

# Quick Guide to Health Literacy



**Fact Sheets**



**Strategies**



**Resources**



**U.S. Department of Health and Human Services**  
Office of Disease Prevention and Health Promotion

# Quick Guide to Health Literacy

## About This Guide

### Who is the Quick Guide for?

The Quick Guide to Health Literacy is for government employees, grantees and contractors, and community partners working in healthcare and public health fields.

It contains:

- A basic overview of key health literacy concepts
- Techniques for improving health literacy through communication, navigation, knowledge-building, and advocacy
- Examples of health literacy best practices
- Suggestions for addressing health literacy in your organization

These tools can be applied to healthcare delivery, policy, administration, communication, and education activities aimed at the public. They also can be incorporated into mission, planning, and evaluation at the organizational level.

If you are new to health literacy, the Quick Guide will give you the information you need to become an effective advocate for improved health literacy. If you are already familiar with the topic, you will find user-friendly, action-oriented materials that can be easily referenced, reproduced, and shared with colleagues.

### How to use the Quick Guide

The guide is designed to be a quick and easy reference, filled with facts, definitions, helpful tips, checklists, and resources you can use on the job. You can print out the materials and keep them at your desk, share them with colleagues, or bookmark this Web page on your computer.



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The Quick Guide is divided into the following three sections:

1. The first section contains **fact sheets** on health literacy, including a basic overview of key concepts and definitions and information on health literacy and health outcomes.
2. The second section contains practical **strategies** for improving health literacy. These include:
  - Improve the usability of health information
  - Improve the usability of health services
  - Build knowledge to improve decisionmaking
  - Advocate for health literacy in your organization
3. The final section contains a list of **resources**, including Web sites, research studies, and additional publications on health literacy.



## Health Literacy Basics

### What is health literacy?

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.<sup>1</sup>

Health literacy is dependent on individual and systemic factors:

- Communication skills of lay persons and professionals
- Lay and professional knowledge of health topics
- Culture
- Demands of the healthcare and public health systems
- Demands of the situation/context

Health literacy affects people's ability to:

- Navigate the healthcare system, including filling out complex forms and locating providers and services
- Share personal information, such as health history, with providers
- Engage in self-care and chronic-disease management
- Understand mathematical concepts such as probability and risk

Health literacy includes numeracy skills. For example, calculating cholesterol and blood sugar levels, measuring medications, and understanding nutrition labels all require math skills. Choosing between health plans or comparing prescription drug coverage requires calculating premiums, copays, and deductibles.

In addition to basic literacy skills, health literacy requires knowledge of health topics. People with limited health literacy often lack knowledge or have misinformation about the body as well as the nature and causes of disease. Without this knowledge, they may not understand the relationship between lifestyle factors such as diet and exercise and various health outcomes.



Health information can overwhelm even persons with advanced literacy skills. Medical science progresses rapidly. What people may have learned about health or biology during their school years often becomes outdated or forgotten, or it is incomplete. Moreover, health information provided in a stressful or unfamiliar situation is unlikely to be retained.

### What is literacy?

Literacy can be defined as a person's ability to read, write, speak, and compute and solve problems at levels necessary to:

- Function on the job and in society
- Achieve one's goals
- Develop one's knowledge and potential<sup>2</sup>

The term "illiteracy" means being unable to read or write. A person who has limited or low literacy skills is not illiterate.

### What is plain language?

Plain language is a strategy for making written and oral information easier to understand. It is *one* important tool for improving health literacy.

Plain language is communication that users can understand the first time they read or hear it. With reasonable time and effort, a plain language document is one in which people can find what they need, understand what they find, and act appropriately on that understanding.<sup>3</sup>

Key elements of plain language include:

- Organizing your information so that the most important points come first
- Breaking complex information into understandable chunks
- Using simple language and defining technical terms
- Using the active voice

Language that is plain to one set of readers may not be plain to others.<sup>3</sup> It is critical to know your audience and have them test your materials before, during, and after they are developed.

Speaking plainly is just as important as writing plainly. Many plain language techniques apply to verbal messages, such as avoiding jargon and explaining technical or medical terms.

### **What is cultural and linguistic competency?**

Culture affects how people communicate, understand, and respond to health information. Cultural and linguistic competency of health professionals can contribute to health literacy. Cultural competence is the ability of health organizations and practitioners to recognize the cultural beliefs, values, attitudes, traditions, language preferences, and health practices of diverse populations, and to apply that knowledge to produce a positive health outcome.<sup>4</sup> Competency includes communicating in a manner that is linguistically and culturally appropriate.<sup>5</sup>

Healthcare professionals have their own culture and language. Many adopt the “culture of medicine” and the language of their specialty as a result of their training and work environment. This can affect how health professionals communicate with the public.

For many individuals with limited English proficiency (LEP), the inability to communicate in English is the primary barrier to accessing health information and services. Health information for people with LEP needs to be communicated plainly in their primary language, using words and examples that make the information understandable.

### **Why is health literacy important?**

Only 12 percent of adults have Proficient health literacy, according to the National Assessment of Adult Literacy. In other words, nearly 9 out of 10 adults may lack the skills needed to manage their health and prevent disease. Fourteen percent of adults (30 million people) have Below Basic health literacy. These adults were more likely to report their health as poor (42 percent) and are more likely to lack health insurance (28 percent) than adults with Proficient health literacy.<sup>6</sup> Low literacy has been linked to poor health outcomes such as higher rates of hospitalization and less frequent use of preventive services (see Fact Sheet: Health Literacy and Health Outcomes). Both of these outcomes are associated with higher healthcare costs.

### Who is at risk?

Populations most likely to experience low health literacy are older adults, racial and ethnic minorities, people with less than a high school degree or GED certificate, people with low income levels, non-native speakers of English, and people with compromised health status.<sup>7</sup> Education, language, culture, access to resources, and age are all factors that affect a person's health literacy skills.

### Who is responsible for improving health literacy?

The primary responsibility for improving health literacy lies with public health professionals and the healthcare and public health systems. We must work together to ensure that health information and services can be understood and used by all Americans. We must engage in skill building with healthcare consumers and health professionals. Adult educators can be productive partners in reaching adults with limited literacy skills.

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<sup>1</sup> U.S. Department of Health and Human Services. 2000. *Healthy People 2010*. Washington, DC: U.S. Government Printing Office. Originally developed for Ratzan SC, Parker RM. 2000. Introduction. In *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*. Selden CR, Zorn M, Ratzan SC, Parker RM, Editors. NLM Pub. No. CBM 2000-1. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services.

<sup>2</sup> Public Law 102-73. The National Literacy Act of 1991.

<sup>3</sup> Plain Language Action and Information Network. What is Plain Language? Available at [www.plainlanguage.gov](http://www.plainlanguage.gov). Accessed on October 21, 2005.

<sup>4</sup> U.S. Department of Health and Human Services. 2001. *National Standards for Culturally and Linguistically Appropriate Services in Health Care*. Washington, DC: Office of Minority Health.

<sup>5</sup> McKinney J, Kurtz-Rossi S. 2000. *Culture, Health, and Literacy: A Guide to Health Education Materials for Adults With Limited English Skills*. Boston, MA: World Education.

<sup>6</sup> National Center for Education Statistics. 2006. *The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy*. Washington, DC: U.S. Department of Education.

<sup>7</sup> Institute of Medicine. 2004. *Health Literacy: A Prescription to End Confusion*. Washington, DC: The National Academies Press.



## Health Literacy and Health Outcomes

Choosing a healthy lifestyle, knowing how to seek medical care, and taking advantage of preventive measures require that people understand and use health information. The ability to obtain, process, and understand health information needed to make informed health decisions is known as health literacy.

Given the complexity of the healthcare system, it is not surprising that limited health literacy is associated with poor health. This fact sheet summarizes key research study findings on the relationship between health literacy and health outcomes.

### Use of preventive services

According to research studies, persons with limited health literacy skills are more likely to skip important preventive measures such as mammograms, Pap smears, and flu shots.<sup>1</sup> When compared to those with adequate health literacy skills, studies have shown that patients with limited health literacy skills enter the healthcare system when they are sicker.<sup>2</sup>

### Knowledge about medical conditions and treatment

Persons with limited health literacy skills are more likely to have chronic conditions and are less able to manage them effectively. Studies have found that patients with high blood pressure,<sup>3</sup> diabetes,<sup>3-5</sup> asthma,<sup>6</sup> or HIV/AIDS<sup>7-9</sup> who have limited health literacy skills have less knowledge of their illness and its management.

### Rates of hospitalization

Limited health literacy skills are associated with an increase in preventable hospital visits and admissions.<sup>10-13</sup> Studies have demonstrated a higher rate of hospitalization and use of emergency services among patients with limited literacy skills.<sup>12</sup>



### Health status

Studies demonstrate that persons with limited health literacy skills are significantly more likely than persons with adequate health literacy skills to report their health as poor.<sup>10,12,14</sup>

### Healthcare costs

Persons with limited health literacy skills make greater use of services designed to *treat* complications of disease and less use of services designed to *prevent* complications.<sup>1,11-13</sup> Studies demonstrate a higher rate of hospitalization and use of emergency services among patients with limited health literacy skills.<sup>10-13</sup> This higher use is associated with higher healthcare costs.<sup>15,16</sup>

### Stigma and shame

Low health literacy may also have negative psychological effects. One study found that those with limited health literacy skills reported a sense of shame about their skill level.<sup>17</sup> As a result, they may hide reading or vocabulary difficulties to maintain their dignity.<sup>18</sup>

#### About the research

In producing this fact sheet, the Office of Disease Prevention and Health Promotion relied extensively on both the Institute of Medicine (2004) and the Agency for Healthcare Research and Quality (2004) reports, which include comprehensive reviews of the literature on health literacy and health outcomes. For your convenience, the original studies are cited.

In these studies, health literacy was measured by the Rapid Estimate of Adult Literacy in Medicine (REALM) or Test of Functional Health Literacy in Adults (TOFHLA). Both the IOM and AHRQ reports conclude that REALM and TOFHLA are assessments of reading ability, and as such are inadequate measures of health literacy.

Persons with limited health literacy were compared to those with adequate health literacy. Although an increasing number of studies have linked limited health literacy to poor health, the causal relationship between health literacy and health is unknown.

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- <sup>1</sup> Scott TL, Gazmararian JA, Williams MV, Baker DW. 2002. Health literacy and preventive health care use among Medicare enrollees in a managed care organization. *Medical Care*. 40(5): 395-404.
  - <sup>2</sup> Bennet CL, Ferreira MR, Davis TC, Kaplan J, Weinberger M, Kuzel T, Seday MA, Sartor O. 1998. Relation between literacy, race, and stage of presentation among low-income patients with prostate cancer. *Journal of Clinical Oncology*. 16(9): 3101-3104.
  - <sup>3</sup> Williams MV, Baker DW, Parker RM, Nurss JR. 1998. Relationship of functional health literacy to patients' knowledge of their chronic disease. A study of patients with hypertension and diabetes. *Archives of Internal Medicine*. 158(2): 166-172.
  - <sup>4</sup> Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, Palacios J, Sullivan G, Bindman AB. 2002. Association of health literacy with diabetes outcomes. *Journal of the American Medical Association*. 288(4): 475-482.
  - <sup>5</sup> Schillinger D, Grumbach K, Wang F, Wilson C, Daher C, Leong-Grotz K, Castro C, Bindman AB. 2003. Closing the loop: Physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*. 163(1): 83-90.
  - <sup>6</sup> Williams MV, Baker DW, Honig EG, Lee TM, Nowlan A. 1998. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest*. 114(4): 1008-1015.
  - <sup>7</sup> Kalichman SC, Ramachandran BB, Catz SP. 1999. Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine*. 14(5): 267-273.
  - <sup>8</sup> Kalichman SC, Rompa D. 2000. Functional health literacy is associated with health status and health-related knowledge in people living with HIV-AIDS. *Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology*. 25(4): 337-344.
  - <sup>9</sup> Kalichman SC, Benotsch E, Suarez T, Catz S, Miller J, Rompa D. 2000. Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine*. 18(4): 325-331.
  - <sup>10</sup> Baker DW, Parker RM, Williams MV, Clark WS. 1997. The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health*. 87(6): 1027-1030.
  - <sup>11</sup> Baker DW, Parker RM, Williams MV, Clark WS. 1998. Health literacy and the risk of hospital admission. *Journal of General Internal Medicine*. 13(12): 791-798.
  - <sup>12</sup> Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, Ren J, Peel J. 2002. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. *American Journal of Public Health*. 92(8): 1278-1283.
  - <sup>13</sup> Gordon MM, Hampson R, Capell HA, Madhok R. 2002. Illiteracy in rheumatoid arthritis patients as determined by the Rapid Estimate of Adult Literacy (REALM) score. *Rheumatology*. 41(7): 750-754.

<sup>14</sup> National Center for Education Statistics. 2006. *The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy*. Washington, DC: U.S. Department of Education.

<sup>15</sup> Friedland R. 1998. New estimates of the high costs of inadequate health literacy. In: *Proceedings of Pfizer Conference "Promoting Health Literacy: A Call to Action."* October 7-8, 1998, Washington, DC: Pfizer, Inc., 6-10.

<sup>16</sup> Howard DH, Gazmararian J, Parker RM. 2005. The impact of low health literacy on the medical costs of Medicare managed care enrollees. *The American Journal of Medicine*. 118: 371-377.

<sup>17</sup> Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. 1996. Shame and health literacy: The unspoken connection. *Patient Education and Counseling*. 27(1): 33-39.

<sup>18</sup> Baker DW, Parker MR, Williams MV, Ptikin K, Parikh NS, Coates W, Imara M. 1996. The health care experience of patients with low literacy. *Archives of Family Medicine*. 5(6): 329-334.



## Improve the Usability of Health Information

Consider the following questions as you develop and deliver health information:

- Is the information appropriate for the users?
- Is the information easy to use?
- Are you speaking clearly and listening carefully?

### **Is the information appropriate for the users?**

The information below is a summary of best practices in health communication that can aid in improving health literacy. Many of these concepts are discussed in depth in the National Cancer Institute's *Making Health Communication Programs Work* (a.k.a. the "Pink Book") and in the Centers for Disease Control and Prevention's tool *CDCynergy*.

### **Identify the intended users of the health information and services.**

Identify the intended users based on epidemiology (who is affected?), demographics, behavior, culture, and attitude. This is known as segmentation.

Be sure the materials and messages reflect the age, social and cultural diversity, language, and literacy skills of the intended users. Consider economic contexts, access to services, and life experiences.<sup>1</sup>

#### **Attention:**

These principles also apply if you are using existing resources. Be sure to select materials that are accurate and appropriate for the intended users.

Beyond demographics, culture, and language, consider the communication capacities of the intended users. Approximately one in six Americans has a communication disorder or difference resulting in unique challenges.<sup>2</sup> These individuals will require communication strategies that are tailored to their needs and abilities.



### **Evaluate users' understanding before, during, and after the introduction of information and services.**

Talk to members of the intended user group before you design your communication intervention to determine what information they need to know and how they will use it. Then, pretest messages and services to get feedback.

Test your messages again, after they have been introduced, to assess effectiveness. Refine content when necessary. Use a post-test to evaluate the effectiveness of the information.

### **Acknowledge cultural differences and practice respect.**

Cultural factors include race, ethnicity, language, nationality, religion, age, gender, sexual orientation, income level, and occupation. Some examples of attitudes and values that are interrelated with culture include:

- Accepted roles of men and women
- Value of traditional medicine versus Western medicine
- Favorite and forbidden foods
- Manner of dress
- Body language, particularly whether touching or proximity is permitted in specific situations<sup>1</sup>

Ensure that health information is relevant to the intended users' social and cultural contexts.

## **Is the information easy to use?**

### **Limit the number of messages, use plain language, and focus on action.** <sup>3,4</sup>

Keep it simple. The number of messages will depend on the information needs of the intended users. As a general guideline, use no more than four main messages. Give the user specific actions and recommendations. Clearly state the actions you want the person to take. Focus on behavior rather than the underlying medical principles.

Use familiar language and an active voice. Avoid long or run-on sentences. Organize similar information into several smaller groups.

Many of the same plain language techniques that make the written word understandable also work with verbal messages, such as avoiding jargon and using everyday examples to explain technical or medical terms the first time they are used.

For more information on plain language, visit [www.plainlanguage.gov](http://www.plainlanguage.gov).

### Supplement instructions with visuals.

Individual learning styles differ. For many people, visuals are a preferred style, especially for technical information.<sup>3</sup> Simple line drawings can help users understand complicated or abstract medical concepts. Make sure to place images in context. When illustrating internal body parts, for example, include the outside of the body.

Use visuals that help convey your message. (Don't just "decorate," as this will distract users.) Make visuals culturally relevant and use images that are familiar to your audience. Show the main message on the front of the materials.

For print communication, use captions or cues to point out key information.<sup>3</sup>

### Make written communication look easy to read.<sup>3-5</sup>

Use at least 12-point font. Avoid using all capital letters, italics, and fancy script. Keep line length between 40 and 50 characters. Use headings and bullets to break up text. Be sure to leave plenty of white space around the margins and between sections.

### Improve the usability of information on the Internet.

Studies show that people cannot find the information they seek on Web sites about 60 percent of the time.<sup>6</sup> This percentage may be significantly higher for persons with limited literacy skills.

#### Remember

Refer to the Office of Management and Budget (OMB) *Policies for Federal Public Websites* for further guidance.

Many of the elements that improve written and oral communication can be applied to online information, including using plain language, large font, white space, and simple graphics.<sup>7</sup> Other elements are specific to the Internet. These include:

- Enhancing text with video or audio files
- Including interactive features and personalized content
- Using uniform navigation
- Organizing information to minimize searching and scrolling
- Giving users the option to navigate from simple to complex information

A critical way to make information on the Internet more accessible to persons with limited literacy and health literacy skills is to apply user-centered design principles and conduct usability testing.

**Usability** is a measure of several factors that affect a user's experience interacting with a product, such as a Web page. These factors include:

- How fast can the user learn how to use the site?
- How fast can the user accomplish tasks?
- Can the user remember how to use the site the next time he or she visits?
- How often do users make mistakes?
- How much does the user like the site?

To learn more about usability, visit [www.usability.gov](http://www.usability.gov).

### **Are you speaking clearly and listening carefully?**

#### **Ask open-ended questions.**

Ask questions using the words “what” or “how” instead of those that can be answered with “yes” or “no.” For example, “Tell me about your problem. What may have caused it?”<sup>3</sup> Try asking “What questions do you have?” instead of “Do you have any questions?”

### Use a medically trained interpreter.

Plain English will not necessarily help individuals who do not speak English as their primary language and who have limited ability to speak or understand English. To better ensure understanding, health information for people with limited English proficiency needs to be communicated plainly in their primary language, using words and examples that make the information relevant to their potentially different cultural norms and values.

### Check for understanding.

The “teach-back” method is a technique that healthcare providers and consumers can use to enhance communication with each other. The person receiving the health information is asked to restate it in their own words—not just repeat it—to ensure that the message is understood and remembered. When understanding is not accurate or complete, the sender repeats the process until the receiver is able to restate the information needed.<sup>8</sup> Consumers also can be asked to act out a medication regimen.<sup>3</sup>

#### Tip: Checking for understanding

Summarize what the patient needs to do. Consider using a handout or written brochure in plain language. Explain what each medication is for, along with the dosage and side effects. Make sure the patient knows where the information is written down.

Then check for understanding:

*“I want to be sure I didn’t leave anything out that I should have told you. Would you tell me what you are to do so that I can be sure you know what is important?”*

(Source: Doak CC, Doak LG, Root JH. 1996. *Teaching Patients With Low Literacy Skills*. JB Lippincott Company: Philadelphia, PA.)

### Participate in plain language and cultural competency training.

Encourage colleagues to do the same. Consider organizing a training for health professionals and staff in your organization.

**Example:**

# Wash Your Hands

After a disaster, staying clean can be hard to do. You may not have running water. But staying clean helps you stay healthy.

## Things you can do to stay clean and healthy

- Wash your hands with soap and clean water. If you don't have soap and water, you can use hand cleaners with alcohol in them.
- Wash your hands many times each day.



## Times to wash your hands are

### BEFORE

- making food
- eating
- touching a sick person
- touching a cut, sore, or wound.

### AFTER

- using the bathroom
- blowing your nose, coughing, or sneezing
- touching things that may carry germs, like
  - diapers or a child who has used the toilet
  - food that is not cooked (raw food)
  - animals or animal waste
  - trash
  - things touched by flood water
  - a sick person
  - cuts, sores, and wounds.



Recommendations from the Centers for Disease Control and Prevention

Easy-to-read flyer developed by the Centers for Disease Control and Prevention. The flyer was developed in multiple languages.

### **Checklist for Improving the Usability of Health Information**

- Identify the intended users
- Use pre- and post-tests
- Limit the number of messages
- Use plain language
- Practice respect
- Focus on behavior
- Check for understanding
- Supplement with pictures
- Use a medically trained interpreter or translator

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- <sup>1</sup> National Cancer Institute. *Making Health Communication Programs Work*. Washington, DC.
- <sup>2</sup> National Institute of Deafness and Other Communication Disorders. Improving Health Literacy. Available at <http://www.nidcd.nih.gov/about/what.asp>.
- <sup>3</sup> Doak C, Doak L, Root J. 1996. *Teaching Patients With Low Literacy Skills. 2nd Edition*. JB Lippincott Co.: Philadelphia, PA.
- <sup>4</sup> Plain Language Action and Information Network. Available at [www.plainlanguage.gov](http://www.plainlanguage.gov). Accessed on October 21, 2005.
- <sup>5</sup> American Institute for Research. 1981. *Guidelines for Document Designers*. Washington, DC.
- <sup>6</sup> U.S. Department of Health and Human Services. Usability Basics. Available at <http://www.usability.gov/basics/index.html>. Accessed on October 13, 2005.
- <sup>7</sup> Baur CE. 2005. Using the Internet To Move Beyond the Brochure and Improve Health Literacy. In *Understanding Health Literacy*. Schwartzberg JG, VanGeest JB, Wang CC, Editors. AMA Press, 141-154.
- <sup>8</sup> Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C, Leong-Grotz K, Castro C, Bindman AB. 2003. Closing the loop: Physician communication with diabetic patients who have low health literacy. *Archives of Internal Medicine*. 163(1): 83-90.



## Improve the Usability of Health Services

Navigation of healthcare and public health systems requires being familiar with the vocabulary, concepts, and processes needed to access health services and information. This includes understanding insurance coverage and eligibility for public assistance, filling out patient information forms, scheduling appointments and follow-up procedures, and locating services.

Strategies to improve the usability of health services include:

- Improve the usability of health forms and instructions
- Improve the accessibility of the physical environment
- Establish a patient navigator program

### Improve the usability of health forms and instructions

Healthcare and public health systems rely heavily on printed materials, including:

- Medical history forms
- Insurance forms
- Informed consent forms
- Patients' rights and responsibilities
- Test results
- Directions to the lab or pharmacy
- Hospital discharge and home care instructions
- Clinical research protocols and announcements

These documents, particularly forms which contain blank spaces to be filled in by the user, are often more difficult to understand than regular prose.<sup>1</sup>



Consent forms and other legal documents related to patients' rights often contain long sentences and difficult legal terms. It is critical that these forms be translated into plain language. According to recent guidelines prepared by the National Quality Forum, healthcare providers should ask each patient to recount what he or she has been told during the informed consent process to check for understanding.<sup>2</sup>

### Tips for improving the usability of health forms and instructions:

- Revise forms to ensure clarity and simplicity.
- Test forms with intended users and revise as needed.
- Provide plain language forms in multiple languages.
- Provide clear information about eligibility for public assistance.
- Train staff to give assistance with completing forms and scheduling follow-up care.

#### Sample informed consent language

##### ***Voluntary participation:***

“You don’t have to be in this research study. You can agree to be in the study now and change your mind later. Your decision will not affect your regular care. Your doctor’s attitude toward you will not change.”

##### ***New information about risks:***

“We may learn about new things that may make you want to stop being in the study. If this happens, you will be informed. You can then decide if you want to continue to be in the study.”

(Source: Paasche-Orlow MK. 2005. The Challenges of Informed Consent for Low-Literate Populations. In *Understanding Health Literacy*. Schwartzberg JG, VanGeest JB, Wang CC, Editors. AMA Press, 119-140.)

## 🎯 Improve accessibility of the physical environment<sup>1</sup>

Settings with a large number of signs and postings have a high literacy demand. Maps, directions, signs, schedules, and instructions are posted throughout the healthcare setting to help consumers locate services and information. Many of these signs contain unfamiliar phrases and symbols. This environment can be intimidating and overwhelming for persons with limited health literacy skills. Too often, confusing signs and postings create more work for healthcare staff and cause embarrassment for patients.

### Tips for improving the physical environment:

- Include universal symbols and clear signage.
- Promote easy flow through healthcare facilities.
- Train staff to create and maintain a respectful and shame-free environment.

Hablamos Juntos, with support from the Robert Wood Johnson Foundation, has developed a set of **Universal Symbols in Health Care**. Visit [www.hablamosjuntos.org](http://www.hablamosjuntos.org) to learn more.

## 🎯 Establish a patient navigator program

Patient navigators can help consumers access services and appropriate health information. Patient navigators are health professionals, community health workers, or highly trained patient liaisons who coordinate health care for patients and assist them in navigating the healthcare system. Patient navigators can help patients evaluate their treatment options, obtain referrals, find clinical trials, and apply for financial assistance.

### Did you know?

Congress recently passed the *Patient Navigator Outreach and Chronic Disease Prevention Act of 2005*. The bill authorizes \$25 million in grants over 5 years to establish patient navigator programs in low-income and rural communities nationwide.

(Public Law 109-18)

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<sup>1</sup> Rudd RE, Renzulli D, Pereira A, Daltroy L. 2005. Literacy Demands in Health Care Settings: The Patient Perspective. In *Understanding Health Literacy*. Schwartzberg JG, VanGeest JB, Wang CC, Editors. AMA Press, 69-84.

<sup>2</sup> Wu HW, Nishimi RY, Page-Lopez CM, Kizer KW. 2005. *Improving Patient Safety Through Informed Consent for Patients With Limited Health Literacy*. National Quality Forum. Available at [http://www.qualityforum.org/docs/informed\\_consent/webinformedconsentMember+public09-13-05.pdf](http://www.qualityforum.org/docs/informed_consent/webinformedconsentMember+public09-13-05.pdf). Accessed October 13, 2005.



## Build Knowledge to Improve Health Decisionmaking

Being an informed consumer of health information requires more than reading ability. People with limited health literacy often lack knowledge or have misinformation about the body and the causes of disease. Without this knowledge, they may fail to understand the relationship between lifestyle factors such as diet and exercise and health outcomes. People with limited health literacy skills may not know when or how to seek care.

Health information can overwhelm even persons with advanced literacy skills. Medical science progresses rapidly. What people may have learned about health or biology during their school years often becomes outdated, forgotten, or is incomplete. Moreover, health information provided in a stressful or unfamiliar situation is unlikely to be retained.

Strategies to build knowledge and improve health decisionmaking include:

- Improve access to accurate and appropriate health information
- Facilitate healthy decisionmaking
- Partner with educators to improve health curricula

### **Improve access to accurate and appropriate health information**

#### **Create mechanisms for sharing and distributing plain language materials among health professionals.**

Healthcare and public health professionals can develop plain language health education materials that can be easily shared among practitioners. Health education materials should be *both* scientifically accurate and culturally appropriate. Develop partnerships among and across regions, audiences, and fields of interest to facilitate dissemination.



Health professionals and researchers may want to examine the impact of participatory action and empowerment research strategies for effective diffusion of health information at the community level.<sup>1</sup>

### Work with the media.

Working with the media to improve health literacy involves:

1. **Increasing the media's awareness of health literacy issues.** Many health stories already have a health literacy angle, but it goes unreported.
2. **Making scientific and medical information easier to understand.** Be sure the information you give journalists is written in plain language and is suitable for a public audience. When you are working with journalists, emphasize that the provision of health information, especially when it fosters stress and anxiety in the public, does not by itself promote public understanding.

### Develop new methods for information dissemination.

Health information seeking on the Internet demonstrates the public's interest in finding health information someplace other than brochures. Personal electronic devices (e.g., cell phones, palm pilots) and talking kiosks could be new methods for delivering health information. Before you create another brochure, consider whether alternate methods for information dissemination could improve communication with your intended users.

#### Message channels

Channels are the routes of message delivery (such as individual, group, organizational, community, and mass media). Select channels that fit your communication objectives, your budget, and your timeline.

For more information, refer to *CDCynergy*.

## **Facilitate healthy decisionmaking**

Research suggests that more information does not necessarily improve decisionmaking and often may undermine it.<sup>2</sup> People process and use a limited amount of information when making a decision. As the choice becomes more complex, people adopt simplifying strategies that allow them to consider only some of the information. As a result, they may ignore or limit their search for information.

We know that obtaining accurate, appropriate health information is only one element of healthy decisionmaking. Increased self-efficacy, that is, a person's belief in his or her ability to accomplish a desired task, is a key factor in decisionmaking.<sup>3</sup> A high self-efficacy for a task may mean that a person is more likely to try it. The way we “package” health information and services can greatly increase self-efficacy.

### **What you can do:**

- Use short documents that present “bottom-line” information, step-by-step instructions, and visual cues that highlight the most important information.
- Align health information and recommendations with access to services, resources, and support.

## **Partner with educators to improve health curricula**

### **Co-develop adult basic education lessons on health content.**

Adult education includes the instruction of people 16 years of age and older who are not regularly enrolled full-time students. Lessons include reading, writing, arithmetic, and other skills required to function in society. Health professionals can work with adult educators to identify the specific skills needed to support health literacy.

Adult education theory maintains that people want information that is relevant to their lives. According to national surveys, health-related content is likely to engage adult learners.<sup>4</sup>

Health professionals can partner with adult educators to develop and deliver health lessons, which simultaneously builds health knowledge and reaches adults who may not connect with traditional health outreach methods. Construct lessons in which students use health-related texts like prescription labels, consent forms, health history forms, and health content from the Internet.

### **Partner with K–12 educators to improve health education in schools.**

The U.S. educational system is a critical point of intervention to improve health literacy.<sup>1</sup> Educators can take advantage of existing skill development and curricula to incorporate health-related tasks, materials, and examples into lesson plans. Many states already have standards for health education that can be enriched to incorporate health literacy skills.

Health professionals can support educators by speaking to elementary and secondary students or helping to organize health-related field trips with local schools.

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<sup>1</sup> Institute of Medicine. 2004. *Health Literacy: A Prescription to End Confusion*. National Academies Press: Washington, DC.

<sup>2</sup> California HealthCare Foundation. 2005. *Consumers in Health Care: The Burden of Choice*. Available at [www.chcf.org/](http://www.chcf.org/).

<sup>3</sup> U.S. Department of Health and Human Services. *Making Health Communication Programs Work*. National Cancer Institute: Washington, DC.

<sup>4</sup> U.S. Department of Health and Human Services. 2003. *Communicating Health: Priorities and Strategies for Progress*. Washington, DC.



## Advocate for Health Literacy in Your Organization

Health professionals must commit to advocating for improved health literacy in our respective organizations. We must embed health literacy in our programs, policies, strategic plans, and research activities.

You can advocate for health literacy in your organization.

- Make the case for health literacy improvement
- Incorporate health literacy into mission and planning
- Establish accountability for health literacy activities

### Make the case for health literacy improvement

#### **Include health literacy in staff training and orientation.**

Training staff will increase awareness of the need for addressing health literacy and improve their skills for communicating with the public.

- Include information on health literacy in staff orientation.
- Make a presentation on health literacy at your next staff meeting.
- Circulate relevant research and reports on health literacy to colleagues.
- Post and share health literacy resources.

#### **Identify specific programs and projects affected by low health literacy.**

How can addressing health literacy improve the effectiveness of these programs? What existing or ongoing organizational activities contribute to the improvement of health literacy? How can these activities be recognized and supported?



### **Target key opinion leaders with health literacy information.**

Brief senior staff and key decisionmakers on the importance of health literacy. Explain how health literacy relates to the organization's mission, goals, and strategic plan and how it can be incorporated into existing programs. Be specific!

Use the following **talking points** to make the case for health literacy improvement:

1. Only 12 percent of adults have Proficient health literacy, according to the National Assessment of Adult Literacy. In other words, nearly 9 out of 10 adults may lack the skills needed to manage their health and prevent disease.
2. Furthermore, 14 percent of adults (30 million people) have Below Basic health literacy. These adults were more likely to report their health as poor (42 percent) and more likely to lack health insurance (28 percent) than adults with Proficient health literacy.
3. There is a mismatch between the reading level of health information and the reading skills of the public. In addition, there is a mismatch between the communication skills of lay people and health professionals.
4. Adults with limited literacy skills are less likely to manage their chronic diseases and more likely to be hospitalized than people with stronger literacy skills. This leads to poorer health outcomes and higher healthcare costs.
5. People's ability to understand health information is related to the clarity of the communication. Health professionals' skills, the burden of medical jargon, and complicated healthcare delivery systems affect health literacy.
6. The benefits of health literacy improvement include improved communication, greater adherence to treatment, greater ability to engage in self-care, improved health status, and greater efficiency and cost savings to the health system as a whole.
7. Enhancing health literacy does not always require additional resources. It is a method for improving the effectiveness of the work we are already doing.

## **Incorporate health literacy into mission and planning**

Include specific goals and objectives related to improving health literacy in strategic plans, performance plans, programs, and educational initiatives. Goals and objectives may be population based (for example, achieving *Healthy People 2010* Objective 11-2) or specific to the mission of the organization.

### **Convene a work group to develop a health literacy agenda for your organization.**

Seek input and collaboration from a broad cross-section of employees.

### **Include health literacy in grants, contracts, and memorandums of understanding.**

Recommend that all products, including educational materials, forms, and questionnaires, be written in plain language and tested with the intended users. Encourage contractors, grantees, and partners to indicate and evaluate how their activities contribute to improved health literacy.

Incorporate health literacy into Funding Opportunity Announcements (FOAs). These include requests for proposals (RFPs), applications (RFAs), corrections (RFCs), and program announcements (PAs). In addition, provide proposal reviewers with basic health literacy information and training when appropriate.

## **Establish accountability**

### **Include health literacy improvement in program evaluation.**

Incorporate health literacy objectives into evaluation criteria for programs and projects.

### **Include health literacy improvement in budget requests.**

Designating funding for health literacy activities will hold staff and management accountable and encourage evaluation.

### **Implement health literacy metrics.**

Implementing metrics or measurable objectives for your organization will help establish accountability for health literacy activities. Below are examples of health literacy metrics.

Our organization will:

1. Apply user-centered design principles to 75 percent of new Web pages.
2. Ensure that all documents intended for the public are reviewed by a plain language expert.
3. Provide all new employees with training in cultural competency and health literacy within 6 months of their date of hire.



## To Learn More About Health Literacy

### ***Health Literacy: A Prescription to End Confusion***

Released in 2004 by the Institute of Medicine (IOM), this report examines the body of knowledge that applies to the field of health literacy and recommends actions to promote a health-literate society. Available at: [www.iom.edu/report.asp?id=19723](http://www.iom.edu/report.asp?id=19723)

### ***Healthy People 2010***

*Healthy People 2010* is a comprehensive set of disease prevention and health promotion objectives developed to improve the health of the nation. Objectives 11-2 and 11-6 specifically address health literacy. Available at: [www.healthypeople.gov/Document/HTML/Volume1/11HealthCom.htm](http://www.healthypeople.gov/Document/HTML/Volume1/11HealthCom.htm)

### ***The Health Literacy of America's Adults: Results From the 2003 National Assessment of Adult Literacy (NAAL)***

This report is the first release of the NAAL health literacy results. The results are based on assessment tasks designed specifically to measure the health literacy of adults living in the United States. Health literacy was reported using four performance levels: Below Basic, Basic, Intermediate, and Proficient. Available at: <http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2006483>

### ***Communicating Health: Priorities and Strategies for Progress***

This publication provides in-depth action plans for each of the six *Healthy People 2010* Health Communication Objectives, including Objectives 11-2 and 11-6 on health literacy. Available at: <http://odphp.osophs.dhhs.gov/projects/HealthComm/>



### ***Literacy and Health Outcomes***

This report from the Agency for Healthcare Research and Quality (AHRQ) provides a systematic review of the literature on literacy, its relationship to various health outcomes and disparities, and the effectiveness of health literacy interventions.

Available at: [www.ahrq.gov/clinic/epcsums/litsum.htm](http://www.ahrq.gov/clinic/epcsums/litsum.htm)

### ***Bibliography Understanding Health Literacy and Its Barriers***

The National Library of Medicine's (NLM) bibliography provides a comprehensive list of health literacy citations from varying disciplines and publications. The bibliography is divided into specific topic areas.

Available at: [www.nlm.nih.gov/pubs/cbm/healthliteracybarriers.html](http://www.nlm.nih.gov/pubs/cbm/healthliteracybarriers.html)

## **To learn more about improving the usability of health information:**

### ***Scientific and Technical Information: Simply Put***

This guide from the Centers for Disease Control and Prevention (CDC) will help you translate complicated scientific and technical information into material that captures and keeps the interest of your intended audience.

Available at: [www.cdc.gov/communication/resources/simpput.pdf](http://www.cdc.gov/communication/resources/simpput.pdf)

### ***CDCynergy (CD-ROM)***

A multimedia CD-ROM used for planning, managing, and evaluating public health communication programs. The planning model is designed to guide the user through systematically conceptualizing, planning, developing, testing, implementing, and evaluating health communication activities, while promoting accountability and the importance of evaluation.

Available at: [www.cdc.gov/communication/cdcynergy.htm](http://www.cdc.gov/communication/cdcynergy.htm)

### ***Making Health Communication Programs Work (the “Pink Book”)***

The planning steps in this guide from the National Cancer Institute (NCI) can help make any communication program work, regardless of size, topic, intended audience, or budget. The Pink Book describes a practical approach for planning and implementing health communication efforts.

Available at: [www.cancer.gov/pinkbook](http://www.cancer.gov/pinkbook)

### **Plainlanguage.gov**

Designed to improve communication from the Federal Government to the public, this Web site contains excellent tools and examples of plain language.

Visit [www.plainlanguage.gov](http://www.plainlanguage.gov)

### ***A Family Physician’s Practical Guide to Culturally Competent Care***

This guide, developed by the Office of Minority Health (OMH), includes cultural competency curriculum modules designed to equip family physicians with awareness, knowledge, and skills in cultural competency to better treat the increasingly diverse U.S. population.

Available at: <http://cccm.thinkculturalhealth.org/>

### ***National Standards for Culturally and Linguistically Appropriate Services in Health Care***

OMH has developed comprehensive standards on culturally and linguistically appropriate services (CLAS) in health care. The CLAS standards provide definitions of culturally and linguistically appropriate services and address organizational structures and policies that help healthcare professionals respond to cultural and linguistic issues presented by diverse populations.

Available at: [www.omhrc.gov/assets/pdf/checked/finalreport.pdf](http://www.omhrc.gov/assets/pdf/checked/finalreport.pdf)

### ***Policies for Federal Public Websites***

The Office of Management and Budget issued the *Policies for Federal Public Websites* in 2004. The policies are designed to improve the usability of Federal Web sites.

Available at: [www.firstgov.gov/webcontent/policies\\_and\\_implementation.shtml](http://www.firstgov.gov/webcontent/policies_and_implementation.shtml)

### **Usability.gov**

A resource for usable, useful, and accessible Web sites. This site contains information, guidelines, and checklists for conducting usability testing and user-centered design.

Visit [www.usability.gov](http://www.usability.gov)

## **To learn more about improving the usability of health services:**

### ***Improving Patient Safety Through Informed Consent for Patients With Limited Health Literacy***

This report, from the National Quality Forum, is designed to provide an overview of major issues involved in providing informed consent for all patients, particularly those with limited health literacy.

Available at: [www.qualityforum.org/docs/informed\\_consent/webinformedconsentMember+public09-13-05.pdf](http://www.qualityforum.org/docs/informed_consent/webinformedconsentMember+public09-13-05.pdf)

### ***Understanding Health Literacy***

This comprehensive resource of health literacy research seeks to improve understanding of this public health challenge and to stimulate research focused on reducing or eliminating the literacy barrier to effective medical diagnosis and treatment. The book includes a chapter on the literacy demands of healthcare settings.

Schwartzberg JG, VanGeest JB, Wang CC, Editors. *Understanding Health Literacy*. AMA Press. 2005.

**To learn more about building knowledge to improve health decisionmaking:**

***Consumers in Health Care: The Burden of Choice***

This report by the California HealthCare Foundation presents the latest research on consumer decisionmaking, explores the methods consumers use to make choices, and looks at what influences affect consumer action. The research suggests important implications for the development of effective information tools for consumers.

Available at: [www.chcf.org/topics/view.cfm?itemid=115327](http://www.chcf.org/topics/view.cfm?itemid=115327)

**healthfinder®**

healthfinder® is an award-winning Federal Web site for consumers, developed by the U.S. Department of Health and Human Services and other Federal agencies. Since 1997, healthfinder® has been recognized as a key resource for finding the best government and nonprofit health and human services information on the Internet. healthfinder® links to carefully selected information and Web sites from more than 1,500 health-related organizations.

Available at: [www.healthfinder.gov](http://www.healthfinder.gov)