



HEALTH LITERACY

**What You Need To Know and
What You Can Do About It**

Objectives

At the end of this presentation, you will be able to:

1. Demonstrate a basic understanding of key health literacy concepts.
2. Communicate the importance of health literacy to colleagues, grantees, and contractors.
3. Identify specific ways to integrate health literacy into your work.



Overview



1. What is health literacy and why is it important?
2. Health literacy at HHS
3. Strategies for improving health literacy
4. Integrating health literacy into your work
5. Resources

HEALTH LITERACY



**What Is Health Literacy
and Why Is It Important?**



What Is Health Literacy?

This slide contains video clips of patients discussing their health literacy experiences. Patients describe in their own words their difficulties reading medication labels, understanding informed consent forms, and following a drug regimen. In the words of one patient, "It's just a language that I'm not familiar with." The video is produced by the Academy of Educational Development in collaboration with the Institute of Medicine with special thanks to the American Medical Association Foundation and the National Center for the Study of Adult Learning and Literacy.



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.
- Health literacy is dependent on both individual and systemic factors:
 1. Communication skills of lay people and professionals
 2. Knowledge of lay people and professionals of health topics
 3. Culture
 4. Demands of the healthcare and public health systems
 5. Demands of the situation/context



What Factors Affect Health Literacy?

1. Health literacy is dependent on the communication skills of lay people and health professionals.
 - Communication skills include literacy skills (e.g., reading, writing, numeracy), oral communication skills, and comprehension.
 - Communication skills are context specific.



What Factors Affect Health Literacy?

2. Health literacy is dependent on lay person and professional knowledge of various health topics.

- People with limited or inaccurate knowledge about the body and the causes of disease may not:
 - Understand the relationship between lifestyle factors (such as diet and exercise) and health outcomes
 - Recognize when they need to seek care
- Health information can overwhelm people with advanced literacy skills.



What Factors Affect Health Literacy?

3. Health literacy is dependent on culture.

Culture affects:

- How people communicate and understand health information
- How people think and feel about their health
- When and from whom people seek care
- How people respond to recommendations for lifestyle change and treatment



What Factors Affect Health Literacy?

4. Health literacy is dependent on the demands of the healthcare and public health systems.

- Individuals need to read, understand, and complete many kinds of forms in order to receive treatment and payment reimbursement.
- Individuals need to know about the various types of health professionals and services as well as how to access care.



What Factors Affect Health Literacy?

5. Health literacy is dependent on the demands of the situation/context.

- Health contexts are unusual compared to other contexts because of an underlying stress or fear factor.
- Healthcare contexts may involve unique conditions such as physical or mental impairment due to illness.
- Health situations are often new, unfamiliar, and intimidating.



What health literacy is NOT...

Health literacy is NOT...

- Plain Language. Plain language is a *technique* for communicating clearly. It is one **tool** for improving health literacy.
- Cultural Competency. Cultural competency is the ability of *professionals* to work cross-culturally. It can **contribute** to health literacy by improving communication and building trust.



Why Is Health Literacy Important?

Health literacy is important because it affects people's ability to:

- Navigate the healthcare system, including locating providers and services and filling out forms
- Share personal and health information with providers
- Engage in self-care and chronic disease management
- Adopt health-promoting behaviors, such as exercising and eating a healthy diet
- Act on health-related news and announcements

These intermediate outcomes impact:

- Health outcomes
- Healthcare costs
- Quality of care



Health Literacy and Health Outcomes

- Persons with limited health literacy skills have:
 - Higher utilization of treatment services
 - Hospitalization
 - Emergency services
 - Lower utilization of preventive services
- Higher utilization of treatment services results in higher healthcare costs.



Health Literacy and Quality of Care

Health literacy affects the quality of health care.

“Good quality means providing patients with appropriate services, in a technically competent manner, with *good communication, shared decisionmaking, and cultural sensitivity.*”*

* From IOM. *Crossing the Quality Chasm: A New Health System for the 21st Century*. 2001.



Health Literacy and Shame

- People with limited health literacy often report feeling a sense of shame about their skill level.
- Individuals with poor literacy skills are often uncomfortable about being unable to read well, and they develop strategies to compensate.



Measuring Health Literacy

- Health literacy is a new component of the 2003 National Assessment of Adult Literacy (NAAL).
 - Nationally representative sample of more than 19,000 adults aged 16 and older in the United States
 - Assessment of English literacy using prose, document, and quantitative scales



Measuring Health Literacy

- Tasks used to measure health literacy were organized around three domains:
 - Clinical: Filling out a patient form
 - Prevention: Following guidelines for age-appropriate preventive health services
 - Navigation of the healthcare system: Understanding what a health insurance plan will pay for

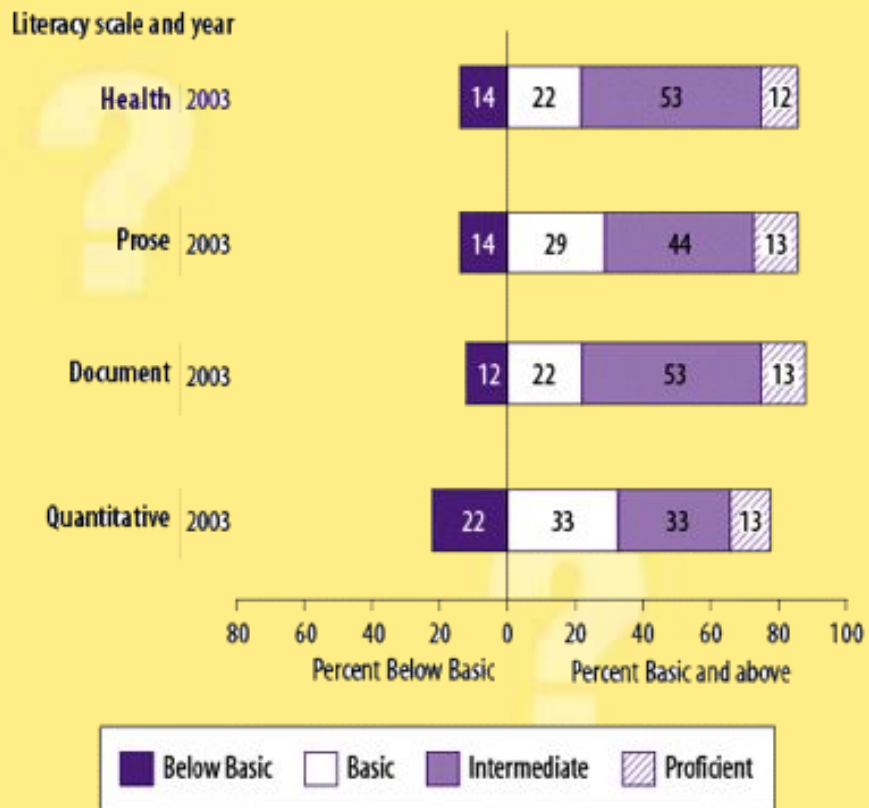


Measuring Health Literacy

- Proficient: Can perform complex and challenging literacy activities.
 - Intermediate: Can perform moderately challenging literacy activities.
 - Basic: Can perform simple everyday literacy activities.
 - Below Basic: Can perform no more than the most simple and concrete literacy activities.
-
- Nonliterate in English: Unable to complete a minimum number of screening tasks or could not be tested because did not speak English or Spanish.



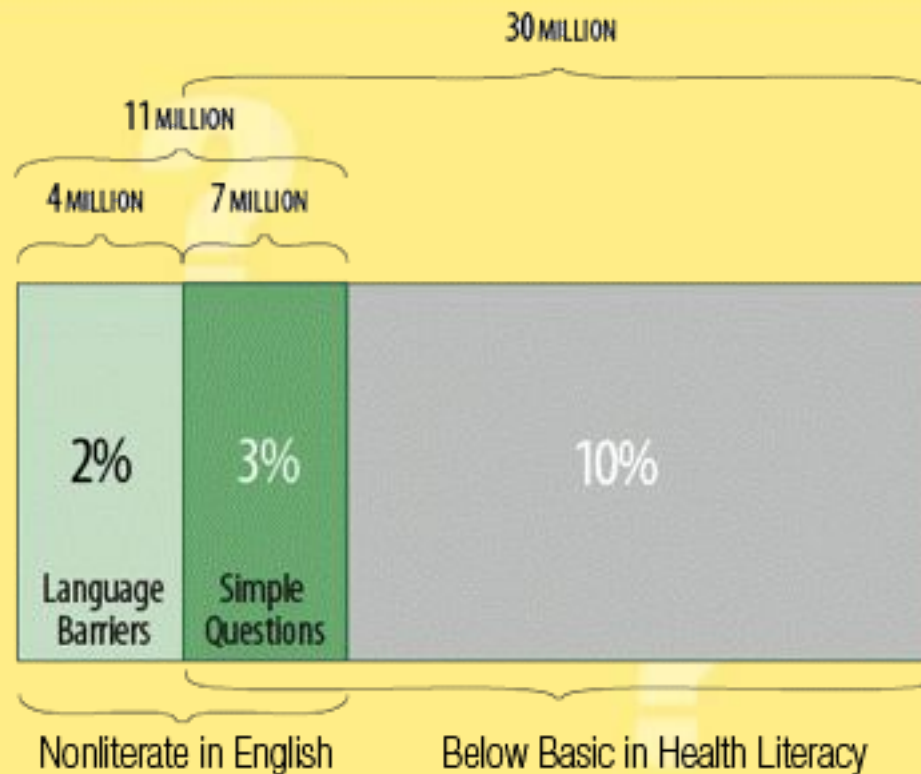
Percentage of Adults in Each Literacy Level: 2003



Source: National Center for Education Statistics, Institute for Education Sciences



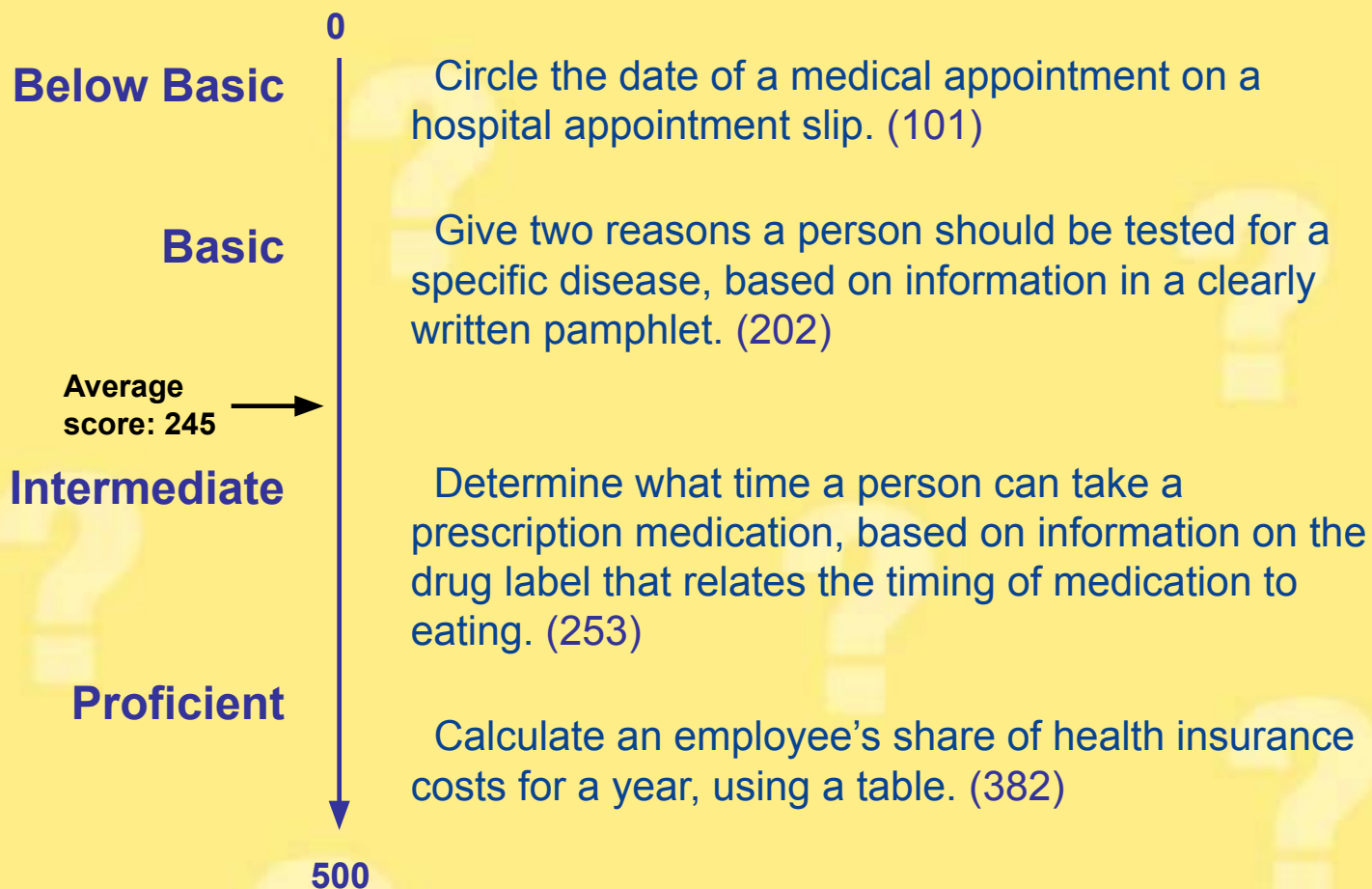
Nonliterate in English



Source: National Center for Education Statistics, Institute for Education Sciences



Difficulty of Selected Health Literacy Tasks





Percentage of Adults in the *Below Basic* Health Literacy NAAL Population: 2003

Characteristic	Percent in <i>Below Basic</i> population	Percent in total population
Did not graduate from high school	51	15
Did not speak English before starting school	39	13
Adults reporting poor health	10	4
Hispanic adults	35	12
Age 65+	31	15
No medical insurance	36	18
Did not obtain health information over the Internet ¹	80	43
Black adults	19	12
One or more disabilities ²	48	30

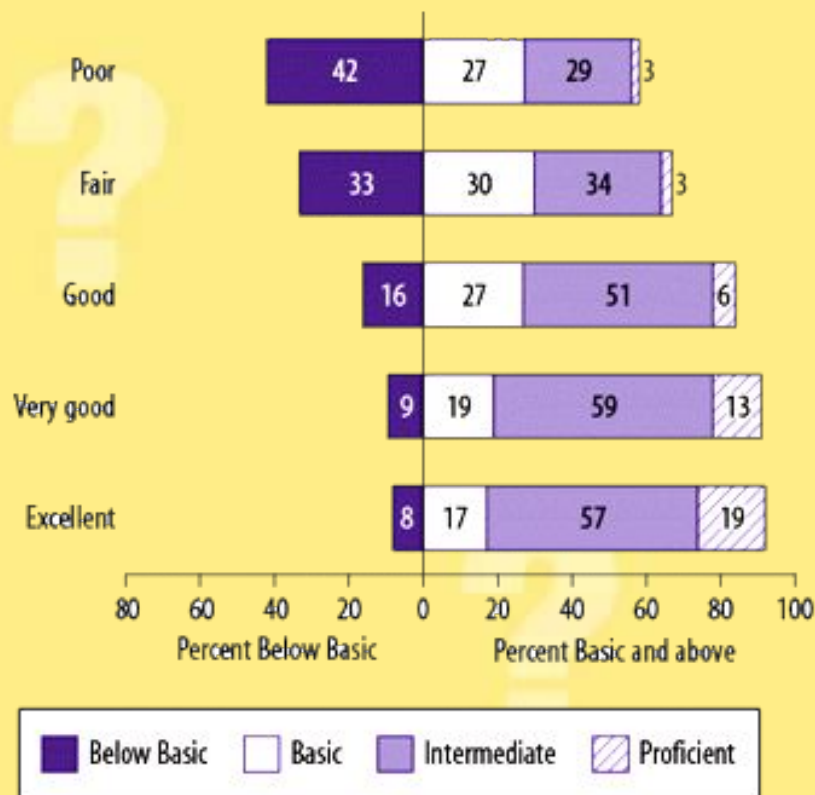
¹ The “Did not obtain health information over the Internet” category does not include prison inmates.

² Disabilities include vision, hearing, learning disability, and other health problems.

Source: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy (NAAL)



Percentage of Adults in Each Health Literacy Level, by Self-Assessment of Overall Health: 2003



Source: U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 2003 National Assessment of Adult Literacy



Sources of Health Information

Percentage of adults with *Below Basic* or *Basic* health literacy who get **little** or **no** health information from the following sources:

Source	Below Basic	Basic
Internet	85%	70%
Magazines	64%	47%
Books or Brochures	62%	45%
Newspapers	59%	51%
Family or Friends	47%	40%
Healthcare Providers	35%	30%
Radio or TV	33%	29%

Source: National Center for Education Statistics, Institute for Education Sciences



The Bottom Line

- Only 12 percent of adults have Proficient health 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 are 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.



Measuring Health Literacy

Measures of health literacy at the individual level were developed in the 1990s:

- Rapid Estimate of Adult Literacy in Medicine (REALM)
- Test of Functional Health Literacy in Adults (TOFHLA and S-TOFHLA)



Measuring Health Literacy

- Health literacy measures based on functional literacy do not capture the full range of skills needed for health literacy.
- Current assessment tools (for populations and individuals) cannot differentiate among:
 - Reading ability
 - Lack of health-related background knowledge
 - Lack of familiarity with language and materials
 - Cultural differences in approaches to health.



Who Is at Risk?

- The problem of limited health literacy is greater among:
 - Older adults
 - Those who are poor
 - People with limited education
 - Minority populations
 - Persons with limited English proficiency (LEP)



Who Is at Risk?

- Many of the same populations at risk for limited health literacy also suffer from disparities in health status, illness (including heart disease, diabetes, obesity, HIV/AIDS, oral disease, cancer deaths, and low birth weight), and death.



Health Literacy: Use of Preventive Services

Persons with limited health literacy skills* are more likely to skip preventive measures such as:

- Mammograms
- Pap smears
- Flu shots

*As defined by these studies



Health Literacy: Knowledge About Medical Conditions and Treatment

Persons with limited health literacy skills:

- Are more likely to have chronic conditions and less likely to manage them effectively.
- Have less knowledge of their illness (e.g., diabetes, asthma, HIV/AIDS, high blood pressure) and its management.



Health Literacy: Hospitalization and Health Status

Persons with limited health literacy skills:

- Experience more preventable hospital visits and admissions.
- Are significantly more likely to report their health as “poor.”



Health Literacy: Healthcare Costs

- Predicted inpatient spending for persons with inadequate health literacy (measured by the S-TOFHLA) was \$993 higher than that of persons with adequate health literacy.
- An earlier analysis found that the additional healthcare resources attributable to inadequate health literacy were \$29 billion (assuming that inadequate literacy was equivalent to inadequate health literacy):
 - This number would have grown to \$69 billion if even one-half of marginally literate adults were also considered not health literate.

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Health Literacy at HHS



Commitment to Health Literacy

- Secretary Leavitt: Prevention and health information technology (IT) are two big priorities for the healthcare system.
- Secretary Thompson's Workgroup on Health Literacy
 - *Prevention: A Blueprint for Action*

"It is critical that individuals have access to health information in a way they can understand and make appropriate health decisions."



Office of the Surgeon General

- Health literacy improvement is one of the Surgeon General's seven public health priorities.
- “Health literacy is the currency of success for everything I am doing as the Surgeon General.”

—Dr. Richard Carmona in his speech to the AMA House of Delegates, June 2003.



***Healthy People 2010* Health Communication Objectives**

- 11-1. Internet access in the home
- 11-2. Health literacy
- 11-3. Research and evaluation of health communication programs
- 11-4. Quality of Internet health Web sites
- 11-5. Centers of Excellence in health communication
- 11-6. Provider-patient communication



***Healthy People 2010* Health Literacy Objectives**

- 11-2. Improve the health literacy of persons with inadequate or marginal literacy skills.
- 11-6. Increase the proportion of persons who report that their healthcare providers have satisfactory communication skills.



Funding

- NIH program announcement: *Understanding and Promoting Health Literacy*
 - Three annual submission dates 2004–2006
 - Thirteen sponsoring institutes and offices with AHRQ
 - NIH spending in FY05 for these grants is close to \$3 million, and it will total more than **\$8 million** during the life of the awarded grants.
- HRSA provides funding to community-based organizations for health literacy activities and research.



Health Literacy Coordination

- Department health literacy workgroup
- Agency health literacy workgroups
- HHS health literacy intranet site
- *Quick Guide to Health Literacy* for HHS employees
- Health literacy action plan

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Strategies for Improving Health Literacy



Four Strategies for Improving Health Literacy

1. Improve the usability of health information.
2. Improve the usability of health services.
3. Build knowledge to improve decisionmaking.
4. Advocate for health literacy improvement.



1. Improve the Usability of Health Information

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



Identify the Intended Users of the Health Information and Services

- Know the intended users of the health information and services:
 - Demographics
 - Behavior
 - Culture
 - Attitude
 - Literacy skills
 - Language
 - Socioeconomic status
 - Access to services
- Decide which channel(s) and format are most appropriate.



Evaluation

Evaluate users' understanding *before* (formative), *during* (process), and *after* (outcome) the introduction of materials.

Test! Test! Test!



Acknowledge Cultural Differences and Practice Respect

- Accepted roles of men and women
- Value of traditional vs. Western medicine
- Favorite or forbidden foods
- Manner of dress
- Body language, especially touching or proximity



What Is Cultural Competency?

Cultural competency is the ability of health organizations and practitioners to recognize the following in diverse populations to produce a positive health outcome:

- Cultural beliefs
- Values
- Attitudes
- Traditions
- Language preferences
- Health practices



Use Plain Language

- Plain language is a strategy for making written and oral information easier to understand.
- Key elements of plain language include:
 - Using simple language and defining technical terms
 - Using the active voice
 - Breaking down complex information into understandable pieces
 - Organizing information so the most important points come first



Speak Clearly and Listen Carefully

- Use a medically trained interpreter if necessary:
 - For those who do not speak English well, plain English will not help.
 - Ensure that all language access services, including translation, are in plain language.
 - Refer to CLAS standards.
- Ask open-ended questions:
 - Elicit cultural beliefs and attitudes: “Tell me about the problem and what may have caused it.”
- Check for understanding:
 - Use the “teach-back” method: Have the person restate the information in his or her own words.



Improve the Usability of Health Information on the Internet

- People cannot find the information they seek on Web sites 60% of the time.
- Many elements that improve written and oral communication can be applied to information on the Web:
 - Plain language
 - Large font
 - White space
 - Simple graphics

Don't forget

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



Improve the Usability of Health Information on the Internet

Health literacy has implications for Web-based communication beyond written text. Consider the following strategies:

- Apply user-centered design principles and conduct usability tests.
- Include interactive features and personalized content.
- Organize information to minimize scrolling.
- Use uniform navigation.



2. Improve the Usability of Health Services

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



Health Forms and Instructions

Healthcare and public health settings rely heavily on forms and printed instructions:

- Medical history forms
- Insurance forms
- Informed consent forms
- Child immunization records for school
- Test results
- Directions to the lab or pharmacy
- Hospital discharge and home care instructions
- Clinical research protocols and announcements



Improve the Usability of Health Forms and Instructions

- Revise forms to ensure clarity and simplicity.
- Test forms with intended users and revise as needed.
- Provide forms in multiple languages.
- Offer assistance with completing forms and scheduling followup care.



Improve the Physical Environment

Settings with lots of signs and postings have a high literacy demand:

- Include universal symbols and clear signage in multiple languages.
- Promote easy flow through healthcare facilities.
- Create a respectful and shame-free environment.



Establish a Patient Navigator Program

- *Patient navigators* are health professionals or community health workers who help patients:
 - Evaluate their treatment options.
 - Obtain referrals.
 - Find clinical trials.
 - Apply for financial assistance.
- Congress recently passed the Patient Navigator Outreach and Chronic Disease Prevention Act of 2005.



3. Build Knowledge to Improve Decisionmaking

- 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 new mechanisms for sharing and distributing understandable health education materials:
 - Create audience or language-specific databases.
 - Partner with adult educators.
- Identify new methods for information dissemination:
 - Cell phones, palm pilots, personalized and interactive content, information kiosks, talking prescription bottles, etc.



Improve Access to Accurate and Appropriate Health Information

- Form partnerships with civic and faith-based organizations trusted in the community.
- Work with the media to increase awareness of health literacy issues.
- Work with providers to ensure that the health information they share is accurate, current, and reliable.



Facilitate Healthy Decisionmaking

- Use short documents that present “bottom-line” information, step-by-step instructions, and visual cues that highlight the most important information:
 - People process and use a limited amount of information when making a decision.
- Align health information and recommendations with access to services, resources, and support!



Partner With Educators

Co-develop adult basic education lessons on health topics:

- Adult learners want information that is relevant to their lives; health content is likely to engage them.
- Construct lessons in which students use health-related texts, forms, and content from the Internet.



Partner With Educators

- The K–12 education system is a critical point of intervention to improve health literacy.
- Incorporate health-related tasks, materials, and examples into lesson plans.
- Design and disseminate health information to support existing state standards.
- Speak to students or help organize health-related field trips for local schools.



4. Advocate for Health Literacy Improvement

- Make the case for improving health literacy.
- Incorporate health literacy in mission and planning.
- Establish accountability for health literacy activities.



Make the Case for Improving Health Literacy

- Identify specific programs and projects affected by limited health literacy.
- Target key opinion leaders with health literacy information:
 - Explain how health literacy improvement relates to your mission, goals, and strategic plan.
 - Circulate relevant research and reports on health literacy to colleagues.
 - Post and share health literacy resources.



Incorporate Health Literacy in Mission and Planning

- Include goals and objectives specifically related to health literacy improvement in:
 - Strategic plans
 - Program plans
 - Educational initiatives
- Goals can be broad (e.g., Achieving *Healthy People 2010* Objective 11-2) or specific to the mission of the office/program.



Include Health Literacy in Grants, Contracts, and MOUs

Recommend that all products, materials, and forms be written in plain language and tested with the intended audiences.



Establish Accountability

- Include health literacy improvement criteria in program evaluation.
- Implement health literacy metrics.



Establish Accountability

Sample metrics

Our office will:

- Apply user-centered design principles to 75% of new Web pages created after January 2006.
- Ensure that all documents intended for the public are reviewed by a plain language expert.
- Provide all new employees with training in cultural competency and health literacy within 6 months of their date of hire.

HEALTH LITERACY



**Integrating Health
Literacy Into Your Work
at HHS**



Integrating Health Literacy Into Your Work at HHS

- Communicate with the public.
- Work with grantees and contractors.
- Conduct and promote research.
- Manage staff and programs.
- Work with external stakeholders and partners.



Communicating With the Public

HHS communication functions include:

- Responding to public inquiries
- Developing public health messages/campaigns
- Developing materials, publications, Web sites
- Improving public access to evidence-based health information
- Promoting and disseminating messages, materials, recommendations, and guidelines
- Working with the media/press
- Acting as public liaisons
- Developing and implementing communication plans
- Providing health research results
- Speechwriting
- Contributing to professional and academic publications



Communicating With the Public

Example: Working with the media

- Write press releases aimed at the general public; use plain language.
- Provide journalists with access to health literacy resources:
 - Create and post a health literacy “backgrounder” for journalists online (focus on data and news “hooks”).
- Highlight health literacy angle embedded in routine stories.



Working With Grantees and Contractors

- Require health literacy expertise as part of the skill set for the teams awarded contracts.
- Encourage grantees to address health literacy issues in their work plans and deliverables.
- Include health literacy improvement as a topic in all technical assistance and materials development grants.



Working With Grantees and Contractors

Example:

Ask Funding Opportunity Announcement applicants to explain how their projects will contribute to meeting the health literacy objectives in *Healthy People 2010*.



Promoting Research

Integrating health literacy into research agendas:

- Review research portfolios.
- Convene research agenda-setting meetings for your topics:
 - Include colleagues from across HHS who share responsibility for these topics.
- Identify health literacy research questions.
- Communicate research findings to health professionals and the public (shared function with Communication staff).



Promoting Research

Example:

- Make presentations at scholarly meetings.
Organize symposia and sessions on health literacy at annual professional association meetings.
- Publish in professional journals.



Managing Staff and Programs

- Incorporate health literacy improvement into performance plans, GPRA, and PART.
- Include health literacy activities in budget requests.
- Communicate the importance of health literacy improvement to staff.



Managing Staff and Programs

Example:

Conduct a senior-level briefing at your office or agency:

- Include formal presentation and handouts.
- Tie health literacy improvement to your specific mission, goals, and objectives.
- Make specific recommendations.



Working With External Stakeholders and Partners

External stakeholders and partners include:

- Healthcare professional organizations
- Patient advocacy and support organizations
- Consumer advocacy organizations
- State, local, and tribal governments
- Federal departments and agencies
- Academic institutions
- Industry trade organizations
- Media vendors and associations



Working With External Partners

Arrangements may be:

- Formal (e.g., Collaborative Research and Development Agreements and signed letters of agreement)
- Informal collaboration

In both cases, agencies can encourage partners to:

- Conduct user-centered research.
- Evaluate the impact of enhanced understandability.



Working With External Stakeholders

- Include representatives from your target population in planning, implementation, and evaluation.
- Be sure to include organizations that represent/serve populations with limited literacy skills.



Working With External Stakeholders and Partners

Examples:

When you are soliciting proposals for presentations at HHS-sponsored events, state your interest in receiving presentations that address health literacy issues.



Who Is Responsible for Improving Health Literacy?

A health literate America is a society in which health systems and institutions take responsibility for providing clear communication and adequate support to facilitate health-promoting actions based on understanding.

—Institute of Medicine, 2004



Who Is Responsible for Improving Health Literacy?

- Our job as HHS employees is to protect the health of all Americans.
- Healthcare providers, public health professionals, health policy makers, and health administrators are all responsible for improving health literacy.



Who Is Responsible for Improving Health Literacy?

We are!

HEALTH LITERACY



Resources



Resources

- AHRQ Report—*Literacy and Health Outcomes* (2004): www.ahrq.gov/clinic/epcsums/litsum.htm
- *Healthy People 2010* (2000): www.healthypeople.gov
- *Healthy People 2010 Health Literacy Action Plan—Communicating Health: Priorities and Strategies for Progress* (2003): <http://odphp.osophs.dhhs.gov/projects/healthcomm/objective2.htm>
- IOM Report—*Health Literacy: A Prescription To End Confusion* (2004): www.iom.edu/report.asp?id=19723



Resources

- NIH Improving Health Literacy Web page:
www.nih.gov/icd/od/ocpl/resources/improvinghealthliteracy.htm
- NIH/AHRQ program announcements—*Understanding and Promoting Health Literacy*:
<http://grants.nih.gov/grants/guide/pa-files/PAR-04-116.html>;
<http://grants.nih.gov/grants/guide/pa-files/PAR-04-117.html>
- *Prevention: A Blueprint for Action (2004)*:
<http://aspe.hhs.gov/health/blueprint/>



Resources

- AHRQ Health Literacy and Cultural and Linguistic Competency Web page: www.ahrq.gov/browse/hlitix.htm
- NLM Bibliography—*Understanding Health Literacy and Its Barriers* (2004):
www.nlm.nih.gov/pubs/cbm/healthliteracybarriers.html
- CDC—*Scientific and Technical Information: Simply Put*:
www.cdc.gov/communication/resources/simpput.pdf
- CDCynergy (CD-ROM):
www.cdc.gov/communication/cdcynergy.htm
- NCI—*Making Health Communication Programs Work* (the “Pink Book”): www.cancer.gov/pinkbook



Resources

- Dynamic search of health literacy articles in PubMed:
http://phpartners.org/hp/health_comm.html
- HHS university plain language course:
<http://lms.learning.hhs.gov/CourseCatalog/index.cfm>
- Plain language Web site: www.plainlanguage.gov
- *A Family Physician's Practical Guide to Culturally Competent Care*: <http://cccm.thinkculturalhealth.org/>
- National Standards for Culturally and Linguistically Appropriate Services in Health Care:
www.omhrc.gov/templates/browse.aspx?lvl=2&lvlID=15