

Health Literacy Resources

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On behalf of the CONSUMER HEALTH LIBRARY PANEL April 2006

According to "Healthy People 2010," health literacy is "the ability to obtain, process, and understand health information and services to make appropriate health decisions." This means that patients must be able to understand the information given to them by their health care providers, and translate that into the appropriate actions to follow and comply with medical advice. The health literate individual is able to read at an appropriate level, listen actively, problem-solve, and make decisions based on the information given.

The 1993 National Adult Literacy Survey (NALS) found that only 3% of individuals could be considered proficient readers. 17% had "adequate" health literacy skills but may have problems with informed consent and quantitative skills. 32% could generally handle every day skills, but lost abilities when sick. 27% were marginally literate (below 8th grade), and the remainder of the population (21%) was functionally illiterate with less than a 5th grade reading level. Since illness, stress and aging tend to lower one's ability to comprehend, the veteran population is even more at risk of suffering the consequences of low health literacy.

The economic impact of low health literacy is enormous. Using 1998 figures, the National Academy on an Aging Society estimated that the inability to understand medical directions cost over \$73 billion in additional health care costs through missed appointments, noncompliance with treatment instructions, inappropriate use of medications, and other misunderstandings of health information that lead to poorer outcomes and increased use of medical care resources. (Friedland RB. *Understanding Health Literacy: New Estimates of the Costs of Inadequate Health Literacy.* Washington, DC: National Academy on an Aging Society; 1998).

The following resources have been compiled by the Consumer Health Library Panel to assist VHA staff in working more effectively with our veteran patients. They include health literacy

materials, readability formulas, free resources for pictograms and graphics, and sites that assist in writing low-literacy patient education materials. It is divided into the following sections:

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"Put it before them briefly so they will read it, clearly so they will appreciate it, picturesquely so they will remember it, and above all, accurately so they will be guided by its light."—An Adventure with a Genius: Recollections of Joseph Pulitzer.

Health Literacy Books

Nielsen-Bohlman, Lynn et all. **Health Literacy: A Prescription to End Confusion**. National Academy Press. ISBN 0309091179. 2004.

Osborne, Helen. Health Literacy From A To Z: Practical Ways to Communicate Your Health. Jones & Bartlett. ISBN 0673745502. 2004.

Schwartzberg, Joanne G., et al. **Understanding Health Literacy: Implications for Medicine and Public Health**. American Medical Association. ISBN 0579476309. Dec. 2004.

Schwartzberg, Joanne G. **Health Literacy: Help Your Patients Understand**. American Medical Association. ISBN 1579475027. 2003.

Doak, Cecelia, et al. **Teaching Patients with Low Literacy Skills**. 2nd edition. Lippincott Williams & Wilkins. ISBN 0397551614. 1996.

Zarcadoolas, Christine. **The New Health Literacy: A Framework for Understanding and Action**. Jossey-Bass. ISBN 0787984337. June 2006.

Literacy and Health Outcomes. Prepared for the Agency for Healthcare Research and Quality. 2004. Available online at http://www.ahrq.gov/downloads/pub/evidence/pdf/literacy/literacy.pdf

Health Literacy Bibliographies

Health Literacy (Current Bibliographies in Medicine 2000-2001)

http://www.nlm.nih.gov/pubs/cbm/hliteracy.html#5

Each bibliography in the Current Bibliographies in Medicine (CBM) series covers a distinct subject area of biomedicine and is intended to fulfill a current awareness function. Citations are usually derived from searching a variety of online databases, including MEDLINE®, AVLINE®, BIOETHICSLINE®, CANCERLIT®, CATLINE®, HEALTHSTARtm, POPLINEtm, and TOXLINE®. The only criterion for the inclusion of a particular published work is its relevance to the topic being presented; the format, ownership, or location of the material is not considered. This bibliography covers January 1990 through October 1999.

Understanding Health Literacy and Its Barriers

http://www.nlm.nih.gov/pubs/cbm/healthliteracybarriers.html

Part of the National Library of Medicine's "Current Bibliographies in Medicine" series, this covers January 1998 through November 2003 and contains 651 citations.

Health Literacy Web Sites

American Medical Association Foundation Health Literacy

http://www.ama-assn.org/ama/pub/category/8115.html

The AMA Foundation sponsors a health literacy campaign in recognition that limited patient literacy influences diagnosis and treatment of disease as well as health maintenance and promotion. The AMA Foundation has been working to raise awareness of health literacy within the health care community. An overview of the problem, news, literacy kit, and tips on how to become involved are included at the site.

America's Literacy Directory

http://www.literacydirectory.org/

America's Literacy Directory (ALD) is a national directory of literacy service providers available via the Internet and the National Institute for Literacy's toll-free number. The ALD connects employers, learners, volunteers, social service agencies, and others to current information about literacy service providers in all 50 states and the U.S. territories.

Ask Me 3

http://askme3.org

Ask Me 3 is a new patient education program designed to promote communication between health care providers and patients in order to improve health outcomes. It is sponsored by the Partnership for Clear Health Communications, a national coalition of health organizations that are working together to promote awareness and solutions for low health literacy. Funding is provided by Pfizer (<u>http://www.pfizerhealthliteracy.org/</u>). The site includes presentation tool kits for professionals and patients, fact sheets, brochures, statistics, logos and guidelines, and more.

Center for Healthcare Strategies Health Literacy Resources

http://www.chcs.org/publications3960/publications_show.htm?doc_id=291711 The Center provides nine fact sheets on a variety of health literacy topics, as well as a bibliography containing more than 200 references used to prepare those fact sheets. This bibliography includes 226 documents published between January 1990 and December 2002.

Harvard School of Public Health—Health Literacy Studies

http://www.hsph.harvard.edu/healthliteracy/

This site is designed for professionals in health and education who are interested in health literacy. It contains introductions to Health Literacy, literature reviews, research reports, health education materials, a 'How To' section on creating and evaluating written materials, curricula, and links to web sites related to health and literacy. Its "Health Literacy Literature" provides bibliographies from January 1990 to December 2002 on the subject.

Health and Literacy Special Collection

http://www.worlded.org/us/health/lincs/index.htm

The Health & Literacy Special Collection is maintained by World Education, Inc., with funding from the National Institute for Literacy LINCS project. Health curricula for literacy or ESOL classes, resources to provide basic health information in simple language, information about the link between literacy and health status, and links to organizations dedicated to health and literacy education are available.

Health Literacy Month

http://www.healthliteracymonth.org/

October is Health Literacy Month, and this site provides facts, articles, links, logos and posters, fact sheets, suggestions for programs and campaigns, ongoing programs, and more. Sponsored by a commercial Health Literacy organization.

Health Literacy: Responding to the Need for Help

http://ihcrp.georgetown.edu/agingsociety/pdfs/CMEReport1.pdf

This 33-page 2001 report by Kristen Kieffer defines health literacy and discusses the individual and societal consequences of inadequate health literacy. It also highlights programs and efforts that address the needs of people with low health literacy and illustrates the techniques they use to identify and assist this population. Finally, this report provides guidelines for program administrators or coordinators to follow in establishing health literacy efforts of their own.

Healthy People 2010. Chapter 11: Health Communication

http://www.healthypeople.gov/document/html/volume1/11healthcom.htm#_Toc4904713 52

This chapter of Healthy People 2010 emphasizes that effective communication cannot take place without considering the literacy levels of both patients and materials. Issues and trends, population disparities, opportunities for health care professionals, and 2010 objectives are included.

How Much Do Health Literacy and Patient Activation Contribute to Older Adults' Ability to Manage Their Health?

http://assets.aarp.org/rgcenter/health/2005_05_literacy.pdf

AARP has published this June 2005 report to "determine the relationships among certain variables so that Medicare counselors, information intermediaries, clinicians, and others can improve their education strategies by providing appropriate, skill-related interventions to Medicare patients on the basis of their health literacy and level of patient activation."

Institute of Medicine (IOM) Committee on Health Literacy

http://www.iom.edu/project.asp?id=3827

This project of the IOM has published the 2004 report **Health Literacy: A Prescription to End Confusion.** A brief overview of the report, health literacy in the news, and other resources are available.

Literacy and Health In America

http://www.ets.org/Media/Research/pdf/PICHEATH.pdf

Dr. Rima Rudd et al, Harvard, focus on issues surrounding literacy and health. They use tasks from these same large-scale literacy assessments that were judged to involve health-related materials about such topics as drugs and alcohol, disease prevention and treatment, safety and accident prevention, first aid, emergencies, and staying healthy. The authors identified 191 tasks and then used them to create a Health Activities Literacy Scale (HALS) that was then linked back to the NALS database. This report links the use of literacy skills to the health context in which they are applied.

Literacy Harvest Fall 2004: Health Literacy

http://www.lacnyc.org/resources/publications/harvest/HarvestFall04.pdf

Literacy Harvest is the online journal of the Literacy Assistance Center, highlighting research, trends and practices in the field. This 44-page issue focuses specifically on health literacy issues.

National Assessment of Adult Literacy

http://nces.ed.gov/naal/

The National Assessment of Adult Literacy (NAAL) is a nationally representative and continuing assessment of English language literacy skills of American adults. It seeks to describe the status of adult literacy in the United States, report on national trends, and identify relationships between literacy and selected characteristics of adults. The National Center for Education Statistics (NCES), which sponsors the NAAL, has conducted adult literacy assessments since 1985. A nationally representative sample of adults will be assessed again in 2003, providing the first indication of the nation's progress in adult literacy since 1992. Historical data, publications and other resources, and assessment designs are included.

National Center for the Study of Adult Learning and Literacy (NCSALL)

http://www.ncsall.net/

NCSALL is "a federally funded research and development center focused solely on adult learning." While its focus is on all literacy issues, it has a number of electronic publications on health literacy (<u>http://www.ncsall.net/index.php?id=60</u>). The online video "In Plain Language, with accompanying PowerPoint presentation, is available at http://www.hsph.harvard.edu/healthliteracy/overview.html#Two.

Tools such as the facilitator's guide for Chronic Disease Management (<u>http://www.ncsall.net/?id=1062</u>) are available as well.

National Institute for Literacy

http://www.nifl.gov/

The National Institute for Literacy (NIFL) was created by the National Literacy Act of 1991, when a bipartisan Congressional coalition acted on the literacy field's request for a federal office focused solely on literacy. The Institute serves as a focal point for public and private activities that support the development of high-quality regional, state, and national literacy services. It focuses on all forms of literacy, including health literacy. A listserv is available.

National Literacy and Health Program

http://www.nlhp.cpha.ca/

The Canadian Public Health Association provides resources to help health professionals serve clients with low literacy skills. These include a Plain Language Service, a document on designing medication packaging and labeling for seniors with low literacy, newsletters and reports.

National Network of Libraries of Medicine—Health Literacy

http://nnlm.gov/scr/conhlth/hlthlit.htm#Skills%20Needed%20for%20Health%20Literacy

Health Literacy is highlighted in a chapter from "Consumer Health: An Online Manual," written for librarians. Contents include definition, Skills needed for health literacy, background, role of the consumer health librarian, support, Health Literacy organizations and programs, bibliographies and webliographies, and Health Literacy listservs. While somewhat dated (last updated in 2000), much of the information is still valuable.

Pfizer Clear Health Communication Initiative

http://www.pfizerhealthliteracy.com/

Pfizer is a member of the AskMe3 organization, and sponsors a number of health literacy resources here.

The Plain Language Initiative

http://www.plainlanguage.gov/

This government web site offers information on the United States government's Plain Language initiative through examples, guidelines for content and layout in documents, an online tutorial, and numerous resources including links to writing tools and winners of the "worst manual contest."

Proceedings: Mini-Conference on Health Literacy and Health Disparities

http://www.ama-assn.org/ama1/pub/upload/mm/433/mini_conf.pdf

The American Medical Association and Blue Cross Blue Shield of America cohosted a White House Conference on Aging (WHCoA) Mini-Conference on Health Literacy and Health Disparities in Chicago on July 21, 2005, with the purpose of exploring "the issue of vulnerable elderly populations at risk for disproportionate burdens of disease, injury, premature death, and disability due, in part, to their limited ability to understand and participate in the 21st century health care system." This 78page report provides the conference outcomes on 3 specific issues: 1) what is known about how to improve communications for better understanding with these vulnerable populations, 2) how to reduce the risk of medication errors by simplifying and standardizing prescription labels, warning labels, and patient instructions and making them available in the patient's language, promising practices to address patient safety health literacy issues through the drug plans and the new Medicare Part D benefit, and 3). examining a variety of health system efforts to improve quality and health outcomes for elderly patients with limited literacy skills and/or limited English proficiency.

The Virginia Adult Education Health Literacy Toolkit

http://www.aelweb.vcu.edu/publications/healthlit/

The Virginia Adult Education Health Literacy Toolkit is a one-stop resource for adult literacy and ESOL programs' health literacy education needs. It provides extensive resources to help educators understand the diverse health literacy needs of adult learners, better understand the U.S. health care system, employ creative and productive approaches to incorporate health education into classes and curricula, and more. While the Toolkit focuses on Virginia, the majority of the information, teaching ideas and teaching materials it contains are useful nationwide.

Development of Patient Education Materials

University of Virginia Patient Education Creating Patient Education Materials http://www.lib.umn.edu/libdata/page.phtml?page_id=839

This site contains a short listing of helpful books and journal citations, internet resources, cultural and cross-cultural resources, places to go for clip-art and graphics, and information on copyright laws.

Patient Education: An Author's Guide

http://www.med.utah.edu/pated/authors/

The University of Utah has compiled a useful guide on all aspects of writing for patients.

Consumer Health: An Online Manual

http://www.nnlm.gov/scr/conhlth/hlthlit.htm

From the National Network of Libraries of Medicine, this manual provides information for librarians on their roles in health literacy.

Clear and Simple: Developing Effective Print Materials for Low Literate Readers http://cancer.gov/cancerinformation/clearandsimple

The National Cancer Institute has developed this guide, outlining a process for developing publications for people with limited-literacy skills. The process was derived from communications, health education, and literacy research and practice. In addition, writers who have produced low-literacy materials contributed their expertise. Thus, the guide features both proven principles and a discussion of the real life issues that individuals developing low-literacy materials face, such as the constraints of time, budget, organizational pressures, and the Government publications process.

Patient/Family Education Author's Guide

http://vaww.collage.research.med.va.gov/Resources/Documents/Author_Guide.pdf The Wausau, Wisconsin Hospital author's guide is on Collage, VA Intranet. Written Materials Resource Manual for Patient Health Education (Note: VHA Intranet)

http://vaww.tampa.med.va.gov/patientEdu/Written%20Materials%20Resource%20Manu al%20-%20PHE.doc

Developed by the Patient/Family Health Education Review Subcommittee at the James A. Haley Veterans' Hospital, Tampa, this manual assists staff members in writing quality health education materials.

Readability Formulas for Materials

How to Test For Readability (SMOG index) http://www.hsph.harvard.edu/healthliteracy/how_to/smog_2.pdf

The Fog Index and Readability Formulas http://www.klariti.com/business-writing/Fog-Index-Readability-Formulas.shtml

Fry's Readability Graph http://school.discovery.com/schrockguide/fry/fry.html

Readability Formulas (Flesch Reading Ease & Flesch-Kincaid Grade Level) http://csep.psyc.memphis.edu/cohmetrix/readabilityresearch.htm

Readability Testing (SMOG, REALM, MS WORD) http://www1.va.gov/visns/visn02/vet/ed/articles/readability.doc

Users can also check the readability level of a passage using the Flesch-Kincaid Reading Level built into the newer versions of Microsoft® Word. In Word XP, to display readability statistics:

- On the Tools menu, click Options, and click the Spelling & Grammar tab.
- Select the Show readability statistics check box, and then click OK.
- On the Tools menu, click Spelling and Grammar.
- When Microsoft® Word finishes checking spelling and grammar, it displays information about the reading level of the document.

See #19 in this article (http://support.microsoft.com/default.aspx?scid=kb;enus;181863) for an explanation of the Flesch-Kincaid statistics.

Literacy Assessment Tools

Development of an Easy-to-Use Spanish Health Literacy Assessment Tool http://www.academyhealth.org/2004/ppt/lee.ppt (PowerPoint)

Shoou-Yih Lee, University of North Carolina at Chapel Hill, has developed and piloted the "Short Assessment of Health Literacy for Spanish-Speaking Adults (SAHLSA). The tool is similar to the REALM, listed below.

Measurement Excellence and Training Resource Information Center (METRIC)

The Department of Veterans' Affairs METRIC site contains a current evidencebased review of the Test of Functional Health Literacy in Adults (TOFHLA) at <u>http://www.measurementexperts.org/instrument/instrument_reviews.asp?detail=77</u>, and the REALM at

http://www.measurementexperts.org/instrument/instrument_reviews.asp?detail=58

The Newest Vital Sign

http://www.newestvitalsign.org

Dr. Barry Weiss and associates' new tool, in English and Spanish, gives patients a sample of a food label. The patients then answer a set of questions about the label; the questions test ability on text and numbers. The test and scoring sheet, along with other information, may be found on the web site as well as in the journal article. (Weiss, BD, et al. "Quick assessment of literacy in primary care: the newest vital sign." Annals of Family Medicine 2005 Nov/Dec; 3(6): 514-22)

Rapid Estimate of Adult Literacy in Medicine (REALM)

<u>http://www.ihs.gov/NonMedicalPrograms/HealthEd/PDF/PtEd_REALM_Instr.PDF</u> (Examiner's Instruction Sheet) <u>http://www.ihs.gov/NonMedicalPrograms/HealthEd/PDF/PtEd_REALM_Examiner_Word</u> <u>List.PDF</u> (Word list)

Dr. Lisa Chew (VA Puget Sound Health Care System) and colleagues evaluated numerous tools for the most valid screening questions. Her group identified 3 questions that "appeared to be useful in detecting inadequate health literacy in a VA population:"

- 1. How often do you have problems learning about your medical condition because of difficulty understanding written information?
- 2. How confident are you filling out medical forms by yourself?
- 3. How often do you have someone help you read hospital materials?

(Chew LD, et al. "Brief questions to identify patients with inadequate health literacy." Family Medicine 2004; 36(8): 588-94)

Parker, R.M., Baker, D.W., Williams, M.V., & Nurss, J.R. (1995). The test of functional health literacy in adults: A new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine*, *10*(10), 537-541.

Describes the development of the Test of Functional Health Literacy in Adults (TOFHLA). TOFHLA uses actual hospital materials and consists of a 50-item reading comprehension and 17-item numerical ability test. It takes 22 minutes to administer. The

TOFHLA, the WRAT-R and the REALM were administered to 500 patients and the TOFHLA was shown to be a valid and reliable indicator of patient ability to read health-related materials.

Free Health Clip Art, Graphics and other Illustrations

NOTE: While the graphics and images may be free, certain restrictions may be noted at the sites. Please be sure to follow all copyright guidelines when using the images.

USP Pictograms

http://www.usp.org/audiences/consumers/pictograms/form.html

The USP's pictograms are images representing proper ways to take or store medications, precautions, or other important information about a medication that a health care provider should provide to his or her patient.

National Cancer Institute Visuals Online

http://visualsonline.cancer.gov/

The NCI Visuals Online database contains images from the collections of the Communication Services Branch and Mass Media Office of the Office of Communications, National Cancer Institute.

CDC's Public Health Image Library (PHIL)

http://phil.cdc.gov/Phil/default.asp

PHIL is an extensive collection of still images, image sets, and multimedia fiels related to public health.

CDC's Diabetes Clip Art

http://www.cdc.gov/diabetes/pubs/gallery.htm

The clip art found here was developed for "Take Charge of Your Diabetes," a CDC publication that is a guidebook for people with diabetes.

Hablamos Juntos Universal Symbols in Health Care

http://www.hablamosjuntos.org/

Hablamos Juntos is a project funded by the Robert Wood Johnson Foundation, and administered by the UCSF Fresno Center for Medical Education & Research. Its signage project of 28 symbols is designed for wayfinding purposes, to assist low-literate and non-English readers in finding healthcare offices. Its workbook can be downloaded at http://www.hablamosjuntos.org/signage/PDF/Best%20Practices-FINALDec05.pdf

National Eye Institute Photos, Images, and Videos

http://www/nei.nih.gov/photo/

The NEI provides photos and images on eye anatomy, disease simulations, clinician/patient interactions, and more.

Health on the Net Foundation Media

http://www.hon.ch/HONmedia/

HONmedia is an unique repository of over 6800 medical images and videos, pertaining to 1,700 topics and themes. This database has been created manually by HON and new image links are constantly being added from the world-wide Web.

Administration on Aging Multimedia Gallery

http://www.aoa.gov/press/multimed/photos/multimed_photos.asp

The AoA features photos from Aging Magazine 1975-1995 and a Seniors Photo Gallery.

MediaNet (NOTE: This is a VA Intranet site and not accessible on the Internet) <u>http://vaww.mam.lrn.va.gov:8080/Cumulus/MediaNetHomeFrames.htm</u>

This system contains media production assets from a variety of VA program offices, including the Employee Education System (EES); Office of Public Affairs; Audio Visual Services, VACO; and Media Production Services throughout VA.

Health Canada Graphics

<u>http://www.hc-sc.gc.ca/english/media/photos/index.html</u> This Canadian public health site features a variety of graphics and photos.

Online Videos for Professionals

AMA Foundation's Health Literacy Video

http://www.ama-assn.org/ama/pub/category/8035.html

The 20-minute video, also included in the AMA's Health Literacy Introductory Kit, can be viewed in its entirety at this link. It is designed to raise awareness and spark discussion about patients' low health literacy skills.

In Plain Language—Rima Rudd

http://www.hsph.harvard.edu/healthliteracy/overview.html#Two

In Plain Language was produced by Dr. Rima Rudd and Dr. William DeJong, with a team of Health Literacy Studies professionals and researchers. This 15minute video/DVD was developed for medical and public health professionals who are interested in learning about adult literacy in the US and implications for medicine and for public health. A PowerPoint presentation is also available.

Online Videos for Patients

Agency for Healthcare Research and Quality

AHRQ has 2 videos of interest: "Next steps after your diagnosis: finding information and support (<u>http://www.ahrq.gov/consumer/nxtstepvid.htm</u>) and "Check your medicines (<u>http://www.ahrq.gov/consumer/chkmedvid.htm</u>)

Healthy Roads Media

http://www.healthyroadsmedia.org/

This site contains free health education materials in a number of languages and a variety of formats, including audio, video and print. Many of the materials are public domain.

Heart Info

http://www.heartinfo.org/ms/nav/video/main.html

Over 80 videos on heart disease, stroke, diabetes, and cardiac anatomy are available. Animations and illustrations of cardiac conditions, stroke and sleep apnea can be found at <u>http://www.heartinfo.org/ms/nav/animation/main.html</u>.

NIH Senior Health

http://nihseniorhealth.gov/videolist.html

Senior Health has short online videos in 20 subject fields on topics pertinent to older people and their caregivers.

MedlinePlus: Interactive Tutorials

http://www.nlm.nih.gov/medlineplus/tutorial.html

While not videos, this part of MedlinePlus contains animated tutorials that explain procedures or conditions in easy-to-read language. Users can also listen to the tutorial or print a written version. Disease and conditions, tests and diagnostic procedures, surgery and treatment procedures, and prevention and wellness topics are included.

MedlinePlus: Videos of Surgery Procedures

http://www.nlm.nih.gov/medlineplus/surgeryvideos.html

This portion of MedlinePlus provides links to pre-recorded webcasts of surgical procedures. These are actual operations performed at medical centers in the United States since January 2004. Caution should be used when recommending them to patients due to the "graphic" content.

Multi-Cultural Educational Services Online Activities

http://www.mcedservices.com/online.html

While aimed at individuals learning English, the Health Literacy Activities page contains 2 learning modules that may prove valuable for non-readers: *Nutrition, Diabetes and High Blood Pressure and Medicine Labels and Warnings*.

Stanford Health Library

http://healthlibrary.stanford.edu/resources/videos.html

A variety of videos grouped loosely under Cancer Supportive Care, Health and Society, Women's Health, and Health Matters can be viewed. Most titles are about 30-60 minutes long