Access + Understanding: The Role of Health Literacy in Patient-Centric Health IT

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By Kevin Heubusch

Improving the ability of patients to understand and apply health information goes hand in hand with designing systems that deliver it. Both are needed to improve outcomes and reduce disparities.

Recent federal initiatives to promote health IT, including the "meaningful use" EHR incentive program, acknowledge that clinical systems should generate information that serves patients as well as clinicians and administrators. Patient-centric measures promote IT systems that deliver information tailored to the patient, helping individuals better manage their health.

It is a big step for clinical systems to produce information intended for patients. It is a bigger step yet to deliver information that is appropriate to the individual's ability to understand and act on it.

Health literacy is an individual's capacity to obtain, process, and understand the basic health information and services necessary to make health decisions, according to a commonly used definition from the Institute of Medicine.

This capacity includes a wide range of activities that may be preventive (such as reading about how to prevent diabetes through diet and exercise) or directly related to care (such as determining the correct dosage for a medication). It can even extend to a person's ability to navigate the healthcare system, such as determining eligibility for public assistance or completing a form.

The health literacy field began in the 1990s as attention turned to the strong correlation between education and health. Research began establishing the connections between reading skills and health-related outcomes. Health literacy became linked to health and wellness, medical errors, and health disparities.

Subsequently, improving health literacy became an objective of federal public health initiatives, and government agencies began promoting the emerging field with research and funding. As health IT initiatives gathered focus in recent years, this foundational work had raised awareness of health literacy and established its value.

A Struggle for One in Three Adults

An estimated 77 million adults struggle with health literacy, according to the 2003 National Assessment of Adult Literacy, the first large-scale national literacy assessment that measured ability to read, understand, and apply health-related information in English.

Although it did not measure all health literacy factors-in particular, the ability to communicate orally-the national assessment has become a touchstone of health literacy research in the US since its release in late 2005 (data and tools were still being released in 2009 at http://nces.ed.gov/naal/index.asp).

The study included a nationally representative sample of 19,000 participants aged 16 years and older. The survey was administered in person in the participant's home (or in the case of 1,200 participants, in prison).

The definition employed in the study was somewhat narrower than the Institute of Medicine definition, with a greater focus on "functional" health literacy. For purposes of the study, health literacy was defined as the "ability to comprehend and use printed and written health information to function in society, to achieve one's goals, and to develop one's knowledge and potential."

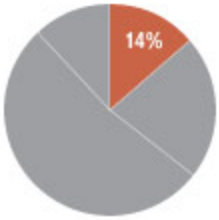
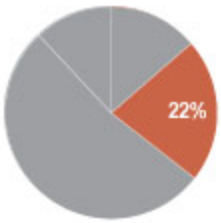
Participants were given three types of tasks. Clinical tasks were associated with provider interactions, diagnosis and treatment, and medication-for example, understanding instructions for a diagnostic test or dosing instructions for a medication.

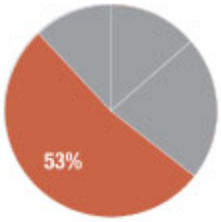
Preventive tasks were defined as those related to engaging in healthy behaviors and self-care, such as reading about ways to lower the risk of heart disease. Navigation tasks involved navigating the healthcare system, both literally and figuratively, such as determining eligibility for public assistance or finding the radiology department in a hospital.

The assessment set four levels of health literacy, ranging from below basic to proficient (see table). Adults with language barriers that prevented them from participating were classified in a fifth category. In the end, the survey found that more than a third of participants had health literacy challenges.

Four Levels of Literacy

The 2003 National Assessment of Adult Literacy was the first large-scale national survey of ability to read, understand, and apply health-related information. It assigned proficiency to four categories associated with key abilities and sample tasks.

Level	Key abilities	Sample Tasks
Below Basic A grasp of no more than the simplest, most concrete literacy skills 	• Locating easily identifiable information in short, commonplace prose texts • Locating easily identifiable information and following written instructions in simple documents, such as charts or forms • Locating numbers and using them to perform simple quantitative operations	• Searching a short, simple text to find what a patient may drink before a medical test • Signing a form
Basic Skills needed to perform simple everyday literacy activities 	• Reading and understanding information in short, commonplace prose texts • Reading and understanding information in simple documents • Locating easily identifiable quantitative information and using it to solve simple one-step problems	• Giving two reasons a person with no symptoms of a disease should be tested for it • Entering names and birth dates in a health insurance application • Calculating what time to take a medication by combining two pieces of information
Intermediate	• Reading and understanding moderately dense, less commonplace prose texts, making simple inferences, determining	• Consulting reference materials to determine which foods contain a particular vitamin

Level	Key abilities	Sample Tasks
Skills necessary to perform moderately challenging literacy activities 	cause and effect, and recognizing the author's purpose • Locating information in dense, complex documents and making simple inferences about the information • Locating less familiar quantitative information and using it to solve problems when the arithmetic operation is not specified or easily inferred	• Finding the age range during which children should receive a particular vaccine by using a chart showing all childhood vaccines and the ages when children should receive them • Determining a healthy weight range for a person of a specified height, based on a graph that relates height and weight to body mass index
Proficient Skills necessary to perform more complex and challenging literacy activities 	• Reading lengthy, complex, abstract prose texts and synthesizing information and making complex inferences • Integrating, synthesizing, and analyzing multiple pieces of information located in complex documents • Locating more abstract quantitative information and using it to solve multistep problems when arithmetic operations are not easily inferred and problems are more complex	• Comparing the power of attorney with a living will and determining the advantages of the power of attorney • Interpreting a table about blood pressure, age, and physical ability • Computing the price per year of an insurance policy

Many Factors Contribute

Much of the NAAL analysis focused on causes. Health literacy is strongly related to general literacy, and the participants with low health literacy tended to lack basic reading skills and had at most a high school education. Nearly half of those lacking a high school diploma had a below basic rating, compared with just 15 percent of adults who reported high school as their highest level of education.

Not surprisingly, those with minimal skills in English had low health literacy ratings (though they may have been literate in their first language). However, the assessment also correlated health literacy to a participant's familiarity with the format of health-related material-such as health insurance forms and drug labels-and familiarity with the workings of the healthcare system.

Low health literacy was also associated with those who reported poor health, had disabilities, lacked health insurance, took few preventive health measures, as well as were racial or ethnic minorities, older, and in prison.

Research and Federal Initiatives

NAAL had been conducted 10 years previously without a health literacy component. The addition to the 2003 survey supported Healthy People 2010, the federal disease prevention and health promotion initiative, which includes a health literacy objective to "improve the health literacy of persons with inadequate or marginal literacy skills."

The Department of Health and Human Services (HHS) and more than a dozen other federal agencies serve as program coordinators. More than 400 national membership organizations, all state and territorial health departments, and national associations of state health officials also take part.

The initiative's influence to date has largely been awareness and research. In its 2005 "midcourse assessment," HHS acknowledged the difficulty of measuring its impact on health literacy, but it cataloged a variety of federally sponsored research, the NAAL health literacy component being the most significant.

Two reports released in 2004 generated additional interest in health literacy improvement: an Institute of Medicine publication titled *Health Literacy: A Prescription to End Confusion* and the Agency for Healthcare Research and Quality publication *Literacy and Health Outcomes*.

Building on its report, the Institute of Medicine convened the public-private Roundtable on Health Literacy, which seeks ways to translate research findings into practical strategies for improving health literacy.

The National Quality Forum and the Joint Commission both initiated projects on patient safety and health literacy improvement, and the National Institutes of Health and the Agency for Healthcare Research and Quality made available grants to foster more research.

HHS is in the process of finalizing Healthy People 2020. The new initiative retains the health literacy objective, now included under a health communication and health IT category: "improve the health literacy of the population."

The Health IT Connection

Within HHS, other groups are acknowledging the importance of health literacy in federal health IT goals. The Office of the National Coordinator for Health IT includes health literacy in its 2008–2012 strategic plan under an objective to further the exchange of health information through interoperability.

One strategy encourages healthcare organizations to provide personal health information in "useable standardized electronic form" to consumers or their designees. "Greater access to usable, electronic health information in standard formats can yield improvements in health literacy, patient-provider communication, care coordination, and overall quality of care," ONC wrote.

When it came time to draft first-stage criteria for the government's EHR incentive program in late 2009, however, the Centers for Medicare and Medicaid Services judged it too soon to make the goal a requirement.

The Health IT Policy Committee, which advised CMS on the program, recommended that providers be required to provide some level of access to patient-specific education resources upon request.

CMS saw the value but not the feasibility. "Providing patients with information and education that is relevant to their condition, actionable, culturally competent, and of the appropriate health literacy level is a critical component of patient engagement and empowerment," it acknowledged in its notice of proposed rulemaking on the program. "Unfortunately, there is currently a paucity of knowledge resources that are integrated within EHRs, that are widely available, and that meet these criteria, particularly in multiple languages."

The assessment illustrates the current gap between understanding the importance of health literacy and improving it.

For its part, CMS stated its intention to work with the policy committee, the National Library of Medicine, and experts in the field to ensure the measure is realistic in future stages of the meaningful use program. ONC's next strategic plan, released in draft form in March 2010, includes the strategy "Develop and implement educational material and tools to improve consumers' health and [health] IT literacy and to promote self-management and self-efficacy using [health] IT."

Actions such as these are steps from the understanding and awareness begun in the 1990s toward the improvement of health literacy.

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