the application of health literacy to clinical trial processes can promote a shared understanding of the intent of a clinical trial, the outcomes of the clinical trial, as well as build trust in the clinical trial process. The application of health literacy processes also potentially accelerates the public adoption of clinical trial findings, which could improve patient adherence.

Finally, each step within this process needs to explain research ethics to produce more public trust in the outcomes of clinical trials. Based on our engagement in and understanding of the clinical trial process, the next steps involve extending the application of health literacy best practices into all aspects of the clinical trial process – from the development phase, to recruitment and retention efforts, and across dissemination and public communication. The authors' experiences, to date, suggest that undergirding all aspects of the clinical trial process with health literacy approaches will foster more sustainable science, the sustainability of organizations sponsoring and conducting clinical trials, and the sustainability of the health and wellbeing of patients and the public.

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Programmatic Approaches to Increase the Health of Children and Senior Citizens Using Health Literacy Best Practices

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Abstract. Effective communication is essential to improving individual health and wellbeing, especially for those with marginalized literacy levels. While there are many populations that benefit from effective communication, this report concentrates on child and senior populations. Three programs developed by the Institute for Healthcare Advancement (IHA) and partner agencies in the U.S. are explored as examples of practical techniques that can be included in programmatic initiatives. The authors also provide suggestions for sustainability. The discussed programs are intended to: reduce emergency department visits; prevent falls among senior citizens; and provide health education and outreach to isolated senior citizens in a Southern California (U.S.) community.

Keywords. Health literacy, reducing emergency department visits, fall prevention, isolated senior citizens, promotora

1. Introduction

The Institute for Healthcare Advancement (IHA) is a California (U.S.) 501(c)(3) not-for-profit public charity with a mission to empower people to better health. Founded in 1993, IHA provides health literacy/health equity tools and resources including:

- 'What To Do For Health,' a series of easy-to-read and easy-to-use self-help healthcare books. An assessment of IHA's 'What To Do When Your Child Gets Sick' suggests reading the book can reduce unnecessary pediatric ED and clinic visits by up to 48% [1].
- The Annual IHA continuing educational conference, Operational Solutions to Improve Health Literacy, now in its 18th year, provides practical, hands-on, operational solutions to issues to improve health literacy and health equity.
- An online, open access, peer-reviewed journal, Health Literacy Research and Practice.
- Job analysis-related tools, including a health literacy specialist job description and, coming in 2019, an assessment-based certificate program, using data from the job analysis task force combined with community survey results.

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IHA supports the efforts of professional health literacy/health equity communities to innovate and share resources. IHA supports the nascent International Health Literacy Association, and in 2019, is launching an online community portal, the IHA Center for Health Literacy Solutions, to convene, connect, and provide resources for these communities. The report covers one mature and two emerging IHA health literacy initiatives/interventions to: reduce unnecessary emergency department visits; prevent falls among senior citizens; and provide outreach and health education to senior citizens in one California (U.S.) community. Specifically, the report describes: reducing child emergency department visits using an easy-to-read book; a senior fall prevention initiative, and outreach and education for isolated seniors using a promotora (community health worker) model.

2. Reducing Unnecessary Emergency Department Visits Using an Easy-to-Read Book

2.1. Background

Many parents do not own a health book to provide guidance on children's health concerns, and when in doubt, many parents opt to take their children to the emergency department (ED) for conditions that could be treated at home [1-3]. Providing parents with tools to successfully identify these conditions as non-urgent can help reduce unnecessary office visits, thereby reducing health burdens on individuals and organizations. IHA's 'What To Do When Your Child Gets Sick' is written at the third to fifth grade reading level; it covers a variety of ailments as well as some recommended treatments.

A 2004 pilot study by Herman and Mayer assessed the impact of distributing 'What To Do When Your Child Gets Sick' (along with a training class on using the book) to some parents of children enrolled in U.S. Head Start educational programs. Prior to participating in the intervention, many parents were unsure of what to do in response to mild conditions (e.g., runny nose or mild fever), and 40% reported they would take their child to the ED or clinic for these conditions [1].

Most parents who received the intervention described the book as 'very useful' (81%) and 'very easy to understand' (96%). The six-month follow-up survey suggested more parents would first use a book for their child's illness, instead of relying on a trip to the clinic or ED. Most parents (84%) felt 'more confident' in caring for their child's health after reading the book. Parents participating in the intervention reported a 48% reduction in ED visits and a 37.5% decrease in clinic visits, resulting in a combined savings of $22,360 per year, or about $99 per family [1].

Also, Bernstein, Crooks, Pigg, and Edwards utilized undergraduate college students in a service-learning model to deliver a similar intervention in which parents received the 'What To Do…' book and completed a one-hour class [3]. The latter results were consistent with Herman and Mayer's findings, and suggested most study participants used the book at least once to avoid calling their physician (82%) or visiting the ED (63%) [3].

2.2. Overall Impact

The aforementioned studies found parents who receive 'What To Do When Your Child Gets Sick' (along with a short class on using the book report) increased confidence in responding to their children's healthcare needs [1-2,4]. In addition, parents were more likely to use the book than to visit the ED or clinic to determine the type of care needed [1-5]. This reduced reliance on the healthcare system results in individual and organizational cost savings that were exponentially greater than the cost of the intervention [1].

2.3. Suggestions for Sustainability

Despite the potential for cost savings, the initial costs of an intervention may be of concern to some organizations. However, there are some promising practices that may reduce initial costs, such as incorporating a service-learning model with volunteer students or online presentations to simulate in-person workshops [3,5]. One study suggested in-person, individual instruction more effectively encouraged participants to utilize the book as a resource [5]. Hence, the findings suggest using a service-learning model with volunteer students may be more cost effective.

3. Senior Fall Prevention Initiative

3.1. Background

Falls are the leading cause of morbidity and mortality among U.S. adults aged 65 years and older [6]. Currently, an estimated 30% of U.S. older adults suffer from injuries related to preventable falls, resulting in roughly $30 billion in annual healthcare costs [7]. Estimates predict in 2030, one in five U.S. adults will be 65 years old or above, which will likely trigger an increase in falls, injuries, and direct medical costs [8]. In addition to physical injuries, many adults suffer from lasting psychological complications due to a fear of falling again and intentionally limit mobility to prevent subsequent falls. Paradoxically, a more sedentary lifestyle leads to muscle atrophy and weakness causing an increased risk for falls [9].

Most fall prevention programs are designed to reduce the preventable fall risks faced by older adults, who strive to remain active as they age. On average, participants in these programs meet once a week for eight weeks to improve strength and balance, remove home hazards, and correct vision problems as needed [10]. While these programs are purported to achieve their intended goals, many studies conducted on fall prevention programs have not examined patients within a clinical setting and are not considered to be empirically robust [11-14].

In turn, IHA and Prospect Medical Group partnered in 2016 to initiate a study among patients aged 65 years and older (who had at least one fall within the previous 12 months) to determine if a fall prevention program reduces subsequent falls by informing participants about physical and psychological risk factors [9]. Additionally, the study was designed to test the efficacy of a program in an integrated, person-centered care delivery system with a patient-provider relationship incorporated within a fall prevention program. This study is the first to integrate a low literacy self-care book that offers comprehensive health information which includes guidance on fall prevention and risks.

Since the research is in progress, the study's goals, outcomes objectives, and sustainability prospects are reported.

3.2. Study Goals

- Assess common characteristics among at-risk patients/Medicare beneficiaries associated with all types of falls including those resulting in treatable injury.
- Compare the efficacy of two fall prevention strategies for older adults.

3.3. Anticipated Outcomes

- Increase the self-reported fall prevention self-efficacy among program participants.
- Decrease the number of self-reported falls.
- Decrease the number of emergency department visits related to falls.
- Decrease the number of hospitalizations related to falls.
- Decrease the number of prescribed medications used by program participants.

3.4. Related Health Literacy Practices

Navigating the healthcare system to make important decisions requires proficiency in health literacy skills. Health literacy, or an individual's capability to obtain, understand, and utilize basic health information and services, is especially important for seniors. Unfortunately, 71% of adults over age 60 have difficulty using print materials while 80% struggle with using charts or forms, which influence their ability to make informed health care decisions [15-16].

The Fall Prevention Program is the first to use low literacy print and audiovisual materials to help patients reduce their risk of falling. Study participants receive a Senior Resource Kit containing materials written at the third to fifth grade reading level to facilitate comprehension and behavior change. In addition, the materials use larger type to accommodate older learners.

3.5. The Senior Resource Kit's Contents

- 'What To Do for Senior Health:' This is a comprehensive self-care book written at the third to fifth grade reading level. The purpose of the book is to guide readers through normal aging changes and inform them about abnormal changes that require medical attention. Additionally, older adults learn about remaining active and other ways to reduce their fall risk.
- 'How to Prevent Falls at Home:' This booklet guides individuals through the exterior and interior of their home to identify potential fall risks. To use the booklet, an individual would go an area of their home (e.g., the living room), turn to the page in the booklet that discusses that area, and inspect the room for factors identified in the guide that might cause falls (e.g., poor lighting). Each area in the booklet includes a checklist of common potential fall risks that individuals use to mark the risks that exist in their home. An action plan is

provided at the end of the booklet to encourage participants to write down what they plan to change and how they plan to accomplish anticipated tasks.

- Exercise Video: Older adults learn basic strength, balance, and flexibility exercises developed by a physical therapist who specializes in older adult rehabilitation.

3.6. Intervention

The Prospect Medical Group will follow two patient cohorts receiving different interventions:

- Cohort 1: Prospect participants who qualify for the program will receive the Senior Resource Kit. A program coordinator will conduct telephone follow-up calls to confirm the material was received and to review program protocols.
- Cohort 2: Members will receive usual patient care that includes:
    - Clinical practice guidelines related to fall prevention for older adults
    - Patient-centered "whole" person care including medication review and management, daily activities patient profile, quality of life assessment, a daily activity profile, a chronic condition profile, and a vitamin D deficiency assessment.

3.7. Suggestions for Sustainability

The demand for self-directed patient education with telephone follow-up has increased due to the high cost of staff live classes. The program's success also depends on the quality of program materials including design, reading level, and comprehensibility. IHA consistently produces resources using health literacy writing and design principles that reduce emergency department visits and hospital readmissions. If the results suggest this program positively affects patient outcomes and reduces subsequent falls, it should be relatively easy to reproduce, implement, and sustain cost effectively.

4. Outreach and Education for Isolated Seniors Using a Promotora (Community Health Worker) Model

4.1. Background

The U.S.' senior population has increased since 2001, with more than 10,000 people turning 65 each day [17-18]. As this population continues to grow, so does the prevalence and incidence of chronic disease as 80% of older adults have at least one chronic disease to manage [19]. Older adults also are at increased risk for mental health problems such as depression and suicide. Currently, one in four U.S. seniors experience a mental health disorder and two-thirds of this population do not receive treatment [19]. The U.S. National Council on Aging estimates the number of seniors suffering from mental health disorders and substance abuse problems will double by 2030 and 2020 respectively [19].

The successful management of a disease requires basic knowledge about the condition as well as an ability to locate and manage services. Prior research suggests older adults are more likely to have low health literacy, making it harder for them to manage their chronic conditions [20]. In addition, many seniors prefer to age at home independently, but often experience difficulties finding trusted resources and services [20]. In response, IHA developed a community-wide promotora home-visit program to assist the anticipated senior population growth in La Habra, California (U.S.). The Connection and Resource Education (CARE) Program aims to increase the sense of control and improve the quality of life among older adults and caregivers.

4.2. Goals and Objectives

The goal of the CARE Program is to promote overall health and wellbeing for isolated, at-risk seniors aged 65 or older by providing resources and services, which enables recipients to remain in their home and live independently. The program is conceptually aligned with a current public policy goal to enhance health among older adults in Orange County, CA (U.S.), where La Habra is located. La Habra is a diverse community of about 65,000 people, located southeast of Los Angeles. The CARE Program also addresses Orange County's goal to implement evidence-based programs that address social isolation and improve health among seniors. Since the research is in progress, the study's goals, outcome objectives, and sustainability prospects are reported.

4.2.1. Goals

The CARE Program will incorporate health literacy principles and wellness coaching techniques to:

- Increase participants' sense of control to achieve their individual health goals.
- Increase the prevalence of La Habra seniors who report improved quality of life.

4.2.2. Outcome Objectives

Upon completion of the program, participants will be able to:

- Locate at least three local resources that provide services related to improving health or reducing fall risks.
- Identify at least three ways to reduce their fall risk.
- Achieve at least one self-identified goal by the end of the in-home visitations.
- Use at least three new skills to maintain a sense of control when faced with health or life challenges after the program is completed.
- State at least three reasons to have a Medicare Annual Wellness Visit.

4.3. Health Literacy Best Practices

The CARE Program incorporates health literacy practices into its design and implementation. Teaching techniques, such as teach-back and motivational interviewing, are incorporated to ensure that participants understand the complex topics and can act upon supplied health information. In addition, all written program materials contain health literacy best practices such as plain language and ample white space.

The program follows a promotora model, where health education is advanced by a person who understands the norms and health behaviors of the community he or she serves. A promotora is especially important in older ethnic communities that face additional barriers to access to care due to challenges such as language and culture [21]. A promotora receives training in communication techniques such as plain language, teach-back, motivational interviewing, and health coaching.

All written participant material uses techniques to facilitate comprehension, such as larger font size, ample white space, bulleting, and headers. Certain handouts also encourage interaction by including checkboxes and goal setting exercises. The curriculum also is prepared using these techniques to reinforce their use by the promotora during a home-visit. In addition, the curriculum provides sample teach-back questions to facilitate the latter techniques during home visits.

4.4. Evidence-Based Approaches

The CARE Program uses an evidence-based multidisciplinary team approach where physician volunteers, health educators, and community volunteers support the work of promotoras. The team provides professional counsel, diverse perspectives, and unique experiences to boost the continuing education of a promotora. While the promotoras selected for CARE will have prior experience in health pedagogy and working within the La Habra community, participating promotoras will receive additional health coach training as part of the CARE Program.

The multidisciplinary approach also is used for CARE marketing and recruitment efforts. The La Habra Action Council, a group of community volunteers, will conduct outreach efforts to identify community participants. Community participants additionally will be identified through hospital referrals at patient discharge, community outreach events, such as the Senior Volunteer Program, and other home visit programs, such as Meals on Wheels.

CARE will utilize diverse behavioral change models to increase the probability that participants will gravitate towards a healthier lifestyle. For example, Social Cognitive Theory provides the conceptual foundation of efforts to increase a participant's sense of control of his or her health [22]. A randomized control trial, undergirded by Social Cognitive Theory, suggests seniors with an increased sense of control experience comparatively improved health outcomes [23]. Different components are included into the latter program to increase the participants' sense of control, including a 'Wellness Wheel.'

The Wellness Wheel enables participants to rank how happy they are in diverse areas including physical health, as well as social, and environmental surroundings. Once completed, the wheel provides a physical representation of dimensions of participant satisfaction and self-identified improvement.

The CARE Program also uses the Transtheoretical Model (TTM) to assess the client's readiness to make changes in their lifestyle [24]. Utilizing TTM, a promotora is trained to recognize the different stages and respond to their client's needs. While reviewing the Wellness Wheel, the promotora and participant identify areas of recent success as well as areas of therapeutic opportunity. The participant then has an opportunity to rank self-identified areas of improvements and discuss his or her readiness to take constructive, future steps. The recipient and the promotora use the latter information to prepare an action plan for the next several weeks.

4.5. Suggestions for Sustainability

Community health outreach programs often are impacted by a lack of time, capacity, and funding. An interdisciplinary approach is designed to offset some of the latter challenges. An interdisciplinary approach refers to a collaborative team built of members of different knowledge, expertise, and resources that combine for a common purpose [25]. Joining members from inside and outside the desired disciplines allows for innovative thoughts and ideas. Each member also brings with them time and possible resources that can be dedicated to the effort. The power of the collaboration can also be beneficial if there are members whose strong suit is funding (i.e., skilled at obtaining funding or able to fund projects directly).

5. Conclusion

Research suggests the provision of easy-to-use and easy-to-understand health education materials and complementary classes is correlated with improved health efficacy and reduced use of emergency services [1-5]. Though many participants stand to benefit from interventions designed with health literacy in mind, achieving such outcomes in the growing (U.S.) population of older adults could yield exponential returns on investment by supporting individuals' ability to age at home independently and by reducing healthcare costs from preventable falls and related psychological trauma. The programs presented in this report provide examples of projects that incorporate health literacy best practices to meet the needs of diverse populations, including older adults and parents of young children. Data from these programs will also build on existing research to provide more robust evidence for the inclusion of health literacy components in programs aimed at achieving positive behavior change.

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Health Literacy Initiatives and Lessons Learned within Public Health Agencies

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Abstract: Located in the northeastern part of the United States, New York State is extremely diverse - from the perspectives of culture, history, language, geography, economy, to name a few. Spreading across approximately 55,000 miles and taking into consideration the diversity of health needs across the state, the New York State Department of Health (NYS DOH) is dedicated to improving the health of all New Yorkers. This is evident in a Prevention Agenda which is New York State's health improvement plan, the blueprint for state and local actions to improve the health and well-being of all New Yorkers, and to promote health equity in all populations who experience disparities [1]. In addition, strategies for successful partnerships include long standing relationships with local health departments, community health centers, hospital systems, community-based organizations, individuals and groups who rely on the State Department of Health for quality services to achieve health equity and eliminate health disparities. This report provides an overview of previous, current, and forthcoming health literacy activities spearheaded by the New York State Department of Health Office of Minority Health and Health Disparities Prevention that support the importance of effective communication and health literacy across the Department.

Keywords. Health literacy, strategic planning, performance measures, initiatives, equity, disparities

1. Introduction

This report provides an overview of previous, current, and forthcoming health literacy activities spearheaded by the New York State Department of Health Office of Minority Health and Health Disparities Prevention that support the importance of the Department's effective communication and health literacy. The report is divided into the following sections: an introduction of the New York State (NYS) Department of Health; a brief history of the NYS' Office of Minority Health and Health Disparities Prevention including its charge, legislative mandates, and purpose; a review of the Department of Health's health literacy (HL) activities, and some remarks about the implications of the latter HL initiatives.

Located in the northeastern United States, New York State contains one of the most diverse socio-demographic populations in the U.S. in terms of culture, history, language, geography, and economics. New York state is spread across approximately 55,000 miles

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and includes much of the densely populated New York City metropolitan area as well as other urban, suburban, and rural regions.

1.1. The New York State Department of Health

The New York State Department of Health (the Department) in the U.S. has overseen the health, safety, and well-being of New Yorkers since 1901 – from sanitation and vaccinations to utilizing new developments in science as critical tools to prevent and treat infectious diseases. Given the challenges of new public health challenges and an evolving health care system, the Department's commitment to protecting the health and well-being of all New Yorkers is unwavering [2]. The mission of the New York State Department of Health is to: "protect, improve and promote the health, productivity and well-being of all New Yorkers" [3]. The Department serves: the general public; health care providers, associations, facilities, stakeholders; public health leaders, researchers/scientific community; media; governments (local state federal); academia/education; health insurance firms and associations, insurers; health care-related foundations; and public health departments in other states. [4].

1.2. Organizational Structure (i.e. Offices, Divisions, Bureaus)

In 2016, the Department employed 3,543 people in its central office, three regional offices, three field offices, and nine district health offices across the state; an additional 1,543 worked in the five Department-operated health care institutions. In the 2016-17 fiscal year, the Department's appropriations totaled $72.4 billion. Of this, approximately $64 billion was the one-year value of a two-year Medicaid appropriation, $8.3 billion supported public health initiatives, and $148 million was allocated to institutions operated by the Department [5]. Medicaid provides health coverage to millions of Americans, including eligible low-income adults, children, pregnant women, elderly adults and people with disabilities. Medicaid is administered by states, according to federal requirements. This program is funded jointly by states and the federal government [6]. Medicare is the federal health insurance program for people who are 65 or older, certain younger people with disabilities, people with End Stage Renal Disease (permanent kidney failure requiring dialysis or transplant, sometimes called ESRD) [7].

1.3. External Relationships (Contractors, County and Subcounty Relationships, Community Groups)

In New York state, 57 county health departments and the New York City Department of Health and Mental Hygiene provide public health services at the local level. New York is one of 27 states where the provision of public health services is decentralized, meaning local health departments operate under the administrative authority of local governments. However, the Department provides environmental health services in 21 counties where local health departments do not have this capacity. While federal and state public health statutes and regulations guide the process, each local health department addresses the needs of its own community [8].

2. History of the NYS Office of Minority Health and Health Disparities Prevention: Its Charge, Legislative Mandates, Purpose

At the federal level, the mission of the Office of Minority Health (U.S. Department of Health and Human Services) is to improve the health of racial and ethnic minority populations through the development of health policies and programs that help reduce health disparities [9]. The formation of state minority health offices was and continues to be crucial to the successful operation of the federal minority health network. The state minority offices link federal and local efforts to improve the health status of minority populations. The federal Office of Minority Health encourages the establishment of offices of minority health in each state, commonwealth, and U.S. - associated jurisdictions [10]. The Office of Minority Health (OMH) in New York was established by Public Health Law in 1992 and became operational in 1994 [11]. The New York OMH is charged with the following responsibilities:

- Promote, support, and conduct research to improve and enhance the health of minority populations.
- Serve as a liaison and advocate on minority health matters in conjunction with the Minority Health Council.
- Assist medical schools and state agencies to develop comprehensive programs that increase the diversity of the health care workforce.
- Integrate and coordinate state health care grant and loan programs.
- Promote and support community strategic planning to improve health equity and health care services within minority communities.
- Assess the impact of programs, regulations, and policies on minority health services.

In December 2011, the breadth and scope of the office was expanded and renamed the Office of Minority Health & Health Disparities Prevention (OMH-HDP). This administrative change more accurately reflected the Office's charge. OMH-HDP's strategic mission to execute its statutory responsibilities is within the New York Department of Health's Prevention Agenda, the United States Department of Health and Human Services (USDHHS) goals to reduce racial and ethnic health disparities, and the goals of the National Partnership for Action. OMH-HDP also currently serves as a statewide resource to foster the elimination of health disparities across all impacted populations. Specifically, OMH-HDP strategic goals include:

- Working across the Department's programs to integrate health disparity reduction efforts in their policies, programs, and agendas and further the goals of the Prevention Agenda Toward the Healthiest State.
- Partner with government systems, public and private agencies, and communities to continue progress towards achieving health equity.
- Support programs and interventions aimed to build community capacity to identify priority issues and map community assets. Mobilize community residents to develop and implement sustainable approaches to improve health and well-being.
- Ensure cultural and linguistic competency, promote health literacy, and increase diversity within the health-related workforce.

- Work with the New York State Minority Health Council (MHC) to identify gaps in services and provide recommendations to the Commissioner of Health that address the broader social and economic factors that lead to poor health.

3. The Department's Health Literacy Efforts

The Health Literacy Community of Practice started as an internal effort introduced within the NYS DOH from 2015-2017. The Community of Practice was comprised of NYS DOH staff who sought to identify opportunities to enhance health literacy practices within the Department. This initiative helped create a space for staff to collect resources, discuss lessons learned, and share information across the Department. NYS DOH's external efforts included the Delivery System Reform Incentive Payment (DSRIP) Program [12]. This program, funded by federal dollars, includes 25 Performing Provider Systems (PPS) that are responsible to create and implement a DSRIP project - and include providers that form partnerships and collaborate in a DSRIP Project Plan. PPS include both major public hospitals and safety net providers - with a designated lead provider for the group. Safety net partners may include an array of providers such as: hospitals; health homes; skilled nursing facilities; clinics and Federal Qualified Health Centers; behavioral health providers; community-based organizations and others [13]. U.S. Federal Qualified Health Centers receive federal funds to provide primary care services within medically underserved areas [14]. Included in the charge to all participants is to identify and implement language access, cultural competency, and health literacy initiatives within their respective communities [14].

3.1. The Commissioner's Charge for Health Literacy Throughout the NYS DOH

In the fall of 2017, under the direction of new leadership for the New York DOH OMH-HDP, the Commissioner (Howard Zucker M.D. J.D) asked OMH-HDP to integrate health literacy efforts within the Department. The initiation of varying levels of understanding, improved awareness of health literacy, and/or implementation of practices drove a planning process during the 2018 calendar year. In addition to maintaining partnerships with existing internal and external initiatives, the planning process identified activities needed to support the Department's vision and mission statement as well as its strategic plan [15].

3.2. New York's Health Literacy Plan in 2018

In formulating a health literacy plan for January through December 2018, an outline suggested diverse areas including:

- How to best infuse health literacy throughout the Department
- Identify the audience for initiatives within the organization
- Learn who externally will benefit from this information
- Identify internal and external needs to better understand, address, and include health literacy in initiatives and general scope of work.
- Structure events based on audiences within direct service providers, researchers, academics, community-based organizations, contractors.

- Plan a forum for the respective audiences (e.g. webinars, workshops, summit, co-sponsorship with other entities, participate at events as a sponsor, guest speaker, panelist, etc.)

Subsequently, OMH-HDP would develop performance measures to monitor these areas and track progress toward meeting program goals and strategic objectives as well as identify opportunities for enhancement and evaluation as needed [16].

3.3. A List of Specific Health Literacy Activities in 2018

In order to proceed strategically, the NY Office of Minority Health and Health Disparities Prevention developed and implemented systematic and multipronged initiatives month-by-month in 2018 as follows:

- February: Health Literacy Out Loud HLOL Podcast: Consider Culture and Language when Communicating About Health (Presenter: Wilma Alvarado-Little). This podcast shared the nuances of the intersection of culture, language, and health literacy.
- March: Center for Public Health Continuing Education University at Albany, State University of New York School of Public Health, Public Health Live: Health Literacy: A Tool for Effective Communication and Engagement. This webcast provided an overview of health literacy, its role in the provision of healthcare services, as well as how to engage communities in this process. The webcast shared lessons learned about preparing oral and written materials, and how to present and review techniques for direct service care [17].
- April: Commissioner Zucker's activities included a focus on Health Literacy during the first week of April (Public Health Week) as well as Minority Health Month. OMH-HDP prepared presentations which included health literacy resources (such as a publication from Helen Osborne, Health Literacy expert and founder of Health Literacy Month initiative), and publications (from the Institute from Healthcare Advancement). The themes of health literacy and effective communication were included in the Commissioner's opening remarks for diverse presentations and in a monthly letter distributed to healthcare providers statewide. During Minority Health Month, approximately three of six statewide presentations from the OMH-HDP staff included health literacy messaging. The latter presentations provided information on strategies to infuse health literacy and effective communication to engage target audiences.
- May: Activities included the submission of a book chapter to a peer reviewed journal publication (which since has been published) [18]. The OMH-HDP's initiatives identified opportunities to move forward with initiatives by reviewing potential health literacy publications and resources for internal use, convened programs across the organization to discuss partnerships, and provided guidance about best practices to develop and sustain best practices to select DOH contractors.
- June: Efforts included meetings with select NYS DOH programs to discuss the role of health literacy and the redesign of health websites as well as the intersections among health literacy, cultural competency, and language access.

- July: Efforts included participation at national meetings to discuss the role of health literacy and behavioral health. A workshop explored issues associated with effective communication with individuals with mental or behavioral health issues and identified strategies for health literacy approaches to facilitate health communication [19].
- August and September focused on the planning of the first New York Health Literacy Summit.
- October: Health Literacy Month: The OMH-HDP hosted the first statewide NYS DOH Health Literacy Summit on October 2, 2018. With the momentum and progress throughout the year, the Health Literacy Summit raised state awareness about the importance of clear and effective communication in the provision of health services. Summit discussions, such as the importance of health literacy and its intersection with health equity, were facilitated by Summit leaders so attendees could better understand the role of health literacy and health literacy initiatives as well as their intersection with policies and programs to advance health equity. In addition, strategies to address enduring disparities among racial and ethnic minority populations were presented by invited speakers. This event provided an overview of health literacy and its importance within local organizations, which enabled NY (and other) initiatives to proceed with stronger footing and support.
- November through December: Participation at national conferences as invited speakers provided OMH-HDP leadership an opportunity to share experiences from an organizational perspective and obtain knowledge to further develop health literacy resources and programs.

The health literacy activities throughout 2018 created an initial inventory of awareness initiatives. The next step was to develop an organization-wide survey consistent with a strategic and performance management plan. OMH-HDP was interested in learning the NYS DOH employees' understanding, experience, and interest about health literacy. A climate survey, which provides a picture of an organization's needs, was developed to better understand what resources are in place, what is needed, and what type of learning platform would be best utilized by staff [20].

Conducted in May 2019, the DOH climate survey was designed to provide current information and identify additional opportunities for improvement. It assisted with obtaining an insight into staff's understanding of health literacy, plain language, and effective communication in both oral and written messaging and the development of materials. The survey was sent to approximately 6,000 NYS DOH employees via SurveyMonkey email and a direct link via the NYS DOH Bureau Mail Log (bml). The survey duration was five weeks, from May thru July 2019.

Prior to the survey's implementation, OMH-HDP created a health literacy committee to develop a climate survey of current and future health literacy needs. Committee members were identified based on knowledge, expertise in health literacy, survey development, qualitative and quantitative analysis.

The survey yields specific activity-based performance metrics to achieve the vision of organization-wide health literacy activities and improvements. In addition to supporting the NYS DOH Strategic Plan, the survey hypothetically serves as a model for initiatives related to achieving health equity and the mission of OMH-HDP. The survey also identifies future opportunities to increase awareness and utilization of health literacy practices and address the social determinants of health, language access, and cultural competence.

The next steps include qualitative and quantitative data analysis, priority-setting, and planning. The Department's communication plans include sharing the results throughout the NYS DOH and with leadership to assess resource and fiscal needs for implementation of a strategic plan.

The survey's performance metrics should enable continuous evaluation and course correction. Once completed, New York State will be the first state Department of Health agency to have conducted an organization-wide health literacy survey. The Health Literacy Strategic Plan not only supports the development, implementation, and execution of activities related to OMH-HDP's legislative mandates, it also speaks to areas of focus related to the DOH's Prevention Agenda and its strategic plan.

4. Implications of New York State's Health Literacy Initiatives

The current initiatives reflect a multilevel approach to improve effective communication and health literacy across the Department's internal and external partners. The NY health literacy initiatives developed within the past two years strengthen the case to address health equity, support innovative programs and policies, as well as posit research efforts for future DOH and statewide initiatives. In addition, the health literacy initiatives promote collaborative efforts across organizations and communities and identify successful strategies to identify disparities among New York's racial and ethnic minority populations. As aforementioned, the New York State Department of Health is the first health department at the state level in the United States to execute an organization-wide health literacy survey. Qualitative insights from the survey will supplement the current knowledge base regarding a spectrum of health literacy issues including: the definition of health literacy; mandated or optional training; and current DOH efforts.

Upon preliminary overview of the data, survey respondents expressed health literacy as being crucial to their work. Respondents also noted a need to address opportunities for enhancement for internal organization-wide policies and external policies impacting public health initiatives. Respondents additionally addressed their own health literacy levels of understanding, and a recommendation to increase health literacy's profile within the Department. The latter information will guide training and education opportunities provided to DOH staff, especially for staff who communicate with external audiences, whose scope of work focuses on health messages, and for those whose work has an indirect impact on the public. The survey's embedded constructs addressing areas such as (employee) self-assessment, suggestions, execution and enforcement, and mission provided valuable information as to the importance of health literacy and the need to address the responses provided.

In light of this information, OMH-HDP plans the Second Annual Health Literacy Summit to be held in October during Health Literacy Month. Participants will:

- Identify resources to develop effective messaging to support health behavior change.
- Discuss how to best design materials that will resonate with individuals and groups accessing services throughout New York State.

- Develop techniques to integrate health literacy in oral and written communication
- Learn of strategies to recognize health literacy disparities which persist among racial and ethnic minority populations.

The New York State DOH Health Literacy efforts are recognized as an important aspect of the provision of healthcare services. With a commissioner who champions effective communication in word and in deed, New Yorkers benefit from initiatives which support healthy outcomes and well-being. The DSRIP initiatives also speak to the importance of the role of health literacy in health actions and access. Health information should be presented in a manner that is relevant, understandable, and resonates with the diverse communities throughout New York State. OMH HDP staff address health literacy in the many aspects of programs and initiatives. It applies to data, the public, and work environments. It also is infused in areas of language access and cultural and linguistic competency. The NYS DOH is perceived to be a front runner in providing information about health and healthcare and can achieve health equity when information is understood, explained in a manner that resonates with the individual, and provides all this in an environment of trust and collaboration.

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MedlinePlus at 21: A Website Devoted to Consumer Health Information

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Abstract. This report is about the consumer health website MedlinePlus.gov. The latter website was created by the U.S. National Library of Medicine and features content produced by the U.S. National Institutes of Health. The report provides an overview, origin, content, and possible future evolution of the website. The report also spotlights the specific features of the MedlinePlus health topic on health literacy and discusses the PubMed Topic Specific Query on health literacy.

Keywords. Health literacy, MedlinePlus, consumer health, National Library of Medicine, National Institutes of Health

1. Introduction

This report is organized into six sections which provide a brief overview of MedlinePlus.gov; discuss its creation; note its audience and inclusion of content guidelines; explain the website's health literacy health topic page; introduce the free MEDLINE/PubMed search of health literacy literature; mention MedlinePlus' recent and future changes; and provide a conclusion. Some past and present efforts to advance health literacy within MedlinePlus.gov are mentioned.

2. MedlinePlus: Brief Overview

The U.S. National Library of Medicine (NLM) launched MedlinePlus.gov in October 1998. Since its first day about 21 years ago, MedlinePlus has provided health information intended for health consumers, or general audiences. MedlinePlus.gov attempts to enhance the public's understanding of health and medicine, so the website might be considered as a working experiment to promote health literacy in English and Spanish and increasingly, in other languages.

MedlinePlus.gov is free of charge and contains no advertising. It is financially supported by the U.S. Congress through its funding of NLM and the National Institutes of Health (NIH). MedlinePlus consists of consumer health information from NIH, other U.S. federal health agencies, and diverse governmental and non-governmental evidence-based health organizations in the U.S. and internationally. MedlinePlus features a comprehensive medical encyclopedia, a drug information database, information about

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vitamins and supplements, laboratory test information, and information in multiple languages. MedlinePlus includes health and surgery video materials.

MedlinePlus is available in English and Spanish. A user can toggle into either language on a link on the top right side of the home as well as other pages on the website.

Much of the content on MedlinePlus is organized into 1030 health topic pages in English (and 1027 in Spanish) that cover prevalent diseases and conditions. The health topic pages include health information for vulnerable populations including: African American health; Hispanic American health; Native American health; rural health concerns; Native Hawaiian and Pacific Islander health; Gay, Lesbian, Bisexual, and Transgender health; and Veterans and Military health.

There is an A to Z list of health topic pages to browse through so users can target information and navigate to a specific topic. There also is a search box located on each page that leads to health topic and other pages. Health topic pages additionally are organized generically by: body location/systems; disorders and conditions; diagnosis and therapy; demographic groups; and health & wellness.

Each health topic page consists of a summary explanation of the topic with relevant information listed below a summary that navigates a user to more in-depth information. The summaries are written for lay audiences and frequently are derived from NIH-developed health information. There are several categories within each health topic. The categories within most health topic pages include: diagnosis and tests; treatment and therapies; related issues; genetics; statistics and research; clinical trials; and others. These categories may vary depending on the topic and length of a health topic page.

Many health topic pages also provide links to patient handouts that come from the Medical Encyclopedia. While physicians are encouraged to print handouts for patients, anyone can print handouts for personal, family, or caregiver use. The Medical Encyclopedia includes more than 4,000 articles about diseases, conditions, tests, symptoms, injuries, and surgeries. In addition, it contains an extensive library of medical photographs and illustrations. The encyclopedia articles are listed in alphabetical order within an A to Z list. Specific articles can also be searched for using the search box. The Medical Encyclopedia is not curated by NLM; it is purchased content published by A.D.A.M. Inc.

The Drugs, Herbs and Supplements section of MedlinePlus section is divided into drugs and herbs and supplements. The drug section includes information on prescription and over-the-counter drugs, which is provided by the American Society of Health System-Pharmacists (ASHP). The Herbs and Supplement information is provided by the U.S. National Center for Complementary and Integrative Health and the U.S. Natural Medicines Comprehensive Database. The latter includes dietary supplements and herbal remedies, so users can learn about their effectiveness, usual dosage, and drug interactions.

MedlinePlus also includes laboratory test information where users can learn more about personal laboratory tests, including what a lab test is used for, why a doctor ordered it, how the test will feel, and how to assess the results.

A videos & tools section provides programs on topics such as anatomy, body systems, and surgical procedures. Users can test their knowledge with interactive tutorials and games. From a staff perspective, one of the surprises regarding MedlinePlus.gov's use has been the enduring popularity of videos of surgeries.

MedlinePlus.gov had about 84 million unique visitors and 179 million page visits from October through December 18, 2018 [1]. By comparison -- during its initial quarter (October-December 1998), MedlinePlus received about 53,000 unique visitors and about

682,000 page visits [1]. User statistics that span MedlinePlus.gov's history are available at: https://medlineplus.gov/usestatistics.html [1]. An outline of MedlinePlus.gov's milestones are available at: https://medlineplus.gov/milestones.html [2].

3. MedlinePlus' Creation

Prior to MedlinePlus.gov's launch, NLM's services primarily were devoted for use by physicians, researchers, and librarians. Health consumers increasingly discovered NLM as its web presence for health care professionals evolved through services such as PubMed, which was launched in 1996. PubMed provides access to research published in international, refereed medical journals [3].

As consumer access to the Internet became more common in the 1990s, NLM's audience for then-professionally oriented services began to attract members of the general public, often including patients or representatives of the families of patients.

Initially, the public's interest was observable via increasing consumer inquiries that NLM's customer service department received. Inquiries began to increase from across the U.S. and internationally in the early to mid-1990s. The questions from non-health professionals included inquiries about diseases, wellness, treatment, locating a physician, locating a hospital and drug information, and sometimes finding health information. NLM's reference librarians often directed persons to then-available Internet (or stored-library) resources to either find or research an answer to individual queries. As the latter increased, the need (and opportunity) for a consumer-oriented health information service became increasingly apparent to NLM's medical librarians and senior staff.

In one of its pre-MedlinePlus launch efforts, NLM completed a pilot project involving 39 public library organizations with more than 200 locations in nine U.S. states (Alabama, Georgia, Maryland, New York, Pennsylvania, South Carolina, Tennessee, Texas and Virginia and the District of Columbia). The Medical Questions project was designed to increase public awareness of - and access to - health information via the Internet [4]. Albeit intrinsically valuable, the Medical Questions initiative helped motivate NLM to find a new way to create a resource that could interactively assist with ongoing consumer inquiries about health and medicine -- and provide an always available, alternative resource to answer public questions (that did not rely on the limited availability of NLM's medical librarians).

During the time MedlinePlus was planned, developed, and launched, NLM's then-director (Donald A.B. Lindberg M.D.) often reminded the project's staff that: a) informed consumers are better patients and b) patients, caregivers, and non-medical professionals have diverse health information needs. Fortunately, the MedlinePlus.gov development team agreed the then-nascent health information service should address these as well as other consumer health information challenges, which included providing access to understandable (or health literate) medical information.

From the outset, MedlinePlus was developed as an easy-to-understand resource for the public. While the term 'health literacy' was not widely used in the mid-1990s, the need to improve the public's understanding of health (that included helping patients comprehend complex medical jargon and terminology) was internally acknowledged as part of MedlinePlus' mission.

A second challenge was to provide a new route for the public to access MEDLINE and NIH's comprehensive and authoritative health information resources. Hence, a comprehensive consumer health portal was created with access to MEDLINE (the world's largest database of peer-reviewed medical literature). Eventually, this was coupled with links to NIH’s other consumer health information resources, clearinghouses from non-governmental and governmental health-related organizations, clinical trials, and even consumer self-help medical groups.

A third challenge was to meet a pressing, ongoing need for health information to be current, updated, reviewed regularly, and clinically valid (or as evidence-based as possible).

To respond to all these challenges, NLM combined the enduring skills of medical librarians and then-pioneering health information technology experts to jointly curate the new, comprehensive, health information service. For more than two decades, MedlinePlus’ depth and diversity have depended on the skills of medical librarians and health information technology experts to organize, collect, classify, and provide health information to the public. MedlinePlus.gov’s utility remains dependent on the latter coordination with an understanding that MedlinePlus should strive to respond to (and anticipate) consumer health needs by providing comprehensive and understandable medical information.

4. MedlinePlus’ Audience and Inclusion of Content Guidelines

The primary audience for MedlinePlus is the ‘public,’ which is operationalized as patients and families of patients. These populations were identified as having the greatest need for evidence-based medical information in the aforementioned *Medical Questions* initiative [4]. Indeed, for the past 21 years, the needs of patients and families of patients have been considered first and foremost in producing, curating, or changing MedlinePlus’ content. A prevailing interest is to help patients and families of patients find authoritative health information from a comprehensive web portal.

MedlinePlus.gov keeps track of the ongoing international and domestic use of the service. Using analytics tools, MedlinePlus.gov’s staff can determine usage by geolocation. For example, North America is the heaviest usage area, followed by Asia, Oceania, and Africa. Within the U.S., more MedlinePlus users are clustered in these high population U.S. states: California; Texas; New York; Florida; Illinois; Pennsylvania; Georgia; Ohio; North Carolina; and Michigan. Visitors to NLM can view monitors that update the geographical dispersion of interest in MedlinePlus as well as some of NLM’s other health information technology services.

Today, MedlinePlus.gov provides free access to information produced by NLM and NIH, such as searches of MEDLINE/PubMed, and ClinicalTrials.gov (the database of clinical research studies conducted at the National Institutes of Health and clinical institutions worldwide).

MedlinePlus adheres to strict quality guidelines that determine what health and clinical information is provided. While most evidence-based information comes from NIH institutes, additional sources include other federal agencies and some nongovernmental health organizations.

MedlinePlus.gov’s quality guidelines, or whether MedlinePlus links to a candidate website’s health information, are based on the following criteria: the quality, authority and accuracy of the provided health content; a candidate website’s advertising guidelines; and the availability and maintenance of a candidate’s website.

Some of the specific criteria within each of these areas are provided below.

4.1. Quality, Authority and Accuracy of Health Content

- In order to be linked, the mission of the organization that provides health information must reflect MedlinePlus' educational goals and intended audience.
- To be linked, a candidate organization must provide accurate, evidence-based information that complements or enhances the government information found in MedlinePlus.
- The source of the candidate's website's content must be established, respected, and evidence-based. A candidate organization needs to publish a list of advisory board members or consultants to their website.
- The information provided on the candidate's website needs to be appropriate to MedlinePlus' audience's reading level, well-organized, and easy to use. (The latter criteria operationalize some health literacy principles) [5].
- Candidate health websites should provide original content.
- Candidate health websites should have a process to review the availability and evidentiary foundation of all provided information and links.

4.2. The Primary Purpose of a Candidate Website Should be Educational and Not to Sell a Product or Service. Most Content Should be Available at No Charge

- MedlinePlus prefers no advertising on candidate web pages. In the infrequent case where advertising is displayed, the advertising should not suggest a commercial influence on the selection and production of health content.
- The candidate website needs to clearly differentiate between its health content and advertising. There should be an advertising policy on the site. Advertisers or sponsors must not play a role in selecting or editing health information.
- MedlinePlus excludes organizations and web resources if the presentation or content might lead a reasonable user to infer an endorsement of health products or services.
- While MedlinePlus provides links to directories to help find health professionals, services, and facilities, NLM does not endorse or recommend the organizations that produce directories, or the individuals and organizations included in the directories.

4.3. Availability and Maintenance of a Candidate Website

- The candidate website should be available consistently and lack technical usability issues.
- The candidate website should link only to reliable sources and maintain the links.
- The source for the contents on the candidate's web page(s) and the entity responsible for maintaining the website (e.g. the webmaster, organization, creator of the content) need to be transparent.
- The information on a candidate website should be current, or an update timeline should be included.
- User registration should not be required to view the information on a candidate's website.

Turning to MedlinePlus' interest in advancing consumer readability, the information on MedlinePlus, such as the summaries on the health topic pages, are written at the fifth to eight grade reading level [6]. MedlinePlus also curates and identifies an easy-to-read collection of health information provided by diverse health institutes and agencies: https://medlineplus.gov/all_easytoread.html.

To encourage other health communicators, NLM provides instructions/guidance about how to write easy-to read health materials: https://medlineplus.gov/etr.html. The link lists step-by-step instructions to create easy-to-read contributions.

To help physicians and health care professionals provide patient materials, MedlinePlus' Patient Handout information is provided in the website's medical encyclopedia. Health professionals can easily print this information and provide it to their patients. MedlinePlus contains thousands of pages identified as patient handouts, which often are available within health topic pages.

Since 2002, MedlinePlus has been available in Spanish. The health topic pages in Spanish are translated directly from the English version. When links are bilingual, they are provided in both languages. Some links to health information in Spanish are available only in the Spanish language. Otherwise, the health information links on Spanish topic pages either utilize trusted NIH resources, or health organizations whose content follows the aforementioned inclusion criteria.

In addition to 1027 Spanish language health topic pages and other information en espanol, MedlinePlus includes other multilingual resources of health information. The process to select health services in other languages is explained in: https://medlineplus.gov/languages/criteria.html [7].

The multilingual resources on MedlinePlus often are derived from the HealthReach collection at https://healthreach.nlm.nih.gov/ [8]. HealthReach identifies, collects, and makes available free resources that are accurate, up-to-date, and assessed for quality. A caveat; MedlinePlus' multilingual collection is not as comprehensive as its health resources in English and Spanish. In some grey areas, such as health resources specific to refugee resettlement and education, some services may be integrated in HealthReach but not within MedlinePlus.gov.

5. Health Literacy Health Topic, MEDLINE/PubMed Search, and Health Literacy Information Resources

MedlinePlus has a health topic page devoted to help consumers understand health literacy: https://medlineplus.gov/healthliteracy.html [9]. The topic page consists of a summary about health literacy and lists (and links to) many related resources.

While the information in MedlinePlus' health literacy health topic page is geared towards general users, it provides an overview of the field for health professionals. Currently, the listed health literacy resources include information from: NIH; the U.S. Department of Health and Human Services (HHS); the U.S. Centers for Disease Control and Prevention (CDC); and the U.S. Food and Drug Administration (FDA). Similar to others, the health topic page is organized into different subcategories so users easily can locate specific health literacy information. The topic page also lists related resources from other areas within MedlinePlus, which incorporates information from the medical encyclopedia, related health topics, and information in other languages.

As a compliment to the consumer-oriented health literacy topic page in MedlinePlus, NLM maintains the MEDLINE/PubMed Search and Health Literacy Information

Resources resource page: https://www.nlm.nih.gov/services/queries/health_literacy.html [10]. The latter resource includes a comprehensive literature search of PubMed that retrieves references about health literacy and provides access to health literacy research that has been published in international medical journals. Users can click on the search link to launch the search and review the results.

The health literacy search strategy is reviewed periodically by NLM medical librarians; it evolved from an early 21st century effort to assist the then-new National Academy of Sciences, Engineering, and Medicine Roundtable on Health Literacy [11]. The health literacy search engine incorporates many of the subfields within health literacy scholarship.

The current search parameters are:

(health[ti] AND literacy[ti])
OR ("health literacy" OR "health literate" OR "medical literacy")
OR (functional[tw] AND health[tw] AND literacy[tw])
OR numeracy
OR ((low literate[ti] OR low literacy[ti] OR literacy[ti] OR illiteracy[ti] OR literate[ti]
OR illiterate[ti] OR reading[mh] OR comprehension[mh]) AND (health
promotion[major] OR health education[major] OR patient education[major] OR
Communication Barriers[major] OR communication[major:noexp] OR Health
Knowledge, Attitudes, Practice[major] OR attitude to health[major])) OR
(comprehension[major] AND educational status[major])
OR (family[ti] AND literacy[ti])
OR (("drug labeling" OR Prescriptions [mh]) AND ("comprehension" OR
"numeracy"))
OR ((cancer[ti] OR diabetes[ti]) AND (literacy[ti] OR comprehension[ti]))
OR "adult literacy"
OR "limited literacy"
OR "patient understanding"[ti]
OR (self care [major] AND perception[mh])
OR (comprehension AND food labeling[mh])
OR (comprehension AND informed consent)
OR (comprehension AND insurance, health)
AND English[la]

The health literacy search strategy is comprehensive. Users who are familiar with PubMed can alter the above terms by substituting or adding terms to limit the results to suit individual needs. Instructions on how to use PubMed are available at: https://www.nlm.nih.gov/bsd/disted/pubmedtutorial/cover.html.

The aforementioned, broader resource page also lists links to a range of health literacy information resources from NLM and NIH and includes links to websites provided by international governmental and nongovernmental agencies as selected by NLM's medical librarians.

6. MedlinePlus' Evolution and Future

MedlinePlus.gov began on the Internet as a curated list of links to consumer health information produced primarily by NIH websites. While the website's scope has expanded significantly since 1998, MedlinePlus.gov also made at least four technical changes in the 21^{st} century that advanced the website's interface and utility. These changes included: a migration from a portal to a search engine model; the use of responsive design; the introduction of MedlinePlus Connect (that links MedlinePlus' information with electronic health record platforms); and the introduction of an extensible markup language (XML) format. Each will be briefly introduced with a discussion of MedlinePlus.gov's future as a repository of health data.

When MedlinePlus began, many Internet developers used a portal model to provide information to users, where information was distributed among 'portal' sites. Portal sites often organize content by subject and user search for a category of interest and then, proceed to narrow a search based on subject identifiers. MedlinePlus adopted a portal architecture at the website's launch, which has migrated in recent years to a search engine model.

Although portal models continue to be a viable source of health information for consumers, an improved search capacity and interface has provided an alternative interface architecture during the past 10-15 years. The evolution of search engines, such as Google, Bing and others, created an interface where a user could type in a plain language term and receive increasingly tailored links to highly relevant information. Some search engines even display a text summary of the answer to specific inquiries.

While search engines have been available on websites since the Internet's inception, an improved responsive capacity to search literature and respond more precisely to plain language inquiries have generated a transition to a search engine model.

Currently, MedlinePlus seeks to reach users by structuring the website's content to be more locatable and work in better tandem with advanced search engines, which requires the adoption of a search engine model. Perhaps a migration to a search engine model is fitting since MedlinePlus originally was developed as an alternative, aforementioned option for consumers to obtain answers to health questions.

Second, in November 2010, NLM introduced MedlinePlus Connect, a free service that enables any electronic health record (EHR) system to link to relevant, authoritative and current health information from MedlinePlus. MedlinePlus Connect delivers information about conditions and disorders, health and wellness, as well as prescription and over-the-counter medications to patients, families, and health care providers as needed by incorporating MedlinePlus' content into diverse EHR systems.

MedlinePlus Connect works by accepting specific requests from EHR systems and then, provides links to the relevant health information in MedlinePlus. To accomplish this, NLM mapped all MedlinePlus health topic pages to the standard diagnostic coding systems used in EHRs. Specifically, NLM used the ICD-9-CM (International Classification of Diseases, 9th edition, Clinical Modification) and the SNOMED CT CORE Problem List Subset (Systematized Nomenclature of Medicine, Clinical Terms, CORE Problem List Subset) as the code mapping foundations.

MedlinePlus Connect also links to medication information using patient friendly language. When EHR systems send MedlinePlus Connect a request containing a standardized medication code, the service returns links to the most appropriate drug information for prescription and over-the-counter medicines. For medication requests, MedlinePlus Connect supports RXCUI (RxNorm Concept Unique Identifier) and NDC (National Drug Code), which are widely used in the U.S.

Third, in 2015 MedlinePlus switched from a separate desktop and mobile version of the website to a responsive web design with an identical and simultaneous display across diverse Internet platforms. Responsive web design optimizes user interaction by adjusting each page based on the device used regardless if it is a desktop monitor or a small mobile touchscreen. Incidentally, this change was preceded by increasing information that most users linked to MedlinePlus via mobile devices rather than desktop computers.

Fourth, in September 2010 NLM released a search-based web service that provides access to MedlinePlus' health topic data in extensible markup language (XML) format. This change enables software developers to build applications that incorporate health information provided by MedlinePlus. Via this process, MedlinePlus data can be transformed into a more customizable view for specific user populations.

MedlinePlus continues to evolve so it can better present selected consumer health information from NIH and other governmental and non-governmental sources. In the future, MedlinePlus.gov could become more of a repository of health data provided by medical journals and organizations. This prediction is based on the International Committee of Medical Journal Editors' (ICMJE) recent decision to ask future authors to plan to deposit the data sets that underlie the findings within a published study [12]. ICMJE's request means someday the electronic version of medical journals may include vast health data sets that will be accessible to readers. As a result, MedlinePlus users would be able to view the details that undergird some medical research in heretofore unavailable detail.

While future data set availability is sometimes perceived as transformative by medical researchers, the impact on consumers remains more difficult to predict because of the complexity and curated accuracy of the health data [12]. So, a new challenge for NLM and MedlinePlus will be to help consumers make sense of vast, new repositories of medical research information and perhaps someday use these services as a resource to answer individual medical questions.

7. Conclusion: How MedlinePlus Advances Health Literacy

MedlinePlus.gov helps advance health literacy by adhering to a strict policy to provide links to consumer health information written for lay users. MedlinePlus.gov is not targeted toward researchers or health professionals and avoids using medical jargon or terms commonly exercised in the medical research community. Written at a fifth to eight grade reading level, MedlinePlus is for patients and friends/families of patients. MedlinePlus encourages communicators to use plain language to explain health and medicine. The website also links to succinct, clear, and patient-friendly materials available on the Internet.

Besides a topic page devoted to health literacy, MedlinePlus adds health topic pages that seek to improve numeracy and the public's understanding of medical research. These include: understanding medical research https://medlineplus.gov/understandingmedicalresearch.html and evaluating health information https://medlineplus.gov/evaluatinghealthinformation.html [13-14] Each of the latter health topic pages provide an array of links about health research and numeracy related resources, which are written for general audiences.

MedlinePlus also helps patients and caregivers with a limited understanding of medical jargon locate relevant information. Similarly, MedlinePlus seeks to bridge comprehension gaps by: furnishing definitions of medical terms; helping explain the data in routine laboratory tests; emphasizing easy-to-understand medical information; and providing questions for patients to ask physicians during office visits for some diseases and conditions.

Overall, MedlinePlus strives to help patients and caregivers navigate the health care delivery system, understand individual, family, and public health, and build a body of knowledge to better take care of oneself, friends, family, and even communities. Ultimately, MedlinePlus.gov's goal is to ease consumer access to evidence-based health information, which helps improve the quality of life of adults, teens, toddlers, and citizens. As such, MedlinePlus.gov remains a working experiment to improve the public's understanding of health and medicine and enhance health literacy in the U.S. and around the world.

Finally, the author pays tribute to the NLM staff members and contractors who have worked on MedlinePlus and embraced its consumer health-oriented mission in the 21 years since the website's inception.

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How the U.S. Agency for Healthcare Research and Quality Promotes Health Literate Health Care

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Abstract. This report traces the U.S. Agency for Healthcare Research and Quality's (AHRQ) strategic approach to promote health literate health care delivery systems. For almost 15 years, the AHRQ Health Literacy Action Plan has served as the framework for the Agency's efforts to: 1) Develop Measures; 2) Improve the Evidence Base and Create Implementation Tools; 3) Create and Support Change; 4) Disseminate and Transfer Knowledge and Tools; and 5) Practice What We Preach. Drawing upon its core competencies in data and measurement, practice improvement, and health services research, AHRQ accelerated the uptake of evidence-based health literacy strategies by health care organizations.

Keywords. Health literacy, quality improvement, health systems, implementation, knowledge transfer

1. Introduction

This report describes the role of the Agency for Healthcare Research and Quality (AHRQ) as a leader in improving health literacy in health care delivery systems. AHRQ's niche in the U.S. Department of Health and Human Services (HHS) is to help improve how health care is delivered and to make sure the care people receive is high quality, safe, and high value. AHRQ has no regulatory authority, nor is it a payer for health care services. Rather, the agency strives to improve the lives of patients through health services research, practice improvement, and data analytics. AHRQ's work typically targets clinicians and health systems to help them have the best evidence and tools to improve the delivery of care.

This report describes AHRQ's strategic approach to promoting health literacy from 2005 to 2018. Using the framework of the AHRQ Health Literacy Action Plan, the

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authors describe how AHRQ used its strengths in innovation and implementation to increase awareness about health literacy and provide the science, the data, and the tools for practice improvement.

2. The AHRQ Health Literacy Action Plan

AHRQ was part of the first national efforts to promote health literacy. In 2004, AHRQ and the Institute of Medicine (IOM) held a joint press conference to release AHRQ's ground-breaking review of evidence linking low literacy to poor health outcomes and the IOM's landmark report, 'Health Literacy: A Prescription to End Confusion' [1-2]. AHRQ's health literacy work intensified after the formation of the HHS Health Literacy Work Group. For the first time, an objective to improve health literacy had been included in the national health promotion program - *Healthy People* [3]. As part of this effort, Cynthia Baur (then-chair of the HHS Health Literacy Workgroup) asked all HHS agencies to form their own health literacy workgroups to foster health literacy improvement.

The AHRQ Health Literacy Workgroup quickly decided that in order to have an impact, it needed to educate AHRQ's senior leadership about health literacy. The Workgroup got on the agenda of AHRQ's Executive Management Meeting and made the case that addressing health literacy was fundamental to achieving the goals of each of AHRQ's portfolios of work. AHRQ's receptive leadership invited the Workgroup to return with a proposal for action.

In 2005, AHRQ leadership approved five points of the AHRQ Health Literacy Action Plan: 1) Develop Measures; 2) Improve the Evidence Base and Create Implementation Tools; 3) Create and Support Change; 4) Disseminate and Transfer Knowledge and Tools; and 5) Practice What We Preach. This report traces AHRQ's progress in implementing that Action Plan during the next decade and a half. Table 1 provides a summary of AHRQ's work within these five areas.

3. Developing Health Literacy Measures

Although AHRQ grantees have developed some measures of individuals' health literacy, AHRQ's main contribution to health literacy measurement has focused on organizational health literacy (OHL), i.e., measuring whether an organization makes it easy for people to navigate, understand, and use information and services to take care of their health [4-6]. AHRQ's work in health literacy measurement has accomplished three important goals. The first is to provide validated questions for health systems to get specific feedback on provider-patient communication. The second is to capture national progress on whether health care providers are using health literacy strategies and are making it easier for their patients to understand what they need to do to manage their conditions and take care of their health. The third is to impel the frontier of OHL measurement by publicizing how organizations can and are using metrics in their OHL improvement efforts.

Table 1. Summary of AHRQ's Work to Promote Health Literate Health Care, 2005-2019

Activity	**Outcome**
Develop Measures	
Developed health literacy patient survey items	Validated CAHPS® survey items that capture distinct communication behaviors that can be targeted for improvement
Identified and assessed organizational health literacy quality improvement measures	Organizational health literacy quality improvement measures that do not rely on patient-reported data which were determined to be useful, meaningful, feasible, and have face validity
Added health literacy items to national household survey (MEPS)	National tracking and reporting of health care providers' communication practices by Healthy People and the National Healthcare Quality and Disparities Report
Improve the Evidence Base and Create Implementation Tools	
Co-sponsored health literacy research program announcement with NIH	Funded grants focused on understanding and promoting health literacy
Commissioned health literacy systematic evidence reviews	*Literacy and Health Outcomes* and *Health Literacy Interventions and Outcomes* summarized and synthesized evidence on the impact of limited literacy and identified effective strategies to mitigate its effects
Created and updated tools to help primary care practices adopt health literacy "universal precautions"	*AHRQ Health Literacy Universal Precautions Toolkit* (1st and 2nd editions)
Developed health literacy educational modules for clinicians as part of ongoing continuing medical education requirements	*AHRQ Health Literacy Knowledge Self-Assessment Module*, offered by American Board of Pediatrics (ABP), American Board of Family Physicians (ABFP), and Optum Health Education; and *Health Literacy Practice Improvement Module* offered by ABP and ABFP
Developed pharmacy health literacy plug-and-play modules for pharmacy colleges	*Advancing Pharmacy Health Literacy Practices Through Quality Improvement* (Four PowerPoint presentations and 17 guides for student projects
Developed health literate approach to obtaining informed consent from prospective research participants and authorization to use medical information	AHRQ Informed Consent and Authorization Toolkit for Minimal Risk Research
Integrated health literacy into other tools	Examples: *Guide to Patient and Family Engagement in Hospital Quality and Safety* (Strategy 2: Communicating to Improve Quality); Guide to Improving Patient Safety in Primary Care Settings by Engaging Patients and Families (Be Prepared To Be Engaged, Teach-Back); SHARE Approach (Tool 4: Health Literacy and Shared Decision Making)
Create and Support Change	
Supported other organizations efforts to promote health literacy	Collaborated (e.g., co-sponsoring meetings, drafting white papers, educating, and serving on expert health literacy advisory groups) with a variety of U.S. organizations, including the American College of Physicians Foundation, the American Medical Association Foundation, America's Health Insurance Plans, U.S. Pharmacopeia, The Joint Commission, and Roundtable on Health Literacy of the National Academies of Science, Engineering, and Medicine
Provided inspirational and conceptual leadership	Articles and presentations: Ten Attributes of Health Literate Health Care Organizations, A Proposed 'Health Literate Care Model' Would Constitute a Systems Approach to Improving Patients' Engagement in Care.

Activity	Outcome
Disseminate and Transfer Knowledge and Tools	
Portrayed how health literacy strategies could help organizations achieve their goals	Crosswalk between the standards for patient-centered care and the tools in the AHRQ Health Literacy Universal Precautions Toolkit
Helped hospitals replicate the Re-Engineered Discharge (RED), a patient safety and health literacy intervention	Program of education and technical assistance, and the Re-Engineered Discharge (RED) Toolkit
Practice What We Preach	
Developed tool to assess the understandability and actionability of print and audiovisual materials and used it to identify areas for AHRQ improvement	Patient Education Materials Assessment Tool (PEMAT), PEMAT checklist, opportunities for AHRQ improvement identified
Applied health literacy principles to U.S. Preventive Services Task Force (USPSTF) Clinician Summary, addressing user feedback and measuring improvement with the PEMAT	Improved Clinician Summary, the summary version of USPSTF recommendations for clinicians, so that only the most important and actionable information is included, easy to find, and easy to understand

AHRQ has developed a family of surveys that capture patient experiences in a variety of health care settings, with providers, and with health plans – the Consumer Assessment of Healthcare Providers and Systems (CAHPS®). The communication composite items are a core part of the CAHPS surveys. They ask people whether their providers: 1) listened carefully to them; 2) explained things in a way that was easy to understand; 3) showed respect for what they had to say; and 4) spent enough time with them.

AHRQ wanted to develop additional items that would provide specific, actionable information to guide and track the impact of health literacy improvement activities undertaken by health care organizations. AHRQ used the rigorous CAHPS survey development process to develop health literacy supplemental items for the CAHPS Clinician and Group Survey, a survey to assess patient experiences with health care providers and staff in ambulatory care practices [7].

AHRQ conducted an environmental scan to identify domains of interest and relevant survey items, issued a Call for Measures in the U.S. Federal Register, interviewed health literacy experts and held stakeholder meetings, and drafted new survey items when existing items could not be adapted. The survey was translated into Spanish using the CAHPS protocol, and cognitive interviews were conducted in English and Spanish to determine whether the items were understood as intended. After adjustments were made and additional cognitive interviews conducted, the survey was field tested and psychometrically assessed. The result was a set of 30 supplemental items from which health systems can select to use with the CAHPS Clinician and Group Survey. Each item captures a distinct communication behavior (e.g., using unfamiliar medical words, talking too fast, failing to answer questions) that could be targeted for improvement. This process was repeated to generate supplemental health literacy item sets for the Health Plan and Hospital CAHPS surveys.

AHRQ measures are used to track national progress in improving health care providers' communication skills. AHRQ produced data for *Healthy People 2010* by inserting the four Health Plan CAHPS items from the communication composite into AHRQ's national household Medical Expenditure Panel Survey (MEPS). For *Healthy People 2020*, AHRQ added additional items from the Health Plan CAHPS Item Set of

Addressing Health Literacy into MEPS. One of the metrics tracks the proportion of adults whose providers always initiated a teach-back method (i.e., how often providers asked them to describe how they would follow instructions), and another tracks the proportion of adults who always were offered help with forms at their physician's office. Table 2 shows data collection began with the 2011 fielding of MEPS, and, as of 2015, the metrics have increased significantly [8]. These data, which also suggest there is substantial room for improvement, also are analyzed and reported in the National Healthcare Quality and Disparities Report [9].

Table 2: Proportion of adults 25 and older who reported receiving health literate care

Health Literacy Metrics	**2011**	**2015**	**Increase**
Instructions always easy to understand	64%	70%	9.6% (p<.001)
Teach-back always initiated	24%	29%	22% (p<.001)
Help with forms always offered	14%	17%	16% (p<.1)

AHRQ also has explored methods to assess organizational health literacy improvement that does not rely on patient surveys. To avoid reinventing the wheel, AHRQ sought out OHL measures already in use by health care organizations. In addition to issuing a Call for Measures in the U.S. Federal Register and conducting a literature review, AHRQ interviewed 20 organizations that were working on OHL. A total of n=233 non-patient-reported organizational health literacy measures were identified. Using a modified Delphi process, consensus was reached that 22 OHL quality improvement (QI) measures were useful, meaningful, feasible, and had face validity [10].

4. Improving the Evidence Base and Creating Implementation Tools

Since AHRQ is key funder of health services research, improving the evidence base about health literacy was an inherent component of the AHRQ Health Literacy Action Plan. In 2004, AHRQ joined the National Institutes of Health in co-sponsoring program announcements, 'Understanding and Promoting Health Literacy.' Although it remained a co-sponsor of the health literacy program announcements until 2012, AHRQ ultimately funded relatively few health literacy grants through this mechanism. The Agency's more significant contribution to solidifying health literacy's evidence base during this time period was the commissioning and 2011 publication of an updated systematic review of the literature. 'Health Literacy Interventions and Outcomes: An Updated Systematic Review,' identified strategies, such as multi-component self-management interventions, that mitigate the effect of low health literacy [11].

However, the availability of increased evidence rarely is sufficient (by itself) to change the behavior of health care providers. Indeed, health care providers need to know how to make changes. As a result, AHRQ has invested in the creation of a variety of tools and training to make it easier for health systems and clinicians to implement evidence-based health literacy strategies.

The first and best known is the AHRQ Health Literacy Universal Precautions Toolkit [12]. Prior to the toolkit's adoption, AHRQ observed an increased awareness and interest among some health care providers to offset limited health literacy, which was perceived as a barrier to achieve good health outcomes. AHRQ responded by commissioning a toolkit to explain how primary care practices could adopt health literacy 'universal precautions' - specific actions predicated on the assumption that all patients may have difficulty comprehending health information and accessing health services. AHRQ's toolkit, first published in 2010, became a touchstone for health literacy improvement in U.S. primary care and throughout the continuum of health care. The release of the second edition in 2015 was accompanied by a guide for practice facilitators or quality improvement (QI) leaders [13-14]. The second edition presented concrete implementation advice based on the experiences of diverse primary care practices that participated in a demonstration of the toolkit. The AHRQ Health Literacy Universal Precautions Toolkit stimulated and informed health literacy improvement and was used by U.S. health systems of varying size and geographic location, such as such Intermountain Healthcare, Carolinas Healthcare Systems, Novant, Wellspan Health, and Johns Hopkins Healthcare [15].

Beyond using toolkits to promote health literate health care, AHRQ identified professional education as a practical lever to change organizational and clinician behavior. AHRQ seized on the requirement that physicians engage in continuing education (in order to maintain their medical board certifications) by developing two health literacy modules that cut across medical specialties.

Thousands of pediatricians and family physicians have received maintenance of certification credits for completing the AHRQ Health Literacy Knowledge Self-Assessment Module, and hundreds completed the Health Literacy Practice Improvement Module, which entails implementing a tool from the AHRQ Health Literacy Universal Precautions Toolkit and tracking its impact. Optum Health Education also has awarded thousands of continuing education credit hours to health professionals who have completed AHRQ health literacy education modules.

A further opportunity to infuse health literacy into professional education arose when AHRQ discovered that pharmacy colleges, rather than pharmacies themselves, were the main users of the tools in AHRQ's Pharmacy Health Literacy Center. AHRQ decided to make it easier for pharmacy colleges to integrate health literacy into their education programs by developing the plug and play curricular modules, 'Advancing Pharmacy Health Literacy Practices Through Quality Improvement' [16].

Recognizing that health care professionals often lack the skills to communicate evidence while engaging patients in shared decision making, AHRQ included a training module and five tools dedicated to communication skills in its SHARE Approach curriculum and toolkit [17]. The latter training addressed limited health literacy and numeracy and used the teach-back method. AHRQ also sponsored train-the-trainer workshops across the country to help health systems, health payers, clinicians, and other professional use the SHARE Approach. The full curriculum and supporting materials, all designed in accordance with health literacy principles, are available online.

In addition, AHRQ developed tools to help the U.S. research community adopt more health literate approaches. AHRQ created the AHRQ 'Informed Consent and Authorization Toolkit for Minimal Risk Research' to help health services researchers obtain informed consent from prospective research participants (and authorization to use medical information in research) via more health literate strategies [18]. In its Funding Opportunity Announcement Guidance, AHRQ communicated its expectation that informed consent and authorization documents should be understandable to all potential research participants, including those with low levels of literacy and limited English proficiency. The guidance also urges grantees to make sure that AHRQ-funded consumer products are appropriate for the target audience, including individuals from diverse cultural, language, and literacy backgrounds, and recommends audience testing be part of the development process.

Finally, in addition to dedicated health literacy products, AHRQ has integrated health literacy into its other tools. For example, when AHRQ created patient safety guides for hospitals and primary care practices on patient and family engagement, it included training on clear communication and tools for staff and patients on teach-back [19-20].

5. Creating and Supporting Change

Creating and supporting change requires more than laying out the evidence and developing tools to help health care organizations become more health literate. It involves collaborating with others and providing inspirational and conceptual leadership. To accomplish this, AHRQ worked with other organizations that are similiarly interested in the diffusion of health literacy research, initiatives, and approaches. AHRQ's collaborators have included: the American College of Physicians Foundation; the American Medical Association Foundation; America's Health Insurance Plans; U.S. Pharmacopeia; and The Joint Commission. Collaboration entailed co-sponsoring meetings, drafting white papers, conducting educational webinars and presentations, and serving on expert health literacy advisory groups.

One of the most fertile collaborations was with the Roundtable on Health Literacy (the Roundtable) of the National Academies of Science, Engineering, and Medicine. The mission of the Roundtable, whose members come from the public and private sectors, is to inform, inspire, and activate a wide variety of stakeholders to support the development, implementation, and sharing of evidence-based health literacy practices and policies. With such alignment of interests, AHRQ actively participated in formulating the Roundtable's agenda and planning workshops and other activities that would help health care organizations seeking to become more health literate. Inspired by what the National Standards for Culturally and Linguistically Appropriate Services (CLAS) has accomplished in promoting CLAS, AHRQ led a collaborative paper with Roundtable members that defined, 'Ten attributes of health literate health care organizations' [6, 15, 21]. The paper was widely cited and became a focus of OHL measurement efforts, which influenced the national health literacy activities of several nations outside the U.S.

Another conceptual contribution to how organizations can become health literate was advanced in a Health Affairs article that proposed the Health Literate Care Model [22]. The article describes how health literacy strategies can be integrated into the renowned Care Model. With its co-authors, AHRQ reasoned that addressing health literacy is a prerequisite for patient engagement and showed how each of the tools in the AHRQ Health Literacy Universal Precautions Toolkit could be used to implement the Health Literate Care Model.

6. Disseminate and Transfer Knowledge and Tools

Health care organizations must see health literacy improvement as critical to attaining their goals, rather than an additional task they have to heap upon an already crushing workload. In addition to using conventional means of spreading the word about AHRQ health literacy tools (e.g., webinars, listservs, publications, blogs, email blasts), AHRQ tried to portray health literacy as a way health care organizations could get their work done, rather than a new thing to do.

For example, AHRQ created a crosswalk between the standards for patient-centered care and the tools in the AHRQ Health Literacy Universal Precautions Toolkit that showed how using a particular tool could help engage patients and qualify for certification or recognition as a patient-centered medical home [23]. AHRQ worked with major accreditation organizations (i.e., The Joint Commission, National Committee for Quality Assurance, Utilization Review Accreditation Commission, and Accreditation Canada) to ensure accuracy in mapping tools to standards. In turn, these organizations let their members know about the crosswalks and, consequently, about the AHRQ Toolkit.

AHRQ's development of the Re-Engineered Discharge (RED) Toolkit provides another example of how health literacy can be mainstreamed by incorporating it within other key initiatives [24]. The RED was developed and tested by an AHRQ grantee to address the myriad of deficiencies in the hospital discharge process. The RED is both a patient safety and health literacy intervention. It tackles not only patient education and communication, but also contains strategies aimed at the challenging navigation of care transitions. The randomized controlled trial of the RED revealed that patients who received it were less likely to return to the hospital (the emergency department or readmission) than patients who received standard discharge practices, and thereby confirmed the importance of addressing health literacy to achieve improved health outcomes [25].

Interestingly, when AHRQ contracted with the Joint Commission Resources (JCR) to support hospitals interested in replicating the RED, enthusiasm for the intervention was tempered by financial realities. Approximately 270 hospitals availed themselves of JCR's instructional webinars and technical assistance. However, some hospitals were concerned about implementing an intervention that might reduce their revenues. This situation changed dramatically when the U.S. Centers for Medicare and Medicaid Services' (CMS) introduced penalties for 'excessive' 30-day readmissions. By the time the penalties kicked in, the RED Toolkit was published (that AHRQ commissioned to provide step-by-step implementation guidance to hospitals serving diverse populations). Within one month of its publication, more than 1,700 visits were paid to the RED Toolkit site. Many partners, including CMS' Hospital Engagement Networks, the Department of Defense, the American Hospital Association, and America's Health Insurance Plans, became interested in disseminating RED tools. By becoming a means to an end (i.e., reducing readmissions), attending to health literacy was embraced as part of a needed overhaul of discharge practices.

7. Practice What We Preach

Although much of AHRQ's health literacy work is externally focused, that is, concentrated on helping health care systems become more health literate, AHRQ also strives to observe health literacy principles. As a U.S. Federal agency, AHRQ is bound by the Plain Writing Act of 2010. The Act requires all new public facing documents use plain writing, defined by the legislation as writing that is clear, concise, well-organized, and follows other best practices appropriate to the subject or field and intended audience [26].

AHRQ's primary audiences are clinicians and health systems that deliver health care services. There is a fear that making products health literate will 'dumb them down.' However, it is important to recognize that AHRQ's audience members are busy individuals who require materials that are clear and actionable. Materials that are excessively wordy, visually dense, or overwhelm readers with too much information, may not be read - much less understood.

AHRQ has used a number of strategies to promote plain writing in its products. These have included staff training, using focus groups to obtain audience feedback, and pilot testing products. For example, when AHRQ tested both the first and second editions of the AHRQ Health Literacy Universal Precautions Toolkit, it discovered the tools had to be short and to the point, while layered with details and tips [27-28]. AHRQ has used a tool it developed – the Patient Education Materials Assessment Tool (PEMAT) – to assess the understandability and actionability of popular publications to identify areas for improvement [29]. AHRQ also created a checklist from the PEMAT and included it in the AHRQ Publishing and Communications Guidelines, which all contractors that produce materials for AHRQ are instructed to follow.

More recently, as part of an HHS-wide health literacy quality improvement effort, AHRQ worked with the U.S. Preventive Services Task Force (USPSTF) to improve communication about its evidence-based recommendations. AHRQ provides the USPSTF - an independent, volunteer panel of national experts in prevention and evidence-based medicine - with scientific, administrative, and dissemination support. As part of the USPSTF's commitment to ensure its recommendations about clinical preventive services are clear and useful to primary care clinicians, the Task Force updated the format of its recommendation statement, as well as its brief summary of each recommendation for clinicians (the clinician summary) [30].

The USPSTF, with support from AHRQ, used a health literacy improvement process that included conducting a literature review, interviews with primary care clinicians and dissemination and implementation experts, and feedback obtained from primary care clinicians on the recommendation statements [30]. AHRQ also solicited and incorporated feedback from USPSTF partner organizations, including clinical professional organizations that help disseminate and implement the recommendations.

To assess whether the new clinician summary format was an improvement from the prior version, two AHRQ staff completed the PEMAT and found the new format was more understandable and actionable. The USPSTF adopted the new health literate template for clinician summaries, which includes only the most important and actionable information and uses informative section headings.

While AHRQ has made progress towards becoming a health literate organization, limited time and funds have constrained achievements. For example, only limited testing of the new clinician summary format could be undertaken, in part due to the U.S. Paperwork Reduction Act clearance process required for any data collection from ten or more individuals. Similarly, tight deadlines prevent AHRQ's funding opportunity announcements from routinely going through a plain language editing process. Nevertheless, AHRQ strives to publish information that audience members understand the first time they read it.

8. Conclusion

AHRQ has pursued a strategic path to promoting health literacy quality improvement in health care delivery systems. Its multi-pronged Health Literacy Action Plan - to develop measures, improve the evidence base and create implementation tools, create and support change, disseminate and transfer knowledge and tools, and practice what we preach - drew upon AHRQ's core competencies in data and measurement, practice improvement, and health services research. AHRQ's work has accelerated the uptake of evidence-based health literacy strategies by health care organizations in the U.S. and influenced related activities in other nations.

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There's a Gap Between Digital Health Information and Users — Let's Close It

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Abstract. Digital health tools have the potential to improve health decision-making. Early evidence suggests their use may even be able to improve health outcomes. However, some health information and digital tools are not understandable or accessible to the majority of the U.S. population. This report explores the current disconnect between online health information and users. The authors provide a summary of practical strategies to address this gap and suggest next steps for further research.

Keywords. Digital health tools, health literacy, patient portals, eHealth, usability, mHealth, insurance enrollment

1. Introduction

Providing health information online - including strategies to prevent and manage diseases and tools to track progress toward wellness goals - can dramatically increase the reach of life-saving information. Almost all Americans (90%) use the internet, and most (81%) have searched online for health-related information in the last year [1-2].

The shift toward digital has led many health organizations, including U.S. government agencies, to move information and services online. But the barriers to access and use online information and tools can prevent leveraging their promise of enhanced reach and improved patient engagement.

This report explores the accessibility and usability challenges that digital health tools present for most people - and how we can overcome them to improve health literacy and health outcomes. The authors discuss practical, evidence-based strategies to improve the clarity and usability of digital health tools, as well as ideas for future research on emerging best practices. Note that for simplicity, we will use the term "digital health tools" to include health websites, apps, and interactive online tools.

The organizing question of this report is: How can we design digital health tools so their usability demands do not limit their reach?

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2. Challenges and Opportunities

Roughly one in two American adults struggle with literacy and read at an eighth-grade level or below [3]. And one in five adults read at a fifth-grade level or below [3]. Research suggests this has direct health implications. For example, Americans with low literacy skills are four times more likely to report fair or poor health than persons with the highest literacy skills [4].

The unique characteristics of digital health information, including context and complexity, make it challenging to communicate and understand. In 2015, the National Quality Health Website Survey identified and reviewed 100 top-ranked health-related websites. Researchers selected the sites based on traffic data, including unique visitors and pageviews. They then evaluated the websites using evidence-based criteria for improving the user experience through design, organization, and content. Fewer than half of the websites (42%) met the pre-selected quality criteria [5].

Additionally, the people most likely to have health problems — including lower income, older, rural, and non-white Americans — also are most likely to struggle to use digital health tools [6]. People with low health literacy are less likely to use online health information and tools, including patient portals and apps that track health behaviors [7-8].

To further complicate matters, people often access digital health information to inform or make health-related decisions. For example, research specific to health insurance decision-making clarifies that Americans struggle to understand health insurance - tasks like comparing insurance plans require consumers to navigate unfamiliar jargon, understand and use numbers (numeracy), and navigate an abundance of choice [9]. Since these activities typically happen online, the usability and accessibility problems with digital health tools become even more significant.

Despite these challenges, the potential of digital information and tools to transform health and health care is significant. Studies with diverse audiences - including young adults, gay men, and older adults - found a correlation between the use of digital health interventions and desired health behavior changes [10]. Among individuals with chronic pain, the use of multiple digital health tools is correlated with better self-reported pain management coping skills [11].

Digital health information also may influence people to get recommended preventive health services, such as vaccinations and screenings for communicable and chronic diseases [12-13]. In a 2017 comparison study (conducted by the Office of Disease Prevention and Health Promotion within the U.S. Department of Health and Human Services and CVS Health, a drug store chain), CVS saw significant increased uptake of flu and pneumococcal vaccinations after the store added myhealthfinder - an online tool that generates tailored recommendations for preventive services using health literacy best practices [13]. myhealthfinder was available at the CVS Minute Clinic website and promoted on CVSHealth.

As the body of evidence supporting the use of digital health tools increases, more Americans are able to better access these services. More than half (62%) of U.S. smartphone users used their phone to get information about a health condition in the past year [14].

The number of 'smartphone-only' internet users has been steadily increasing as well [1]. One in five American adults now go online exclusively using their phones [1]. According to the Pew Research Center, "reliance on smartphones for online access is especially common among younger adults, non-white, and lower-income Americans" [1].

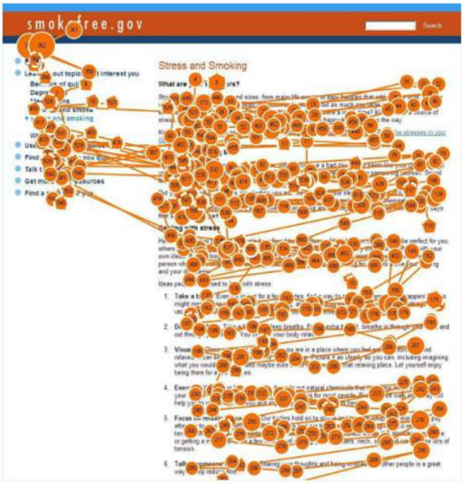
Meanwhile, non-white and lower-income individuals are more at risk for health disparities [6]. It is a concern that the latter overlaps with people who are dependent on smartphones. Overall, some health information websites may not keep up with the increase in smartphone use: many websites are not mobile friendly and their pages are not built to scale down to small screen sizes. So, while there is more access to the internet, there is also potential for a new digital divide. While people can get online, most online information is not written or designed to meet their needs [6].

3. Literacy and Digital Health Information

Most digital health tools fail to meet the needs of the majority of the population. To understand why this persists and to identify promising strategies for improvements, the authors believe it is helpful to look at these key areas of research:

- How people with low literacy search for and read online health information
- The unique challenges of accessing health information exclusively on mobile
- The complexity of health-related decisions and strategies that can reduce the burden on consumers
- The potential of decision aids to facilitate decision-making

The ability to find, interact with, and use health information online depends largely on users' health literacy skills. Techniques like eye-tracking have helped researchers understand how literacy levels affect the way users look at online content (see Figure 1 below).



Gaze path of a user who has limited literacy skills reading (and re-reading) every word.

Source: Colter, A., & Summers, K. (2014). Eye Tracking with Unique Populations: Low Literacy Users. In J. Romano Bergstrom & A. J. Schall (Eds.), Eye Tracking in User Experience Design (pp. 331–346). Waltham, MA: Morgan Kaufmann Publishers/Elsevier.

Figure 1. Accessed from https://health.gov/healthliteracyonline/what-we-know/section-1-1.

Users with stronger literacy skills tend to quickly scan pages and focus on the information most relevant to them [15]. In contrast, users with limited literacy skills are more likely to either skip whole sections on a page or, alternatively, to read every word [15-18]. Both behaviors can foster problems such as skipping sections that provide key health information. And trying to read every word can make content seem overwhelming.

The complexity of health information places a greater cognitive burden on people who read more slowly and who are likely to reread words, sections, or elements on a website (such as buttons or menus) [15]. These users are less able to remember what they have read and less likely to report a positive experience when they evaluate online health information [19].

Users with limited literacy skills also may have difficulty with website search and navigation. When using search features, users may find it challenging to pinpoint search terms, and users may struggle with spelling, or become overwhelmed by the number of search results [17,20-21]. Users may also get distracted by hyperlinks, clicking on multiple links and losing their place on the site [15,22].

The association between retention and reading speed is directly relevant to reliance on mobile for internet access. When information is easy to read, users comprehend it as well on mobile as they do on desktop platforms [23]. However, reading speed decreases significantly on mobile platforms as informational complexity increases [23]. This suggests the need for short, to-the-point health information is significantly greater for people who access health information on their smartphones [23].

Even as the number of mobile health (mHealth) apps continues to increase, fewer Americans are downloading and using them consistently [24-25]. Findings from a survey of both consumers and mHealth experts suggest the most promising way to increase the use of mobile health apps is to align them better with users' needs. Liew et.al. found consumers were primarily concerned with the familiarity of the interface, how easy it was to integrate into existing habits, and the accuracy of the information provided [24].

Consumers have to make complex decisions about their health and health care. Environmental supports, such as data visualization and decision aids, can facilitate decision-making about complex topics, including health insurance and treatment options [26-27]. Data visualization techniques communicate numbers and statistics visually, making it easier for users to see patterns and implications. For example, in a study with older adults, participants were able to make faster and more accurate decisions about Medicare plan options when presented with data visualization instead of tables. The latter was especially applicable when data visualization was used to describe one aspect of the plans at a time [26].

Several studies also suggest decision aids can be effective to help patients choose between treatment options. When there is more than one treatment available, decision aids help patients narrow the options down based on individual preferences and priorities. In a systematic review and meta-analysis, Van Weert et al. reviewed the literature on older adults and decision aids [28]. Van Weert et al. found the use of decision aids was correlated with increases in older adults' knowledge and perception of risk, participation in shared decision-making, and ease of decision-making. Decision aids additionally help patients feel less conflicted about their decisions and more engaged in their care [29-30].

Digital health information offers more opportunities to put decision aids in patients' hands when and where they need them. Patient portals provide consumers with 24-hour access to their electronic health records (EHR). Portals can help patients manage chronic diseases, follow through with medication plans, and get recommended screenings [12].

As health literacy professionals seek strategies to make health information easier to read and use, we also must look at ways to build decision aids and other environmental support into the tools consumers use to make everyday health decisions - from patient portals to health insurance exchanges.

4. Practical Strategies to Improve Digital Health Tools

The research summarized above illustrates the diverse challenges to provide quality, online health information. Yet, there are evidence-based strategies to address some of these challenges.

Much current knowledge is summarized in *Health Literacy Online: A Guide for Simplifying the User Experience*, created by the U.S. Office of Disease Prevention and Health Promotion (ODPHP). The latter guide first was published in 2010, and updated in 2015 to include challenges and strategies specific to mobile use and online forms [31]. The current authors highlight a few of these strategies below.

Health information often needs to include complicated terms and concepts, but this increases the need to write clearly. In addition to using plain language and taking the time to explain medical terms, the authors suggest writers need to:

- **Put the most important content at the beginning**. Users may not read everything, so it is vital to immediately communicate the main message. Also, users with limited literacy skills may struggle with site scrolling — they are more likely to skip content as they try to find their place again to continue reading.
- **Write actionable content** — and less of it. People use digital health information to make decisions, so it is important to focus on specific action steps and instructions.
- **Engage users with interactive content**. This makes it more likely that users will read and remember important health information.

How health content is displayed and organized also affects readability. If something looks difficult to read, people are less likely to try [32-34]. Moreover, if it is difficult to find what users seek - particularly if they struggle to use search functions - they may give up before they succeed. Hence, the authors suggest:

- **Break up text into short chunks**. This helps keep users from skipping over important content — and keep them from getting overwhelmed by a "wall of words."
- **Design for mobile first**. Adults with limited health literacy skills are more likely to be smartphone dependent. Ensure digital tools are optimized for mobile — including both display and performance (e.g., page load speeds).
- **Use labels that set clear expectations**. Navigation labels prepare readers for what they will see when they click. Clear labels help users navigate and find what they're looking for more easily.

One of the benefits of online health information is it creates opportunities to engage readers in novel ways. It is possible to reach people with key health information using multiple methods, such as video *and* data visualization. And interactive tools like decision aids can be available in context - exactly where people already are looking for related health information.

In addition, it is essential to test products with users - particularly those who are likely to have limited health literacy skills. When online health information is developed and revised based on input from those most likely to struggle with online health information, the results foster more inclusive, effective, accessible health information products.

5. Ideas for Future Research

The rise in the use of digital health tools offers diverse opportunities to conduct applied and outcomes research, particularly with individuals with limited literacy and limited health literacy skills. Specifically, the field needs more research on how users interact with health information on mobile platforms. As outlined above, mobile platforms pose unique challenges and opportunities. Additional usability research - including research with eye-tracking software - will help health literacy practitioners better understand how to leverage the widespread internet access now provided by smartphones. Although users may be more willing to scroll to get information than previously, there is a dearth of research whether this extends to persons with limited literacy skills [35].

We also need to explore the barriers to an uptake of patient portals and similar tools to improve care coordination. While patient portals have an unprecedented potential to put personal health information directly into patients' hands, portals are underused by consumers - especially by people with limited health literacy skills [8,12]. More research is needed to understand how to increase consumer trust in these tools, ensure caregiver and proxy access, and improve the overall user experience.

In addition, it is important to build on the emerging outcomes research that suggests associations among the use of health literate digital health tools with improved health outcomes. A better documentation of the successes of digital health interventions reinforce a critical need for tools that follow best practices in health content and design.

6. Summary

The authors believe there is an unprecedented opportunity to reach people with the information and tools they need to manage their health more effectively. As more people seek health information online, there is parallel evidence that the use of digital tools facilitates improved health outcomes, and population access to the internet is increasing thanks to smartphones.

There is much to do and learn in order to realize an omnipresent opportunity. At the same time, there are strategies to make health information more accessible, usable, and actionable. Health organizations now have the opportunity to capitalize on the popularity of digital health tools with content and formats to help users become more informed and confident partners in managing their health.

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The FDA's Message Testing: Putting Health Literacy Advice into Practice

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Abstract. Acting on health literacy principles in a large agency requires not only knowledge of the research base, but also creative work to implement the concepts in practice. Sound scientific advice needs practical development, shaped for the specific working environment. For example, the U.S. Food and Drug Administration (FDA) needs to test communications with intended audiences, but must work within constraints including:

- Widely varied audiences
- Significant time pressure
- Complying with multiple reviews designed to protect potential message testers

Testing messages with the intended audiences is a basic communications responsibility, not just an option. Yet, how to do the testing can be challenging. The FDA's experience suggests two practical approaches for user testing:

- Internal message testing with a network of employee volunteers
- External message testing with consumer panelists

The report briefly explains how the FDA assesses some public communication internally and externally to attain insights about a target audience or a health message as well as discover how a communication might be modified to improve its usability by an intended audience. The report suggests internal or external message testing is superior to controls (no testing) and such testing can be accomplished by a large governmental agency embedded within a complex regulatory environment.

Keywords: Message testing, health literacy practice, health literacy research, health communication

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1. Introduction

The U.S. Food and Drug Administration's (FDA) mission is to protect and promote the public's health by regulating food, tobacco, human and veterinary drugs, biological products, and medical devices; a mission supported by communicating information about these products to lay audiences and medical professionals [1]. The FDA provides clinical and public health information, which is critical for consumers, patients, and health care professionals to make informed decisions about when and how to use FDA-regulated products.

However, the FDA's biomedical information is most useful when it is understandable to its intended audience. Communication science, including its special fields of risk communication and health literacy, has developed a solid body of evidence about how to maximize clarity and minimize cognitive barriers for more understandable messages. In addition to following the principles of good communication during message creation, pretesting messages with intended audience members is critical. Testing a health communication message with the intended audience may uncover facets that are unclear or distracting.

The FDA's Risk Communication Advisory Committee (RCAC), a panel of communication experts external to the agency, addressed this point in their first committee meeting in 2008, and in subsequent gatherings [2]. In turn, the FDA acted on the advisory committee recommendation to find a time-and cost-efficient way to provide some testing of communication materials before releasing them, which is illustrated in the examples below.

The intended audiences for the FDA's health messages vary widely, from the U.S. general population (who purchase food, nonprescription drugs, or products for animals) to highly specialized health care professionals. As a result, the FDA's messages must be designed for their intended audience and tested with members of the intended audience to ensure the messages are understandable and usable.

The FDA's message testing protocols use in-depth interviews with a small sample of individuals. Then, a qualitative analysis is applied to identify themes in the responses, which are used to develop recommendations to improve messages. Each project is different, calling for specific interview guides. An individualized, semi-structured approach enables interviewers to explore responses in context and reveal what may be unclear or may not resonate, and why.

Prior research suggests "saturation," or the point at which interview results become repetitive so more interviews reveal little new information, can occur with as few as twelve interviews when the intended audience is fairly homogeneous [3]. The FDA's experience likewise confirms interviewing a small sample size can lead to saturation. Therefore, to the extent that messages testers and the intended audience share characteristics, the FDA's small samples help obtain useful feedback to improve messages for intended audiences.

2. Findings And Results

As noted, while each message testing project is a unique quality improvement effort, the FDA's testing repeatedly suggests where to provide changes to improve message clarity and audience usability. To obtain feedback, the FDA pursues both internal and external message testing strategies. An example of each strategy is provided immediately below.

Example 1: The first example comes from a project tested through the FDA's Internal Message Testing Network, which is explained below. In this case, the FDA's Office of External Affairs requested a review of two draft versions of a graphic designed to illustrate a Consumer Update article regarding over-the-counter (nonprescription) cryogenic wart removers [4]. The key message for consumers was the FDA received reports of some products catching fire at home -- without an identifiable ignition source. The Consumer Update's call to action was intended to instruct readers on safer use, along with suggestions for alternative treatments. The graphic's intent was to summarize its key message.

A need for audience testing quickly surfaced during the message's development period when the project's graphic designers debated where to place a flame, and whether to show the applicator that came with the product.

FDA employee volunteer message testers, then, provided feedback on items that were initially overlooked. The employee volunteer testers suggested:

- The terms "OTC" and "Cryogenic" were problematic in the graphic, even when defined in the text of the article
- The slash made the graphic seem disjointed
- The image on the left gave the wrong impression that consumers should spray the product directly onto the wart
- The image on the right looked too much like a cotton swab and people mistakenly thought more than one type of product was depicted
- An image of a wart needed to be included to better communicate the purpose of the product

Figure 1.

Before

After

The black dividing line made some people think that two products were being discussed here instead of a "cause and effect" look

Not everyone understood the word "cryogenic"

This graphic didn't have enough context. People didn't know what it was trying to say

People thought this was a cotton swab rather than the product applicator

Thanks to feedback from FDA employee volunteer testers, message designers redesigned the visual, creating a simpler and more direct image. They replaced the terms "OTC" and "Cryogenic" with frosty "Freeze Gone," removed the slash, and kept the wart image.

Example 2: A second example is derived from an external consumer panel that received an FDA contract. The draft communication to be tested was an opioid analgesic patient counseling guide [5,7]. The guide outlined the risks of taking opioid analgesics and explained how to take them safely. The target audience for testing was mostly women, adults with lower health literacy, and persons with a range of opioid user experiences. The 15 participants recruited as testers included:

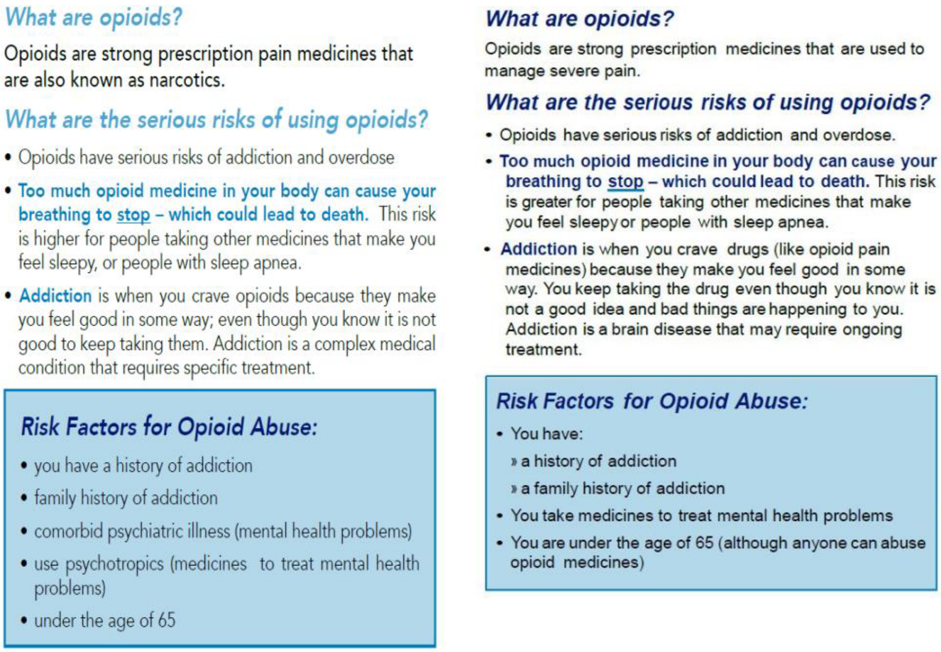
- Ten women and five men

- A diverse mix of races from regions all around the country
- Testers with a high school education or less
- Testers mostly aged 45-64
- Seven persons who were opioids users and eight people who had never taken opioids before.

All the participants found the counseling guide helpful and useful. The participants understood the guide's core call to action, which encouraged consumers to talk to their healthcare provider about opioid use and abuse. The participants also made recommendations for clearer language and suggested:

- Deleting medical terms or replacing them with plainer language followed by medical terms in parentheses
- Providing a clearer explanation of the difference between "tolerance" and "addiction"
- Revising the description of naloxone to explain more clearly how to use it
- Consider brighter or more varied colors to highlight text related to dangers or risks.

Figure 2.



Before

What are opioids?

Opioids are strong prescription pain medicines that are also known as narcotics.

What are the serious risks of using opioids?

- Opioids have serious risks of addiction and overdose
- **Too much opioid medicine in your body can cause your breathing to stop – which could lead to death.** This risk is higher for people taking other medicines that make you feel sleepy, or people with sleep apnea.
- **Addiction** is when you crave opioids because they make you feel good in some way; even though you know it is not good to keep taking them. Addiction is a complex medical condition that requires specific treatment.

Risk Factors for Opioid Abuse:

- you have a history of addiction
- family history of addiction
- comorbid psychiatric illness (mental health problems)
- use psychotropics (medicines to treat mental health problems)
- under the age of 65

After

What are opioids?

Opioids are strong prescription medicines that are used to manage severe pain.

What are the serious risks of using opioids?

- Opioids have serious risks of addiction and overdose.
- **Too much opioid medicine in your body can cause your breathing to stop – which could lead to death.** This risk is greater for people taking other medicines that make you feel sleepy or people with sleep apnea.
- **Addiction** is when you crave drugs (like opioid pain medicines) because they make you feel good in some way. You keep taking the drug even though you know it is not a good idea and bad things are happening to you. Addiction is a brain disease that may require ongoing treatment.

Risk Factors for Opioid Abuse:

- You have:
  - » a history of addiction
  - » a family history of addiction
- You take medicines to treat mental health problems
- You are under the age of 65 (although anyone can abuse opioid medicines)

Following this feedback, the creators of the opioid analgesic patient counseling guide simplified the language and used color more liberally. The FDA also assessed the draft guide using the U.S. Center for Disease Controls and Prevention's (CDC) Clear Communication Index [6]. After the editing revisions above, the guide's Index score improved ten points compared to the pre-testing version. Figure 2 above illustrates the before-and-after-versions of a section of the patient counseling guide [7].

3. Background Information: The FDA's Internal And External Message Testing Projects

3.1. Internal Message Testing

The FDA's Internal Message Testing initiative began with a pilot project in 2009 as a proof of concept within the agency. The initial concept was to: develop an internal network of volunteers willing to devote up to one hour on message testing; conduct message testing interviews with small samples of those volunteers; and report recommendations to the message developer based on themes from interview discussions. The pilot results were encouraging: some FDA staffers were eager to volunteer as message testers in sufficient numbers to form the network; supervisors were willing to have employees take an hour to do message testing of a communication from diverse FDA divisions; and staff across the FDA reported they enjoyed an opportunity to contribute to mission-critical quality improvement.

Volunteers: To participate, FDA staff volunteers first completed a form to provide basic demographic data including year of birth, gender, race, ethnicity, education level, professional training, years at the FDA, languages(s) spoken, and caretaking for children, elders, or animals. From the start, it was important to solicit new volunteers to replace those lost to turnover, to avoid overburdening FDA staff, and to prevent volunteers from becoming so experienced in message testing that they were less representative of the intended audience. Over time, the most effective internal recruitment tool became a simple and no-cost insertion of a request for volunteers within the FDA's agency-wide daily news announcements.

BOX 1: MESSAGE TESTING BASICS

Who – That is, who is the message for? The creator of the communication should have characteristics of the intended audience in mind. Message testing coordinators then identify from a database of volunteers approximately twelve testers who share characteristics with the intended audience.

When – Testing a communication should occur when the draft is solid but not yet final. The message itself should be well-formed and approved so it will not become obsolete, but the overall communication should be subject to change in response to the testing results.

What – The coordinators develop a semi-structured interview guide to ensure relevant feedback about the draft communication. They conduct in-depth, one-on-one interviews, then compile a report including quotes, findings, and recommendations.

How – Interviews are typically 30 to 45 minutes long, can be face-to-face, online, or by telephone. Coordinators analyze and organize the responses to look for qualitative themes, using either a coding matrix or NVivo software. At least two coordinators do the analysis to ensure consistency.

Why – Individual interviews allow probing for deeper understanding of comprehension and language by asking participants to paraphrase items, discuss thoughts or emotions that come to mind, and offer suggestions for improvement. Every message testing project has yielded suggestions for improvement, sometimes in surprising ways.

Currently, the Internal Message Testing Network has about 900 volunteers. In terms of possible confounding variables among employee participants, the FDA is large enough (approximately 18,000 employees) that staffers in one office often are unfamiliar with the products and regulatory issues in some other areas of the agency. To avoid additional confounds, the volunteers most often sought for testing are those who recently have joined the FDA and do not have four years of college education. The latter demographic characteristics are similar to some of the FDA's intended audiences.

In contrast, the FDA also targets messages to health care professionals, and this network includes volunteers who are pharmacists, nurses, and physicians.

Coordinators: The Internal Message Testing Network's coordinators, who are social scientists, have several tasks. They maintain the FDA's network, recruit new volunteers, update information, and use the database to identify the proper participants for a project. They also conduct, analyze, and report findings from individual interviews.

Experience: The FDA's Internal Message Testing Network process assessed more than 60 projects from 2010 to 2018. While most assessments focused on safety communications or other web content, other examples included proposed label changes as well as guidance to industry, forms, pamphlets, and posters. The suggestions from the Internal Message Testing Network helped many of the FDA's developers tailor messages towards their intended audience. Besides increased understandability, participant suggestions helped enhance graphics for clarity and visual appeal, and rearranged web content for user-friendliness.

Strengths: Overall, the FDA's no-cost Internal Message Testing Network has improved the speed, ease, and cost of assessments by facilitating a feedback channel between message creators and employee volunteer message testers.

Limitations: The staff volunteers in the FDA's Internal Message Testing Network program often are not ideally representative of a health message's target audience. Compared to the general public, FDA staff members have more years of education as well as more knowledge about the agency and regulated products. Also, a comprehensive evaluation of the program's effectiveness is challenging because post-implementation feedback is not always available. Yet, the frequency of requests within the agency for internal message testing suggest the process and its results improve health messages.

3.2 External Message Testing

Parallel to the Internal Message Testing Network, the FDA has explored external message testing options, including online user panels. Opt-in, incentivized consumer panels have emerged as an important strategy to collect consumer information and responses. In addition, reputable vendors who can provide access to large diverse panels enable the FDA to select participants based on geography, age, race, ethnicity, as well as other pertinent demographic characteristics representative of specific intended audiences.

In 2017, the FDA awarded a contract to conduct rapid message testing with small samples drawn from an external online panel of more than two million U.S. consumers. While each of these message testing projects fit the patterns outlined in Box 1, the larger pool of potential testers provided participants who were more representative of intended audiences. The FDA's social scientists also worked with a contractor on the selection criteria for participants and developed subsequent interviews with panelists.

External message testing helps address the limitations of internal message testing noted above. A large panel of potential respondents often yields samples that resemble target audiences, which potentially improves the reliability of the findings.

The protocol also calls for FDA coordinators to compare the initial health communication with its post-evaluation final version, using the Centers for Disease Control's Clear Communication Index (to facilitate consistent assessments) [6]. Since the CDC's Clear Communication Index is based on health literacy principles, 'before and after' comparisons suggest the revised messages are easier to read or understand.

Experience: Currently, the FDA contracts for ten message testing projects per year. As projected, the evaluations that utilize a larger external panel have facilitated the participation of: racial and ethnic minorities; participants with lower education and socioeconomic status; persons with specific chronic diseases; participants with roles such as a caregiver or primary grocery shopper; as well as specific age groups. Some recently evaluated initiatives included: several types of brochures; public service announcements to consumers and patients; and tools for health care professionals, such as patient-provider agreements and counseling guides.

Strengths: The primary strength of an external panel approach has been improved access to diverse participants that more closely resemble specific intended audiences. External testing also has increased the FDA's capacity to support message developers.

Limitations: External testing with a vendor requires sustained funding. Since the participant/panelists are not FDA employees, the materials must be screened to be appropriate for the public. Additionally, while the goal is to connect with hard-to-reach populations online, many participants greatly prefer phone-only interviews. When participants prefer phone interviews, a contractor can send materials by overnight mail and then conduct an interview over the phone.

4. Discussion: The FDA's Communications Responsibilities And Mission

The FDA's public communication responsibilities cover a spectrum from proactively developed communications campaigns, such as 'Real Cost' from the Center for Tobacco Products, to reactive and time-sensitive announcements of new and emerging information [8]. The FDA's intended audiences range from members of the general public to highly specialized health care practitioners. The science of risk communication provides principles to facilitate communication to each group. To make the state of the science and its practical implications more accessible, the FDA's Risk Communication Advisory Committee (RCAC) collaborated on a report that collected scientific advice for government communicators on special topics, such as quantitative communication and communication across the life span [9]. Most notably, the RCAC panel's report consistently recommended testing and evaluating communications to understand an intended audience's perspective.

4.1. Addressing The Common Knowledge Effect

The critical importance of message testing with the intended audience is a recurrent theme within risk communication because it helps overcome communicators inadvertent, tacit assumptions that can interfere with the understanding of health messages. As Baruch Fischhoff (the panel's chair) noted: "[P]eople exaggerate how well they understand others' perspectives. This general tendency, perhaps familiar to most people in their everyday communication has many expressions. One is the common knowledge effect: people exaggerate how much of their knowledge is shared by others" [9, p. 42].

The FDA's internal and external message testing projects directly address the common knowledge effect: the FDA seeks feedback on a draft communication from a sample of participants similar to the intended audience, and their comments show how message developers could improve the communication. Similarly, the suggested improvements also demonstrate where the draft reflects some assumptions about what should be clear or engaging (which sometimes needs modification). For instance, in example 1, message developers thought the terms 'OTC' and 'Cryogenic' would be clear once explained in the text, but message testing results showed their assumptions were incorrect.

4.2. Programmatic Constraints

The FDA's initial message testing implementation has continued in spite of some practical barriers to its quick implementation. Institutionally, it is difficult to initiate optimal external message testing without sufficient budgetary support. Also, the FDA's responsibilities to provide immediate information about an urgent public health risk, such as foodborne illness, can compress the timeline for message development.

Likewise, it can be time consuming to identify persons with lower health literacy and other specific audience characteristics to participate in message testing.

Also in the U.S., an array of regulations limit the capacity of federal agencies to quickly set up an external consumer testing panel. For example, U.S. laws require: securing the informed consent of participants; protecting the privacy of public participants; as well as the FDA's required compliance with the U.S. federal government's Paperwork Reduction Act (PRA).

The PRA seeks to shield the American public from the burden of repetitive federal government information collections. Since the PRA requires a federal agency to pursue public comment and obtain approval from the U.S. Office of Management and Budget before collecting information from ten or more persons, the process can add considerable time to an information collection project. Moreover, the FDA must comply with U.S. regulations for the protection of human subjects, which requires an Institutional Review Board review and approval of research [10]. Although these regulations are specific to the U.S. federal government; there may be similar rules in institutional or legal contexts in other nations.

To minimize the anticipated delays, the FDA works collaboratively and proactively with persons who supervise human subjects protection as well as federal PRA offices.

More positively, despite the delays, the FDA staff usually completes each external testing project within six weeks. In contrast, the internal message testing approach is generally classified as a quality improvement initiative (rather than human subjects research), which shortens the implementation process to about four weeks.

5. Conclusion

The authors suggest the message testing projects using the FDA's Internal Message Testing Network or external panels consistently have yielded practical health communication feedback and prevented possible public message missteps. The authors suggest the FDA's internal and external message testing especially has yielded contextual insights about a target audience or a message and sometimes has provided constructive feedback regarding unintentionally mistaken assumptions about an audience or a specific health topic. In summary, the FDA's experience to date suggests internal or external health message testing is superior to no testing and assessments can be accomplished by a large governmental agency embedded within a complex regulatory environment.

The authors note that both internal and external message processes are examples of applied health literacy practices. In general, the authors recommend a draft communication for testing initially needs to be created within an enduring public communication framework of: a main message; language appropriate to a target audience; and a layout that reinforces the main message. Even then, message creators sometimes incorporate tacit assumptions, which is why empirical testing with members of an intended audience is strongly recommended. No matter how carefully a communication is created and crafted, it is only as good as the message that is actually received and understood by an intended audience, which suggests a foundational need for audience involvement and testing. Message testing also is an extension of the principles to make health information more understandable and involve intended audiences in the creation of health communications.

Finally, the authors suggest internal message testing may be feasible within agencies that are large enough to have employees who work in diverse health topic areas. In addition, the authors suggest it is helpful to develop a large volunteer network; online consumer panels are increasingly available if agencies invest funds in this potentially helpful resource.

For health literacy practitioners, the FDA's experience strongly suggests testing is preferable to no testing, and some testing may be possible internally even without dedicated funding (given a workforce large enough to include members who are not directly familiar with the topic of a draft communication). That said, if some funding to access to large external panels is available, then, health communication processes will benefit by testing messages with participants more similar to the specific intended audience.

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Applying Lessons Learned from CDC's Health Literacy Initiatives

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Abstract. This report describes health literacy initiatives at the Centers for Disease Control and Prevention (CDC) and the lessons learned from more than 20 years of commitment to health literacy. Efforts described include CDC's training and tools, the Science Ambassador Fellowship program, and an action plan and report card. The report concludes with recommendations on how to meet the needs of communities and systems.

Keywords. Health literacy, Science Ambassador Fellowship, Clear Communication Index, Health Literacy Council

1. Introduction

The Centers for Disease Control and Prevention (CDC) is the U.S. government's public health agency. CDC has nine national Centers specializing in various areas of communicable and non-communicable diseases and crosscutting topics such as: global health; emergency preparedness; epidemiology; surveillance; and laboratory sciences. CDC has offices around the world and is an agency within the U.S. Department of Health and Human Service (HHS).

This report provides an overview of the CDC's: health literacy initiatives; Science Ambassador Fellowship program; health literacy report card; health literacy educationally focused; as well as lessons learned and concluding thoughts.

2. CDC's Health Literacy Initiatives

CDC's commitment to health literacy spans more than 20 years. The CDC's activities include: developing tools and resources; convening its Health Literacy Council (the Council); creating and providing training for staff; incorporating health literacy and plain language elements into all communications—including contracts; and providing technical assistance to programs as needed.

One of the first and most widely used tools (created at CDC in the 1990s) was Simply Put, a plain language manual that helped users create clear communication materials. Despite its age, users continue to download the manual and find it useful and concise.

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Regarding training, one of the CDC's health literacy websites (https://www.cdc.gov/healthliteracy/index.html) provides a combination of CDC-created courses in addition to services from other agencies, which supplies learning options for public health and healthcare professionals. The health literacy website also hosts these tools and resources, including other materials such as research summaries, state-based activities, an overview of guidelines and standards, and much more. Specific information is provided below about some of the educationally-focused information within the broader CDC health literacy website.

The U.S. Plain Writing Act of 2010 reenergized CDC's health literacy initiatives. Initially, the implementation of the Plain Writing act required a senior official at all U.S. federal agencies to provide and monitor training - and ensure the staff who write or clear materials for public communication were trained in plain language principles and techniques. Although an overall effort fostered a broader awareness about the importance of plain language within many federal agencies, CDC established a group of representatives from all 12 CDC Centers to spread awareness and practice of plain language principles. The CDC Health Literacy Council meets regularly to share each Center's health literacy initiatives, receive training on new plain language assessment tools and advise on carrying out the Plain Writing Act.

The Council drafted an internal action plan based on the Health Literacy National Action Plan, which was initiated by the HHS with the assistance of CDC staff members. While the U.S. Health Literacy National Action Plan has seven goals, the CDC decided to focus on three: 1) develop and spread health and safety information that is accurate, accessible, and actionable; 2) use clear communication and health literacy in public health planning, funding, policy development, research, and evaluation; and 3) include accurate, standards-based, and developmentally appropriate health and science information and curricula in educational settings from childcare through university levels. The Council annually develops strategies and monitors progress in an annual report. The Council meets periodically to assess the continued relevance of the goals and strategies considering CDC's evolving work in health literacy and plain language.

The design and development of the Clear Communication Index (the Index) is an example of the CDC's national response to improve health literacy. The Index is a 20-item assessment tool used to design or redesign communication materials for the public. Programs within the CDC use the Index to improve communication and have shared the Index with the agency's partners. The Index also has been translated into Portuguese, Japanese, French, and Spanish.

Through a dedicated website, the CDC staff (and others) can use the Index, and resources such as a user guide and before-and-after examples of redesigned documents. The utility of the Index to assess the clarity of communication materials has been evaluated in diverse studies [1-6].

Periodically, the Council uses the Index to conduct quality improvement efforts. For example, one initiative used the Index to determine the clarity of the CDC's most downloaded fact sheets. Reviewers independently used the Index to score 160 fact sheets and shared recommendations to improve clarity and make them more actionable.

Currently, CDC uses complementary commercial software to conduct monthly electronic plain language assessments of the agency's most visited Web pages for each Center and sends reports to the respective Council member for review and action. In addition to the Index and the mentioned software, CDC uses and promotes other important resources such as the Federal Plain Language Guidelines, CDC's health literacy web sites, and the CDC/Agency for Toxic Substances and Disease Registry health literacy action plan.

Almost a decade after the U.S. Congress passed the Plain Writing Act, there is evidence at CDC of an evolution from awareness training to application of plain language principles, such as the Science Ambassadors program that is discussed below.

To capture and measure this evolution, CDC uses the automated Health Literacy Report Card as it tracks the work of each Center. CDC also supports an educationally-oriented health literacy website. This report concludes with lessons learned and a look toward the horizon.

3. Science Ambassador Fellowship Program

The CDC Science Ambassador Fellowship program strives to ignite student interest in public health as a science, technology, engineering, and math (STEM) career choice, as well as to improve health and science literacy in the United States. Since 1999, the CDC Science Ambassador Fellowship program and antecedent agency programs have provided national leadership, resources, and teacher training in public health content that is relevant for middle and high school classrooms.

Through the program, teachers have worked with CDC scientists to publish more than 100 public health lesson plans. From 2004–2019, the program indirectly reached an estimated one million students in 46 U.S. states and territories, and five other countries through the 505 STEM teachers who participated in the program. Of note, from 2012 to 2018, 39 percent of these STEM teachers were, at the time of participation, teaching at a school or in a school district receiving U.S. Title 1 funding. Title 1 funds from the U.S. Department of Education provide financial assistance to local educational agencies and schools with high numbers or high percentages of children from low-income families [7].

The CDC Science Ambassador Fellowship program recruits teachers from across the United States who want to teach epidemiology and public health science content in their classrooms. Program eligibility includes being a current middle or high school teacher or holding a position in education leadership within a school, district, or state. The program's alumni praise the benefits of participating, which include networking, obtaining practical, real-world examples for their students, and working alongside public health experts [8].

3.1. Training and Implementation

Applied learning is at the core of the CDC Science Ambassador Fellowship program. Once accepted, fellows complete an online introductory course, followed by a five-day in-person training course at CDC's headquarters in Atlanta, Georgia. During the free, weeklong course, fellows learn strategies to deliver public health content, attend presentations by CDC scientists on current public health topics, tour CDC facilities, work in teams to apply the national competency standards to their lesson plans, and create a network within their cohort.

Following the summer course, fellows participate in a yearlong professional development component delivered through distance learning technology. Fellows also receive continuing education credits for their participation and are encouraged to share resources by presenting at local, state, and national teacher conferences and to add resources (within a growing inventory) on the program's website: www.cdc.gov/careerpaths/scienceambassador.

Demand for the program prompted CDC to give regional two-day workshops to support more educators in their efforts to teach public health to students. Similar to the first two days of the fellowship weeklong course, regional workshops provide a unique opportunity for teachers to learn strategies to engage their students in public health and network with CDC scientists and their local public health professionals. During 2018–2019, the program held regional workshops at diverse U.S. sites including: St. Louis, Missouri; Seattle, Washington; Chapel Hill, North Carolina; Chicago, Illinois; and Atlanta, Georgia.

3.2. Curricula

A primary outcome of the training is for middle and high school teachers to develop and use resource lessons plans. Table 1 lists the five overarching lesson plan categories and the 21st century scientific/public health skill addressed by each.

Table 1: Topics and Related Skills

Lesson Plan Category	21st Century Skill
Introduction to Epidemiology	Scientific Design
Public Health Surveillance	Identifying Trends
Investigating an Outbreak	Decision-making
Careers and Roles in Public Health	Collaborative Performance
Preparedness and Response	Implementing Action Plans

Lesson plans are consistent with epidemiology's and public health's core competencies. Each lesson plan has a cover page with activity details, such as grade level, learning objectives, national education standards, duration, and materials. The multipage plans include an introduction section about the topic, resources, and activity instructions broken down into phases (explain, instruct, discuss). The plans include copies of handouts and an answer key. Each plan acknowledges contributing authors, who are fellows from the program and CDC subject-matter experts. Once approved and formatted, CDC publishes the plans and makes them free to download from the program website: www.cdc.gov/careerpaths/scienceambassador. CDC encourages teachers to adapt the plans to meet their students' needs.

The epidemiology and public health science content covered in these plans seeks to contribute to improving health and science literacy among youth. Exposure to crosscutting public health concerns with immediate relevance yields a contextual framework for students and encourages them to learn requisite biology and mathematics. The exposure also provides students and schools with scientific and mathematics' training derived from practical applications of epidemiology and public health. The latter supports the development of critical thinking across domains and disciplines among young persons.

3.3. Demand

The national demand to participate suggests teachers perceive the value of including epidemiology and public health curricula within middle and high school instruction, and the need for professional development opportunities. For example, the Science Ambassador Fellowship program annually receives more than 150 applications from around the world to fill 30 fellowship openings. The increasing numbers of applicants, high demand for regional training, and a growing inventory of lesson plans help steer the program toward continuing to meet the critical needs of teachers, their students - and indirectly families and communities.

4. CDC's Health Literacy Report Card

CDC created a Health Literacy Report Card to track progress on each operationalized goal and strategy within the Action Plan for Health Literacy, and to recognize accomplishments as well as growth opportunities. The report card began as a Microsoft Word document, but in time, CDC developed an electronic format. Twice each year, each Center completes its report card identifying:

- how many staff it has trained in plain language
- the number of - and reference to - materials created or redesigned with the Index
- whether staff were rewarded for effectively using health literacy and plain language principles.

CDC has used the report card's data to inform the annual Plain Language Act report to the U.S. Department of Health and Human Services as well as to guide training for the year, and support related data requests.

CDC additionally used the report card to guide its Center-specific strategic planning. Council members met periodically in brief teleconferences to discuss successes, challenges, and share lessons learned. Council members identified two measures from the report card that most aligned with their Center's priorities, conducted a SWOT (strength, weakness, opportunity, threat) analysis for each measure, and created a work plan for the year.

Each work plan included milestones, completion goal dates, and the names of responsible persons. During its implementation, the work plan process yielded 78 milestones. More than half were reported as completed or in-progress at the end of the first year. Centers continued to work on milestones in-progress during year two and refined their work plans to exclude those tasks not started.

After two years of using the aforementioned work plan process, the Council decided to reassess the measures included in the report card and consider new measures that include evolving strategies such as digital communication. CDC will continue to use the action plan to identify initiatives and implement the report card to chart a forward course of health literacy strategies.

CDC's health literacy website can be a valuable tool for organizations to consult when developing an action plan for health literacy. Web use data from nearly 400,000 page views per year indicate visitors to the CDC health literacy website seek to download resources such as checklists and toolkits and foundational information found on the

'What is Health Literacy?' and 'Understanding Health Literacy' pages. The website is organized as a guide for users to create a health literacy plan, find community organizations to collaborate with, and assess a program or organization's opportunities to advance health literacy. Visitors to the site can also practice using guidelines and standards supporting plain language, including how to develop and test materials for clarity. Additional resources include an overview of health literacy research and activities by states with health literacy coalitions. A cornerstone of CDC's health literacy website is the training section.

Sharing health information with the public often requires explaining risk and describing the prevalence or incidence of a health condition. CDC's online health literacy training is designed for public health professionals who must communicate with the public about emergencies, natural disasters, or routine health practices. More than 11,000 learners have completed the introductory course, Health Literacy for Public Health Professionals. CDC hosts five other online courses supporting key public health functions such as communicating risk, explaining risk through use of numbers and graphs, and communicating with the public in writing and through speech. A variety of federal, academic, and non-profit organizations have created training courses that complement those CDC created. These courses are listed under the non-CDC training section of the website. The topics include: health literacy; plain language; culture and communication; shared decision-making; and consumer and patient skill building. The skill-building tab includes resources for people with low literacy. The availability of free and comprehensive resources advances the website's utility for public health practitioners and many others.

5. Lessons Learned and Concluding Thoughts

The CDC has led and benefitted from many of the health literacy field's accomplishments, such as the legal requirement for plain language and the presence of health literacy as a critical component of the U.S.' Healthy People framework for a healthier nation. CDC's past work has reached important milestones in advancing health literacy by:

- developing validated tools and resources that assess clarity of communication products
- using and sharing products guided by health literacy and plain language standards
- training thousands of staff and partners in health literacy
- establishing networks and systems such as the action plan, the Council, and the report card to sustain progress

As CDC looks toward the horizon, there is an opportunity to advance how the agency measures success and contributes to the development of applied programs such as the Science Ambassadors program (where CDC improves the health literacy of communities through existing partnerships). When CDC considers how to meet the needs of communities and systems, CDC calls upon researchers, practitioners, and students to support:

- Top-to-bottom engagement in health literacy from senior leaders to frontline staff
- Making health literacy part of routine work
- Measuring health literacy progress and effects
- Providing access to health literacy information through comprehensive websites
- More studies to expand the science of health literacy.

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Preparing a Health Literate Workforce: The Role of Area Health Education Centers

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Abstract. Area Health Education Centers (AHEC) play a vital role in creating health literate organizations. In this report, we highlight the work of three AHECs. The Massachusetts AHEC trains oral language healthcare interpreters who can effectively convey complex medical information to patients with limited English proficiency (LEP). The University of Kentucky AHEC trains providers to use the Universal Precautions Health Literacy Toolkit. Finally, the Wisconsin AHEC prepares community health workers (CHWs) to play a vital role in making it easy for people to navigate the healthcare system. These three AHECs serve as models of health literacy's diffusion.

Keywords: health literate organizations, health professions, interpreter, toolkit, community health workers

1. Introduction

The Area Health Education Centers (AHEC) Program, administered by the U.S. Health Resources and Services Administration (HRSA), Bureau of Health Workforce (BHW), plays a vital role in creating health literate organizations. In this report, we highlight the work of three AHECs in service to their community who make it easier to navigate, understand, and use information and services, which improves overall population health.

HRSA is the primary U.S. federal agency that improves access to health care by strengthening the health care workforce, building healthy communities, and achieving health equity. HRSA's programs provide health care to people who are geographically isolated and economically or medically vulnerable. HRSA's Office of Health Equity (OHE) serves as principal advisor and coordinator for culturally and linguistically appropriate services standards, including health literacy. BHW improves the health of underserved and vulnerable populations by strengthening the health workforce and connecting skilled professionals to communities in need. BHW prepares a quality, skilled workforce, improves workforce distribution and advances modern healthcare, by focusing on telehealth, rural and underserved populations, and community-based training. OHE and BHW collaborated to write this report highlighting AHECs.

The AHEC program develops and enhances education and training networks within communities, academic institutions, and community-based organizations with the broader goal to improve health care delivery to rural and underserved areas and U.S. populations. Originally established by the U.S. Congress in 1971, the AHEC program underwent an extensive redesign in 2017 to better align and focus on HRSA/BHW priorities of distribution, diversity, and health practice transformation.

Historically, AHECs focused heavily on the continuing education and professional development of health professionals, as well as programmatic activities focused on exposing young persons to health careers at elementary and secondary school levels. The redesigned AHEC program helps focus the resources of academic medicine to address local community health needs. AHEC programs connect students to health care professions, health care professionals to communities, and communities to better population health.

Currently, there are six core topic areas to ensure the program has a more sustainable, long-term impact. The core areas are: inter-professional education; behavioral health integration; social determinants of health; practice transformation; current/emerging health issues; and cultural competence. The focus on strategic partnerships, evaluation, community-based experiential training (and the new HRSA-branded AHEC Scholars Program) are designed to increase the development of a well-prepared diverse and culturally competent primary care workforce - committed to serving underserved populations.

The strength of an AHEC lies in its ability to adapt U.S. national initiatives to help address local and regional healthcare issues, such as health literacy. Today, 49 AHEC programs with more than 261 centers operate in almost every U.S. state and the District of Columbia. Approximately 120 medical schools and 600 nursing and allied health schools work collaboratively with AHECs to improve healthcare for underserved and under-represented populations. The authors selected three AHEC programs located in Kentucky, Massachusetts, and Wisconsin for their particular contributions to promoting health literate organizations.

In 2012, the Health Literacy Roundtable of the Institute of Medicine (now called the National Academies of Sciences, Engineering, and Medicine) published ‘Ten attributes of health literate organizations’ in which they defined health literate organizations as those that “make it easy for people to navigate, understand, and use information and services to take care of their health” [1]. The three AHECs highlighted in this report have programs that address three of the Roundtable’s attributes: prepare the workforce to be health literate and monitor progress; use health literacy strategies in interpersonal communications and confirm understanding at all points of contact; and provide easy access to health information and services and navigation assistance.

More specifically, the Massachusetts AHEC trains oral language healthcare interpreters who can effectively convey complex medical information to patients with limited English proficiency (LEP). The University of Kentucky AHEC trains providers to use the Universal Precautions Health Literacy Toolkit. Finally, the Wisconsin AHEC prepares community health workers (CHWs) to play a vital role in making it easy for people to navigate the healthcare system. Each of the three programs are discussed below.

2. Massachusetts AHEC Integrates Language Access and Health Literacy

Improving spoken communication, especially for an increasingly diverse population that includes people with limited English proficiency, is vital to improve health literacy. In turn, the Edward M. Kennedy Community Health Center (Kennedy CHC) in the U.S. state of Massachusetts provides a comprehensive array of primary care services to a multi-cultural patient population.

Racial/ethnic minorities comprised 70 percent of the Kennedy CHC's patient population in 2017 and a recent study found patients spoke 83 different languages. These findings suggest a continuing, pressing need for trained medical interpreters, which the Massachusetts AHEC Network (MassAHEC) has offered for more than 20 years.

MassAHEC, hosted by the University of Massachusetts Medical School, provides services to the state through six regional AHEC centers. Its mission is to reduce health disparities by:

- Enhancing the skills and increasing the diversity of the health care workforce, and
- Facilitating access to culturally and linguistically responsive health care services.

MassAHEC has trained more than 5,000 bilingual employees and freelance interpreters in more than 40 languages. The program has been recognized as one of the few programs in the U.S. region of New England that offers language coaching to participants to improve their medical terminology within their target language. The MassAHEC curriculum was one of ten selected from around the country for review by the U.S. National Council on Interpreting in Health Care, which ultimately led to the creation of national standards for medical interpreter training programs.

One of the MassAHEC training program's significant innovations is to raise awareness and clarify the concept of 'preserving the register' of the original speakers. 'Register' refers to the stylistic level of language used by a speaker. U.S. National interpreter standards state: "an interpreter replicates the register, style, and tone of the speaker" [2]. This means interpreting the complexity of the vocabulary and language used by providers as well as the plain or idiomatic language used by patients.

This program's focus (to build and integrate cross-cultural communication) fostered a long-term strategy to train providers and staff to improve health literacy and plain language - with a recent expansion to include health insurance literacy. MassAHEC's staff attended training to learn more about plain language practices, and then leveraged this expertise to conduct training sessions and workshops to diverse health care institutions, health care providers, and allied health professionals throughout Massachusetts. The same sessions were offered to medical interpreters.

MassAHEC also provided consultations on writing patient information materials in plain language from diabetes education to how to access health insurance. The principles of plain language were incorporated in the editing of MassHealth (Massachusetts' Medicaid/health insurance services) and other documents in English, with the subsequent translation of MassHealth documents into eight additional languages.

Easy-to-understand forms are important to improve translation, as well as sight translation, which is when interpreters read a document written in one language and simultaneously interpret it in a second language. Overall, health literate forms and documents help an interpreter assist a patient.

With the onset of national medical interpreter certification, MassAHEC continued to train across the state, using a 60-hour course, Fundamentals of Medical Interpreter Training. The curriculum provides the critical skills and knowledge needed by medical interpreters to pursue national certification. The curriculum provides training in interpreting skills and the basics of anatomy, physiology and medical terminology in the target language - with role-play simulation activities.

In addition to the Fundamentals course, MassAHEC delivers diverse, ongoing continuing education training workshops to improve interpreter skills and/or knowledge on topics as varied as: the opioid crisis; working with lesbian, gay, bisexual, transgender and queer patients; interpreting an oral health interaction; and preparatory classes for taking the national certification exams. Similar workshops and skill building sessions are included in an annual two-day conference, “Paving the way to healthcare access: a conference for medical interpreters” for more than 300 interpreters. A newly developed 30-hour Mental Health Interpreter Training fosters the development of in-depth knowledge and skills to interpret behavioral health encounters. Clinicians teach the course with the assistance of language coaches through role-plays and case studies.

While it is imperative to train medical interpreters, training for providers and future providers also is a key to a balanced triad as well as quality patient health outcomes. Working with the Kennedy CHC and other health care sites, MassAHEC developed a Language Access clerkship for future medical providers. In this clerkship, University of Massachusetts graduate nursing and medical students learn how interpreters are trained, qualified, and certified. They learn how medical interpreters follow a code of ethics and standards of practice similar to other health professionals. The students have an opportunity to shadow interpreters on the job in hospital and community health settings. In the process, students learn providers often lack skills to work effectively with an interpreter; and participants learn new modalities to interpret with technology as well as strategies to become better prepared clinicians.

Students from the clerkship have conducted research to support the work of medical interpreters, such as conducting surveys to determine the potential lack of knowledge of providers to work with interpreters and pilot a curriculum redesign for students to learn how to effectively work with medical interpreters. This ongoing work continues to constructively impact the nursing and medical school curricula at the University of Massachusetts Medical School.

3. University of Kentucky Regional AHEC: Forging a Path for Health Literacy

In 2010, the U.S. Agency for Healthcare Research and Quality (AHRQ) published the first edition of the ‘*Health Literacy Universal Precautions Toolkit’* [3]. The toolkit recommends resources to health care providers and their practices to address and enhance diverse patient health literacy levels. When implemented properly, the AHRQ toolkit increases provider and institutional awareness of health literacy and provides practice assessments for health literacy and interpersonal communications. Specific tools are included to help practices improve particular health literacy needs (e.g., teach back, a method for checking understanding by asking patients to state in their own words what they need to know or do about their health and supportive program materials such as posters, PowerPoint slides, and handouts to implement health literacy interventions). In

2012 and 2013, the Southern Kentucky AHEC found few rural practices in Kentucky were aware this toolkit existed or how to implement it. To address this gap, the Southern Kentucky AHEC designed the Assess Connect and Empower (ACE) Health Literacy Project.

The Southern Kentucky AHEC is one of eight regional centers under the umbrella of the University of Louisville Kentucky AHEC Program. The Southern Kentucky AHEC is a collaborative effort of the University of Louisville Health Sciences Center and the University of Kentucky Medical Center. The Commonwealth (or state) of Kentucky is in the southeastern region of the U.S.

The Southern Kentucky AHEC supports, trains, and retrains health care professionals to positively impact a more equitable distribution of health professionals throughout the state. More specifically, the Southern Kentucky AHEC, which is hosted by the Rockcastle Regional Hospital and Respiratory Center in Mt. Vernon, covers 15 counties in rural areas.

After a successful pilot of the ACE Health Literacy Project, which used a toolkit in Garrard County, the project expanded with support from the Humana Foundation. Initially, the staff intended to reach 30 practices in 15 underserved counties in rural Appalachia. The overall program's objective was to increase awareness of health literacy challenges and implement changes based on the practices' increased awareness and self-identified practice gaps. Improved health communication and subsequent improvements in quality of care and health outcomes were targeted as immediate and long-term outcomes of the project.

ACE's original program format involved four one-hour lunch and learn educational sessions at individual physician's offices. The lunch and learn educational strategy was familiar to the target population and proved an excellent approach to introduce and advance health literacy. To accommodate the needs of the pilot sites, the Southern Kentucky AHEC adapted ACE in other formats including: a) two two-hour sessions, b) one two-hour session plus two one-hour sessions and c) an abbreviated version containing two hours of didactic learning limited to two hospitals (that did not have participating physicians, advanced registered nurse participants, or physicians' assistants). Despite changes in the format, the content and order of the information remained mostly the same.

Each participating practice encouraged the entire staff to attend training sessions because a central tenet of the health literacy universal precautions is *all* staff who work with patients benefit from improved communication/health literacy skills. While scheduling was a challenge, the flexibility and willingness of the facilitators to repeat sessions ensured maximum participation. Continuing education credits served as incentives.

The sessions are described below. Note that the pilot required participants to implement the skills they learned between the third and fourth session:

- Session #1: Overview. An overview of health literacy addressed the scope of the problem and associated poor health outcomes. This session included a pretest to assess knowledge about health literacy among health care professionals and some clinic staff.
- Session #2: Practice assessment process. Facilitators administered a practice assessment tool (a 49-question survey) from the AHRQ toolkit without modification after a brief explanation. The assessment contains questions about written communication, signage, dealing with language issues, encouraging questions, and confirming understanding within several other areas related to

health literacy. Allowing time for completion during the session increased the rate of return.

- Session #3: Skills-building. This session began with a report about the leading communication gaps identified by the prior assessment. A facilitator emphasized areas where the majority of participants thought health literacy and health communication practices were ‘doing well.’ Facilitators explained the teach back method to check patient understanding as a strategy to address the top two or three identified interpersonal communication gaps. Participants were instructed on how to use the Teach Back Log and collect the data necessary for the project.
- Session #4: Follow-up. Together with the participants, the results of the health literacy intervention were reviewed at each site and additional training was provided regarding the gaps not addressed in previous sessions. The AHRQ Toolkit’s practice assessment was re-administered and the project concluded with a guided tour of the electronic version of Health Literacy Universal Precautions Tool Kit. Each participating practice received a flash drive with a copy of the AHRQ Toolkit.

For physicians, dentists, dental hygienists, Advanced Registered Nurse Practitioners, and Physician Assistants, the Southern Kentucky AHEC offered up to 20 continuing education credits based on full participation in the performance improvement component of the program. To participate, a health care provider attended four hours of didactic instruction and participated in performance improvement activities. Performance improvement activities included pre-and-post-intervention practice assessments, personal communication assessments, and a Teach Back Log derived from ten patient interventions. Approval to provide equivalent credit for the Maintenance of Certification was obtained from the American Board of Family Practice. Nurses and some other providers were able to receive continuing education credits for the actual classroom hours of didactic instruction.

Based upon the demand and requests for training, the target population expanded geographically and in scope beyond physician offices to include staff at hospitals, transition care units in nursing homes, dental clinics at Federally Qualified Health Centers, local/county health departments and the Kentucky Department of Public Health (state health department). In aggregate, 279 unique health care providers (MD/DO/DMD, ARNPs, PAs, nurses and other staff) received 95 hours of training and approximately 1200 contact hours from the Kentucky Southern AHEC.

Although scheduling, recruitment, travel, and the time intensive nature of the intervention were challenging, the flexibility of the intervention proved valuable as well as the capacity to provide rapid feedback from the practice assessments after the second and fourth sessions. Overall, practices and participants completing the assessments suggested quick improvements occurred within the identified gap areas. Improvements also were reported in areas related to health literacy, which was attributed to participants becoming more aware of health literacy and the importance of better interpersonal communication.

4. Wisconsin AHEC: Community Health Worker (CHW) Integration to Advance Health & Health Literacy

CHWs are lay community members who serve as a bridge between a community and its health care delivery system. CHWs contribute to health literacy by providing easy access to health information and services as well as navigation assistance. The Wisconsin AHEC Program Office sowed the seeds for the 'Community health worker integration: advancing health & health literacy project' more than a decade and a half ago. These early efforts funded projects throughout the U.S. state of Wisconsin that underscored the importance of prevention, health promotion, and health literacy - utilizing an emerging workforce of CHWs.

The Wisconsin AHEC system seeks to improve the supply, distribution, and quality of health care professionals in Wisconsin, a Midwestern U.S. state. The system is comprised of seven regional Centers (located in Beloit, Cashton, Manitowoc, Marengo, Milwaukee, Rhinelander, and Rothschild), and a statewide program office located at the University of Wisconsin-Madison School of Medicine and Public Health.

The CHW Integration program is supplemented through the efforts of the Milwaukee AHEC (MA- HEC) who train and place CHWs in both clinical and community settings. In collaboration with community and clinical leaders, MAHEC implemented the CHW Best Practices Conference in 2012. This laid a foundation for the Wisconsin Community Health Worker Alliance (WICHWA), a voice for healthcare workforce innovation, quality healthcare delivery, and healthcare access specifically for underserved and disenfranchised populations.

During the next four years, the WICHWA, under the auspices of MAHEC, regularly convened more than 32 organizations from Milwaukee and surrounding areas, representing eight sectors. This group came together to discuss how to transform Wisconsin communities through dedicated partnerships, collaboration, innovation, and interventions aimed at poor health, substandard healthcare access, and addressing preventable illnesses that occur in the inner-city neighborhoods of Milwaukee (Wisconsin's largest city). The Wisconsin Community Health Worker Alliance developed a strategic plan, trained alliance members, and significantly expanded the visibility and role of CHWs within the medical community and across Milwaukee. Several partnerships with health plans and Medicare and Supplemental Security Income (SSI) providers emerged from this alliance.

The report, 'Health literacy interventions and outcomes: an updated systematic review,' underpins this project's methodology and documents the relationship of health literacy to a variety of health outcomes [4]. The report suggests limited health literacy impacts an individual's: knowledge of disease; use of health care services and resources; preventive screenings; and self-management of chronic conditions. Through efforts to address local social determinants of health, the WICHWA focused on advancing patient health literacy to improve the quality of health care and decrease health disparities.

The WICHWA program trains community health workers how to contribute to integrated care teams - and to advance health literacy - by addressing the social determinants of health and advance prevention and screening, health coaching, and health promotion. The project involves two integrated care teams: (1) Health coach team comprised of one CHW supervisor and fourteen trained CHWs, and health coaches, specialty-trained CHWs with greater responsibilities, and (2) Wisconsin intensive care team (WICT) comprised of one supervisor, one Trauma Informed Care Specialist, two CHWs, one Registered Nurse, and one Care Coordinator.

The latter project provides a seamless structure of services through team-based care coordination and focuses on: (1) addressing the social needs for 10,000 Medicaid supplemental security income enrollees; (2) enhanced care management; (3) improved access to primary care; and (4) increasing health literacy. CHWs help participants navigate a myriad of health and human service referrals. A participant's medical data help the care teams identify individuals who need more intensive interventions. Within this group, there is a subset known as 'high utilizers,' and the WICT provides additional support to improve health outcomes.

Intensive case management and care coordination may include the following: connecting to behavioral health resources; addressing chronic homelessness by helping member to secure shelter; utility assistance referral; securing food and transportation; and attending primary care visits. This approach ensures diverse social needs are addressed that adversely impact participants.

Overall, WICT improves the quality of health care delivery by: (1) reducing the number of emergency visits and admissions; (2) reducing the cost of care due to appropriate use of health care resources; and (3) increasing the use of preventive services and screenings.

5. Conclusion

HRSA/BHW plays a vital role in creating health literate organizations as illustrated by the three programs outlined in this report. Due to the ability of AHECs to adapt national initiatives to address local and regional healthcare issues, the AHECs in Massachusetts, Kentucky, and Wisconsin have created training programs that address at least three of the attributes of a health literate organization. AHECs are leaders across the U.S. in the development and enhancement of educational and training networks with the broader goal to improve health care delivery to rural and underserved areas and populations. AHECs are on the frontline and well positioned to tackle the emerging and current needs of the communities they serve.

The authors salute the staffs of the AHEC's across the U.S. and hope they serve as models of health literacy's diffusion.

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Section Two Summary: Taking Stock of Health Literacy Practices

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Abstract. This summary of the brief reports notes common themes, activities, and directions in health literacy practices across diverse settings, organizations, and populations. The summary also discusses how a 'best practices' approach could help build an evidence base, solidify evidence of impact, and advance the use of health literacy techniques.

Keywords. Health literacy, best practices, projects, activities, quality of evidence, evidence of impact

1. Introduction

During the last two decades, the health literacy field has produced enough projects and activities that practitioners and researchers can take stock of what we have learned to date. We also can consider the extent to which "best practices" have emerged to guide future work. According to the framework proposed by U.S. Centers for Disease Control and Prevention (CDC) staff, a best practice is "a practice supported by a rigorous process of peer review and evaluation indicating effectiveness in improving health outcomes, generally demonstrated through systematic reviews." [1]

Practices can be evaluated according to their public health impact and the quality of the evidence and fall along a continuum of emerging, promising, leading, and best, with best having the largest impact and strongest evidence. Some of the impact assessment criteria come from Green and Glasgow's RE-AIM model (Reach, Effectiveness, Adoption, Implementation, and Maintenance), which the *HLRP: Health Literacy Research and Practice* journal also recommends for practice-focused paper submissions [2-3]. However, the RE-AIM model is not well-known in the health literacy field, and few of the activities or project reported so far in *HLRP* practice papers have used the model.

Although many health literacy projects and activities, including some described in this volume, have been evaluated through a peer review process and may show effectiveness for health and non-health outcomes, few meet the standards of a systematic review that would qualify the project or activity as a best practice, per the CDC framework [4-6]. Instead, the reports in this section fall into emerging, promising, or leading practices, meaning that the projects or activities need more implementation

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examples with varying circumstances and populations and more thorough evaluation with higher quality evidence. In general, the practices described in this section's reports demonstrate feasibility and adoption, some signs of sustainability, but less evidence of extended reach or transferability to other contexts.

The CDC framework and the RE-AIM model represent necessary design and evaluation rigor that can advance health literacy evidence and a base for best practices. Health literacy stakeholders should consider adopting the CDC framework, RE-AIM model, other equally rigorous guidelines, or evidence-based guidelines that the field develops itself. To produce more evidence of impact and design higher-quality projects and activities, teams will need significantly more resources than a typical health literacy project or activity often receives. Although formative research and pilot or single-site demonstration projects are essential steps in the development of robust interventions, limited funding for health literacy projects and activities means they often do not advance beyond these early stages with small numbers of participants or convenience samples. While health literacy work can occur in the context of other programs, such as obesity prevention or chronic disease management, health literacy stakeholders will have to advocate for resources devoted to collecting, analyzing, and reporting high-quality data on health literacy's impact on process and outcomes.

In addition, the health literacy field should begin a dialogue about the standards for best practices for health literacy organizational assessments, processes, and change. Several of the reports acknowledge internal process changes were necessary to undertake health literacy projects or activities. Currently, the *Ten Attributes of a Health Literate Health Care Organization* function as a working set of standards for health care delivery organizations, but they have not been validated and recognized through a formal process [7]. Also, the *Ten Attributes* are likely not universally applicable because they describe activities in healthcare organizations, and other types of organizations, such as public health agencies or community-based service organizations, may need to aspire to different attributes. Moreover, the proliferation of organizational assessment tools, such as the *AHRQ Health Literacy Universal Precautions Toolkit* and the *HLE2: The Health Literacy Environment of Hospitals and Health Centers*, reflect the vitality of tool development activities as well as an ambiguity and uncertainty about the essential health literacy elements to assess and the most effective processes to support health literacy work [8-9].

Several of the reports are from organizations that have restructured processes and crossed disciplinary or expertise boundaries to accomplish their health literacy projects or activities. For example, the Bristol-Myers Squibb team not only created health literacy tools for staff use but also re-tooled their internal processes for getting patient input, reviewing and testing information products, and evaluating communication as part of their business model [10]. The team also brought in new expertise to inform their design work. O'Leary and colleagues describe a similar process of re-thinking health literacy's place in the conduct of clinical trials. They argue that infusing health literacy in medical research and drug testing will produce better results for patients and the pharmaceutical industry [11]. The Davis and Arnold report on health research in rural areas suggests collaborations across traditional boundaries of research and practice can result in more participation and better outcomes [12].

One common theme in almost all the practice reports suggests health literacy techniques expand people's access to information in multiple ways. The number and variety of channels and formats increase, and information products become easier to understand and use by more people and groups. Several reports identify designing information and services to match the audience as a best practice; yet, multiple authors note that far too few organizations and professionals follow this practice. This general practice is addressed, for example, by Ahmed in his discussion of the National Library of Medicine's MedlinePlus service and Hilfiker et al. in their review of consumer and patient digital health research and design principles in Health Literacy Online [13-14]. Some specific examples come from Peña Gonzalez et al. and their projects using the Institute for Healthcare Advancement's educational materials for different audiences and Davis and Arnold's report on health literacy techniques to reach rural populations for research and clinical services [12, 15].

A second theme suggests health literacy (HL) is increasingly becoming a matter of how organizations pursue their mission and goals. The reports from U.S. Department of Health and Human Services' agencies, the New York Department of Health, the pharmaceutical company, and the clinical trial team suggest health organizations are reviewing their internal processes, considering how HL insights and techniques contribute to their work, and offering tools and resources to help internal staff and external stakeholders implement health literacy-infused solutions [11, 13-14, 16-20]. The emergence of an international association to bring together health literacy stakeholders attests to the ongoing diffusion of the health literacy concept across geopolitical boundaries and organizations [21].

2. Summary of NGO Reports

The three NGO submissions on health literacy practices span an international professional association aiming to foster collaboration to local projects with rural residents or adult learners. The common thread among the reports is the practice of collaboration and partnership that can serve a variety of aims, including participatory research and service projects and the building of networks of like-minded professionals promoting health literacy. Davis and Arnold state their studies show health literacy strategies can help reach rural populations with plain language information that motivates persons to participate in research. Davis and Arnold recommend taking time to establish mutually beneficial relationships with rural clinic staff and using a fully participatory approach with staff and patients to design and implement research projects [12]. Similarly, the Wisconsin Health Literacy team emphasizes the importance of community partnerships to identify the most important topics to address and ensure robust participation from providers and community members. The Wisconsin HL team also stress knowing the audience and ensuring intended participants are part of each project phase. The Wisconsin HL team offer a number of tips about how to set up workshops, create materials using health literacy techniques, and involve patients and consumers in projects [22].

The final report in this group takes a global perspective, and Kurtz-Rossi et al. describe health literacy organizations that have emerged within countries, at the country and region level, as well as internationally. Kurtz Rossi et al. recount the origins of several different groups, such as the International Health Literacy Association and the Asian Health Literacy Association. The authors observe the latter organizations provide important opportunities for professionals to learn, network, and communicate about health literacy. Although not every country or region has a health literacy organization, Kurtz Rossi et al. suggest the existing organizations can provide critical professional development, principles, and standards that benefit all professionals working to advance health literacy [21].

3. Summary of Corporation and Organization Reports

The reports in this group illustrate that health literacy-informed materials can be part of broader programmatic and organizational agendas. Two reports demonstrate that straightforward projects to revise patient informational materials can evolve into more general reconsiderations of how to relate to patients. The third report suggests health literacy strategies, such as easy-to-read materials, can contribute to diverse program outcomes such as reducing emergency department use or preventing older adults from falling.

In the case of the pharmaceutical corporation (Bristol-Myers Squibb - BMS), the company responded to a changing regulatory and competitive environment and patient feedback about the confusing nature of drug information with a health literacy program they dubbed ‘Universal Patient Language.’ The report is an inside look at how a large, complex organization rethought its patient information work, engaged stakeholders in an overhaul, and implemented an organization-wide strategy that serves multiple stakeholder interests [10].

The chapter clarifies a top-to-bottom overhaul of how to create patient information takes perseverance, participation, and support from many parts of an organization. A few lessons stand out. First clear communication as an activity and result requires organizational capabilities that must be developed and supported over time. BMS’s transformation took five years and is still ongoing. Second, stakeholder involvement is key to identify and validate process improvements. In large organizations, many units and people may have a stake in how patient information is created and distributed, and even small changes might generate unintended consequences.

O’Leary and colleagues also refer to a changing regulatory environment as an impetus for plain language communication about clinical trials information. O’Leary et al. suggest a comprehensive approach that involves applying health literacy techniques in the complete clinical trials process from a drug protocol’s development to the summary of results. The authors discuss unique features of the scientific challenges in clinical trials information, and they provide the multiple health literacy techniques they apply to make clinical trials information understandable and useful. The authors caution against overly strict adherence to templates intended to be illustrative. They use templates as a starting point that can be modified by user testing results. O’Leary and colleagues conclude a health literacy approach to clinical trials information creates new opportunities to deepen public understanding of medical research and can possibly change the research process itself [11].

The report from the Institute for Healthcare Advancement (IHA) team reviews several projects in which they used their easy-to-read book series. The books are targeted to different audiences around common problems, such as caring for a sick child, or life stages such as adolescence or aging. The IHA team reports the books function as part of broader programs to address key issues such as emergency department use or fall prevention for older adults. The program to reduce emergency department visits has a multi-year, positive track record, while the other two programs for older adults are still in process. Given the positive feedback from the example programs, the authors conclude health literacy techniques can play a critical role in effective health and social services program delivery [15].

4. Summary of Government Agency Reports

The reports from the U.S. Department of Health and Human Services' agencies and the New York State Department of Health show the critical role public agencies play in shaping and diffusing health literacy practices. These agencies can raise awareness, establish priorities, provide resources (including funding, tools, and training), conduct research and evaluations, and initiate and sustain programs. Because of their size, reach, and public responsibilities, federal and state health agencies provide unique core support that other organizations can build on [13-14, 16-20].

The New York State Department of Health report provides a model approach to health literacy strategic planning and implementation for state health departments. Associate Commissioner Wilma Alvarado-Little describes how the department's health literacy initiative emerged from a staff working group and the attention it brought to health literacy; federal policy changes that opened opportunities for reimbursed health literacy work; and new departmental leadership directing a strategic health literacy approach. The staff pursued health literacy implementation as important in its own right and as a critical link to other priorities, such as disease prevention and health equity. The report includes many specific activities that have helped raise awareness with stakeholders and integrate health literacy in key programs. Alvarado-Little acknowledges the importance of supportive leadership and concludes health literacy is becoming central to how the department supports health services and information to benefit all New Yorkers [20].

The brief history of MedlinePlus.gov at the National Library of Medicine (NLM) by Terry Ahmed describes expanding public access to its vast stores of health, medical, and scientific information in the context of a changing policy and technology environment. Digital access to information in the 1990s changed the profile of who was interested in NLM's health information. Formerly an information service for researchers and health professionals, Ahmed explains that NLM and eventually MedlinePlus became a go-to source for patients and families looking for a wide range of health and medical information [13].

Technology changes continue to inform NLM's and MedlinePlus' approach to its services as it looks for ways to make information accessible to a wider range of people. According to Ahmed, MedlinePlus.gov serves the health literacy field by making health literacy topic information available and helping inform and educate patients, families, and caregivers about health, medicine, and science. The report provides a timely reminder that information quality should be a topic of high concern to the health literacy field as the public can be equally exposed to reliable and unreliable information through digital channels [13].

Similar to New York State, Brach and Borsky's report on some HL initiatives from the U.S. Agency for Healthcare Research and Quality (AHRQ) suggests the positive results when staff think strategically about health literacy work. AHRQ staff developed an internal action plan to guide choices about how to invest agency resources in the health literacy activities. The report recounts how the agency has built a large, varied portfolio of health literacy research and practice improvement resources that align with its mission of fostering healthcare quality and safety. While AHRQ's strategic approach helps the agency prioritize its activities, it also provides a rationale when elected officials, the news media, or the public want to know why the agency is focused on health literacy [16].

Hilfiker et al. report on the work of the U.S. Office of Disease Prevention and Health Promotion (ODPHP) to make online health information accessible to the broadest range of people, especially people with limited health literacy. To backup, the Office of Disease Prevention and Health Promotion operates a major publicly-funded consumer health information website, www.healthfinder.gov. After reviewing the literature on differences between high and low health literacy online behaviors and digital challenges and barriers to online health information, the authors share the practices they have learned through research and evaluation of the Healthfinder service. Hilfiker et al. argue digital barriers can be overcome, and health agencies and organizations could reach many more people with digital health information and tools if these products were designed for understandability and accessibility. Similar to MedlinePlus' history, the Hilfiker et al. report suggests government agencies sometimes need to provide leadership regarding health information and digital access to ensure equitable public access for all [14].

Meanwhile, the U.S. Food and Drug Administration's (FDA's) message testing process suggests government agencies - determined to apply health literacy principles and include audience feedback on materials - can overcome significant internal barriers to get needed feedback. Duckhorn et al. report two ways FDA obtains feedback on public health communication materials: an internal, volunteer employee-based system and an external contractual process that recruits members of the public. The internal system uses employees who volunteer to review materials from a different part of the agency. The external system uses a contract agency and an online panel of consumers. The authors discuss the pros and cons of each approach and conclude that despite limitations, both approaches have prevented the agency from making 'public message missteps' and mistaken assumptions about what audiences might understand. Duckhorn et al. conclude testing is a best practice; some testing is better than none; and agencies should find ways to do message testing that fit their circumstances [18].

Along with NLM and ODPHP, the U.S. Centers for Disease Control and Prevention (CDC) has been a national leader in making health information accessible to diverse audiences, and accomplishes this through the implementation of diverse health literacy techniques. Dr. Lourdes Martinez recounts CDC's evolution from basic plain language techniques to an agency-wide strategic approach with an internal Health Literacy Council, staff training, plain language software, the CDC Clear Communication Index, measurable objectives, and regular report cards. Dr. Martinez notes a large, complex organization such as CDC needs participation from across the agency, which the CDC accomplishes through its internal Health Literacy Council with representatives from the agency's 12 main units. In addition to the internal staff resources, CDC provides free online resources and training for public health professionals. Although CDC has made measurable progress to address internal barriers and diffuse health literacy practices, Martinez notes more leadership, staff engagement, routine application, and research and evaluation are needed to ensure a sustainable health literacy program in the service of public health [19].

Finally, the authors from the U.S. Health Resources and Services Administration (HRSA) describe the health literacy activities of three Area Health Education Centers (AHECs) – one each in Massachusetts, Kentucky, and Wisconsin. AHECs are HRSA-funded, community-level organizations that undertake multiple activities, including provider training, to make healthcare more accessible to rural and underserved populations. The three AHECs use different approaches and health literacy tools and adapt their health worker interventions to match local needs. The AHEC examples suggest the role of public agencies to disseminate health literacy practices and train a wide range of health workers in health literacy issues [17].

5. Conclusion

Section two describes practices that are a cross-section of the health literacy field in 2019. The reports include many frequent practices such as: be strategic; get senior leadership support; adapt to local circumstances; build partnerships; use as many health literacy techniques as necessary; prepare staff; and always test drafts or prototypes with the audience or end-users of the health information or service. The evidence from health literacy research and related fields, such as communication and psychology, suggests audience or end user testing is a foundational ‘best practice’ in public communication initiatives about health. The challenge for both new and experienced practitioners is to find the combination of other practices that are necessary and will produce the best results for a given situation. More research and evaluation of these emerging, promising, or leading practices - per the CDC’s framework - is required before the field has a confirmed set of best practices.

Most of the government agency reports and Bristol-Myers Squibb’s contribution demonstrate the importance of being intentional and strategic when undertaking a health literacy initiative, especially within large, complex organizations. Health literacy competes with other priorities for senior executive attention and funding, and unless staff are fortunate to work for a rare leader who ‘gets’ health literacy, the staff who introduce health literacy practices need to anticipate significant competition.

The cumulative impact of activities of agencies within the U.S. Department of Health and Human Services is impressive and suggests how, over two decades, staff progressively elevated health literacy as a public heath priority. The latter reports also reinforce the need for public health agencies to be fully engaged in health literacy work because of the scale of the impact they can have.

Collectively, the reports make the case for implementing and evaluating a core set of health literacy practices across many organizations. Although the reports do not comment on failed initiatives or activities, the reality is that niche or ‘pet’ projects rarely outlive their funding or a few interested staff. The plans, activities, and staff engagement evidenced in the New York State, AHRQ, CDC, and Bristol-Myers Squibb reports suggest strategic and intentional practices are the ones that survive the inevitable ups and downs of leadership changes and funding cycles.

Institutionalized health literacy initiatives also will survive long enough to contribute to the evidence base of what works and what doesn’t. When health literacy practices become ‘the way we do things at XYZ organization’ and there is a critical mass of supporting organizations, then, we will accumulate sufficient evidence to validate best practices, which will inform and advance the health literacy field for decades to come.

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Section Three

Health Literacy's Similarities With – and Differences From – Related Health Disciplines

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Health Literacy in Clinical Practice and Public Health
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Reintegrate Empowerment and Health Literacy to Advance Public Health and Healthcare Delivery

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Abstract. Empowerment has been described as a prerequisite for health and the ultimate goal of health literacy in both clinical practice and health promotion. Improving health literacy and empowerment is central to national and international public health and healthcare policies. While initially merged in the construct of critical health literacy, and currently linked without question in policy and discourse, health literacy and empowerment have been dichotomized - treated as two separate fields of study and practice - and partitioned further into condition-based lines of inquiry. Few studies have addressed both concepts. Indeed, references to empowerment in health literacy studies have decreased over the last decade. This chapter summarizes and interprets the significance of these fault lines for current and future research. Divergent clinical and health promotion perceptions of health empowerment, its expected outcomes, processes, interventions and measures are reviewed. Gaps in the literature are identified and recommendations are suggested to build a more robust science around health literacy and empowerment by addressing those limitations. The chapter reinforces recent calls for increased attention to empowerment in health literacy research and the reintegration of the critical health literacy concept to better reflect policy, achieve global public health goals, advance healthcare delivery, and foster multidisciplinary career opportunities for students, researchers, and practitioners.

Keywords. empowerment, health literacy, critical health literacy, patient empowerment, community empowerment, women's empowerment, popular education

1. Empowerment, Health Empowerment, and Patient Empowerment

The World Bank defines *empowerment* as a person's or a community's ability to make a choice and transform that choice into their desired actions and outcomes [1]. The World Health Organization (WHO) defines *health empowerment* as: a personal or community process through which people gain greater control over decisions and actions affecting their health [2]. Health empowerment is foundational to health promotion practice and emphasizes personal or social action to improve social determinants of health.

More specifically, WHO defines health empowerment in healthcare settings, or *patient empowerment* as: "a process in which patients understand their role, are given the

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knowledge and skills by their healthcare provider to perform a task in an environment that recognizes community and cultural differences and encourages patient participation" [3]. Patient empowerment is differentiated from health empowerment by reference to individuals (and sometimes their families or caregivers) who are engaged with a healthcare system. Patient empowerment is further differentiated by its focus on information, reading skills, and the role of clinicians in leading the process and mitigating the negative consequences of low literacy in clinical settings [4]. Within the domains of health literacy, patient empowerment applies in the disease treatment and healthcare domain, while health empowerment applies in the disease prevention and health promotion domains [5].

According to the WHO's landmark review on the effectiveness of empowerment to improve health, participatory health empowerment strategies can lead directly to health improvements, but more frequently foster intermediate steps on a pathway to actual physical changes in health [6]. Empowerment-focused interventions have been shown to: strengthen self and collective efficacy; increase social capital; foster neighborhood cohesion and influence; and improve a sense of community as well as community capacities [6]. A cluster of studies on a single empowerment-focused intervention implemented in multiple sites across the US, showed consistent overall improvement in health literacy [7]. Sustained health empowerment initiatives have fostered public policy changes, increased equity, and improved material or environmental conditions. In turn, these empowerment outcomes have been linked to improved health outcomes, including better self-reported health, fewer depressive symptoms, increased condom and women's contraceptive use, reduced HIV infection rates, improved nutrition, increased immunization rates, and lower child mortality rates [6].

In the healthcare arena, patient and family empowerment strategies are reported to improve health, facilitate adoption of healthier behaviors, increase patients' abilities to manage disease, help individuals use services more effectively, and strengthen caregiver coping skills and efficacy [6]. Similar claims are made for health literacy [8].

Still, with few exceptions, the evidence for these claims is based on multilevel economic development studies and is not empirically robust. Like health literacy, empowerment is variously defined, inconsistently operationalized, and measured by study- or condition-specific instruments [5,9]. Since approaches, interventions, and policies are unclear regarding the aims and purposes of empowerment as a construct, it is difficult to impossible to evaluate or compare effectiveness [9-12].

1.1. Health Literacy and Empowerment

While health literacy and empowerment are commonly dichotomized in both research and practice, a few public health initiatives have addressed both concepts, most often with 'disadvantaged' populations in low-income countries [6,7,11]. Clinical studies addressing both health literacy and empowerment are especially hard to find. One recent study used increased level of participation in prenatal care visits to demonstrate patient empowerment [13]. While the number of health literacy studies has increased steadily since the early 1990s, there remains a paucity of data or discussion on empowerment [14-15]. Indeed, references to empowerment in health literacy studies have appeared with *decreasing* frequency since 2008 [11].

This neglect of empowerment by researchers seems antithetical to the widely held and unquestioned belief that empowerment is essential to health and closely related to health literacy. Empowerment is considered a prerequisite for health; and health literacy is considered a prerequisite for empowerment [6,16]. Empowerment has been described as the ultimate goal of health literacy in both clinical contexts and in health promotion [17-18]. Empowerment is deemed a way to describe health literacy; and health literacy is deemed a way to accomplish empowerment [11,17].

Improving health literacy and empowerment is a central element of national and international public health and healthcare policies [9,19]. Yet most policies are aspirational; they lack funding, monitoring and accountability [19]. Indeed, the widely accepted health literacy-empowerment link is not supported by robust evidence [8-9]. Still, it is not questioned or discussed in detail in the medical or public health literature.

The dearth of empowerment research may be explained in part by a reporting bias in which empowerment is a small part of articles that address it [8,14-15]. Some published reports include the term 'empowerment' in their titles or key words but present no data or discussion on the topic. The lack of references to patient empowerment may be further influenced by use of the MeSH term 'empowerment', which refers to 'participation'; and by the World Health Organization's suggestion that 'patient participation' may be "a less emotionally charged and challenging term more acceptable to health care workers, patients and cultures" [3, p.190].

Findings from multi-level studies suggest it is feasible and promising to integrate health literacy and empowerment approaches within clinical care and health promotion initiatives [6,7,20-21]. A cluster of studies on a single intervention implemented in multiple home-based maternal-child health promotion programs across the US confirm these findings with direct evidence [7,22-25].

A broader conceptualization of medical care and health literacy improvement that begins with patient, family, and community empowerment also may help advance healthcare delivery along more progressive, integrative lines [7]. Further, an approach that recognizes and builds on the interactions of health literacy and empowerment in personal and public health fosters multidisciplinary career opportunities for students, practitioners, and researchers [7].

1.2. Chapter Overview

This chapter reinforces recent calls for renewed attention to empowerment in health literacy research and practice [17]. The authors urge researchers and practitioners to link health literacy and empowerment in intervention and evaluation to better reflect national and international health policies, achieve global public health goals, and advance health care delivery. Readers are encouraged to incorporate health literacy initiatives into existing empowerment-focused prevention and health promotion programs; and to include empowerment approaches in planning, implementing and evaluating health literacy initiatives and patient care programs.

A selective review of reviews from the public health and medical literatures guides a discussion of conceptual frameworks for empowerment in relation to health literacy. Reviews were selected from results of searches conducted January-March 2019 via EBSCO, PubMed CINAHL, ERIC PsychInfo, Google Scholar, using key words 'health literacy' and 'empowerment' and 'review', along with other resources. The conglomeration of perceptions of empowerment is addressed, including its purposes, processes, outcomes, and measures. Since the well-documented divergence of clinical and public health approaches to health literacy extends to empowerment, the authors examine each in turn [26-27].

Following this introduction, Section 2 covers clinical approaches to patient empowerment and reviews the current state of that body of research, which is characterized by condition-based clusters of studies. For example, there is a large body of literature on initiatives to empower patients to better self-manage diabetes; and there are studies on empowering cancer patients, and those with lung disease, or heart failure [9].

Attempts to synthesize results of randomized controlled trials of patient empowerment initiatives demonstrate such one-dimensional studies have produced findings applicable only within the silo that produced them. Results cannot be generalized to yield an evidence-based theory of patient empowerment or contextualized to yield insights about the interactions of patient empowerment with health literacy.

Section 3 presents a parallel discussion of public health approaches to individual and community health empowerment. Few public health studies have addressed both health literacy and health empowerment. Studies linking empowerment with health have focused on individual empowerment, and most have been published in the community development literature [6]. Community empowerment initiatives are necessarily comprehensive and longitudinal with multiple targets and outcomes at many levels [6]. Therefore, health empowerment initiatives may be impossible to evaluate by conventional methods [6]. Women's empowerment warrants a separate line of inquiry due to power relationships with men and issues around childbearing [28].

In Section 4, the intersection where empowerment and health literacy meet and can beneficially interact is identified. In Section 5, the authors suggest steps to overcome gaps and limitations in the literature and develop a more robust science around health empowerment and health literacy. Section 6 closes the chapter with the authors' conclusions.

2. The Clinical Perspective: Empowerment in Healthcare

This section discusses patient empowerment research. Subsection 2.1 covers the medical perspective on empowerment and the purposes of patient empowerment. Subsection 2.2 addresses the expected outcomes of patient empowerment initiatives. Subsection 2.3 discusses various clinical perspectives on the processes by which patients become empowered. Subsection 2.4 reviews intervention strategies thought to empower patients. Subsection 2.5 considers the array of indicators that have been used to measure patient empowerment, along with issues related to the number and variety of untested instruments in use. Other gaps and limitations in the literature on patient empowerment are outlined in subsection 2.6.

2.1. Patient Empowerment: Individualistic and Functional

Clinical interest in patient empowerment stems from the resolve to move from a paternalistic style of healthcare to a more collaborative and equitable, cost-effective model for the third era of modern healthcare [7,9]. The commonly stated purpose of patient empowerment is to address systemic challenges presented by patients living with long term conditions by increasing their capacity for participation and responsibility in decision-making, recovery, and outcomes. The medical literature reveals an individualistic and functional perspective on patient empowerment in alignment with the clinical focus on individual functional literacy. Authors have specifically questioned the need for a social aspect or involvement of peers in patient empowerment initiatives, suggesting that social support is available online, and facilitating patient empowerment is easier within an individual setting [10]. Although patient empowerment efforts focus on individuals, study populations are defined almost exclusively by their disease. Ethnic, social and gender differences are largely ignored [10,14].

2.2. Expected Outcomes of Patient Empowerment

Theoretically, patient empowerment results in increased adherence to treatment and medication regimens, and patient satisfaction, healthier behaviors, better use of services, more independence from health care professionals, and actual physical changes in long term conditions, (e.g. biomarkers of insulin control) [6]. These patient empowerment outcomes mirror the theoretical, and unverified, outcomes of critical health literacy [8]. Authors have variously equated patient empowerment to health literacy or more specifically to *critical* health literacy [7,12]. Others have viewed critical health literacy as a prerequisite for patient empowerment, or identified patient empowerment as an outcome of health literacy [11,17].

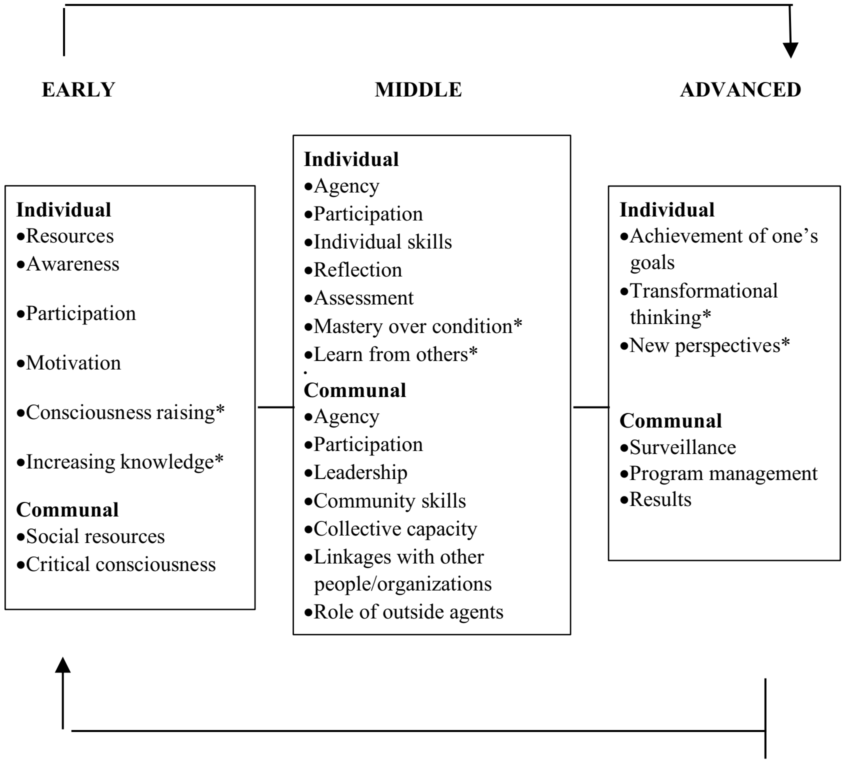
Paradoxically, in a review of randomized controlled trials of patient empowerment initiatives (21 of 33 with diabetic patients), Werbrouck and colleagues found the most commonly reported outcome was behavior change, typically described as knowledge gain [10]. The paradox is that, by itself, knowledge is insufficient for behavior change and for patient empowerment [29]. Minimal effective behavior change that would document achievement of patient empowerment has not been identified. The most effective type and number of behavioral change techniques to achieve patient empowerment outcomes also remains unknown [10].

Outcomes of patient empowerment are frequently described as ‘self-management’, ‘self-efficacy’, ‘self-care’, or ‘self- determination’ highlighting the shift of responsibility away from the clinician toward the patient, and an expectation that health literate and empowered patients “adjust to prescribed care plans” [12, p.644,33]. Calvillo et al. conclude many empowerment-focused, technology-based interventions increased clinical efficiency but not patient empowerment [12]. Similarly, in a 2016 review of 34 interventions with diabetes patients identified as having low health literacy, Kim and Lee found initiatives using multimedia devices effectively increased knowledge during the short term but were insufficient to change behavior or health status [30].

In a 2016 review of concepts and measures of patient empowerment, Cerezo and colleagues concluded the final outcome of patient empowerment is participation in decision-making [15]. Indeed, ‘participation’ is considered a synonym for ‘empowerment’ in healthcare by the U.S. National Institutes of Health and WHO [3,31]. The term and conclusion reflect a clinical understanding of health literacy as the passive ability to understand information needed to make “appropriate” health decisions. This perspective neglects the social and subjective aspects of literacy, health, and illness and guards clinicians’ power to deem patients’ decisions inappropriate. In a mixed-methods conceptual analysis, the Cochrane Group posited longer-term, broader outcomes of patient empowerment including increased quality of life and well-being, and adaptation to long term conditions [9].

2.3. Patient Empowerment Processes: A Top-down Approach

A number of authors have described elements, domains, components or steps in the process by which patients become empowered. See Figure 1. These processes are discussed using terms such as 'enablement', 'activation', and 'permission'. The terms reflect a top-down approach in which clinicians aim to manage the perceived risks of low health literacy to systems and patients (inefficiencies, high cost, low compliance with treatment regimens, poor outcomes, and inequities [32].



*Specific to patient empowerment.

Figure 1. Compilation of Proposed Steps in the Empowerment Process

Researchers have drawn on the management literature to describe the process of patient empowerment. Schultz and Nakamoto differentiated health literacy from patient empowerment stating, "Health literacy asks whether patients *can* make choices. Empowerment asks whether they *may*…" [33, p.7)]. This characterization reflects an understanding of health literacy as a passive cognitive capacity for patient empowerment. It equates power to position and the process of patient empowerment to permission by clinicians. It makes patient empowerment a privilege granted to those judged to be adequately skilled and knowledgeable (health literate) by providing them information and opportunities to participate in decision making and assigning them responsibility to transform those decisions into 'appropriate' actions and outcomes.

Schultz and associates further assessed an oft-raised question relevant to the empowerment process in clinical practice: Do patients want to make decisions? [34]. In turn, they framed patient empowerment as the willingness to participate in decision-making, along with permission and information to do so. They emphasized separating health literacy and empowerment conceptually while intervening for both simultaneously in order to avoid mismatches in empowerment and functional literacy. Schultz and Nakamoto suggest the latter can lead patients to be needlessly dependent on health care professionals or dangerously self-managed [33].

Qualitative evidence suggests clinicians share this understanding of patient empowerment emanating from permission to participate in treatment decisions. Sykes and colleagues found health care professionals stressed that health literacy, especially at advanced levels (interactive and critical health literacy), would exist only where clinicians committed to provide accessible information and shared decision-making [8]. Similarly, Jorgensen and associates found studies with cancer patients defined patient empowerment in relational terms, indicating a need for a health care provider who shares or hands over control to patients [14]. In interviews on the meaning of patient empowerment, Bravo et al. reported clinicians stressed patient responsibility, while patients stressed control [9].

However, others suggest the conceptualization of patient empowerment as power bestowed by clinicians on those judged capable does not transfer from a business environment to the health arena. Instead, they argue, informed choice is every patient's right and empowerment is self-generated, not bestowed [6,11,21,28]. This divergence was noted by Calvillo et al. who identified the reluctance of doctors to lose power as a major obstacle to enhancing patient empowerment through technology [12]. Cerezo and colleagues concluded that a paradigm shift in healthcare is needed to achieve patient empowerment [15].

2.3.1. Integrative Medicine Introduces Health Empowerment in Clinical Settings

Efforts to shift the paradigm and integrate patient empowerment into U.S. health systems and clinical practice currently are led by the military. Mind-body skills development programs in healthcare settings intend to "empower military patients and their families to be responsible for and participatory in their health and healing process, to instill them with a sense of control over their recovery, and to increase operational efficiency" [36, p.18]. Proponents acknowledge it is essential to integrate empowerment-focused programs into communities as well as healthcare settings.

Civilian healthcare organizations, in response to consumer demand, are increasingly integrating a variety of complementary and alternative medicine (CAM) practitioners into patient care teams [37]. These CAM practitioners include chiropractors, naturopaths, acupuncturists, midwives, massage therapists, homeopaths and Asian and traditional Chinese medicine practitioners. A primary component of all these fields is a broadened conceptualization of patient empowerment that addresses the physical, emotional, spiritual and social aspects of health and illness. CAM positions practitioners as facilitators of self-healing, prevention, and health promotion [38].

CAM practitioners are introducing an alternative understanding of patient empowerment. From their perspective, patient empowerment is less about handing over power, and more about creating new shared power that resides in the patient and grows through a trusting therapeutic partnership [38-39]. The emerging field of integrative medicine, exemplified in the patient centered medical home model, seeks to integrate conventional medical care and CAM to assist the body's innate healing response. In addition to facilitating empowerment of patients, integrative medicine advocates that practitioners work to empower themselves for health and healing in order to understand the mechanisms of self-healing and empowerment [38]. Stahnisch and Verhoef provide a historical perspective on how traditional healing methods were forced out of U.S. healthcare and now, a century later, are being re-established [40].

2.4. Intervention Strategies for Patient Empowerment are Systems-focused

While interventions to promote patient empowerment are often described as patient-centered, most have been top-down, system-initiated, and practitioner-directed [11]. Interventions believed to be empowering include: shared decision-making, patient-centered training, counseling, health coaching, signposting, clinician training, patient education, and motivational interviewing [9-10,15,30].

In addition, Kim and Lee's 2016 review of 34 health-literacy-sensitive diabetes self-management interventions, classified the following as empowerment strategies: 'behavior activation' (print information focused on behavior), action plans, encouraging questions, and motivational interviewing [30]. During a 15-year period (2000-2015), seven interventions used one of these strategies; by inference, 27 studies (79%) used no strategy intended to facilitate empowerment. Two of the strategies (action planning and providing information on beneficial behavior instead of facts about diabetes) were found to be empowering; that is, patients who experienced them increased self-care and glucose control.

2.4.1. Empowerment Strategies can be Disempowering

Some authors argue strategies to promote [functional] health literacy are insufficient to achieve patient empowerment [11,15,34]. To achieve critical health literacy and patient empowerment, interventions must focus on other social determinants of health [11]. In addition, what is empowering for one patient may not be for another [14].

In articles about empowerment of cancer patients, Jorgensen et al. identified a theme that knowledge is power, *if* it is acknowledged by a health care professional. While knowledge can form the basis for autonomy, it can be disregarded or anxiety producing [14]. Participation, often considered the desired outcome of patient empowerment, can be viewed as utilitarian, serving primarily to ensure clinical efficiency [6,12]. Participation also can be limited, manipulative, and passive when participants serve only as informants [35]. Empowered patients also may choose not to use their power, so non-participation may or may not indicate disempowerment [14].

Behavior change techniques can be used in disempowering or controlling ways, such as chiding drug users to 'Just say No' [9]. Crondahl and Karlsson concluded a functional approach to patient empowerment (focused on behavior change) is a "waste of resources in populations lacking basic needs" [11, p.4]. For example, poverty precludes some healthful practices (e.g. consuming nine servings of fruits and vegetables per day when living in a food desert). Concerns about paying the rent and putting food on the table exceed anxieties about the negative effects of smoking or potential benefits of dental hygiene.

2.5. *Measures and Indicators of Patient Empowerment*

No consensus exists on how to measure patient empowerment. Multiple instruments are in use; most are disease- or study-specific and based on a unique definition [9]. Cerezo et al. evaluated 10 measures of patient empowerment and concluded (where participation is the main outcome of interest) 'enablement' and 'activation' can be considered synonyms for 'patient empowerment' [15]. Under this presumption, the Patient Activation Measure and similar activation metrics could be viewed as robust measures of patient empowerment. Alternatively, some authors suggest patient empowerment may be meaningfully assessed by patient reported outcome measures [9,41]. However, these instruments evaluate participation in clinical encounters, which, by itself is insufficient for empowerment [6].

Meanwhile, Nafradi et al. found no association between patients' scores on the [patient] Health Empowerment Scale and established measures of health literacy (Newest Vital Sign, Test of Functional Health Literacy in Adults), which suggests health literacy and patient empowerment are separate concepts [33-34]. Critics argue the latter finding supports the hypothesis that empowerment, as permission plus information and willingness to use it and functional literacy are unrelated. The claim also demonstrates a neglect of critical health literacy in research, and a dilution of empowerment-related aspects of the concept [8].

While some authors see health literacy and patient empowerment as unrelated, some see health literacy as a prerequisite for patient empowerment. Still others consider health literacy, particularly critical health literacy, as an indicator of patient empowerment. Similarly, researchers variously describe participation as an outcome or an indicator of patient empowerment, and also as a mechanism through which a patient becomes empowered. In this way, participation is to patient empowerment what reading ability is to health literacy.

Reading test scores have been used as indicators of patients' level of functioning in healthcare contexts [32]. However, just as proficient reading ability does not guarantee health literacy, and poor reading ability does not necessarily demonstrate low health literacy; participation in clinical encounters does not guarantee patient empowerment, and non-participation does not necessarily indicate disempowerment [7,14,42]. Clearly, functional literacy skills and participation are advantageous to reduce dependence on clinicians and enhance health, but insufficient for empowerment [6].

Other reported indicators of patient empowerment and their overlap with health literacy indicators are shown in Table 1. Bravo found no reported measure adequately captures the indicators of patient empowerment [9].

Table 1. Overlapping Indicators and Outcomes of Health Literacy and Empowerment

INDICATORS	Health Empowerment	Patient Empowerment	Health Literacy	Critical Health Literacy
Self-confidence	X	X	X	X
Condition-specific knowledge		X	X	X
Condition-/domain-specific self-efficacy	X	X	X	X
Behavior change	X	X	X	X
Determinants of health knowledge	X			X
Participation in treatment decisions	X	X	X	X
Critical consciousness	X	X		X
Participation in community action	X			X
Program impact	X	X	X	X
Speaking, listening skills	X	X		X
Reading, numeracy skills			X	
Problem solving, goal setting, action planning	X	X		X
Critical thinking	X			X
Advocacy	X			X
Adherence/Compliance		X	X	
Self-management of disease		X		X
Health literacy	X	X		
Autonomy	X	X	X	X
Reflection	X	X		X

2.6. Gaps and Limitations in the Literature on Patient Empowerment

Research on patient empowerment and health literacy is limited in scope, quantity, and quality. Limitations include a wide variety of measurement approaches, lack of attention to collective empowerment and to participants' understanding of empowerment, imprecise reporting, and bias. Due to the variety of measurement approaches and instruments and other limitations in the metrics surrounding patient empowerment, the relative effectiveness of interventions currently cannot be evaluated or compared [9]. This conclusion is confirmed by the results of a meta-analysis of 23 randomized controlled trials of patient empowerment interventions reported between 2002 and 2017. High heterogeneity (differences in outcomes) was not explained by subgroup analysis. Overall, 88% of between-study differences were not due to chance, which suggests the findings of the included studies were inconclusive and not generalizable [10].

Crondahl and Karlsson's review using keywords 'empower' and 'health literacy' and no search time limits, found no articles that explicitly addressed a health literacy-patient empowerment link [11]. Only five papers addressed both concepts. Of those, four were based on Nutbeam's theory of health literacy. A 2018 review of interventions that aimed to improve functional, interactive or critical health literacy in immigrant populations also used Nutbeam's theory and alluded to patient empowerment as an outcome of health literacy [43]. The review found positive changes only at a functional level, and no improvement in interactive or critical health literacy.

Patient empowerment studies have focused on individuals as separate from their families, communities, and cultures. Cerezo and associates' 2016 comprehensive review with no time limits, and Jorgensen's systematic review of articles published between 2000-2015 each found only one author addressed both individual (patient) and collective (family, in this case) empowerment [14-15]. Jorgensen et al. also found little or no attention to cancer patients' understanding of empowerment [14]. Study populations have been defined almost exclusively by their disease; demographics are rarely reported. There is a lack of attention to social and gender differences; and "ethnicity is almost invisible" [14, p.301].

The quality of the research is compromised by vague descriptions of interventions and study populations, and widely varying definitions and measures. Werbrouck and associates's recent review of 38 randomized controlled trials of patient empowerment initiatives found all were at a high risk for bias related to blinding [10]. Consequently, the literature offers little guidance on how to facilitate patient empowerment, who should do it, or how to evaluate effectiveness of efforts.

To summarize, the clinical perspective on empowerment is individualistic and functional. Clinicians are said to empower patients by giving them information, sharing decision-making authority, and giving them skills needed for treatment-related tasks. The overarching purpose, process, indicator and outcome of patient empowerment is participation in treatment decisions by individuals with long term conditions. However, participation alone is insufficient to guarantee empowerment and can be disempowering; and lack of participation does not necessarily indicate disempowerment. While other expected outcomes of patient empowerment overlap those of health literacy, these outcomes are unverified. The relationship of patient empowerment and health literacy is widely accepted and largely unquestioned, but variously understood and uncertain. At the same time, a debate continues over whether the provision of information, and encouragement to participate to some degree in treatment decisions, and completing specified tasks is akin to becoming empowered. Do these actions help one to gain control of decisions and actions that affect one's health, or rather simply shift responsibility for disease management?

From a public health standpoint, health empowerment differs fundamentally from patient empowerment.

3. The Public Health Perspective: Health Empowerment in Everyday Life

This section focuses on research related to health empowerment. Subsection 3.1 covers the public health perspective on individual and community empowerment, and women's empowerment as a separate line of inquiry. Subsection 3.2 addresses two ways in which empowerment impacts health: directly and indirectly. The achievement of empowerment is considered an ultimate outcome of health promotion initiatives, and an intermediate health outcome. Subsection 3.3 discusses public health perspectives on the process of becoming empowered individually and collectively. Subsection 3.4 reviews intervention strategies thought to facilitate health empowerment. Subsection 3.5 considers indicators and instruments that have been used to assess health empowerment. The gaps and limitations in the literature on patient empowerment are highlighted in subsection 3.6.

3.1. Health Empowerment: Social and Dynamic, Individual and Collective

In the prevention and health promotion domains (outside the disease treatment and healthcare domain), empowerment initiatives aim to enhance and protect individuals' health and quality of life by addressing and preventing the root causes of ill health [5,44]. Health empowerment initiatives aim to facilitate an individual's or group's efforts to achieve personal and social change that improves health [6,45]. Hence, from a public health perspective, health empowerment is social and dynamic, rather than individualistic and functional. While empowerment is self-generated and individual, what it means to be empowered, and how empowerment is achieved is determined in relationships and interactions with family, neighbors, co-workers, classmates, policy makers, local government, healthcare providers and organizations. Activities, desired outcomes, and indicators of health empowerment initiatives evolve and change, sometimes rapidly, with time, context and society.

Health empowerment can be individual (sometimes called psychological empowerment) and collective (also called community empowerment) [21]. Individual and collective empowerment are linked because collective empowerment builds from individual action. The term 'psychological empowerment' refers to an individual's belief that people working together can make a difference; it implies critical thinking ability and participatory behavior [6]. Hence, psychological empowerment marks a transition from individual to community empowerment. Still, the prevailing research focus on individual empowerment is limiting since it does not consider powerful environmental influences on health, such as employment and poverty, and leaves the public health and medical literature on community empowerment in a rudimentary stage [6,21,35,46].

3.1.1. Women's Empowerment: Separate Line of Inquiry, Global Health Strategy

Adding to the complexity, women's empowerment is a separate line of inquiry due to power relations with men and issues around fertility and childbearing [28]. Because low empowerment is linked with adverse economic and health consequences for women and their children, it has drawn particular policy attention. Promoting women's empowerment is a human rights goal [28]. The United Nations' Sustainable Development Goal #5 aims to "achieve gender equality and empower all women and girls" [47]. Promoting health literacy and empowering women is a global health promotion strategy to reduce the burdens of non-communicable diseases [48].

3.2. Direct and Indirect Outcomes of Health Empowerment

A landmark review on the effectiveness of empowerment to improve health was commissioned by the World Health Organization-Europe [6]. While it does not address health literacy, this wide-ranging comprehensive review of several bodies of literature through 2005 (500 sources reviewed; 257 citations) found references linking empowerment and health were plentiful in the economic development literature, less so in public health, and non-existent in medicine.

While the overall evidence was not seen as empirically rigorous, findings from a broad spectrum of multilevel studies suggest empowerment-focused participatory strategies can improve health and comprise a viable public health strategy [6]. Improvements are perceived to be achieved directly via the process of becoming empowered, and indirectly through the effects of being empowered [6]. The achievement of empowerment is an ultimate outcome of health promotion efforts.

For example, empowering processes integrated into home-based maternal and child health promotion programs resulted in mothers' increased ability to negotiate use of family planning methods. Mothers became empowered to plan and space their future pregnancies, directly improving their personal and family health [7]. Achieving empowerment is, at the same time, an intermediate health outcome, a milepost on the pathway to actual physical changes in health status. For instance, the same mothers demonstrated health promotion effects of their empowerment including increased ability to manage personal and family health at home; to effectively use adult and child medical and dental services and community resources; and to adopt and sustain healthier behaviors, preventive practices, and methods to support healthy child development [7].

3.2.1. Outcomes of Individual Health Empowerment

Participation is an outcome and an indicator of empowerment, as well as a process through which empowerment is achieved. According to the World Health Organization, engaging with others in communication and action for health seems critical to achieve empowerment, to enhance individual and population health, and to reduce dependence on health professionals [6]. Participation is essential to attain psychological empowerment, that is to transition from individual to collective empowerment, to ensure that programs are culturally appropriate and adapted to local conditions, to initiate and sustain health action, and to produce desired outcomes. Although participation is foundational to empowerment, it is insufficient by itself. Collective action can be thwarted by non-responsive governing bodies and institutions, and by power imbalances that may be hidden. As previously noted, participation can be limited, manipulative and passive, and therefore, disempowering.

According to the World Bank, the following characteristics differentiate authentic empowering community participation from limited or nominal participation: access to information on public health issues; autonomy in decision-making; local organizational capacity to make demands on institutions and governing structures; and accountability of institutions to the public [1]. Local leadership and community control of project funding help ensure inclusion and promote authentic participation [6].

A behavior can be seen as an expression of health and as an expression of empowerment [49]. A review of 26 studies that operationalized empowerment as a process to achieve health located five studies that linked empowerment with the following health behaviors: fruit and vegetable consumption; breastfeeding; condom use; alcohol use; and health services utilization [50]. Other studies linked empowerment to seeking treatment for postpartum depression, well-child check-ups and immunizations, birth spacing, and support of child development [7,22-24].

Agency is the primary indicator of women's empowerment. Defined as ability to articulate one's goals or make a choice and act on those goals/choices, agency integrates critical thinking and negotiation skills [28]. Also referred to as 'autonomy', agency is closely related to empowerment and critical health literacy. Most choices women may or may not make for themselves are not 'strategic life choices' that could change their health trajectory. Who to marry when, whether and when to have children, where to live, whether, when, and where to seek employment – all represent strategic life choices. Since such choices are infrequent, in most studies the indicator of a woman's empowerment has been participation in everyday household decisions like what to cook, how to dress, or with whom to go to market [28]. Therefore, the potential for implicit bias in introduced; and the link between women's empowerment and health may be stronger than the data suggest.

3.2.2. Health Outcomes of Community Empowerment Initiatives are Elusive

Community empowerment initiatives are necessarily complex, dynamic, and comprehensive with multiple targets and outcomes at many levels [6]. Attributing results to a particular element of an intervention is challenging. In addition, the long time line required to achieve and document the transition from individual to community empowerment, and for environmental improvements to demonstrate actual physical changes to health, exceeds the financial resources of most researchers. Consequently, few studies have measured the sustained health benefits of community participation [21].

Community-engaged empowerment initiatives that improved health outcomes have focused on environmental changes which impact behaviors. For example, community participation in a water supply project was associated with 25-30% more child immunizations than in a comparison village where the project was completed without participation [6]. This example also demonstrates the motivation to improve health must come from within the community, not from outside experts [21].

3.3. Processes of Health Empowerment

Scholars have drawn on the economic development and community development literature to describe collective health empowerment processes. The work of Freire and the principles and methods of empowerment education (aka popular education) are foundational [51. These include starting with what people already know and do; valuing practical experience; building on strengths to address needs; equality of professionals and participants as co-learners; use of art, music, and drama for social learning; and critical thinking employed in a cycle of action-reflection-action to achieve change and social justice [52]. Freire's guidelines on working with communities that differ from professionals' own culture are of particular interest to empowerment practitioners. His reflective questions, abbreviated as 'SHOWED' facilitate critical dialogue to understand the determinants of health, become empowered and plan action. SHOWED means: See - what do we see here? Happening - what is really happening here? Our - how does it relate to our lives; how do we feel about it? Why - what are the root causes? Empowered - how can we become empowered? and Do - what shall we do about it? [52]. Another framework that has been effectively applied for health empowerment is TED* The Empowerment Dynamic [24,53]. Here the most basic reflective conversation is described as facilitator/coach and participant in a three-step dance: What do you want? (How will you know you got it?), What have you got? (What is working? What's missing or in the way?), and What is next? (What small step can you take now?).

Empowerment education methods have been used to improve health and equity for four decades, primarily with disadvantaged populations in low income countries [45,51]. Empirical evidence of effectiveness is limited, largely due to study periods of insufficient length to establish progress beyond individual empowerment or to demonstrate health outcomes.

Empowerment education methods are still unfamiliar and under-utilized in Western industrialized countries [46,49]. Examples from the public health and medical literature seem limited to a cluster of intervention studies in which Freirean methods were integrated into existing home-based maternal-child health promotion programs to promote health literacy and empowerment in mothers of children aged 0 (pregnancy) to 3 years [7,22-25]. The service providers (paraprofessionals, PHNs, MSWs, and mixed teams) retained their first goal to establish and maintain a trusting relationship with participants as the foundation for the intervention. The main change in practice was to shift emphasis from delivering standardized expert-designed curricula to engaging mothers in a collaborative, personalized, participant-directed process through which participants identified priority health concerns and goals, analyzed their current situation, planned action, marshaled resources, and evaluated their progress [7,53-54]. In other words, the service providers shifted from educating (providing information and answering questions) to empowering (facilitating self-directed learning by asking questions) [7]. In analyses of combined data from six of these programs, Smith and Carroll found individual empowerment began with an increase in an individual's self-esteem and self-confidence signaled by articulation of a goal or choice ('I want…') which proceeds to a better understanding of root causes, barriers, and facilitators to plan and take action[7].

In a community development sense, community empowerment builds on individual action, proceeds to psychological empowerment and to collective critical consciousness and social action [46,51]. Individuals and groups develop critical consciousness through critical reflection and group dialogue to examine systems and conditions within a framework of equality and social justice.

3.4. Interventions for Individual and Community Health Empowerment

Literature reviews consistently find community-based empowerment-focused interventions and their participants are vaguely described and not replicable [42,49]. The majority of interventions that aimed to promote health empowerment in any clinical or community population employed one or more participatory strategies, such as the processes described above, as well as collective action, advocacy and leadership training, and transfer of power to participants. Despite sparse details, it is clear many studies allude to community involvement when in fact, the approach is top-down, individualistic and unlikely to be embraced by the community [42].

A cluster of studies evaluated multiple implementations of an intervention that aimed to promote health literacy and empowerment in socioeconomically disadvantaged mothers of young children. The intervention was integrated into nine disparately located U.S. home-based maternal-child health promotion programs with different but overlapping goals, methods, and staffing models. A focus on developing interactive and critical health literacy skills, especially reflection (critical thinking), through a collaborative, mother-directed, problem-focused process consistently and significantly improved health literacy and empowerment scores[7]. For example, in two studies depressed mothers' care-seeking and participation in treatment demonstrated increased understanding of information and services, appropriate utilization of services, and increased control over a dyad's health, all indicators of health empowerment and health literacy [22-23].

Using combined data from six programs (n=2395 primary care givers, 69 service providers) Smith and Carroll analyzed the interactions of 36 factors thought to influence health literacy and empowerment [7]. The results showed all the factors were correlated and all the correlations were positive, indicating that gains in one item score correlated with gains in multiple related items. Hypothetically, then, the data suggest data-informed service providers could tailor interventions to address almost any issue that motivates participants, and reasonably expect to see simultaneous or subsequent improvement in health literacy and empowerment (and advance program priorities and positively influence the health trajectory of a dyad at the same time) [7]. The aforementioned finding also suggests the complexity of the home environment does not preclude strategic intervention or impede understanding of what helps or hinders improvement; rather it reveals pathways to progress.

Other findings from the cluster of studies included the following: empowerment education overcame known barriers; empowerment benefits extended to service providers and unskilled readers; and the intervention reduced disparities related to literacy, age and mental health [7]. These findings suggest community-based health literacy promotion through an empowerment education model may be a pragmatic intervention to empower women and thereby improve infant health and future adult health. This approach may be adaptable to other settings and populations.

3.5. Measures and Indicators of Health Empowerment

There are no standards, identified best practices, or guidelines to evaluate empowerment in health promotion interventions. Methods have been incompletely reported [49]. Lindacher and colleagues' 2017 systematic review of 26 empowerment-focused intervention studies (published between 1989-2015) found each study used its own instrument. All were questionnaires that assessed only a few items [49].

As previously noted, participation in individual or collective learning, decision-making and action are indicators as well as outcomes of empowerment. Behaviors serve as indicators of individual empowerment as well as health [49]. The health issues addressed most frequently in empowerment initiatives were HIV/Aids, legal drug consumption, and physical activity [49]. While agency is a direct measure of women's empowerment, resources (e.g. education, available health services) and achievements are indicators of women's empowerment. However, there is a dearth of research on the methodological reliability of the utilized variables [28]. Table 1 shows health behaviors that have been used as indicators of empowerment.

The impact of empowerment education on participants has been largely self-reported; the impacts on families, schools and communities are unknown [52]. The World Health Organization's review of evidence on empowerment and health cautions empowerment outcomes must be assessed at many levels simultaneously and over time for an accurate picture [6].

3.6. A Potential Model for Measuring Health Literacy and Empowerment

The Life Skills Progression instrument, known as the LSP, may serve as a model to measure critical health literacy [54]. The programs that are the subjects of the cluster of studies described in this section used the LSP before a health literacy initiative was integrated into interventions. The instrument, which was published by Brookes in 2006, has been used by public health promotion programs since 2004. It meets the need to assess health literacy and empowerment on several levels over time and includes contextual data to help influence and explain change. In addition, The LSP strengthens assessment over self-reports with direct observation, interviews, formal assessments and in some cases, review of medical records [54].

The LSP enables service providers to continuously collect and synthesize intermediate outcomes (actions, practices and behaviors) and contextual data (family situations, social support, resources) to monitor mothers' progress toward demonstrating life skills needed to raise a healthy competent child, including health literacy and health empowerment. Two scales derived from the instrument are described in detail elsewhere [55]. Briefly, the healthcare literacy scale shows progress in demonstrating skills pertaining to use of health information and services for a mother-child dyad. The self-care literacy scale shows progress in demonstrating skills that pertain to everyday choices, preventive practices, and health promoting behaviors which influence family health.

The LSP's method to measure health literacy and empowerment has several advantages compared to other current methods, which have been previously described [7,54-55] In short, the LSP makes data part of routine practice and enables service providers to tailor intervention elements to particular individuals and circumstances. It monitors progress over time, on multiple items (n=36). It identifies strengths as well as needs and requires no reading by the participant. The LSP may therefore be a model for evaluation of future initiatives.

3.7. Gaps in the Literature: Health Empowerment Research

The current evidence base regarding the health literacy-health empowerment link is vastly underdeveloped [8,35, p.19]. With the exception of a few conceptual analyses of critical health literacy (and the aforementioned cluster of studies on a maternal-child health literacy promotion initiative), the link remains unexamined. The literature is weakened by the limited scope and quantity of research, implicit bias, insufficient data and incomplete reporting.

While health empowerment research stresses the social aspects of empowerment and promotes the concept of community empowerment, 85% of studies and almost all indicators focus on individuals (See Table 1) [6]. The limited number of studies, and their organization within condition-based clusters, has hampered attempts to synthesize and analyze findings. For instance, a 2015 systematic review of literature on empowerment approaches to healthy nutrition in non-clinical populations found only eight relevant articles [49]. It was not possible to analyze how empowerment was operationalized in different settings and samples because of the small number of studies. It was suggested the plethora of studies is explained by the nutrition field's fidelity to the biomedical model, which imposes difficulties on positing how empowerment goals (other than understanding information, participating in treatment decisions, and completing assigned self-care tasks) could translate into health. By ignoring social and subjective aspects of health, literacy, and empowerment, the biomedical model disregards social determinants of health and empowerment. For example, a patients' goal to obtain a driver's license may seem unrelated to health; but the ability to drive could enable the patient to get a job, gain insurance, and obtain preventive services; travel to well-stocked grocery store, and improve nutrition for herself and her family.

Many health empowerment studies have not reported, or not used, a definition or theory of empowerment [35]. Among those studies that did report theoretical foundations, definitions and approaches to measurement varied widely. Few studies have integrated theory and methods [28,42,50]. In addition to the lack of longitudinal research, the literature reveals a paucity of experimental and quasi-experimental health empowerment studies. Comparisons with control groups and randomization are missing.

Lindacher and associates' 2017 review of original reports of empowerment-based interventions suggested studies are concentrated in industrialized countries, especially in North America [50]. The review confirmed Shearer's 2012 finding that nearly all empowerment studies with seniors have been conducted in Western societies with Caucasians [42]. Most literature reviews also have been limited to the English language. However, in a survey of non-English findings Wallerstein found nothing to add to existing evidence reviews [6].

The methods and measures of women's empowerment suggest a high risk of implicit bias. For example, most research classified women as empowered using specific criteria and cut points that reflect Western values. Other biases were introduced by assessing women's participation in decisions about small matters in contrast to participation in strategic life decisions with the potential to alter the health trajectories of a woman and her children [28].

Studies on empowerment among seniors commonly overlook factors that significantly influence both health and empowerment, such as income and education levels [42]. Shearer et al. found a common research bias that chronic illness or risk among older adults is associated with low levels of empowerment. Moreover, the assumption of disempowerment based on interventionists' beliefs and unverified by data can result in interventions being delivered to those who do not need them and will not benefit from them [42].

Data from health empowerment research often is insufficiently comprehensive to capture empowerment because of the following: small study populations; low statistical power; short study time frames; and one-dimensional perspectives on empowerment. As a result, the relative effectiveness and sustainability of intervention strategies are not assessed and longer-term outcomes remain unknown [21,28,46]. Indeed, the timeline for most empowerment education programs has been too short for participants to experience collective actions and progress to psychological and community empowerment [46]. The short duration of studies may explain why the literature rarely provides empirical evidence that empowerment education is more effective than conventional expert-driven health education. Similarly, most community empowerment interventions have been too short to demonstrate health effects [35].

Incomplete reporting contributes to the difficulty of gleaning guidance from the literature. Neither measures and methods nor study populations and intervention elements are described in detail [42,46,49-50]. This imprecision is especially problematic because health empowerment strategies are usually part of larger interventions. While combined approaches increase effectiveness, they also increase the difficulty of attributing changes to a particular program element [46].

To summarize, from a public health standpoint health empowerment is central to health promotion practice and is an essential component of health literacy. In this broader context, health empowerment is both individual and collective, obtainable by skilled and unskilled readers, and operational inside and outside healthcare systems, in everyday lives at home and in communities. The role of professionals is facilitative rather than directive. Power is claimed rather than bestowed.

While sharing an individual focus, in contrast to patient empowerment, health empowerment aims further to build capacity for political action, leadership, and collective agency. Women's empowerment in particular affects not only their current health, but also the health of their children and families into the future. Due to the complexity of community empowerment initiatives, measures of their success are challenging and there remains a scarcity of data on validity and reliability of indicators.

Novel approaches are needed to overcome enduring barriers to studying, facilitating, and measuring health literacy and health empowerment. After re-integrating health literacy and empowerment conceptually, the primary need is for an evaluation framework that recognizes individuals and communities develop health literacy and empowerment over time with need, opportunity, experience, and support. The challenge is to track progress toward health empowerment along unique non-linear pathways in complex and dynamic everyday environments.

4. Reintegrating Health Literacy and Health Empowerment: Lessons from the Literature

While initially merged in the construct of critical health literacy, and currently linked without question in policy and discourse, health literacy and empowerment have been dichotomized, that is, treated as two separate fields of study and practice, and partitioned further into condition-based lines of inquiry. This section summarizes and interprets the significance of these fault lines for current and future research.

4.1. Critical Health Literacy: Starting Point for Future Research

As long as health literacy is limited to healthcare settings and patients are defined by their disease; as long the demands and challenges of their everyday lives are ignored as irrelevant, and their non-clinical sources of information are disregarded as unreliable, patients will remain dependent on clinicians. Their power will be limited to following instructions. Research findings will remain largely uninformative.

If health literacy initiatives are to achieve their potential to reduce the burdens of chronic disease and advance healthcare delivery, it will be necessary to find new approaches that start from an intent to empower patients and their communities for health, rather than an intent to explain and mitigate systemic problems in healthcare.

New approaches are to be found by changing the point of departure and the direction of research. Decades of effort have proceeded from low functional health literacy, declared it unmodifiable, and taken the only available route from there - information improvement. The resulting body of work is credited with focusing attention on the issue and making information more accessible for many. However, this route now seems a dead end. Seeing the signs, thought leaders are calling on researchers to embrace the empowerment aspects of health literacy. That call, and gaps in the literature, suggest critical health literacy as the starting point for future research. Although the construct has lost much of its meaning over the last decade (particularly its potential to drive health promoting social change), it is clear that health literacy and empowerment intersect in critical health literacy.

While there are multiple connector routes to the junction of health literacy and empowerment, the intersection is not well marked, and each route is signed with different names, descriptions, and roadside attractions. Although this crossroads has been visited by researchers and practitioners from various fields over decades, only parts of it have been explored. The intersection rarely has been a destination for health literacy researchers, or health empowerment researchers. Travelers on these paths have come with different research interests, intervention and measurement approaches, and outcomes of interest, which may have led them to look past each other. Their reports suggest most have been unaware of the nexus of their efforts and have passed through without engaging others who arrived at the crossroads from another approach - yet encountered the same barriers and challenges. Although one dimensional efforts have left significant limitations in the literature, multidisciplinary collaboration to address these shortfalls may lead to more informative future research, better global health, and advances in healthcare delivery.

Critical health literacy is a unique concept closely related to empowerment [8]. It is differentiated from empowerment by its focus on cognitive skills to understand information and apply it in healthcare settings [4]. Information skills are considered essential to health literacy, but not to empowerment [8,22]. In contrast, action (both individual and collective) is considered essential to empowerment, but not to functional health literacy. Beyond understanding information, critical health literacy implies empowerment to act on information for personal and/or community benefit.

An empowered critically health literate person uses combinations of skills from Nutbeam's three categories of health literacy (functional, interactive, and critical skills) to address challenges in one of Sorensen et. al.'s three domains of health literacy (disease treatment and health care, prevention, and health promotion) [5,8,56]. Since the domains represent different contexts, literacy demands, and required actions, a person may attain critical health literacy, and so empowerment, to a high degree in one domain and to a lesser degree, or not all, in another.

The medical literature on health literacy stresses the role of information in patients' use of services, behaviors, and treatment outcomes. The public health literature gives less attention to information, emphasizing instead the determinants of health and what information enables a person to do about the latter. Empowerment at both individual and community levels, as well as social and political action are key attributes of critical health literacy [8,56]. However, the elements of empowerment and action rarely have been specifically addressed by researchers [8].

4.2. Critical Health Literacy Partitioned

The eroding of the critical health literacy concept is largely a consequence of a widely-accepted premise that: a) 'adequate' reading skill (functional literacy) is necessary to obtain the benefits of healthcare; b) adequate reading skill is prerequisite to 'advanced levels' of health literacy; and c) adult reading skills are unmodifiable. This outdated conceptualization of adult literacy (and how it develops) places critical health literacy and empowerment out of reach for most of the population, makes health literacy a problem of the public education system, and focuses attention on mitigating the negative impacts of low literacy in clinical settings and public health emergencies by reducing the literacy demands of information.

Although separating health literacy from empowerment, dividing the concept into a hierarchy of levels, and restricting its application to healthcare settings fosters 'cleaner' research, it promotes a false dichotomy. In turn, a resulting overemphasis on functional literacy, and the erosion of the critical health literacy construct, have inhibited the effectiveness of both health literacy initiatives and patient empowerment efforts, and relegated health empowerment to other fields. Consequently, there is little in the literature to elucidate the interactions of health literacy and empowerment, and how to harness them to improve health and healthcare. In the following section, the authors recommend steps to close the gap.

5. Authors' Suggestions to Build a More Robust Literature

In this section, the authors suggest steps to advance health literacy research and practice by addressing gaps and limitations in the literature. The guidance is gleaned from published studies and the authors' experience. Subsection 5.1 recommends refocusing intervention and research on critical health literacy instead of functional literacy. Subsection 5.2 discusses the need for increased attention to theoretical foundations and operational definitions. Subsection 5.3 suggests intervention planners reconsider who is positioned to promote health literacy. Subsection 5.4 calls for promoting equal relations among professionals, participants and communities. Subsection 5.5 encourages practitioners to redirect information initiatives to provide direct support to transform knowledge to action in context for personal benefit. Subsection 5.6 recommends professionals shift their roles from educating and directing to facilitating and supporting participants' self-directed learning and action. Subsection 5.7 suggests researchers conduct longitudinal studies and report in detail what was effective and not effective. Subsection 5.8 calls for new approaches to measure critical health literacy/empowerment that monitors progress as the primary outcome of interest and considers regression normal and informative. Finally, Subsection 5.9 recommends reassessing the value of conventional medical research designs for studying health literacy, a social phenomenon. These recommendations reflect the authors' knowledge and interpretation of the literature.

5.1. Refocus on Critical Health Literacy; De-emphasize Functional Literacy

To contribute to a more robust literature, interventionists and researchers can build on conclusive findings that while functional literacy increases capacity for interactive and critical health literacy, it is neither necessary nor sufficient for empowered functioning in today's health arena. Critical analyses from both camps, and evidence from few public health studies, conclude critical health literacy, and by definition health empowerment, can develop without technical skills [4,7-8,22-24]. Where basic literacy is lacking, dialogue can take the place of printed information and conventional patient - or health education [6-8,51]. These findings suggest the current emphasis on functional health literacy may be misplaced and potentially disempowering.

5.2. Increase Attention to Theoretical Foundations and Operational Definitions

From a research standpoint, the most notable limitation in the literature is lack of attention to theoretical foundations. This gap is a source of assumptions, bias, and a conglomeration of purposes, definitions, and indicators. Advances in science led global health scholars to advocate promoting health literacy as a pragmatic intervention to improve health, empower women, and reduce disparities [48]. Notably, around the year 2000, research findings from multiple fields of science coalesced into the comprehensive theory of the Developmental Origins of Health and Disease (DOHaD) [57]. This current understanding of health as constantly developing and socially determined ushered in the third era of modern health care. It offers a more solid theoretical basis for future health literacy research [7].

Since health evolves over a lifetime, so do the challenges of health protection, promotion, and management. As a person's health challenges change, so do their health literacy tasks and the skills required to accomplish them. This realization led the United Nations General Assembly to recommend all nations develop plans to promote health literacy across the life course [48]. Parents' health literacy and women's empowerment were prioritized because parents' health and health literacy, along with their education, employment and social and political conditions, determine their children's developmental and adult health. DOHaD, Life Course Health Development, and related theories, position parents, especially mothers, at the foundation of personal and public health [7].

These advances in science suggest health literacy promotion needs to be part of every clinical encounter, public health intervention, school health education program, and medical education. DOHaD further suggests that instead of the current silos of research-by-disease, studies might be more usefully organized around life stages (early development, childhood, adolescence, adulthood, parenting, decline). The importance of life course development is discussed in other chapters in this book.

In order for efforts to serve their intended purposes and be meaningfully evaluated, the initial step to plan a health empowerment initiative is to articulate its theory. The theory of the intervention explains the approach and guides searches and observations, evaluation and intervention planning, implementation, and reporting of results.

The theory and purpose of an intervention form the basis for operational definitions. Since the terms health, literacy and empowerment, and combinations of these terms are understood differently from multiple perspectives, it is imperative to articulate their meaning for the purposes of a particular initiative. Future research reports should include definitions of terms.

Health literacy/empowerment is culture, society, population, and context-specific; therefore, a single universal definition to underpin all research is infeasible. Definitions may be from public health, medicine, human development, economic development, management or other sources (e.g. from World Bank, NIH, WHO). If a definition or conceptual framework originated in another field of study, an explanation of how it translates or can be adapted to health empowerment and the local context will strengthen the study and serve fellow researchers. In patient empowerment, the local context includes a patient's everyday life, relationships and resources. Community-based initiatives must also consider relational, social, political and environmental barriers (often hidden) and facilitators to empowerment.

5.3. Reconsider Who is Positioned to Promote Health Literacy

Further, the distinct separation of interactive health literacy from critical health literacy is false, except where it is understood as a set of skills used to exchange and understand information, and thereby increase capacity for critical health literacy without achieving it. On the other hand, interaction implies participation; that is, direct involvement with others in communication or action, which is the backbone of empowering initiatives. Interaction is a social process for personalizing (making meaning from) information and choosing whether and how to use (act on) it. Therefore, interaction is essential to the process to become empowered for health; that is, achieving critical health literacy. While clinical consultations represent important interactions, most interactions related to health occur outside the clinical encounter in home or community settings with non-professionals. This calls into question the assumption that clinicians are uniquely or ideally positioned to enhance health literacy.

5.4. Promote Equal Relations Among Professionals, Participants, Communities

Incorporating the social aspects of health literacy and empowerment into initiatives implies extending health literacy intervention planning, implementation, and evaluation in both clinical and community settings beyond clinicians and academics. Representative participants bring deep knowledge of social networks, sources of information and influence, and the often-hidden barriers and facilitators of empowerment in their daily lives. An inclusive approach compensates well for its relative messiness by promoting equal relations between professionals and participants, which in turn help unmask local conditions and solutions not otherwise visible to experts, ensure cultural appropriateness, and encourage participation. Equal relations form the foundation for trusting relationships that can facilitate empowerment.

Similar efforts are needed to promote equal relations between health professionals and communities. Public health studies have recognized the social aspects of health empowerment, yet for practical reasons, most research has focused on individuals and has not progressed to psychological or community empowerment. More research is needed to understand how social networks increase and decrease individual and collective health empowerment, and how individual and collective empowerment develop into community empowerment.

5.5. Redirect Information Initiatives to Focus on Direct Support for Action

Practically, reintegrating health literacy and empowerment in intervention means extending the aim of initiatives beyond information-giving for knowledge gain to empowerment for health-promoting action. The solution lies not in information, but in what information enables a person to do for health. Equal attention is needed to the crafting of information and direct support to use it in context to facilitate progress to optimal functioning.

To refocus intervention and research on critical health literacy, instead of functional literacy, is to recognize and seek to influence the collective, subjective, and social aspects of health and health literacy. The latter matters because individuals' understanding, interpretation, and ultimate use or disregard of information are determined not only by what they are told or given to read by experts. Interactions with family, friends, co-workers, support groups, the popular press, the Internet and social media may be equally or more influential, as other chapters in this book attest.

5.6. To Shift the Paradigm Toward Empowerment, Shift Roles

Since empowerment interventions cannot be standardized (and since empowerment cannot be provided or bestowed), the role of clinicians and practitioners needs to shift from planning and directing implementation to facilitating participants' individual and collective efforts to gain control of their health and its determinants. This can be accomplished by adopting the CAM and integrative medicine models to embrace equal relations and emphasize empowerment of practitioners as well patients and communities. Adopting an integrative approach shifts the paradigm by recognizing the source of health and healing is innate; therefore the effective role of professionals, science and technology is supportive.

The authors suggest the role of researchers needs to shift from seeking the one thing that works to empower people for health, to discovering a universal process to facilitate an individual, family, group or community to discover their own path to health empowerment. Through such a process, *participants* would identify their health-related priorities and motivations, define indicators that will tell them they have achieved the priority, identify the action(s) they are willing and able to take to move toward their desired outcome, and constantly assess their progress. A universal facilitated process applied across settings may reveal common intervention elements that work, and methods to adapt them to local contexts. In this way, initiatives can build on earlier efforts.

5.7. Conduct Longitudinal Studies, Report in Detail

The quality of the literature is particularly limited by short study periods. Health status changes attributable to individual or community empowerment are unrealistic in short time frames. Long-term effects and sustainability of improvements are unknown. Steps to address this limitation include planning longitudinal studies in phases; conducting pilot studies; and allowing a sufficient start-up phase.

Lead time is necessary to elicit and understand local dynamics, participants' health priorities, their culture, strengths, needs and resources. Further, sufficient lead time supports building rapport and trust as professionals and participants work together to test, revise and retest intervention elements and outcome indicators. Once an initiative is underway, time is required to constantly assess and hone the intervention elements and evaluation criteria to maintain a close fit with dynamic local conditions. Funders can advance health literacy research by recognizing the need to fund larger, longer studies with multiple targets, frequent evaluation points, and evolving intervention elements and outcome indicators.

Such studies require longer more detailed reports to guide practice and inform future initiatives. Researchers may discover that a community-based program is unable to overcome political, socio-economic, or institutional barriers to change. Causal relationships may be too complex to discover within dynamic social environments. While incomprehensibly complex causation might be frustrating to researchers, such results represent important findings and provide insights. Informative reports identify what works - and what does not work - for whom, under what circumstances, and why. Precise comprehensive descriptions of theoretical foundations, participants, intervention content, processes and challenges enable readers to determine what might be adapted or avoided in a similar situation. Funders and publishers can advance health literacy by supporting longer-term, mixed method studies and encouraging articles of sufficient length to accommodate such detail.

5.8. Consider New Approaches to Measurement

Everyday lives are punctuated by potentially disempowering physical, mental, spiritual, and environmental challenges, especially in poverty and chronic illness. Therefore, regression in health literacy/empowerment is to be expected and not taken as evidence of cognitive deficits. Instead, regression should be examined as closely as progress to better understand how to facilitate sustained empowered health promoting action. New approaches to assessment, along with willingness to embrace complexity, can produce new insights into what is worth doing and who should do it. The Life Skills Progression is one such approach that could serve as a model [7,23,54]. Routine use of data on intermediate outcomes and the contextual changes that influenced them can enable practitioners to tailor intervention to individuals' (or a community's) goals and circumstances [7] Theory-based evaluation that combines outcome measures with contextual data can elucidate both the extent of improvement and how the change occurred [7-8].

Empowerment, like literacy, is not something you have or you do not. Empowerment develops in a non-linear fashion with frequent setbacks and occasional quantum leaps [53]. As a result, it is important to increase understanding of barriers and facilitators of progress and regression. To do so, it is necessary to assess progress at many levels simultaneously and over time [6]. The literature suggests that labeling individuals as empowered or not empowered using specific criteria and cut points introduces bias and therefore should be avoided [28]. Instead, measures, indicators and instruments should focus on actions, practices, and behaviors that demonstrate progressive levels of knowledge, skills, participation, and accomplishments [7,54].

A single universal measure of health empowerment is prone to confounding research variables, and probably unfeasible. While some researchers consider action a direct measure of empowerment, the specific actions demonstrating progressive empowerment depend on the context and, by themselves, suggest an incomplete picture [7,28]. Participation is often identified as an outcome of empowerment, but for reasons discussed previously, participation alone is not a reliable measure of empowerment and its absence does not reliably indicate disempowerment. Some clinical studies have used biomarkers as measures of patient empowerment arguing, for example, a normal insulin reading shows a patient with diabetes has controlled their insulin, and thereby improved their health status. In other words, the biomarker demonstrates empowerment. The confound is that changes in biomarkers may be attributable to many causes; and since behavior changes impact patients differently, failure to achieve a biomarker, (e.g. uncontrolled insulin) does not necessarily demonstrate non-compliance or disempowerment.

Most research has relied on one or a few indicators of empowerment [9]. It is clear that single indicators cannot capture empowerment's multiple aspects and elucidate other elements of participants' lives that are impacted by empowerment [9]. Even when using a direct outcome measure, multiple indicators are needed to capture the full picture of empowerment effects; and the indicators need to be tested for reliability with participants. The addition of qualitative methodology can help explain complex relationships that do not reach significance with standard quantitative approaches [6].

Since professionals' culture and socioeconomic status often differ from study participants', the risk of implicit bias is omnipresent. To reduce this risk, researchers have used multiple locally identified indicators that reflect the study's theoretical foundation and operational definition of empowerment. Another protection against implicit bias is to combine data from multiple locally identified sources. Data should include indicators to alert professionals and participants to potential unintended consequences. For example, women's empowerment initiatives have been reported to increase risk of intimate partner violence [28]. To further address bias and to ensure acceptability and reliability of measures and indicators, researchers can engage participants in their development and testing.

An individual's or a group's degree of empowerment in a given context is not fixed, but rather can be expected to increase or ebb with changes in their health, and in home, social and political environments. Hence, constant monitoring and adjustments to indicators are required to retain alignment with local conditions, and to explain empowerment gains and losses. Empowerment experts emphasize the need to continuously monitor and adapt indicators and all evaluation procedures in a reflective, iterative process *with participants* and influential others [6].

Instead of adding to the long list of reported study-specific measures, consider whether, how, and with whom reported variables and instruments were developed and tested. Then, select and adapt an existing instrument that reflects an approach that fits the project's theoretical foundations and operational definitions; test and hone the adaptations. For patient empowerment studies, it may be feasible and beneficial to define comparable core indicators common to patients with long term conditions supplemented by condition-specific, culture-specific, and funder-specific measures.

The Life Skills Progression instrument, known as the LSP, is one example of a validated, field-tested instrument and evaluation framework to assess health literacy and empowerment [54]. Designed to assess progress in developing life skills for early parenting, including critical health literacy, the LSP could be adapted for various populations and settings [7]. Another innovative model that may be particularly useful in community-based efforts is GapMinder, a method of using locally produced photographs as statistics to make visible in context progressive empowerment and changes in social and environmental determinants of health and quality of life. See https://www.gapminder.org.

The critical innovation of these instruments is that they assess *progress over time* toward optimal functioning and control of the determinants of health. Progress is demonstrated through changes in actions, practices, behaviors and determinants of health. New approaches to assessment, along with willingness to embrace the complexity of everyday lives, can produce new insights into what is worth doing and who should do it [58]. Emerging evidence suggests non-scientist practitioners can effectively collect, interpret and use data on intermediate outcomes and surrounding conditions to tailor intervention to individuals' (or a community's) goals and circumstances [7].

5.9. Reconsider Research Design

The patient empowerment literature suggests applications of the gold standard of medical research, the randomized controlled trial (RCT), have not been practical in health empowerment studies [10,30]. The RCT is not an appropriate research design for empowerment-focused intervention studies because it intends to develop evidence for medical treatment. The desired evidence from an RCT is a defined causal relationship, typically between a particular drug or intervention and change in a disease condition [59]. Applied to empowerment studies, an RCT aims to define a causal relationship between a single defined intervention (e.g. providing behavior-focused information) and empowerment [9-10,30].

However, empowerment is neither a medical treatment nor a single defined intervention. The causes of empowerment or disempowerment are varied, complex, and occur in dynamic social environments; they may be impossible to untangle. Therefore, empowerment interventions are necessarily comprehensive and complex; and trials of single intervention elements are likely to confirm a null hypothesis. In addition, interventions and their delivery are not standard; but are tailored to individuals and circumstances. Moreover, what constitutes empowerment is unclear.

To conduct RCTs of empowerment interventions, researchers have typically grouped patients by their disease and ignored significant differences (e.g. gender, culture, employment, education, income, disease stage, home environment). As a consequence of this oversimplification, the evidence is of limited value and is not generalizable.

While the primary protection against bias in RCTs is blinding, few patient empowerment studies have been able to maintain blinding [9]. RCTs of empowerment interventions have typically not complied with RCT reporting standards [9]. Meta-analysis to synthesize findings of RCTs has proven difficult to impossible due to differences in definitions of empowerment, study populations and interventions, plus systematically different outcome assessments [9,30]. Experimental and quasi-experimental studies with internal or external comparison groups have been shown to be feasible in empowerment studies, but remain rare [7,9]. To improve the quality of evidence, researchers have employed confirmatory factor analysis, mixed methods (qualitative and quantitative), reflective loops, and triangulation to capture full effects [6]. Action research methods are themselves empowering - and are well suited to empowerment studies [6-7,52]. These involve participants and professionals together in iterative cycles of reflection-action-reflection to examine both process and outcomes through facilitated dialogue.

To summarize, health literacy and empowerment intersect in the construct of critical health literacy, although the intersection rarely has been visited by researchers and the meaning of critical health literacy has eroded over the last decade. In particular, the elements of empowerment and action have been largely ignored in favor of near exclusive focus on low functional literacy in clinical settings. While this one-dimensional deficit approach to health literacy produced more precise research, it also reduced its ultimate value by creating a false dichotomy separating health literacy and empowerment. The quality of the literature is further reduced by division into condition-based lines of inquiry, imprecise definition, construction, and measurement. In this section, the authors suggested concrete guidelines to strengthen the science, beginning with reintegration of health literacy and empowerment into all aspects of the research process and shifting health care practitioners' and researchers' roles to support the authors' recommendations. Longitudinal, theory-based, mixed methods, participant-informed studies using both outcomes and contextual data are critical to the evolution of the field.

6. Conclusion

Since its inception, the premise of health literacy research has been that low functional literacy in the population explains disparities, high costs, low quality, and poor outcomes of healthcare; and better information is the remedy. Research expected to support this premise has instead produced conclusive evidence that skillfully crafted information is helpful for following instructions, but insufficient to manage personal and family health and healthcare, cope with long term conditions, or participate effectively to improve community health. This still-dominant deficit approach has stymied health literacy research, disempowered patients and service providers alike, and ignored those without need or access to care.

To advance health literacy, researchers must first embrace current scientific understanding of the developmental origins of health and disease and the innate, social and political determinants of a person's health trajectory over the life course. These advances offer a solid theoretical foundation for future health literacy research. DOHaD also suggests research may be more productively organized by life stages with particular focus on parents, especially mothers. Scientific advances further suggest a more robust science can be built around health literacy through longitudinal and follow up studies using innovative methods that assess regression along with ongoing progress to optimal functioning in clinical and everyday community contexts.

The focus of research and practice must broaden to address critical health literacy in the fullness of its meaning. Clinicians and health literacy experts can work with communities to use their knowledge and skills in new ways to facilitate health empowerment through a process that supports development and use of interactive and critical skills. In other words, researchers can advance health literacy by shifting attention and resources away from quantifying and mitigating negative impacts of low literacy in healthcare settings to instead identify and build on existing individual and collective assets and skills needed to regain, manage, maintain, and promote health. By working to achieve individual, psychological, and community empowerment, the new facilitators can empower themselves to advance critical health literacy, healthcare delivery, and global health.

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K-12 Health Education, Health Communication, and Health Literacy: Strategies to Improve Lifelong Health

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Abstract. To promote a health literate K-12 population, this chapter focuses on intersections of Health Literacy (HL), Health Education (HE) and Health Communication (HC) and urges collaborations among professionals from these disciplines as well as with stakeholders who share their interests and concerns. Core definitions and evolutionary highlights of these disciplines are presented, as well as their intersection and promise of impact on student academic and health outcomes. . The Whole School, Whole Community, Whole Child (WSCC) model is used as an example of a framework embraced by education and health experts to help students become health literate. Internal and external stakeholders, models of what works, resources and strategies for developing or strengthening school health and health communication practice are presented. Selected contemporary threats to the social and emotional health and safety of youth are reviewed; as are successful, evidence-based, collaborative HE, HC, and HL programs and strategies. Finally, recommendations for future research and strategic actions in combining HE and HC for HL are discussed to empower, build resilience, and improve the lifelong health of children and adolescents as they become adults.

Keywords. Health literacy, health education, health communication, school health, Whole School, Whole Community, Whole Child (WSCC), children's health, adolescent health, coordinated school health, health education standards, K-12, e-cigarettes, bullying, diabetes, substance abuse, mental health, social media

1. Introduction

Children are the future. The observation attributed to Frederick Douglass suggests it is easier to build strong children than to repair broken men (and he probably would have added women). Many scholars emphasize the *health* of our children determines the quality of their future. This chapter addresses an application of this principle: to build a

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stronger population with Kindergarten to 12th grade (K-12) health literacy skills will benefit the present and future health and wellness of children and youth, as well as society.

1.1. Overview of this Chapter

To promote a health literate K-12 population, this chapter focuses on intersections of Health Education (HE), Health Communication (HC), and Health Literacy (HL), and urges collaborations among professionals from these disciplines and stakeholders who share their interests and concerns both during and after school to help children thrive and become productive adults.

Releasing the 30th Kids Count Data Book (2019) (https://www.aecf.org/), the president and CEO of the Annie E. Casey Foundation noted, "America's children are one quarter of our population and 100% of our future. All of the 74 million kids in our increasingly diverse country have unlimited potential and we have the data, knowledge and evidence to create the policies that will help them realize it." An important part of that future is health.

In a discussion of the potential power of focusing on the K-12 environment, Kolbe reports about 130,000 U.S. public and private schools in 13,000 school districts employ some six million teachers and staff for 55 million pre-kindergarten (pre-K) through grade 12 students during the most formative years of their lives [1]. In 2014, 10.2 million children participated in out-of-school programs [2]. So, the opportunity to reach a sizeable population, especially during formative years when lifelong health-related habits are formed, should not be underestimated.

Nearly 50 years ago Simonds called for health literacy to become part of a national strategy to improve public health. Simonds' belief was health education was on the cutting edge of social responsibility and three institutions - health, education, and mass communication—shared major responsibility for the forward movement in this field [3]. Much has changed in the last half century; but the need for shared responsibility remains and, arguably, is even a more pressing obligation in light of contemporary societal challenges.

In 2017 a National Academies of Medicine (NAM) Perspective increased attention to the convergence of goals and potential collaborations among HE, HC, and HL professionals [4]. They "share the idea that strategic communication—using the tools of spoken, written, and gestured communication in a variety of cultural settings—can help individuals, groups, and whole systems grow, learn, and make positive health decisions …" The NAM Perspective also notes the importance to the three disciplines of evidence-based materials and of access by vulnerable populations to health information and resources observing "the professionals and the lay people in the K-12 arena also have a common goal of improving the lifelong health of children." Subsequently, a NASEM consensus report noted the rich developmental period of adolescence and recommended new policies and practices for the health, education, and criminal justice systems to close the gaps on inequities for these young people [5].

Considering this as background, the authors focus on selected public health threats affecting K-12 students. They summarize promising research and gaps in knowledge about reaching children, professionals, family, and community to enhance decision-making and resilience of K-12 students.

Work in this arena must be grounded in cultural respect, too often given tacit mention or overlooked. The chapter's authors suggest health is a personal subject viewed differently in different cultures. Cultural respect in schools and communities is an important element of any successful plan to promote health literacy. Professional and community leaders must prepare for cultural differences without sacrificing important public health messages. The needs of groups or individuals are too easily generalized, and assumptions can lead to unintended biases in actions and communication. To guard against errors in messaging, including community members in communications is vital in the development of tools and materials. Program developers and implementers should remember that cultures are not monolithic and individual needs can vary.

The chapter's authors suggest a potential framework for shared collaborations is the Whole School, Whole Community, Whole Child (WSCC) model. This framework underscores collaboration among lay, professional, and private stakeholders for effective implementation and optimal education and health outcomes.

For purposes of this discussion, stakeholders are clustered in two groups as internal or external. Internal stakeholders are in the school system (e.g., teachers, principals, school health nurses, school health educators, nutritionists). External stakeholders are outside the schools but affect and interact with the school system (e.g. parents, public health officials, governmental and NGO organizations such as boys' and girls' clubs, private organizations and businesses).

This chapter's examples are predominantly from U.S. programs because of educational goals set within the U.S. system. State, and local regulations and policies differ from jurisdiction to jurisdiction. Promising international examples or observations are included. In a National Academies of Sciences, Engineering, and Medicine (NASEM) proceedings of a workshop, Hudson noted: "we expect individuals to have these skills, but we do not teach them." "If we truly wanted to teach health literacy, we would teach it in elementary and secondary school along with reading, writing, and math as a life skill everyone needs" [6].

Some data referenced in this chapter are relevant to Pre-K or reach beyond grade 12 into early adulthood with differences noted in the discussion. The results from pre-K programs have implications for K-12 student health and for pre-K parents involved in health literacy programs.

Increased empowerment and self-confidence after training, resulting in a demonstrable decrease in emergency room and clinic visits are reported [7]. Improving K-12 health literacy could not come at a more important time in history when so many serious threats are facing our nation's children and youth, as suggested below.

The chapter's authors acknowledge more in-depth reviews, data sources, and policy discussions are available related to aspects of the content in this chapter. The chapter's authors prepared a more extensive bibliography, covering all the topics in this chapter, to be available on the Society for Public Health Education (SOPHE) website.

1.2. Organization of This Chapter

This chapter is organized into ten sections: It is comprised of the introduction, overview, and this explanation of the organization of the chapter. It provides working definitions for K-12 HE, HC, and HL for context and to ensure common ground for readers from different disciplines. This is followed by a discussion of the historical intersections of HE, HC, and HL and a discussion of the relationships between K-12 student health and the child's achievement. The chapter's authors provide background on an approach to improving health education of children and teens. In the next section, there are examples of collaboration followed by barriers and challenges. The following section identifies internal and external stakeholders, followed by a description of selected public health threats that affect K-12 students. The chapter provides selected evidence-based resources and a description of four programs with positive outcomes. Based on their review of the literature, the authors recommend research opportunities and identify gaps. The chapter's authors provide a framework for establishing effective collaborations. The chapter's authors suggest immediate, intermediate, and long-term goals and discuss strategies for social justice moving forward. After indicating uses for the chapter, the chapter's authors conclude with a call-to-action for collaboration across HE, HL, and HC.

2. Defining Health Literacy, Health Education, and Health Communication and Their Intersections

HE, HC, and HL each have a rich history of definitions and variations in their scholarly perspectives. The chapter's authors provide working definitions to help clarify each field's useful insights for K-12 and where crossovers exist.

2.1. Defining Health Literacy

Myriad health literacy definitions have been discussed and published [8-10]. A cornerstone definition from Ratzan and Parker adopted by the National Academy of Science, Engineering, and Medicine, The American Medical Association and others is: "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" [11]. This definition is also similar to the one used in the National Health Education Standards in 1995. A discussion paper from NASEM looked at potential areas for clarifying and expanding on a definition of health literacy [12].

Health literacy, for purposes of this discussion pertaining to a K-12 population, is defined by the chapter's authors as:

> the degree to which children in grades K-12 have the capacity to obtain, process, and understand health information to make decisions fostering improved lifelong health and wellness through the support of health literate institutions, professionals, and communities.

This definition builds on several notable definitions of health literacy. Each contributes to a better understanding of the chapter's authors' working definition of health literacy for use in K-12 settings and incorporates several assumptions: (1) capacity depends upon developing cognitive and social skills; (2) a child's (or adult's) age and stage in life influence capacity; (3) other important influences from culture, environmental and organizational structures exist; and (4) access to services is necessary to facilitate change. Consequently, the working definition is more situational, people-centered, and organizationally sensitive than a definition that focuses on specific skill or *lack* of skill, abilities, or attributes of an individual.

Several scholars have noted health literacy must be taken into the context that is appropriate for a given individual in a given situation or at a specific age, or in a specific environment. This principle is important in considering the K-12 population. Zarcadoolas, Pleasant, and Greer discussed how "a health literate person can use health concepts and information generatively—applying information to novel situations" [13]. They also write that health literacy:

> . . . evolves over one's life and, like most complex human competencies, is impacted by health status as well as demographic, sociopolitical, psychosocial and cultural factors. Thus, the benefits of health literacy have an impact upon the full range of life's activities—home, work, society and culture.

Focusing on childhood and youth, Bröder, et al. systematically reviewed models and definitions of health literacy in children and young people published in English and German and concluded that ". . . given the relevance of social structures and support on the way health literacy skills are acquired, applied and hence practiced in very varying life situations, children's and young people's distinctiveness from adults, however, should become a crucial consideration when understanding health literacy" [14-15]. Peralta et al. identified key components and principles necessary for adolescent health [16]. Massey et. al., describe an expanded definition of health literacy focused on adolescents and the need "to include navigation of the health care system, rights and responsibilities, preventive care, information seeking, and patient–provider relationships" [17].

In 2015, Nutbeam defined health literacy more relatively and situationally as a person's ability to perform knowledge-based literacy tasks (e.g. understanding and using information) required to make health-related decisions in a variety of different situations" [18]. Nutbeam further emphasized "these cognitive and social skills are content and context specific and are greatly influenced by a person's age and stage in life. In these circumstances, developing a 'universal' population measure of health literacy has been very difficult." Nutbeam also asserts: "health literacy can be improved through education and can be regarded as a measurable outcome to health education."

Beyond the original emphasis on individual skills, health literacy's conceptual focus has broadened to include the larger responsibilities of 'health literate organizations.' In an Institute of Medicine discussion paper the attributes of health literate organizations were delineated [19]. The framework identifies key components for organizational health literacy that include: leadership that makes health literacy integral to its mission, structure and operations; the development of policies and standards, goal setting, accountability and incentives; allocation of fiscal and human resources; and the redesign of systems and space. Attention to the principles of a health literate organization inform this discussion for two reasons. First, organizational structures in local schools, government, and in public and private organizations may be enlisted for K-12 health literacy. Leaders must understand their roles in improving efficiency and access. Second, professionals and community members involved in K-12 education for health, and who belong to professional societies and local organizations, may partner or collaborate to address organizational factors affecting health literacy. Focusing on aspects of organizational commitment to improve health education and communication for health literacy may help to ensure more holistic collaboration and ultimately more beneficial long-term outcomes.

2.2. Defining Health Education

Health education is described by the U.S. Coalition of National Health Education Organizations (http://cnheo.org/files/empl_guide.pdf) in three parts: (1) A social science that draws from the biological, environmental, psychological, physical and medical sciences to promote health and prevent disease, disability and premature death through education-driven voluntary behavior change activities; (2) Health education is the development of individual, group, institutional, community and systemic strategies to improve health knowledge, attitudes, skills and behavior; and (3) The purpose of health education is to positively influence the health behavior of individuals and communities as well as the living and working conditions that influence their health [20].

For purposes of a working definition the chapter's authors add:

> K-12 health education focuses on the needs and changing capabilities of the K-12 student. Health education is influenced by both internal and external stakeholders and is dependent upon institutions understanding and supporting health-related learning and all participants identifying and meeting the health needs of children and adolescents.

Recognition of the importance of school health education dates back to the early 20th century; but was not a U.S. national priority. Then in 1971, President Nixon signed an executive order to address the state of health education in the U.S. A committee was to describe the 'state of the art' in U.S. health education; to define the nation's need for health education programs; to establish goals, priorities, and immediate long-term objectives . . . to raise the level of health communication citizenship; to propose the most appropriate scope, function, structure, organization, and financing of such an effort; and, to develop a plan for implementation [21]. After extensive data gathering from public and private stakeholders, a final report was delivered with the recommendation that the U.S. needed a private center for health education to stimulate, coordinate, and evaluate health education programs within the federal government.

The history, evolution and even successes of school health are well documented. The Institute of Medicine (IOM) chapter describing the evolution of school health provides a helpful history of school health programs in the United States [22]. In 1987, the Centers for Disease Control and Prevention (CDC) adopted the Coordinated School Health (CSH) approach (developed by as a model for integrating health-promoting practices in the school setting) [23]. Notably, in 1995, IOM's Committee on Comprehensive School Health Programs credited the School Health Education Study (SHES) with reforming health education as practiced in U.S. public schools. The SHES was largely responsible for establishing the value of comprehensive health education (rather than separate disease-specific units) and the introduction of a concept-based approach to education in general. Most health curricula have followed the SHES model. However, the study noted concerns by professionals in the field that a gap existed between the goals of health education and its actual practice in public schools.

America's first comprehensive school health education curriculum, Growing Healthy, America, was developed by the National Center for Health Education (NCHE) (www.nche.org/growinghealthy.htm) to provide school health teachers with needed tools. With CDC support, the NCHE developed and disseminated school health education curricula nationally in an effort to:

- prepare students to analyze the influence of culture, media, and technology on health;
- use interpersonal communications skills to enhance health
- develop plans through individual goal setting and decision making
- understand health promotion and disease prevention concepts
- know how to access valid health information, products, and services
- become advocates for good individual, family and community health
- develop positive health behaviors.

The standards recommended for curriculum in K-12 health education are outlined in The National Health Education Standards (NHES) first issued in 1995 and revised in 2004. These U.S. standards provide a framework for teachers, administrators, and policymakers to design or select curricula, allocate instructional resources, and assess student achievement and progress. The standards describe what students should know and be able to do by grade to promote personal, family, and community health. Students may practice such skills within the safety of a classroom before attempting to apply them in the real world.

However, the chapter's authors note learning about health is complicated. Successful health education uses relevant and effective communication theories and models for messaging—ones that promote transformational knowledge, shared decision making and literacies (e.g., food, physical, emotional, environmental) as opposed to didactic transmission of facts from teacher to student. Effective training has an impact upon an individual's overall health and wellness, resilience, and communication competence. Education for literacy is effective when it is transactional, dynamic, and potentially transformative.

2.3. Defining Health Communication

Communication is a broad academic discipline, represented by a wide range of interest groups and divisions within professional communication associations. The academic communication field prepares scholars to advance science, build knowledge, understand deeply, measure with thoroughness, and ensure methodological rigor [25-26]. Simply and broadly, the National Institutes of Health (NIH)'s National Cancer Institute and the CDC jointly define the field of health communication as: the study and use of communication strategies to inform and influence individual decisions that enhance health.

Freimuth, Linnan, & Potter point out health communication can take many forms, ranging from the use of modern mass and multi-media to traditional and culture-specific forms of communication, such as storytelling [27].

Harrington suggests: "health communication is the study of messages that create meaning in relation to physical, mental and social well-being" [28]. Harrington and Poe both reference Everett Rogers who asserted that communication "is a vital ingredient in almost every form of medicine and health" [29-30]. Harrington explained that since much of the work in health communication focuses on reducing health risks, health communication is often defined in terms of health risk communication and notes: "some would argue all health communication is risk communication but not all risk communication is health communication."

For example, health communication campaigns often focus on what one should or should not do to prevent or minimize risk of illness, injury, or death. However, risk communication scholars also study ways to best communicate the genetic risk, environmental risk, cyber risk or a variety of other risks. The Annenberg Adolescent Health and Risk Communication (APPC) Archives includes a wealth of research about the latest scientific advances in communication to reduce risks to adolescent health.

For purposes of this chapter, health communication related to K-12 is defined as:

> . . .health communication with, to, and for young children and adolescents K-12, framed for their age and capabilities, using communication strategies implemented by internal

> and external stakeholders to inform and influence individual decisions and peer group understanding. The purpose is to enhance health and wellness and reduce risk and disease.

Health communicators include public health promoters, educators, and communicators who use many evidence-based social marketing strategies to advance health. Scientists and science journalists are increasingly noting the corporate influences on some health messaging that also uses social marketing strategies for what is termed 'corporate determinants of health' or 'commercial determinants of health.' As noted by Hessari, "there is a growing understanding of how manufacturers of harmful products influence health policy" [31]. Such corporate investment in targeting audiences via multi-platform outreach to control health messages requires professionals, community, and family members to be alert to these messages and be prepared to discuss them with their K-12 population.

As an example of addressing these influences, scientists from the University of Chicago and the University of Texas developed a novel intervention that framed manipulative food marketing as incompatible with important adolescent values (including social justice and autonomy from adult control) [32]. The framing intervention reduced boys' and girls' implicit positive associations with junk food marketing and the intervention improved boys' daily dietary choices in the school cafeteria. The latter behavioral change was monitored over time and the effects were sustained. The authors emphasized: "reframing unhealthy dietary choices as incompatible with important values could be a low-cost, scalable solution to producing lasting, internalized change in adolescents' dietary attitudes and choices."

2.4. Intersections of HE, HC, and HL Studies

The studies and practices of HE, HC, and HL have many roots in common and many similarities in practice. Together they can further advance the application of each discipline as well as U.S. federal, state, and local health and education policies. The intersections of HE, HL, and HC are implicit, if not explicit, in each discipline; and the goals of health communication scholarship are complementary, even necessary, to health education. Both HE and HC fields seek a transfer of knowledge, 21st century skills building, the formation of good health habits in youth that persist into adulthood, and a facilitation of life-long health literacy [22].

The following few paragraphs address some of the research and resources that demonstrate the interdependency of HE, HC, and HL and some additional contributions from related fields. The disciplines share practices, and all may incorporate a variety of shared strategies to improve and sustain health.

Mass media for HE, and HC have long histories of positive and negative influences on children. In 2003, the IOM published a chapter examining the potential role of the mass media as an actor in the U.S. public health systems, and the media's omnipresence and power. [33]. Social media has become ubiquitous reaching youth and having an impact on behaviors [34]. Some studies include: Huang et. al, who noted the impact of The Real Cost Campaign on adolescents' recall, attitudes, and risk perceptions regarding tobacco use [35]. Noar's 10-Year Retrospective of Research in Health Mass Media Campaigns, asked "where we go from here" before e-cigarettes and vaping were 'a thing' [36]. Niederdeppe, et. al. reviewed the media campaigns designed to promote smoking cessation among socioeconomically disadvantaged populations—and a systematic review by Ross, Noar and Sutfin summarized known health messaging about non-cigarette tobacco products [37-38].

Scholars and practitioners who study and teach communication and education are intimately aware of interrelationships between communication and pedagogy (the teaching profession and the science of education), according to Thompson [39]. Thompson asserts scholars and practitioners are aware: “the study and practice of health communication have never been confined to the classroom context, as health communication is inherently practice-oriented while being simultaneously based on theory.”

With translational research illustrating significant potential, better applied communication research/strategies for K-12 schools and communities are essential. The use of emerging technologies (e.g., apps and social media messaging) within educational settings suggest great promise and opportunities for interdisciplinary collaborations and offer even greater reach for communication to individuals and groups. As such, ‘transdisciplinary’ areas of interest converge. There are significant opportunities for collaboration [40].

‘How to’ guides for communication strategies offer traditional HE and HC tools (such as audience segmentation analysis) that are useful for educators and public health professionals. Though audience segmentation may be useful for instruction in large K-12 groups, segmentation alone is no substitute for collaboration with people (who have experience using this communication tool) as part of a larger strategy in a variety of situations and environments.

According to Lai et. al., teachers are only truly prepared to effectively teach health and wellness topics for K-12 health literacy when they understand the dynamics of health communication, not just the content [41]. Understanding student and teacher communication apprehension and willingness to communicate may affect classroom communication [42]. Thus, teachers' nonverbal immediacy, clarity, and socio-communicative style on students' affective and cognitive learning are important [43]. In McCroskey and Richmond’s study of power in the classroom, they note: “the importance of effective communication in the classroom cannot be overstated. Communication is central to the teaching process. Some even argue that communication *is* the teaching process” [44].

Unfortunately, health literacy studies of new multi-disciplinary, trans-disciplinary, and cross disciplinary initiatives and ‘lessons learned’ focus on *adult* health literacy. Even studies of childhood immunization and chronic illnesses in the U.S. typically are about parents’ health literacy, not the children. In fact, scholars know little of how, in their everyday lives, children make sense of health-relevant information [45]. The research (published literature—albeit in silos—of theories, methods, best practices, policy) often links childhood circumstances and health practices with adult health.

Nobiling and Lyde provide a history of the conceptual approach to school health education [46]. It includes the NHES structure incorporating many health content areas, skill sets, and values from a range of disciplines that effectively promote health and reduce risk. Communication is perceived to be a necessary part of NHES’ student performance indicators. For example, as a result of health instruction in Grades 9-11, students are expected to: (a) evaluate the effectiveness of communication methods for accurately expressing health information and ideas; (b) express information and opinions about health issues;(c) utilize strategies to overcome barriers when communicating information, ideas, feelings, and opinions about health issues; (d) demonstrate the ability to influence and support others in making positive health choices; (e) demonstrate the ability to work cooperatively when advocating for healthy communities; and, (f) demonstrate the ability to adapt health messages and communication techniques to the characteristics of a particular audience.

All of these in some way represent the application of traditional communication skills that should be introduced or reinforced within curricula, some more explicitly than others. The NHES denotes that: "essential skills encompass analysis and communication that lead to the practice and adoption of health-enhancing behaviors.'' The application of functional health knowledge to promote health or avoid or reduce risk requires cognitive and behavioral skills.

By 2000, health literacy outside the clinical setting was described by international researchers and communication experts as necessary to the process of health education. Nutbeam used 'health literacy' as a composite term "to describe a range of outcomes to health education and communication activities" [47]. St. Leger explained school health education is essential to achieve health literacy and recognized schools are fundamental institutions to build the health (and wealth) of nations [48]. St. Leger noted it is vital to appreciate how schools can equip young people with the knowledge and skills that enable them to be active participants in shaping policies and practices that impact health outcomes and enhance health policies.

But, for the NHES to establish, promote, and support health-enhancing behaviors for students from pre-K to 12, required action is needed at the local, state, and national levels to support its implementation (and impact health literacy). The U.S. No Child Left Behind Act of 2002 (an update to the Elementary and Secondary Education Act of 1965), held schools accountable for academic outcomes if they were to receive federal Title I funding and required standardized testing for math and reading. The impact of this law was that non-assessed subjects (including health education, language arts, and social studies) were de-emphasized by schools across the U.S. [1].

The National Education Association Health Information Network (NEA HIN) held a symposium—"Health Literacy in the 21st Century: Setting an Education Agenda" [49]. The symposium was convened to best prepare young people to make personally appropriate decisions related to health and health care. In the proceedings, collaborative programs are described including the Health Education Assessment Project (HEAP) published by the Council of Chief State School Officers. HEAP provides free and fee-based e-resources for teaching and learning 21st Century health education skills.

Recent research examines the relationship between education in the context of population health using behavioral and social science insights. More emphasis is being put on health behaviors, effective communication strategies and assessments, environmental and social influences (including the influence of media and the need for information literacy) evolving media and technology, and digital access for "digital citizenship." Disparities remain, and these also offer significant opportunities for future collaboration.

3. The Relationship between Health and K-12 Academic Success or Failure

> *"Schools could do more than perhaps any other single institution in society to help young people, and the adults they will become, to life healthier, longer, more satisfying, and more productive lives."*
>
> —Carnegie Council on Adolescent Development

Health outcomes are linked to the academic success of America's youth [50-51]. In data reported by the U.S. Department of Education on chronic absenteeism in 2019, it is reported that about 1 in 5 high school students is chronically absent [52]. The analysis notes: "frequent absences from school can shape adulthood." Poor health is noted both a cause of absenteeism and a potential outcome in the accompanying analysis.

Leading national education groups recognize a close relationship between health and education, and the need to foster health and well-being within a student's educational environment. Ample research also suggests healthy students are better learners [53]. Children who do not graduate are likely to have lower literacy, limited employment and economic opportunities, and higher rates of illness. Hahn et. al. reviewed programs to increase high school completion (HSC) and suggest HSC is an established predictor of long-term morbidity and mortality [54]. Kolbe emphasized HSC fosters better a better return on investment for individuals and society [1].

Basch discusses implications for educational policy and practice relevant to closing the achievement gap and calls for a renewed focus on health as a missing link in school reforms [55]. Schools have a historical role to provide preventive health services. Schools also have an opportunity to reach diverse populations in educational settings [56].

A 2018 NASEM roundtable described the interdependent relationship between the health and education sectors and shared examples of public health interventions and activities in schools that support school success [57]. The Hamilton Project and the Brookings Institution in 2018 reports health problems and socioeconomic status predict poor attendance, and that chronic absenteeism persists over time [58]. In a discussion of implications for educational policy and practice relevant to closing the achievement gap, Michael et. al. summarized literature connecting student health and academic achievement and addressed health-related barriers to learning and suggested an association between chronic conditions and decreased achievement [59]. Safe and positive school environments were associated with improved health behaviors and achievement. Michael et. al. suggested family and community member engagement in schools positively affected students' health and achievement. They conclude schools can: improve the health and learning of students by supporting opportunities to learn about and practice healthy behaviors; provide school health services; create safe and positive school environments; and engage families and community.

National legislation also has had an impact on health education in schools. Two examples of the outcomes of these laws are the standardization of achievement tests and accountability for scores in specific areas.

3.1. The Whole School, Whole Community, Whole Child (WSCC) Framework

The overall intent of WSCC (helpful to this discussion) is that it keeps a child's progress as the focal point of the health communication and education effort involving multiple stakeholders to facilitate cooperation, collaboration, commitment, and facilitate understanding among professionals, parents, and all other stakeholders in school settings. In a recent resolution published by SOPHE (https://www.sophe.org/wp-content/ploads/2019/02/Final-WSCC-Model Resolution.pdf), the utility and background of the WSCC model is described:

> **Whereas,** in 2014 the Whole School, Whole Community, Whole Child model (WSCC) was developed through a partnership with ASCD (formerly the Association for Supervision and Curriculum Development) and the Centers for Disease Control and

Prevention (CDC) to align (the ASCD's Whole Child approach with CDC's Coordinated School Health model to allow for integration and collaboration between the education and health sectors. The WSCC framework uses an ecological approach to address the relationship between learning and health.

THE WHOLE SCHOOL, WHOLE COMMUNITY, WHOLE CHILD MODEL

The WSCC model is designed for schools, but it also is relevant to internal and external stakeholders and organizations that work with schools. Rooney et. al. identified strategies, steps, and resources within each phase of the WSCC model that can be integrated into existing processes to help improve health outcomes and academic achievement [60]. Rooney et. al. concluded with careful planning, implementation, and evaluation efforts, the use of the model has the potential of "focusing family, community, and school education and health resources to increase the likelihood of better health and academic success for students and improve school and community life in the present and in the future." Rooney et.al. suggest all dissemination efforts should communicate the transfer of conclusions from the evaluation into appropriate health program revisions and future actions because they are critical to success.

Slade describes the integration of the WSCC model for policy, process, and practice to improve learning and health [61]. Overall, the WSCC model is supported by the neighborhood in which the school is located and within the school. The student is the center of attention—placed in the middle to remind all who work with and for youth to work collaboratively to provide services and resources to the child. Slade adds the WSCC model has: "provided the impetus to make sure all agencies and services are in communication and engaged in continued discussion and ongoing planning." The WSCC model has demonstrated it can help a department of education create partnerships between schools and parents, city municipalities, emergency health services, and local businesses that serve the needs of the youth and community—contributing to student well-being and learning.

The chapter's authors suggest policies and laws regarding health education must inform planning and modeling for collaboration across HE, HC, and HL. Most state laws address child social and emotional well-being, physical and mental health and knowledge, and parent/community engagement. Fewer U.S. states have adopted programs to enhance school nutrition environments, physical activity/physical education, and employee wellness. The latter observations were among the findings of The National Association of State Boards of Education (NASBE). In 2019 NASBE released an updated significant on-line resource (http://statepolicies.nasbe.org/about). It details how states are implementing the WSCC and other aspects of school health. NASBE notes its resource is used by individuals to learn about and assess their own state's school health policies, as well as to find exemplary policies from other states.

3.2. Ten Examples that Demonstrate Elements of Collaboration

In changing times HC scholarship can help translate theory to practice in many areas of K-12 HE, public health education, public health promotion, and content areas—such as environmental health and understanding health risks. HC research examines what works and what does not work with what audiences in which environments. The growing focus in public health on communication—which led to the development of transdisciplinary frameworks for research, education, practice, and public health communication—might well be focused on better applied communication research for schools and communities and systematic and strategic integration of evidence-based information.

3.2.1. Using Communication Strategies

Smith et. al. reinforce the assertion that: "health communication extends beyond simply promoting or disseminating a particular product or proposed behavior change; it involves the systematic and strategic integration and execution of evidence-based, theory-driven, and community engagement strategies." It historically complements efforts to promote health education and health literacy in a variety of ways [62].

3.2.2. Conducting Environmental Scans

Using the communication strategy of an “environmental scan” to identify all potentially relevant programs and their evaluations provides a good starting point for collaborations. It enables a shared review of what the research shows (as well as what is being discussed in public and social media settings) that is pertinent to the needs of the specific student population.

3.2.3. Finding and Implementing ‘How-to’ Guides and More

The Compass (https://www.thecompassforsbc.org/how-to-guides), The Rural Health Information Hub ((https://npin.cdc.gov/) and others, offer “how to” guides based on evidence for some strategies. These are based on what works or has worked for others related to health and risk communication. Potential collaborators also can explore resources of centers, programs, agencies, and organizations that specialize in implementing and evaluating communication. These include the Southern Center for Communication, Health and Poverty the Annenberg Public Policy Center, The University of Georgia Center for Health and Risk Communications (CHRC), The Center for Health and Risk Communication at the University of Maryland, and other university health communication programs which are established sources of communication guidance.

3.2.4. Understanding Adverse Life Experiences and Their Impact

Schools and stakeholders can be pivotal to build resilience and support young people who experience adverse life experiences (ALEs) including violence and trauma [63]. Training and resources are available from groups with shared concerns. The Center for Promise in Boston (https://www.bu.edu/wheelock/research-action/centers-labs-institutes/the-center-for-promise/), a research institute for America’s Promise Alliance, recommends schools invest in professional development and pre-service training on the impact of ALEs on educational outcomes and emotional well-being as well as career preparation.

3.2.5. Promoting Parent Advocacy

Action for Healthy Kids (AFHK) in Chicago, IL and the National PTA have a partnership to support parents in creating healthier schools through their Parents for Healthy Kids program. Parents for Healthy Kids (http://www.actionforhealthykids.org/what-we-do/parents-for-healthy-kids) features a website, online community forum, trainings and grants to educate, engage and empower parents nationwide to improve school and student health.

3.2.6. Acknowledging School-based Health Centers: Strengths and Challenges

The Brookings Economics discussion paper on Building Healthy Neighborhoods by Price addresses some lessons learned from school-based health centers’ (SBHCs) approaches to community health [64]. Price discusses SBHCs as an example of schools and the health care system collaborating effectively. Price also underscores challenges in such partnerships. They range from misaligned missions of health and educational organizations, as well as incompatible financing systems and organizational cultures, to privacy and technical challenges associated with sharing student information.

3.2.7. Assessing and Understanding Outcome Data

RAND Health produces materials and data related to child health. (https://www.rand.org/topics/child-health.html). These include examination of influences on health behaviors, such as health literacy, as well as the social and physical environment (e.g. health effects of the local food environment, nearby parks, the socioeconomic status of neighborhoods, and other neighborhood and environmental effects on health).

3.2.8. Acknowledging Law and Health Aspects of Disability

In New Jersey, professionals and graduate students in the fields of law, health sciences, and social work collaborate to help low-income children with disabilities and their families address social and legal problems affecting health and well-being. The H.E.A.L. Collaborative is a Joint Project of the Rutgers Law School-Newark's Education and Health Law Clinic and Rutgers-New Jersey Medical School's Outpatient Pediatrics Department. (https://www.rutgershelpsnj.org/organization.528114-HEAL_Collaborative_Education_and_Health_Law_Clinic_Rutgers_U_School_of_Law)

3.2.9. Finding Models for Change in the School Environment

The Healthy Schools Campaign in Chicago, IL offers resources—from tip sheets to model policies and reports—to support efforts to make healthy changes. https://healthyschoolscampaign.org/resource-center/

3.2.10. Finding Examples of Effective Community Collaboration

The Harlem Health Promotion Center (HHPC) (https://www.mailman.columbia.edu/research/harlem-health-promotion-center) is 20+-year collaboration of community, academic, and public health stakeholders that uses research, education, advocacy, and service delivery to improve the health and well-being of the Harlem community.

3.3. Barriers and Challenges to Collaboration

In any discussion about creating new initiatives, considering the current and potential barriers, obstacles, and challenges also is important. In 1995, an IOM committee examined obstacles to school health programs in an interim statement [24]. The IOM committee identified important elements (that when misaligned or misunderstood) can thwart progress. Some of the identified areas included: fundamental understandings; program outcomes; comprehensive programming; health education; health-related services; research and evaluation; funding; local, state, and federal policy; and personnel and training issues. In a description of additional significant challenges, Kolbe notes many school students and staff are variously exposed to a variety of environmental health challenges related to the actual building and grounds facilities [1]. Citing Filardo and Paulson and Barnett, Kolbe asserted: “No federal, state or local agency is authorized, funded, and staffed to protect students from these threats” [65-66,1]. Other barriers and challenges for K-12 health literacy remain; five are introduced below.

3.3.1. Training Deficits

Cheung et al. discuss both barriers and facilitators to sustaining school health teams in coordinated school health program [67]. While Cheung et.al. note teacher training may be another barrier to effective communication of health education in school health programs, they add training is an issue across the related professions.

3.3.2. Absenteeism and Health Issues

Student absenteeism is a national problem. Allison and Attisha provide an overview of the relationship between school absenteeism and health and offer recommendations. Allison and Attisha identify specific diseases and the links to absenteeism [51].

3.3.3. State-by-State Differences

State variations are a significant challenge (http://statepolicies.nasbe.org/health) on several dimensions including how health education is defined, and how comprehensive and inclusive the definition is regarding curriculum content. Is teaching health mandatory or encouraged? To what extent are details about required health curricula included in the law? What regulations or guidance documents exist? Is health education required for graduation? Who is responsible for communication and assessment? Other important considerations are whether or not partnerships and outside collaborations are practical, allowable and sustainable? What approval (and by whom) needs to be sought and confirmed in advance?

3.3.4. Lack of Resources and Leadership

Important community challenges include resources, leadership, coordination, sustainability, and access. Students and healthcare professionals working with children in a community might be overwhelmed by lack of resources, potential lack of engagement, and methods for active assessment.

3.3.5. Missing Outcomes Data and Resistance to Cross-disciplinary Results

In the *Special Report: Barriers to Success*, Porche notes: “while many young people in America continue to be bombarded by severe adversity, few receive the supports and resources they need to be resilient” [63]. The report discusses major challenges as: (1) health outcomes are rarely assessed; and, (2) a possible resistance to accepting research from other domains.

4. Identifying Internal and External Stakeholders

For purposes of this chapter, internal stakeholders are professionals in the formal school system and individual school setting. External partners can include a wide variety of potential collaborators. Reviewing health improvement programs for K-12 children and teens noted in this chapter and in its development, the authors conclude that a HE, HL, HC effort will be weaker if it does not take advantage of *all* potential partners. The chapter’s authors identify potential stakeholders with the understanding that there are many more who can be engaged.

As for coordinating the efforts of a variety of stakeholders, The School Health Advisory Council (SHAC) represents one approach to fostering collaboration among all stakeholders involved in the WSCC. Some U.S. states, such as Texas, require local education agencies to have SHACs. SHACs are distinct from but may overlap with school wellness committees.

Wellness committees are required by law under the Child Nutrition and Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) Reauthorization Act and Healthy, Hunger-Free Kids Act of 2010. Schools participating in the National School Lunch program must have school wellness councils or committees that address nutrition education, minimum nutrition standards, physical activity, and food and beverage sales outside of school meals. USDA policy guidelines require parent involvement and other criteria that foster collaboration among some school stakeholders.

4.1. Selected Internal Stakeholders

The American School Health Association (http://www.ashaweb.org/asha-position-statements/) lists position statements for the roles of some of the important internal stakeholders including school administrators and school health coordinators. Roles may vary with needs. Understanding the way professionals interact to implement health-related curriculum and activities in a local school or system promotes student health literacy. Professional stakeholders also share concerns surrounding safety, security, and increasing access to mental health supports for children and youth: “efforts to improve school climate, safety, and learning are not separate endeavors” [68].

4.1.1. School Administrators and Principals

The National Center for Educational Statistics in the U.S. Department of Education notes there are some 90,400 principals in public schools and an estimated 25,000 private school principals. Institutional support and leadership are two of the most important elements to foster a positive school climate that enhances staff and student engagement and student academic achievement. Fetro explains: “an essential key to success is a school principal or assistant principal who recognizes the importance and value of CSH (coordinated school health) and how it can support teaching and learning within the school” [69]. The principal is an opinion-leader and is: “a direct link between the school and district office, the principal can often help to secure needed fiscal and human resources as well as administrative support.” The CDC has identified strategies and actions that principals can take to encourage school connectedness.

4.1.2. Teachers

Regardless of discipline, teachers are a vital source of health communication and school health education [70]. As noted earlier, teachers may need guidance and opportunities for professional development especially in changing health and communication environments [71]. And even as teachers are trained or given a curriculum, they may not effectively communicate to alter health-related knowledge, attitudes, or beliefs of students. Ineffective communication can actually impair understanding.

4.1.3. Health Professionals

Lear suggested in the early twenty-first century (in the U.S.), an estimated 56,000 school nurses; 1,725 school-based health centers; 99,000 school counselors; 30,000 school psychologists; 14,000 school social workers; and smaller but unknown numbers of dentists and dental hygienists, physicians, substance abuse counselors, family planning counselors, and HIV/AIDS counselors worked in about 95,000 public schools serving more than 50 million students [72]. Added to these should be the uncounted community providers who spend some part of their work weeks in school settings but whose presence might not be captured in national surveys or reported to the U.S. Department of Education. Further, the assignments and responsibilities vary among community providers.

4.1.4. School Nurses

The National Association of School Nurses (NASN) has defined roles and standards for school nurses [73]. Challenges for school nurses include expectations that they represent the public health's 'eyes and ears' for the nation's children and families. Further, school nurses must constantly readjust to changing social ethics and privacy issues [74]. As with teachers, school health nurses' time, skills, and assignments vary from school-to-school and system-to-system. The American Academy of Pediatrics recommends a full-time nurse in every school [75]. State school nurse consultants may guide the development and delivery of health services in local settings. As with other school professionals, time constraints and confidentiality additionally are issues for school nurses. Emphasizing collaboration between public health and school nurses provides an additional avenue for health education [76]. The Association of Nurses (https://www.nasn.org/nasn-resources/practice-topics/environmental-health) has a guide on its website for working with schools to create healthier environments.

4.1.5. Community Physicians

Community physicians can play vital roles in supporting both children's and parent's health literacy and empowerment. In the late 1960s, James P. Comer at the Yale Child Study Center envisioned schools addressing the needs of the whole child with special concern for isolated, disadvantaged children. Comer noted a structure in New Haven that enabled parents, educators, and medical specialists to develop a comprehensive school plan. The New Haven plan contained both social-emotional and academic components [77]. As New Haven created better social climates within area schools, there were improvements in the integration of academic learning and social emotional development.

4.1.6. School Counselors, School Psychologists, Speech-language Pathologists and Audiologists.

Other internal professionals serve important roles. The American School Counselor Association (https://www.schoolcounselor.org/) offers mental health educational and support resources to members, as does the National Association of School Psychologists https://www.nasponline.org/). Those working on health initiatives within education have unique challenges, such as the steep learning curve (or in some cases, 'unlearning' curve). The National Association of Chronic Disease Directors has a guide that includes recommendations to more effectively work with the education sector ("Pitfalls to Avoid") and offers many supportive resources [78]. The School Social Work Association of America (https://www.sswaa.org/school-social-work) and the American Counselor Association (https://www.schoolcounselor.org) offer educational and supportive resources to members, as do the National Association of School Psychologists (https://www.nasoponline.org/) and the American Speech, Hearing, and Language Association (https://www.asha.org). Legal and ethical challenges for school counselors, school psychologists, speech-language pathologists, and audiologists are similar to those faced by nurses and teachers.

4.2. Examples of External Stakeholders

Many concerned external stakeholders, including parents, may engage in efforts to improve the health literacy of K-12 students outside of health education classrooms—if provided with appropriate information, materials, and strategies. Existing national efforts have been developed by both governmental and non-governmental organizations (NGOs) as well as businesses as summarized in the three examples provided immediately below.

4.2.1. Community Groups

Parent groups including PTAs, other community groups, such as scouts, boys' and girls' clubs, wellness groups, sports groups, arts groups, science clubs, local public service businesses, and expert influential speakers, are all examples of local external stakeholders that are eligible community partners to support K-12 health education and health literacy.

4.2.2. After-school Programs

The U.S. Centers for Disease Control and Prevention (CDC) and others have funded diverse groups to address youth nutrition, physical activity—and engagement in those settings. Collaborations among such external stakeholders (and in coordination with internal stakeholders) can serve as resources to stimulate ideas, reinforce concepts, or to adapt working models locally.

4.2.3. Governmental, Non-Governmental, and Private Organizations and Businesses

U.S. federal resources exist to help schools establish community partnerships to accommodate local needs. Some recent U.S. laws enable community partnership as an appropriate use of taxpayer funds (e.g., the Allowable Student Support and Academic Enrichment fund of the U.S. Department of Education for 'Safe and Healthy Students' (ESEA section 4108). Other authorized community partnership areas include Safe and Supportive Schools and Physical and Mental Health.

Successful partnerships benefit whole communities. Blank concludes: "to build deep health-education partnerships and grow community schools, a working leadership and management infrastructure must be in place that uses quality data, focuses on results, and facilitates professional development across sectors. The leadership infrastructure of community school initiatives offers a prototype on which others can build. Moreover, as leaders build cross-sector relationships, a clear definition of what scaling up means is essential for subsequent long-term systemic change" [79].

A few examples of these kinds of partnerships include governmental, non-governmental, private organizations, and businesses. These include:

- The Allowable Student Support and Academic Enrichment fund of the U.S. Department of Education for "Safe and Healthy Students," ESEA section 4108
- The Safe and Supportive Schools grants, and other U.S. laws/grants to enable community partnership as an appropriate use of taxpayer funds.
- The U.S. Department of Education Fund for the Improvement of Education (FIE) Full-Service Community Schools (FSCS) grants
- The CDC and other federal agencies resources for building community partnerships https://www.cdc.gov/chinav/case/
- The NIH National Institute on Drug Abuse (NIDA) and the National Institute on Alcohol Abuse and Alcoholism (NIAAA) annual National Drug & Alcohol Facts Week® (NDAFW).
- The U.S. Department of Agriculture's Cooperative Extension Service across states.
- The American Cancer Society Promoting Healthy Youth, Schools, and Communities: A Guide to Community-School Health Councils in partnership with the American School Health Association, the American Academy of Pediatrics, and the National Center for Health Education.
- The National Association of School Psychologists with the Institute for Educational Leadership and the Coalition for Community Schools white paper.
- The American Heart Association and Robert Wood Johnson Foundation Voices for Healthy Kids (https://voicesforhealthykids.org/about-the-initiative/).
- Community Youth Creative Learning Experience (CYCLE).
- The Community Tool Box supported by the University of Kansas Kids' Well-being Indicators Clearinghouse (KWIC) and its 12 member agencies.
- The National School Climate Center (NSCC) https://www.schoolclimate.org/

More general activities groups, such as physical fitness and sports, also potentially provide tangible and intangible benefits to a school's community interaction. A special application of these benefits is allied sports, which provide inclusive programs giving students with disabilities an equal opportunity to participate and for school/community partnerships to improve health for disabled children.

5. Selected Public Health Threats that Affect K-12 Students

Many contemporary threats exist to the health and well-being of children. Threats are not always straightforward and are not always observable. Important, too are complicated interrelationships among social behaviors (e.g. texting, substance abuse, distraction). In this section, a few primary examples highlight the complexity and range of such threats, and demonstrate the need for collaborative health education, health communication, and health literacy interventions.

In this section, a few examples highlight the complexity and range of threats to K-12 students. Each of these is significant and requires effective risk education and risk communication [80]. Many additionally compel young people to make decisions, comprehend risk, and advocate for their own health as dangers arise when they are unattended by adults. Overall, K-12 students need understanding, context, and tools to protect themselves. The chapter's authors emphasize that building the knowledge and skills for improved health based on age and threat provides a basis for lifelong wellbeing and health literacy.

5.1. Leading risks: Vehicle Crashes and Firearms

In December, 2018, *The New England Journal of Medicine* (*NEJM*) released a special report on the leading causes of death in children and adolescents in the U.S. [81]. “Motor vehicle crashes were the leading cause of death for children and adolescents, representing 20% of all deaths; firearm-related injuries were the second leading cause of death, responsible for 15% of deaths.” A research team also studied intentional versus unintentional injury and found: “unintentional injuries were the most common cause of injury-related death.” In an editorial accompanying the report, a *NEJM* executive editor, noted significant discrepancies between the U.S. and other developed nations [82]. For example, the U.S. rate of death from motor vehicle crashes was more than triple that of other developed countries. The *NEJM* executive editor added firearm injury is only a ‘minor contributor’ to childhood mortality in other developed countries writing: "children and adolescents in the U.S. were more than 36 times as likely to be killed by gunshots as their counterparts in other high-income countries.”

5.2. Tobacco and E-Tobacco Products

According to the 2018 National Youth Tobacco survey, although a reduction in traditional cigarette smoking has occurred in recent years, a ‘staggering’ 78 percent increase in high school e-cigarette use occurred from 2017-2018 [83-84]. The survey also found: (1) More than 27 percent of high school students in the U.S. use at least one tobacco product, including e-cigarettes; (2) 7.2 percent of middle school students use at least one tobacco product, including e-cigarettes; and, (3) in addition to high school increases, middle school e-cigarette use increased by close to 50 percent in 2018. Advances made with traditional anti-smoking prevention efforts are losing ground to new challenges with e-cigarettes and more potent products, such as JuuL, in spite of mounting evidence of harm.

It is important for all adolescents to understand how producers of e-tobacco and vaping products use advertising media to communicate to them as well as the risks of nicotine addiction. Perikleous et. al. reviewed e-cigarettes use among adolescents [85]. Their international results attest to the enormity of a rapidly emerging problem among adolescents inside and outside the U.S. The Truth Initiative (formerly the American Legacy Foundation), funded in part from the 1998 Master Settlement Agreement between major U.S. tobacco companies and 46 U.S. states, the District of Columbia and five territories, issued a direct warning to parents of middle or high school students: “. . .the popular new e-cigarette JuuL is reigniting concerns about nicotine addiction in youth. The Truth Initiative explains that the amount of nicotine in one JuuL cartridge is roughly equal to the amount of nicotine in a pack of cigarettes, or about 200 puffs, according to the product website” [86].

An American Academy of Pediatrics fact sheet for parents and pediatricians highlights the latter product is not only increasing in high school and college classrooms, but is shared in school hallways or in restrooms, with peers who ‘encourage’ nonusers, and ‘enable’ students too young to purchase the product [87]. As this chapter is going to press, JuuL is s revising its marketing strategy, but as noted in an Atlantic article, “Juul’s New Marketing Is Straight Out of Big Tobacco’s Playbook” [88].

Ross et. al. conducted a systematic review to examine existing literature on health communication for non-cigarette tobacco products and identified research gaps. They also examined potential new ways to communicate risk [38].

Another e-cigarette concern appears in a national sample of U.S. adolescents and young adults, which reported the use of e-cigarettes at baseline was associated with progression to traditional cigarette smoking [89]. And a 2017 review of e-cigarettes concludes that: "based on the existing scientific evidence related to e-cigarettes and optimistic assumptions about the relative harm of e-cigarette use compared to cigarette smoking, e-cigarette use currently represents more population-level harm than benefit" [90]. The report agrees with Pimack, et. al. that comprehensive tobacco control efforts are needed to reduce the appeal of e-cigarettes to youth.

Shih and colleagues studied individual, peer, and family factor modification of neighborhood-level effects on adolescent e-cigarette use (as well as alcohol, cigarette, and marijuana use) [91]. Shih et. al. conclude community-level programs may prevent use that increase social cohesion among neighbors, neighborhood monitoring of deviant behaviors, and better policing of open drug selling. Programs also should target resistance, self-efficacy, and minimize affiliations with peers who use abused substances. Shih et. al. highlight that higher neighborhood disorganization is associated with improved odds of substance abuse and suggest more self-efficacy for resistance may curb substance abuse among youth within unsafe neighborhoods. Meanwhile, Shih et. al. also provide examples how external stakeholders can be collaborators.

Among the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) 'programs that work' is Project Towards No Tobacco Use (TNT) (https://tnt.usc.edu/) and variants of it. Project TNT has been implemented in schools across the country (teacher training prior to program implementation by a certified Project TNT trainer, is recommended.) The theory underlying Project TNT is youth will best be able to resist using tobacco products if they:

1. are aware of misleading social information that facilitates tobacco use (e.g., pro-tobacco advertising, inflated estimates of the prevalence of tobacco use);
2. have skills that counteract the social pressures to achieve approval by using tobacco; and
3. appreciate the physical consequences that tobacco use may have on their own lives. More 'programs that work' are included in the SAMHSA Model Programs Guide.

In the context of tobacco-related health literacy, Parisod et. al. found an array of determinants of health literacy among adolescents [92]. They argue that the personal determinants of adolescents' health literacy include: their age; knowledge and access to health information; media use; health status; social skills; attitudes; perceptions and experiences; motives; self-efficacy; and role expectations. External determinants include: interpersonal relations with authorities; idols, random people, and socio-cultural atmosphere; peers and family members; mass media; social mores; living environment; and educational system. Further, they suggest adolescents' health literacy is mediated by their interpretation of the health message, balancing personal and external determining factors, and the capacity to process conflicting messages.

5.3. Mental Health (e.g. Bullying, Sexting, Suicide, and Violence)

The mental health of K-12 students remain a persistent challenge. Not only do childhood behavioral disturbances predict lower scores on academic tests and curtail educational attainment, but schools may not have adequate levels of school-employed trained mental health professionals [93].

More than a decade ago, Adelman and Taylor suggested health policy and practice call for health and mental health parity and for a greater focus on universal interventions to promote, prevent, and intervene early onset: "and schools are essential partners for doing the work" [94]. According to the National Alliance on Mental Illness (www.nami.org), schools provide a unique opportunity to identify and treat mental health conditions by serving resident students. School personnel play an important role to potentially identify the early warning signs of an emerging mental health condition and to link students and families with effective services and supports.

According to the NIH's National Institute of Mental Health (www.nimh.nih.gov), one in five youths ages 13–18 experiences a serious mental health condition. Fifty percent of chronic mental illnesses begin by age 14. Yet, on average, it takes 8-10 years from the onset of symptoms until intervention. An American Institutes of Research review of mental health programs and services emphasized the need for evaluation of mental health challenges among children and teens [95]. Merikangas et. al report on the lifetime prevalence of mental disorders among U.S. adolescents [96].

The scope of mental health in children is addressed by CDC data. Hansen and Diliberti found a modest percentage of schools provided any diagnostic assessment for mental health disorders in 2018 [97]. Based on data from the NCES School Survey on Crime and Safety, only 63 percent of public schools in 2015-16 offered any treatment for mental health disorders [98].

Child and teen mental health literacy also differ from adult mental health literacy. Different social and emotional skills and ways of communicating are needed for school age children to understand uncertainty and risk about threats to safety, decision-making, and the ability to be resilient in the face of threats to them or their peers [99].

In a chapter on Mental Health Literacy for Students and Teachers, Canadian researchers describe a 'School Friendly' approach [100]. They identify four 'distinct but related components.' They are: understanding how to obtain and maintain good mental health; understanding mental disorders and their treatments; decreasing stigma; and enhancing help-seeking efficacy.

A white paper from the Mental Health Association in New York describes the many elements (including legal and policy implications) to integrate more mental health education in schools within one state [101]. The paper also identifies national trends and compare the experience within New York state.

TeenMentalHealth.org identifies unique integrated components for school mental health literacy including: (1) understanding how to optimize and maintain good mental health; (2) understanding mental disorders and their treatments; (3) decreasing stigma; and, (4) increasing health-seeking efficacy. The organization's publication, The Mental Health & High School Curriculum Guide, is a free evidence-based Canadian mental health literacy curriculum resource designed for use in schools (grades 7-10). (http://teenmentalhealth.org/schoolmhl/school-mental-health-literacy/mental-health-high-school-curriculum-guide/download-the-guide/)

5.3.1. Bullying and Victimization

Research suggests bullying, a type of adolescent victimization, occurs frequently, particularly in middle school grades, and can result in serious consequences for both bully and victim. The National Conference of State Legislatures produced An Overview: School Bullying (2011) (http://www.ncsl.org/research/education/school-bullying-overview.aspx). The CDC and the U.S. Department of Education released the first federal uniform definition of bullying to be used for research and surveillance: "any unwanted aggressive behavior(s) toward a youth by another youth or group of youths, who are not siblings or current dating partners, involving an observed or perceived power imbalance." Adding: "These behaviors are repeated, or have the potential to be repeated, over time. Bullying can happen in person and electronically (known as cyberbullying) and can occur at school or in other settings." Bullying and cyberbullying in school as issues of crime and safety are reported by Musu et al. [102].

According to data from 2017 Youth Risk Behavior Survey: "Lesbian, gay, bisexual, transgender, or questioning (LGBTQ) youth and those perceived as LGBTQ are at an increased risk of being bullied." Several federal agencies report in "Bullying (StopBullying.Gov) puts youth at increased risk for depression, suicidal ideation, misuse of drugs and alcohol, risky sexual behavior, which can affect academics as well." For LGBTQ youth, these risks are even higher [103].

A 2018 report, Supporting Safe and Healthy Schools for Lesbian, Gay, Bisexual, Transgender, and Queer Students: A National Survey of School Counselors, Social Workers, and Psychologists (GLSEN) provides data from across the U.S. and focuses on improvements in school climate for impacted students [104]. The report also offers a curriculum for educators.

Flannery, et. al. reviewed literature that supports bullying as a significant and preventable public health problem [105]. "The consequences of bullying—for those who are bullied, the perpetrators of bullying, and the witnesses—include poor physical health, anxiety, depression, increased risk for suicide, poor school performance, and future delinquent and aggressive behavior."

Bosworth and Judkin suggest addressing bullying requires a comprehensive approach that includes a focus on school climate [106]. Bosworth and Judkin review some school climate features shown to reduce bullying and illustrate School-wide Positive Behavioral Interventions and Supports grounded in multiple theories—behaviorism, social learning theory, prevention science, and systems change.

The Technical Assistance Center on Positive Behavioral Interventions & Supports (PBIS), funded by the U.S. Department of Education's Office of Special Education Programs (OSEP), supports schools, districts, and states to build systems capacity to implement a multi-tiered approach to social, emotional, and behavior support. PBIS provides a growing evidence base that suggests social, emotional, and academic improvements in outcomes for all students, including students with disabilities and students from underrepresented groups.

Research from The Bullying Prevention and Mental Health Promotion Lab at the University of Maryland (https://education.umd.edu/research-college/labs/bullying-prevention-and-menal-health-promotion-lab) provides tool-based mental health services and prevention of mental health problems, mental health literacy, help-seeking among culturally and linguistically diverse students, parenting practices, and family involvement.

The U.S. Office of Juvenile Justice and Delinquency Prevention offers a literature review of interventions for bullying. It includes an extensive bibliography on the topic [107]. The office also provides a similar analysis of protective factors for prevention [108]. Otherwise, bullying via new media and sexting increase K-12 student vulnerability. In a 2018 report for Pew Research Center, Anderson notes 59 percent of U.S. teens have been bullied or harassed online, and a similar percentage say it is a significant problem among their peers [109]. Teens also think that teachers, social media companies and politicians are failing to address bullying issues.

Emerging issues, such as how sexting has an impact upon the health and safety of adolescents, was addressed in a recent systematic review and meta-analysis by Madigan et. al. [110]. Their study focused on the prevalence of sending, receiving, and having one's sext forwarded without consent. The meta-analysis found: (1) the prevalence of sexting has increased in recent years; and, (2) sexting increases as youth age. The meta-analysis' authors suggest: "teen-focused health care providers should consider screening for sexting behaviors, so as to provide age-specific education about the potential consequences of sexting, and as a mechanism for discussing sexual behaviors."

Roberto, et. al. describe outcome evaluation results of school-based cyber safety promotion and cyberbullying prevention interventions for middle school students [111]. Guided largely by the Extended Parallel Process (Communication) Model, the Arizona Attorney General's Social Networking Safety Promotion and Cyberbullying Prevention presentation seeks to shape, change, and reinforce middle school students' perceptions, attitudes, and intentions related to important social issues.

5.3.2. Suicide

Suicide rates among children and adolescents from 2000-2017 are discussed in a 2019 letter in *JAMA* and an analysis of CDC data reports suicide is the second leading cause of death for adolescents in the U.S., and can be associated with bullying [112-114]. Fisher suggests literacy educators have a significant role in suicide prevention [115]. Lack of mental health literacy for students who have major depression and suicidal ideation (or those who do not recognize this in others) may impede communication and help-seeking behavior—even if prevention resources exist. To reduce depressive episodes and suicide risk, it may help to increase the availability of school-based mental health services and prepare educators with suicide sensitivity and communication strategies.

Recent findings about the impact of a television series, '13 Reasons Why' demonstrate the need to know (through careful research and translational application of knowledge) how to deal with complex issues such as suicide in youth. The aforementioned Netflix series is based on a popular book is about a 17-year old girl who is bullied, sexually assaulted, and commits suicide. There was serious public concern about the potential 'contagion effect' (the Werther effect) of the book and then the series.

A study by Arendt et. al. of the two first seasons found: "viewers who stopped watching the second season partway through reported greater risk for future suicide and less optimism about the future than those who watched the entire season or didn't watch at all" [116]. In an April 25, 2019 news release some of the study's authors added: "viewers who dropped out of watching the series midway, students were at a significantly higher suicide risk than non-non students." Students who watched the full second season were less likely to report self-harm and thoughts of ending their lives compared to students who did not watch the series at all. On July 15, 2019 Netflix announced that it had edited out the last episode of the first season prior to the release of the third season.

A beneficial effect noted by the researchers occurred in the second season among students who saw the full set of episodes: “viewers in general were more likely to express interest in helping a suicidal person, especially compared with those who stopped watching.” The teams also studied responses to the Netflix pre-program warning for viewers of the second season. The warning appeared “*to increase viewing but did not appear to prevent vulnerable viewers from watching the season.*” Knowing about teen exposure, potentially differing viewing strategies, actual outcomes of ‘warnings’ are just part of what can be learned from this type of research.

5.4. Other Threats

A myriad of other significant health concerns persists for K-12 students. For example:

- The CDC estimates that youth ages 15-24 make up just over one quarter of the sexually active population, but account for half of the 20 million new sexually transmitted infections in the United States each year.
- Opioid and prescription drug abuse have been addressed collaboratively by federal, state and local agencies. A program from SAMHSA and the U.S. Department of Transportation, The Opioid Crisis and K-12 Schools: Impact and Response 2018, details how the opioid crisis affects students and families with insights into practices and policies to help address the crisis in schools.
- Traumatic brain injury (TBI) in children occurs from sports injuries, accidents and intentional harms is another risk. Some common disabilities that may result from TBI include cognition problems (thinking, memory, reasoning), sensory processing (sight, hearing, touch, taste, smell), communication (expression, understanding), and behavior or mental health (depression, anxiety, personality changes, aggression, acting out, social inappropriateness). If undiagnosed, children disabled by TBI are likely to be mainstreamed to regular classrooms. Only one to two percent may be appropriately classified as having TBI [117]. Failure to properly classify them places 98-99 percent of them at risk of academic failure and personal maladjustment.

To address the health risks identified here and other risks, school health collaborators should examine the health data in their own local K-12 school population, obtaining input from all stakeholders. Armed with this information, collaborators should develop a comprehensive plan to address those specific health needs.

6. Selected Evidence-based Health Education/Community/Multidisciplinary Practices and Resources

Health literacy improves when individuals understand the language used to communicate, especially when learning new health concepts or information. Achieving health literacy requires appropriate educational and communication strategies including the use of language that is clear (‘plain’) for specific audiences or individuals. The U.S. Health and Human Services, Office of Disease Prevention and Health Promotion finds some of the systematic factors to be considered in any K-12 and stakeholder strategy include: communication skills and knowledge of health topics of lay persons and professionals;

culture; demands of the healthcare and public health systems; and the demands of the situation/context.

Some sources of evidence-based practices in health communication programs for health education and health literacy include:

- The NIH's National Cancer Institute *Making Health Communication Programs Work* (a.k.a. the 'Pink Book'). The practices are grounded in theory and method and have evidence of successful application.
- The CDC National Prevention Information Network website lists more sources and methods. These are evidence-based strategies that may, with local adaptation, be helpful for collaborative programs.
- The NIH 'Evidence-Based Practices & Programs' page links to U.S. federal resources to identify disease prevention approaches with potential to impact school and community health.
- The What Works: Health Communication and Health Information Technology Evidence-Based Interventions for Your Community from The Community Guide of the Community Preventive Services Task Force provides proven intervention strategies to develop successful health communication and health information technology interventions

Summaries of all U.S. federally-sponsored research can be found and searched on the (https://www.grants.gov/) site. These can be useful to introduce the outcomes of research projects and to find potential external links to successful health literacy interventions.

While this has been a sampling of differing resources, other pertinent programs and materials can be identified via an environmental scan, which should be done at the start of a new collaborative K-12 health educational effort.

6.1. Four Other Youth Intervention Initiatives

6.1.1. Obesity and Diabetes Prevention with Youth-Created Messages

Schillinger put research into practice with a community youth generated health communication campaign. In 2010, Schillinger described community research program development, including partnering with relevant decision makers and target audiences to increase translation of evidence-based interventions and evaluation, with attention to context and external validity [118]. Then, in 2014, Schillinger and colleagues noted the initial results of a campaign for at-risk youth to increase knowledge of (and attitudes about) preventing type 2 diabetes, changing social norms, and motivating participation in health-promoting initiatives.

Schillinger et. al.'s research was the result of a partnership between the University of California San Francisco Center for Vulnerable Populations at San Francisco General Hospital and Trauma Center, and the staff of Youth Speaks: 'whose wisdom, expertise, and candid feedback made this collaboration possible' [119]. This youth-created health communication campaign used a public health literacy framework with targeted, relevant, and compelling messaging. The campaign addressed an unmet need to engage youth in identifying solutions to reverse the trajectory of type 2 diabetes development via a prevention campaign that targeted minority and low-income youth in selected areas of California.

6.1.2. The Coordinated Approach to Child Health (CATCH)

CATCH (https://catchinfo.org/about/) community health programs impact the messaging and interventions a child receives to influence his/her choices. The messaging may be in physical education, the lunchroom, the classroom, and/or at home. All attempt to influence a child's health and other decisions not only in school, but lifelong. The CATCH platform has launched kids and communities toward healthier lifestyles for more than 25 years. For example, the CATCH obesity prevention program uses the WSCC framework and multiple influences in a child's life to create a community of health. The success of the CATCH intervention to prevent childhood obesity is supported by 120 academic papers that suggests as much as an 11 percent decline in overweight and obesity among target audiences.

6.1.3. Whole Family/Two-Generation Improved Health Outcomes

The Center for Promise recommends the expanded development of two-generation programs that support families dealing with adversity as well as increased availability of school-based services, which is recommended as the initial strategy to support engagement. Two-generation approaches include: health and wellness support (accessible healthcare); educational support (e.g. skills trainings, credentialing programs); economic support (e.g. food, housing, transportation); and social capital support (e.g. career coaching, learning communities).

The Ascend program at the Aspen Institute provides examples of two-generation best practices. The Ascend Network membership includes 250 partners from more than 42 U.S. states, the District of Columbia, and Puerto Rico in a national network of practitioners, policymakers, philanthropic leaders, and researchers to advance two-generation approaches for whole-family outcomes. Since its launch in 2014, Network Partners have reported successful outcomes among family participants. The2Gen Outcomes Bank (http://outcomes.ascend.aspeninstitute.org/) captures research, tools, and evidence-based outcomes, for two-generation approaches, strategies, and programs. The database is organized across the core 2Gen components of education, economic assets, health and well-being, and social capital. Materials are crowdsourced from those active in two-generation approaches and related fields.

6.1.4. Prevention of Antisocial Behavior and Al's Pals

The U.S. Department of Justice's National Institute of Justice (NIJ) addresses the need to include bullying and cyberbullying, as violence and disciplinary problems in schools (among other issues). One popular NIJ supported health education/health literacy resilience-based prevention program for young children is called 'Al's Pals.' It is an early childhood curriculum meant to increase protective factors for early and persistent aggression or antisocial behavior and is used in diverse national programs.

Interactive health education lessons teach children to practice positive ways to express feelings, relate to others, communicate, brainstorm ideas, solve problems, and differentiate between safe and unsafe substances and situations. Fifteen to twenty-minute lessons are delivered twice a week over 23 weeks typically consisting of two or three activities including 'puppet-led' discussions, brainstorming, role plays, and guided creative play. Teachers use activities to express clear messages that using violence or abusing drugs and alcohol is unacceptable. The emphasis is on making healthy choices and prosocial behavior, such as getting along with others.

Some lessons invite parental involvement. For example, some letters from 'Al' update parents about the skills and lessons their children are learning, and suggest concept reinforcement activities that can be completed at home. 'Al-a-Gram' interactive health education lessons teach children to practice positive ways to express feelings, relate to others, communicate, brainstorm ideas, solve problems, and differentiate between safe and unsafe substances and situations.

7. Research and Resource Opportunities for Sharing across Fields

In this chapter, the authors provided a body of knowledge regarding policies, programs, and resources. The chapter's authors cited opportunities and challenges for work ahead to de-silo scholarship of HE, HC, and HL with combined efforts that address serious and complex health needs of the K-12 population. This discussion has drawn upon existing research within and across the disciplines of HE, HC, and HL.

7.1. Efforts for Moving Forward

Going forward, the chapter's authors suggest risk communication, dissemination, and other evidence-based strategies can be further integrated by internal and external stakeholders for delivery of K-12 content and skills to close knowledge gaps and promote health literacy.

Health education and risk prevention cannot work effectively without effective health communication strategies. For example, in the field of injury prevention, Aldoory and Bonzo find there are missed opportunities to incorporate communication research and theory that could increase the impact of campaigns [120]. Although dozens of communication campaigns have been designed and implemented on local, state, and federal levels to reduce injury related risks and rates of injuries (both unintentional injury and intentional injury resulting from violence), Aldoory and Bonzo explain practitioners rarely turn to communication research and theory to design and implement campaigns. Aldoory and Bonzo, among others, maintain theory-driven research and literature from the communication disciplines provide useful insights about campaign development; and offer guidelines that may improve the results of campaigns using communication tools to reduce injury rates in the U.S.

In Canada, The Education and Early Childhood Development Violence Prevention Best Practices 2015 is an on-line document outlining school-based best practices for violence prevention in K-12 schools. The selected programs highlight building both communication and prevention skills, home-school communication to strengthen the understanding and responses to bullying and community support for bullying prevention programs in schools, among other practices. All initiatives chosen by PREVNet and the Public Health Agency of Canada are peer reviewed and evidence based. All initiatives include implementation strategies, specific initiatives and programs as well as a list of principles across diverse age groups. Resilience or coping training provides a specific example of a selected best practice initiative. The findings assert schools, and the internal stakeholders within them, can be pivotal to support young people who have adverse life experiences (ALEs).

Social marketing campaigns and entertainment education provide effective health communication strategies with evidence bases to engage populations in health-promoting behaviors [120]. Nutbeam, McGill, and Premkumar offer a progress review of improving health literacy in community populations and include examples of community health literacy programs for youth [121]. Among the campaign strategies, the researchers mention entertainment education (also called "edutainment") [122].

Training and resources are available from groups with shared concerns. The aforementioned Center for Promise in Boston recommends schools invest in professional development and pre-service training regarding the impact of ALEs on educational outcomes, emotional well-being, and career preparation. The Barr Center (https://barrcenter.org/) suggests The Turn Around for Children and Building Assets and Reducing Risks program provides school-based examples that identify and provide support to youth experiencing adversities.

Among other useful RAND health resources, RAND Health data about Healthy Populations and Communities includes information about diverse influences on health behaviors—including health literacy, the social and physical environment, health effects of the local food environment, and other neighborhood and environmental impacts.

7.2. Needed Research

Overall, the chapter's authors find K-12 HL, HE, and HC research focused on health learning and health outcomes for children and teens needs to be de-siloed. To achieve the vision of such models as the WSCC and promoting lifelong health, the latter work needs to be undertaken by HE, HL, and HC interdisciplinary teams.

Research is needed across the spectrum of basic applied, mixed method, qualitative and quantitative research and evidence-based results need replication and generalizability for differing audiences and age groups. A careful analysis of useful models or frameworks of collaboration (such as the WSCC) as well as a review of representative programs that include internal and external stakeholders in cooperative, supportive collaboration offer potential directions for investigation. Each field has much to contribute to the interdisciplinary work that is needed.

To strengthen the preparation of future K-12 health education teachers, research is needed on the essential courses and experiences to support implementation of effective pedagogical approaches to prepare practitioners to teach health skills using active learning teaching strategies [123]. Also, research is needed on ways elementary teachers can integrate health education instruction within other academic subjects such as language arts and mathematics.

The WSCC framework needs further research. Some suggested research areas include: what strategies are successful in formation, implementation, and sustainability of school wellness councils in implementing the WSCC; how can academic institutions better prepare school health teachers and administrators to implement the WSCC; what are successful methods of engaging students and parents in the WSCC; what messages and modes of communication (e.g., social media) are most successful in gaining public support for more school resources so that the needs of the whole child can be better addressed; what early students' social and emotional health issues are important to be addressed early on in and should be incorporated in the training of K-12 health teachers and school personnel; and how do children develop empathy, especially in light of differences and on social platforms?

Other suggested research questions include: how to identify the ways students, at different ages find, gather, and process both accurate and inaccurate health information sources. A clear need exists to understand how K-12 students make use of mass media as it affects their health. For example, how do students differentiate between news and opinion and learn to identify misinformation on platforms such as Facebook and Twitter? How do students develop the skills to advocate for themselves, especially among peers to make healthy choices? What behavioral change models work for each age group and with differing topics? How is risk best communicated to youth at different ages increased investigation into how to communicate risk with youth at different ages about the health topics that are relevant to them? How is knowledge improved for creating most appropriate methods and tools to assess health literacy in children? The internal and external stakeholders need to have evidence of the best communication strategies and tactics.

HE, HL, and HC experts share concern about the best way to address the cross-cultural needs of differing groups who experience disparities. The health of children with challenges or disabilities and their health and health literacy levels also need additional research. Research can better inform stakeholders to create or strengthen successful stakeholder groups that share values related to cross-cultural and disability inclusion, and to build on students' assets.

8. Taking Action: The Path Forward

The chapter's authors have provided a body of knowledge of policies, programs, and resources. The chapter's authors have cited opportunities and challenges as background to the work needed ahead to de-silo HE, HC, and HL to provide for the serious and complex health needs of the K-12 population. The intent, going forward, is to engage all stakeholders, internal and external, to build the skills and abilities of young people, as they mature, to understand how to promote health and wellness throughout their lives. To build upon the often currently fragmented strengths of diverse partners through conscious and conscientious collaboration is a key to successful health improvement.

In the K-12 health environment., the chapter's authors suggest true and effective collaboration is paramount to future success. Models such as the WSCC model, the internal and external stakeholders, and the health improvement targets, might be best organized by developing a timeline. The timeline of immediate, intermediate, and long-term goals and objectives should be established at the beginning of any new K-12 health collaboration. To maintain momentum, the goals should be outlined and shared with all partners at the beginning of any effort with planned, frequent re-evaluation of needs, partners, and commitments. Examples of immediate, intermediate, and long-term goals and objectives are provided immediately below.

8.1. Immediate Goals

The chapter's authors emphasize that successful collaborations prioritize needs, understand multiple audiences (including the children, the professionals and the organizations), and need to be modeled on evidence-based research. The collaborations that are focused on opportunities and challenges in the *specific* environment can help to create and sustain effective programs. Collaborations for health education in the schools should be as inclusive and representative as possible.

The chapter's authors also suggest a 360-degree view of (a) potential people, (b) student needs, (c) available resources, and (d) timelines. Some tapped resources should include location, expertise, and training, to form a much broader agenda than just financial support. Efforts that use formative evaluation and plans for continuing evaluation in their immediate goals (with revisions as needed) should encourage incremental improvement and help participants stay focused. As collaborators initiate a project, process and impact evaluation planning should be embedded. The chapter's authors emphasize that overlooking assessment planning often fosters failure.

A 360-degree view is of a collaborative community of practice that reviews evidence-based examples and decides together how to appropriately integrate them into plans. A collaborative community of practice should share its knowledge using or creating an effective, accessible, and sustainable communication tool that meets immediate and subsequent goals for all collaborators. As visualized in the WSCC model, the responsibility for success should be shared and not pigeonholed into a single role.

8.2. Intermediate Goals

The chapter's authors suggest intermediate goals often include expanding partnerships, an initial evaluation of efforts to improve the quality of resources created, a needs assessment of the individuals delivering messages, as well as a determination of the usefulness to the children (based on their ages and needs). The specific goals for efforts to support the K-12 population include principles of understanding disease mechanisms, the ability of K-12 students to problem solve about health, and improve their decision-making. The latter should help children and youth develop their ability to advocate for their own health by effectively communicating about health choices in their school and community environments. Boosting self-efficacy for K-12 youngsters should remain the focus of health education/health literacy efforts. The latter should transform into similar self-efficacy as adults.

8.3. Long-term Goals

The chapter's authors suggest long-term goals include the prevention or reduction of disease and illness for lifelong health and wellness and the elimination of health knowledge disparities to address social injustice. The path to achieve these goals is suggested by research about effective and meaningful health education of young people within K-12 school and community settings. The idea of the whole child and a whole community standard can be reinforced through the convergence of continuous integration of health education, health communication, and health literacy leading to better health decisions, greater understanding of risk, and knowledge and skills for disease prevention—to enjoy lives that are longer, healthier, and more productive.

8.4. How to Use This Chapter

Health literacy students, practitioners, and/or scholars can use this chapter to better understand shared and interconnected K-12 health literacy goals for health educators, health communicators, as well as health literacy researchers and practitioners. This chapter explores a combined evidence base across disciplines for the benefits of collaborative thought, dialogue, experience, and research. Promoting a healthy population depends upon a careful and thoughtful integration of what all stakeholders have learned and will continue to learn and share. HE, HC and HL each have provide track records for appropriate health information to advance youth learning, empowerment, informed decision-making, and behavior change. However, the scholarship across the fields remains siloed. This chapter promotes efforts to work more collaboratively within youth educational and health enterprises.

9. Conclusion

The chapter's authors suggest health education, health communication, and health literacy collaborations must be sensitive to the changing environment of health threats to youth. The chapter's authors encourage clear understanding of roles of professionals and community members to synthesize learning about health for K-12 children. The engagement of all stakeholders is foundational to continuously refresh and share knowledge for quality improvement in programs and systems. Dissemination must include formal sharing of what does or does not work following fundamental principles of diffusion of information and fostering of appropriate innovation. The chapter's authors urge continued infusion of knowledge and quality improvement.

Progress in health education for K-12 students will require powerful collaboration across HE, HL, and HC. We need to make further progress to measure knowledge growth among children and the application of their knowledge to health and behaviors. The ability to communicate and advocate for one's own health becomes critical within a young person's school years. Staying alert to the opportunities to build health literate organizations and institutions that support health education (using the skills and tools of health communication) can deter serious challenges such as obesity, tobacco, e-cigarettes, injuries, infectious diseases, opioids, suicide, or yet to be recognized dangers. Collaboration is imperative. True social justice includes the reduction of disease and the elimination of health disparities-during the creation of 'teachable moments' for K-12 students.

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Nurturing Context: TRACE, the Arts, Medical Practice, and Health Literacy

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Abstract. This chapter builds upon prior research on the interconnectedness of context to content as it relates to health and health literacy. The authors focus on the use of the arts as a novel way to engage with and to promote health and health communication.

Most published efforts exploring the humanities and health emphasize how healthcare practitioners can enhance their clinical skills, promote wellness, and prevent burnout through engagement with the arts. The current chapter adds how the arts inform us about health, and more broadly, the lessons to be learned from appreciating multidimensional contexts. The authors underscore the role of the arts to address context and introduce how the arts impact health literacy. The authors provide an overview of TRACE, a unique pedagogical program that explores both the content and context communicated via the arts, with a focus on lessons for medicine and health, including health literacy. The chapter suggests enhanced provider apperception via arts exposure has implications to improve clinical practice and health literacy.

Keywords. Health literacy, the arts, context, content

1. Introduction

This chapter introduces a pedagogical program developed almost two decades ago by one of the authors [1]. The program, offered through Emory University's The Renaissance Academy at the Center for Ethics (TRACE), is a curricular immersion that encourages learners to glean lessons related to what the arts communicate as well as how arts advance the role – and understanding – of context and individual apperception. The authors participated as students and faculty in TRACE, which helps participants engage with the content communicated about health through the arts [1]. The latter experience develops an appreciation of the unique role the arts play in defining and utilizing context to communicate about health.

In this chapter, the arts are operationally defined as fine or classical art without bias against popular culture that use drawing, painting, photography, sculpture, music, dance, theater, film, video, print and broadcast media as communication mediums. Apperception is operationally defined as one's ability to monitor the external world and simultaneously reconsider one's observations, knowledge, understanding of history,

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interpretation of cultural and professional paradigms, ideological framing, and social mores; understanding of qualitative and quantitative evidence, beliefs (or internalized truths), feelings, impressions, emotions, preferences, hunches, expectations, notions, and opinions [2]. Apperception (or the expansion of one's apperceptive mass or perceptual lens) is seen as an elastic skill integral to human development, which can be nurtured via formal education and informal learning [2].

As part of TRACE, medical students and undergraduate students (accompanied by practicing physicians and professionals from law, public health, and industry) engage in an intensive cultural immersion in Italy. The course explores themes of professionalism, compassion, and health through in-depth analysis of Italian culture, medical history, and the arts. Site specific visits and reflective writing foster an understanding of health-related context, and multidisciplinary discussions highlight the role of the arts in engaging context to communicate messages relevant to health and medicine.

Prior to departure, students and participants are introduced to visual literacy using a Visual Thinking Strategies (VTS)-inspired curriculum, which provides a well-established method for interacting with visual content [3]. There are three central questions to answer when employing this method: *What is going on in this picture? What am I seeing that is making me say that? What more can I find [3, 4]?* To articulate their experiences, students are asked to write a journal using a "See, Think, Wonder" framework, which echoes VTS with the following questions: What do you see? What do you think about what you see? What do you wonder? [4]. Students also are exposed to the Toledo Museum of Art's 'Art of Seeing Art' curriculum which builds upon the basic framework of VTS, but adds a vocabulary and analytical basis to deconstruct an image [5].

The authors suggest the TRACE program may be a pedagogical model to engage healthcare professionals (at all levels of training) with the arts to better relate to and ultimately communicate with patients and multidisciplinary teams in an increasingly multicultural and technologically complex health system. The authors additionally suggest the post-exposure expansion of physicians' apperceptive capabilities is consistent with at least two of health literacy's goals: a) to generate interventions that are tangible, relevant, and patient-centered and b) foster more thoughtful, interactive, and culturally competent patient-centered care [6].

The chapter provides an introduction to the prior literature about arts and health literacy, reviews selected literature about the impact of arts interventions in medicine, and notes a few studies where arts exposure is associated with improved participant understanding of specific diseases. A description of the pedagogical approaches within the TRACE program and a conclusion are provided.

2. Prior Literature about the Arts and Health Literacy

Several prior articles about the arts and health literacy provide a foundation for TRACE's pedagogical and professional training efforts as well as this chapter. In one article, Ike, Parker, and Logan emphasized the connection of context to communication and the extrapolation from understanding art to impacting health and healthcare experiences and improving health literacy [2, 7].

In a second article, Parker and Ike introduce visual literacy as an underutilized component of health literacy [7]. Parker and Ike suggest the arts reflect shared human experiences and values, and such values infuse the understanding of content [7].

Developing visual literacy through purposeful implementation of validated techniques, including VTS and other related curricula, enables healthcare practitioners to improve their ability to engage the visual world and its complexities, and by association fosters a deeper apperceptive appreciation for the contexts that are foundational to cross-cultural communications [7]. Parker and Ike suggest medicine and health are inextricably linked to culture [7]. In turn, patients and communities are more likely to engage in activities that promote wellbeing (medication compliance, exercise, community engagement, education, etc.) if content is articulated within an appropriate context [7].

In this subsequent commentary, Parker and Ike argue the arts are underutilized in understanding and communicating the contextual dimensions of perception [7]. Parker and Ike suggest efforts to preserve, revere, and study the arts reflect an appreciation for culture and human value systems [7]. Using the *Smoketown Lifeline Project* as an example, Parker and Ike argue Andrew Cozzens' sculptural installation within an impoverished community center manifests health inequity and creates a platform to discuss broader health disparities [7].

The aforementioned articles introduce a range of current efforts to promote arts appreciation within North American medical schools and residency training programs [4, 8-14]. Some arts initiatives for medical students also evaluate their impact based on a pre/post-exposure methodological framework. For example, a small prospective study by Klugman et al. suggests medical students exposure to the VTS curriculum resulted in more time devoted to patient observations and an increased vocabulary to describe clinical observations [15]. An earlier prospective (and partially randomized) study at Harvard Medical School similarly suggests exposure to an arts-based course, 'Training the Eye: Improving the Art of Physical Diagnosis', resulted in a statistically significant increase in student ability to describe and note physical exam findings [16]. Other interventions suggest diverse benefits in patient care through engagement with the arts, which in aggregate provide an emerging quantitative evidence base [4, 8-14].

Some North American medical schools also have implemented arts-based programs in an effort to train compassionate and cognizant health care workers, who understand and can navigate the mosaic of cultures providers are licensed to serve. In a short piece, 'Beyond Dr. Feel-Good': A Case for Medical Humanities in Medical Education,' Arno Kumagai, a professor of medicine at the University of Toronto and Vice Chair for Education, proposes while the arts have frequently been marginalized or simply used to prevent physician burnout and teach visual diagnostic skills, their true power is to inculcate 'excellence, compassion, and justice' in medical practice [17].

Kumagai describes five distinct ways in which engagement with the humanities improves the training of physicians [17-18]. First, Kumagai suggests the arts serve as a form of disruption [17-18]. The arts complicate and obscure commonly held beliefs and practices by presenting them in new and different lights [17-18]. As highlighted in an analogous piece, the arts 'makes strange' and "distort our perceptions of common objects, relationships, ideas, identities, or beliefs to force us to look at them anew" [17-18]. The history of art is populated with examples, such as Dadism, that attempted to redefine the perception of visual reality in the first third of the 20th century.

Kumagai adds arts and humanities teach us to pause. For clinicians, arts exposure interrupts the automaticity of much of clinical practice and requires a viewer to wrestle with ambiguity and uncertainty. Since evidence-based uncertainty is ubiquitous in clinical practice, the arts function as a tool to enhance providers' capacities to reconsider how ambiguity is perceived and communicated. This additionally improves how medicine's uncertainty is communicated, which potentially enhances patient/provider interactive health literacy.

Kumagai also explains engagement with the arts tasks providers to imagine the environment their patients inhabit [17-18]. Kumagai suggests "[the arts] help us to peel back the different layers that compose up ideas, institutions, conditions, or practices to understand them through the lens of history, ideology, and power" [17].

Kumagai adds the arts offer a means for physicians to exercise one's moral imagination, or to ponder the experience of others while paying particular attention to their innate humanity [19]. Kumagai emphasizes the role of literature to transport a reader into the mind of characters and how such acts develop a compassion and empathy for the lived experiences of others. Finally, Kumagai notes engagement with the humanities and arts enable a broader understanding of the human experience and by association "ultimately…prompt awareness of the space in which physicians care for human beings in their moments of greatest need and bear witness to fundamental changes in their patients and in themselves" [17].

In summary, the authors suggest arts exposure potentially advances a provider's apperceptive capabilities that aggregate many of the professional developmental dimensions which Kumagia cites [17-18].

3. Recent Literature: The Intersections of Art and Health

Other research about the connections between content, context, the arts, and health has focused on specific health outcomes. While the references below are a sampling of the available literature and projects, the authors selectively will summarize some recent, interesting findings.

For example, Schillinger recently suggested the effectiveness of a social and culturally cognizant mass communication campaign about the prevention of type 2 diabetes [20]. In a video intervention, entitled *The Bigger Picture,* young minority poets produced spoken word public service announcements (PSAs) for at-risk youth regarding the prevention of type 2 diabetes. The project's intent was to reframe a spike in in obesity-related type 2 diabetes among California youth within a novel socio-environmental context targeted at young minority populations. The rap-music grounded poets focused on aspects of diabetes prevention and communicated through the perspective of impacted at-risk peer adolescents.

The campaign's assessment suggests full recognition of the nine PSAs' intended public health messages ranged from 22.2% to 70% among intended audiences. On average, 43% of respondents demonstrated a comprehensive understanding of the intended message about type 2 diabetes' prevention. The use of video arts and poetry suggested: "the ability of [a] spoken word medium to make these challenges [related to diabetes education] visible and motivate action." Schillinger et. al. suggest the arts have a unique ability to "change behavioral norms and build capacity to confront the social, economic and structural factors that influence behaviors" [20].

Kirkland describes how the arts can shape physicians' perceptions and communication habits by encouraging them to critically analyze and describe a painting [21]. Kirkland aptly quotes Anaïs Nin, "We don't see things as they are, we see them as we are" [21]. In other words, an individual's perception of content is directly linked to their contextual or apperceptive lens. In this example, context is linked to medical specialty, and Kirkland suggests awareness of the role of context and different approaches prompts more compassionate care [21].

Oldfield describes how a mutual interest in a music artist enabled interactions between an internist and a previously disengaged, uncommunicative teen patient [22]. Through discussion of the artist's lyrics addressing structural conflicts and equity, the patient openly discussed the social determinants of health he constantly struggled to overcome. Oldfield suggests openness to the art one appreciates as well as to the art valued by patients (and cultural communities) represents an underutilized strategy to enhance patient-centered care and communication [22]. Oldfield argues for arts interactions among patients and providers as "a mutual sort of health literacy" [22]. Through appreciating the context in which a patient lives, content can be communicated more effectively, which fosters better health and patient outcomes for specific medical conditions.

Thomas notes the art in medical facilities, community-created public art, and art in community spaces is associated with therapeutic health impacts [23]. Thomas notes engaging community members to paint neighborhood murals resulted in increased perception of social cohesion, neighborhood aesthetic and safety, as well as a relative decrease in stigma towards individuals with mental health and substance use problems. These findings are consistent with similar studies introduced in Ike, Parker, and Logan's chapter on health literacy and the arts [23-24].

In contrast with projects that formally assess the impact of arts interventions on target populations, additional efforts use the arts to therapeutically impact physician training as well as the emotional health of communities and military veterans. For example, the National Academies of Sciences, Engineering, and Medicine (NASEM) recently used visual art to address physician burnout in their program, "Expressions of Clinical Well-Being" [25]. The NASEM program hosted an electronic and traveling art gallery in which clinicians' displayed their experiences with burnout, resilience, and well-being [25]. The intent of the gallery was to generate conversation around these issues to encourage steps towards understanding, support, and possible solutions. The authors add such engagement enhances a provider's ability to communicate and to appreciate the varying contexts in which health services are delivered [25].

Doerries uses ancient Greek tragedies to highlight the multiple dimensions of trauma and loss to address public health and social concerns [26]. More specifically, Theater of War Productions performs Greek tragedies designed to foster a broader discussion about complex socio-cultural and public health issues. Theater of War summarizes their efforts this way:

> Theater of War Productions works with the leading film, theater, and television actors to present dramatic readings of seminal plays—from classical Greek tragedies to modern and contemporary works— followed by town hall discussions designed to confront social issues by drawing out raw and personal reactions to themes highlighted in the plays. The guided discussions underscore how the plays resonate with contemporary audiences and invite audience members to share their perspectives and experiences, and helping to break down stigmas, foster empathy, compassion, and a deeper understanding of complex issues [27].

The integration of classical Greek texts and plays with modern venues and interpretations suggests the ability of the arts to instruct across time and cultures [27]. The combined Greek tragedy/contemporary issues intervention suggests the arts can be used to bring attention to socio-cultural issues and communicate themes about complex medical policy challenges, such as health disparities [27].

Similarly, the Feast of Crispian utilizes Shakespearian theater to develop emotional resilience for post-deployment U.S. veterans [28]. In this program, U.S. veterans are paired with professional actors and taught various acting techniques including improvisation, emotional expression, and utilizing a strong stage voice. The organization's mission statement reflects these aims:

> Using the basic acting tools and techniques and the power words and stories of William Shakespeare, we help these wounded warriors to be heard and seen in the expression of their thoughts and feelings. This allows them to more easily hear, see and respect the thoughts and feelings of others, reconnecting them with their own sense of self-worth and their communities [28].

Herein, theater is utilized to heal, educate, and empower veterans to act upon the personal health challenges that occur after military service. These programs operationalize health-specific aims using directed arts-based interventions that observationally and qualitatively have emotional and physiological impacts for both participants and coordinators. In terms of health literacy, the programs also encourage health information seeking and health interactions among military peers and with providers.

Turning to a music based intervention, cellist Yo-Yo Ma recently sought to advance public dialogues about healing socio-cultural disparities and improving public health through a concert series [29]. Ma and "his team partner with artists and culture makers, cultural and community organizations, and leaders from across sectors to design conversations, collaborations, and performances. These public events and creative experiences…aspire to local relevance and global significance; they demonstrate culture's power to create positive change [and] inspire new relationships…and ask us to keep culture at the center of our efforts to build a shared future" [29].

Overall, the arts offer an underappreciated opportunity to utilize context to enhance communication and promote the prevention of specific diseases, emotional and psychological health, or create a dialogue about public health challenges. Meanwhile, the link of these efforts to health literacy includes an expanded apperceptive – patient-centered capability among providers as well as an improved capacity among health care organizations to respond to the complexities of patients and communities. The latter represent two of the platforms of contemporary health literacy research and practice [6].

4. The TRACE 2018 Colloquium: Exploring Evidence, Truth, and Wisdom Communicated through the Arts

The 2018 TRACE colloquium involved medical students, undergraduates, and professionals from the fields of medicine, ethics, law, and the humanities who journeyed together to several Italian cities including Rome, Pisa, Florence, and Siena. The 9-day colloquium uses arts immersion to help future and current physicians appreciate and understand cross-cultural biopsychosocial, economic, and cultural contexts.

Site visits and city explorations were intentionally paired with selected written works and visual art to integrate three themes: 1) communication and compassion; 2) death, dying, suffering; and 3) beauty, balance, harmony. A prior qualitative analysis by course faculty described the origins of these central themes using modified crowd-sourcing [1].

The authors view TRACE as a unique exercise to expand health professionals' apperception as well as inculcate an enduring understanding of patient and provider health literacy. The decision to focus on the contextual nature of evidence, truth, and wisdom during site visits (or apply enduring questions in diverse settings) additionally helps participants turn the consideration of foundational constructs into a habitual skill.

The following subsections describe how paintings and architecture can be utilized to challenge a health professional's apperception of three enduring clinical questions: what is evidence, what is the truth, and how does one derive wisdom when evidence and truth are equivocal.

4.1. Art and Consideration of What is Evidence?

The TRACE Colloquium first turns to the arts as a medium to explore the strengths and limits of evidence, or ask what is evidence?

The arts featured during TRACE frequently focus on the Black Death, a plague that ravaged Italy from 1347 to 1351. The visual evidence of the plague is especially well-captured in the *Trionfo della Morte (The Triumph of Death)* fresco in a remarkable cemetery in Pisa that dates from this period.

Buonamico Buffalmacco, The Triumph of Death, 1336, Pisa, Italy. [Public Domain]

Painted by Buonamico Buffalmacco in the mid-1300s shortly after the arrival of the plague in Pisa, the fresco depicts a complex scene. On the left side of the composition, those bedraggled by illness beg for death's mercy while a personification of the Grim Reaper turns instead to bring death to courtly ladies and gentlemen depicted on the right side of the composition. In essence, the fresco communicates the universality of death and its disregard for established cultural castes. At the time of horrific death, dying, and suffering, this painting communicated to the predominately illiterate citizens of Pisa a universality; the plague comes for all. It is instructive about a belief system and offers layers of complexity surrounding broader themes of death.

Despite its creation nearly seven centuries ago, the fresco remains instructive and offers its observers an opportunity to reflect. For example, TRACE participants were asked to discuss death and loss in their own professions and personal lives.

Given its setting within a monumental cemetery next to the well-known Pisa Cathedral complex (and its Leaning Tower), TRACE participants probed additional existential questions such as: What does it mean to honor the dead in times of great loss? How did the population respond? How would I have responded, and why would I respond that way? What motivates a city to construct such a beautiful and monumental structure for burial of their dead? What are the lessons of the *Triumph of Death* fresco that transcend time? Is the fresco evidence of the sense of loss, suffering, and the scale of population decline that occurred in Pisa during the Black Death? Other than newer mass mediums and data, what are some key differences between contemporary and medieval interpersonal and mass communication about death and catastrophes? Are contemporary efforts to inform impacted populations about public health emergencies occasionally culturally divisive and dysfunctional? Are the dysfunctional efforts a byproduct of health disparities and limited population health literacy?

As Pisa provided an opportunity to consider evidence about death, dying, and suffering, a hospital in Siena encouraged participants to consider themes regarding evidence, human compassion, and public communication. Santa Maria della Scala, which is Europe's oldest hospital, is located across the piazza from Siena's Grand Cathedral [30]. Built initially to care for those traveling the Via Francigena, a pilgrimage route linking Rome to Gran San Bernado, this *ospedale* later became Siena's and Europe's original healthcare institution.

As the hospital grew and acquired significant landholdings to support its mission to the poor and sick, artist Domenico di Bartolo and his workshop were charged with decorating the Pellegrinaio (central entrance hall) which served as a vestibule to welcome visitors, volunteers, and the city's needy populations.

Painted in the early 15th century shortly after the Black Death wiped out much of the Italian (and European) population, the fresco cycle communicates the function of the hospital and its role in caring for pilgrims, orphans, the poor, and the sick. The diverse panels depict the founding of the hospital, the care for orphans by wet nurses, the feeding of pilgrims at a communal dining table, and the intimate care for the dying and sick.

The caring, provision, receiving, and other messages about healing are expertly conveyed. The content is fundamentally linked to Siena's 15th century as well as its enduring cultural values and belief systems about life, death, health, and public welfare. The contemporary efforts to preserve the fresco cycles through charitable donations and the building's conversion into a museum suggest the paintings' capacity to communicate through time and space.

The images portray themes of hospitality and compassion and serve as one of the earliest known efforts to suggest the centrality of individual and public health to social welfare, the needed capacity for health care providers to utilize evidence to benefit individuals and society, and the importance of providers and citizens to care about the welfare of others. In short, the frescos provide qualitative evidence regarding what values should underlie health care and the appropriate role for society to care for the sick, disabled, and underprivileged.

The TRACE participants who engaged the Siena fresco cycles were asked to ponder an array of questions related to their own respective institutions, such as: outside of mission statements and websites, are there additional physical manifestations of your hospital's value system? If so, is this clear to providers, patients, or both? Why does communicating institutional values provide an opportunity to elevate health literacy as well as demonstrate institutional goodwill? What can one of the world's first public hospitals teach us about the principles of hospitality and healing?

Albeit challenging to answer, the Siena frescos provided a means to discuss some of the current sociocultural challenges for health care institutions as well as their role in improving medical practice and contributing to their surrounding communities. The Siena frescos provided an opportunity to discuss the need for clinical institutions to integrate health literacy principles within routine practice and outreach to patients, caregivers, and communities. The frescos also provided a means for participants to discuss the role of art in community and individual healing and the importance of provider humility and socio-cultural compassion.

Domenico di Bartolo and others, Pellegrinaio of Santa Maria Della Scala, Siena, Italy. Early 14th Century. Museum. (Shared with Permission)

In addition to exploring the role of hospitals and health systems in medieval Italy, TRACE explored other civic institutions such as orphanages. Humanism flourished in 14th and 15th century Florence and the latter cultural movement fostered a new interest in civic and social responsibilities that spawned the start of public orphanages (among other advances).

The 'Spedale degli Innocenti (Hospital of the Innocents), an orphanage in Florence, illustrates civic responsibilities, the plague's impact, and a response to social stigma and dysfunction. Following the Black Death, Florence's orphans increased significantly. In a 1419 effort to meet a growing demand, the civic government and the Silk Guild contracted Brunelleschi, an architect renowned for his work on Florence's Duomo Cathedral, to design the 'Spedale.'

Utilizing a restrained design that blended both the Romanesque and Gothic architectural vocabularies, Brunelleschi created a system of repeating arches that evokes harmony and balance – the height of each arch is directly equal to the distance between columns. Between each arch, spandrels were decorated with tondi that were later filled with porcelain sculptures of swaddled infants by Andrea della Robbia. Underneath the arched portico was a ‘wheel’ that enabled families unable to care for their infants to anonymously deposit their children into the care of the orphanage’s staff.

Filippo Brunelleschi, Hospital of the Innocents, early 15th century, Florence Italy. (Public Domain)

At this site, participants were asked to discuss the architectural principle of ‘form meets function’ and the role of design to communicate the values and legacies of social institutions and their civic sponsors. The Florentian structure, through its architectural vocabulary and civic purpose, also suggests the importance of civic duties in times of community strife. The restrained use of inexpensive but elegant building materials reinforces frugality, but not at the cost of beauty and harmony. The building’s preservation and conversion to a museum, which was completed in 2016, suggests the enduring values the structure has conveyed through seven centuries of Florence’s history.

In terms of evidence, the orphanage additionally conveys a 15th century understanding of the need to counter family/personal stigma via a social commitment to care for the city’s children.

Using the site as inspiration, TRACE participants were asked to consider human experiences in times of catastrophe. What evidence does the orphanage structure suggest about medieval Italy’s frailty during a time of great strife? Similarly, participants were asked to consider more recent, significant international epidemics such as the Spanish Flu of 1919 and the ongoing Ebola epidemic in West Africa. Participants also discussed

Camus' *The Plague*, which describes the impact of the same disease in a fictional mid-20th century Algerian village.

Subsequent TRACE conversations included the scarcity and shortages of clinical essentials, such as vaccinations, tertiary medical care, and medications both today and in past centuries. Some of the other discussed issues included: How does the Florentine structure provide evidence about how people responded to the plague 700 years ago? How do we respond to contemporary catastrophes? What is a health providers' duty to humanity, and has this changed with time and circumstances? How should health care professionals attempt to overcome social stigma when there is cultural apathy or rejection of clinical evidence that adversely impacts individual and public health? To what extent should medical professionals be vigilant when popular efforts represent threats to public health, such as current anti-vaccination factions, or the prevalence of easily preventable diseases that are exacerbated by routine behaviors such as an imbalanced diet, smoking, lack of exercise, and substance abuse?

> Utilizing the plague to explore enduring themes, Italy's architectural and artistic treasures serve as primary sources to explore the nature of qualitative, observational evidence and how this differs from the quantitative evidence that undergirds contemporary clinical practice. The art raises questions about the enduring aspects of historical evidence and learning from history. The experiences additionally raise questions about the roles and responsibilities of medical professionals and the importance of improving the public understanding of individual and public health, which are important dimensions of health literacy [31].

4.2. Art and Consideration of What is Truth?

The arts in Italy enabled consideration of the nature of enduring truths as well as the strengths and limits of contemporary clinical protocols derived from evidence-based data. The content and context provided by the aforementioned Pisa, Florence, and other examples raise consideration of diverse truths among professions and religions, as well as the need for a tolerance of ambiguity to assess and communicate multidimensional social and clinical challenges.

More specifically, TRACE participants were exposed to Plato's Allegory of the Cave from *The Republic* because of its allegorical exploration of truth's complexity and its link to context and apperception.

The hospital frescos in Siena and Pisa suggested the artists' understanding of the contrasts and paradoxes between religious and professional truths, as well as the enduring limits of the later to provide enlightened responses during public emergencies. For example, the Siena and Pisa paintings posit divine intervention was sufficient to explain the death and destruction that occurred during Italy's medieval plague, while also capturing the secular challenges health providers (and family members) faced during an overwhelming tragedy and civic emergency.

In other words, the paintings (and Camus' writing in *The Plague*) suggested how perceived truth's differing dimensions are impacted by religion as well as by contemporary cultural and professional assumptions and protocols.

For TRACE participants, the arts exposure also raised specific discussions about the differences in the determination of truth among diverse professions. TRACE visits included discussions of how evidence and fact are perceived differently among attorneys, journalists, scientists, medical professionals, and clergy, and how these sometimes contrast (or are consistent) with cultural beliefs. The discussion often triggered insights among participants about the importance of personal and professional information seeking, the need to occasionally challenge professional predispositions, and the need to challenge social norms. As participants considered the intricacies of truth, questions emerged such as: How does evidence relate to and inform truth? Is truth eternal, or relevant to time and place? What is the price of being on the side of truth? How is truth related to health?

4.3. Art and Apperception: Deriving Wisdom When Evidence and Truth are Equivocal

The arts visited during TRACE also depicted liminality, or the challenging leap of faith health professionals are forced to make to derive contextual wisdom (the best available response) although clinical evidence and larger truths frequently are equivocal, uncertain, ambiguous, or conflicting.

To illustrate this flow of decision making and to consider the nature of wisdom, TRACE participants engaged with art that represented a liminal space. A liminal space is “a threshold, a crossing, an in-between state that is neither here nor there” [32].

Liminality was operationalized by a 5th century BC sarcophagus now housed in an archaeological museum in Pasetum, Italy. Intricately decorated with frescoes on its internal surfaces, the sarcophagus’ inner lid faces the deceased so it cannot be viewed externally by onlookers. The frescos depict the image of a man suspended in flight between a diving pier and a body of water below. His journey is thought to represent the voyage from the world of the living to a spiritual home amongst the dead.

However, the deceased is presented with the unknown space between life and death rather than either of their realities. The deceased is suspended in flight for eternity. The conundrum is a metaphor for liminal space and the unpredictability found in the limbo where contemporary professional and humane decisions often arise.

While the Pasetrum sarcophagus represents limbo, it also provides a space to find wisdom in spite of prevalent uncertainty. In addition, the Pasetrum sarcophagus metaphorically suggests: a) the self-reflective space health professionals need to nurture so they are considerate during difficult decisions; and b) the need to empower patients and caregivers to overcome the conundrum of equivocal health care decisions. The centrality of patient and caregiver empowerment often are presented as foundations to enhance health literacy and improve specific patient health outcomes [33, 34].

5. Conclusion

The authors suggest the TRACE program is a pedagogical model to engage healthcare professionals (at all levels of training) with the arts to better relate to and ultimately communicate with patients and multidisciplinary teams in an increasingly multicultural and technologically complex health system.

The aggregate experiences during TRACE reflect all five of Kumagai’s aforementioned goals to engage the meaningful professional development of physicians and other health care providers. TRACE provides an intervention that directly impacts many of apperception’s multidimensional levels, which ultimately fosters a provider’s professional growth and development.

Through an appreciation of culture and context, a physician’s ability to communicate across time and cultural boundaries improves, becomes more sincere, and ultimately, more humane. The authors posit that dialogues based on mutual understandings of context enhance patient-centered care. As technology increasingly dominates the cultural landscape of the clinical practice of medicine in traditional healthcare settings, novel efforts become correspondingly exigent to maintain and enhance meaningful interpersonal communications.

As the arts build apperception, or the capacity to interconnect context to immediate content and immediate experience, TRACE provides a range of interventions that imbue contextualization. The authors suggest similar experiences with the arts can occur in many communities, as health professionals, educators, patients, and others find appropriate catalysts.

Finally, the authors suggest TRACE fosters at least two of health literacy's primary goals: a) to generate care that is tangible, relevant, and patient-centered and b) to foster more thoughtful, interactive, culturally competent, patient-centered care. To advance health literacy, there is no substitute for multidimensionally trained providers and similar efforts to engage and empower patients, caregivers, and surrounding communities.

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Health Literacy's Impact On Health Law & Policy

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Abstract. Law and policy are an integral part of any health system, in the U.S. and abroad. This chapter discusses the trend towards incorporating health literacy or patient understanding requirements into the varied laws and policies that impact all parts of healthcare. After reading this chapter, healthcare providers, hospital executives, biomedical researchers, industry sponsors, and public health professionals will better understand the regulatory trend towards health literacy and how they can use these sources of authority to advocate for change in their respective fields.

Keywords. Health literacy, plain language, regulations, law, health policy, informed consent, medical malpractice, Common Rule, public policy, clinical trials

1. Introduction

Although a frequently used used definition in the U.S. focuses health literacy on a person's ability to "obtain, process, and understand" health information, the health care delivery system provides additional burdens to patients, caregivers, and consumers [1]. An individual may be fully capable of handling the demands of a family practice, but struggle in a large hospital setting, when trying to understand a newly diagnosed condition, or when navigating health insurance coverage. Thus, health literacy is situational and, in part, is determined by the organizational, informational, and administrative burdens placed on patients.

Unfortunately, the laws, policies, and regulations that address the healthcare system in many countries often increase the challenges placed on those using the system. In the United Kingdom, the burdens are largely determined by the government itself - the services covered, the provider reimbursement, the way innovations are approved, and the notices and paperwork required are largely determined by government laws, policies, and regulations [2]. In the United States, the competing interests of serving the public interest while also fostering innovation and free-market capitalism further complicate the healthcare system.

In the U.S., the executive, legislative, and judicial branches of government all help determine how the healthcare system functions, yet many of the services, actions, and innovations themselves often are delivered by for-profit or non-profit entities [3]. Hence, the laws, policies, and regulations that govern the U.S. system help determine how the entities that undergird the system operate and engage with the people they serve. No

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matter the type of healthcare delivery model used in a country, the laws, policies, and regulations in place determine how difficult the system will be for people to understand and use.

Because of this, any systemic effort to improve health literacy or reduce the burdens placed on individuals using the health system should consider its legal or policy ramifications. Any health literacy initiative can be strengthened by referencing laws or regulations that mandate or support the effort. Also, even if no law directly mandates it, referencing government policy that supports the effort helps it gain traction. Yet many health literacy initiatives fail to capitalize on the legal or policy implications involved to further promote the effort. Partly, this is because very few resources have been published that attempt to compile or explain the laws, regulations, and policies that promote health literacy or patient understanding [4].

This chapter addresses the latter void by exploring various laws, regulations, and policies that either mention health literacy directly or require information to be communicated in a clear, understandable manner. While many of these do not specifically use the term 'health literacy,' the core concepts involved seek to promote patient understanding or engagement. Through this expansive view of health literacy, this chapter will clarify how health literacy research and practice have influenced laws, regulations, and health policy which have been crafted during the past decade.

Specifically, this chapter begins by discussing major policy initiatives that promote health literacy, including national action plans from the U.S., Germany, and Scotland. It also discusses policies from the World Health Organization, the U.S. Department of Health & Human Services, the Center for Disease Control, and the Food & Drug Administration. This chapter then, introduces the major U.S. federal laws and regulations that promote health literacy principles or require that information be explained in clear, understandable ways. Among other things, the chapter explores certain provisions of the U.S. Affordable Care Act, regulations from the U.S. Center for Medicare & Medicaid (CMS), and the recently amended U.S. Common Rule requirements to conduct human subjects research. Following this, the chapter explores how certain aspects of the U.S. common law relate to health literacy, and introduces selected state regulations and policies that require or support health-literate communication. While this chapter primarily covers U.S. initiatives, is concludes by discussing selected laws from other countries that relate to health literacy and improving public understanding. The inclusion of the latter helps to demonstrate a global trend towards reducing the burdens placed on people using health systems.

This chapter does not attempt to cover all law and policy; nor does it purport to cover any law or policy in great detail. To do so would require a multi-volume tome, as many U.S. regulations are themselves thousands of pages. Instead, the point of discussing the various laws and policies is to help build a regulatory foundation of support for health literacy initiatives. To that end, the sections in this chapter include advice on how health literacy advocates can use the information to advance health literacy initiatives within their respective organizations.

2. The Difference Between Law and Policy

This chapter discusses both laws related to health literacy and policies that support efforts to improve health literacy or reduce the demands placed on individuals to understand and use the health care system. However, it is first important to understand the difference between law and policy, and how each develops, to effectively use this chapter to advance health literacy efforts.

In general, laws mandate that certain actions occur or otherwise incentivize certain actions, while policies (or public policy in a government context) help set the goals and objectives that an agency or organization strives to achieve [5]. Despite these differences, there is often an interplay between law and policy – policies can help create or shape laws, and laws can help create or shape policy.

Public policy has evolved differently than laws. "Law is universal and almost as old as civilization itself" [5]. Public policy, on the other hand, began in the Nineteenth Century and was only a construct of the English language. Originally, public policy was synonymous with politics or public opinion. But, over the years, it has transformed, in a governmental context, to embody 'what the government does.' To further complicate things, the terms 'law' and 'policy' have been used interchangeably on the theory that government 'policy' sounds less authoritarian than a government 'law' or 'regulation' [5]. However, this chapter uses the term 'policy' to be an expression of what the government does or intends to do. This recognizes that policies are not mandates, but expressions of goals and objectives that shape how a government entity acts.

Throughout the world, government agencies (and their internal subparts) use policy statements to set out their goals and actions. Accordingly, health literacy advocates need to understand what these policy statements say regarding health communication and health literacy. If certain policy statements support the advocate's initiative, these can be used to further justify and advance the proposal. In contrast to laws, policy statements cannot be used to mandate a certain action. Instead, policy statements can be used to persuade - after all, shaping action is the raison d'etre to create policy statements in the first place.

On the other hand, laws can be used to influence a specific action. But not all laws apply in every instance and to every class of persons. Many laws apply only to a certain class of actors (e.g. government agencies, researchers, providers, insurers). In addition, jurisdiction matters in the law. That is, some U.S. federal laws apply only within a certain government agency, while others apply more broadly to an entire industry (e.g. the Affordable Care Act regulates most actors in the healthcare industry). Meanwhile, U.S. state laws typically apply only within that state – this means, for example, that the laws in Massachusetts can differ from the laws in Michigan. Health literacy advocates should be aware of these limitations so they do not assert that a certain law requires some action when it may not do so. Yet, even if a law does not apply to a certain industry or jurisdiction, the fact that a law exists *somewhere* can be very persuasive in advocating for change.

The term 'law' itself is a very broad and there are many types of 'laws.' This chapter refers to the following types: (1) statutes, (2) administrative rules and regulations, and (3) case law. In the U.S., all three types of law develop from different branches of government: the legislative branch creates statutes, the executive branch creates administrative rules and regulations, and the judicial branch creates case law and interprets the other types of laws. What's more, the authority to create and modify law is often an interrelated concept between the U.S.' three branches of government. For example, a state or federal legislature can create a statute that is enforced by an agency that is part of the executive branch, and the actions of both branches regarding the statute can be challenged within the judicial system. The latter checks and balances are a fundamental component of the U.S. legal system [6]. While it is not necessary to understand the nuance of how this happens, understanding the basics of each type of law discussed in this chapter can be useful for health literacy advocates.

2.1 Statutes

In the U.S., a statute is a law enacted by a legislative body, typically called a legislature. The authority of the legislature is derived from the U.S. Constitution or founding document of a state, which creates the legislative bodies and enables them to enact statutes. In the U.S., each state has a legislature and there is one federal legislature. The U.S. Senate and House of Representatives comprise the federal legislature. These legislative bodies come together to vote and enact "formal rules to govern behavior and transactions, protect individual rights and promote social policies" [7].

Hence, statutory law develops over time as new laws are passed and existing laws are amended or repealed. Many statutes create incremental changes or additions to existing law. But some statutes can create sweeping change within an industry. For instance, the Patient Protection and Affordable Care Act created sweeping changes within the U.S. healthcare industry when it was passed and signed into law in 2010.[2] However, since the ACA went into effect, both federal and state legislatures have passed statutes that further explain, fund, change, or build on the original ACA. As a result, statutes, and the process of creating and advocating for statutes, are an often overlooked, yet essential, component of the U.S. healthcare system.

2.2 Administrative Regulations

U.S. administrative regulations are a bit different than statutes, but they are necessarily intertwined with statutes. Regulations (sometimes called administrative rules or laws) are laws issued by a specific agency in government. However, the agency only has the power to create regulations if authority is given to the agency by an underlying law. For this reason, regulations are sometimes referred to as 'delegated' legislation.

U.S. governmental agencies, then, are created and empowered by statutes to carry out the duties created by the underlying law. Since U.S. government agencies are part of the executive branch, the underlying statute often gives power to a committee of the legislature, or the courts, to examine the regulations issued and review their scope and effectiveness, as well as their conformity with the general policy behind the original legislation [7]. Thus, the checks and balances of the U.S. legal system are intertwined with the status of administrative regulations.

To be sure, administrative regulations have significant important within the healthcare industry. In the U.S., the Department of Health and Human Services (HHS) is the broad, umbrella agency that governs many of the agencies that regulate healthcare. Here are a few of the major federal governmental entities that are part of HHS:

- The U.S. Food and Drug Administration (FDA)
- The Center for Disease Control (CDC)
- The Center for Medicare and Medicaid Services (CMS)
- The Health Resources & Services Administration (HRSA)
- The National Institutes of Health (NIH)

All of these entities create regulations that govern the healthcare industry. The ensuing regulation creates a maze that makes it difficult for many organizations to navigate. Many regulations create additional burdens on healthcare organizations, which ultimately lead to added burdens on the people they serve.

Conversely, some regulations actually promote patient engagement and clear health communication. Section 4 of this chapter highlights the main regulations that can be used to support health literacy initiatives.

2.3 Case Law

The last type of 'law' discussed in this chapter is case law. U.S. case law is made by courts within the judicial system rather than legislatures or administrative agencies. The latter courts write decisions after lawsuits have been filed that challenge an act.

Subsequent decisions, then, can be cited in subsequent litigation, and depending on the court that wrote the decision, the later court may be bound to follow the prior outcome [7].

The concept of following prior decisions is called *stare decisis* or case precedent. The level of the court that wrote the decision determines whether a prior case is binding (or merely persuasive). To simplify a complex topic, the general rule is that courts lower in the court hierarchy are bound by decisions from higher courts in the court hierarchy. Thus, while all lower courts must follow U.S. Supreme Court opinions on federal laws, the latter often is not the case for state-specific laws.

Of course, since many lawsuits involve different circumstances or are filed in different jurisdictions, lower courts often distinguish the original decision or modify it to fit the circumstances of the case to help get around the binding nature of the prior decision. As a result, the 'binding' nature of the case is often hard to determine. In turn, it is often best for advocates to use past cases to persuade a certain action, instead of trying to mandate it.

Broadly speaking, there are two types of U.S. case law: (1) cases that interpret and apply statutes, regulations, and rules, and (2) cases that develop the common law. The court decisions for cases involving a statute or administrative regulation help shape how the underlying law is enforced and implemented. These decisions often lead to changes in statutes or administrative regulations.

However, court decisions can advance law that is not a part of any statute or regulation. The latter is called the common law, which develops over time from written court opinions in a particular jurisdiction (i.e. a state or territory) that set out the requirements for an area of law. For example, medical malpractice and the concept of informed consent for medical procedures are concepts that originally developed through the common law – though some states now use statutes to further regulate these areas. As a result, how the common law develops through case decisions often influences future regulation in that area. It should be noted this is broad explanation of the common law, as multi-volume treatises have been written on the subject.[3]

While precedent and common law (or both types of case law) are involved in the U.S, healthcare industry, cases that interpret or apply statutes or regulations play a fundamental role in shaping the industry. Lawsuits often challenge the validity or application of a certain statute or rule to an individual or organization. The lawsuits challenging the validity of the ACA are examples of the latter type of case law.[4] Still, cases have developed a common law that governs some healthcare issues, such as the status of informed consent, and medical malpractice liability. While there have not been many cases that directly mention health literacy, there are a handful of decisions that focus on a person's lack of health understanding. Section 6 of this chapter will discuss some of these cases, largely in the context of medical malpractice and informed consent.

3. Major Policies that Promote Health Literacy Efforts

Section 3 highlights the major policy statements that promote or encourage health literacy improvement efforts. It first discusses the many national policy statements on health literacy that have been adopted around the world, to date. Then, it turns to other U.S. government policies. A caveat: this chapter does not attempt to identify all policy statements that are available, as policies often change and new policies are created. However, the policy statements identified in this chapter should provide needed support to help advance many health literacy initiatives.

3.1 National Action Plans

From a policy perspective, many government organizations, and even governments themselves, create 'action plans' that outline how to address certain issues. In 2010, the U.S. Department of Health and Human Services (HHS) published its 'National Action Plan to Improve Health Literacy,' which is a key resource for any health literacy advocate. Among other things, the action plan envisions a healthcare system that: (1) provides people with "access to accurate and actionable health information;" (2) "[d]elivers person-centered health information and services;" and (3) "[s]upports lifelong learning and skills to promote good health" [1].

Notably, the U.S. action plan was created via input from numerous U.S. government agencies and from other interest groups across all sectors of the U.S. healthcare system. The latter broad support and input can be persuasive in garnering support for new initiatives especially if a specific, proposed health-literacy initiative aligns with the action plan. Moreover, for advocates seeking ideas to improve health literacy in their organization, the national action plan provides plenty of guidance. Indeed, the Action plan contains health literacy guidance for healthcare executives, providers, health educators, persons in higher education, among many others [1].

Fortunately, the U.S. is not the only country that has created an action plan related to health literacy. The United Nations (UN) has a goal to improve global health literacy and has called "for the development of appropriate action plans to promote health literacy" [8]. The U.N's call to action has led a number of countries to develop their own plans.

For example, the Scottish Government published its first action plan focused on reducing the burdens that health systems put on individuals in 2014. In 2017, it released an updated version of the action plan titled, "Making it Easier: A Health Literacy Action Plan for Scotland" [9].

The latter plans seek to remove barriers to patient understanding and engagement and "preventing them being put there in the first place." The plans also focus on how Scotland will 'design and deliver' healthcare services in the future. The combined Scottish plan highlights three action areas: (1) increasing awareness; (2) embedding health literacy into policy and practice; and (3) changing the culture towards improving health literacy in organizations and communities [9]. Notably, the plan describes numerous Scottish programs and initiatives and explains how they improve health literacy and reduce burdens. The latter descriptions serve as useful examples for health literacy advocates seeking to advance their own efforts – whether in Scotland or in other nations.

In 2018, Germany also published a national action plan to promote health literacy [10]. The German action plan recognizes that improving health literacy is "a task for all of society which requires a systematic approach and a comprehensive, nationwide programme." To achieve this, the German plan provides 15 recommendations to improve and integrate health literacy into many aspects of society, including the education system, in public health communication, and, of course, throughout the German healthcare delivery system. Because of the breadth of these recommendations - and the supporting evidence the plan provides - health literacy advocates can use the applicable recommendations to demonstrate that local initiatives parallel issues that are addressed by other countries and organizations.

In 2019, Portugal developed a national action plan that seeks to increase and sustain health literacy levels, enhance the ability of people to navigate the Portuguese National Health Service (in the context of their everyday lives), as well as improve self-care and disease management [11].

In addition, other countries also have created national action plans or issued other major policy statements that incorporate health literacy as a priority, including[5]:

- Australia – National Statement on Health Literacy [12]
- Austria – National Health Target No. 3: Improving Population Health Literacy [13]
- China – National Plan of Health Literacy Promotion Initiatives [14]
- New Zealand – New Zealand Health Strategy 2016-2026, Actions 1-5 [15]

The aggregate (as well as individual) policy statements represent five continents, which evidences that improving health literacy is a global concern. Even outside of these formal, government-sanctioned policy statements, more countries are actively advocating to create national action plans or other policies that incorporate health literacy. These nations include: Canada; Ireland; the Netherlands; Singapore; Switzerland; and Wales [16]. More will continue to do so in the future.

Overall (from these collective of policies), health literacy advocates can likely find government-sanctioned guidance and recommendations that support most of the initiatives that they seek to advance.

3.2 Other U.S. Policies

Outside of the National Action Plan to Improve Health Literacy, many U.S. federal agencies have incorporated improving health literacy and reducing burdens on patients as a policy goal. While most of these policy statements are broad and apply to the functions of a particular agency, this section highlights the portions of those policies that relate to improving health literacy or patient understanding.

3.2.1 Healthy People 2020

Healthy People 2020 is perhaps the major public health policy statement in the U.S. A Federal Interagency Workgroup developed the statement with the collaboration of agencies within the U.S. Department of Health & Human Services (HHS) as well as diverse stakeholders. Healthy People is far reaching and covers diverse topics, from health disparities and access to healthcare to managing chronic diseases and the social determinants of health.[17]. Health literacy is a key issue within two areas: 'health and healthcare domain' - the social determinants of health and the 'health communication and health information technology' topic subareas.

The inclusion health literacy in these areas led a collaboration among government agencies to create Health Literacy Online, a toolkit to help organizations create better websites and digital health tools. [18] It also led to the development of the Health Literate Care Model, which models how health literacy can become "an organizational value infused into all aspects of planning and operations" [19]. The latter tools are evidence that policy statements impact change - they set goals and objectives that can be used to gain approval, and funding for, health literacy initiatives.

3.2.2 Strategic Plan (2018-2022) – Department of Health & Human Services

Another major policy statement that demonstrates government support for health literacy initiatives is HHS's current strategic plan [20]. Similar to Healthy People 2020, HHS's strategic plan covers many topics and health literacy is featured prominently to achieve some of HHS's strategic objectives. For example, under strategic objective 1.1, that focuses on promoting affordable health care, HHS is "working to strengthen informed consumer decision making and transparency about the cost and value of healthcare." To do so, one HHS strategy is to "[s]upport health literacy tools . . . which focus on increasing health literacy and consumer connections to healthcare, as well as partnership efforts to promote understanding of health coverage, costs, and terminology, so that consumers can choose the most appropriate, affordable health plan to receive the healthcare services they need [20]."

Health literacy also is mentioned directly in strategic objective 1.2, which focuses on expanding patient safety and reducing disparities among patients. Specifically, one listed strategy provides "health information in culturally appropriate and health-literacy-appropriate levels, and in alternative formats, such as in languages other than English, to improve access to health information [20]."

In addition, health literacy plays a prominent role to achieve strategic objective 2.1, which focuses on empowering people to live a healthier lifestyle. This part of the strategic plan recognizes that "[i]nadequate health literacy can lead Americans to make uninformed health choices and engage in behavior that can put their health at risk ... ." Health literacy is specifically mentioned in the following proposed strategies related to this objective:

- "Form public-private partnerships to promote health in academic and religious institutions, such as wellness workshops, physical activity, health literacy, and nutritional excellence programs."
- "Strengthen oral health literacy, and integrate oral health awareness into clinics, early childhood settings, and social service agencies."
- "Support programs and build partnerships with organizations (including faith-based and community organizations) that build the health literacy skills of

disadvantaged and at-risk populations, and promote proven methods of checking understanding to ensure individuals understand health and prevention information, recommendations, and risk and benefit tradeoffs [20]."

Moreover, outside of strategies that directly relate to health literacy, clear health communication to improve understanding is embedded within the HHS strategic plan's other objectives. For example, one strategy focuses on encouraging "providers to communicate effectively with patients, families, and caregivers by offering tools and resources to assist discussions centered around care and healthier living [20]." This cannot be done effectively without applying health literacy best practices when designing communications and training providers. In fact, any objective within the strategic plan that addresses health communication in some way relates to health literacy. As a result, HHS's strategic plan provides a wealth of options and strategies that advocates can use to show their initiative(s) align with HHS's goals and objectives.

3.2.3 Rural Health Strategy – Center for Medicare & Medicaid Services

Clear health communication also is a central feature of the U.S. Center for Medicare and Medicaid Services' (CMS) Rural Health Strategy. CMS developed this strategic plan to improve healthcare in rural America and apply a "rural lens to CMS programs and policies [21]." While the term 'health literacy' is not mentioned directly in CMS' strategic plan, it is an essential ingredient to carry out some of the plan's health communication objectives.

For example, objective 4 of the plan seeks to "empower patients in rural communities to make decisions about their healthcare." This cannot be done without considering the health literacy needs of rural Americans and designing health communications to suit those needs. To that end, the plan specifically aims to "[c]ollaborate with rural communication networks to develop and disseminate easy-to-understand materials to help rural patients navigate the health care system." Advocates can use this statement and the strategy itself to advocate for their own rural health improvement initiatives. To backup, if the federal government supports such initiatives, it makes it easier to convince a state government agency or other healthcare organizations to do so.

3.2.4 Health Literacy Action Plan – Center for Disease Control

Based on of the National Action Plan to Improve Health Literacy, the U.S. Centers for Disease Control and Prevention (CDC) created their own health literacy action plan [22]. The CDC has long been an advocate to improve health literacy - and some of its health literacy activities are explained elsewhere in this book. The CDC's health literacy plan charges the Office of Communications to "identify and track the most important actions the agency can take to improve health literacy." To that end, the plan empowers the CDC to do the following:

1. "Develop and disseminate health and safety information that is accurate, accessible, and actionable.
2. Integrate clear communication and health literacy in public health planning, funding, policy development, research, and evaluation.

3. Incorporate accurate, standards-based, and developmentally appropriate health and science information and curricula in educational settings from childcare through university levels." [22]

Because on these three goals, the CDC has developed a number of resources that aid health literacy advocates, practitioners, and researchers. These resources include seven online health literacy training modules for health professionals, links to research grants that relate to health literacy, and guidance to help others agencies and organizations create their own action plans. All of these resources are freely available on the health literacy page of the CDC's website: https://www.cdc.gov/healthliteracy/.

3.2.5 Strategic Plan for Risk Communication and Health Literacy – Food & Drug Administration

The U.S. Food & Drug Administration (FDA) also understands the importance of health literate communication and features it prominently within the agency's goals and objectives. A 2017 strategic plan helps the "FDA more effectively communicate the benefits and risks of FDA-regulated products" to its target audiences [23]. The plan recognizes that to improve health literate communication, the FDA must focus on the following four outcomes:

1. "Increased use of clear communication best practices and plain language in developing messages.
2. Increased development of messages and communications specifically for target audiences.
3. Improved efficiency of internal operations for writing and developing communications.
4. Improved dissemination of communications and information" [23].

To help achieve these outcomes, the plan identifies numerous activities that will help encourage and promote health literacy best practices throughout the FDA. Specifically, the plan says the FDA will develop "a cross-agency approach to track health literacy actions," and it will promote plain language by developing training for FDA staff and create Plain Language Awards [23]. Notably, the plan also promotes research on health literacy and risk communication. The plans states this "research will focus on: 1) how best to communicate information to target audiences and 2) how communications can improve the effectiveness of FDA programs [23]."

Significantly, the FDA's plan is one of the few to expressly recognize the value of message testing as an important step to improve communication effectiveness. The best way to understand how a message is perceived as seeking feedback from individuals who are as close to the target audience as possible [23]. To backup, many organizations do not appreciate the value of such message testing, so the fact the FDA acknowledges its importance can be persuasive to organizations that are regulated by the FDA, such as pharmaceutical companies, device manufacturers, biotech start-ups, and even academic medical centers. Some of the FDA's message testing and health related activities are explained elsewhere in this book.

3.2.6 Other Policy Initiatives

The policies discussed in this section are, of course, not inclusive of all government or some important non-governmental agency (NGO) initiatives. To be sure, many other government and NGO agencies value improving health literacy and health communication. For example, the National Academies of Sciences, Engineering, and Medicine established the Roundtable on Health Literacy specifically "to inform, inspire, and activate a wide variety of stakeholders to support the development, implementation, and sharing of evidence-based health literacy practices and policies [24]." Over the years, the Roundtable has helped lead the push for widespread awareness of the role health literacy plays in society.

In addition, the omission of certain policy initiatives in this chapter do not mean that they are insignificant in helping to improve health literacy and reduce organizational burdens. In fact, health literacy advocates can and should look for other policy statements that they can use to advance their efforts.

The aim of this section is to highlight a range of policies that apply to different sectors of the U.S. health system. Advocates should use any applicable statements as support for improvement initiatives either within the same agency or in organizations that are regulated by that particular agency. For example, health literacy advocates at multinational drug or device manufacturers can use the strategic plan from the FDA and the various national action plans to add policy support to their organizational initiatives. Similarly, rural health advocates can use CMS's Rural Health Strategy along with related statements in HHS's strategic plan to advance their initiatives. In the end, advocates should look for relevant policy statements from agencies that regulate their organization, regardless if they are included in this chapter. Remember, policies change as agencies adapt, so be vigilant in looking for persuasive policy support.

4. U.S. Statutes & Regulations Related to Health Literacy

While policy statements from U.S. government organizations can be persuasive in advocating for health literacy, laws and regulations from these agencies can demonstrate that a certain activity is mandated or is, at least, incentivized by the law. Accordingly, this section focuses on major U.S. statutes and administrative regulations that either directly mention health literacy or require clear, health-literate communication. While not every law or regulation is included in this section, health literacy advocates from all sectors of healthcare should find some authority to help advance their interests.

4.1 The Affordable Care Act

Perhaps the foundational legislation in the U.S. healthcare system is the Patient Protection & Affordable Care Act (ACA), commonly referred to as Obamacare [25]. It created sweeping change in nearly all facets of healthcare when it was passed and signed into law in 2010. No chapter on U.S. health laws related to health literacy would be complete without discussing the impact it has had on the U.S. health care delivery system.

Importantly, the ACA establishes a statutory definition of the term health literacy as "the degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to make appropriate health decisions [25]." This definition is consistent with a widely accepted definition of the term. Yet referencing this statutory definition, which you can find in Title V, subsection A of the Act, can be helpful when talking to attorneys or regulators about what health literacy means.

Aside from defining 'health literacy,' the ACA uses the term 'health literacy' four other times in reference to four different sectors of the health system: research, shared-decisionmaking, medication labeling, and workforce development [26]. This breadth of coverage helps provide legal support for proposed initiatives in these areas. Here is the section number and relevant language of each part of the statute:

- Sec. 3501: This section requires that certain research from the Agency on Healthcare Research & Quality be made "available to the public through multiple media and appropriate formats to reflect the varying needs of health care providers and consumers and diverse levels of health literacy."
- Sec. 3506: This section authorizes a "program to update patient decision aids to assist health care providers and patients." It states that the "[d]ecision aids must reflect varying needs of consumers and diverse levels of health literacy."
- Sec. 3507: This section focuses on how risk and benefit information is presented for prescription drugs. To determine this, subsection (b) requires the Secretary of HHS to "consult with drug manufacturers, clinicians, patients and consumers, experts in health literacy, representatives of racial and ethnic minorities, and experts in women's and pediatric health."
- Sec. 5301: This section relates to training healthcare providers. In addition to authorizing training grants for many aspects of health communication, the act specifically authorizes "training in cultural competency and health literacy." [25, 26]

Although health literacy is directly mentioned in the ACA a few times, it is important to recognize that one of the main features of the ACA is to improve communication with "consumers, patients, and communities in order to improve the access to and quality of healthcare." As a result, health literacy is indirectly related to achieving many of the goals of the ACA and complying with its legal mandates [26].

For example, health literacy is required to fulfill the requirements of section 1557 of the ACA - the non-discrimination provision of the Act. Section 1557, itself, prohibits discrimination in certain health programs and activities based on "race, color, national origin, sex, age, or disability [27]." While this seems innocuous and unrelated to health literacy, how an organization chooses to communicate with patients with disabilities or with those with limited English proficiency can amount to discrimination. In turn, in 2016 the HHS Office of Civil Rights issued a Final Rule to aid healthcare organization to comply with this requirement. Regarding limited English proficiency, the Final Rule requires many healthcare organizations to take "reasonable steps to provide meaningful access to each individual with limited English proficiency eligible to be served or likely to be encountered in their health programs and activities. In addition, covered entities are encouraged to develop and implement a language access plan [27]."

As language-access advocates know, this Final Rule provides the legal incentive needed to help justify improvement activities. Importantly, the Final Rule also provides legal recourse for individuals with limited English proficiency, who have not been communicated with in an appropriate manner. While it is impossible to track every lawsuit filed in the U.S., in 2018, a patient in Houston, Texas, may have been the first to seek damages against a provider under Section 1557 of the ACA.

The lawsuit alleges the patient was inappropriately discharged from a hospital, which led to his readmission for a stroke. Upon discharge, the patient was given English-only discharge instructions, which neither he nor his son could read and follow. The lawsuit alleges that under Section 1557, an interpreter should have been present during the discharge conversation and that he should have been given translated instructions [28]. Although we will likely never know the outcome of this case (since most lawsuits settle before trial), the publicity this lawsuit received helps advocates make the case for health literacy initiatives related to limited English proficiency. After all, few hospitals or health systems want to create the next headline.

4.2 HIPAA Notice of Privacy Practices

The other widely known healthcare legislation in the U.S. is the Health Insurance Portability and Accountability Act of 1996 (HIPAA) [29]. This broad legislation is best known for the privacy protections it affords people using the U.S. health system. One of HIPAA's main tenets is covered health organizations must provide notifications if an unauthorized person or entity gains access to the individual's protected health information. Covered organizations also must notify people what data it will collect, how it will use the data, and how it will protect that data, among other mandates. This notice is called the organization's Notice of Privacy Practices.

The format and content of these notices are mandated by a federal regulation issued by HHS. Importantly, the regulation requires that the notices be written in 'plain language' [30]. Subsequent notices must provide "a clear, user friendly explanation of individuals' rights" and explain how the organization will protect health information [31].

Despite this, many early HIPAA notices were still too difficult for many to understand [32]. To remedy, the Health Resources and Services Administration (HRSA) created a guide called, 'Plain Language Principles and Thesaurus for Making Notice of Privacy Practices More Readable' [33]. This guide gives useful advice on how to apply principles of plain language and health literacy to legal notices. As such, the guide and the plain-language requirement can be very useful for health literacy advocates looking to change how their organization creates legal notices - even those that are unrelated to HIPAA.

4.3 The Plain Writing Act of 2010

The Plain Writing Act of 2010 is a broad statute that can be particularly helpful for advocates seeking to advance health literacy improvement efforts [34]. The Act requires federal agencies to designate a 'plain language' officer, train staff on using plain language, establish procedures for ensuring compliance with the Act, and write annual compliance reports on the agency's progress. Regarding agency content itself, the Act requires that all federal agencies use plain language in any document that:

- "is necessary for obtaining any federal government benefit or service or filing taxes,
- provides information about a federal government benefit or service, or

- explains to the public how to comply with a requirement that the federal government administers or enforces." [35]

Notably, the Act does not require lawmakers to write statutes or regulations in plain language. Yet the Act encouraged U.S. President Obama to issue an Executive Order in 2011, which states the government "must ensure that regulations are accessible, consistent, written in plain language, and easy to understand" [36]. To be sure, executive orders are not legislation. They are issued by sitting presidents and only apply to entities within the executive branch of government. This explains why President Obama's order only targets regulations and not how statutes themselves are written.

Yet, all this does not mean that U.S. legal regulations are any easier to understand. The executive order set a broad goal without any specifics or a penalty for noncompliance - the Plain Writing Act also does not contain any penalty provisions.

More positively, the Act and the Executive Order have impacted the quality of content that most government agencies create and distribute. The Act led to the creation of plainlanguage.gov, an official government website to help advance plain language efforts [35]. The government also created the 'Federal Plain Language Guidelines,' which is a detailed guide to a range of strategies from clear writing principles to usability testing [37]. The Plain Writing Act also led to some concerted efforts by federal agencies to adopt plain language. For example, the FDA created a webpage called 'Plain Writing at Work' that is dedicated to the FDA's plain writing efforts. Specifically, the FDA is now committed to providing the public with 'reader-friendly information that can be easily located, understood, and acted upon' [38].

Overall, the Plain Writing Act has created momentum for plain language, which helps advocates in their efforts to improve government communication. For example, the advocacy group – the Center for Plain Language – issues report cards that grade how well various government agencies are complying with the Act's requirements.[6] This advocacy effort applies public pressure that has prompted some agencies to accelerate their compliance efforts.

Importantly, the U.S. Plain Writing Act also can be utilized by health literacy advocates. It can be used directly as a source of authority for advocates seeking to improve how a federal government agency communicates about health-related issues. For example, if an advocate works with the FDA, the Plain Writing Act (and the FDA's compliance efforts to date) can be used to advance further efforts.

Moreover, the Plain Writing Act can be used *indirectly*. To backup, many organizations are regulated by U.S. federal government agencies that must comply with the Act. Since the Plain Writing Act itself requires federal agencies to use plain language when "providing information about a federal government benefit or service," it is easier to persuade health systems, drug or device manufacturers, health insurers, and state agencies to do the same.

4.4 The Medicare Access & CHIP Reauthorization Act

The Medicare Access & CHIP Reauthorization Act (MACRA) is another broad statute that significantly impacts the U.S. healthcare system. MACRA seeks to improve the quality of care and reduce healthcare costs by incentivizing certain activities. MACRA helped advance the adoption of electronic medical records and the use of incentive payments to motivate health systems [39]. At first glance, MACRA does not appear to be related to health literacy, as the latter term does appear anywhere within the Act. Yet Table 8 of MACRA suggests a number of specific improvement activities, many of which only can be effectively implemented by using health literacy best practices.

For example, one of the care coordination activities encourages health systems to implement "practices/processes to develop regularly updated individual care plans . . . ." Relatedly, another activity encourages health systems to "engage patients, family and caregivers in developing a plan of action and prioritizing their goals for action . . . .[39]." No health system can do either of these effectively without considering consumer health literacy needs.

Indeed, there are other examples of health improvement activities that could benefit from health literacy best practices. Hence, health literacy advocates should search for MACRA recommended activities that may directly or indirectly relate to their initiatives. This may add a legal as well as financial incentive to develop the initiative.

4.5 Conditions of Participation – Center for Medicare & Medicaid Services

Another source of authority (that is easy to overlook by health literacy advocates) is CMS's Conditions of Participation (CoPs). CoPs provides conditions that healthcare organizations must meet in order to participate in the U.S. Medicare and Medicaid programs. CMS issues conditions for nearly every type of healthcare organization that provides patient care - hospitals, home-health agencies, and long-term care facilities, to name a few.[7] Put simply, if a healthcare organization wants to be reimbursed under the Medicare or Medicaid programs, it must follow CoPs' conditions.

While CoPs are comprehensive and cover many parts of healthcare, the conditions form the "foundation for improving quality and protecting the health and safety" of patients [40]. The latter goal provides opportunities for health literacy advocates to search for conditions that either require or support their initiatives.

It should be noted that CMS issues both CoPs and Conditions for Coverage (CfCs). However, due to the sheer volume of the varied conditions, only CoPs will be covered in this section. Here are summaries of three relevant conditions and explanations of how advocates can use them to advance health literacy improvement efforts.

- *CoP Critical Access Hospitals (C-320):* This condition discusses the requirements for informed consent before a patient can undergo a surgical procedure. Specifically, it recognizes that "[i]nformed consent requires that a patient have a full understanding of that to which he or she has consented. An authorization from a patient who does not understand what he/she is consenting to is not informed consent" [41]. This condition can be useful to help convince hospital administrators and attorneys to create health-literate consent forms and processes.

- *CoP Long-Term Care Facilities (F-156):* This condition outlines how long-term care facilities must informed residents of their rights and responsibilities while at the facility. It requires that residents be notified either orally or in writing "in a language that the resident understands." CMS defines this to mean communication "that is clear and understandable to each resident, to the extent possible considering impediments which may be created by the resident's health and mental status" [42]. While this definition does not use the term 'health literacy,' it implicitly requires the facility to consider factors that might inhibit understanding of the notice. As a result, this condition is useful for advocates who seek to improve communications in long-term care facilities.

- *CoP Home-Health Agencies (Sec 484.50):* Similar to long-term care, this condition requires home-health agencies to notify a patient of their rights "in a language and manner that the individual understands" [43]. It also requires this information be "provided to patients in plain language that is accessible and timely" to patients with disabilities or limited English proficiency. Interestingly, after receiving public comments about this requirement, CMS commented the goal is for patients to achieve a general understanding, which means that "patients achieve a grasp of the explanation of something and not necessarily a verbatim written translation" [43]. The latter requirement can be especially helpful for advocates to implement a teach-back initiative or for advocates who face agency resistance to providing clear medical instructions. Since agency resistance sometimes turns on the choice of language or the delivery method used, advocates can counter by highlighting CMS's explanation that the objective is to enhance understanding, not simply to use required language or a form.

4.5 Accreditation Standards

Healthcare organizations that seek reimbursement from Medicare or Medicaid can be deemed 'in compliance' with CMS' conditions through either a survey that is conducted by a state agency on behalf of CMS, or via a national accrediting agency, such as the Joint Commission. Once an organization is accredited, CMS then grants them 'federal deemed status' so the hospital/clinic qualifies to participate in Medicare or Medicaid [44].

Although accreditation standards are not 'law' per se, the impact of the standards are similar impact to CoPs for the healthcare organizations that receive a 'deemed' status. As such, accrediting agency standards and guidance can be quite persuasive for advocates who seek changes in hospitals and other health systems.

Perhaps the best source of guidance is the Joint Commission's 2007 Publication: 'Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care.' This detailed guide emphasizes the importance of the topics in the title as "important components of safe, quality care." Moreover, the guide weaves health literacy throughout its recommendations, which provide many useful points to aid advocacy efforts [45].

Specifically, the Joint Commission's guide emphasizes the importance to support a patient's ability to act on and use information. More specifically, the guide recommends using teach-back, using plain language instead of medical jargon, and using a health-literacy screening question. Regarding informed consent, the Joint Commission's Standard RI.01.03.01 explains that "informed consent is not merely a signed document. It is a process that considers patient needs and preferences, compliance with law and regulation, and patient education. Utilizing the informed consent process helps the patient to participate fully in decisions about his or her care, treatment, and services" [46]. To help meet this standard, the Joint Commission recommends "informed consent materials that meet health literacy needs. Materials should be written at a 5th grade or lower reading level. Consider revising written materials to address the health literacy needs of all patients." It also makes similar recommendations for other types of patient materials [45].

4.6 The Revised Common Rule

To this point, the laws discussed in this chapter have been related to healthcare delivery. The focus suggests the regulatory trend to improve health outcomes by embracing principles of clear health communication, cultural competency, and health literacy.

However, a development that recently occurred in the U.S.' research sector may provide a new dimension for health literacy advocates in the future. On January 19, 2019, major revisions to the U.S. Common Rule took effect, which (among other things) seek to improve understanding of those considering whether to join a research study [47]. The Secretary's Advisory Committee on Human Research Protections (SACHRP) stated that the revisions to the Common Rule consent requirements provide "an opportunity to fundamentally change and improve the consent process and the consent form in human subjects research" [48].

The revisions now require researchers to present information in a way that "facilitates the prospective subject's . . . understanding of the reasons why one might or might not want to participate" [49]. The latter requires consent be written in "language understandable to the subject or the legally authorized representative" [46]. Since the revisions directly relate to how a consent form is written, they present an opportunity to promote health literacy best practices to advance research participant understanding.

In addition, the revisions address how key materials should be highlighted and organized. The Revised Common Rule now requires consent forms "begin with a concise and focused presentation of the key information that is most likely to assist a prospective subject or legally authorized representative in understanding the reasons why one might or might not want to participate in the research" [46,49]. It is no longer acceptable to merely list requirements without regard for how people may receive or process them.

To be sure, the new 'key information' requirement is a significant change - U.S. researchers and institutional review boards currently are struggling to understand how to best adopt the new requirement. Yet, this is where health literacy best practices can help. Health literacy initiatives can help determine what information is important to potential research participants and how to present that information in ways that facilitate understanding and informed decisionmaking.

For example, while message testing and user testing are common in the health literacy realm, they are rarely used in the context of research compliance. However, the Revised Common Rule conveniently supports their use within the Preamble to the rule. It states that the "requirement that key information be concise and focused will require an assessment that is specific to a study and its informed consent" [49]. The latter 'assessment' emphasizes the importance of involving the study population at all points of the research. Because of this and the other consent-related changes to Common Rule, health-literate communication suddenly has become an integral part of research consent practices. Advocates in academic medical centers, in research compliance, or in other parts of the research industry can use the Revised Common Rule to advocate for change. The law now supports - even mandates - providing clear and well-organized information for research participants.

5. Selected U.S. State Laws Related to Health Literacy

Outside of the aforementioned federal statutes and regulations, there are numerous U.S. *state* statutes and regulations that relate to health literacy or to improving patient understanding. Yet since there are too many of these laws to discuss in this chapter, this section selectively introduces laws that apply in diverse healthcare areas. Importantly, unlike federal laws and regulations, state laws only apply to people or entities residing or conducting business in that state. Yet because healthcare organizations are increasingly multi-state organizations, these laws may have more future impact. In addition, even if a law does not apply in an advocate's state, it can be used persuasively to make the legal case to adopt a change effort.

5.1 State-based Caregiver Acts

For the past several years, the American Association of Retired Persons (AARP) has been advocating for states to pass laws that protect and promote caregiver rights. The promoted laws are called CARE Acts – short for the Caregiver, Advise, Record, Enable Act. As of 2018, at least 40 states had passed CARE Acts [50]. While the language passed in each state can differ, many state CARE Acts have requirements that directly relate to health literacy and improving public understanding.

For example, Arkansas' Lay Caregiver Act requires that a hospital "educate the caregiver concerning the aftercare of the patient in a manner that is consistent with current accepted practices and is based on the learning needs of the caregiver" [51]. This cannot be done effectively without using health literacy best practices that help determine what the caregiver needs and how best to meet them.

Delaware's CARE Act uses similar language. But it also requires that patient discharge plans reflect "the active engagement of a patient, a patient's agent, or a lay caregiver in the discharge planning process and to incorporate the goals and preferences of a patient or a patient's agent as much as possible" [51]. This, too, requires health literacy best practices to accomplish effectively.

In short, for advocates looking to advance patient and family-engagement initiatives, the cluster of CARE Acts can be a useful source of authority to support the effort. Since at least 40 states have passed these acts, many U.S. advocates will find authority specific to their state.

5.2 State Informed Consent Statutes

Unlike research consent explained above, informed consent for medical procedures is largely controlled by common law cases in each U.S. state. However, over the decades, many state legislatures have passed statutes to help determine the broad parameters of informed consent within their jurisdiction. Many of these statutes explain what must be included and help set parameters for how the information is delivered. For example, Ohio's statute says consent is not presumed to be valid if "the person executing the consent was not able to communicate effectively in spoken and written English or any other language in which the consent is written" [52]. While this does not directly mention health literacy, it clearly requires the provider to consider a patient's health literacy needs.

A similar informed consent statute in Oregon says a provider must use ‘general terms’ to describe the procedure, the methods used, the risks, and the alternative. The statute also requires a provider to “ask the patient if the patient wants a more detailed explanation” [53]. The Oregon statute does not mention how the provider should ask the question, which might lead to inartful phrasing that shames the patient for not understanding. However, advocates can use this language as authority to advocate for teach-back training for persons who seek patient consent.

Many other states have similar consent statutes, so advocates should look to the statute in their state as a source of authority to improve informed consent practices in local healthcare organizations.

5.3 Other State Laws & Administrative Rules

There are many other areas of regulation where clear health communication has been integrated into the law. For example, most U.S. states have regulations regarding the creation of an advance directive to make informed end-of-life decisions. Similar to informed consent statutes, these laws vary by state, but some states have started to require health-literate communication within their statutes. For example, in 2018, Oregon updated its advance directive laws to make its state-authorized advance directive more patient friendly. In doing so, the Oregon statute required the committee creating the form to “use plain language, such as ‘tube feeding’ and ‘life support’” instead of medical jargon [54].

State legislatures have funded other sorts of initiatives that seek to improve health communication and decisionmaking. In 2017, the Michigan legislature appropriated funds for a web-technology project to “test the cost containment capabilities of a program that uses financial incentives to improve health and health care by promoting health literacy and doctor/patient mutual accountability.” Specifically, the Michigan program aims to create a “web-based technology that links providers, beneficiaries, and health plans, in real-time, for the purpose of addressing deficiency in medical literacy and demonstrating that personal responsibility [can be] enhanced by technology” [55].

South Carolina also recently instituted a tax credit for providers who practice in ‘health enterprise zones.’ To get the tax credit, providers are required to demonstrate competency in cultural, linguistic, and health literacy . . . . [56]” Meanwhile, the funding for these types of projects helps advocates suggest support for similar efforts in their own states.

Additionally, outside of specific legislation, state agencies have begun to require plain language when conducting agency business. For example, in 2011, the California Health & Human Services Agency began requiring all health education documents (issued as part of ‘Medi-Cal’ coverage plans) should be written in plain language. While materials must score at or below the sixth-grade reading level, the guidelines permit “state-mandated legal language” to be excluded. Additionally, a ‘qualified health educator’ must review and approve health educational materials [57]. Importantly, the latter guidelines suggest a regulatory trend within local health care delivery systems that can then be used to advance similar policies and guidelines for the healthcare organizations which create educational materials.

6. U.S. Case Law Related to Health Literacy

Until now, this chapter has discussed laws that originate from the executive and legislative branches of the U.S. government that relate to health literacy or improving patient understanding. However, the judicial branch also plays an important role in interpreting and enforcing these laws. In addition, the judicial system creates and develops the common law, as explained in more detail in section 2.3 of this chapter.

Court opinions that find liability or otherwise penalize a provider or healthcare organization can be particularly effective in advocating for change. This section starts within the context of Medicaid policy by highlighting the court's role in interpreting and enforcing regulations. It then turns to the traditional common law principles of medical malpractice and informed consent. While none of the authority in this section directly mentions health literacy, the decisions all relate to clear health communication and a person's ability to comprehend medical/health information and materials. In short, it is safe to say that using health literacy best practices might have changed the outcome in all of the situations discussed immediately below.

6.1 The Court's Role in Enforcing Statutes & Regulations

As mentioned, U.S. courts play an important role in interpreting and enforcing statutes, regulations, or administrative decisions. One excellent example of a court's authority to interpret and enforce regulations occurred in 2014 in the Louisiana case of *Wells v. Kliebert* [58]. This class-action lawsuit sought to require the Louisiana Department of Health & Hospitals (LDH) to provide adequate notice of Medicare denials. The main plaintiff was a minor with complex medical needs. Her request for extended home-health services was partially denied, and the lawsuit arose because the denial did not provide an adequate explanation of the reason for the denial. The case resulted in a court-approved settlement between the parties – the class of similarly situated people receiving denials and the Louisiana Department of Health & Hospitals.

Specifically, the Wells settlement requires that Medicaid denial notices from the LDH or its contractors must "describe the specific reasons for the denial or partial denial of the requested item or service, in plain language and in sufficient detail to informed the recipient and his or her physician . . . ." [58]. The settlement also defines 'plain language' as "language that the intended audience, including individuals with limited English proficiency, can readily understand and use because the language is concise, well-organized, and follows best practices of plain-language writing." [58].

The settlement may be a major victory for patient rights and for health literacy advocates. It can be particularly effective if applied (in Medicare denials) by health insurance companies, government agencies, and other organizations within the U.S. Medicare and Medicaid system. In fact, the Wells Settlement has prompted LDH to issue templates, compliance bulletins, and a Wells Compliance Guide, all of which help explain how to clearly convey information in denial notices [59]. This material can also prove useful for those advocating for change within the latter industries.

6.2 Medical Malpractice Based on Communication Problems

Medical malpractice liability is typically an area that develops through the common law within each U.S. state. It is based on a negligence standard, which usually focuses on whether a provider or an organization meets a certain standard of care [60]. The ensuing standard of care typically develops over time as lawsuits with differing scenarios are decided. The latter does not mean statutes and regulations do not play a role in determining liability - they do. A provider or healthcare organization's failure to follow relevant statutes or regulations can result in a breach of the standard of care - this is typically called negligence per se liability.[8] As a result, failure to follow some of the state laws discussed earlier in this chapter can form the basis for medical malpractice claims.

From a common-law perspective, a patient's health literacy and an organization's efforts to clearly communicate can play a role in medical malpractice liability. In 2007, the Joint Commission reviewed data on deaths and serious injuries (sentinel events) and found that "poor communication contributed to nearly 70% of the events reported in 2005" [61]. Also, more recent research of 24,000 claims and lawsuits filed between 2009 and 2013 found that "poor patient-provider and provider-provider communication were factors that contributed to patient harm in 30% of the cases under review, with communication problems contributing to incurred losses of $1.7 billion" [62]. While published case law discussing health-literacy related communication problems is limited, the courts that have addressed it consider "whether malpractice can arise when there is poor provider communication in gathering information and giving the patient enough information to appreciate the severity of the condition" [60,63]. In turn, malpractice attorneys can use this precedent, coupled with research that shows the prevalence of communication errors and limited health literacy, to help advocate to redefine the standard of care in medical malpractice cases involving communication errors. In this way, health literacy becomes a sword that can be used to motivate healthcare organizations to act.

Simultaneously, health literacy also can be used as a shield to better protect healthcare organizations from lawsuits, which is what the Communication and Optimal Resolution (CANDOR) system was designed to do. Specifically, the CANDOR system was developed to reduce liability costs for healthcare organizations, while increasing patient safety outcomes, and improving patient engagement through ethical, effective error communication. The model was premised on replacing a previous 'deny and defend' mentality that health organizations often employed when errors occurred with a system that acknowledges and addresses the errors. The original CANDOR pilot programs were so successful that the U.S. Agency for Healthcare Research & Quality created a CANDOR toolkit to help other healthcare organizations adopt the model [64]. While the toolkit itself does not mention health literacy, it directly relates to a clear, transparent communication of errors, which only can be effective via the use of health literacy best practices. As such, advocates can use this tool to promote efforts to improve how an organization communicates about bad news or medical errors, while also reducing legal liability.

6.3 Informed Consent Claims and Common Law

Of course, case law itself can be used as authority to advocate for change - particularly in the realm of informed consent. Prior sections of this chapter have discussed efforts to regulate informed consent practices in specific healthcare areas. For research consent (as explained in section 4.6), government regulation controls the ethical conduct of human subjects research. In fact, it is fair to say that addressing research consent has become a byproduct of regulations and regulatory oversight.

Conversely, informed consent *for medical treatment* is rooted in the common law, or the body of law developed over time as lawsuits were filed and cases were decided. While state governments have begun to regulate informed consent within medical treatment, it predominantly remains a common law concept (where court decisions play a central role).

Informed consent for medical treatment has evolved into a negligence-based malpractice claim that focuses on ensuring that a patient receives enough information to be able to make an informed decision. The law typically requires that patients be told about what happens in the procedure itself, its risks, its benefits, and the alternatives. [60]. Since informed consent has evolved to be malpractice based, the standard of care is important in deciding the outcome. Two different standards exist for determining what is necessary for informed consent: a physician-based standard and a patient-based standard.

A breach under the physician-based standard is measured by what "a reasonably prudent practitioner of the same skill" would disclose, while a breach under the patient-based standard looks at what "a reasonable patient would consider material in making a decision" [60]. Each state legal system determines what standard it will adopt; to date, there is almost a 50/50 split among U.S. states.

To be sure, the patient-based standard is more easily connected to health literacy efforts because health literacy research provides more information what a "reasonable patient" would understand. Advocates can use the research data to demonstrate what the average U.S. adult struggles to understand. Thus, health literacy can also be a sword in advancing consent efforts in this context.

Yet health literacy-based arguments also can be helpful in the states that adopted the physician-based standard. As this chapter has helped define, many government healthcare agencies and accreditors know the importance of health literacy and have issued supportive policy statements or standards. These help define what a "reasonably prudent practitioner" would do, which directly impacts the standard of care required. As a result, healthcare organizations that embrace the health literacy best practices supported by U.S. federal agencies and accreditors can better shield themselves from liability as the standard of care shifts over time.

Regarding specific consent case law related to health literacy, a number of cases have focused on whether consent information was communicated in an understandable manner. In 2000, the Oregon Supreme Court decided a case that helped interpret the Oregon informed consent statute discussed in section 5.2. In *Macy v. Blatchford*, the plaintiff challenged the inform consent that occurred before the plaintiff had surgery to remove an ovary and her uterus [65]. The plaintiff claimed the surgeon did not adequately advise her of options to surgery and she did not understand the surgeon's explanation prior to the surgery.

Under the physician-based standard, the Oregon Supreme Court said a "physician's failure to 'advise' of treatment alternatives may arise solely out of a physician's silence, but it also may arise in circumstances when the physician mouths the words to a patient who, for whatever reason, at that time lacks the capacity to listen to or to understand the significance of what is being said." The court further said an 'explanation' is "something that explains or that results from the act or process of explaining [65]." The decision's reasoning suggests the court found a rationale to explain treatment consent information is to ensure that patients understand information so they can better decide whether to agree to the recommended treatment. In turn, the decision is highly consistent with health literacy best practices, even though the court never used the latter term.

Next, courts in states that use the patient-based standard have examined whether the consent information provided was understandable. In *Hidding v. Williams* (a Louisiana case), a patient sued for malpractice claiming a lack of informed consent before undergoing a laminectomy. The doctor warned the patient that surgery could result in a "loss of function of body organs," but did not elaborate or attempt to further educate the patient about this risk. The court noted the patient only had a sixth- grade education, minimal reading skills, and that his wife regularly accompanied him because he was afraid that he would miss important information. Based on this, the court found the physician's limited warning was not specific or clear enough, and that "[a]n ordinary layperson would not gather that he or she is [being] asked to encounter the specific material risk of being rendered permanently incontinent through loss of bladder control [66]."

Moreover, courts have held that the inability to read a consent form, a lack of understanding of medical terminology, and a rushed consent process can invalidate a patient's consent. In *Quintanilla v. Dunkleman* (a 2005 case from the California Court of Appeals), the plaintiff was told to sign and initial a consent form in Spanish, which she could not read even though she spoke Spanish. The plantiff did not read the documents and did not ask what she was signing. She also did not know the meaning of certain medical terms (e.g. lesion, excision, laparoscopy). Nevertheless, she signed the forms without receiving an explanation [67]. The court held the patient's inability to read the consent form invalidated her signed consent and shifted the burden to the physician to prove that informed consent was provided in some other way. The court noted that the patient, while fluent in Spanish and English, could not read Spanish and only attended school in the U.S. through the tenth grade [60,67].

From these cases, it is clear that consent is not a transactional event – it is an educational process. The cases also demonstrate that health literacy concepts play a significant role in defining the legal doctrine of informed consent.[9] Because of advancing research on the importance of health literate communication, there will continue to be cases in this area in the future. As a result, health literacy advocates can use an emerging line of case law to press for consent practices to focus on developing an educational process that explains information in ways that all patients can understand. By doing so, health literacy best practices also help shield organizations who adopt such efforts.

7. Selected International Laws Related to Health Literacy

While this chapter primarily addresses U.S. law and policy, many laws and regulations in other countries emphasize concepts related to health literacy, such as plain language, patient understanding, or clear, transparent disclosure of information. For example, South Africa has long regulated its insurance industry by requiring that all information to policyholders be "in plain language" to help "avoid uncertainty and not be misleading" [68].

Also in January 2019, Ireland proposed a Plain Language Bill that is similar to the U.S. Plain Writing Act of 2010. The proposed Irish law requires that "every government department and State body must use plain writing in every new and updated document it produces for the public. This means every department and State body in Ireland must make sure that every old document it revises is only released after it has been written or revised in plain language" [69].

Moreover, two significant European Union (EU) laws have impacted the interpretation and use of clear health communication. First, on May 25, 2018, the EU's General Data Protection Regulation (GDPR) went into effect to enhance privacy protections and better secure personal data for individuals in EU countries [68]. It was the EU's first update of its data privacy laws since 1995 and provides significantly more protections for individuals than prior privacy laws. One of those protections is the right to be clearly informed.

The official guidelines to obtain consent under GDPR says organizations "should ensure that they use clear and plain language in all cases. This means a message should be easily understandable for the average person and not only for lawyers [70]." Importantly, because children are often asked to provide personal data online, the guidelines specifically state the following: "Given that children merit specific protection, any information and communication, where processing is addressed to a child, should be in such a clear and plain language that the child can easily understand [70]." This language is about as direct as language can be to require clear, understandable communication that is audience specific. What's more, GDPR applies to any industry seeking personal data, not just the healthcare industry. As a result, GDPR can be quite useful in persuading many organizations to adopt plain language if they collect data from people who live in EU countries.

Second, the European Medicines Agency (EMA) also recently changed its laws to promote clear, transparent communication of clinical trial results. The EU's updated Clinical Trials Regulation requires, among many other things, that research sponsors provide summary results of clinical trials "in a format understandable to laypersons [71]." This plain-language summary requirement has fostered considerable discussion about how to comply with the regulation and make trial results more understandable, while simultaneously preserving the integrity of the research. The latter provides an opportunity for health literacy best practices as a central part of the solution. In fact, expert guidelines have been created that explain how to use health literacy best practices to create clinical summaries [72]. The latter development is welcome news for advocates in the research sector, who can deploy the EMA requirement to support the integration of health literacy in diverse research endeavors, even those not subject to the EMA regulation.

8. Conclusion

This chapter covers a lot of ground in an effort to show the regulatory trend of including health literacy best practices into health laws and policies. As research has helped us learn more about the importance of clear health communication, the ensuing principles are increasingly essential features of newly created health laws and policies. The additional goal of this chapter is to provide advocates in all sectors of healthcare with legal and policy arguments that can be used to advance their own improvement initiatives.

No matter the initiative, it is prudent to consider the following three points when developing legal and policy arguments.

First, look for policy statements from government agencies or other organizations that regulate or accredit your healthcare organization. Finding supportive language can help convince skeptical leaders that there is broad support for your initiative. Second, look for federal or state statutes or regulations that relate to your initiative. While ideally, there would be a specific law that mandates your initiative - in cases where none exist - the chapter notes if diverse laws and regulations do not use the term 'health literacy' they often are undergirded by health literacy best practices. So, search for laws and regulations that relate to patient understanding or clear health communication. Third, do not forget that health literacy can be a sword or shield to help aid advocacy efforts.

As the laws and policies in this chapter show, organizations can better shield themselves from liability by integrating health literacy best practices into their compliance efforts. However, health literacy also can be used offensively, as a sword, to help promote change due to the threat of liability. In short, by not adopting health literacy best practices, an organization can be subject to fines, penalties, or other money damages. From an advocacy perspective, the sword and the shield of health literacy are two sides of the same coin. In the end, combining these approaches can help strengthen the legal and policy justifications to reduce the burden a healthcare organization places on the persons served.

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Endnotes

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Health Literacy: Global Advances with a Focus Upon the Shanghai Declaration on Promoting Health in the 2030 Agenda for Sustainable Development

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Abstract. In a steadily growing effort, the world has witnessed more than three decades of effort in research, practice, and policy to socially construct what has been identified as 'health literacy. While much of the earlier work in health literacy was in the United States, the extent of scholars and practitioners is now truly global. To advance international health literacy, the chapter highlights the role of the World Health Organization (WHO) and a series of international conferences that began in 1980s. More specifically, the chapter outlines World Health Organization's overarching health literacy efforts, notes the importance of health literacy within WHO's new organization structure, briefly describes how the concept of health literacy emerged throughout a generation of the WHO's international conferences, suggests an ethical foundation for the WHO's health literacy work, and explains how the groundwork set by the WHO provides some challenges and foundations for future health literacy research and practice.

Keywords. Health literacy, World Health Organization, Sustainable international development, Ethics

1. Introduction

On one hand, there is nothing unique in human experience about the skills, abilities, and resources identified within the theories, definitions, conceptual frameworks, understandings, or rhetoric about health literacy. Those complex yet simple attributes of being alive and aware are – to varying degrees – present in nearly every act of being human.

On the other hand, the collection of ideas that have slowly cobbled together under the label of health literacy is proving to be among the strongest determinants of the quality and length of human life. Health literacy is, indeed, a life and death issue.

That is the core justification for more than three decades of effort in research, practice, and policy to socially construct what has been identified as 'health literacy' [1-4].

Such a strong attribution of life and death to health literacy is socially unfair to practitioners and proponents of literacy, plain language, education, accessibility, media literacy, public communication of science and technology, and a host of other related fields

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of activity. The shared set of skills, activities, ideas, and knowledge underpinning those fields clearly has a strong effect upon human longevity and productivity. Many of those relationships were well-grounded before health literacy emerged and, in fact, were a significant basis for the initial development of health literacy.

Nonetheless, health literacy has been highlighted in many ways and an ensuing movement continues to gain momentum around the world. In fact, even a casual observer would note that much of the impetus of health literacy has shifted outside the United States in recent years. Perhaps the field of health literacy is simply riding in the wake of the socially constructed importance of medicine while simultaneously critiquing the actions of the medical field – which also is perhaps the field of health literacy's greatest benefactor and obstacle. Ideally, a collective consensus of health literacy ultimately will prove capable of building a foundation for a cohesive and significant global movement to raise the bar on the determinants of health, health outcomes, and related costs. Time will tell.

Over time, the sheer volume of scholarly publications focused on health literacy has increased steadily. While authors from the United States created most of the academic literature early on, it seems fair, accurate, and very welcome to observe that the momentum around the world has shifted. Europe, Australia, New Zealand, and Asia are now active in addressing health literacy followed in level of activity by South America and Africa [5-6]. Importantly, the latter assessment refers only to the quantity of work, which is distinct from its quality.

At this point, it almost seems self-evident that policies addressing health literacy have progressed more rapidly outside than inside the United States. The authors are aware of no national effort to advance health literacy policy in the United States since the U.S. National Action Plan to Improve Health Literacy in 2010 [7]. Perhaps one could argue that the ongoing (at this writing) effort to create a new definition of health literacy for the Healthy People 2030 plan qualifies, but the outcomes of that effort are undetermined. By and large, however, the U.S. government and related institutions, such as the National Academies of Sciences, Engineering, and Medicine, have remained steadfast in their use of a now nearly 20-year-old definition of health literacy and the accompanying baggage of an inaccurate and outdated definition [8].

While the current political environment in the United States does not seem conducive to further advancing health literacy within national policy - many advances in policy and practice have occurred and continue to arise at local, state, and regional levels. For example, the non-profit organization Health Literacy Media, which was founded a decade ago in Missouri, now works around the world. (www.healthliteracy.media)

In comparison, an incomplete (but hopefully somewhat representative) list of policies, policy statements, and activities addressing health literacy that have emerged around the world since 2008 includes (in no order of significance):

- The Eurobarometer: Measuring health literacy across Europe
- National Statement on Health Literacy in 2014 in Australia
- Health literacy identified as one of ten health targets for Austria, drafted in 2012.
- The Austrian Ministry of Health released the policy National Health Target No. 3: Improving Population Health Literacy, 2014
- The National Plan of Health Literacy Promotion Initiatives for Chinese Citizens in 2008
- Strategic Plan on Health Literacy Promotion for Chinese Citizens (2014-2020) in 2014

- The New Zealand Health Strategy 2016–2026 addressing health literacy as key priority
- The first and second releases of Making it Easy: A Health Literacy Action Plan for Scotland in 2014 and 2017-2025
- A Vision for a Health Literate Canada: Report of the Expert Panel on Health Literacy, in 2008
- The Public Health Association of British Columbia discussion paper, An Intersectoral Approach for Improving Health Literacy for Canadians in 2012
- Many South American public health policies are mentioning health literacy as an important element for dealing with some health conditions, particularly NCDs. These efforts most often, albeit not without disagreement, call health literacy "alfabetización en salud" and are mostly concerned with language and comprehensibility
- In Chile, health literacy is mentioned in at least three National Laws: Food Labeling (Ley 20.606 de 2012), Tobacco (Ley 20.660 de 2013) and Physical Education and Health at Schools (Decreto 614 de 2014)
- In Brazil, health literacy is being considered a key-element to improve people's health (particularly regarding NCDs) in a few national health policies from the Brazilian Ministry of Health since 2010. These include the National Policy on Health Promotion, the National Policy on Primary Health Care, and the National Policy on Food and Nutrition. Also in Brazil, the Program 'Health at School' mentions health literacy. This is a national inter-sectorial policy to promote positive health behaviors at public schools
- Perú and Argentina are reported to mention "alfabetizatión en salud" in health policies but the authors could not find examples online
- Across the continent of Africa, health literacy has perhaps made the least headway to date, but there are signs a shift. For example, a national health literacy organization in Zambia (Health Literacy Zambia) was founded by medical students.

For a more complete earlier reporting of health literacy around the world, see Health Literacy Around the World Parts 1 and 2 at: https://www.ncbi.nlm.nih.gov/books/NBK202445/ and https://www.researchgate.net/publication/258201195_Health_Literacy_Around_the_World_Part_2_Health_Literacy_Efforts_Within_the_United_States_and_a_Global_Overview

A recent qualitative analysis of national health literacy policies and strategies focused on six examples from Australia, Austria, China, New Zealand, Scotland, and the United States. The analysis concludes:

- All of the six examples provide some response to perceived deficiencies in patient communication and engagement. The authors of this analysis do not mention other potential drivers, such as public health or disease prevention
- Most of the analyzed health literacy policies present health literacy as a universal challenge; some identify high priority groups
- All policies recognize the importance of health and medical professional education
- Most policies recognize health systems as a needed area for improvement
- There is 'significant variability' in linking resources to specific strategies and actions and to systems for quality and outcome monitoring

- The differences in political systems and contexts is reflected in differences in health systems and approaches to health literacy within those systems
- A lack of specificity within such policy documents poses a threat to the priority given to health literacy and the sustainability of actions to improve health literacy.

To advance international health literacy, the chapter highlights the role of the World Health Organization (WHO) and a series of international conferences that began in 1980s. More specifically, the chapter outlines the World Health Organization's overarching health literacy efforts, notes the importance of health literacy within WHO's new organization structure, briefly describes how the concept of health literacy emerged throughout a generation of the WHO's international conferences, suggests an ethical foundation for the WHO's health literacy work, and explains how the groundwork set by the WHO provides some challenges and foundations for future health literacy research and practice.

2. Health Literacy Highlights from the World Health Organization

In addition to aforementioned national efforts, the level of health literacy activity within the World Health Organization (WHO) and United Nations (UN) clearly is an overarching topic [9].

The WHO identified health literacy as an area of interest and needed activity much earlier than most national governments. For example, the WHO glossary definition produced in 1998 is often described as the first formal definition of health literacy [10].

The WHO Seventh Global Conference on Health Promotion in Nairobi in 2009 recognized the importance of health literacy and included explicit calls for action. Still, the topic did not seem to be a central driver of WHO efforts until the lead-up to the 9th Global Conference on Health Promotion held in Shanghai in 2016. That conference produced the Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development. (https://www.who.int/healthpromotion/conferences/9gchp/shanghai-declaration.pdf?ua=1) While this document's effects are still largely undetermined, it remains was one of the highest profile efforts to advance health literacy on a global stage.

Moreover, the WHO's efforts to advance health literacy are ongoing, with a strong focus coming from the European (EURO) and South East Asia (SEARO) regional offices. For example:

- Recent reporting out of the third session of the Twenty-sixth Standing Committee of the Regional Committee for Europe (SCRC), included discussion that, "since its establishment in February 2018, the WHO Action Network on Measuring Population and Organizational Health Literacy (M-POHL Network) had been very active and had garnered the involvement of 22 highly committed Member States. The Regional Office had produced a Health Evidence Network (HEN) synthesis report on existing policies and linked activities and their effectiveness for improving health literacy at national, regional and organizational levels in the Region" [11].
- SEARO also has actively produced and promoted health literacy focused efforts such as the health literacy toolkit for low and middle-income countries.

All of these recent developments are to varying extents based on the foundation created by the nine WHO sponsored global health promotion conferences that have occurred during the last four decades.

3. New World Health Organization Structure

Early in 2019, Tedros Adhanom, WHO's Director-General, announced a new organizational structure for WHO headquarters' staff [12-14].

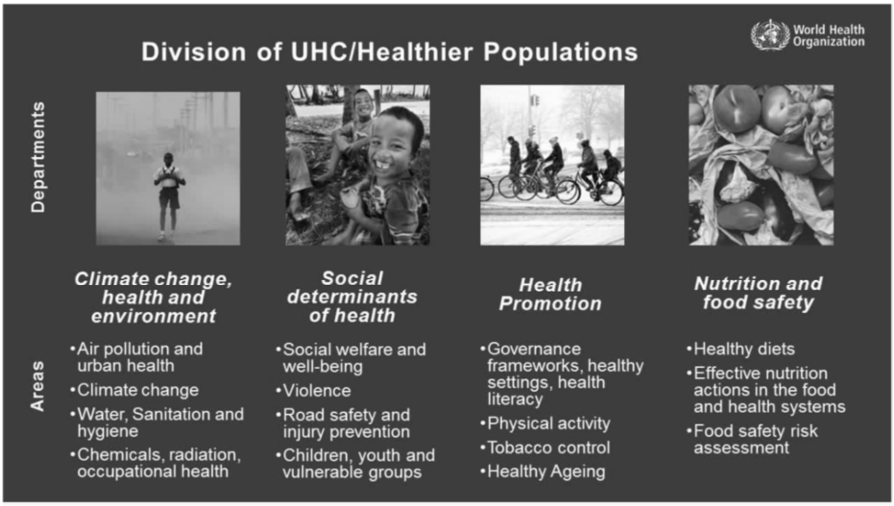
In relation to its health literacy efforts, the WHO's new organizational structure creates a new division of Healthier Populations. This new division is proposed to function as cross-cutting all WHO activities, divisions, departments, and regional offices.

The departments within this new division of Healthier Populations are:

- Climate change, health and environment
- Social determinants of health
- Health promotion
- Nutrition and food safety

The department of health promotion is described as focusing upon:

- Governance frameworks, healthy settings, health literacy
- Physical activity
- Tobacco control
- Healthy aging



World Health Organization

Division of UHC/Healthier Populations

Departments

Climate change, health and environment

- Air pollution and urban health
- Climate change
- Water, Sanitation and hygiene
- Chemicals, radiation, occupational health

Social determinants of health

- Social welfare and well-being
- Violence
- Road safety and injury prevention
- Children, youth and vulnerable groups

Health Promotion

- Governance frameworks, healthy settings, health literacy
- Physical activity
- Tobacco control
- Healthy Ageing

Nutrition and food safety

- Healthy diets
- Effective nutrition actions in the food and health systems
- Food safety risk assessment

Areas

Priorities for the WHO's new division of healthier populations

This relatively unprecedented new pillar of WHO operations was the focus of a technical briefing at the 72nd session of the World Health Assembly in Geneva [15]. The Assistant Director-General for this new division will be Dr. Naoko Yamamoto, who was most recently WHO's Assistant Director-General for Universal Health Coverage and Health Systems.

As one participant in the technical briefing at the 72nd World Health Assembly announcing the new Healthier Populations effort said, “Health is created where people live, love, work and play, and that means that we need to structure environments in a way that they are healthy and that relates to people’s wellbeing, not a narrow understanding of health.”

The development of an office focused on health promotion within the new division on Healthier Populations can only be a promising sign for further developments and applications within the field of health literacy. Clearly, the WHO staff who will advance the new effort (and can trace its roots back to the earliest of the global conferences on health promotion), provide a reservoir of experienced leadership. While the WHO staff will face challenges to fund initiatives from within WHO and from external funders (and they need to demonstrate outcomes in a rigorous evidence-based manner), the overall effort promises to develop and test new approaches to advance health literacy around the world.

4. Global Health Promotion Conferences: A Brief Health Literacy Review

At this point, any causality of change in the world’s health simply cannot be attributed to the series of global health promotion conferences or the policy statements the latter conferences have produced. While it could be designed and put in place, there is currently no existing, efficient, or cost-effective evaluation of the effects of the large and ongoing global efforts to promote health and well-being. Certainly, the fields of health promotion and health literacy have grown in parallel with steady improvements in many, but not all, health and health-related indicators of global health and wellbeing. For example, while key global indicators such as the literacy rate, life expectancy at birth, and poverty have improved since 1980, the percent of deaths caused by non-communicable (chronic) disease has steadily increased. One would hope that efforts at health promotion would largely focus on prevention of disease.

What is certain is the series of conferences, held on average about every four years, furthered a very public and large stage for issues and ideas regarding global health and wellbeing as well as for the proponents of ensuing issues and ideas. In chronological order, these conferences, the key documents they produced, and any mention of health literacy in those documents are provided:

- 1st Global Conference on Health Promotion held in Ottawa, Canada in 1986 (https://www.who.int/healthpromotion/conferences/previous/ottawa/en/)

  Produced the Ottawa Charter for Health Promotion which does not use the phrase health literacy.

- 2nd Global Conference on Health Promotion in Adelaide, Australia in 1988 (https://www.who.int/healthpromotion/conferences/previous/adelaide/en/)

  Produced the Adelaide Recommendations on Healthy Public Policy which does not use the phrase health literacy.

- 3rd Global Conference on Health Promotion in Sundsvall, Sweden in 1991 (https://www.who.int/healthpromotion/conferences/previous/sundsvall/en/) Sundsvall 1991

  Produced the Sundsvall Statement on Supportive Environments for Health which does not use the phrase health literacy.

- 4th Global Conference on Health Promotion in Jakarta, Indonesia in 1997 (https://www.who.int/healthpromotion/conferences/previous/jakarta/declaration/en/)

  Produced the Jakarta Declaration on Leading Health Promotion into the 21st Century which does not use the phrase health literacy.

- 5th Global Conference on Health Promotion held in Mexico City, Mexico in 2000 (https://www.who.int/healthpromotion/conferences/previous/mexico/en/hpr_mexico_plans_action.pdf)

  Produced the Framework for Countrywide Plans of Action in Health Promotion which has one mention of health literacy is included within the section on evaluation of health promotion efforts. This document states: "Health promotion outcome measures can include: health literacy measures, including health-related knowledge, attitudes, motivation, behavioural intentions, personal skills, and self-efficacy"

- 6th Global Conference on Health Promotion held in Bangkok, Thailand in 2005 https://www.who.int/healthpromotion/conferences/6gchp/hpr_050829_%20BCHP.pdf?ua=1)

  The Bangkok Charter for Health Promotion in a Globalized World provides one mention of health literacy, which states all sectors and settings should: "build capacity for policy development, leadership, health promotion practice, knowledge transfer and research, and health literacy."

- 7th Global Conference on Health Promotion held in Nairobi, Kenya in 2009 (http://www.ngos4healthpromotion.net/wordpressa4hp/wp-content/uploads/2017/04/Nairobi_Call_to_Action_Nov09.pdf)

  In the Nairobi Call to Action for Closing the Implementation Gap in Health Promotion 2009, one of the five key strategies and actions to reduce health inequities and poverty and enhance health and quality of life focused on initiatives to improve health literacy and health behaviors. The key areas highlighted for health literacy were to: support empowerment; enhance information and communication technologies; and build and apply health literacy's evidence base.

- 8th Global Conference on Health Promotion held in Helsinki, Finland in 2013 (https://apps.who.int/iris/bitstream/handle/10665/112636/9789241506908_eng.pdf;jsessionid=B1B1A39C07F93312AAF7CAA105BAC70B?sequence=1)

  The Helsinki Statement on Health in all Policies mentions health literacy one time, in a call for nations to: "Include communities, social movements and civil society in the development, implementation and monitoring of Health in All Policies, building health literacy in the population."

- 9th Global Conference on Health Promotion held in Shanghai, China in 2016 (https://www.who.int/healthpromotion/conferences/9gchp/shanghai-declaration.pdf?ua=1)

  The Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development at one page in length is by far the shortest within the history of documents produced by global conferences on health promotion. Given that, this document mentions health literacy seven times. See below for further discussion of this document.

As the information in Table 1 indicates, the exact phrase 'health literacy' has not been consistently featured in the documents produced by the series of global health promotion conferences that began in Ottawa in 1984. 'Health literacy' first appeared within the Framework for Countrywide Plans of Action in Health Promotion generated in Mexico City in 2000. While the earlier documents produced by these global health promotion conferences may not have used the exact phrase 'health literacy,' there are instances throughout where the spirit of health literacy (the idea of an equitable approach to health, a focus on prevention, and a larger integrative approach to health and wellbeing) are evident.

Meanwhile, the term 'health literacy' has appeared the most in documents produced by two of the three most recent conferences - eight times from Nairobi in 2009 and seven from Shanghai in 2016. The use of health literacy is clustered within specific sections of both documents. In the Nairobi Call to Action, the section is titled "Health literacy and health behaviours" and in the Shanghai Declaration the section is titled "Health literacy empowers and drives equity."

Uniquely by comparison, "The programme of the Shanghai Conference revolved around three thematic 'pillars:' good governance; healthy cities; and health literacy" [16].

The text of those sections in each document that focuses on health literacy follows in Figures 1 and 2.

Table 1. Quick analysis of the core documents produced by each Global Health Promotion Conference (On following page, bold faced font indicates best from a health literacy perspective)

Document name	City	Nation	Year	Number of letter-sized pages	Number of words	Number of times the phrase 'health literacy' appears	Use of 'health literacy' per word count	Reading level using SMOG online tool	Readability consensus - Grade level
Ottawa Charter for Health Promotion	Ottawa	Canada	1986	5	1,489	0	-	13.8	16
Adelaide Recommendations on Healthy Public Policy	Adelaide	Australia	1988	6	2,378	0	-	13.5	15
Sundsvall Statement on Supportive Environments for Health	Sundsvall	Sweden	1991	5	2,112	0	-	13.6	15
Jakarta Declaration on Leading Health Promotion into the 21st Century	Jakarta	Indonesia	1997	NA as is available only in online format[1]	1,754	0	-	14.1	16
Framework for Countrywide Plans of Action in Health Promotion	Mexico City	Mexico	2000	8	3,163	1	1:3,163	**13.2**	**15**
Bangkok Charter for Health Promotion in a Globalized World	Bangkok	Thailand	2005	6	1,535	1	1:1,535	14.5	17
Nairobi Call to Action for Closing the Implementation Gap in Health Promotion	Nairobi	Kenya	2009	7 (not provided online by WHO)	2,725	**8**	1:341	19.5	23
Helsinki Statement on Health in all Policies	Helsinki	Finland	2013	2	1,071	1	1:1,071	14.8	16
Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development	Shanghai	China	2016	**1**	**1,041**	7	**1:149**	15.5	17

Figure 1. Health literacy focused section of the Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development

Health literacy empowers and drives equity

Health literacy empowers individual citizens and enables their engagement in collective health promotion action. A high health literacy of decision-makers and investors supports their commitment to health impact, co-benefits and effective action on the determinants of health.

Health literacy is founded on inclusive and equitable access to quality education and life-long learning. It must be an integral part of the skills, and competencies developed over a lifetime, first and foremost through the school curriculum.

We commit to:

- recognize health literacy as a critical determinant of health and invest in its development;
- develop, implement and monitor intersectoral national and local strategies for strengthening health literacy in all populations and in all educational settings;
- increase citizens' control of their own health and its determinants, through harnessing the potential of digital technology;
- Ensure that consumer environments support healthy choices through pricing policies, transparent information and clear labelling.

Comparing the content of both sections of each document focused on health literacy (using two coders who agreed on the final coding displayed below), the authors suggest both documents provide a justification for addressing health literacy, a series of action steps that are proposed within each document, and brief lists of possible outcomes from health literacy actions.

Both documents, in different wording, generally agree that the links between health literacy, basic literacy, education, and lifelong learning provide a justification to address health literacy at a high level within an international health policy document. The documents envision these linkages as underpinning advances in both individual and collective global health promotion.

This direct description in both documents of what some have referred to as the 'two-sided' nature of health literacy by addressing collective - and thus systematic - action suggests a revision of previous definitions, such as that initially proposed by Ratzan & Parker almost 20 years ago now, that is often used as the definition of health literacy by U.S. governmental agencies [17].

Although both documents recommend numerous action steps, each clearly has different foci in this regard. While endorsing health literacy, the Shanghai Declaration does not contain the same level of detail as the Nairobi Call to Action. While the Shanghai Declaration calls for both local and national strategies to be developed - they are left undefined. In contrast, the Nairobi Call to Action lists several fairly specific action steps that are not mentioned in the later Shanghai document.

The Nairobi Call to Action also includes a section that explicitly recommends its proposed efforts are evaluated and evidence-based. While this could be read as implied in the Shanghai Declaration, it is not explicitly stated.

Figure 2. Health literacy focused section of the Nairobi Call to Action for Closing the Implementation Gap in Health Promotion

HEALTH LITERACY AND HEALTH BEHAVIOURS

Basic literacy is an essential building block for development and health promotion. Health literacy interventions need to be designed based on health, social and cultural needs.

ACTIONS THAT MAKE A DIFFERENCE:

Support empowerment
- by ensuring basic education for all citizens;
- by building on existing community resources and networks to ensure sustainability and enhance community participation;
- by designing health literacy interventions based on community needs and priorities in their political, social and cultural context, with particular consideration for the needs of people with disability;
- by ensuring that communities are able to access and act on knowledge and overcome any barriers.

Embrace information and communication technologies (ICT)
- by formulating a strategic framework on ICT to equitably improve health literacy;
- by ensuring that public policies increase affordable access to ICT through wider coverage of remote and underserved areas;
- by building the ICT capacity of health professionals and communities, and maximize the use of available ICT tools.

Build and apply the evidence base
- by developing a core set of evidence-based health literacy indicators and tools based on constructs and concepts relevant to health using quantitative and qualitative methods;
- by surveying and monitoring health literacy levels of individuals and communities;
- by setting up a system to monitor, evaluate, document and disseminate health literacy interventions.

Table 2. Comparing justifications for addressing health literacy in the Shanghai Declaration and the Nairobi Call to Action

Justification for addressing health literacy	Shanghai Declaration	Nairobi Call to Action
Links to basic literacy, education, and lifelong learning empowers individual citizens and enables their engagement in collective health promotion action	x	x

Table 3. Comparing actions steps suggested for health literacy in the Shanghai Declaration and the Nairobi Call to Action

Action steps suggested	Shanghai Declaration	Nairobi Call to Action
Recognize and invest in development and individual control of health and health literacy as a determinant of health	x	x
Local strategies – undefined	x	
National strategies – undefined	x	
Use of ICT/ digital technology for consumers	x	x
Improve ICT/digital technology use from health professionals		x
Improve ICT/digital technology in remote/ underserved areas		x
Improve 'consumer environments' by using markets to supply healthier choices (e.g. pricing, labeling, etc.)	x	
Design health literacy interventions based on community needs, priorities, and contexts to enhance participation		x
Consider needs of people with disability		x
Ensure access to knowledge and basic education		x
Ensure use (act on) of knowledge		x
Develop core set of evidence-based health literacy indicators		x
Develop core set of evidence-based health literacy tools		x
Survey and monitor health literacy levels of individuals and communities		x
Set up system(s) to monitor, evaluate, document and disseminate health literacy interventions.	x	x

Table 4. Comparing outcomes suggested for health literacy in the Shanghai Declaration and the Nairobi Call to Action

Outcomes	Shanghai Declaration	Nairobi Call to Action
Strengthens commitment to health	x	
Increases equity	x	
Empowers individuals	x	x
Increases engagement in collective health promotion action	x	
Improves development (international)		x
Improves outcomes of health promotion efforts	x	x
Improves sustainability of health promotion outcomes		x
Creates consumer environments that support healthy choices	x	

Overall, the documents produced by both the Nairobi and Shanghai conferences collectively advance health literacy. As aforementioned, each contains strengths and weaknesses. Hopefully, policymakers and practitioners will utilize them collectively rather than individually as the foundations of future efforts. To reinforce a conclusion from the aforementioned policy document analysis, the lack of specific detail creates shorter, easier-to-read and share documents but their generalities may not persuade readers and policymakers to give priority to health literacy - or generate the vigor and actions needed to foster sustainable efforts to improve health literacy. Further negative outcomes also could stem from a lack of rigorous, valid, and reliable evaluation of recommended efforts over the long-term.

5. Looking Forward

In retrospect, it seems too easy to find evidence that health literacy's initial development was dominated by siloed efforts internationally - as practitioners and institutions struggled to define and claim territory and importance. The latter occurred most frequently in the guise of definitions, measurement, and interventions.

Yet looking forward, there is hope on the horizon. The emergence of health literacy as an evidence-based approach to preventing poor health and improving public health on the international stage is replacing the U.S.-based approach that primarily focused on introducing health literacy within medical care after people become ill.

As we move forward - hopefully as a collectively collaborating and cooperating field of research, practice, and policy - the authors suggest the field especially embrace a strong ethical foundation and approach. In other contexts, the authors have suggested 'the 5E approach' to health literacy. In brief, this approach suggests that ethics in health literacy is a function of addressing effectiveness, efficiency, equity, and evaluation. In short:

Ethical health literacy = **E**ffectiveness + **E**fficiency + **E**quity + **E**valuation

The authors propose that health literacy research, programs, and policy should focus on ethics. Further, the authors suggest an ethical approach necessitates health literacy should be conducted and assessed as a continuous measurement. The latter approach would challenge past binary classification systems (e.g. low to high health literacy) or sets of poorly-labeled hierarchical health literacy levels that frequently dominated past measurement approaches.

In making this suggestion, the authors' logic is simple. To be ethical in health literacy, you must be effective, efficient, and equitable. To demonstrate health literacy efforts are effective, efficient, and equitable, researchers and practitioners need to evaluate. Therefore, to evaluate is to be ethical.

The authors operationally define the health literacy components as:

- **Effectiveness -** The health literacy effort has proven effects on key indicators; the authors highly encourage going beyond self-report measures and including objective health metrics
- **Efficient -** The health literacy effort produces change at an equivalent or better scale per amount spent compared to other intervention types
- **Equity -** The health literacy effort focuses on reducing or eliminating inequities in health and well-being - access to health as a resource for living is key in this regard
- **Evaluation -** The health literacy effort is rigorously evaluated to build health literacy's evidence base in order to advance the field and assure the other components within the proposed equation have been addressed.

The authors propose such an approach is the best and most effective way to continue to raise the bar on health literacy. We strongly suggest organizations, such as the World Health Organization, make this or a similar approach central to all health literacy efforts. The authors' experience indicates the latter is an effective way to develop, test, and implement evidence-based and effective new solutions to the challenges of health literacy in public health and in public systems that can impact health and wellbeing.

Further, the authors strongly suggest it is important to highlight the continued need to expand the conceptualization of health literacy beyond medical care. We live in a world marked by threats to individual and public health that arise from complex global, regional, and local sources ranging from food production systems to climate change, from educational systems to the design of cities and transportation, from individual preferences and behaviors to cultural beliefs and practices.

In this context, the authors urge practitioners and researchers to continue to blur the traditional distinctions between health and environment as they continue their work to advance health literacy. A person cannot be healthy in an unhealthy environment just as unhealthy behaviors produce an unhealthy environment. As a holistic approach to such issues emerges within health literacy, the authors applaud and urge its continuation.

Finally, the authors maintain if there is a golden rule to health literacy, it is to engage with people and communities early and often. This naturally leads to an approach grounded in integrative health. Embracing an integrative approach to health requires that health literacy address the entire lives of people, not just their medical condition or disease. By doing so, the focus of activities increasingly shifts to health prevention rather than medical care. The ensuing logical progression is how health literacy helps create a world with a healthy and sustainable environment populated by empowered and engaged people living a life of health and wellbeing. To reach that admittedly normative goal - albeit required in so many ways – the authors recommend that efforts continue to build on the most recently produced Shanghai Charter through:

- Informed advocacy for health literacy at all levels
- Development of more and better practical actions and tools that address health literacy. Such developments in health literacy must be disseminated freely
- A sustained and active focus on helping the world become healthier and happier with health literacy

In closing, the authors would be derelict in our responsibility if we did not highlight the unfortunate truth that the level of health literacy activity is often the lowest in areas of the world where the need is the greatest. Health literacy efforts should not only be available to those who have socio-economics means, the best practices of health literacy should be available to all. While the authors encourage efforts to counter the historical reality of unequal access to health and wellbeing, we caution that great care must be taken so health literacy does not become yet another tool of cultural hegemony or colonization through ideas or economic servitude.

In such efforts, health literacy is needed in all contexts of human interactions and life - not just medical systems. Doing so, in our opinion, will in the long run create:

- Better health
- Greater social cohesion
- Effective communication across diverse populations and ideas
- Lower costs of producing health and medical care
- More resources to allocate toward living and enjoying life versus staying healthy
- Shift in goals from being healthy to using health to advance global wellbeing

Ultimately, the authors hope our work and the work of everyone engaged in health literacy always keeps in mind the core idea of the first global health promotion conference that produced the Ottawa Charter for Health Promotion - health is a resource for everyday life, not the objective of living.

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The Role and Impact of Health Literacy on Peer-to-Peer Health Communication

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Abstract. This chapter explores the impact and role of health literacy in peer-to-peer health communication contexts, such as social media platforms and online patient support groups. The chapter contends that health literacy efforts of researchers, health care providers, and public health practitioners will need to include innovative strategies to help consumers critically evaluate and appropriately utilize the health information found in online communities. The chapter first discusses the rise of peer-to-peer sharing of health information and accompanying health literacy concerns. Next, a series of case studies are presented that illustrate the potential role of health literacy in three different online settings: clinical trial patient support networks, social media channels, and personal blogs. The chapter then explores common themes highlighted in these examples and discusses the range of health literacy benefits and pitfalls that accompany the use of these channels for health information. Finally, the chapter explores existing individual-level and system-level health literacy initiatives for peer-to-peer health communication and suggests opportunities for future work in this area. Such efforts to address and improve health literacy can help individuals and communities successfully navigate online platforms where peer-to-peer health information is exchanged.

Keywords. Health literacy, peer-to-peer health communication, social media, patient support groups

1. Introduction

In the years between 2014-2017, hundreds of Tweets appeared using the hashtag "#VaccinateUS". While most vaccination hashtags explicitly take a point of view (e.g., #vaxwithme, #CDCwhistleblower), Tweets using the #VaccinateUS hashtag curiously promoted both anti and pro-vaccine messages. The tweets included:

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> “At first our government creates diseases then it creates #vaccines. what’s next?! #VaccinateUS”
>
> “Do you still treat your kids with leaves? No? And why don’t you #vaccinate them? Its medicine! #VaccinateUS”
>
> “Apparently only the elite get ‘clean’ #vaccines. And what do we, normal ppl, get?! #VaccinateUS”
>
> “#vaccines cause autism—Bye, you are not my friend anymore. And try to think with your brain next #VaccinateUS”

An analysis of this hashtag revealed the “VaccinateUS” was likely a hashtag created by Russian “troll” accounts, which used both pro and anti-vaccine messages with the intention to sow discord about vaccination in the U.S. [1]. Messages employing this hashtag tried to frame the vaccine debate using polarizing health themes, such as conspiracy theories, attempted to revitalize a debunked vaccine-autism link, and promoted controversial mandatory vaccinations.

This use of trolls and malicious social media messaging techniques provides an example of an increasingly sophisticated, opaque, and complex online health information ecosystem that today’s health consumers must navigate. Popular social media platforms, such as Twitter, Facebook, and Pinterest, are common channels through which individuals may be exposed to and influenced by peer-provided (mis)information about health topics online, although exposure occurs on a variety of other online platforms as well. From online patient networks and advocacy boards, to user-generated content on YouTube and Instagram, individuals find many online avenues to share information and connect with one another about health. However, because the information being shared is typically provided by peers rather than health care professionals, it has often not been vetted or verified, and it can be difficult to identify the original source of information. Given the prevalence of online health information searching and the amount of medical and scientific information that individuals may be exposed to on peer-to-peer platforms, it is vital to study how individuals process and evaluate this information. As health information becomes increasingly available and complex (e.g., genetic information, personalized medicine), the need for consumers to critically evaluate information found on these platforms and make health-related decisions based on the provided information will intensify in the future.

Adding to this complexity, research suggests a substantial proportion of health-related messages on peer-to-peer platforms contain misinformation. For example, a content analysis of prostate cancer videos on YouTube reported 77% of the videos and comments contained biased or false information [2]. Similarly, a content analysis of n=800 vaccine-related posts on Pinterest revealed that 21.5% of posts mentioned a conspiracy perpetrated by either the government or the pharmaceutical industry [3]. Alarmingly, the most popular and frequently shared posts and videos are often the ones that contain misinformation [2,4]. This suggests the health literacy efforts of researchers, health care providers, and public health practitioners also will need to include innovative strategies to help consumers successfully identify and distinguish between evidence-based and non-evidence-based information.

The first step to help individuals navigate this complex online environment is to consider the role of health literacy in peer-to-peer online health communication. A better of understanding an individuals' beliefs, abilities, and perceived efficacy to navigate online health (mis)information provides insights into strategies to help consumers with different health literacy levels discern the meaning and usefulness of health information discovered on peer-to-peer platforms. Appreciating the role of health literacy in this context also may facilitate the design and development of more effective health communication interventions designed for and delivered through peer-to-peer platforms.

In this chapter, the authors discuss the important role health literacy plays in online peer-to-peer communication. We first define and operationalize online peer-to-peer communication and health literacy. Next, the authors present three short case studies centered on cancer patient support networks, Instagram wellness accounts, and parenting blogs. These examples showcase the range of potential benefits and challenges of peer-to-peer communication about health, while highlighting health literacy as an important factor to consider within an increasingly complex mass communication context.

The authors contend that efforts to address and improve health literacy can help individuals and communities successfully navigate online platforms where peer-to-peer health information is exchanged. Such efforts can help inoculate individuals against health misinformation, facilitate decision-making among those with limited health literacy, and increase the effectiveness of health communication campaigns and patient-provider communication by reducing the influence of health (mis)information.

2. The Rise of Peer-to-Peer Communication

The use of social media in the United States has increased from 5% in 2005 to 69% as of 2018 [5]. This remarkable growth may outpace health professionals' understanding of the way social media affects how individuals process, interact with, and act on the health information found on these platforms. A line of research spanning the past decade has attempted to address this phenomenon.

Much of the early work focused on understanding how individuals attempt to reconcile the health information they find online with offline sources. For example, some studies focused on how patients would discuss information found online during interactions with their healthcare providers [6]. Recent research examined the impact of mobile and social media on health communication across a variety of health topics, such as the impact of online support groups for breast cancer survivors, and the use of mHealth to deliver lifestyle interventions and social support for weight loss [7-8].

Peer-to-peer platforms have become rich sources of health information for patients and the public. In this chapter, the authors define peer-to-peer health information as user-generated health information that is created and shared with virtual communities or networks via computer-mediated technologies. Peer-to-peer platforms have benefited patients and public health researchers in many ways including: providing more opportunities for social support; increasing patient engagement and empowerment in health decision-making; facilitating adoption of recommended health behaviors; improving public health surveillance; and expanding the reach and cost-effectiveness of health promotion campaigns and interventions [9-10]. However, theoretical and empirical work points to pitfalls of online peer-to-peer health information sharing. These include increased distress and confusion in individuals when they receive conflicting information, and ‘contaminating’ research design (e.g., unblinding a randomized controlled clinical trial) [11]. Additionally, information sharing could lead to the deterioration of trust in government, scientists, and health care professionals when information found online contradicts a provider’s recommendation or prescription. A recent study found a strong association between an individuals’ efficacy related to searching for health information on-line and their trust in federal health agencies and national health organizations [12].

Among the most pressing concerns is the increased frequency of online peer-to-peer health information sharing may be associated with a concomitant increase in the volume of misinformation to which individuals may be exposed. Although definitions vary, in this chapter the authors define misinformation as a health-related claim of fact that, on its conventional interpretation, is currently false, because it: lacks scientific evidence; and/or is contrary to the accumulated scientific evidence; and/or is contrary to expert consensus, in whole or in part [13-14].

Some evidence suggests misinformation is processed and shared differently than evidence-based information on peer-to-peer platforms. For example, a recent study used rumor cascade methodology to better understand how misinformation and true information spread online [15]. In their analysis of 126,000 rumors spread by about three million people, the authors found that even after controlling for bot activity, “false news still spread farther, faster, deeper, and more broadly than the truth in all categories of information.”

To maximize the benefits and minimize the potential harms of online peer-to-peer communication about health topics, individuals must be able to understand and critically evaluate the health information found on these platforms. There are diverse opportunities for public health practitioners, health care systems, and industry partners to support individuals in developing these skills, which are necessary to consumers’ meaningful engagement within the online health information environment.

2.1. Health Literacy in the Context of Online Peer-to-Peer Communication

Various well-cited definitions note health literacy is more than the ability to access or read health information. Rather, health literacy encompasses the capacity to comprehend the information provided and the ability to act on that information to improve health outcomes [16-17]. The rise of peer-to-peer platforms has helped limited literacy individuals overcome traditional barriers related to accessing health information [8]. However, in doing so, new health literacy challenges have been introduced, including the added challenge of evaluating peer-provided health information.

Previous research suggests health literacy plays a prominent role in how individuals discern and process health information found online. For example, one study found people with HIV who had lower health literacy were more likely than patients with high health literacy to give low quality ratings to a high-quality website and high-quality ratings to a low-quality website [18]. Other studies using education as a proxy for health literacy found educational level to be positively correlated with the number of successful information tasks participants completed (e.g., defining search options, evaluating information sources) and with their perceived self-efficacy in evaluating online health information [19-20].

Health literacy also has been associated with trust of online information and may help explain different levels of trust across peer-to-peer platforms. For example, one study found African Americans with lower health literacy were more likely to trust YouTube and Twitter for information, while African Americans with higher health literacy were more likely to trust online governmental and religious groups [21]. Moreover, the same study found that older adults who had low health literacy were more likely to trust information from Facebook but expressed lower trust in online support groups for health information.

3. Case Studies of Health Literacy in Peer-to-Peer Online Networks

To illustrate the potential role of health literacy in online peer-to-peer contexts, the authors next turn to three case studies that showcase the range of online settings where health is discussed: clinical trial patient support networks; social media channels; and personal blogs. The authors deliberately provided a broad approach to consider a variety of online peer-to-peer networks where health information might be exchanged. Each case study explores some of the nuances and complexity of peer-to-peer health information sharing, which in aggregate, demonstrate the role of health literacy.

3.1. Case Study 1: Online Patient Support Groups and the Angiosarcaoma Project

Online patient support groups are one of the earliest forms of social media. In the early 1990s, patients, caregivers, and health consumers began to gather online to exchange information, offer personal illness stories and experiences, and provide and receive support from each other. Today, online patient support communities for conditions such as cancer are numerous. Online patient support communities transcend spatial boundaries and span organization-based communities, such as Cancer.net and the American Cancer Society's Cancer Survivors Network, and for-profit companies, such as PatientsLikeMe. Support communities can also take the form of member-only ("secret") groups on commercial platforms such as Facebook. Active online peer-to-peer networks focused on health issues are now an established channel of health communication.

For instance, a patient newly diagnosed with a rare disease may join an online peer community to hear about others' experiences living with the disease, find information about treatment options and side effects, seek social and emotional support from people that have had similar experiences, and even solicit and receive instrumental support (e.g., transportation to appointments). Moreover, such online communities, especially those with good administrative oversight, can provide unique opportunities for patients to engage in medical research and process disease-specific treatment information because these communities often become valued and trusted outlets for clinical trial information and relevant research.

In addition to peer-to-peer support for those with shared health challenges, online communities can serve to support cutting-edge medical research. One example of an online network that facilitates scientific research is the Angiosarcoma Project, founded by survivor, patient advocate, and scientist Dr. Corrie Painter [22]. This project has enabled the establishment of a large database of medical data (e.g., tumor samples and patient-reported outcomes data). The Angiosarcoma Project illustrates when thoughtfully created and consistently moderated, online communities help overcome information access barriers and facilitate patients' navigation and understanding of health challenges. In this way, peer-to-peer communication serves to overcome some health literacy challenges by making relevant information (e.g. treatment options, participation in research) much more accessible and personally salient.

Despite their potential benefits, online peer support communities also present new health literacy challenges, particularly as patients increasingly share complicated and personalized medical information and exchange medical opinions and advice. Trusted platforms for health information and disease-specific support may be even more vulnerable to the spread of misinformation about disease etiology and treatment options as well as the misinterpretation of scientific research results and clinical implications. For example, a patient financially compensated (i.e., "sponsored") by a pharmaceutical company might share information with her online peer support community about a drug purported to cure or benefit individuals with their shared health condition. Although the information may lack scientific support, peers within a network may view the information as credible since trust has been established within the community through shared experiences. While skillful online community administrators can help ensure group dynamics are supportive and helpful to community members, there also is a risk of creating an 'echo chamber.' The latter occurs when most members of the community express strong support for a particular treatment option (or doctor or health care setting) and drown out dissenting voices. The result may be a communication environment that feels unsafe, uncomfortable, or unsupportive for some individuals in the community who have different views. In such scenarios, an individual with limited health literacy may be more easily misguided by misinformation if he or she relies on advice from others as a way to cope with volumes of information perceived to be complex or confusing.

The Angiosarcaoma Project illustrates the importance of sustaining a 'health literate' online support community. Thanks to Dr. Painter's professional background, her team's attention to and careful moderation of online discussions, and the strong support of a research institute (Broad Institute), the information shared by peers about the disease remains evidence-based and community members feel empowered to participate and collectively contribute their clinical data to critical scientific endeavors. In turn, the Angiosarcaoma Project offers a model to create online environments that are conducive to the provision of evidence-based health information as well as improve individuals' understanding of their role in supporting others and contributing to research that may eventually alleviate suffering.

3.2. Case Study 2: Lifestyle Influencers on Instagram

There is a an emerging group of popular influencers on Instagram who promote the idea of 'clean eating.' 'Clean eating,' which focuses on the consumption of whole, minimally-processed foods, has the potential to benefit individuals by inspiring them to incorporate more fruits and vegetables into their diets and decrease the volume of processed foods they consume.

However, health providers are growing increasingly concerned about the potential harms of these accounts, suggesting they may be leading to increased distress and the development of eating disorders among followers [23]. For example, Orthorexia Nervosa (a new disordered eating pattern characterized by a fixation on eating only foods that are considered to be 'healthy' or 'pure') may be more prevalent because of the influence of digital media [24]. Persons who suffer from this disorder typically perceive foods that contain artificial ingredients or are grown by conventional means (e.g., with the use of pesticides) to be dangerous, and tend to avoid certain foods, such as those containing carbohydrates and fats.

A recent study suggests higher Instagram use is associated with greater Orthorexia Nervosa symptoms [23]. This is likely due to the influence of Instagram clean eating 'celebrities,' who regularly dispense dietary advice to the hundreds of thousands of followers they have on this platform, despite typically having no formal training in health or nutrition. While some aspects of the diets these influencers promote may be consistent with scientific evidence (such as the emphasis on fresh produce), many of these accounts also implicitly or explicitly encourage the elimination of entire food groups, which runs counter to evidence-based nutrition guidance, and may lead to malnutrition and an unhealthy fixation on food.

Individuals who follow these Instagram accounts may have problems distinguishing between the scientifically accurate, legitimately helpful advice provided by these influencers and the more extreme, non-evidence-based views that are sometimes espoused in the same communities. The latter especially may be problematic for individuals with lower health literacy who may find the clear, simple, black-and-white messages about how to eat healthfully to be especially appealing. Acceptance of misinformation may be further enhanced by the attractive images that often accompany these Instagram posts (e.g., green smoothies, salad bowls), which may connote healthfulness even if the advocated pattern of eating is not healthy overall and the claims being made about specific ingredients are insufficiently evidence-based.

Indeed, many of the specific foods promoted by the "clean eating" movement, such as almond milk, or coconut oil, are not considered as especially healthy by certified nutritionists [25]. However, because influencers have a large following and an attractive appearance that reflects a healthful ideal, influencers are perceived as authorities on health. In one case, a popular Instagram influencer admitted that the raw vegan diet she was following - and promoting - was in fact making her very ill [25].

Furthermore, because most social media platforms are designed to continue exposing users to content they have liked previously, individuals who are interested in clean eating can get caught in an echo chamber where they are exposed to similar types of behaviors and information. This fosters a false impression about content veracity and normative behaviors [23]. Instagram's algorithms prioritize certain content and create echo chambers, making it less likely that people will be exposed to contradictory information, which might engender more self-reflection and personal research on the topic.

Yet, while popular 'wellness' accounts on Instagram are problematic in their current form, they demonstrate some potentially effective techniques that public health practitioners could adopt to promote healthy behaviors. For instance, advice from a personable, relatable, or even aspirational spokesperson may be better received than a factsheet from a faceless organization. Attractive, compelling imagery can make dry health information more engaging and motivational. People also appreciate practical tips and straightforward instructions they can act on compared to vague nutrition advice such as 'choose a variety of nutrient-dense foods' or recommendations that require math, such as 'consume less than 10 percent of calories per day from added sugars' [26]. These strategies can help public health agencies make their health communication material more accessible for individuals at all health literacy levels.

3.3. Case Study 3: The Motherhood Blogging Community

Mothers who blog, sometimes called ‘mommy bloggers,’ frequently post information about a variety of health topics pertaining to women and their family members [27]. As an example, The Motherhood (www.themotherhood.com) is a blogging community of mothers, many of whom were willing to facilitate the dissemination of evidence-based health information about environmental risks of breast cancer as part of an intervention study [28]. The bloggers worked with researchers to tailor blog posts that included evidence-based information about actionable steps that mothers and daughters can take to reduce the environmental risk of breast cancer. Often sharing personal family stories with family photos, their blogs may help people find, process, and understand scientifically complex environmental risk information by making it approachable. Their blog posts also inspired many mothers and daughters to discover and share health information on social media.

Findings from this research suggest peer-to-peer forums are a promising channel to make information more accessible and boost participant health literacy. By working collaboratively with mothers who blog, scientists can influence exposure to and diffusion of scientifically-informed health information in a way that is easier to process. Blog readers exposed to the researcher-adapted (www.bcerp.org) and blogger-tailored environmental breast cancer risk/prevention information were more satisfied with and influenced by the information when compared to readers who were not exposed (or did not recall seeing the messages).

Moreover, exposed blog readers were more likely to share the information with others in their social networks, especially their daughters [28]. Demonstrating the potential for improved health literacy among mothers and daughters, one blog reader said, “You read a lot of these white papers [educational handouts] and it’s like, ‘Look at all these words,’ and I don’t know what they mean. So, when you have something that’s like this [information translated for blogs], it’s easy to digest. It’s easier to recall when you need it for a conversation [with daughters].” Tailoring evidence-based health information for readers by providing personal accounts may increase the relevance of health-related information and comprehension, which improves the likelihood that readers will act on the guidance.

3.4. Case Study Discussion

Online peer-to-peer networks are increasingly used as a source of health information, and the three case studies suggest a range of benefits and pitfalls that accompany the use of these channels for health information. The common themes highlighted in these case studies include issues related to information quality and accuracy, the risks introduced by echo chambers, and the value of personal narratives and opinion leaders as possible sources to present information to individuals at all health literacy levels.

As discussed in the blogging case study, blogger-researcher partnerships and personal narratives can make peer-to-peer platforms a powerful tool to disseminate health information, engage with audiences, and make scientific material easier to comprehend and act on. In this way, opinion leaders such as bloggers may empower consumers with limited health literacy by making health information much more accessible, easier to evaluate, and therefore, more useful. Similarly, well-monitored online support groups, such as The Angiosarcaoma Project, can become trusted sources of health information.

However, the first two case studies suggest how health information sharing on social media platforms (online patient support communities, Instagram) also can complicate health decision-making and lead community members/followers to act on erroneous health information or flawed recommendations. Together, these case studies highlight the need for additional research about the benefits and drawbacks of sharing personal health experiences and information on peer-to-peer platforms.

Additionally, the first two case studies emphasize potential issues with echo chambers – either because dissenting voices are drowned out (as described in the patient support network case study), or because social media algorithms may prevent individuals from being exposed to dissimilar views (as described in the Instagram case study). When this occurs, it may prevent individuals from questioning false or non-evidence-based information, which reinforces their confidence to act based on misinformation.

The concerted efforts of health care providers, public health practitioners, and peer-to-peer network administrators are needed to identify effective strategies aimed at improving health literacy in a social media environment. Because the regulation of platforms in regard to misinformation is limited in the U.S. by First Amendment issues, a more reasonable and efficacious approach may be to engender consumers' personal agency by improving their health literacy levels. Using the example of Instagram 'clean eating' accounts, improved health literacy could help consumers distinguish between scientifically-informed nutrition advice and dubious claims. Given the need for more research and practical approaches to help improve the health literacy of the public, the authors next turn to individual and systems level interventions that help consumers navigate and evaluate online health information encountered on peer-to-peer platforms similar to those presented in the three case studies.

4. Interventions to Support Health Literacy in Online Peer-to-Peer Contexts

Consider the hypothetical example of Janice, a woman with low health literacy, who has recently been diagnosed with lymphoma, a type of blood cancer. Wanting to learn more about lymphoma but not knowing where to start, Janice frantically searches online forums for information about the cancer, shares the diagnosis on her Facebook page where she seeks help finding a doctor, and uses Twitter to search for discussions about 'cancer cures.'

Janice quickly is confused by the conflicting information found through her searches and replies to her pleas. One Facebook page called 'Society of Natural Cures' claims her lymphoma can be cured by adhering to an alkaline diet, while an acquaintance hypothetically comments on her Facebook page she should try magnetic therapy. Janice's confusion is compounded by watching a YouTube video that teaches her about 'cupping,' which is touted as an alternative cancer treatment in the video. At her appointment with an oncologist, Janice mentions the peer-provided information she found online only to be scolded by the provider for not trusting his advice and treatment recommendation.

What might happen if Janice had a higher level of health literacy from the outset of this difficult but commonly experienced situation? What factors might establish and foster the development of her health literacy in this context? For example, throughout her elementary education, Janice could receive instruction about how to recognize misinformation (e.g., distinguishing between legitimate and non-legitimate organizations) [29]. With this foundation, as Janice searches for information, she can more easily distinguish between credible and non-credible information found on these platforms.

Janice's health literacy could be addressed throughout her cancer information seeking experience by receiving notifications from Facebook when information she has viewed is flagged as potentially false and she is subsequently shown related articles that provide a different viewpoint on the same topic. Finally, after discussing her information seeking experience with an oncologist, the physician could validate her efforts and provide an 'information prescription,' which includes a list of online caregiver support networks, Facebook groups, and other websites where credible information about lymphoma can be found. The prescription preemptively addresses Janet's need for various types of social support (e.g., emotional support, instrumental support) in addition to meeting her information needs [30].

These contrasting scenarios highlight the need for different health-literacy interventions to help individuals navigate health information found on peer-to-peer platforms. Here, the authors take a health systems perspective on health literacy, noting that supporting health literacy efforts through effective interventions can and should occur both at the individual and information environment level [31-32]. The latter approach has been used most commonly in clinical healthcare settings [33]. Herein, the authors extend the context of the model to focus on the role of both individual-level 'activation' and system-level accessibility in the context of health information found in peer-to-peer platforms.

Below, the authors describe existing interventions and provide suggestions for additional interventions to support health literacy in peer-to-peer communication contexts. Educational initiatives and individual-level interventions are discussed first. Then, we turn to system-level interventions, focusing on clinical and industry initiatives.

4.1. Individual-Level Educational Initiatives

First, there are efforts to promote health literacy within school curriculum reform initiatives. Most notably, the National Health Education Standards (NHES) was created to guide curricula development from kindergarten to 12th grade and encourages incorporating health literacy competencies into all public school disciplines [34-35]. Some school systems may also require health literacy as a competency for graduation [36].

Taking a developmental approach, the NHES sets benchmarks as children go through the public school system. For example, the approach says that by the age of 10, a child should be able to "describe how the media can influence health behaviors," and by 14, they should have the ability to "evaluate the validity of health information, products and services [36]."

To date, many of the examples of published K-12 curricula on health literacy have focused on helping students navigate the health care system with modules on understanding your medical history, finding a healthcare provider, and filling out medical forms [34]. While these topics are essential to a healthy and literate population, the authors contend that health literacy training also should include instruction to navigate an increasingly complex online information ecosystem [35].

Despite their nickname as ‘digital natives,’ a need for K-12 online health literacy training was emphasized by a recent study by the Stanford History Education Group. The Stanford group conducted a series of experiments with middle-school and high-school students to study how students evaluated health and political information found in peer-to-peer platforms (e.g., Facebook, imgur). The researchers found most middle-school students were unable to distinguish between ‘sponsored content’ and an authentic news story. Similarly, more than 80% of high-school students did not critically evaluate a bogus image of ‘nuclear flowers’ on imgur, and more than 30% thought a fake news source was more credible than an authentic news source on Facebook [37].

Given the need to expand health literacy training, the authors propose health literacy curricula include examples and lectures that are specific to social media and peer-to-peer platforms. This training could include modules for topics such as: how to evaluate the source of health information found online (e.g., what a blue checkmark means on Facebook); how to critically evaluate health claims found on peer-to-peer platforms, and how to confirm health information by checking multiple sources.

4.2. Systems-Level Interventions

The authors contend it also is the responsibility of industry, clinicians, and health care systems to support patients/individuals to make evidence-based decisions and avoid adding more confusion. Here, the need is to change the design and tools available to individuals on peer-to-peer platforms in order to make health information more accessible and understandable, and to help consumers distinguish between credible and non-credible information.

4.2.1. Clinical Initiatives

Clinic-based initiatives offer another opportunity to improve the health literacy of individuals and help them navigate peer-to-peer platforms. In order to optimize patient-centered communication, physicians and health care systems can utilize internet information to improve physician–patient interactions and relationships. As it becomes more common for patients and caregivers to find misinformation or claims on peer-to-peer networks, conversations with providers about the latter also are becoming more common. To prevent patients from coming across or accepting this misinformation in the first place, it may be helpful for physicians to refer their patients pre-emptively to trusted sources to ensure the quality of health-related internet information consumed by patients. These referrals are often called ‘information prescriptions [38].’

4.2.2. Industry Initiatives

In April 2018, Mark Zuckerberg, CEO and Founder of Facebook, testified in front of the Senate. In his prepared opening remarks, Zuckerberg apologized for “not doing enough to prevent [Facebook] from being used for…fake news. It’s not enough to just give people a voice, we have to make sure people aren't using it to hurt people or spread misinformation [39]."

Following his testimony, Facebook and other peer-to-peer platforms have tested and produced new industry initiatives to help users engage and interface with information found on social media. One initiative alerts users via a 'warning label' before they share a post, if other users have tagged the content as false or misleading.

Previously, Facebook released a 'related stories' algorithm which automatically displays additional news stories on the same topic below the original post [40]. A study by Bode and Vraga suggests correcting a post that contains misinformation using a related stories function, can reduce misperceptions about GMOs and illness, as well autism and vaccination [41]. Focusing on this strategy, the product manager for Facebook's News Feed tasked with reducing misinformation noted, "Even if something is false, we don't prevent people from sharing it. We give them context. [42]"

In addition to these efforts, social media platforms are testing other initiatives to help individuals with lower health literacy navigate their services. For example, YouTube is rolling out a feature in India that shows individuals 'information panels' – text that provides verified information – along with videos when individuals search for information about topics that are prone to misinformation [43]. In addition to efforts that directly target misinformation, industry platforms also could provide tips regarding how to evaluate information or provide pro-bono campaigns so national health agencies and organizations can highlight legitimate news and reach a wide audience with health updates.

5. Conclusion

The democratization of communication has moved so quickly that researchers still do not fully understand its implications for health and health information seeking. In this chapter, the authors discussed and provided specific examples of the promise and potential pitfalls of increased peer-to-peer information, as well as introduced some individual- and system-level interventions to address health literacy. Advancing health literacy research is foundational to fully maximize the benefits and minimize the harm of the increased information access enabled by peer-to-peer platforms.

The need for the interventions discussed here will increase as the misinformation found on social media becomes more sophisticated – such as use of fake videos [42]. As health information and social media progress, individual and social health literacy efforts can help inoculate the public against health misinformation, and increase the effectiveness of public health campaigns and patient-provider communication.

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Will Improvements in Health Journalism Improve Health Literacy?

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Abstract. Today's health care journalists work in a very different environment than those of yesterday. The demand for stories and broadcasts has grown exponentially, and the resources available have shrunk dramatically. While it may therefore be difficult to see how improvements in health care journalism are possible, let alone a way to improve health care literacy, there is an important connection that, if illuminated, could help both fields. To understand the literature on the quality of health care journalism, it is critical to understand the backgrounds of today's health care journalists and the challenges they face. That literature also goes hand in hand with studies of the effects that news coverage has on the public's understanding of health care issues. There are training and educational programs designed to help health care journalists do their jobs better, and this chapter concludes with a discussion of how cooperation between health journalists, physicians, and other stakeholders can lift all boats.

Keywords. health literacy, health communication, health journalism

1. Introduction

Today's health care journalists in high-income countries are in some ways similar to their health care journalist predecessors. They are doctors-turned-reporters at newspapers and on television. They also are editors with bachelor's degrees in English and journalism. Some of them work in niche publications with specialized audiences, and others work at trade publications with professional audiences.

The environment in which these journalists work, however, has changed dramatically during the past few decades. As is the case across journalistic fields of specialization, particularly politics, news cycles have shortened significantly - and competition for attention has grown exponentially. Journalists do not just worry about scooping each other. They worry about being scooped by non-journalism outlets, and even a story's sources on social media. Meanwhile, journalism resources are being gutted by struggling news media business models.

Against this backdrop, it may seem counterintuitive, or even foolhardy, to explore what we know - and don't - about how improvements in health care journalism could improve health care literacy. By the time scholars have refined their models and knowledge, the argument could go, the state of journalism could be even more precarious. As I will argue in this chapter, however, the two go hand in hand, and making

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the connection between improved health care outcomes and improved health care literacy could provide an important argument for more health care journalism resources. At the same time, conceptual models of health literacy and communication will need to take into account journalism's ever-changing realities.

Section two describes the backgrounds of today's health care journalists. Section three explores some of challenges that health journalists face. With this background, section four reviews the literature on the quality of health care journalism while section five examines the current evidence for what effects - if any - news coverage has on the public's understanding of health care issues. Section six describes some educational initiatives designed to remedy some issues facing health journalism. Section seven addresses whether improving health care journalism can improve the public understanding of relevant medical and public health issues. Section eight concludes the chapter with some suggestions for cooperation between health journalists, physicians, and some of the health care delivery system's other stakeholders.

Similar to clinical medicine and health literacy, the field of health journalism is advanced by understanding the experiences of professional practitioners as well as extant research findings. While section three summarizes health journalism practices mostly from the experiences and perspective of contemporary practitioners and section six describes some university and institutional initiatives, sections two, four, five, and seven are more grounded in mass communication and health communication research.

2. Who Are Today's Health Care Journalists?

In a rare 2005 comprehensive survey of U.S. health care journalists, Viswanath et. al. found: "almost 70% of the respondents to our survey had at least a bachelor's degree; 19% reported having a master's degree; 4.5% reported having a doctorate, including about 3% with an M.D. Almost half of the respondents graduated with a degree in journalism and 13% with a degree in communications. Eight percent reported they were 'life sciences' majors in college" [1]. Although two-thirds of those surveyed were women, minorities were not well represented among health care journalists - and both trends remain unchanged.

The nearly 1,500 members of the Association of Health Care Journalists (AHCJ) span the U.S., with a smattering of members in other countries. Freelancers account for a quarter of the organization's members, with more instances of members affiliated with a particular outlet taking on occasional freelance assignments elsewhere. In 2019, members who self-identified as working predominantly online exceeded those who perceive themselves as strictly employed by newspapers. AHCJ's minority membership reached 16 percent for the first time in 2019.

3. What Challenges Do Health Care Journalists Face?

A 2008 study of health news concluded: "media institutions are being affected by critical issues such as new technology, low profits, layoffs, and media fragmentation" [2]. To meet news traffic targets, contemporary health reporters are asked to produce high volumes of stories, sometimes several per day, which does not facilitate in-depth reporting, or context.

According to one journalist laid off in 2008, quoted in a Kaiser Family Foundation report on the state of health care journalism: “the new mantra is that you must do one to two stories a day - I used to do three a week” [3]. In 2009, when the author became executive editor of Reuters Health (a wire service for laypeople and physicians owned at that time by Thomson Reuters), staff reporters were expected to file four or five stories per day, all about clinical studies. Even for seasoned and specialized journalists, this is a Herculean task. As executive editor, I shifted the expected burden to two stories per day - still a challenge, but as low as I could go and still satisfy clients who needed high volumes to meet their own traffic needs. Otherwise, editors are encouraged to push for headlines that will drive clicks, which can encourage sensationalism and even inaccuracy.

Science sections retreated from almost 100 in 1989 to a third of that by 2005 - a trend that seems to have continued [4]. While some science sections refocused more on health because of the large direct-to-consumer advertising market, the transition cannot make up for the overall loss of editorial space within print health news outlets. The elimination of science sections often goes hand in hand with the eradication of the newsroom jobs that staffed them, although sometimes the stories that appeared in specialized sections migrate to other pages.

In online journalism, the aforementioned distinctions between sections are more confusing. Readers may not differentiate a health story that appears in a newspaper’s style section, written by a reporter with little subject matter expertise, from a piece that appears in the paper’s science or health section. A newspaper may run a story that is highly critical of a new health craze in one section with another that glorifies a celebrity for his or her efforts to promote the same fad.

In 2009: “forty percent of AHCJ staff journalists who participated in a recent survey said the number of health reporters at their outlet had gone down since they’d worked there, while 16% said it had gone up. And 39% said it was at least somewhat likely that their own position would be eliminated in the next few years” [3]. Working in conditions like these is harmful because it forces everyone to produce more - and anxiety about one’s professional future is counterproductive.

In contrast, specialized outlets spring up frequently - driven by technology that allows targeted advertising. Some specialized outlines fall within the category of trade journalism, and many of them publish and broadcast extraordinary and award-winning work. However, specialized health news outlets tend to reach more limited audiences who often are knowledgeable about the subject matter, which makes it unlikely that their content will have a significant effect on public understanding, health literacy, or desired health behaviors. One assessment of journalistic quality among trade sites also recently characterized their reporting as ‘misleading’ [5].

The journalists who work for trade, legacy, and digital news organizations also are not the only generators of health news and biomedical research. The democratization of publishing, particularly the advent of blogging, means nearly anyone can find an audience. In order to fill their pages, newspapers and online outlets often recruit physician-authors for their blogging networks. Entire sites, such as MassiveSci and The Conversation, are grounded in the concept that it is best to use physicians and scientists (instead of traditional journalists) to communicate directly with readers. While the expertise of clinicians and researchers is welcome (and some of their work has significant impact), the latter trend means a decline in the pool of health writing jobs (and careers) for journalists.

In addition, the shrinking job market is impacted by non-journalism sites such as Futurity.org and ScienceDaily.com that publish health press releases - some of them quite well-funded. When the author asked some first-year students at New York University to critique stories about scientific papers, several of them sent links to press releases on these or similar sites, not realizing they were produced by the universities or journals involved. Some of this probably stems from journalists who fail to add value with their reporting, thanks to volume demands and other requirements. However, Google and other news search engines categorize these sites in the same way they classify independent journalism outlets, which is misleading.

Even when reporters want to add value to health news research and policy coverage, there are other persistent constraints. For example, news cycles are dramatically shorter, and at the myriad outlets that seek to capture a share of the public's attention on a particular news event, health reporters often are forced to act without the benefit of time to contextualize findings. Pre-emptive strikes that inhibit thoughtful reporting loom persistently. For instance, one tweet can result in making into "old news" a carefully crafted story a reporter has been working on for days or even weeks. In turn, the time it takes to develop health stories, sources, and understand a biomedical topic well currently are experiencing an unprecedented intra-professional decline.

Health journalists who cover new findings also find themselves at the mercy of research journals who use embargoes - and the Ingelfinger Rule - to control the flow of information. As the author noted previously, the use of embargoes by refereed biomedical journals has changed [6]. While journals once embargoed stories several days in advance (which gave reporters a little time to delve into a subject, interview experts, and write a meaningful story or produce a well-considered broadcast), the current trend is to embargo for much shorter periods [6]. When embargoes (which have grown like kudzu as companies, the government, and even doctors' practices use them) are short, they offer no real advantage to the news audience because reporters have no time to develop stories properly [7].

Paradoxically, the Ingelfinger Rule (which embargos journalists from publishing, at a journal's discretion) undermines public understanding because the process creates the impression that scientific discussions and the diffusion of knowledge mostly occur when journals publish findings. Embargoes force a rushed and contrived episodic process that cultivates a public misunderstanding that breakthroughs are the norm rather than the exception. Overall, the more journalists are pressed for time, their capacity for contextualization and their capacity to counter stereotypes in public perception are jeopardized.

Moreover, the genesis of a persistent (and false public impression) of frequent research breakthroughs is exacerbated by the amount of spin generated within press releases - and sometimes even by the depiction of a study's findings within a journal article [8-10]. While it is tempting to believe spin is the provenance of industry press releases, much of it stems from academic press releases, presumably because 'breakthroughs' are more likely to capture the attention of reporters, which in turn captures the attention of funding agencies and peers [11].

More specifically, Yavchitz et.al. found the 'spin' in press releases was associated with presence of 'spin' in the article abstract's conclusion [12]. Similarly, Summer et.al. found: "for health and science news directly inspired by press releases, the main source of both exaggerations and caveats appears to be the press release itself" [13]. Schwartz et.al. added: "high quality press releases issued by medical journals seem to make the quality of associated newspaper stories better, whereas low quality press releases might make them worse” [14]. A study of coverage in Dutch newspapers came to similar conclusions [15].

The volume of press releases distributed by the largest provider EurekAlert! also means health reporters hypothetically can write several health stories per day without ever having to generate anything new or enterprising. The author has urged mass communication scholars to assess the degree a 2016 inadvertent outage (or lack of access) to EurekAlert! fostered significant changes in interim health news coverage [16].

Some research and practitioner experience suggest press releases have an outsized influence on the quality of health news coverage [17]. For example, Haneef et.al. found, “most important factors associated with high online media attention were the presence of a press release and the journal impact factor. There was no evidence that study design with high level of evidence and type of abstract conclusion were associated with high online media attention” [18]. Section five of this chapter discusses attempts to minimize the effects of spin on news coverage.

Finally, many health reporters (similar to the researchers whose work they cover) have been caught blindsided by what is occasionally referred to as the ‘replication crisis.’ Although many scientific leaders avoid the use of the term ‘crisis,’ because it presumes things are getting worse, there is no question that many studies are not replicable in preclinical medicine, psychology, and other fields [19-20]. The latter development suggests relying on single studies for news reports makes it highly unlikely that the ensuing reporting is isomorphic with reality. And yet: “journalists preferentially cover initial findings although they are often contradicted by meta-analyses and rarely inform the public when they are disconfirmed” [21].

Hence, the bread and butter of daily health journalism turns out to be a nutrition-poor meal [22]. It would be a great outcome if the replication ‘crisis’ led journalists away from coverage single studies in an effort to be wrong less frequently.

4. How Good (or Bad) Is Today’s Health Care Journalism?

For nearly 13 years beginning in 2005, Health News Review (healthnewsreview.org) critiqued more than 2,500 news stories about health care interventions based on a set of 10 rigorous and consistent criteria ranging from “Does the story adequately discuss the costs of the intervention?” to “Does the story use independent sources and identify conflicts of interest?” The criteria are so insightful that the author asks NYU students to them in a weekly exercise to critique - and rate - current news stories.

In 2008, Gary Schwitzer, the site’s founder, wrote: “after almost two years and 500 stories, the project has found that journalists usually fail to discuss costs, the quality of the evidence, the existence of alternative options, and the absolute magnitude of potential benefits and harms” [23].

Schwitzer and several colleagues repeated and broadened their initial analysis using 1,889 reviews completed between 2005 and 2013. They found: “on average, the stories reviewed during 2005–2010 successfully met just less than half of the criteria, but by 2010–2013, that average had improved to almost 70%. There were significant improvements over time in news organizations’ success in meeting six of HNR’s 10 criteria for a successful health news story related to drugs, devices, surgery and other medical procedures, and diet; however, when data for television stories were excluded, only the improvement in avoiding disease-mongering remained significant. In addition, there was a statistically significant decline in the percentage of stories rated satisfactory on establishing the true novelty of the intervention discussed in the story. There was no improvement in quantification of possible harms from medical interventions" [24].

The latter findings also seem to be partially reinforced by similar health journalism research. In a 2000 study of 207 text and broadcast health/medical stories, "83 (40 percent) did not report benefits quantitatively. Of the 124 that did, 103 (83 percent) reported relative benefits only, 3 (2 percent) absolute benefits only, and 18 (15 percent) both absolute and relative benefits. Of the 207 stories, 98 (47 percent) mentioned potential harm to patients, and only 63 (30 percent) mentioned costs. Of the 170 stories citing an expert or a scientific study, 85 (50 percent) cited at least one expert or study with a financial tie to a manufacturer of the drug that had been disclosed in the scientific literature. These ties were disclosed in only 33 (39 percent) of the 85 stories" [25].

A 2003 study of 193 articles about newly approved drugs in Canada found: "overall, 62% (119/193) of the articles gave no quantification of the benefits or harms. Thirty-seven (19%) of the 193 articles reported only surrogate benefits. Other information needed for informed drug-related decisions was often lacking: only 7 (4%) of the articles mentioned contraindications, 61 (32%) mentioned drug costs, 89 (46%) mentioned drug alternatives, and 30 (16%) mentioned nondrug treatment options (such as exercise or diet)" [26]. Cassels et. al. concluded their findings raise: "concerns about the completeness and quality of media reporting about new medications" [26].

Similarly, Wells et.al. found: "newspapers tended to overrepresent support for screening mammography for women aged 40 to 49 years" [27]. Screening for breast cancer, of course, has been one of the most fraught issues covered by health care journalists for at least two decades. The results of Wells et. al.'s 2001 study, published two years before the inception of Health News Review, led its authors to conclude that "medical journalism may benefit from identification of standards similar to those used for reporting medical research" [27].

Health care reporters, particularly those on short deadlines, additionally tend to rely on a narrow range of sources. In a study published in 2018 that replicated the then 20-year-old Woodhull Study: "nurses were identified as the source of only 2% of quotes in the articles and were never sourced in stories on health policy" [28]. That led its authors to conclude: "nurses remain invisible in health news media, despite their increasing levels of education, unique roles, and expertise." While the latter findings may be shaped by the fact that nursing is a female-dominated profession and journalists tend to quote men more frequently, a gender skew seems insufficient to explain the study's overall findings.

There also is some evidence that health news stories which include external comments tend to feature less hyperbole. Bossema et. al. found: "the relative odds that an article without an external expert quote contains an exaggeration of causality is 2.6" [29]. While observational in nature, this study still suggests an argument to give reporters more time to find a diversity of opinions.

The net effect of these limitations and resource constraints is that coverage of medical research is often one-dimensional, oversimplified, and fails to provide readers and viewers with the kind of narrative and information that is desirable to improve public understanding about health and medicine. In turn, this begs two questions: if all of the aforementioned limitations impact the behavior of readers and viewers, which is discussed in section four; and what counter efforts are underway to advance health journalism, which is addressed in section five.

5. Does News Coverage Influence the Public's Health Literacy, Attitudes, and Behavior?

A 2002 Cochrane review found: "despite the limited information about key aspects of mass media interventions and the poor quality of the available primary research, there is evidence that these channels of communication may have an important role in influencing the use of health care interventions" [30].

Cochrane's conclusion has been reinforced by a handful of studies of specific medical news episodes that occurred before and after the 2002 Cochrane review. For example, a 2000 study linked "a decline of 1.4% in coverage of the MMR vaccine for children in [Wales] who reached their second birthday during the evaluation quarter (July to September 1998)" to "a protracted campaign against the MMR vaccine" in the South Wales Evening Post"[31].

In 2014 a study found: "during the 2009 H1N1 influenza outbreak in Israel, an increase in mass media coverage was associated with an increase in pediatric [emergency department] visits" [32]. And in 2016, Matthews et. al. found: "a period of intense public discussion over the risks:benefit balance of statins, covered widely in the media, was followed by a transient rise in the proportion of people who stopped taking statins" [33].

While the former research suggests a preliminary association between news editorial publicity and public behaviors, other research assesses whether news coverage impacts the public's understanding of how scientific research works. For example, Chang found: "overrepresenting findings with dramatized characteristics has negative implications not only for the target news but also for the scientific community in general" like "loss of interest or trust in science" [34]. Rezbach et.al. "found that frank discussions of uncertainty in stories about research didn't undermine public trust in science," suggesting that readers and viewers appreciate nuance [35]. Bott et. al. found including caveats and limitations within stories did not diminish their news value or interest to lay audiences [36].

Yet, other research about how health policy and other 'non-clinical' news is covered suggests outcome variables should be more comprehensive than changes in public behavior, awareness, or health literacy. For instance, the 2018 reporting of undisclosed conflicts of interest at Memorial Sloan Kettering Cancer Center was followed by the resignation of a top official there, as well as changes to the Center's related policies [37].

The example is part of a trend - there has been an increase in health news stories about research misconduct and fraud, and sexual harassment within research institutions [38-40]. While the latter work by journalists plays a key role in attitudes and potentially even behaviors as they reflect trust -- or lack of trust -- in our health care system, it is often less assessed (or well-contextualized) in terms of its contributions to scientific integrity and accountability.

An illuminating 2019 Pew Research Center survey provided some possible clues about how news coverage might influence public attitudes about medical practitioners and the underlying findings that guide clinical practice [41]. Pew's findings suggested Americans are not confident that researchers are transparent about potential conflicts of interest as well as skepticism "that those engaged in misconduct routinely face serious consequences." Pew also found: "Americans tend to trust science *practitioners*, who directly provide treatments and recommendations to the public, more than *researchers* working in the same areas" [41].

The latter suggests future studies regarding the mass media's effects on health literacy, public attitudes, and behaviors should incorporate more diverse stories and broadcasts that include coverage of health care policy and the medical research process, rather than just studies about interventions or publicity about a current public health risk. The latter also suggests the outcome variables of research should be broader than increases in public awareness, opinion, and health behavioral inclinations. One framework for such research might focus on the publish or perish incentives that drive so many problematic trends in both science and journalism [42]. The author will return to this theme in section eight of this chapter.

6. What Efforts Are in Place to Improve Health Care Journalism?

Fortunately, the flaws in medical journalism have not gone unnoticed by its practitioners, and a number of efforts are underway to improve professional practice. These efforts range from academic programs that offer degrees, to ongoing professional education for working journalists, to organizations that connect researchers to reporters and editors.

The Science, Health, and Environmental Reporting Program (SHERP) at New York University's Arthur Carter Journalism Institute, where the author has taught a medical reporting course since 2002, is one such program. SHERP, which offers graduate journalism degrees, was founded in 1982 in the wake of concerns that science coverage in the mainstream U.S. press was superficial or even wrong. SHERP students typically have some scientific background, from a bachelor's degree to a Ph.D., or work in a research-related role. The 16-month course of study includes everything from newswriting to critical analysis of studies and investigative journalism. Along the way, students intern at leading publications. The program's hundreds of alumni can be found in key roles at many of these publications, with regular bylines in The New York Times, Washington Post, and Wall Street Journal, among other top outlets.

Somewhat similar programs have been in place in the U.S. at MIT, and the University of California-Santa Cruz. The journalism programs at the University of North Carolina-Chapel Hill, and the Grady School of Journalism at the University of Georgia focus more on public and personal health than biomedical research reporting.

The Association of Health Care Journalists (AHCJ), of which the author is president at the time of this writing, was founded in 1998 to offer resources, training, and networking to working health care journalists. Its founders recognized a gap in career-long learning, and in the 21 years since, the organization has grown to nearly 1,500 members and a wide - and deep - set of offerings. Those include an annual conference that routinely draws more than 700 attendees, specialized workshops and fellowships on subjects ranging from cancer research to comparative effectiveness research, a busy electronic discussion list used daily to find sources and information, and more. A medical studies topic leader routinely guides AHCJ members through research, and the model of all of AHCJ's offerings is 'see one, do one, teach one,' with members generously giving their time to support the work of their peers. AHCJ's annual awards program recognizes the best of the best.

Health News Review represents another effort that strives to improve the state of health journalism. In addition to its thousands of reviews of news stories - and for a few years, press releases - the website included coverage of important issues in health care journalism, and tip sheets on subjects such as avoiding cause-effect language when writing about observational studies. The site's criticisms led several health organizations to change their policies on fundraising and oversight [43]. Regrettably, the end of philanthropic support means healthnewsreview.org is updated only infrequently as of December 2018.

The mission of the Center for Health Journalism, based at the University of Southern California, is to give journalists the resources they need to improve their work [44]. The Center for Health Journalism offers fellowships, including partnerships with media organizations, as well as grants, and helps journalists collaborate on larger projects.

Variations on Science Media Centers also have sprung up around the world. These organizations put together briefings on scientific subjects, often those that are more controversial, and connect vetted experts with reporters who need sources on deadline. While many reporters make use of these resources, as evidenced by the number of media center experts who appear in news coverage, some have expressed concerns that these organizations can limit discussion of problems in science and may be too allied with industry [45]. SciLine, supported by the American Association for the Advancement of Science, is a recent entry with a somewhat different model [46].

While this discussion is not exhaustive, it gives a sense of existing efforts and where gaps might persist. Regarding current gaps, there is a pressing need for programs that work with general interest editors and producers whose purview includes health coverage. Health journalism educational organizations have struggled to engage this group because of the demands on their time and because health care is just one of the diverse socio-professional topics for which general interest news editors are responsible. The influence of general interest editors is especially significant at smaller local and regional outlets that lack specialized reporters.

While progress is evident in the diversity of current initiatives, there are remaining opportunities to assist health journalists at entry to advanced levels.

7. Does Improving Health Journalism Really Improve Public Understanding?

While it is not controversial to say that spin provides a negative force in published studies, press releases, and stories and broadcasts, the evidence for the negative *effects* of such spin on the public's understanding of health care news has been assumed to exist, despite a lack of any prospective studies.

In contrast, Boutron has been leading the "first prospective meta-analysis of randomised controlled trials for interpretation of health news items reporting the results of studies with or without spin" [47]. The author is part of this effort, which eventually will comprise 16 randomized clinical trials [47].

As the authors describe in a paper reporting on the first three such trials: "We conducted three two-arm, parallel-group, Internet-based randomized trials (RCTs) comparing the interpretation of news stories reported with or without spin. Each RCT considered news stories reporting a different type of study: (1) pre-clinical study, (2) phase I/II non-RCT, and (3) phase III/IV RCT. For each type of study, we identified news stories reported with spin that had earned mention in the press. Two versions of the news stories were used: the version with spin and a version rewritten without spin. Participants were patients/caregivers involved in Inspire, a large online community of more than one million patients/caregivers. The primary outcome was participants' interpretation assessed by one specific question 'What do you think is the probability that 'treatment X' would be beneficial to patients?' (scale, 0 [very unlikely] to 10 [very likely])." We found that "Spin in health news stories reporting studies of pharmacologic treatments affects patients'/caregivers' interpretation." That was not a surprising result, but the authors felt that empirical evidence - or, had it not been present, the lack of empirical evidence - was important if policy and practice were being shaped [48].

Although there is observational evidence that spin in health press releases is linked to hyperbole in news reports, there has been a dearth of prospective evidence to test the hypothesis that better press releases would improve health news stories. As posted on Twitter, Chambers et. al.: “took press releases on health-related science, altered them before they were issued to journalists, and then studied what effect the changes we made influenced science reporting” [49].

Chambers’ results, published in BMC Medicine, found: “News headlines showed better alignment to evidence when press releases were aligned (intention-to-treat analysis (ITT) 56% vs 52%, OR = 1.2 to 1.9; as-treated analysis (AT) 60% vs 32%, OR = 1.3 to 4.4). News claims also followed press releases, significant only for AT (ITT 62% vs 60%, OR = 0.7 to 1.6; AT, 67% vs 39%, OR = 1.4 to 5.7). The same was true for causality statements/caveats (ITT 15% vs 10%, OR = 0.9 to 2.6; AT 20% vs 0%, OR 16 to 156). There was no evidence of lost news uptake for press releases with aligned headlines and claims (ITT 55% vs 55%, OR = 0.7 to 1.3, AT 58% vs 60%, OR = 0.7 to 1.7), or causality statements/caveats (ITT 53% vs 56%, OR = 0.8 to 1.0, AT 66% vs 52%, OR = 1.3 to 2.7). Feasibility was demonstrated by a spontaneous increase in cautious headlines, claims and caveats in press releases compared to the pre-trial period (OR = 1.01 to 2.6, 1.3 to 3.4, 1.1 to 26, respectively)” [50].

As relevant as these prospective findings are, they are insufficient to demonstrate that improvements in news stories foster changes in the public’s understanding of health, subsequent behaviors, or ensuing changes in public health as community health literacy improves. The future of research should be to initiate the latter types of studies, that by their nature will require a long follow-up which is mindful of some of the macroscopic initiatives suggested below.

8. Where to Go From Here

With apologies to scholars in health literature and health communication, I will now attempt to place the state of research into the effects of health journalism on health literacy and behavior into the context of a wider conceptual framework that encompasses research into health literacy and science communication.

In many ways, the issues described in the previous section of this chapter parallel efforts in health literacy and science communication. While these two fields have the benefit of decades of prospective scholarship demonstrating that evidence-based, well-tailored information can help audiences become more aware of relevant issues, one discipline -- health communication -- has found it challenging to show a therapeutic impact of awareness on subsequent health behaviors and clinical outcomes. The few studies that I have cited in this chapter that suggest associations among news exposure, public awareness, and healthy outcomes represent the rare exceptions that someday may prove the rule.

To cite a successful exception, a 2015 JAMA study found in one Maine county, the introduction of “community-wide programs targeting hypertension, cholesterol, and smoking, as well as diet and physical activity, sponsored by multiple community organizations, including the local hospital and clinician” were “associated with reductions in hospitalization and mortality rates over 40 years, compared with the rest of the state” [51]. While the Maine study suggests that health information campaigns can therapeutically impact health behaviors, the study suggests public health information interventions need to be lengthy to generate therapeutic health outcomes.

What typically makes successful efforts even more challenging is the growing evidence of the so-called ‘backfire effect,’ where awareness campaigns only bolster non-evidence-based opinions and behaviors. For example, one study of “three potentially effective strategies in vaccine promotion: one contrasting myths vs. facts, one employing fact and icon boxes, and one showing images of non-vaccinated sick children” found “existing strategies to correct vaccine misinformation are ineffective and often backfire, resulting in the unintended opposite effect, reinforcing ill-founded beliefs about vaccination and reducing intentions to vaccinate” [52]. In other words, the attempt to improve health outcomes could be counterproductive within some populations. It should be noted that in political science, an oft-cited study which demonstrated a similar effect was not found to be replicable [53-54].

In contrast to other disciplines that assess public health communication, health literacy researchers have suggested more frequent associations among public exposure to health information, subsequent improvements in health literacy, and improved clinical outcomes. To be clear, many of these improved outcomes occurred within the intervention groups of diverse clinical studies rather than in public health contexts. Yet, some of the suggested therapeutic outcomes even seem to occur without prolonged follow-up, unlike in health communication research. And health literacy is now considered a social determinant of health, which reinforces its importance.

At the risk of oversimplifying with a metaphor, a broad comparison of the research in the two fields suggests while health communication is treating the symptoms of a disease, health literacy may target the underlying cause. In turn, the latter could mean that journalism which helps readers and viewers better understand how to decide what is trustworthy information could improve health literacy, and thereby therapeutically impact health outcomes. Such reporting would include not just the findings of studies, but deeper dives into how science and medicine work, including a look at the incentives - financial and otherwise - that drive so much contemporary research.

As Timothy Caulfield has written: “science hype is a complex phenomenon that involves many actors. And it is, at least to some degree, the result of systemic pressures imbedded in the current incentives associated with biomedical research” [55]. For that reason, relying on what is published in the peer-reviewed literature may be necessary but it is insufficient. The clinical research literature is constrained by the very incentives and structures that should be the subject of external examination. It is akin to expecting a car with a speed limiter set to 65 miles per hour to accelerate to 85 miles per hour.

The latter view is consistent with how many health journalists tend to see themselves, and what differentiates them from health communicators [56]. Health journalists are often quick to note they are not educators, and their role is instead to hold institutions accountable, and represent the reader and viewer when interviewing sources. Thus, any education or improvement in health literacy that results from journalistic efforts becomes more of a byproduct rather than its initial goal. On the other hand, I am appreciative of any health journalism improvements that impact therapeutic changes in individual and public health.

Given the accelerating constraints on health care journalists, some may argue that it is time to focus more attention on this welcome byproduct and consider ways to boost it, not just because of the obvious benefits for the public but because it provides a greater rationale for health journalism resources.

However, the author suggests a push to define the quality of journalism by how readers and viewers absorb health information could create a risk that reporting on accountability will become further marginalized, just as in-depth reporting has been supplanted by superficial stories that editors, in a never-ending search for traffic, think readers will click on. While this is not an easy set of priorities to balance, I suggest health literacy researchers, health communication scholars, and working journalists find common ground that could benefit all three disciplines.

The metrics for success in such improvement are, to the author's knowledge, yet to be developed. It is not a matter of measuring comprehension of particular facts or figures, but instead measuring comprehension of how a system works, and what effects the workings of that system can have on its products, and on our health.

And the latter is not the only challenge. Engaging working journalists - a requirement of any effort like this - will be difficult because of the various demands on their time, and the fact that they do not have sabbaticals or research time naturally built in their careers. It might be necessary to create a program that allows journalists to have some time off without forfeiting their employment, much as journalism fellowship programs at universities once supported.

Overall, these efforts seem well worth it for all of health communication's diverse stakeholders. Arora, Rousseau, and Schwitzer, recently argued in JAMA that: "bolstering trust in journalism could help strengthen trust in medicine," suggesting that clinicians also should be added to the mix [57]. The latter authors encourage physicians and health's other stakeholders to support high-quality health care journalism engage media to amplify and share truthful stories, and actively correct stories that are not accurate [57]. I would add that stakeholders should support reporters who tell the stories of how science and medicine actually work, instead of glorifying breakthroughs, game-changers, and cures.

My hope is just as reporters should focus on studies and developments that matter, rather than superficial studies that simply assess what is easy to measure, researchers can do what is in their power to ensure that their studies focus on the more difficult - but critical - issues that are likely to improve individual and public health. Moreover, these efforts should be of mutual interest to policymakers, funders, and health care professionals.

In the interim, health journalists are standing by.

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Promoting Convergence Between Health Literacy and Health Communication

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Abstract. Health communication and health literacy are complementary areas of study and application. However, the important connections between the work conducted in these two related areas of inquiry do not appear to have always been well understood, nor appreciated, leading to limited integration and coordination between health communication and health literacy inquiry. Part of the problem may be that these two related areas developed from different professional trajectories, with health communication developing primarily from a social science orientation, and health literacy emerging primarily from a health professional application perspective. While health literacy grew out of the professional disciplines of medicine and education, health communication was undergirded by communication and social science research. Due to these different initial starting points, a lack of understanding has grown between these two areas of inquiry, resulting in a lack of appreciation for how well these fields fit together and how they can be mutually supportive in both research and applications. While there are many scholars who study both health communication and health literacy, some researchers are not well-versed in both areas, and do not understand how they can contribute to one another. In this chapter, the authors examine the parallel development of these two interdependent areas of study, trace their inter-connections, and propose strategies to enhance collaboration and integration within health literacy as well as health communication research and applications.

Keywords. Health literacy; health communication

1. Introduction

Although health communication and health literacy are highly complementary areas of study and application, the connections between these two related areas of inquiry do not appear to have always been well understood, nor appreciated, leading to a limited integration and coordination between two interdependent disciplines [1]. It often seems like the two fields of study are becoming more insular and disconnected. The authors suggest this is a serious problem, since these both areas of inquiry would benefit from

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closer collaboration and sharing of information and methods. This chapter examines the parallel development of the health communication and health literacy areas of study, addresses their inter-connections, and proposes strategies to enhance the convergence and integration between health literacy, health communication inquiry, and ensuing applications.

The disconnect between health literacy and health communication inquiry may be related to the different ways these two areas of research and application developed from unique professional trajectories. For example, health literacy developed largely from an applied health professional orientation, grounded in the evaluation of educational attainment, development of reading skills, and the effectiveness of delivering health care [2-4]. The latter professional orientation helped to ground health literacy inquiry in relevant real-world contexts where applications could be introduced to enhance health professional practices and policies [5].

Health communication inquiry, on the other hand, developed primarily from an academic research orientation, with strong contributions from the fields of communication science, other social sciences such as psychology and sociology, and professional academic fields such as medicine, public health, and psychotherapy [6-8]. The latter scholarly focus has enhanced the breadth of health communication inquiry, as well as the development of relevant health communication theories, research methods, and a large body of research literature [9-10].

Due to the different initial starting points between the study of health literacy and health communication, a lack of understanding has grown between these two areas of inquiry, resulting in a lack of appreciation for how these fields fit together and how they can be mutually supportive in both research and application. Although there are scholars who study both health communication and health literacy, some researchers are not well-versed in both areas, and do not understand how they can contribute to one another. In fact, there are separate conferences about health literacy and health communication research, separate journals, and limited cross-pollination between health literacy and health communication scholars. It is the authors' contention that greater transdisciplinary integration between health literacy and health communication inquiry can enhance the applications and rigor of work conducted in these two important and interrelated areas of inquiry [1,9].

To backup, the links between health literacy and health communication are crucial to understand because each ultimately impacts public health and clinical medicine. A 2006 American Medical Association Foundation and American Medical Association (AMA) report finds at least 50 percent of adults in the United States: "are at increased risk for serious consequences due to low health literacy" and 80 percent of medical errors are due to communication problems [1,11]. At risk individuals often mask their problems understanding important health information, which leads to a misunderstanding of health care instructions, prescriptions, and appointments, poorer health outcomes, increased medical costs, and medical errors in general [10]. Health literacy and effective health communication especially can impact vulnerable and at-risk populations. For instance, older adults have different communicative needs and desires as well as unique language, cognitive, physiological, and social issues compared to other age groups - and all of these directly and indirectly affect health literacy and outcomes [10]. The AMA report notes the common challenges in health literacy and health communication include: 1) patient difficulty to obtain, process, and understanding health information; 2) the health care system's complexity; 3) clinical practice pressures, such as limited time for provider/patient interpersonal communication; 4) cultural and language issues; and 5) lack of clinician training on effective communication strategies [11].

The objectives of this chapter are to: 1) briefly describe the unique development of health communication and health literacy fields; 2) describe the contributions of each field to the other; and 3) recommend ways to strengthen the integration of these fields. The authors hope this chapter promotes dialogue between health literacy and health communication scholars to encourage collaborations to advance both fields of study and improve health care and health promotion practice. To achieve these goals the following sections of this chapter will:

- Describe the unique evolution and areas of fruitful overlap between health literacy and heath communication inquiry;
- Introduce how the academic orientation in health communication inquiry has influenced the social scientific research focus and methods used in this area of study;
- Examine how the professional orientation of health literacy inquiry has encouraged an intervention-based orientation to this area of study;
- Draw conclusions about ripe areas for convergence between health literacy and health communication inquiry;
- Recommend specific action strategies and directions for promoting convergence between health literacy and health communication inquiry that has the potential to enhance the quality and influence of health literacy scholarship (research, education, and applications).

2. Evolution and Areas of Overlap/Difference Between These Areas of Inquiry

The study of health literacy and health communication each focus on examining the communication of relevant health information to promote therapeutic health outcomes. Nevertheless, there are some key variations in the development, focus, and methods used between these two interrelated areas of inquiry. In this section, the authors introduce some of the key similarities and differences between the two areas of study and suggest an integrated approach to examining the best ways to use communication to promote health.

While the issue of promoting the understanding of relevant health information is a central part of the study of health communication, health communication scholars also focus more broadly on assessing other related communication issues. Some of the other related areas of health communication inquiry include: studying the role of communication in social influence/persuasion (such as promoting health behavior change); health information seeking and scanning; disseminating health information; seeking and providing social support; using social networks to access health information; cultural factors in health communication; international and global health promotion; interpersonal communication between clinicians, patients, and caregivers; health communication campaign (interventions); health education; health communication media and channels; coverage of health information in news, entertainment, and social media; relationship development between health care providers and consumers; health advocacy; risk, crisis, and emergency communication; family communication related to health; informal caregiving and advocacy; communication in health care teams, managing communication and sharing information within health care delivery systems;

and coordinating activities between health care delivery systems and other related social systems (such as suppliers, regulators, payers, etc.) [12-13]. Health literacy issues are germane to each of these health communication research focus areas, so it makes sense to integrate the targeted examination of understanding health information with the broader examination of the many ways that communication is used in the delivery of care and promotion of health [1].

In contrast, health literacy inquiry traditionally has focused on patient/caregiver/consumer understanding of relevant health information, both in the delivery of health care to patients and in educating diverse populations about disease/illness prevention issues [14]. There has been a strong emphasis in health literacy research and practice to help consumers develop functional health literacy skills to enhance informed health decision making and to improve health outcomes [15]. There is a strong pragmatic rationale to address the complicated and relevant issues related to promoting health care consumer's comprehension of relevant health information, especially given widespread consumer misinformation in health care and health prevention, especially among many vulnerable and at-risk populations [16]. There also has been a growing interest in institutional and relational communication factors needed to communicate relevant health information effectively to consumers, broadening the focus of health literacy studies [1,10,14,16].

The authors recommend greater attention by health literacy and health communication scholars and practitioners to the areas of overlap and shared interest between these two interrelated fields of study and to draw on the unique strengths and contributions from each area. Health communication scholars can benefit from examining the ways that health literacy programs, tools, and policies have been implemented within health care systems to enhance consumer understanding of relevant health information, building on the successes in translating health literacy research into practice [5]. Health literacy researchers can expand the scope of their work by applying many of the key findings from the broad body of health communication research concerning consumer-provider interactions, health promotion strategies, and health care system communication, as well as the use of health communication theories and diverse research methods to understand how communication impacts the consumer understanding of health information [16-20].

For example, there are several evidence-based health communication models and theories that can be usefully applied to guide health literacy research. The Relational Health Communication Competence Model (RHCCM) provides a theoretical perspective that combines relevant aspects of health communication and health literacy research [21-25]. The model was first introduced by Kreps in 1988 to describe and predict the influences of the quality of interdependent consumer-provider communication to achieve specific health outcomes [21]. The model describes communication interactions between key participants in health care and health promotion activities and explains how higher levels of communication competence skills: establish cooperative health care relationships; boost the intra-professional and inter-professional sharing of relevant health information; help consumer make informed health care decisions; and assist the coordination of initiatives (in health education and other areas) to achieve desired health outcomes. The suggested relationships between the quality of interpersonal communication and health outcomes have been validated by health communication researchers [22-25]. RHCCM provides a conceptual framework that illustrates the connections between communication inquiry (concerning key interpersonal communication encoding and decoding skills) and improvements in health understanding, cooperation, and health promotion.

Other frequently used health communication theoretical perspectives that are relevant to health literacy inquiry include the Elaboration Likelihood Model (ELM), the Communication Privacy Management (CPM) theory, and Weick's Model of Organizing. The Elaboration Likelihood Model (ELM), introduced by Petty and Cacioppo, describes how adults interpret health messages and information through a central (direct) route and a peripheral (indirect) route. The ELM is used by health communication researchers to explain how consumers make sense of and are influenced by health messages [26-28]. Specifically, the ELM helps researchers understand whether health messages are likely to be interpreted centrally or are likely to be interpreted peripherally, which ultimately influences the consumer understanding of health messages.

The Communication Privacy Management (CPM) theory, introduced by Petronio, examines the boundaries that influence the sharing of health information, as well as strategies to preserve information privacy and respond to violations of privacy [29]. CPM represents a theoretical perspective to assess health communication challenges, especially in scenarios where the personal sensitivity of health information influences a consumer's understanding of messages [30-31].

Similarly, Karl Weick's Model of Organizing explains how the level of equivocality (complexity) of information demands specialized forms of communication that impact consumer interpretation and response to complex health challenges and situations [32-35]. For example, Weick's Model of Organizing helps assess the best communication strategies to manage uncertainty (in Weick's terms, equivocality) in order to promote consumer understanding of complex health information.

Within health literacy research, there is a reservoir of applied interventions that develop and field-test innovative assessment tools, educational programs, and health care delivery strategies to address health literacy challenges (36-38]. Baker's work suggests some powerful associations between health literacy and health outcomes and provides important information about the influences of health communication to achieve specific health care goals [39-40]. More specifically, Baker and his colleagues suggest a 'teach to goal' communication intervention helps heart failure patients understand the information needed to manage their illness, which additionally provides a specific example of a provider-patient health educational initiative [40]. In addition, the Health Literacy Universal Precautions Toolkit (described by DeWalt and colleagues) provides health communication scholars with several robust communication intervention tools to use in applied healthcare delivery studies [41]. Other health literacy intervention studies (designed to improve patient understanding of prevention, diagnosis, and treatment information) are especially relevant to patient empowerment, informed health decision making, health education, and adherence to treatment regimens (42-44).

3. Examining the Influences of the Academic Orientation of Health Communication Inquiry

Health communication inquiry developed as an applied social scientific area of study (within the larger field of communication studies) that uses both qualitative and quantitative research to examine the diverse ways that communication influences health, health care delivery, and health promotion [45]. Since health communication was introduced in the 1970's, it is a generation older than health literacy research and features a body of scholarly literature advanced in many nations and cultures. Health communication research is published in a variety of scholarly outlets representing the fields of communication, health sciences, public policy, computer science, and a variety of social sciences, and often focuses on identifying, examining, and solving health risk, health care, and health promotion problems. Health communication scholars frequently evaluate the influences of communication practices and policies on health care and public health, often using the gathered data to enhance the delivery of health care and enhance interventions designed to deter health risks.

The study of health communication is interdisciplinary and combines as well as applies important theories, concepts, and methods from diverse areas of communication science (such as the study of language and behavior, interpersonal communication, group/organizational communication, persuasion, media studies, intercultural communication, and new communication technologies), as well as from the diverse academic fields of public health, health education, health psychology, medical sociology, medical anthropology, health economics, epidemiology, and medical informatics. Health communication also draws liberally from the literature and theories within health professional fields, such as medicine, nursing, social work, and clinical psychology. *Health Communication*, a five-volume reference work published in 2010, identifies five primary areas of health communication inquiry across multiple levels, channels, and settings for communication: (1) health communication in the delivery of care; (2) health communication and health promotion; (3) health risk communication; (4) health communication and new information technologies; and (5) health communication and the health care system [46-50].

Moreover, there has been a commitment within health communication inquiry to conducting basic (or theoretical development) research to explicate key models and evaluate the relationships among the diverse constructs and variables involved in health communication processes.

In contrast, health literacy research has been more atheoretical and has focused on the individual and institutional challenges that impact the understanding of health as well as health outcomes and consumer utilization of the health care delivery system.

Despite disciplinary differences, there is a natural synergy between the basic and applied orientations of health communication and health literacy research that could elevate both disciplines [1,51-52]. For example, Johnson, Baur, & Meissner posit the need to combine basic and intervention research approaches to develop effective health literacy intervention programs, which suggests an opportunity to combine basic health communication research with more applied health literacy studies [51]. Similarly, Logan describes the need to develop a multidimensional conceptual approach to studying health literacy that could draw from basic research and the developments of theoretical frameworks within the health communication field [52].

Scholars in health communication are well equipped to conduct studies using a variety of methodological skillsets to examine complex research questions, frequently combining and triangulating relevant quantitative and qualitative research methods in sophisticated multimethodological research designs [53-55]. From a measurement perspective, health communication scholars can develop rigorous and comprehensive measurements of not only health literacy, but also evaluating the effectiveness of programs and interventions intended to increase health literacy and improve patient-provider communication [56-58]. Health communication scholars also can supply a diverse methodological toolkit that can be used to evaluate health risks, assess the impact of health information programs, as well as measure how diverse outcome variables impact health outcomes and utilization of the health care delivery system.

Health communication scholars provide expertise in social influence, persuasion, social marketing, and behavior change interventions. Given the interdisciplinary nature of health communication, its researchers are privy to a wide range of theoretical and practical knowledge such as behavior change, social marketing techniques, and intervention design [59-61]. As Pleasant has explained, health literacy is not just a matter of individual skill but motivation [62]. In terms of desired outcomes, it may not be sufficient to write materials for low health literacy levels, or even to improve the cognitive skills needed to find and understand health information. Health literacy scholars can benefit from a strong grounding in social influence research that has been conducted in health communication to help increase the motivation and self-efficacy needed to seek, understand, and use health information more effectually [16,62].

Within health communication scholarship, the study of health risks and crisis communication represents a specific area that is relevant to health literacy research. Health risk and crisis communication are growing research areas that can be used to guide health communication strategies relevant in public health challenges. These include the prevention and effective response to health risks and crises, such as the spread of infectious diseases, natural disasters (floods, hurricanes, droughts, hurricanes, tsunamis, volcano eruptions, forest fires, etc.), industrial accidents, and acts of violence, warfare, and terrorism. Policy makers, media representatives, and emergency response personnel need to promote clear, relevant, meaningful, timely, and influential risk and crisis communication to diverse audiences who confront health emergencies (both professional and public audiences) [63- 67]. The building of an evidence-based to address public health risk challenges represents a ripe area for cooperation between health communication and health literacy scholars.

Health communication scholars also provide a half century of research about mediated health communication, which examines the influences of print, radio, television, film, and digital media communication channel dissemination of health information in society (such as news, entertainment, web-based, social, and mobile media systems) [68]. The effectiveness of mediated health information systems depend on how well key audiences can understand and apply relevant the health information disseminated by these channels to guide important health decisions [68]. Thanks to prior health communication research there is an evidence base about how the mass media: cover health issues; disseminate health information; influence health behavior change; provide social support; and can help deliver health promotion interventions [68]. The rapidly growing area of e-health communication also has provided recent evidence-based research regarding how social media and apps impact individual and public health [68-71]. A combination of health literacy and health communication research would boost the evidence to design mediated health messages that are appropriate and meaningful for intended audiences and anticipate distinct responses among diverse populations [72-76].

4. Examining the Influences of Professional Orientation on Health Literacy Inquiry

While health communication evolved largely from the social sciences disciplines as an academic research field, the field of health literacy emerged as a professional response by healthcare providers to persistent challenges regarding poor patient comprehension of health information, instructions, and counsel [77-79]. This section provides more information about the significant expansion of health literacy definitions, frameworks, research methods and practice applications in the 21st century [80].

Beginning in the late 1980s, a growing consensus developed among many healthcare providers that many patients lacked the abilities to understand and use the health information they received, making them more vulnerable to poor health outcomes [77]. As healthcare providers' concerns about patient literacy barriers mounted, the concept of health literacy emerged. It began to receive U.S. national attention after the publication of the 2003 National Assessment of Adult Literacy (NAAL) [78]. The latter U.S. population-based survey assessed both adult literacy and health-related literacy skills and notably found health-related literacy skills represented a separate research construct. To put this another way, the NAAL findings strongly suggested the assessment (and advancement) of adult, teen, or child literacy and health literacy were dissimilar and should be addressed via separate platforms of research and practice. The NAAL's findings also suggested about 44% of adults (more than 90 million Americans) had low levels of health literacy and were unlikely to understand basic health information, such as medication instructions. The NAAL results additionally found only 12% of the US population had the 'proficient' skills needed to understand and use health information within the demands of the healthcare system (e.g. making informed choices about health insurance).

In 2004, the U.S. Institute of Medicine (National Academy of Medicine-NAM) convened an expert panel to review the nascent evidence about health literacy which generated: Health Literacy: A Prescription to End Confusion [79]. The report defined health literacy as: "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." The World Health Organization (WHO) proposed a slightly different definition, provided earlier by Nutbeam, that referred to health literacy as: "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health" [3]. Both the NAM and WHO recognized health literacy as comprising cognitive and psychosocial abilities that are antecedents to health behaviors.

The initial study and practice of health literacy focused at the individual level and often assessed how well patients, caregivers, and consumers understood health terms and information. The latter research assessed individual health literacy skill levels in order to identify when people exhibited low or limited health literacy [14-15,39,52,81-82]. Other research investigated the associations between people's health literacy levels, their risk of poor health outcomes, and consumer utilization of the health care delivery system [83]. Health literacy research also identified important relationships between health literacy levels and an individual's health knowledge, attitudes, behaviors, outcomes, and disparities [84-85].

A systematic review conducted by the U.S. Agency for Healthcare Research and Quality (AHRQ), further associated limited health literacy with specific problems such as: increased hospitalizations; greater emergency care use; lower use of mammography; lower receipt of influenza vaccine; less ability to demonstrate taking medication appropriately; less ability to interpret labels; reduced ability to understand health messages; and, among seniors, reduced health status coupled with higher mortality rates [36]. Importantly, the AHRQ review added there was sufficient evidence to suggest health literacy is an independent predictor of health outcomes and suggested health literacy is an intermediate variable that mediates among the other social and structural determinants of health [36,39,52,84].

To back up, health literacy research includes efforts to assess the relationships among health literacy skills and the capacities of patients, caregivers, and consumers to understand complex health/medical information. More than 1,000 studies of health print materials (including medication labels) and websites suggested text readability significantly exceeded the estimated health literacy skills of the audiences for whom they were intended [82]. The latter findings prompted efforts to define health literacy principles to help design and assess 'plain language' communications. These include reducing reading levels and improving syntax, cultural appropriateness, and format for easier comprehension. Descriptions of these recommended practices are provided by the U.S. Centers for Disease Control and Prevention (CDC) and AHRQ [38,41].

In one of health literacy's few comprehensive research models (or conceptual frameworks), Paasche-Orlow and Wolf proposed a causal pathway describing how an individual's socio-demographic characteristics was linked to his/her health literacy level, which, in turn, impacted his/her access to (and use of) health care, self-care, and eventual health outcomes [83]. The Paasche-Orlow/Wolf conceptual framework (and its evidence base from the NAAL study, the AHRQ systematic review as well as other examples) provided a foundation of what Logan termed the ongoing 'first platform' of health literacy research and practice, which focuses on the skills and capacities of the persons who utilize the health care delivery system [52].

Alternatively, health literacy's 'second platform' has addressed the factors within the health care delivery system that impact patient, family, and provider health understanding and communication skills, such as whether healthcare settings are 'health literate' (easy to navigate, welcoming. and 'shame free') [84]. Hence, the second platform recognizes that health literacy efforts within health care organizations are one within an array of enduring 'structural' determinants of health [37]. Some other organizational 'structural' health determinants include: the institutional capacity to handle adverse events, provider-based medical errors, and patient discharge instructions (all of which can impact health outcomes).

The addition of a second platform adds some health literacy antecedents and consequences - and partially shifts the burden for health care and wellbeing from individuals to a shared responsibility among healthcare providers, health care organizational structures, and health care policy makers [84-85]. The second platform also fostered some new health literacy initiatives, such as assessing whether a healthcare organization meets the '10 attributes of a health literate organization' [84].

The evolution of the second phase of health literacy research and practice resulted in new definitions and more sophisticated models, summarized by Sorensen and colleagues, as well as new research variables and strategies consistent with the field's conceptual expansion (See Boston University's Health Literacy Tool Shed accessible at: http://healthliteracy.bu.edu) [86-87].

More recently, a third platform of research and practice has suggested health literacy is one of the societal factors that impact people's health and health outcomes [52]. The societal factors that impact individual and public health often are called the 'social determinants' of health. The third platform of research and practice partially seeks to assess the degree health literacy is a social determinant of health compared to other identified social determinants such as: income; education; employment; geographic residence; surrounding environment; race/ethnicity; discrimination; and other socio-cultural and socio-economic factors [43,88].

The third health literacy platform suggests the first two (individual and organizational) are situated within a larger social framework in which health literacy can be a mediator or moderator of health outcomes. The social determinants of health are hypothesized to operate within the public health 'social-ecological' model at multiple individual, family, interpersonal, neighborhood, institutional, cultural and societal levels over the life course [89-90]. Individual determinants can operate within and across multiple levels and interact with other determinants [52]. Currently, health literacy and public health scholars are developing concepts of 'public health literacy' that expand the understanding of how health literacy interacts with other health determinants [91-92].

Overall, the development of health literacy's conceptual and applied dimensions within all three platforms represents an effort to depict the construct of health literacy more holistically as well as assess how health literacy interacts with diverse health influences within a large number of nested factors. In turn, Logan suggests an enduring quality of health literacy may be that it represents a rare indicator and interventional variable that operates across the individual, structural, and social dimensions of health [52]. In addition, there are some examples of health literacy interventions that draw on all three platforms. For instance, an intervention with migrant factory workers in Changzhou, China, was grounded in the public health social-ecological model, and used health literacy principles to create written communications, improve interactions between workers and providers, overcome structural barriers to healthcare access, and address social issues [93]. Early results show improvements in many worker health areas [93].

The efforts to improve the assessment of health literacy (generated within all three platforms) also have eclipsed the initial measures that focused on reading comprehension skills [94-96]. Most of the criticism of health literacy acknowledges a need to move beyond improving the measurement of health literacy skills to develop more comprehensive strategies to address and evaluate health literacy's role in medicine's and public health's contemporary challenges [97-98].

5. Directions for Transdisciplinary Convergence of Health Literacy and Health Communication Research

The authors suggest collaborations among health literacy and health communication scholars, which are partially addressed in this section, can synergistically enhance conceptual depth, methodological rigor, and the strength of research applications in both fields [1,9,52,82,84,98]. Health literacy and health communication are ideally suited for transdisciplinary collaborations because of a shared focus on promoting effective communication in care delivery as well as their complementary strengths in terms of relevant theories, research methods, interventions, and grounding in health care/promotion contexts, professions, and policies [9,52,84,99].

As aforementioned, applications of theoretical models, such as the Relational Health Communication Competence Model (RHCCM) and the Communication Privacy Management (CPM) Theory could be used to increase understanding about the unique individual and relational communication factors that impact the understanding of (and response to) health information [25,29]. The latter work also could help overcome a key weakness of health communication intervention initiatives that are often expert-designed/directed, overly generic, and not adapted well to the unique individual needs of the users [73,100].

Moreover, the authors identify five additional areas for collaborative work between health literacy and health communication. Some suggested collaborative initiatives include:

5.1. Convergence between Health literacy and Health Communication can Provide Insights about How People can Use Communication to Overcome Literacy Barriers

A broad array of health literacy principles can be applied to provide evidence-based guidance to align communication efforts with people's needs and preferences [16,96]. For instance, at the first conference on artificial intelligence and health communication (held in 2011 at Stanford University), the diffusion of new technologically-advanced digital health communication applications were not based on health literacy and health communication principles [101-102]. As a result, the health communication applications often did not meet user expectations or improve health outcomes. Developers commented they would welcome health literacy and health communication expertise on their teams. Similarly, the need for collaboration to guide the development of consumer health information applications is growing as computer science, engineering and bioinformatics programs become more sophisticated and common in health care and health promotion.

5.2. Convergence between Health Literacy and Health Communication Scholarship can Improve Patient-Provider Communication

Health literacy research has identified specific interpersonal challenges that are underexplored in the health communication literature, such as the provision of informed consent to patients [103]. Similarly, health communication research provides insights into how to advance and maintain patient/provider and other interpersonal relations within health care venues [21-22,25]. When combined, the fields provide an inventory of practice-based strategies to address enduring challenges, such as the use of 'teach-back' methods, avoidance of jargon, use of simple illustrations, use of understandable ways to deliver numeric health information (address 'health numeracy'), and enhance web usability. Also, both fields cover practices designed for diverse health care stakeholders, that include the pharmaceutical and medical device industry [44,104].

5.3. Collaborative Work can Enhance Understanding about Patients' Needs, Abilities to Access, Utilize Health Information/Messages for Critical Health Decision-Making

Some areas within both the health literacy and health communication fields help patients locate and then evaluate health information for credibility and quality, analyze relative risks and benefits, calculate dosages, interpret test results, and so on. Health literacy research provides insights into how consumers access and understand information and services, which can constructively impact patient and provider interaction [105]. Health literacy strategies additionally can improve written and oral informed consent processes [42,103].

5.4. Collaborative Efforts can Enhance the Understanding of How Healthcare Environments Affect How People Manage their Healthcare and Understand Information

Health literacy research helps identify the associations between organizational factors and intermediate health outcome factors such as whether people keep appointments, feel comfortable in healthcare interactions, become engaged in health decision-making, and understand and act on health advice. Further, the '10 attributes of a heath-literate organization' provides a blueprint for effective organizational change that had not been previously available within the field of health communication [37]. The latter is a fruitful area to explore within health communication, such as to enhance the effectiveness of risk communication in healthcare contexts by creating 'shame-free' environments.

5.5. Convergence between Health Literacy and Health Communication Inquiry Can Promote a Better Understanding of the Need to Address the Social Determinants of Health

The hypothesis that health literacy is one of the social determinants of health opens the opportunity for health communication scholars to find explanatory variables that mediate or moderate between communication factors and health outcomes. The hypothesis that health literacy is a social determinant of health additionally provides an opportunity to explore the degree that diverse social determinants impact health outcomes within vulnerable and other populations. While the latter determination will require sophisticated qualitative and quantitative handiwork, it opens the opportunity for health communication and health literacy research to contribute to the understanding of health disparities and the underlying factors that impact public and individual health.

6. Specific Recommended Actions to Promote Transdisciplinary Convergence between Health Literacy and Health Communication Scholarship

In this section, the authors briefly identify five opportunities to advance the convergence between health literacy and health communication fields.

6.1. Establish Active Collaborations between Health Literacy and Health Communication Scholars on Joint Research Projects, Perhaps as Transdisciplinary Members of Research Teams

6.2. Sponsor Targeted Research and Practice Conferences that Focus on the Interrelations between Health Literacy and Health Communication Inquiry

The annual National Conference on Health Communication, Marketing, and Media (sponsored by the CDC) is an ideal interdisciplinary conference that can promote transdisciplinary convergence. Smaller targeted health communication conferences, such as the biennial Kentucky Health Communication Conference (offered on even years) and the DC Health Communication Conference (offered on odd years) can be designed to focus on areas of convergence between health literacy and health communication. Similarly, there are several annual health literacy conferences that can be designed to promote transdisciplinary convergence, such as the conference sponsored by the Institute for Healthcare Advancement (iha.org) the research-focused HARC conference, and the forthcoming meetings of the International Health Literacy Association (i-hla.org).

6.3. Create Special Theme Issues of Health Literacy and Health Communication Journals and Books that Publish Articles that Illustrate the Connections between Health Literacy and Health Communication

6.4. Offer University Classes that Examine the Connections Between Health Literacy and Health Communication Research and Applications

6.5. Encourage Health Communication and Health Literacy Scholars and Practitioners to join Teams of Public Health Promotion, Computer Science, and Bio-informatics Developers who Create Mediated Health Applications

An example is provided by the transdisciplinary team who developed health applications for patients with Crohn's disease and for their providers [106]. The team included health communication and health literacy experts, application developers with artificial intelligence expertise, public health researchers, and others.

7. Attention Areas for Transdisciplinary Convergence of Health Literacy and Health Communication

In the chapter's final section, the authors suggest researchers should more frequently address the *dynamic* nature of health literacy and focus on the cognitive and social skills needed to improve functioning in the healthcare environment, which impacts health outcomes [62,107]. The current evidence suggests health literacy levels reflect more than an enduring 'trait' condition. Health literacy levels are influenced by a number of situational 'state' conditions, such as changes in an individual's health conditions, emotional states, and environmental conditions (which need to be accounted for to improve health communication efforts) [108].

In addition, the authors suggest health literacy's disciplinary growth inevitably is linked to its theoretical grounding, which is needed to contextualize its evidence base. Although several major theories of health communication and health promotion address the importance of self-efficacy and response efficacy (such as the Trans-theoretical Model, the Health Belief Model, and the Extended Parallel Process Model), these theories have not been utilized to their full potential to inform how health literacy functions in contexts that include patient/provider and other interactions [109-111]. In their call for increased efforts toward conducting basic research on health literacy, Johnson, Baur, and Meissner reinforce the need for health literacy researchers to ground their research in existing theory or to propose newer, more comprehensive models [51].

A pressing need for improved intervention designs and consistent measurement strategies additionally has been identified by health literacy researchers [95]. For example, critics note some widely used measures of health literacy assess how individuals obtain, understand, and apply health information in their everyday lives [62,96]. Yet, McCormack, Huan, Sorensen, and Valerio propose improved measures of health literacy might include the evaluation of: health status; attitudes; motivation; self-efficacy; emotions; culture; socioeconomic status; and other ecological factors [94]. McCormack and colleagues add: "to effectively monitor health literacy over time, examine its relationships with key variables, and promote stability across studies, more widely accepted measures… are needed" [94, p.13]. Meanwhile, the development of a conceptual model of health literacy that accounts for individual, group, and population-level characteristics would provide clarity and rigor to a rapidly growing area within health communication [94]. A universally accepted and validated measure of health literacy also could augment the evidence regarding the effectiveness of health interventions [62]. In order for health communication scholars to truly engage in health literacy scholarship, a measurement instrument must be developed and validated which better accounts for the dynamic, fluid nature of health literacy.

Finally, effective health communication is inextricably linked to health literacy. The synergistic convergence of these two areas of study can encourage improvements in health goals across the continuum of care; promoting healthcare prevention; informing detection and diagnosis; guiding treatment; supporting successful survivorship; and even promoting end-of-life care – which in aggregate, can lead to better health outcomes [99]. The authors are eager to work with colleagues to help achieve these important goals!

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Beyond the Bench and Bedside: Health Literacy Is Fundamental to Sustainable Health and Development

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Abstract. Thirty years after the Ottawa Charter for Health Promotion, the 2030 Agenda for Sustainable Development - predicated on seventeen Sustainable Development Goals (SDGs) - were unveiled to the global community. Health literacy is an essential precondition and indicator of achieving the SDGs. Efforts to define and describe health literacy within public health and medicine have identified that the skills and abilities of many populations are inadequate to navigate the demands and complexity of health and healthcare. The authors suggest health literacy must move beyond the bench and bedside in clinical practice to achieve the aspirations and objectives of the SDGs.

This report synthesizes major developments in health literacy and draws from related disciplines to propose opportunities and future directions to improve health literacy across the lifespan. It introduces the cases of early childhood vaccinations; alcohol intake in adolescence; and dementia care in older adults to demonstrate the need for health literacy across the life course. It also draws on digital health data and technology and multisectoral partnerships to define the future of health literacy. The authors believe these approaches can and will lead to unlikely collaborations that advance health and well-being throughout and beyond the 2030 Agenda for Sustainable Development.

Keywords. Health literacy, communications, digital health technology, data-driven approaches, multisectoral engagement,

1. Introduction

In 1986, Member States of the United Nations congregated in Ottawa, Canada for the First International Conference on Health Promotion. Its seminal output was the Ottawa Charter for Health Promotion, which included provisions to achieve Health for All by the year 2000 and beyond [1]. Thirty years later in 2016, the global community pledged support to the United Nations 2030 Sustainable Development Agenda. Seventeen Sustainable Development Goals (SDGs) were advanced to help facilitate coordinated action to end poverty, protect the planet, and ensure peace and prosperity [2]. With regards to human health, the third SDG focuses on advancing “good health and well-being” [2].

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While not explicitly included in the indicators or targets of the SDGs, health literacy - defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" - is essential to achieving the economic, environmental, and social ambitions of the SDGs [3]. Better health literacy across all populations underpins improvements in the other SDGs, including eradication of poverty and hunger, quality education, and reduced inequalities [4]. Achieving the SDGs will require a dedicated focus on health literacy by all actors in global partnership to ensure no one is left behind and to deliver universal health coverage.

Despite increased multisectoral interest and compelling scientific evidence regarding the effectiveness of health literacy, the inadequacy of the skills and abilities of individuals to navigate the demands and complexity of health and healthcare persists. While these concerns affect communities in the United States (U.S.) and many other high-income countries, the gap is particularly acute in low- and middle-income countries (LMICs) that are often characterized by underdeveloped health systems. Within both contexts, the ability for individuals to prevent and manage complex and costly diseases is limited by poor health literacy. Beyond the individual, however, equal attention must be targeted on governments and healthcare systems to provide accurate and accessible health information [4].

Realizing the need for improved health literacy in achieving the SDGs during the next thirty years and beyond, this chapter synthesizes major developments and proposes opportunities and future directions for health literacy across the lifespan. It uses the cases of early childhood vaccinations; alcohol use in adolescence; and dementia care in older adults to demonstrate the need to develop health literacy across the life course. It also draws on digital health data and technology and multisectoral partnerships to define the future of health literacy. The authors believe this can and will lead to unlikely collaborations that advance health and well-being throughout and beyond the 2030 Agenda for Sustainable Development.

2. Moving Beyond Definitions and Research

Since the turn of the 21st Century, health literacy has gained momentum as a necessary precondition and indicator of a well-functioning healthcare system that prevents, manages, and treats disease. An April 2019, simple search on Google Scholar shows a total of 217,000 results for the term "health literacy," with only 99,200 results for "media literacy" and 49,900 results for "science literacy" through similar searches.

In an attempt to clarify and coalesce global public health and medical sciences academics and practitioners around health literacy, various definitions have permeated the literature. These definitions are focused in two areas: (1) health literacy as a continuum between high or low levels of literacy; and (2) health literacy as a multidimensional concept focused on the interaction of skills within broader social and cultural contexts [5]. This divergence had resulted in lack of unity around a common definition of health literacy [6]. Notwithstanding definitional agreement, reviews of the health literacy literature conclude Ratzan and Parker's aforementioned definition has been the most cited [3,6]. Within the U.S., this definition has been adopted by the Department of Health and Human Services, the National Academies of Sciences, Engineering, and Medicine (formerly the Institute of Medicine), and the National Library of Medicine [3,7-8]. It also was the definition used in the U.S. Patient Protection and Affordable Care Act of 2010 [9].

The natural question is: to what extent are varying definitions consequential for accelerating action and progress in improving health literacy among disparate global populations? The authors contend an approximate definition is adequate for moving the field from definitional semantic debates to sustained practical action on health literacy. In the next section, we review past developments in public health clinical practice and policy reforms to provide a foundation for accelerated action on health literacy.

3. Public Health Clinical Practice and Policy Reform: Building on Progress

The term health literacy was first used in 1974 to describe the impact of health education on both healthcare and education systems and outcomes [10]. Since then, various models (such as functional, interactive, and critical health literacy) have been proposed to identify and delineate and relationship between health literacy and the healthcare and education systems [11-12]. The integration of health literacy into public health and clinical care practice has led to progress in developing health literacy into a field that interacts with the healthcare and education systems. The latter has entailed cataloguing the problem, proposing definitions, encouraging health literacy as a mechanism to decrease healthcare costs, improving the quality of healthcare, and reducing disparities. It also resulted in assessment tools for measuring health literacy [13].

More recent efforts to promote health literacy commenced in the early 2000s. In 2004, the U.S. Institute of Medicine summarized the medical literature on health literacy to establish that: “efforts to improve quality, reduce costs, and reduce disparities cannot succeed without simultaneous improvements in health literacy”[8]. The Institute of Medicine additionally proposed a model to describe how individual health literacy skills can be influenced by culture and society as well as the health and educational systems [8].

In 2006, the first health literacy assessment tool was developed; the U.S. National Assessment of Adult Literacy [13]. This served to collect longitudinal data on the health literacy of adults living in the U.S. These early academic efforts eventually were integrated into public health education. One example is Columbia University’s Mailman School of Public Health, which proposed a “Public Health Oath” in 2008. This oath articulated the professional commitment and guiding principles for students, graduates, and faculty in public health. It explicitly called out health literacy: “I will advance health literacy for all and seek equity and justice for vulnerable populations” [14].

As health literacy gained momentum in academia, it also infiltrated national health policy reform. A “blueprint for change” to achieve a health-literate America was proposed in 2003. This included four policy-oriented strategies to advancing health literacy: (1) research and measurement; (2) reducing health disparities; (3) engaging the federal government; and (4) improving medical practice [15]. These efforts led to Louisiana becoming the first U.S. state to pass health literacy improvement legislation in 2002 [16].

While a majority of the literature and policymaking on health literacy has occurred within the U.S., advances in other parts of the world have occurred. Although 15 percent of the literature on health literacy has been generated in the European Union (EU), the European Centre for Disease Prevention and Control (an agency of the European Union) actively promotes health literacy [17-18]. In response to the EU’s public consultation on a legal proposal to provide health information to patients, the European Federation of Pharmaceutical Industries and Associations (EFPIA) (a coalition of national associations and pharmaceutical companies leading the research-based pharmaceutical industry in Europe) advanced the need to place product information within a broader context to improve health literacy [18-19]. In the United Kingdom (UK), the UK Committee on Safety of Medicines highlighted the importance of health literacy in identifying and communicating health information to make informed health decisions [19]. In 2009, the United Nations Economic and Social Council (ECOSOC) held a regional meeting on health literacy in Beijing, China and later issued a declaration exploring ways to strengthen multisectoral collaboration at the national, regional, and international levels. This was intended to undertake joint actions to increase health literacy; find ways to promote better access and use of information through information and communication technology and empowerment; and build capacity for sustained action to increase health literacy [20]. More recently in South East Asia, the World Health Organization (WHO) regional office released a health literacy toolkit for LMICs that focuses on integrating health literacy into policymaking processes [20].

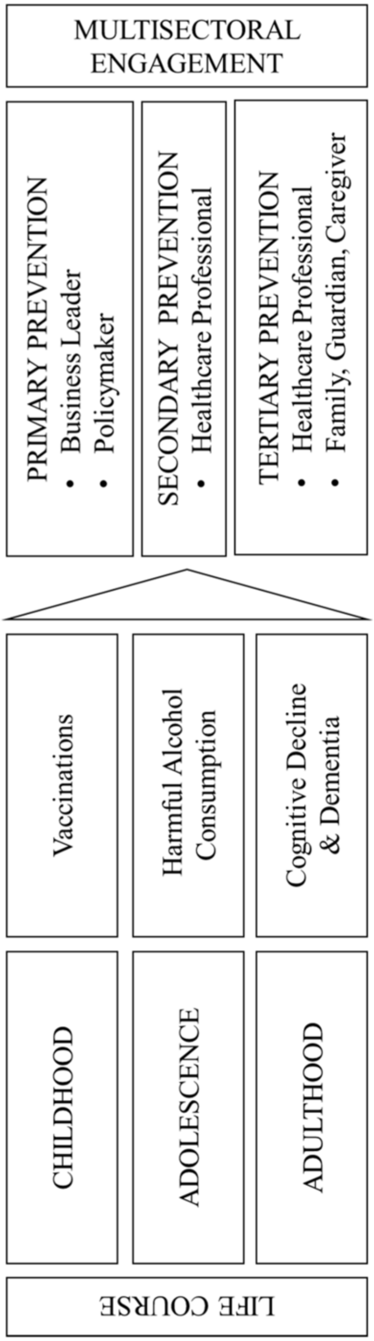
While the diffusion of health literacy into public health clinical practice and national policy reforms has led to a productive expansion of the field, the authors believe the time is now to build on past progress. The authors suggest it is important to move health literacy beyond its public health and clinical origins to facilitate broader global impacts. In doing so, we propose a life course for health literacy.

4. Ubiquitous Health: A Life Course Approach for Health Literacy

Low health literacy has been associated with poorer health outcomes, increased risk of mortality, and unnecessary use and costs of healthcare services [21]. Unfortunately, individuals with low literacy have a poorer understanding of behaviors to promote health and disease management. Individuals with low health literacy also are less likely to use preventive services compared to individuals with average or above average literacy [15]. As one example, a U.S. national survey on health literacy skills concluded 85 percent of individuals cannot calculate an employee's share of health insurance costs using a table, while more than one-third of adults are uncertain as to how to take prescription medicines based on instructions on container labels [15].

In order to improve health and well-being outcomes as well as reduce healthcare costs, the authors propose a life course approach for health literacy. This requires dedicated efforts to promote health literacy across the lifespan. Realizing that each stage of life represents a spectrum of health and different levels of interaction with the healthcare system, the capacity for health literacy should be developed from before birth through childhood, adolescence, adulthood, and old age. For example, an older adult with multiple co-morbidities will use healthcare services differently than a younger individual. Figure 1 demonstrates a continuation of health literacy across the lifespan. It depicts a life course approach with three cases: childhood vaccinations, harmful alcohol consumption in adolescence, and cognitive decline and dementia in adulthood and older age.

Figure 1: Health Literacy Across the Lifespan



The authors also provide examples of the stakeholders required to improve health literacy in each of the examples shown in Figure 1. Primary prevention, or 'staying healthy' via intervention before health effects arise, commonly requires the engagement of health leaders such as policymakers and business leaders. They are frequently responsible for introducing measures that boost access to vaccinations or reduce access to alcohol. Secondary prevention - screening to early detect diseases before signs and symptoms - often resides with healthcare professionals operating in clinical settings such as a hospital or clinic. The healthcare professional engages in activities such as mammography and blood pressure testing to screen for diseases. Lastly, tertiary prevention - managing disease to prevent or slow progression - requires the involvement of healthcare professionals along with a caregiver, such as a family member or guardian. The interaction and collaboration of these stakeholders across the lifespan demonstrates the need for multisectoral engagement in health literacy.

In partnership with the stakeholders outlined in Figure 1, diverse strategies have been proposed to advance health literacy across the lifespan. These strategies cover the education, healthcare, business, and policy sectors. They are cross-disciplinary, cross-cutting, and cross-cultural, and have potential to accelerate efforts to improve health literacy in the coming decades. Table 1 presents a summary of these potential strategies for advancing health literacy.

Table 1: Potential Strategies for Future Health Literacy Advancement

	Category	**Change Agent(s)**	**Goals & Tactics**
EDUCATION	Capacity for critical thinking and skill development	Primary and secondary educators	High-school graduates equipped with literacy, numerical, and other skills to understand and evaluate health information
	Evaluation of research	Colleges & universities	Baccalaureate degree holders understand limitations of scientific methods and can assess the strength of scientific evidence
HEALTHCARE	Patient engagement on value of prevention	Physicians, nurses, and other healthcare professionals	Healthcare professional engages with patients on the value of primary prevention such as modifiable behavioral risks and vaccinations
	Educational training on cognitive decline and dementia	Physicians, nurses, and other healthcare professionals; family, guardians, caregivers	Online educational training for healthcare professionals and caregivers to be fully equipped to support individuals with cognitive decline and dementia
BUSINESS	Access to preventive healthcare services	Retailers	Offering of preventive services with educational materials in retail clinics, pharmacies, schools, and elsewhere
	Technological platforms for	Technology platforms	Development of technologies with adequate privacy controls and cultural

	engagement in health		adaptation to enable engagement in health outside of hospital
POLICY	Legislation to support health activities	Federal, state, and local policymakers	Legislation to further prevent access to alcoholic beverages combined with education for adolescence
	Caregiver compensation	State policymakers	Legislation to offer tax credits to unemployed caregivers

Finally, it is worth noting the general semantic differences needed to more precisely describe health literacy. For example, the authors contend: a) vaccine literacy is different from health literacy for vaccines; b) alcohol literacy is different from health literacy for alcohol; and c) dementia literacy is different from health literacy for dementia. The distinctions highlight the challenges posed by each of these life events, which require broader communication strategies to meaningfully engage multiple stakeholders to develop and integrate comprehensive 'health information and services needed to make appropriate health decisions.' This novel approach to health literacy is more than simply addressing healthcare or education systems. It includes partnerships with the public and private sector, along with academia and civil society.

4.1 Early Childhood Vaccinations: Vaccine Literacy

The leading public health achievements of the 20th Century include the global decline in vaccine-preventable deaths. Since 1792 when the first vaccination was developed, smallpox has been eradicated, child mortality has declined, and numerous birth disabilities have been prevented in many parts of the world [22].

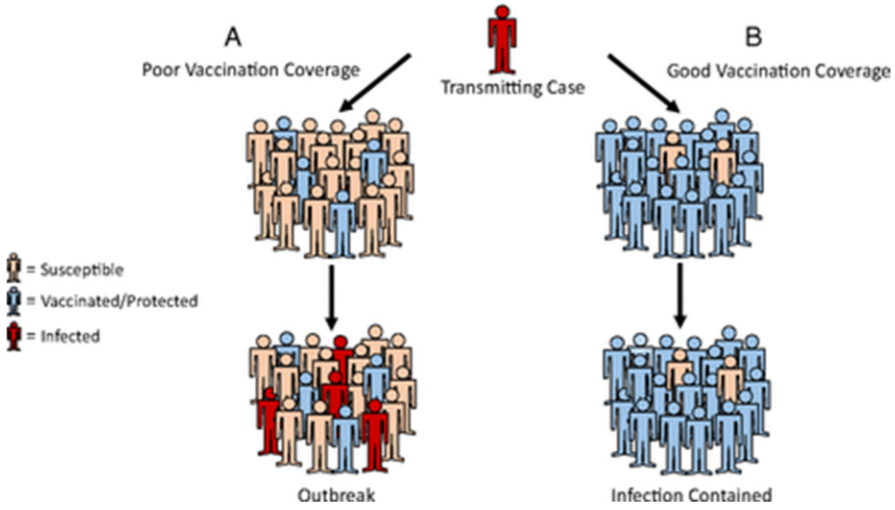
However, these global health gains are threatened by rapid increases in vaccine hesitancy - defined as "the delay in acceptance or refusal of vaccines despite availability of vaccination services" - that has progressed in many countries [24]. The threat of vaccine hesitancy is so urgent that the WHO ranked it as a top ten health threat for 2019, alongside climate change, non-communicable diseases (NCDs), and high-threat pathogens such as Ebola [23].

While anti-vaccine statements date back to the 1800s, more recent sentiments stem from now debunked evidence regarding the relationship between childhood vaccines and autism. This relationship initially was proposed by the British physician Andrew Wakefield and was published in a prestigious medical journal, *The Lancet*, in 1998. Nonetheless, the study included serious methodological flaws. Among them were a sample size of only 12 participants and no control group. The *British Medical Journal* later exposed the fraud and subsequent scientific reports show no causal relationship [25]. Despite no association, anti-vaccine sentiments have expanded beyond vaccines for measles, mumps, and rubella (MMR) to include human papilloma virus (HPV) and influenza [26]. U.S. states with medical and philosophical exemptions for childhood vaccines have reported declines in vaccine coverage [27].

A growing anti-vaccine movement is aligned with the proliferation of social media platforms that can propagate misinformation — such as Facebook, Twitter, and YouTube [28]. In 2018, Russian-operated bots were found to promote discord and disinformation to sway vaccine sentiments on Twitter [29]. Although many people turn to their healthcare provider to access vaccine-related information, evidence suggests vaccinehesitant parents are more likely to look to the Internet for information [30]. As a result, the proliferation of dysfunctional content has fostered increased vaccine hesitancy, delay, and refusal. The authors suggest the companies that operate social media platforms have a responsibility to filter misleading information on vaccines to promote population coverage [31].

Until now, the response to vaccine hesitancy has been articulated through disease prevention goals focused on developing ‘herd immunity’ within a population. Coined in 1923, the term refers to the percentage of vaccinated individuals required to protect an entire community (or herd) from a disease. For measles, herd immunity requires a 95 percent immunization rate in order protect a community. This means two doses of measles vaccine (to be 97 percent effective), while one dose is effective 93 percent of the time [32]. As vaccine hesitancy continues to gain momentum, calls have been made to shift from a focus on herd immunity to one centered on community protection [31,33]. Community protection entails individual protection for people who are vaccinated as well as reducing the spread of the disease within a population [34]. Figure 2 (which is adapted from the Proceedings of the National Academies of Sciences) demonstrates the effect of community protection within a population [34].

Figure 2: Community Protection



(A) represents a highly susceptible population, whereby a transmitting case will likely encounter a susceptible person. This will lead to a line of person-to-person transmission, and eventual outbreak.

(B) represents an immune population with good vaccination coverage. A transmitting case will likely not encounter a susceptible person. This breaks the line of transmission, yielding indirect protection of the remaining people who are susceptible.

Vaccine literacy can play an effective role in combatting anti-vaccine sentiments and to improve vaccine coverage among parents and their children [35]. Vaccine literacy entails improving the strength of systems that place value on both knowledge of the benefit and importance of vaccines in addition to promoting and integrating vaccines within a functioning health delivery system [36]. Building on previous efforts proposed by Parker, the authors contend vaccine literacy is composed of three interrelated elements: the individual and system that provides for skills, ability and knowledge to get vaccinated; simpler and stronger healthcare and education systems that generate demand for vaccines; and accelerated leadership and investments in digital health and communications to increase vaccine coverage as a social norm throughout the world.

4.2 Adolescent Health: Alcohol Literacy

The WHO estimates that three million people died from alcohol in 2016, representing one in 20 deaths worldwide [37]. More than 75 percent of these deaths were among males, with a majority occurring in high-income countries, primarily Europe and the Americas [37]. Adolescents are especially affected; an estimated 27 percent of individuals between 15 and 19 years of age (totaling 155 million adolescents) drink alcohol globally [37]. School surveys suggest alcohol use commences before the age of 15 among males and females in many countries [37]. This can contribute to the onset of many NCDs in later life, such as cardiovascular disease, type 2 diabetes, and various cancers, as well as poor mental health, including depression and anxiety, across the life course [38].

Government policies have shown to be effective to curb alcohol intake. Common strategies include: increasing taxation on alcoholic beverages; restricting advertising across multiple types of media; and limiting access to alcohol in retail outlets [37]. Despite the demonstrated effectiveness of these policy interventions, the implementation of these policies by governments has varied among countries and has been piecemeal in its approach [37].

The field of alcohol literacy is emerging to address challenges associated with adolescence and harmful alcohol use. Alcohol literacy encourages better understanding of the risks by the broader public that are associated with binge alcohol consumption from adolescence through adulthood [37]. Although the relationship between health literacy and alcohol intake is poorly defined, the initial evidence suggests a positive correlation [39-40]. As an example, one study assessed individuals with Type 1 diabetes between the ages of 18 and 30. Among this group, it was found alcohol consumption was common, though knowledge of alcohol and carbohydrate content was limited [41]. The study highlights the importance of labeling and communications in improving alcohol health literacy. Similarly, other research suggests the importance of communication on alcohol consumption with health professionals rather than technological platforms to better understand alcohol risks [42].

4.3 Cognitive Decline in Older Ages: Dementia Literacy

Changing demographics characterized by increased life expectancy and decreased fertility rates contribute to an aging global population. By 2050, one-fifth of the world's population will be more than 60 years old [43]. Rates of cognitive decline and other dementias are predicted to increase simultaneously. In the U.S., the Centers for Disease

Control and Prevention (CDC) estimates that Alzheimer's and related dementias will double by 2060 [44].

Moreover, the economic toll of Alzheimer's disease and related dementias is significant and growing. In the U.S., Alzheimer's disease cost $259 billion per year in 2017, with U.S. Medicare and Medicaid spending more than $175 billion linked to its consequences [45]. At least 50 percent of Americans living with Alzheimer's disease remain undiagnosed, while less than half of people who have the disease have been told of their diagnosis [46]. Unfortunately, these statistics are not significantly different outside of the U.S. Internationally, there is a pervasive and troubling stigma associated with Alzheimer's disease.

In the past few years, scientific progress has been made to treat Alzheimer's disease. There is a better understanding of Alzheimer's biomarkers, including β-amyloid, tau protein, and neurodegeneration. Nevertheless, effective commercially biomedical treatments remain unavailable for Alzheimer's disease [47].

Alzheimer's economic toll is combined with its social burden. In both the U.S. and other countries facing an aging population such as the UK, as well as many parts of Europe and Japan, there are growing concerns about the social and economic burdens of unsupported caregiving. Close to 18 million family and unpaid caregivers support Americans with disabilities [48]. Caregivers are often females (as much as 75 percent), who provide caregiving for senior family members (and others) in addition to employment and child caregiving [49-50].

While diverse nations grapple with the challenges associated with delivering improved dementia prevention, care, and caregiving, the U.S. state of Massachusetts provides a current example of policy leadership. Massachusetts is the first U.S. state to modify state laws to support caregiving. In 2018, the Massachusetts legislature passed a multifaceted bill titled "An Act Relative to Alzheimer's and Related Dementias in the Commonwealth" (H.4116) [51]. Broadly, the law grants additional support to individuals, healthcare professionals, and caregivers who provide dementia care. Realizing that healthcare providers are in a unique position to diagnose and provide quality care to those with dementia, the Massachusetts Act requires formal training for healthcare professionals that interact with patients with various forms of dementia. The training is delivered through continuing medical education programs. In time, training will be required as part of license renewals for medical professionals, including physicians, physician assistants, registered nurses, and licensed nurse practitioners [46]. Beyond training, the law mandates clinicians "report the diagnosis to a family member or legal personal representative of the patient" and offer information on care planning, treatment, and support services [51].

In addition to legislative activities, new technologies can support older adults and their caregivers. Some initial research suggests voice interfaces have the potential to recognize vocal biomarkers of changes in a person's neurological or mental health status, aiding with broader diagnostic support [52]. Amazon's "Alexa" - a socially assistive robot - provides an example where older adults have interacted directly with the technology to improve social well-being in the home. Conversely, these technologies are poorly integrated into the healthcare system and often are used independently of the system or a caregiver [52].

5. Future Directions for Health Literacy: Strategic Opportunities

Realizing that health literacy should be developed across the lifespan, the authors propose the creation of a new area of focus called dementia literacy that equips policymakers, healthcare professionals, business leaders, and employees with the tools to better navigate appropriate courses of action for cognitive decline and dementia care. This may include offering training that could include certification for caregivers by employers and education providers [48]. The training additionally should advance data collection regarding the prevalence of caregiving by individuals [49].

While the aforementioned ideas highlight three examples for action, this section provides strategic opportunities and future directions to improve health literacy. In particular, the expansion of treatment and caregiving requires data and technology through new mobile health tools as well as multisectoral engagement through collaborative partnerships.

5.1 Digital Health: Data & Technology

eHealth literacy has been proposed to capture health literacy in a digital context. eHealth literacy refers to “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem” [53]. While this definition is predicated on health literacy in the context of electronic medical records, the authors contend there are other opportunities to apply data and technology to improve health literacy.

The emergence of personal, predictive, and preventive mobile technologies enables consumers to take control of their health through quantified tracking and monitoring. These mobile technologies range from wearables to remote monitoring devices to care coordination technologies predicated on artificial intelligence. For consumers, these technologies foster the passive tracking of one’s health outside of a hospital setting. For physicians, mobile technologies enhance a provider’s ability to use data and technology to help inform diagnosis and treatment of complex and costly diseases [54].

Although public health has traditionally focused on data-driven, epidemiological methods for drawing conclusions, the authors propose integrating insights from design thinking to improve health literacy using data and technology [55]. Stanford’s d.school has identified five steps to design tools and technologies using design thinking. These include: (1) empathize by developing a deep understanding of the problem; (2) define the problem you want to solve; (3) ideate by brainstorming potential solutions; (4) develop a prototype to design and test various components of the solution; and (5) engage in short testing process to refine the solution [56]. A component of this process entails understanding, testing, and refining design features with end users of different ages, cognitive abilities, and socioeconomic status. This ensures that the solutions developed align with the needs and abilities of end users.

A practical example is The Mental Health Bridges Project, which proposes various guiding practices to design technological interfaces for individuals with poor mental health. These range from using vivid, warm colors and consistent formatting; including infographics; incorporating videos, audios, and images of ‘people who look like me’ and role models; and making the web pages printable [57]. At its core are design principles used to develop technological solutions that are appropriate for a target population’s health literacy. The latter ensures information is delivered at the right time, to the right people, with the intended effect [58].

Despite the proliferation of these technologies, it is important to note that many individuals do not reap their benefits. The latter often stems from poor design or unaffordability. Individual privacy and confidentiality additionally can be invaded, leading to microtargeting or discriminating against various population segments [54]. Strong regulations combined with actions by technology companies can serve to address these challenges.

5.2 Multisectoral Engagement

During the past two decades, partnerships have guided the development of health literacy as a discipline and field of study. These have been primarily academic and public sector collaborations. Nevertheless, decades of distrust between the public and private sectors — specifically big food, tobacco, alcohol, and pharma — has inhibited cross-sector collaborations to better health and well-being.

Years of documented evidence on activities to undermine the health efforts by government and public health institutions has led to the public sector largely viewing the private sector with suspicion. As Dr. Margaret Chan, the former Director General of WHO said: “Few governments prioritize health over big business … efforts to prevent noncommunicable diseases go against the business interests of powerful economic operators” [59].

However, the authors suggest this scenario is starting to change. The burden of development action and finance can no longer rest on national governments and philanthropic institutions. In turn, the private sector and civil society is part of the multidimensional efforts to achieve the 2030 Global Agenda. The SDGs explicitly call for multisectoral - including private sector - engagement. Indeed, SDG 17 focuses on the formation of ‘Partnerships for the Goals’ to strengthen implementation and revitalize global partnerships [2].

Given the history of mistrust among these sectors, an interdisciplinary collaborative at the Mossavar-Rahmani Center for Business and Government at the Harvard Kennedy School released a set of guiding principles to serve as a frame of reference for multisectoral engagements to achieve SDG3. These principles recognize health as a public good, and are driven by evidence, science, and values [60].

The seven guiding principles (depicted in Figure 3) include: (1) agree on shared mission and goals in alignment with targets identified in health-related SDG targets; (2) ensure alignment of interests related to the SDG target(s), including identification and management of actual or potential conflicts of interests; (3) establish credibility and strengthen coordination with key actors; (4) clarify contributions with financial, technical and in-kind support with each parties’ contribution; (5) commit to ethical communication with transparent, accountable, and just systems; (6) create an evaluation plan with adequate support and independence to report progress on key metrics internally and externally; and (7) advance long-term stewardship for sustainable social change through partnership structure and terms of collaboration [60]. The authors contend these principles can guide productive collaborations between the public, private, and academic sectors to promote health literacy in the U.S. and globally.

Figure 3: Guiding Principles for Multisectoral Engagement for Sustainable Health (MESH)

GUIDING PRINCIPLES

MULTISECTOR ENGAGEMENT FOR SUSTAINABLE HEALTH (MESH)

1. **MISSION:** Agree on shared mission and goals in alignment with targets identified in health related SDG targets
2. **INTERESTS:** Ensure alignment of interests related to the SDG target(s) including identification and management of actual or potential conflicts of interests
3. **LEGITIMACY:** Establish credibility and strengthen coordination with key actors
4. **RESOURCES:** Clarify contributions with financial, technical and in-kind support with each parties' contribution
5. **GOVERNANCE:** Commit to ethical communication with transparent, accountable, and just systems
6. **MEASUREMENT and EVALUATION:** Create an evaluation plan with adequate support and independence to report progress on key metrics internally and externally
7. **SUSTAINABILITY:** Advance long-term stewardship for sustainable social change through partnership structure and terms of collaboration

Integrating these principles into future multisectoral engagements on health literacy in support of SDG3 will help facilitate the shift from improving individual health literacy among patients in clinical care settings to encouraging broader systems-level change.

6. Conclusion: A Call to Action for Advancing Health Literacy

However ambitious, the 2030 Agenda for Sustainable Development is attainable with dedicated and concerted action. For the global community to achieve the health-related targets and indicators of the SDGs, health literacy must be integrated in new ways that build on past achievements.

Since the turn of the 20th century, the essential building blocks for health literacy have been established. There has been substantial growth in the academic literature on health literacy, which establishes the scientific evidence and credibility of the field. Definitional debates have defined the core of health literacy, along with other considerations on offshoots. Policy agendas in both the U.S. and other countries have included health literacy to advocate its deeper integration into healthcare and education sectors. These are all important accomplishments to elevate health literacy as an area of activity and action among academic and policy professionals within public health and the medical sciences.

The next twenty years augur leveraging existing progress to expand the influence of health literacy. In this chapter, the authors propose ideas on how this may be accomplished. First, we believe a life course is necessary for health literacy, one that spans life from before birth through death. Specifically, this means coalescing efforts within three areas where health literacy is critical: vaccinations in childhood, alcohol consumption in adolescence, and cognitive decline and dementia in adulthood and old age. Each of these phases of life should integrate health literacy through primary, secondary, and tertiary prevention efforts.

Second, new mobile technologies and digital communication tools should include guiding practices from health literacy. These tools and technologies have the potential to deliver healthcare at scale to improve outcomes and reduce costs. Yet, efforts to improve health are unlikely to succeed without thoughtful design to develop easy-to-navigate interfaces and protocols for data privacy and confidentiality. These technologies should be engineered using principles from design thinking, with collaborators across schools of engineering and healthcare.

Finally, multisectoral engagement is essential to facilitate the proliferation of health literacy beyond public health and the medical sciences. This requires leaders in academia and policymaking to interact with business, multilateral organizations, and civil society. Realizing the potential for competing priorities and conflicting interests, some guiding principles have been proposed. In addition, metrics inclusive of evaluation frameworks should be developed to determine the extent to which these partnerships promote health literacy and other indicators of the SDGs.

Gains in health literacy will not be realized simply through individual actions. It will be systems working in harmony that facilitate improvements in health and well-being for families, communities, and countries. The time is now for health literacy to move beyond the bench and bedside in clinical practice to achieve the aspirations and objectives of the 2030 Agenda for Sustainable Development. We look forward to making this a reality.

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Integrated Measures of Health Literacy, Language Access, and Cultural Competency Would Improve Health Care Quality and Value

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Abstract. Improving health care quality and value requires increased attention to patient and family-centeredness as well as care equity. Although health literacy, language access, and cultural competency have been perceived as separate constructs. each represents a dimension of patient and family-centeredness and care equity. Developing and using integrated measures of health literacy, language access, and cultural competency could provide a viable strategy to improve patient and family-centeredness and equity in health care. While there are challenges to the development and use of integrated measures, some responsive strategies include: using more patient, family and caregiver-reported information; utilizing patient demographic data from electronic health records; and incorporating the latter elements within measures of patient experience. Integrated quality measures also create opportunities for collaborative and interdisciplinary research, and for health care delivery innovation.

Keywords. Quality improvement, patient-centeredness, equity, health literacy, language access, cultural competency, quality measures

1. Background on Quality Improvement in the U.S.

While the merits of the 2010 U.S. Patient Protection and Affordable Care Act (ACA) continue to be debated, there is emerging agreement among most health care stakeholders that health care system reform will need to focus on improving both health care quality and value [1]. In 2000, a U.S. Institute of Medicine (IOM) report, To Err is Human: Building a Safer Health System, first called to national attention the serious lapses in patient safety that resulted in more than 44, 000 preventable deaths each year [2]. A year later, another IOM report, Crossing the Quality Chasm: A New Health System for the 21st Century, outlined a framework to enhance health care quality by improving safety, timeliness, effectiveness, efficiency, equity, and patient-centeredness [3].

Meanwhile, other health care stakeholders were developing complementary frameworks to foster improved quality and value. For example, the MacColl Institute for Healthcare Innovation developed the chronic care model and the Institute for

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Healthcare Improvement (IHI) articulated the triple aim of improving access and quality simultaneously while reducing costs [4-5]. The leading primary care provider associations developed principles for patient-centered medical homes, which evolved into formal programs, including a widely-used recognition program developed by the National Committee for Quality Assurance (NCQA) [6-7]. The U.S. Department of Health and Human Services (HHS) Centers for Medicare and Medicaid Services' (CMS) Physician Payment Demonstration Project became the blueprint for implementing accountable care organizations, and to establish the feasibility of value-based payments to improve quality and reduce costs [8].

Many of these frameworks and concepts were incorporated into the ACA and its implementation, including the adoption of the first ever National Quality Strategy, which was based on the IHI's triple aim, support for patient-centered medical homes, and several models of accountable care organizations [9-12].

Meanwhile, the Health Information Technology for Economic and Clinical Health (HITECH) Act that was part of the 2009 American Recovery and Reinvestment Act also advanced significant change in health care delivery systems, scaling up the use of technology by hospitals, physicians, and other health care providers at an unprecedented pace through the infusion of billions of dollars in U.S. federal funding. Prior to 2009, only 12 percent of hospitals and less than half of physician practices were using health information technology (IT). By 2017, after the investments funded by the HITECH Act, 96 percent of hospitals and more than 85 percent of physician practices were using health IT [13-14]. There will be continued deployment and refinement in health IT, particularly patient-facing that will improve communication between providers, patients, and their families and caregivers [15-16]. These future innovations also will provide opportunities to develop and use integrated measures of health literacy, language access, and cultural competency [17-18].

2. Patient- and Family-Centeredness and Equity are Essential Elements of Health Care Quality and Value

While the IOM Crossing the Quality Chasm report's definition of patient-centeredness focused on understanding and meeting the needs and "preferences" of individual patients, the evolving conceptualization of high quality, high value health care highlights the importance of the patient, family, and caregiver experiences of care. For example, the triple aim redefines 'access' as patient experiences of health care across a health care delivery system instead of the availability of health insurance, or health care providers. Stakeholders have encouraged the consideration of the experiences of a patient's family members and caregivers as additional indicators and sources of information about health care quality and value [19]. Especially as the U.S. population continues to age, the role of caregivers - both traditional family caregivers such as spouses, adult children, and siblings - (as well as others in caregiving roles such as friends, neighbors, and extended family members) - will continue to increase [20].

As patient and family-centeredness is essential to improve health care quality and value, the latter requires health care systems and providers to pay more attention to issues of health literacy, language access, and cultural competency. One of the foundations of patient and family-centeredness is the creation of a long-term relationship of trust among providers, patients, and a patient's family. The core idea of patient-centered medical homes is building such relationships with primary care providers.

In addition, there is significant evidence that patients seek and are more trusting of providers from a concordant racial and ethnic background, who speak their primary language [21]. Having health care providers who can communicate effectively with patients from all educational and socioeconomic backgrounds, including those with lower health literacy, similarly contributes to patient and family-centeredness [22-23].

While continuing to ensure access to all needed and preferred health care, there is an emerging trend towards sharing health care decision-making with patients (and their families and caregivers, consistent with the directives of the patients). Shared decision-making means that treatment options are offered with the best and most complete information available about benefits and risks, including probability of success, the urgency of making a decision, and side effects. Fundamental to effective shared decision-making is effective communication - and trust - with all involved health care providers. For example, there are likely to be multiple providers engaged in the care of patients with multiple and complex health conditions (and at the end of life) that require the participation of families and caregivers. Yet, there are socio-cultural barriers to patient-centered, shared decision-making care initiatives. For example, U.S. African American and Hispanic patients and Spanish-speaking patients do not participate in shared decision-making processes compared to White and English-speaking patients [24-25].

Similarly, there has been less attention paid to how best to measure and improve equity as an essential component of health care quality and value [26]. The World Health Organization defines health equity as the absence of avoidable, unfair, and remediable differences among groups of people, as defined socially, economically, demographically, geographically, or by other means of stratification [27]. The key part of this definition is that such differences or disparities are avoidable, unfair, and remediable. The U.S. Department of Health and Human Services adopts this approach in its National Stakeholder Strategy to Achieve Health Equity by defining health equity as the attainment of the highest level of health for all people. The latter requires valuing everyone equally, with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities. [28]. The National Quality Forum has developed a roadmap to use existing quality measures, and how to address the remaining gaps in measure development and advance health equity, which includes the use of composite and integrated measures [29].

3. Current Challenges in Measuring Quality Improvement

With the increasing agreement that both health care quality and value need improvement, health care providers and systems, as well as payers, face several challenges to choose which measures are used to confirm progress. An initial challenge is the wide range of health care delivery settings - from hospital in-patient settings, to ambulatory settings such as clinics and physician offices, to home and other community-based settings. There also are different levels of accountability - from state health systems, health plans, hospitals, clinics and physician practices, health care teams and medical homes, to individual providers. Each of these levels has varying degrees of administrative capabilities and burdens in implementing interventions, compared to the payment incentives and rewards that might be available. For example, an individual physician contracting with multiple health plans may not be sufficiently incentivized to make quality improvements being supported by a health plan when payments from one health plan represent a fraction of the overall revenue that a physician receives.

At the same time, there are legitimate concerns about the proliferation of quality improvement measures, and the lack of common or standardized measures. There are increasing pressures to use fewer measures across more settings and accountabilities [30-31]. Balancing all these competing pressures provides another reason to consider development and use of integrated quality measures.

4. Health Literacy, Language Access, and Cultural Competency are Separate but Related Concepts

Each of the concepts of health literacy, language access, and cultural competency has separate histories, evolutions, and champions. Yet an IOM report noted health literacy skills and capacities are mediated by education, culture, and language, and the problem of limited health literacy is often greater among those with limited English proficiency [32]. In addition, there is an overlap between language access and health literacy to provide effective written translations. Should clinical terms or even medical jargon be literally translated if the translated words would be difficult to understand by the reader? Should a translation into Spanish use a formal or informal pronoun tense that does not exist in English? Similarly, in oral interpreting, should a health care interpreter adjust the register of words spoken by a provider to be more colloquial to improve the understanding of a patient, especially a patient with lower health literacy or education [33]? Beyond academic interest, operationalizing these related concepts will help ensure quality health care for diverse patients and families.

4.1. Health Literacy

The concept of health literacy evolved from the health education field, with an initial focus to ensure written health education materials were understandable to diverse patients (and not just those with more education and literacy). There has been significant work to develop assessments of health literacy in order to identify patients who experience barriers in comprehension that stem from limited health literacy. There also has been significant work to adapt and edit written health education materials to increase comprehension and readability.

More recently, health numeracy has received attention since clinical calculations such as medication dosages, blood pressure, body mass index, and other numerical measurements, are foundational elements of patient care [34].

Given the increasing utilization of technology within health care, there is an emerging, related concept of ‘eHealth literacy’, or literacy in health-related technologies. This includes how to use a smartphone to receive and send text messages, how to access one’s electronic health record from a computer, and how to make an appointment or refill a prescription through an internet-based patient portal or mobile phone application [35].

4.2. Language Access

Separately, the field of health care interpretation to support language access has evolved, led by state and national organizations, who developed training curricula, standards of ethics, standards of practice, testing and certification, and most recently, accreditation of continuing education programs for health care interpreters [36-41].

Technology relevant to language access additionally has evolved, including significant reductions in the cost and usability of video-based technologies for oral interpreting (and sign language interpreting), as well as increased access to machine learning and artificial intelligence to support automated memories and glossaries (for greater efficiencies in written translations). The widespread availability of some of these technologies also facilitates consumer readiness to adopt and use these technologies in health care settings (e.g. grandparents who use their smartphones to have videoconferences with their adult children and grandchildren are more likely to be comfortable using a health care interpreter through a videoconferencing service). On the other hand, health care-based technologies have not always kept up with these innovations. Very few patient portals have capabilities to support communications in languages other than English and Spanish although in the U.S. and globally, individuals use their smartphones to text and exchange electronic messages in dozens of languages, with no special enhancements or adaptations required.

4.3. Cultural Competency

Finally, the field of cultural competency first developed in health professions' education, especially in nursing and medicine [42-43]. The understanding of cultural competency has evolved to become more of a continuing education concept, requiring life-long learning [44]. For example, some advance the concept of cultural humility, which emphasizes the role of the provider as a learner from patients instead of a didactic, know-it-all provider [45]. Others suggest the concept of cultural agility, which emphasizes the skills required to navigate a variety of cross-cultural environments and encounters [46-47]. Another emerging concept from the business world is cultural intelligence, which is associated with work that identifies emotional intelligence. The latter suggests innate and learned (teachable) knowledge and skills that identify what matters to another person culturally, and how to respond, communicate, and interact appropriately and effectively [48].

Self-reflective skills are a commonality among all these concepts (especially about one's own worldview, and about what is not known about differing worldviews). Other suggested provider skills include interests in: active listening; curious and continuous learning; and seeking dyad guidance during communications and behavioral interactions. Individuals who are effective in cross-cultural communications and relationships can be generalists who adapt and apply past knowledge and experiences to new situations (or specialists who know and work with a specific culture, community, or population).

In a current, broadened understanding of culture, a generalist approach would empower a health care provider, who has become familiar working with Spanish-speaking Latino patients to provide culturally and linguistically appropriate care to a transgender patient (who prefers to be identified by specific names and pronouns and presents health and social issues that may be unfamiliar to many providers). Similarly, a provider who works with Chinese-speaking patients should be able to accommodate the mobility needs of patients who use wheelchairs.

4.4. Towards System Approaches

Health literacy, language access, and cultural competency are evolving from operationalizing each construct as a response to individual-level barriers. Hypothetically, the latter might focus on a patient who is not able to read or understand prescription medication instructions because of limited health literacy, a patient who speaks a language other than English and needs a health care interpreter, or a provider who has more rapport with patients from a concordant cultural background [49].

In contrast, a shift to a system-level understanding of these concepts, and a ‘universal precautions’ approach to solutions means that all communications, not just patient education materials, should adopt more universally accessible health literacy levels, qualified health care interpreters should be available (either in person or by phone 24 hours a day/7 days a week) at all points of service, and an optimal health care workforce should reflect the racial, ethnic, linguistic, cultural, and other diversity of patient populations served, at all levels within a health care organization [50-53].

As health care organizations continue to understand and develop interventions to advance patient-centeredness and equity as essential elements of health care quality and value, the concepts of health literacy, language access, and cultural competency provide useful ways to develop these dimensions.

5. Prior Work Integrating Concepts of Health Literacy, Language Access, and Cultural Competency

5.1. Integration Activities by the Federal Government

In 2000, the U.S. Department of Health and Human Services (HHS) Office of Minority Health (OMH) published National Standards for Culturally and Linguistically Appropriate Services (CLAS), which addressed language access and cultural competency [54]. While health literacy issues were not addressed in OMH’s initial standards, the agency published an update that addressed language access for individuals with disabilities in addition to individuals with limited English proficiency. Moreover, the revision touted health literacy as essential to culturally and linguistically appropriate communications [55]. Unfortunately, the CLAS standards have not be proactively enforced or integrated by OMH into other HHS quality improvement activities [56-57].

One of the first articles to propose a more integrated approach to measuring and operationalizing these concepts was published in 2007 [58]. The Agency for Healthcare Research and Quality (AHRQ) developed Supplemental Item Sets on Health Literacy, Cultural Competence, and Patient-Centered Medical Homes for its Consumer Assessment of Health Providers and Systems (CAHPS) surveys [59-61]. After the enactment of the ACA, the Centers for Medicare and Medicaid Services (CMS) also developed a CAHPS survey specifically for accountable care organizations [62]. While there was some overlap in each of these Supplemental Item Sets, there was no formal integration of the concepts. There also seems to have been very little utilization of any of the Supplemental Item Sets [63].

Meanwhile, the U.S. Health Resources and Services Administration (HRSA) developed a Unified Health Communication training that addresses health literacy, language access, and cultural competency together and collected resources on all three topics on its website [64]. Similarly, the National Institutes of Health (NIH) developed guidelines for Clear Communication that addressed health literacy (plain language), language access, and cultural competency (cultural respect) [65].

5.2. Calls for Integration by Institute of Medicine and National Academies of Sciences, Engineering, and Medicine

External to the federal government, health care stakeholders have advocated a conceptual integration of health literacy, language access, and cultural competency as part of the ongoing implementation of quality improvements in health care. In 2008, three committees within the Institute of Medicine - its Forum on the Science of Health Care Quality Improvement and Implementation, Roundtable on Health Disparities, and Roundtable on Health Literacy - jointly convened a workshop to explore the integration of efforts to address health literacy, reduce disparities, and improve quality. Language access and cultural competency were posited as two important interventions for disparities reduction [66-67]. In 2015, another IOM workshop convened by the Roundtable on Health Literacy continued to explore this integration [68-69].

In 2016, the National Academies of Sciences, Engineering, and Medicine (NASEM) Roundtable on Health Literacy commissioned a discussion paper from the National Committee for Quality Assurance (NCQA) on how integrated measures might advance patient-centeredness and equity, and overall quality improvement. A workshop was conducted in 2017 to provide feedback to NCQA, who then revised and finalized the discussion paper [70-71].

Earlier this year, the NASEM published a perspectives paper (authored by members and participants in the NASEM Roundtable on Health Literacy), which described opportunities to develop, test, and implement integrated measures of health literacy, language access, and cultural competency as part of the ongoing improvements within the health care delivery system as well as payment reforms [72]. The perspectives paper noted current activities by CMS within the federal government, and current activities by health care stakeholders outside the federal government, including national health care quality organizations (National Quality Forum, Institute for Healthcare Improvement, and Patient-Centered Outcomes Research Institute) and national health care leadership organizations (American Hospital Association's Institute for Diversity and Health Equity and Families USA).

6. How Integrated Measures of Health Literacy, Language Access, and Cultural Competency Would Improve Quality and Value

What would integrated measures of health literacy, language access, and cultural competency look like? A patient-centered, family-centered and equitable approach could measure how a health care system or provider meets diverse patient needs and preferences. The latter approach contrasts with separately assessing individual patients (or families or caregivers) about their specific health literacy level, their personal need for language access, or their personal preference for a culturally appropriate provider.

To address concerns about how to implement such measures across diverse settings of care, such measures initially could be used at broader systems levels (health plans, hospitals, large medical groups), and then eventually establish benchmarks and quality improvement goals at more granular levels (individual health care providers). Such measures could leverage other activities within quality improvement to use data from electronic health records, measures of patient and family experiences of health care, and patient-reported (and family and caregiver-reported) outcome measures [73-78].

The following are some potential examples of integrated measures:

- Percentage of unique patients with complete demographic data documented in the electronic health record, e.g., patient's age, sex, primary language, race, ethnicity, sexual orientation, gender identity, disability, and social and behavioral factors (including education and income) [79-81]
  - Establish benchmark: e.g., complete demographic data is documented for 50% of all unique patients [82]
  - Set goals for improvement: e.g., by next year, complete demographic data will be documented for 80% of all unique patients. Percentage of all patient communications, including verbal, written, and electronic communications, available in plain language, available in the patient's primary language, are culturally and linguistically appropriate, and accessible for patients with disabilities using assistive and adaptive communications devices and technologies

- Percentage of all patient communications, including verbal, written, and electronic communications available in plain language, available in the patient's primary language, are culturally and linguistically appropriate, and accessible for patients with disabilities using assistive and adaptive communications devices and technologies
  - Establish benchmark: e.g., 25% of all patient health education materials are available in Spanish and Chinese
  - Set goals for improvement: e.g., by next year, 50% of all patient health education materials will be available in Spanish and Chinese

- Percentage of all patient shared decision-making aids and tools, including verbal, written, and electronic aids tools, available in plain language, available in the patient's primary language, are culturally and linguistically appropriate, and accessible for patients with disabilities using assistive and adaptive communications devices and technologies
  - Establish benchmark: e.g. 10% of all shared decision-making aids and tools are accessible for patients with disabilities
  - Set goals for improvement: e.g. by next year, 50% of all shared decision-making aids and tools will be accessible for patients with disabilities

- Degree of concordance between the self-reported race and ethnicity, and objectively validated language proficiency of providers (defined as primary care providers) with the race, ethnicity, and primary language of patients served

  - Establish benchmark: e.g. 69% concordance in race and ethnicity of providers (55% of providers are Latino within care systems when 80% of patients served are Latino); and 85% concordance in primary language (55% of providers speak Spanish proficiently in care systems where 65% of patients served speak Spanish as their primary language)
  - Set goals for improvement: e.g. by two years, increase concordance in race and ethnicity of providers with patients served from 69% to 75% through recruitment, hiring, and retention of Latino providers (would achieve 75% concordance when 60% of providers are Latino when 80% patients served are Latino); and 90% concordance in primary language (59% of providers speak Spanish proficiently when 65% of patients speak Spanish as their primary language)

- Documentation of regular requests for feedback (through surveys, interviews, focus groups, and other data collection) about diverse patients' experiences of care (and the experiences of care by diverse patients' designated family and caregivers); this feedback would specifically include patients with lower health literacy, less common primary languages, diverse racial, ethnic, and cultural backgrounds, and a range of disabilities
  - Establish benchmark: e.g. one annual patient focus group is conducted with African American patients
  - Set goals for improvement: e.g. by next year, begin conducting an additional patient focus group with Latino patients

- Documentation of the development, implementation, and evaluation of specific quality improvement plans based on feedback from diverse patients, family, and caregivers
  - Establish benchmark: e.g. quality improvement plan to improve access to after-hours nurse advice phone service for patients with hearing or speech disabilities through improved synchronization with telecommunications relay services [83].
  - Set goals for improvement: e.g. by next year, develop, implement, and evaluate additional plan to ensure access to after-hours nurse advice phone service for Spanish-speaking patients with hearing or speech disabilities through improved synchronization with Spanish-language telecommunications relay services

One of the advantages of using integrated measures is the inclusion of specific vulnerable patient populations who are often overlooked from quality improvement activities. For example, some research suggests the feasibility of adapting patient-reported outcome measures to ensure that patients with low literacy skills and learning disabilities can participate in reporting their outcomes [84-85]. The provision of surveys and measures of patient experience in multiple languages ensures feedback from diverse patient populations [86].

7. Conclusion

Additional work is needed to develop, test, and use integrated measures of health literacy, language access, and cultural competency to improve health care quality and value. Such work could bring together multiple disciplines, with complementary expertise, to contribute to the science of quality improvement, including health educators, health care interpreters and translators, and health professions' educators, trainers, and preceptors. These fields have both academic and practice perspectives that often are excluded in the development and use of quality measurement, or in quality improvement. Working together on integrated measures also could promote inter-disciplinary research collaborations, and inter-professional collaboration in health care delivery transformation and innovation [87-88]. Such inter-disciplinary research and inter-professional collaboration to support the development and use of integrated quality measures will help break down silos and create more patient-centered and equitable health systems, which better serve the diverse needs of patients, families, caregivers, and communities.

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Summary and Comments About Section Three

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Abstract: The chapters in section three of the book address health literacy's capacity to foster progress in: multidisciplinary research and practice; clinical care; public health; institutional accountability; and social progress. Unlike sections one and two, section three contains only chapters and it focuses on research or multidisciplinary health literacy practice opportunities. In contrast to the other sections, section three's emphasis is on research and the section is written more for current and future researchers in diverse areas where there is potential to integrate more health literacy (HL) research.

1. Introduction

The chapters in section three of the book address health literacy's capacity to foster progress in: multidisciplinary research and practice; clinical care; public health; institutional accountability; and social progress. Similar to section one, section three's ten chapters span three platforms of conceptual change within the field of health literacy. Unlike sections one and two, section three contains only chapters and it focuses on research or multidisciplinary health literacy practice opportunities. In contrast to the other sections, section three's emphasis is on research and the section is written more for current and future researchers in diverse areas where there is potential to integrate health literacy (HL) research.

Section three is divided into five subsections. Subsection two addresses health literacy's similarities and differences with related disciplines. It includes four chapters about the interactions among health literacy research and patient empowerment, health education, medicine and the arts; and law. Subsection three addresses health literacy and three other health-mass communication subfields. It includes three chapters on: peer to peer communication; health communication; and health journalism. Subsection four addresses health literacy as a gateway to progress. It includes three chapters about: health literacy and smart health choices; a proposed, integrated measure of health literacy language access, and cultural competence; and recent World Health Organization's conferences that addressed health literacy issues.

The chapters in the second, third, and fourth subsections cross disciplinary boundaries that potentially dovetail with health literacy research/practice. Some chapters in section three discuss health literacy's interactions and contributions within enduring interdisciplinary research areas, such as medicine and the arts and heath communication. However, some authors address cross-disciplinary interests that have been less discussed including: patient empowerment; health education from K-12; law; peer to peer

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communication; health journalism; and a proposed, integrated measure of health literacy language access, and cultural competence.

Subsection five provides a summary of section three with some added commentary. Subsection five notes how health literacy (HL) may be more than a gateway to address: individual skills and clinical outcomes; clinical accountability and health care institutional outcomes; as well as the socio-cultural determinants of health. Instead, HL provides a focal point for future research in diverse disciplinary areas, which provide an array of opportunities for researchers and practitioners.

Section's three summary thematically intersperses the section's ten chapters. Similar to section one, the discussion provided below follows the order of publication within the book.

2. Health Literacy's Similarities and Differences with Related Disciplines

Section three begins with a comparative overview of the research in three areas with implications or similarities to health literacy. In the first chapter in subsection two, Smith and Carbone suggest patient empowerment and health literacy usually are assessed separately and despite their disciplinary similarities are rarely combined in research to improve public and individual health [1]. Smith and Carbone suggest an interactive approach to empowerment and health literacy research (and the development of a more overarching conceptual framework) could yield strategies that are superior to addressing each within current silos [1]. Smith and Carbone add a more interactive approach fosters more multidisciplinary career opportunities for students, practitioners, and researchers [1].

Allen, Ault, and Zorn clarify that health literacy initiatives are not confined to clinical care and public health and explain HL's role in K-12 education indirectly impacts population health [2]. Allen, Ault, and Zorn suggest an understanding of health literacy's social impact is incomplete without noting health educational contributions and understanding the current barriers to progress. Allen, Ault, and Zorn introduce an overarching conceptual framework (The Whole School, Whole Community, Whole Child model) to improve student health and achievement, which strengthens the collaboration among school personnel to improve health education, health literacy, and health communication in K-12 schools [2]. Allen, Ault, and Zorn also discuss some gaps in the current literature and provide a path forward for researchers and practitioners. Much of the chapter updates recent work by the U.S. National Academies of Sciences, Engineering, and Medicine Roundtable on Health Literacy [3]. Incidentally, Aldoory discussed health literacy efforts within higher education in the editors' previous health literacy book [4].

In the current book's salute to the humanities, Postlethwait, Ike, and Parker explain individual and public health education often occur outside of classrooms and can be expanded via lifelong exposure to the arts [5]. More specifically, Postlethwait, Ike, and Parker suggest the arts are a gateway (and an underutilized resource) to inform both providers and patients about medical treatment and broader health issues, which potentially broadens the overall understanding of illness and wellness [5]. Postlethwait, Ike, and Parker suggest the contributions of the arts lie in their ability to foster contextualization, or the situational awareness of providers and patients/caregivers and citizens [5]. Postlethwait, Ike, and Parker review the recent literature about how arts exposure is associated with contextual awareness, greater health literacy, and more prescient clinical practice.

Postlethwait, Ike, and Parker also introduce a novel curriculum for medical students, which focuses on context (to advance the communication of health content) that uses visual literacy and immersive arts' experiences. The curriculum is discussed as a starting place to explore the opportunities the arts provide to advance health and the apperceptive mass of health care professionals. The term 'apperception' describes personal situational awareness, understanding, applied knowledge, communicability, as well as a heightened consideration of situational feelings, impressions, and emotions [6-7].

In a review of health literacy's impact on health law and public policy, Trudeau explains the growing trend in the U.S. and the EU to integrate health literacy (or patient understanding) as a foundation of diverse laws, regulations, and health policies [8]. Trudeau details health literacy's integration into selected U.S. statutes, regulations, administrative orders and guidance, as well as case law. Importantly, Trudeau notes the definition of health literacy that is embedded within a U.S. statute is: 'the degree to which an individual has the capacity to obtain, communicate, process, and understand health information and services in order to make appropriate health decisions' [8]. In contrast, some other chapters in the book (such as Smith and Carbone; Pleasant, O'Leary, and Carmona) critique the conceptual limitations of this HL definition [1,9]. Providing examples from the U.S. and the EU, Trudeau explains how the integration of health literacy within the law and policy may be better understood by lay persons and HL practitioners [8]. The evolution and integration of health literacy within the law broadens the appreciation and embedded application of health literacy's socio-cultural and policy impact.

3. Health Literacy and Three Mass Communications Subfields

The mass communication (or the third subsection in section three) includes three chapters on: understanding the implications of peer-to-peer health communication via social media and health literacy; understanding health journalism - and if journalistic quality contributes to a better public understanding of health and medicine; and a chapter on the commonalities and differences between health communication and health literacy research. Overall, two of the three chapters focus on two of the key media sources of public health information (peer-to-peer communication and the news media). The third chapter focuses on the disciplinary similarities/dissimilarities between health communication and health literacy. The latter chapter covers the intersections between separate yet somewhat interdependent fields.

As an increasingly important source of public information about health, Peterson et al. suggest the increasing use of peer-to-peer communication (via social media) poses new, special challenges in health communication [10]. Peterson et al. provide some examples where peer-to-peer communication about health via social media has fostered misinformation as well as evidence-based information about diseases, conditions, and public health issues. Peterson et al. suggest improving health/science literacy, addressing misinformation, and supporting decision-making in limited literacy populations are keys to help individuals and communities successfully navigate peer-to-peer contexts where health information is exchanged [10].

In terms of specific strategies to address peer-to-peer communication challenges, Peterson et al. highlight some interventions in schools (K-12), the utilization of communication inoculation theory to counter misinformation, and more industry/influencer partnerships. Peterson et al. conclude the democratization of communication (via peer-to-peer networks) has moved so quickly that its implications for health and health information seeking have yet to be well understood. The authors suggest efforts to advance research in health/science literacy are needed to maximize the benefits (and minimize the potential harm) from increased public access to health knowledge that is advanced by lay peers as much as medical professionals and organizations, the news media, pharma, advertising, and non-governmental and governmental public health/medical agencies [10].

In a chapter that focuses on the news media's influence, Oransky provides insights into whether health journalism's (and institutional health communication) challenges may derail efforts to improve the public's understanding of health and medicine [11]. Oransky (a physician and the president of the U.S.-based Association of Health Care Journalists at the time of the chapter's preparation) presents independent research about health journalism's quality and suggests some current barriers to progress. Oransky describes some of the ongoing intramural efforts by journalists to improve the quality of health news reporting [11].

Oransky also addresses a key issue: would improving the quality of health journalism enhance the public understanding of health and medicine (and contribute to health literacy)? Although Oransky explains the issue is receiving overdue scrutiny, it is premature to suggest data-undergirded insights. However, by raising the latter issue, Oransky suggests an interdisciplinary intersection and a range of career opportunities for journalism and health literacy researchers [11].

In a comparison of the academic fields of health literacy and health communication, Kreps et al. note the parallel development of two interdependent (but separate) areas of study [12]. Kreps et al. explain health communication and health literacy developed from different professional roots. Kreps et al. note health communication developed primarily from an academic orientation, and health literacy developed from more to address enduring challenges among health care professionals. While health communication grew out of communication and the social sciences, health literacy evolved from the professional disciplines of medicine and education [12].

Kreps et al. provide a brief history of the professional development of each area and note the key areas in health literacy that contribute to overall health communication research and practice. Commendably, Kreps et al. find some areas of convergence and suggest rapprochement strategies between health communication and health literacy including overlapping conceptual areas, and shared research interests. Overall, the chapter helps researchers in both health literacy and health communication learn about closely related, but slightly different, fields of scholarship and practice [12].

Incidentally, the Kreps et al. chapter coupled with the Allen et al. chapter provide significant background into the development of the field of health communication and its correspondence with health literacy [12,2].

4. Health Literacy as a Gateway to Social and Professional Progress

The fourth subsection in section three includes three chapters about: how health literacy contributes to smart individual health choices; the need for an integrated measure of health literacy, language access, and cultural competence; and a series of World Health Organization's conferences that have associated health literacy with social progress. The section focuses on how health literacy initiatives are an integral part of focused and broad efforts to improve patient health, health institutional progress in patient-centered and equitable care, and even broader social advancement.

Christie and Ratzen suggest how improved health literacy foster smart health choices among individuals [13]. Christie and Ratzen also discuss how to build sustainable health literacy at individual, local, national, and global levels. The chapter reinforces that health literacy efforts (that initially help patients and consumers make decisions and understand physician and health care institutional instructions and health care information) also have a multidimensional impact on local, national, and global health [13]. The chapter is especially relevant in nations, such as the U.S., where outbreaks of preventable illnesses, such as measles, have been fostered by anti-vaccination efforts among health consumers. Anti-vaccination issues also are discussed in Peterson et al.'s chapter [10].

In an example of health literacy's integration as a gateway to progress in U.S. health care, Bau explains the suggestion for health care organizations to assess their health literacy efforts opens an opportunity for an integrated measure of health literacy, language access, and cultural competence [14]. Bau notes while efforts to advance and assess health literacy, language access, and cultural competence advanced differently within U.S. health care professional practice and research, there is a current interest within major U.S. health care leadership organizations to make improvements in all three areas and set a measurable baseline to evaluate ongoing progress [14]. While acknowledging a common measure of health literacy, language access, and cultural competence will be challenging to develop, Bau suggests its availability would exemplify the type of innovative approach that is advocated by some health care organizations to improve institutional accountability [14]. Bau adds an integrated measure could serve as a needed gateway to progress in patient centered and equitable care and demonstrates leadership in the assessment and implementation of improved health care standards [14].

Bau's chapter updates a perspective from the National Academies of Sciences, Engineering, and Medicine Roundtable on Health Literacy that broadly endorsed the integration of health literacy, language access, and cultural competence measures [15]. Bau concludes patient-centered, integrated measures also provide opportunities for collaborative, interdisciplinary research as well as innovative approaches to improve health care delivery [14].

In the section's third chapter, Pleasant, O'Leary, and Carmona explain how the World Health Organization (WHO) and other United Nations' organizations have framed the role of health literacy more macroscopically than: a) as a personal resource to understand physician instructions and health care information, or b) as a responsibility of health care providers to respond to patient needs, or governments and health institutions to present clear, accurate, appropriate, and accessible information to diverse audiences [9]. Pleasant and O'Leary note the WHO ongoing conferences conceptually have framed health literacy's role as associated with social progress. In other words, the conferences suggest as a discipline that health literacy should not be conceptually limited to the impact of interventions to improve health outcomes and enhance the utilization of the health care delivery system. Indeed, Pleasant, O'Leary, and Carmona explain the conferences suggest health literacy improvements can mobilize communities to address the social, economic, and environmental determinants of health.

Pleasant, O'Leary, and Carmona highlight the key points from WHO conferences, some missing elements, and implications for future health literacy practice and research. Pleasant, O'Leary, and Carmona address how the WHO's efforts challenge the development of the health literacy field and suggest how researchers and practitioners can build on the charter’s macroscopic conceptual scope in the future [9]. Finally, Pleasant, O’Leary, and Carmona propose a conceptual framework (the ‘5 E approach) to undergird ethical research and practice in health literacy [9].

5. Conclusion: Learning from Section Three

The chapters in section three strongly suggest the field of health literacy potentially expands the research in several affiliated areas and opens significant opportunities for collaborations with a range of other disciplines. The scope of the disciplinary possibilities for health literacy researchers outlined in section three include: personal empowerment; K-12 education; the arts and humanities; peer-to-peer lay health communication; health journalism; health policy; combining health literacy with cultural competence and measures; smart health choices; and a proposed, integrated measure of health literacy language access, and cultural competence.

The disciplinary horizons introduced in section three are consistent with the three platforms of health literacy introduced in the conclusion to section one and suggest a possible fourth platform.

For example, Christie and Ratzan’s chapter on smart health choices suggests innovative initiatives to work with individuals, which advances the first HL platform of research and practice [13]. Postelthwait, Ike, and Parker’s chapter details how health literacy efforts contribute to the revitalization of health care institutions and medical practice, which develops the first and the second HL platforms [5]. The chapters from Allen, Ault, and Zorn and Pleasant, O’Leary, and Carmona note the importance of health literacy initiatives in public education and fostering social progress, which enhance the third HL platform [2,9].

However, the diverse disciplinary chapters in section three suggest a fourth platform where collaborative research contributes to the mutual and simultaneous growth of health literacy with: arts and humanities; public education; patient empowerment; peer-to-peer lay health communication; health journalism; health policy; and an integrated measure of health literacy language access and cultural competence. In short, section three proposes a foundation for multidisciplinary convergence and synergy that may conceptually supplement the aforementioned three platforms

To put this another way, most of the chapters in section three note the desirability to address diverse personal, institutional, and social health issues via the integration of health literacy with the aforementioned disciplines. More specifically, the aggregate chapters in section three suggest a response to Christie and Ratzan’s call to integrate health literacy issues to understand and address vaccination resistance would integrate HL measures and interventions with: social psychology; social work; epistemic communities; health communication;, health journalism; legacy and social media; other social determinants; educational initiatives; individual, family, and community empowerment - and utilize new integrated measures such as health literacy, language access, and cultural competence [13]. Metaphorically, the resulting findings could lift many disciplinary boats and underscore the value of comprehensive efforts to address health’s individual, institutional, and social issues.

Yet, it should be noted that a proposed fourth platform of research (based on the suggestions within the chapters in section three) identifies an overall approach to research rather than its focal point. In contrast with the other three platforms, the proposed fourth suggests the importance of interdisciplinary work that might focus on any of the focal points identified within the other three platforms. Hence, in the fourth platform, the focus could be on individuals, health care institutions, social determinants and progress (or any combination) as long as the conceptual framework that undergirds the research is multidimensional and multidisciplinary.

The range of possible collaborations of health literacy researchers with peers in the affiliated disciplines identified in section three additionally provide a significant range of areas for research and mutually beneficial professional progress. For health literacy students and future researchers, section three reminds us: a) health literacy is not limited to the three platforms of research and practice and b) a health literacy researcher's role is to provide leadership in the mutual evolution of similar discipline by collaborating with peers.

Overall, section three suggests HL's distinctiveness as a platform and variable for research and practice and extols the important of adding a multidisciplinary-grounded fourth platform within health literacy research and practice. Section three moves beyond research and initiatives that illustrate literacy in clinical practice and public health and provides new initiatives and lessons learned at the intersection with other disciplines.

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