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What is Health Literacy?

Health literacy is the ability to read, understand, and act on health care information.

***Healthy People 2010* defines health literacy as** "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[1]

The AMA Council of Scientific Affairs more specifically defines *functional* health literacy as "the ability to read and comprehend prescription bottles, appointment slips, and the other essential health-related materials required to successfully function as a patient."[2]

- A study of 483 asthma patients found that although two-thirds reported graduating from high school, only 60% could read above the sixth-grade level. Reading ability was the single strongest predictor of asthma knowledge. Twice as many patients reading below the third-grade level had poor metered-dose inhaler technique as patients reading at high-school level (89% vs. 48%).[3]

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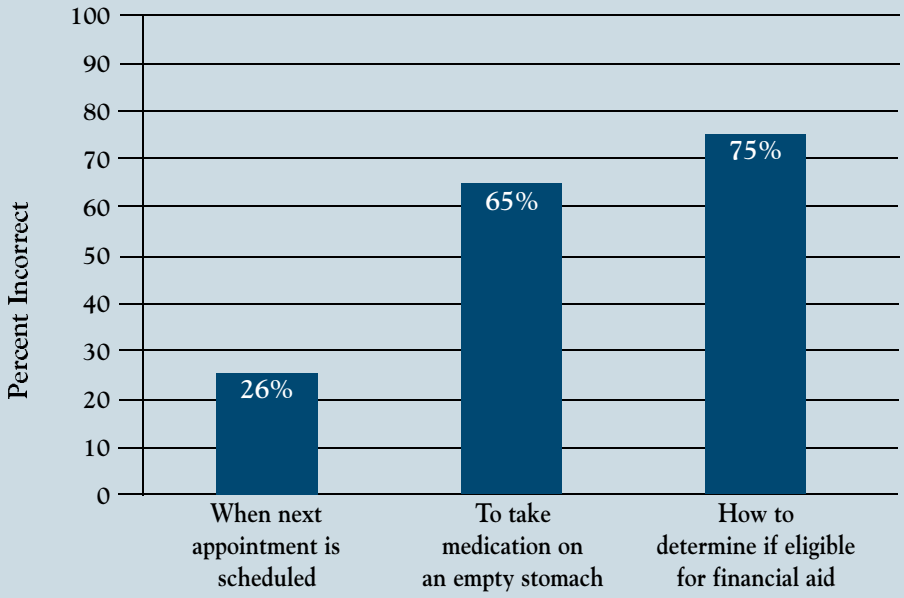
Many Public Hospital Patients* Do Not Understand Basic Health Care Information[4]



*% of 979 low-income patients

Source: Williams, et al., 1995.

People with low functional health literacy are less likely to:[5-7]

- Understand written and oral information given by physicians, nurses, pharmacists, and insurers.
- Act upon necessary procedures and directions such as medication and appointment schedules.
- Be able to navigate the health system to obtain needed services.

People with low functional health literacy are more likely to:[8-10]

- Receive health care services through publicly financed programs, even after controlling for such factors as age, education, or socioeconomic status.
- Incur higher health care costs. A study of Medicaid patients found those reading below third-grade level had average annual health care costs four times those of the overall Medicaid population.

Several studies have indicated poor health status is disproportionately high among patients with low functional health literacy. For example:

- A study of 212 low-income men found that low literacy is a better predictor than race or age of advanced prostate cancer.[11]
- A study of 182 HIV-positive adults found that those with low functional health literacy were more likely to miss treatment doses than those with high health literacy because of confusion about the instructions.[12]

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Who Has Health Literacy Problems?

Health literacy problems affect people from all backgrounds, especially those with chronic health problems.

Older people, non-whites, immigrants, and those with low incomes are disproportionately more likely to have trouble reading and understanding health-related information.

- According to the National Adult Literacy Survey (NALS):[1]
  - 66% of U.S. adults age 60 and over have inadequate or marginal literacy skills.
  - 50% of welfare recipients read below fifth-grade level.
  - 50% of Hispanic Americans and 40% of African Americans have reading problems.
- Inadequate literacy was an independent risk factor for hospital admission among 3,260 elderly managed care enrollees.[2]
- Health literacy problems were independently associated with worse glycemic control among 408 English- and Spanish-speaking patients with diabetes.[3]

Those with poor health literacy are more likely to have a chronic disease and less likely to get the health care they need.

- According to the NALS,[1] 75% of Americans who reported having a long-term illness (six months or more) had limited literacy. This may mean they know less about their conditions or how to handle symptoms.
- Emergency room patients with inadequate literacy are twice as likely to be hospitalized as those with adequate literacy — even after adjusting for self-reported health, health insurance, and socioeconomic characteristics (32% vs. 15% in a study of 979 patients).[4]

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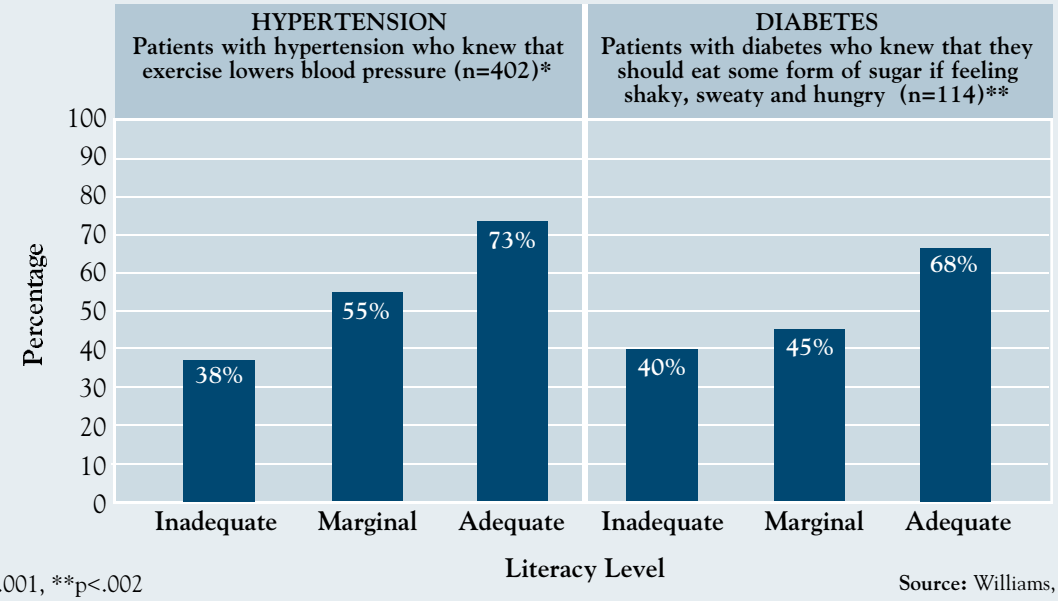
Patient Knowledge about their Chronic Disease by Level of Functional Health Literacy[5]



* p<.001, **p<.002

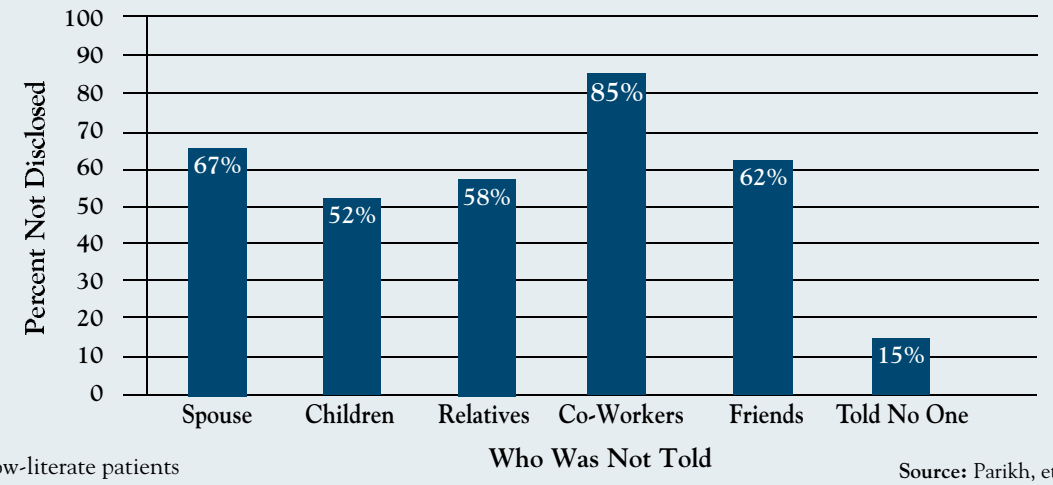
Source: Williams, et al., 1998.

But "You can't tell by looking."

Even practitioners who have worked with low-literacy patients for years are often surprised at the poor reading skills of some of their most poised and articulate patients.[6]

- Two-thirds of 58 patients who admitted having reading difficulties had never told their spouse. Nine of them had told no one.[7]
- Physicians at a women's health clinic could identify only 20% of their patients who were at the lowest literacy level (<third grade).[8]

Lack of Disclosure of Reading Difficulty by Patients* Who Admit Low Literacy[7]



*58 low-literate patients

Source: Parikh, et al., 1996.

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Impact of Low Health Literacy Skills on Annual Health Care Expenditures

Poor health literacy can have profound financial consequences. In 2001, low functional literacy resulted in an estimated $32 to $58 billion in additional health care costs.

According to the National Adult Literacy Survey (NALS), as many as 44 million people (age 16 and older), or 23% of all adults in the United States are functionally illiterate. An additional 28% of all adults — 53.5 million people — had only marginally better reading and computational skills. This suggests that nearly 50% of all adults may have problems understanding prescriptions, appointment slips, informed consent documents, insurance forms, and health education materials.[1]

After adjusting for health status, education level, socio-economic status, and other demographic factors, people with low functional literacy have less ability to care for chronic conditions and use more health care services. In 1998, for example:

- Adults whose functional literacy was in the bottom 20% were more than 1.5 times more likely to visit a physician than adults with higher functional literacy.[2]
- Adults whose functional literacy was in the bottom 20% were likely to have 3 times as many prescriptions filled than adults with higher functional literacy.[3]

This finding was recently confirmed by modeling the probability of low functional literacy skills using data from NALS and applying those probabilities to people in the 1998 Medical Expenditure Panel Survey (MEPS).[4] A model was estimated, using information that was similar in both NALS and MEPS that would predict the observed literacy scores in the NALS. This model included age, educational attainment, race, gender, marital status, and employment status. The study found that people whose estimated level of functional literacy was in the lowest 20% used substantially more health care services, resulting in greater health care expenditures. The study controlled for age, gender, health status, income, and type of insurance coverage.

The following tables show average expenditures per person by health status and family income among people whose estimated functional literacy is in the bottom 20% compared to the rest of the population. Average per person expenditures were greater among those most likely to have low functional literacy.

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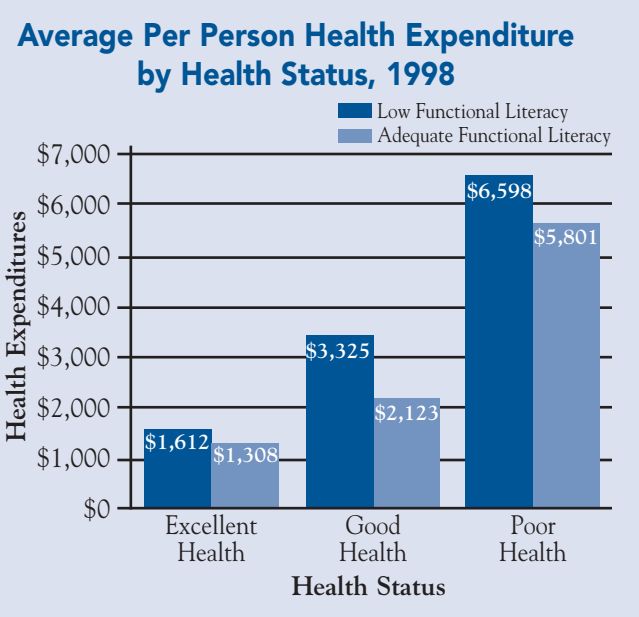
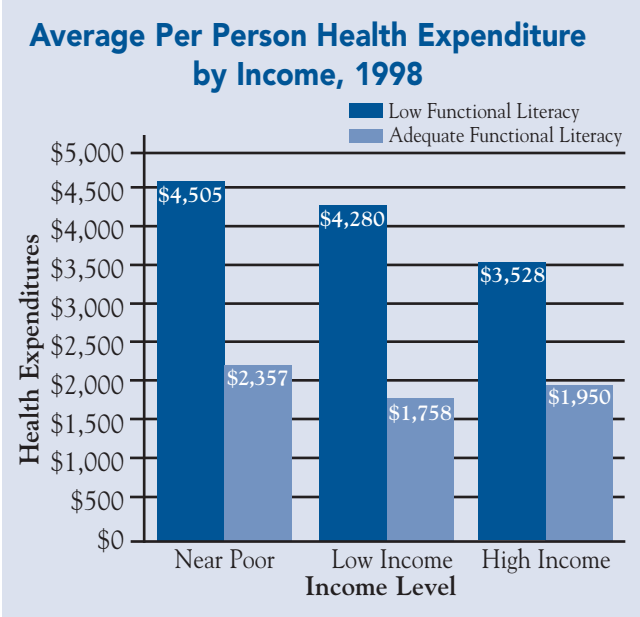




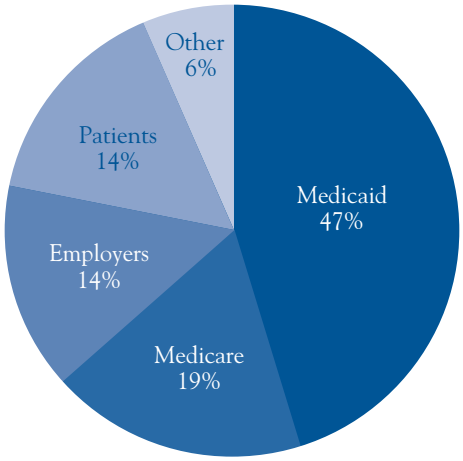
Source: Estimates from 1998 Medical Expenditure Panel Survey by the Center on an Aging Society

Comparing health care use and expenditures for all health care services by those above and those in the bottom 20% in functional literacy skills provides an estimated cost for low functional literacy. These calculations, which adjust for age, gender, income, health status, and insurance, suggest that low functional literacy results in 3 to 6% greater health care expenditures.

The direct medical costs of low functional literacy are financed through additional hospital and office visits, longer hospital stays, extra tests, procedures, and prescriptions. While all payers fund these additional resources, taxpayers finance a disproportionate share:

- Medicaid finances 47% of the additional health care expenditures.
- Medicare finances 19% of the expenditures.
- Employers may be financing as much as 14% of the additional health care expenditures for their employees and their employees' dependents.
- The patients who have the poorest health literacy skills finance 14% of these additional health care expenditures as out-of-pocket co-payments and deductibles.

Who Pays for the Cost of Low Health Literacy?



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Health Literacy and Understanding Medical Information

Patients with poor health literacy skills struggle to understand basic medical forms and instructions.

"… [W]hen they give you papers to fill out … you want to know what it means before you sign it … [but it's] sign this, sign that. I don't know what that means." — A patient[1]

- It is especially difficult for less literate patients to fill out intake forms, enroll in insurance programs for which they may be eligible, get services once enrolled, follow medical instructions, or give informed consent.
- Most informed consent and insurance forms, and most medication package inserts, are written at high school level or higher.[2, 3]
- Of 979 emergency department patients with inadequate health literacy:[4]
  - 81% could not read the rights and responsibilities section of a Medicaid application.
  - 74% did not know if they were eligible for free care.

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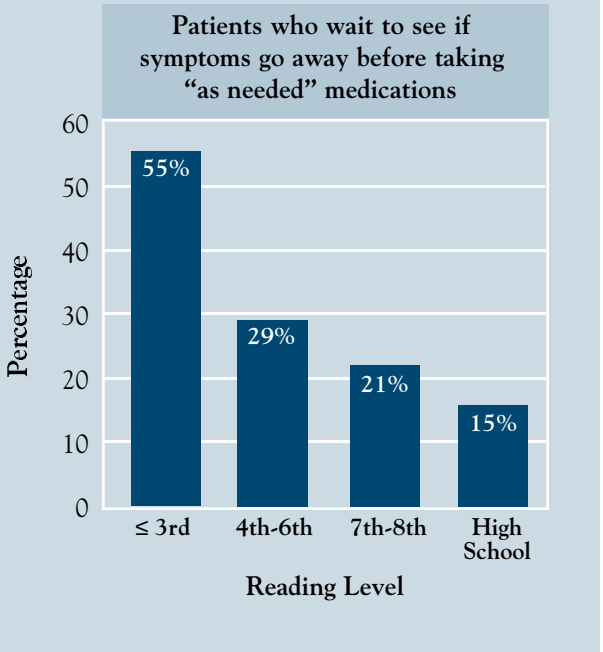
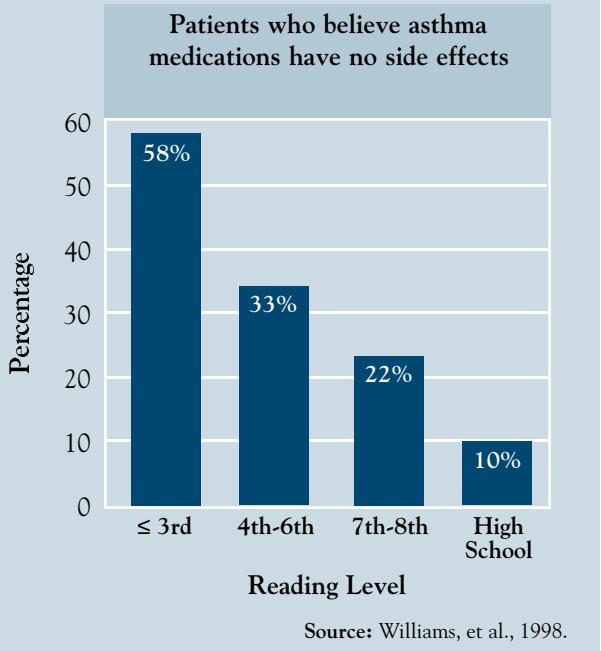
Asthma Patients' Misunderstanding Regarding Medications[6]





Source: Williams, et al., 1998.

Prescription labels and self-care instructions are among the most important written materials patients receive.

Poor compliance with medication and care regimens can be dangerous. Yet serious mistakes may occur because the patient cannot read the instructions.

- Among 659 public hospital patients, those with poor health literacy skills were five times more likely to misinterpret their prescriptions than those with adequate skills.[5]
- Reading skill was the strongest predictor of asthma knowledge in a study of 483 patients. Only 11% of those reading below a third-grade reading level could use their metered dose inhaler correctly.[6]
- HIV-positive adults with low functional health literacy missed more treatment doses than patients with high health literacy because they were confused by the instructions in a study of 182 patients.[7]

Poor health literacy has legal ramifications for health care professionals.

It is up to the health care system to be sure patients understand the information they receive well enough to apply it.

- The Food and Drug Administration, Joint Commission on Accreditation of Healthcare Organizations and the National Committee for Quality Assurance all require that health care institutions be able to document evidence of patient understanding of the medical information provided to them.[8-11]
- But none of these can document whether a particular patient understands the one form they need at the moment. This leaves it up to the person requesting the data, the provider conducting the procedure or writing the prescription, or the practitioner providing the instructions *to ask* the patient what s/he understands.

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Strategies to Assist Low-Literate Health Care Consumers

Providers can create a "shame-free" environment where low-literate patients can seek help without feeling stigmatized.[1-3]

- Providing surrogate readers can help patients with reading difficulties understand key information. Family members also can fill this role and reinforce medical information at home.
- Prior to an appointment, clinic or office staff can tell a patient what information will be needed — medicines they are already taking, what kind of insurance they have, as well as the reason they are seeing the doctor. Staff also might suggest that the patient bring a family member.
- Tailoring medication schedules to fit a patient's daily routine, color coding medicines, and using daily events as reminders can help increase compliance.
- To verify that patients understand, or to uncover health beliefs and tailor teaching, providers might ask patients to "teach back" by repeating or restating the instructions as the patient might tell a friend (i.e., "Can you tell me in your own words what we have discussed?").

  A study conducted at San Francisco General Hospital found improved glycemic control when physicians used the "teach back" method with patients with diabetes.[4]

Low Health Literacy and Verbal Communication[5]

Patients with poor health literacy tend to be more responsive to information designed to promote patient action, motivation, and self-empowerment than detailed facts.

- If a provider thinks a patient is having difficulty understanding written or spoken directions, a good approach is to say, "A lot of people have trouble reading and remembering these materials. How can I help you?"
- Use commonly understood words. For instance, use "keeps bones strong" instead of "prevents osteoporosis."
- Slow down and take time to listen to a patient's concerns. Create an atmosphere of respect and comfort. Build trust with the patient.
- Limit information given to patients at each visit. Remember that less than half of the information provided to patients during each visit is retained.

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Oral and visual tools help patients absorb new information, which increases learning.[6, 7]

Pretest material to ensure that your strategy is acceptable and appropriate for the intended audience.

- **Diagrams or pictures.** Visuals help the patient understand the action recommended. Patients also can take them home as reminders. The behavior should be clear and language easy to understand.
- **Audiotaped instructions.** Tapes of one to five minutes hold attention and are more effective than longer tapes. Limit the number of messages given (no more than two). Focus on behaviors rather than facts.
- **Videotapes.** Videos with run times of eight minutes or less are the most helpful. The most valuable video will be interactive or instructional (on-screen activity or accompanying workbook).
- **Interactive computer programs**. Touch-screen computer programs that are user-friendly at a low reading level, and use graphics to illustrate intended behavior are most appropriate.

Illustrations Help Patients Visualize Instructions

Breathing and coughing exercises for heart surgery patients.

After several deep breaths, breathe in slowly through your nose. Open your mouth, stick out your tongue, and cough hard three times as you breathe out.

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Preparing Patient Education Materials

People at all literacy levels prefer written materials that are simple and attractive.

Most people, even those who read well, use visual clues to reinforce learning.

- Graphics and videos can help patients absorb new information, especially when used with written materials.[1-6]
- Brochures alone cannot change health behavior, but written materials can provide accurate information in a way that is easy to read and easy to understand.
- Elderly patients given a simplified leaflet that included graphics were five times more likely to get their pneumococcal vaccine than were those in a control group who received a text-only brochure. They were also four times more likely to talk to their doctors about getting the vaccination.[7]

The most helpful written materials for all users, especially poor readers:[4-6, 8]

- Emphasize the desired behavior rather than the medical facts. Education is more important than information.
- Have just one or two educational objectives — what the reader needs to learn and do. In this case, less really is more.
- Use clear headings, bullets instead of paragraphs, and ample white space (a Q&A format works especially well).
- Use short sentences, active voice, and conversational language — "give" instead of "administer" and "birth control" instead of "contraception."
- Use pictures and examples to illustrate important points.
- Supplement written material with conversation, video, and audio sources.

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Revision of the Package Insert for "The Pill," Based on Patient Interviews[9]

SIDE EFFECTS OF ORAL CONTRACEPTIVES

Vaginal bleeding

Irregular vaginal bleeding or spotting may occur when you are taking the pills. Irregular bleeding may vary from slight staining between menstrual periods to breakthrough bleeding which is a flow much like a regular period. Irregular bleeding occurs most often during the first few months of oral contraceptive use, but may also occur after you have been taking the pill for some time. Such bleeding may be temporary and usually does not indicate any serious problems.

Original (6 pt. type)

Bleeding side effects

You may have some spotting or light bleeding between periods, especially after you miss any pills.

Revision (10 pt. type)

Involve patients in developing the materials.[3, 5,10-12]

- Bring together members of the intended audience to discuss how to make the message attractive, relevant, and understandable.
- Field test, revise, then re-test content, language, illustrations, and layout until you are sure the material accomplishes its purpose.

The Internet is not yet a viable option.

Searching the Internet requires high-level literacy skills.

- This puts poor readers at another disadvantage, one that becomes more critical as reliance on using the Internet as a primary resource increases.[3, 13]
- However, the Internet can be an excellent resource for those who are providing and/or developing information for patients.

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Tools to Evaluate Patient Education Materials

Written materials are the most accessible and least costly way to provide information in the clinical setting.

Patient literature must be evaluated to determine whether it is understandable for patients. A few tools are available to measure the readability of materials as well as the health literacy of the patients.

Evaluating the suitability of education materials for the audience[1,2]

- Pretesting is the single most valuable tool to evaluate whether materials will be attractive and understandable enough to be used by the intended audience.
- *The Suitability Assessment of Materials*[1] and the *Medicaid Checklist*[2] assess how readable and understandable education materials are, and also evaluate how well materials stimulate learning and motivation and whether the materials are culturally appropriate.
- Many of the items on these two checklists can be used with any kind of education materials, whether written, audio, video, web-based, or interactive.

Example of Suitability Assessment Questions from Medicaid Checklist[2]

Writing Style

- Is the material written primarily in the active voice and in a conversational style?
- Is the reading level of the document appropriate for the intended audience?
- Are the words and sentences generally short, simple, and direct without being choppy or sacrificing cohesion and meaning?
- When you use technical terms, are they clearly explained with helpful examples?

Responses: Yes, Needs improvement, Not sure or Not applicable, plus Comments.

Testing the readability of the education materials

Readability formulas measure only one aspect of readability, but they are a place to start, providing scores that can be converted to general grade levels:[3]

- *Easy-to-read:* Fifth- to sixth-grade reading level. This level can reach the majority of those who need the information and is recommended for all health education materials.
- *Average reading:* Eighth grade. *USA Today* is written at the eighth-grade level.
- *Difficult-to-read:* For most of the population, this is anything above eighth-grade level, especially when it includes medical jargon and more information than needed.

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Formulas to measure readability provide a good general estimate. The formulas used most widely for medical documents and patient education materials are:[1, 4]

- The *Flesch-Kincaid Grade Level* and *Flesch Reading Ease Score* count the number of syllables per word and words per sentence. The Reading Ease Score takes other readability measures into account as well. Word for Windows can calculate these as part of its spelling and grammar function.
- The *SMOG (Simple Measure of Gobbledygook) Index* is based on average sentence length and number of words with three or more syllables in a total of 30 sentences. Two readability packages — Grammatik® and RightWriter® — include the SMOG.

Testing the health literacy of those who need the information

Two measures of health literacy have been validated — the REALM and the TOFHLA.

- The *REALM: The Rapid Estimate of Adult Literacy in Medicine* is a one-to-two-minute test that measures a patient's ability to recognize and pronounce common health and medical terms.[5]
- The *TOFHLA: The Test of Functional Health Literacy in Adults* uses hospital materials to test reading comprehension and numerical skills. It takes 20-25 minutes to administer. It is available in Spanish and English.[6,7]
- These tests are most often used in research but the REALM and the S-TOFHLA, a 10-15 minute version of the TOFHLA, also can be useful in the primary care setting to evaluate individual patients.[8]

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Health Communication and Cultural Diversity

Providers can improve communication by addressing cultural beliefs and values.

By 2050, almost half of the U.S. population will be non-white.[1]

Health care providers must recognize the cultural beliefs, practices, and linguistic differences of all patients or risk poor health outcomes.

- The Commonwealth Fund's 2001 survey of 6,722 adults found that minority populations are more likely to have chronic disease, lack health insurance, and have difficulties communicating with their health care providers as compared with whites.[2]
- Understanding that cultural beliefs and literacy play an important role in health care is essential to addressing communication problems.
- The U.S. Office of Minority Health offers the following definition of cultural and linguistic competence in the provision of health care:[3]

  Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations.

  In other words, cultural and linguistic competence is the ability of health care stakeholders to effectively address the language and cultural needs of consumers.

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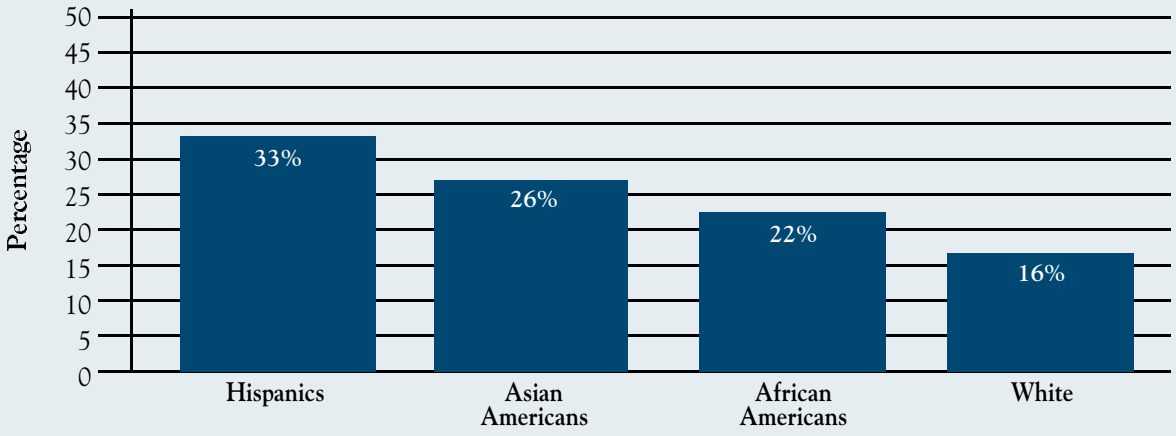
Consumers Experiencing Communication Problems with Providers[2]



Source: The Commonwealth Fund, 2002.

Strategies for developing culturally appropriate materials[4]

- Identify the population segments and tailor messages to incorporate the audiences' beliefs and values. For example, a study to test an obesity program for African-American families took into account cultural attitudes toward food and food preparation techniques. It also used culturally relevant music and dance in exercise routines and materials on diet and exercise from magazines geared toward African Americans. Mothers in the program reduced the percentage of fat in their diets from 40% to 32% in 12 weeks.[5]
- Collaborate with other organizations. Contact other community organizations and/or the State Office of Minority Health to develop useful, targeted materials. For example, a program on a Navajo reservation increased the proportion of mothers breastfeeding their infants from 64% to 78% by collaboration among local organizations to reinforce and demonstrate traditional understanding about infant feeding.[6]
- Incorporate the National Standards for Cultural and Linguistically Appropriate Services into organizational policies, professional training programs, and quality improvement activities.

Techniques to consider when preparing patient materials[4, 7]

- Choose words that show respect for the patient's culture as well as their individual goals. For example, advise cutting back on, not eliminating, the amount of cooking oil to reduce fat intake and avoid chronic illness in the Hispanic population.
- Some cultures may respond to treatment if it is emphasized as "important" rather than "helpful."
- Use graphics, pictures, and examples that reflect the audience in written materials.
- Field test materials for comprehension and cultural acceptance.
- Translate materials into the language(s) of the population(s) served.
- Involve members of the population served in developing strategies and materials. Researchers at the University of Washington worked with Latino parents and teens to help prepare a novella to influence attitudes about alcohol and improve parent-youth communications among Latino families.[8]

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Resources for Health Literacy Information and Publications

The number of health literacy websites, bibliographies, publications, and other resources is growing rapidly.

Following are selected sources of information and publications about health literacy. Many of the publications can be downloaded directly from the web and also provide links to additional resources.

Overview of Health Literacy Issues

- ***National Adult Literacy Survey (NALS)*** and ***National Assessment of Adult Literacy (NAAL).*** The 1993 NALS did not measure health literacy, but did provide data to support the need for improving health literacy. The 2002 NAAL will include a section on health literacy. **www.nces.ed.gov/naal**
- **National Institute for Literacy (NIFL).** NIFL has a health literacy discussion group at **www.nifl.gov/lincs/discussions**. Click the "Discussions" box and scroll down to "health and literacy" to subscribe. The Institute also funds some related programs and research. **www.nifl.gov**

Bibliographies

- ***Health Literacy (January 1990-October 1999) Current Bibliographies in Medicine.*** Bethesda MD: National Library of Medicine, NIH, 2000. Selden C, Zorn M, Ratzan SC, and Parker RM. **www.nlm.nih.gov/pubs/resources.html**
- ***Health and Literacy Compendium: An Annotated Bibliography of Print and Web-Based Health Materials for Use with Limited-Literacy Adults,*** 1999 and ***Literacy: A Guide to Health Education Materials for Adults with Limited English Literacy Skills,*** 2000. Boston MA: World Education Health and Literacy Initiative. **www.worlded.org**
- ***Overview of Medical and Public Health Literature Addressing Literacy Issues: An Annotated Bibliography.*** NCSALL Report #14, January 2000, updated 2001. Cambridge MA: Harvard School of Public Health. Rudd R, Colton T, and Schacht R. **www.hsph.harvard.edu/healthliteracy**
- ***"PubMed"*** (includes *Medline*). National Library of Medicine: This website includes articles published in peer-reviewed journals. Search keywords "health literacy," "literacy," "readability," "reading skill," and the "related articles" are linked to each citation. **www.ncbi.nlm.nih.gov/pubmed**

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Sources of Plain Language Guides and Materials

- **Centers for Disease Control and Prevention/Office of Communication.** *Beyond the Brochure* and *Scientific and Technical Information Simply Put* can be downloaded. This site also has publications on special populations and specific illnesses. **www.cdc.gov**
- **Centers for Medicare and Medicaid Services.** *Writing and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies*. Order by fax at 410-786-1905. (An updated version will be available in 2003.)
- **National Cancer Institute/Office of Communications.** *Clear and Simple: Developing Effective Health Materials for Low-Literate Readers* and *Making Health Communications Programs Work* can both be downloaded. **www.nci.nih.gov**
- **Plain English Network.** This site provides resources, including updates specifically on health, to improve federal government communications to the public. *Writing User-Friendly Documents* can be downloaded. **www.plainlanguage.gov**
- **U.S. Food and Drug Administration/Office of Consumer Affairs.** This site's brochures on breast-feeding and how to give medicines to children demonstrate the variation in the quality of materials that the Food and Drug Administration classifies as "low-lit." **www.fda.gov**

Other Resources

- ***Health Literacy Introductory Kit.*** American Medical Association. Chicago. AMA Foundation, 2001. This kit includes the video "*You Can't Tell by Looking*," CHCS' Health Literacy Fact Sheets, "Health Literacy: Report of the AMA Council on Scientific Affairs," and materials for community presentations. The site provides information on how to obtain continuing medical education credits for using the kit. **www.amafoundation.org/go/healthliteracy**
- ***National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS).*** This website provides information about CLAS and a guide to assist in implementing the standards. **www.omhrc.gov/clas**
- ***Diversity Rx.*** This website provides information about meeting the health care needs of multicultural populations. **www.diversityrx.org**
- **FirstGov.** This website offers links to government agencies and departments, by keyword or agency name, e.g., Agency for Healthcare Research and Quality, Health Resources and Services Administration, National Institutes of Health, and Office of Minority Health. **www.firstgov.gov**

Education and Training

- **Health and Literacy Studies Program: Harvard School of Public Health.** [Note: Most schools of public health offer courses relevant to health literacy in their health behavior, health education and/or communication programs.] **www.hsph.harvard.edu/healthliteracy**
- **Health Literacy Center.** Based at the University of New England, Biddeford, Maine, the Health Literacy Center offers a four-day Health Literacy Institute on writing plain language health education materials. **www.une.edu/hlit**

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