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Helping Decipher Doctorspeak: Health Literacy and the Library Community

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Introduction

In her 2008 *Against the Grain* article “Trends in Consumers’ Health Information Needs and Expectations,”¹ **Patricia Pinkowski** highlighted some current issues and challenges affecting any library whose mission included “building and serving consumer collections.” Her choice of topics was based on her experience working with patrons in a health sciences environment, and she covered literacy as it relates to health literacy. This article will look at the evolving issues and challenges of health literacy and outreach initiatives surrounding or encompassing library support for creating and maintaining a health literate community.

Health Literacy Outreach: What it is and Why it Matters

Healthcare is changing. People are increasingly asked to be actively engaged in their own health care decision-making process. This engagement or patient empowerment, has the potential of increasing the quality and efficacy of their health care by encouraging people to adhere or comply with health care regimens as well as participate in preventative care thereby reducing healthcare costs and enjoy the benefits of a healthier lifestyle.

It is acknowledged health information and health literacy outreach play an important part in increasing the quality of a person’s health status.² Libraries have long been seen as a connector between the public and health information, whether it is a public, hospital or an academic health sciences library.³

The term “health literacy” was first used in the literature by **Scott Simonds** in his article “Health education as social policy.”⁴ He advocated for health to be part of “standard education requirements, like writing and math.” However, it wasn’t until the 1999 report on health literacy by the Ad Hoc Committee on Health Literacy by the **American Medical Association’s (AMA)** Council on Scientific Affairs that there was any national attention paid to health literacy. The **AMA** report responded to the results of the 1992 National Adult Literacy Survey (NALS) that found nearly 50% of the adult U.S. population had marginal literacy skills.⁵ This raised concerns about the ability of Americans to “function adequately in health care settings” which was seen as the ability to “read and comprehend prescription bottles, appointment slips, and other essential health-related materials required to successfully function as a patient.”⁶ One of **AMA’s** recommendations was to include health literacy questions in the next iteration of the National Assessment of Adult Literacy (NAAL). The 2003 NAAL asked 28 questions specifically related to health; 3 clinical; 14 prevention; 11 system navigation.⁷ The health literacy tasks

and scales were based on definitions of health literacy used by the **Institute of Medicine (IOM)** in their 2004 report “Health Literacy: A Prescription to End Confusion”⁸ and Healthy People 2010,⁹ a nationwide health promotion and disease prevention program launched by the **U.S. Department of Health and Human Services (HHS)** in November 2000.

The **IOM** and Healthy People 2010 definitions were based on a February 2000 **National Library of Medicine (NLM)** *Current Bibliographies in Medicine* on the topic of health literacy. The authors of the bibliography 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.”¹⁰ The **IOM** recognized health literacy is vital to the health of individuals and was more than just the ability of the individual to read. It also involves the ability to be able to be analytical about the information provided, make decisions based on the information, and apply it to their healthcare environment.

The 2003 NAAL revealed that the majority of U.S. adults, 53% had intermediate health literacy, 22% had basic health literacy while on either end of the scale, 15% of adults had either below basic or proficient health literacy. Average health literacy increased with increased educational levels, while poverty and racial/ethnic groups were associated with lower than average health literacy. The 2003 NAAL also revealed that the average reading level is 8th grade, but at least 20% of the population reads at a 5th grade level or below.

Since the **IOM** report, the definition or concept of health literacy has been updated due to changes in health care reform. The **Patient and Affordable Care Act (ACA)** of 2010, Title V¹¹ defines health literacy as “the degree to which an individual has the capacity to obtain, *communicate*, process, and understand basic health information and services in order to make appropriate health decisions.” Additionally, one must be able to understand the information *and* communicate it back to the health-care provider.

The **Agency for Healthcare Research Quality (AHRQ)** recently updated a 2004 systematic review of studies on the relationship between literacy and health outcomes that concluded, “Low literacy is associated with several adverse health outcomes, including low health knowledge, increased incidence of chronic illness, poorer intermediate disease markers, and less than optimal use of preventive health

services.”¹² The 2011 update addressed health literacy and health outcomes and showed consistency in “low health literacy with increased hospitalizations, greater emergency care use, lower use of mammography, lower receipt of influenza vaccine, poorer ability to demonstrate taking medications properly, and among seniors, poorer overall health status and higher mortality.”¹³

Key Initiatives Since 2008

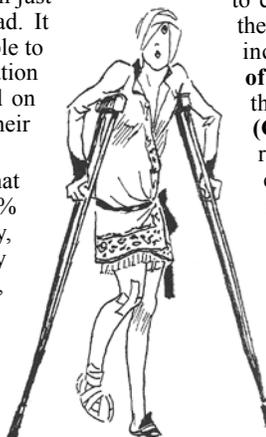
Government Initiatives

The emphasis on health literacy became more urgent with the enactment of the **ACA** in 2010, as consumers needed to be more informed about health care plans. The **Plain Writing Act** of 2010, signed into law in October 2010, requires federal agencies to use clear government communication guidelines to convey health-care information to the public.¹⁴ Several **HHS** agencies, including the **National Institutes of Health (NIH)**, the **AHRQ**, and the **Centers for Disease Control (CDC)**, joined together to support research efforts on health literacy concepts, theory, and interventions, as these relate to **HHS** public health priorities outlined in its Healthy People 2010/2020 initiatives.

The **Office of Disease Prevention and Health Promotion (ODPHP)** has “created tools and resources to help health care facilities, providers, and other professionals effectively communicate with health consumers.”

Its Health Literacy Workgroup developed the **National Action Plan to Improve Health Literacy** in 2010 to engage organizations, professionals, policy makers, communities and individuals in a large scale effort to improve the health literacy of U.S. adults. The **Action Plan** has two core principles: “all people have the right to health information that helps them make informed decisions” and “health services should be delivered in ways that are easy to understand and that improve health, longevity and quality of life.”¹⁵ The **Action Plan** “specifies the roles of librarians to help train all health care staff to create collections or repositories of materials and to help to disseminate existing communication tools and resources for patients.” Two outcomes of the **Action Plan** are the National Quality Health Website Survey, which evaluates samples of health websites, and the 2nd edition of the **Health Literacy Online: A Guide to Simplifying the User Experience**, a research-based guide to “help design health websites and other digital health information tools.”¹⁶ This guide “offers practical insights into a full range of users’

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navigation experiences, particularly those who struggle with reading and health literacy, and can be used to help create intuitive, easy to use digital health information tools.²⁰

Other federal agencies have created tools or resources for health literacy. The **AHRQ** developed the *Health Literacy Universal Precautions Toolkit*,¹⁷ now in its second edition, which provides 21 “tools” that can help primary health care practices reduce the complexity of healthcare. The tools address spoken communications, written communications, self-management and empowerment, and supportive systems. The **CDC** maintains a page providing information and tools to improve health literacy (<https://www.cdc.gov/healthliteracy/>). The **CDC** page, among other information, follows health literacy activities by state and has a section on collaborating with libraries to begin or expand educational and community health literacy activities. The **Centers for Medicare & Medicaid Services (CMS)** created a *Toolkit for Making Written Material Clear and Effective*, an 11-part module that provides a set of tools that cover written materials, graphic design, readability formulas and addressing an older adult audience.¹⁸

The **NIH Office of Communications and Public Liaison (OCPL)** serves as a liaison to the **HHS** on issues related to health literacy. **OCPL** established the *NIH Clear Communication* (<https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication>) initiative to focus on achieving two key objectives of health literacy (1) “providing information in the form and with the content that is accessible to specific audiences based on cultural respect” and (2) “incorporating plain language approaches and new technologies.” **NIH** updated and expanded *Clear & Simple: Developing Effective Print Materials for Low-Literacy Audiences*, which serves as a resource dedicated to the subject of health literacy. Another nationally recognized resource, *Making Health Communication Programs Work*, the **National Cancer Institute (NCI or Cancer.gov)** *Pink Book*, provides extensive guidelines and best practices on clear communication for all **NIH Institutes and Centers**.

Public Libraries Initiatives

Why libraries and specifically, public libraries and health literacy outreach?

A large-scale study of who uses computers and internet access in public libraries conducted by the **Institute of Museums and Library Services (IMLS)** and funded in part by the **Bill & Melinda Gates Foundation**, found that over a 12-month period, an estimated 28 million people used the public library to find information about health and wellness.¹⁹ This included researching medical conditions and procedures, diet and nutrition, finding health care providers and learning about insurance options. Other studies found similar uses of public libraries for health information. The

2013 *Health Online* report by the **Pew Research Center** found one in three U.S. adults reported they went online to learn more about a medical condition they, or someone they knew, had.²⁰ A later study by **Pew**, found 73% of people who visited a public library were looking for information about health issues.²¹ Finally, a 2016 **Pew** study found at least 38% of library users get their health information from libraries.²²

Since the enactment of the *ACA* there have been many initiatives focused on public libraries and their role in providing health insurance and healthcare information to their communities. One of the first products of the Healthy People 2010 Library Initiative was the booklet, *The Challenge of Providing Consumer Health Information Services in Public Libraries*²³ developed as an introduction for librarians to the Healthy People 2010 Library Initiative and to share resources and information gathered during the first phase of the project.

Since public libraries are located in nearly every community and provide access to computers and spaces suitable for workshops or informational meetings, the **American Libraries Association (ALA)** and **IMLS** collaborated with **CMS** and **OCLC** in 2013 to develop a series of programs utilizing *WebJunction.org* (<https://www.webjunction.org/>), a professional development program of **OCLC** to ensure librarians would have the information and local connections that would be needed to connect patrons to information about the Health Insurance Marketplace for when open enrollment began in October 2013. The program *Health Happens in Libraries* (<https://www.webjunction.org/explore-topics/ehhealth.html>), was developed and implemented to provide public library staff with resources so they could assist patrons with health information needs. The formal program ended in June 2016, but the resources and materials continue to be available for anyone to use. These materials include recorded webinars on health information resources, library profiles presented as inspiration for developing community health programming, and library guides which include a series of booklets. One, the Pathways includes “Developing health literacy through health information and services,” “Understanding ethics & privacy in health information and services,” and “Supporting healthy communities through information and services.” A similar *WebJunction.org* offering was the *Public Health and Public Libraries: Librarians as Health Literacy First Responders* (<https://www.webjunction.org/events/webjunction/public-health-and-public-libraries.html>), a webinar exploring health-related outreach, programming, training, and funding so libraries could improve the health literacy of the local community. The webinar is a panel presentation providing an overview of the field of public health and covered training and funding resources for health-related library outreach and programming. As with all *WebJunction.org* offerings, the webinar recordings are archived, along with related slides and resources.

The **National Network of Libraries of Medicine (NNLM)** continues to develop and

sponsor the most current set of training courses on topics related to health information, highlighting **National Library of Medicine** freely available consumer orientated resources such as *MedlinePlus*. An introductory course *Health and Wellness @ the Library: The Essentials of Providing Consumer Health Services (NNLM)* (<https://nnlm.gov/classes/healthwellness>), based on the toolkit, *Finding Health & Wellness @ the Library: A Consumer Health Toolkit for Library Staff*,²⁴ now in its second edition is an interactive, 4-week online course centered around eight core competencies. The course helps to build all of the essential skills for providing consumer health information services by examining issues of health literacy and the health information needs of special populations, such as older adults, teens and immigrant populations. The next scheduled session is February 2019 and is eligible for the **Medical Library Association’s** Consumer Health Information Specialization (CHIS) continuing education credits (<http://www.mlanet.org/page/chis>). The *Stand Up for Health: Health and Wellness Services for Your Community* (<https://nnlm.gov/classes/stand-up-for-health>) is a course in two formats: a 4-week online or an 8 session in-person with lecture and group learning, including pre- and post-class assignments. It is specifically designed to provide public library staff with the foundation of health and wellness reference, programming and outreach for their communities. The course was a pre-conference offering at the 2017 **Public Library Association (PLA) Conference. Promoting Healthy Communities** (<http://www.ala.org/pla/initiatives/healthliteracy>), is a new nationwide initiative from **PLA** in partnership with the **Greater Midwest Region of NNLM (NNLM-GMR)** designed to enhance **NNLM** resources and services to increase public library staff’s awareness, knowledge and skills related to consumer health information needs and services in their communities. **PLA** and **NNLM** will be assessing health information needs among public librarians and launched in May 2018 a website, *Healthy Community Tools for Public Libraries* (<https://publiclibrary.health/>), which lists free resources and professional development opportunities for public library staff. **PLA** and **NNLM-GMR** teamed up with the **Medical Library Association (MLA)** to sponsor a *Symposium on Health Information for Public Librarians*, which took place at the 2018 **MLA Annual Meeting** in Atlanta, GA. The symposium was designed to provide unique opportunities for public and health sciences librarians to network and collaborate on consumer health information programming. The **NNLM** also partnered with **ALA** as part of the *Libraries Transform* public awareness campaign to create a free *Health Literacy Toolkit* (<http://www.ilovelibraries.org/librariestransform/health-literacy-toolkit-intro>) for Health Literacy Month. The toolkit includes customizable materials such as bookmarks, stickers, posters or social media graphics, as well as key messages, such as “Because language shouldn’t be a barrier to health,” “Because fake news is harmful to your health,” “Because libraries are partners in a healthy community.”

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Conclusion

Collaboration between public libraries and health sciences libraries helps to promote awareness of health literacy, provide health information materials that are easy-to-read, accessible in many languages and culturally appropriate, and by developing approaches and materials to teach consumers how to find and evaluate health information resources, especially those found on the Internet. Though the examples offered here are primarily produced and offered in the non-profit or government sectors, the publishing community and more professional groups should check out the Additional Recommended Resources for journals and conferences focused on health literacy to help them better understand and become more involved in health literacy issues/projects. 🐼

Additional Resources

Recommended Resources

National Library of Medicine — Medline Plus: Health Literacy — <https://medlineplus.gov/healthliteracy.html>

National Library of Medicine — PubMed Health Literacy Search — https://www.nlm.nih.gov/services/queries/health_literacy.html

National Network of Libraries of Medicine: Health Literacy — <https://nmlm.gov/initiatives/topics/health-literacy>

Centers for Disease Control & Prevention (CDC) — Health Literacy — <https://www.cdc.gov/healthliteracy/index.html>

Journal of the American Medical Association (JAMA) — Patient Page: Health Literacy — <https://jamanetwork.com/journals/jama/fullarticle/1104329>

RUSA Health and Medical Reference Guidelines — <http://www.ala.org/rusa/resources/guidelines/guidelinesmedical>

Health Literacy Toolshed — <http://healthliteracy.bu.edu/>

Journals

Journal of Consumer Health on the Internet (<https://www.tandfonline.com/toc/wchi20/current>)

Journal of Health Communication: International Perspectives (<https://www.tandfonline.com/loi/uhcm20>) which devotes an entire issue to the topic in each volume.

Health Literacy Research & Practice (<https://www.healio.com/public-health/journals/hlrp>) is a new interdisciplinary and international publication dedicated to promoting excellence in research and practice to advance the field of health literacy, promote health equity, and reduce health disparities.

Conferences

Wisconsin Health Literacy Summit (bi-annual). <http://wisconsinliteracy.org/health-literacy/training-conferences/health-literacy-summit.html>

Institute for Healthcare Advancement (IHA) Health Literacy Conference: held annually in Irvine, CA. <http://hlc.ih4health.org/>

Boston University Medical Campus Health Literacy Research Conference (HARC): held annually in Bethesda, MD. <http://www.bumc.bu.edu/healthliteracyconference/>

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