2 | Background

> "Health literacy 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." (Ratzan SC, Parker RM, 2000)

This commonly-used definition of health literacy focuses on the individual.[1] Yet, health literacy is the product of individuals' capacities and the health literacy-related demands and complexities of the health care system.[2,3] So, addressing health literacy means not only improving the skills of individuals, but also the skills of the system in communicating with those individuals as patients, family members, employees, staff, and communities.[4] Improved health literacy comes as the result of an ongoing process of education and thoughtful give-and-take among health systems, providers, patients and families, and the community.

The ideas and background information in this chapter are designed to help you:

- Recognize that health literacy is a factor of individual capacities and the demands and complexities of the health care system.
- Identify key health literacy research, policies, and guidelines, and incorporate that information into your work.
- Connect your work at the local level to national efforts to improve health literacy.

Why is Health Literacy so Important?

Many Health Problems Are Linked to Low Health Literacy

Limited health literacy is associated with:

- Less use of preventive health measures (e.g., influenza vaccination[5,6] and pneumococcal vaccination[5], and mammography[6]).
- Less knowledge about one's own health conditions and self-care, especially for chronic diseases needing complex self-management (e.g., heart failure).[5]
- Less healthy behaviors (e.g., more smoking).[5]
- Poor ability to demonstrate taking medicines appropriately.[6]

- Poor ability to interpret labels and health messages.[6]
- Less understanding of treatment choices.[5]
- Greater use of emergency care.[6]
- More hospitalizations.[6]
- Increased mortality and poorer health status.[6]
- Higher health care costs.[7]

Low Health Literacy Is Very Costly

The 2007 report *Low Health Literacy: Implications for National Health Policy*[7] estimated yearly costs to the U.S. economy of $106 billion to $238 billion associated with low health literacy. These costs result from premature death (mortality), avoidable illness (morbidity), racial, ethnic, and socioeconomic disparities in health and health care, and many other avoidable costs.

Only 12% of U.S. Adults Have Proficient Health Literacy Skills

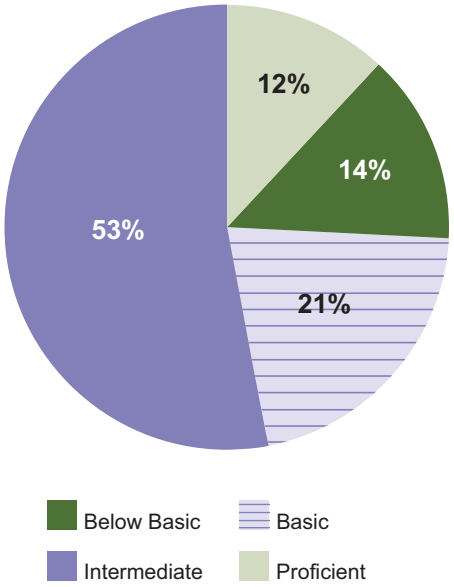
The health care system assumes, and often demands, a high level of literacy, making it very hard to use for many people. The 2003 National Assessment of Adult Literacy (NAAL)[8] was the first national survey of adult literacy to specifically look at health literacy by assessing the ability to perform health literacy-related tasks in three areas: clinical, prevention, and navigation of the health care system. Findings from this survey show that most U.S. adults have difficulty with health-related tasks:

- 14% have below basic health literacy. Sample task: Name what is OK to drink before a medical test, based on information in a clearly-written booklet.
- 21% have basic health literacy. Sample task: Give two reasons a person with no symptoms of a specific disease should be tested for the disease, based on information in a clearly-written booklet.
- 53% have intermediate health literacy. Sample task: Figure out what time a person can take a prescription drug, based on information on the label that relates the timing of the medicine to eating.

- Only 12% have proficient health literacy. Sample task: Calculate an employee's share of health insurance costs for a year, using a table that shows how the employee's monthly cost varies depending on income and family size.

The bottom line — 88% of U.S. adults find it difficult to handle the literacy-related tasks needed to manage their own or their family members' health.[8]

Adults' Health Literacy Level: 2003



Source: America's Health Literacy: Why We Need Accessible Health Information. An Issue Brief From the U.S. Department of Health and Human Services. 2008. Available at: http://www.health.gov/communication/literacy/issuebrief/.

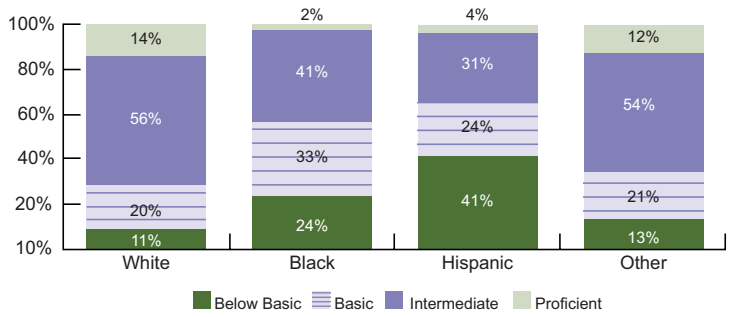
Limited Health Literacy Affects Certain Groups More than Others

The NAAL health literacy report found important differences in the risk for low health literacy among certain groups. Adults aged 65 years and older; those having Medicare, Medicaid, or no insurance; and those of Hispanic ethnicity or black race are among those with the highest percentages in the basic and below basic categories.[8]

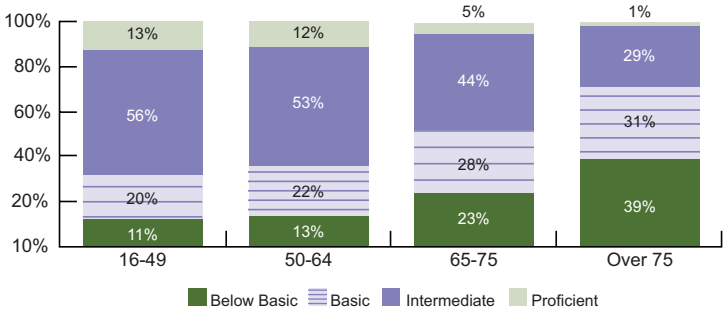
The IOM notes that inadequate health literacy may contribute to health disparities and is integral to cultural and linguistic competence.[9]

Percentage of U.S. Adults in Each Health Literacy Level

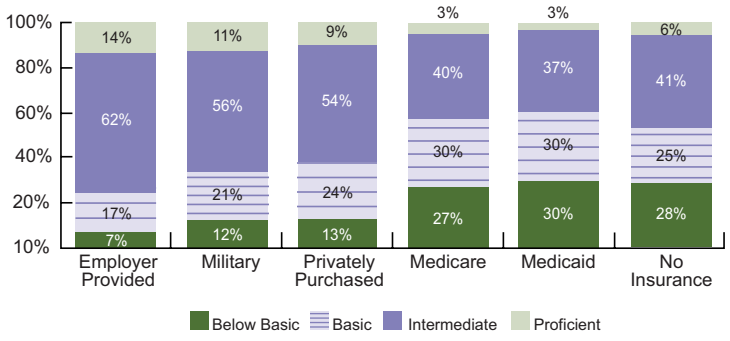
By Race/Ethnic Group



By Age



By Type of Health Insurance



Source: America's Health Literacy: Why We Need Accessible Health Information. An Issue Brief From the U.S. Department of Health and Human Services. 2008. Available at: http://www.health.gov/communication/literacy/issuebrief/.

Too Much Health Information is Too Hard to Understand

Health information comes from many competing sources, such as the media, the Internet, marketing, education, consumer protection groups, the health system, and informal networks. Yet most written health-related information far exceeds the average reading skill of most U.S. adults.[5]

Health Literacy Is an Ethical Issue

There is a relationship between health literacy and the ethical and legal foundation for safe medical practice and patient-centered care.[10] Health care providers have an ethical duty to address health literacy in their practice. The U.S. Supreme Court ruled as early as 1891 that the patient's right to determine what will or will not happen to his or her own body is a basic concept of American law. Later court decisions upheld the patient's right to understand conditions and risks before agreeing to treatment.

> "Patients have the right to understand health care information [they need] to safely care for themselves... Health care providers have a duty to provide information in simple, clear and plain language, and to check that patients have understood the information before ending the conversation."[11]

Stories of failed or near-failed communication between health care providers and patients can illustrate what might happen if patients and families don't understand. *Art's Story* is one of them.

Art's Story

Art was a 78-year-old retired parole officer with emphysema. He had recently developed recurrent throat cancer. His cancer surgeon recommended surgery to remove the cancer. Art asked for advice from his lung doctor, who had been treating Art for years. The doctor tried to explain what would happen during the surgery and some of the risks. The doctor used many terms, such as "laryngectomy," "hemi-laryngectomy," (later, simply "a hemi"), "palliative trach," "ventilatory problems," "bronchiectasis," and "purulent bronchitis."

"OK," said Art. "You've saved my life before. I think I better follow your advice. Let's do it."

Art's adult daughter was in the room, listening and taking notes. She sat next to her father and said, "Dad, what the doctor is saying is that with the surgery, you would have your voice box taken out. You wouldn't be able to talk anymore. You'd have a breathing hole through the front of your throat for the rest of your life. You'd have to keep the hole protected so germs couldn't go straight into your lungs. And you'd have a tube in your breathing pipe that you'd have to take care of every day."

Art's eyes got wide, then angry, and he asked, "What the hell do you mean … I won't be able to talk?"

Health Literacy Policy Can Do More for More People

Federal Policy Initiatives

Federal policy initiatives are advancing health literacy as an integral component of improving health outcomes, increasing quality, and controlling costs.[12,13] They are driving healthcare reform, patient-centered medical home initiatives, and development of accountable care organization, Medicare, and other payment structures to improve quality and outcomes and reduce health disparities. Each of these calls for accessible, actionable health information, effective patient-provider communication, improved patient satisfaction, and consideration of language and cultural issues. For example:

- Under the Affordable Care Act, newly-insured individuals need clear information to choose a health plan and interact with the health system.[14]

- Addressing cultural and linguistic competence can help reduce racial and ethnic health disparities.
- Strategies to improve health literacy can support practice transformation into patient-centered medical homes.
- Providers have incentives to work collaboratively to improve quality and patient satisfaction. Surveys like the Consumer Assessment of Healthcare Providers and Services (CAHPS) and Hospital Consumer Assessment of Healthcare Providers and Services (HCAHPS) have questions related to health literacy and cultural competence. Working to improve these patient experience survey scores, especially for communication with doctors and nurses, can lead to improvement in health communication.[15]
- National quality and safety goals include lowering unplanned readmissions and associated costs.[16] Ensuring patients understand what they need to do to manage their own and loved ones' health is fundamental to ensuring safe transitions home and optimizing self-care for increasingly prevalent chronic conditions.

Accreditation and Quality Improvement

Health literacy is increasingly recognized by accreditation and quality care programs. The Joint Commission states "…the safety of patients cannot be assured without mitigating the negative effects of low health literacy and ineffective communications on patient care."[17] The National Quality Forum endorses teach-back and reader-friendly documents during the informed consent process as best practices for universal use to reduce harm to patients.[18]

Professional Associations

The American Medical Association (AMA), AMA Foundation, and American College of Physicians Foundation have been leaders in physician and other health care professional education and training, highlighting the linkages between providers' responsibility for clear communication and patient safety and improved outcomes. Other professional associations, like the American Dental Association and American Academy of Pediatrics, play roles in raising awareness, providing training, tools, and resources, and evaluating health literacy-related strategies and interventions.

Improving Health Literacy Requires System Changes

Shift Your Focus to the Health Care System

It's easy to focus on the limited skills of millions of people in coping with health literacy tasks. But shift your focus to the health care system and you see a different picture. Perhaps the data do not suggest that nearly 90% of U.S. adults lack skills but, instead, that the health care delivery system is not easily used by 90% of the people it is supposed to serve.

How many poor outcomes occur because health systems are too hard for almost 90% of U.S. adults to use?

Health literacy is a dynamic systems issue reflecting the complexity of the health information being presented and care system being navigated.[19,20] Addressing the challenge of low health literacy requires system-level changes for both health professionals and organizations.[12]

Health Literate Health Care Organizations

System-wide organizational change is needed to stop what has been described as a cycle of crisis care where there can be a wide gulf between what providers mean to convey verbally and in writing, and what patients and families understand and do. A system-wide approach makes promoting health literacy an organizational responsibility and prepares and expects all employees, including health care providers, office staff, and hospital personnel, to address health literacy and patient understanding as a priority. Implementing health literacy strategies at the system level can help transform the ineffectiveness of crisis care, shift the focus to patient-centered care, and ultimately improve health access, quality, and cost management.[12]

At a system level, health literate health care organizations take into account that miscommunication and misunderstanding are common and that the ability of individuals to process and utilize health care information may diminish when they are sick, frightened, or impaired. They appreciate that language and culture are important

dimensions of health literacy.[21] They underscore that system changes are needed to better align with the skills and abilities of the public.[22,23] And they acknowledge that everyone benefits from clear communication. All health care organizations can become health literate, not just hospitals and health centers. Being health literate will benefit all health care professionals and a broad range of health care delivery-related organizations, including health plans and insurance providers.

Moving from a Cycle of Crisis Care to Health-Literate Care

The cycle of crisis care[12] is demonstrated when a sick patient seeks care and is asked to fill out complex forms, examined and given a diagnosis using technical language, offered a treatment plan and prescribed medications without confirming understanding, and sent home with no support or follow-up. This may lead to the patient taking their medicines incorrectly, altering or not following the treatment plan, and missing appointments. The sick patient then seeks care again, is perhaps given a new treatment plan, and the cycle continues.

In a cycle based on health-literate care, a sick patient is given simple forms and help filling them out. Explanations are given using easy-to-understand wording, questions are solicited and answered, and understanding is confirmed by asking the patient to explain the treatment plan back using their own words. Reader-friendly hand-outs are given and follow-up calls made to help the patient carry out the plan.[12]

The National Action Plan to Improve Health Literacy

The *National Action Plan to Improve Health Literacy*[24] reflects a national commitment to providing health information that is usable for all populations and promotes a vision of a health literate society that:

- Provides everyone with access to accurate, actionable health information.
- Supports life-long learning and skills to promote good health.
- Delivers person-centered health information and services.

The *National Action Plan* envisions a restructuring of the health care system and invites multi-sector participation. It has seven goals and offers evidence-based and best practice strategies for achieving a health literate society. The second goal specifically calls for promoting changes in the health care system that improve health information, communication, informed decision-making, and access to health services to meet the communication needs of patients and improve quality.

The National Action Plan to Improve Health Literacy

Seven Goals to Achieve a Health Literate Society

1. Develop and disseminate health and safety information that is accurate, accessible, and actionable.
2. Promote changes in the health care system that improve health information, communication, informed decision-making, and access to health care services.
3. Incorporate accurate, standards-based, and developmentally-appropriate health and science information and curricula in child care and education through university level.
4. Support and expand local efforts to provide adult education, English language instruction, and culturally- and linguistically-appropriate health information services in the community.
5. Build partnerships, develop guidance, and change policies.
6. Increase basic research and development, implementation, and evaluation of practices and interventions to improve health literacy.
7. Increase dissemination and use of evidence-based health literacy practices and interventions.

Source: U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. *National Action Plan to Improve Health Literacy*, 2010.

UnityPoint Health

UnityPoint Health is a large integrated health system. Its mission is to provide the "Best Outcome for Every Patient Every Time."[25] Through hospitals and clinics in metropolitan and rural communities throughout Iowa, Illinois, and Wisconsin, it provides care through more than 4 million yearly visits.

Implementing a Plan

UnityPoint Health incorporates health literacy as a cross-cutting, system-wide quality initiative. In 2003, UnityPoint Health established a multidisciplinary group called the Health Literacy Collaborative to implement improvements in health literacy. The Collaborative worked with hospital, outpatient clinic, and home health teams to develop communication tools and strategies to increase patient understanding and provide a better experience for patients and their families.[26,27] Teams were asked to:

- Test health literacy tools and techniques in busy real-world settings.
- Assess how easy, acceptable, and practical it is to introduce and adopt various health literacy approaches.
- Speed up use of evidence-based and best practice health literacy interventions.
- Identify strategies for sustaining and spreading improvements.

Health literacy interventions such as plain language, teach-back, and reader-friendly print materials were used to support understanding of discharge instructions, medication safety, informed consent, and navigation (finding your way around). Teams used strategies like staff training and coaching; competencies, policies, and checklists; and management incentives to promote long-lasting improvements.

Working with Partners

UnityPoint Health's Health Literacy Collaborative has worked with patients, families, and diverse public and private partners to address health literacy. One invaluable partner is the New Readers of Iowa, an organization run for and by people learning to read as adults, who help each other and advocate for adult literacy.

Health Literacy Collaborative Partners

- Adult literacy programs and community colleges
- Des Moines University
- Drake University College of Pharmacy
- Health Literacy Iowa
- Iowa Department of Education
- Iowa Department of Public Health
- Iowa Geriatric Education Center
- Iowa Healthcare Collaborative
- Iowa Hospital Association
- Iowa Medical Society (IMS)
- IMS Alliance
- Iowa Nurses Association
- New Readers of Iowa
- Pfizer
- Reach Out and Read Iowa
- The Wellmark Foundation
- University of Iowa Center for Disabilities and Development
- University of Iowa College of Public Health
- University of Northern Iowa Center on Health Disparities

Using the Model for Improvement

The Model for Improvement[28] is a simple yet powerful tool used by health care organizations to test and implement changes in real-world settings to improve health care processes and outcomes. Plan-Do-Study-Act (PDSA) cycles guide the tests of change to determine if there is improvement. The Model for Improvement helps answer three basic questions:

- What are we trying to accomplish?
- How will we know that a change is an improvement?
- What change can we make that will result in improvement?

Testing Changes

PDSA stands for:

- Plan—Develop a plan to test the change.
- Do—Carry out the test.
- Study—Observe and learn from what happens.
- Act—Decide what changes to make to the test for the next cycle.

PDSA cycles break down changes into a series of small tests that can be tried in real working settings. Multiple PDSA cycles in a quick series can lead to successful change that ultimately involves many stakeholders. They make it possible to:

- Learn how to adapt the change to the local environment.
- Allow failures without impacting performance.
- Predict how much improvement might come from the change.
- Increase belief the change will result in improvement.
- Minimize resistance to change.

Other advantages include the chance to evaluate costs and side-effects, refine the process before it becomes a done deal, and run multiple PDSA cycles in multiple areas at the same time.

To be considered a complete PDSA test, the following must apply:

- The test or observation was planned (including a plan for collecting data).
- The plan was attempted (do the plan).
- Time was set aside to analyze the data and study the results.
- The next action was based on what was learned.

The Model for Improvement is especially well-suited to addressing health literacy, since it can create a *pull* as much as a *push*. This pull represents the fact that organizational change can begin on the front lines, through people who work with patients and families, as well as a push from leadership.

Learning Collaboratives and the Model for Improvement

The Model for Improvement can be applied in any setting, from individual clinics, departments, or hospitals, to formal Learning Collaboratives. Learning Collaboratives focus on improvement using a philosophy of "all teach, all learn." They are comprised of health care organizational teams committed to making major, rapid changes and working together to identify improvement strategies and test changes.

A Learning Collaborative involves Learning Sessions that allow participants to come together to share, teach, and learn. Between Learning Sessions there are Action Periods for PDSA testing and conference calls to share progress, problem-solve, and report lessons learned. Testing leads to implementation—making changes part of the day-to-day operations of the organization, where support processes and resources become more important. Ultimately, testing leads to sustainability and spread. Long-term, this may involve strategies like:

- Assigning ownership.
- Formally including changes in orientation and training.
- Setting up standard processes and policies.
- Measuring, observing, and auditing.
- Changing job descriptions.

Source: UnityPoint Health. Institute for Healthcare Improvement: Model for Improvement, 2009.

Summary of Key Points

- Low health literacy is associated with poor health outcomes and increased costs.
- Nearly 90% of adults in the U.S. do not have the health literacy skills needed to navigate the U.S. health care system.
- Seniors and ethnic and racial minorities are at increased risk of low health literacy.
- Improving health literacy requires system changes and establishment of health literate organizations that address health literacy and patient understanding as a priority.
- The *National Action Plan to Improve Health Literacy* calls for a multi-sector approach and suggests evidence-based and best practice strategies for achieving a health literate society.
- The Model for Improvement is a useful tool for small tests of health literacy changes and interventions to promote quality care.
- A health literate organization recognizes that health literacy arises from individuals' capacities and the health literacy-related demands and complexities of the health care system.

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