

Appendix E: Repository of Readability References and Resources

I. Large-scale Health Literacy and Plain Language Initiatives

[American Medical Association Foundation Health Literacy Initiative](#)

Working to raise awareness among health care providers about the link between health and literacy. Find out more about their toolkit Health Literacy: A Manual for Clinicians, and train-the-trainers seminar.

[National Institutes of Health - Clear Communication: Health Literacy Initiative](#)

Defines health literacy and discusses why it's an issue and how to improve communication strategies for health professionals. Links to current research in health literacy supported by the NIH.

[Pfizer Clear Health Communication Initiative](#)

Pfizer supports research in clinical settings to begin to develop solutions that center around clear communication. Tools are provided for clinicians, researchers, the media, and public health professionals.

[Plain Language Action and Information Network](#)

Federal government's contribution to the plain language movement. This site provides a history of this movement, examples of documents before and after being rewritten using plain language principles, and links to key articles supporting the use of plain language in organizational settings.

[Plain Language Association International](#)

An international group called The Plain Language Network. Members of the network include editors, writers, attorneys, and educators from around the world. Provides links to advice and information on writing and designing clear communication materials using plain language.

[U.S. Department of Health and Human Services](#)

One of the primary objectives of Healthy People 2010 is the improvement of health literacy. Read the full text of the objective: Health Literacy Action Plan—Communicating Health: Priorities and Strategies for Progress (2003):

II. Key background reports on general literacy and health literacy

[Results of the 2003 National Assessment of Adult Literacy \(NAAL\)](#)

[Health Literacy Report from the 2003 National Assessment of Adult Literacy](#)

[Health Literacy: A Prescription to End Confusion](#)

More health literacy Web resources

[Agency for Healthcare Research and Quality](#)

Health Literacy and Cultural and Linguistic Competency resource page provides links to research studies, implantation strategies, evidence reports and tools for testing the quality of your materials.

[Harvard School of Public Health, Health Literacy Studies](#)

Information for researchers and practitioners in the public health, medical, and adult education fields. Links to Easy-To-Read health information sites, grouped by health topic.

[Health and Literacy Special Collection](#)

A clearinghouse of information related to teaching and learning health literacy skills, including links to health education resources, easy-to-read and multilingual health information, and health literacy research.

[Health Literacy Consulting](#)

Resources and articles to help individuals and organizations communicate about health information in ways patients, families, and employees can more easily understand.

[Plain Language: A Promising Strategy for Clearly Communicating Health Information and Improving Health Literacy](#) PDF

From the U.S. Department of Health and Human Services: An overview of plain language and health literacy terms, tips on writing and speaking plainly, and a summary of reasons why plain language has the potential to improve health literacy.

[Quick Guide to Health Literacy](#)

From the U.S. Department of Health and Human Services: A summary of issues related to health literacy, suggestions for improving health literacy in your organization, and examples of health literacy best practices.

[Teaching Patients with Low Literacy Skills.](#)

Second Edition (1996). Doak, Doak, & Root. Considered a classic text in health literacy, the authors are often introduced at health literacy conferences as 'the grandparents' of health literacy.

[Low Health Literacy: Implications for National Health Policy.](#)

This recent report from the University of Connecticut School of Business “dollarizes” the financial burden on the U.S. economy, and advocates that low health literacy be addressed as part of national health care reform.

[Medical Library Association](#)

Contains many hyperlinked resources listed that currently are developing health literacy standards

[National Library of Medicine/National Institutes of Health](#) –

definitions, research findings, economic impact of low health literacy, bibliographies, a compendium of web sites, and health literacy listservs.

[“What Did the Doctor Say?:” Improving Health Literacy to Protect Patient Safety.](#) The Joint Commission on Accreditation of Healthcare Organizations developed this comprehensive 2007 report on the real and potential impact of health literacy.

Writing tips and how-to guides

[Simply Put](#) PDF

Tips for creating easy-to-read print materials from the Centers for Disease Control and Prevention (CDC).

[How to Write Easy to Read Health Materials](#)

Tips from the smart folks at Medline Plus, who develop lay-oriented health information.

[Health Literacy Style Manual](#) PDF

Southern Institute on Children and Families

[Guidelines for Developing Easy-to-Read Health Education Materials](#)

State of Washington Department of Health

[Patient Education Materials: An Author's Guide](#)

University of Utah, Health Sciences Center

[Improving Readability By Design](#)

Tips on seven design elements to improve the readability of patient education materials, from healthcommunications.org.

Three resources especially worthwhile for researchers and IRBs

[The AHRQ Informed Consent and Authorization Toolkit for Minimal Risk Research](#)

Developed by the Agency for Healthcare Research and Quality (AHRQ), this toolkit aims to make informed consent and HIPAA authorization more meaningful for participants. It includes sample easy-to-read consent documents for informed consent and authorization and a model process for obtaining written consent and HIPAA authorization.

[Simplification of Informed Consent Documents](#)

Plain language recommendations from the National Cancer Institute and a consent form template for cancer-related clinical trials.

[Universal Use of Short And Readable Informed Consent Documents: How Do We Get There?](#)

Summary of Strategic Planning Meeting May 30, 2007 held by the American Association of Medical Colleges to review potential approaches and available resources to move the research community toward common usage of informed consent documents that are both short and written in simple and comprehensible language.

Web pages with lists of alternative wording suggestions for medical and research terminology

[University of California at Davis](#)

[University of Michigan Medical School](#)

[University of Utah Health Sciences Center](#)

Enhancing provider/patient communication

AskMe3

Sponsored by the Partnership for Clear Health Communication (PCHC). The PCHC serves as an information source regarding the scope and impact of health literacy in the U.S., as well as what providers and patients can do to improve health communication in every provider-patient interaction.

Familydoctor.org

Patient-friendly site has an extensive index of conditions, health tools, including a dictionary of common medical terms, and a section on healthy living. All material is written and reviewed by physicians and patient education professionals.

FDA Easy-to-Read Publications

This site has a collection of easy-to-read brochures in English and Spanish on a variety of health topics. You can print them or order free copies.

FDA Information for Seniors

Easy-to-read articles on a variety of health issues that affect older adults. Topics include arthritis, cancer, nutrition, food safety, and women's health. Also links to other organizations with information for older adults.

KidsHealth

Sections for parents, kids, and teens, including interactive games. The kids' articles are easy to read and written for children. Also appropriate for adult learners with low-literacy skills.

Medline Plus

Interactive tutorials teach about health topics with animated graphics and simple text.

Health in Plain Terms.

A call to action from the Puget Sound Health Alliance. This is a resource for both consumers (helping them get the care they need), and providers (tools to help them talk to their patients in language that is easily understood).

Health Literacy: A Manual for Clinicians.

American Medical Association and American Medical Association Foundation, 2003

An abbreviated list of published articles on literacy and readability in health research (this is an ever-growing bibliography)

Berkman ND, et al. Literacy and health outcomes. Summary, Evidence Report/Technology Assessment No. 87. AHRQ Publication No. 04-E0007-1. Rockville, MD: Agency for Healthcare Research and Quality. Jan 2004.

Bjorn E, Rossel P, Holm S. Can the written information to research subjects be improved – an empirical study. *J of Med Ethics*. 1999;25:263-267

Cox K. Informed consent and decision-making: patients' experiences of the process of recruitment to phases I and II anti-cancer drug trials. *Patient Educ Couns*. 2002 Jan;46(1):31-8.

- Coyne CA, et al. Randomized, controlled trial of an easy-to-read informed consent statement for clinical trial participation: A study of the Eastern Cooperative Oncology Group. *J of Clinical Oncol.* Mar 1, 2003;21(5):836-842.
- Davis TC, et al. Literacy and misunderstanding prescription drug labels. *Annals Int Med.* Dec 2006;145(12):887-894.
- Davis TC, et al. Informed consent for clinical trials: a comparative study of standard versus simplified forms. *J of Natl Cancer Inst.* May 6, 1998;90(9):668-674.
- Davis TC, et al. Parent comprehension of polio vaccine information pamphlets. *Pediatrics.* 1996;97:804-810.
- Goldfarb NH and DuBay WH. Writing good at a seventh-grade reading level. *J of Clinical Research Best Practices.* Vol.2, No.1, Jan 2006
- Hochhauser M. Is it ethical to give out unreadable information? *Managed Care Quarterly.* Spring 2003.
- Hopper KD, Tenhave TR, Hartzel J. Informed consent forms for clinical and research imaging procedures: how much do patients understand? *Am J Roentgenol.* 1995 Feb;164(2):493-6.
- Kalichman SC, et al. Adherence to combination antiretroviral therapies in HIV patients of low literacy. *Journal of General Internal Medicine,* 1999.
- Meade CD. Improving understanding of the informed consent process and document. *Seminars in Onc Nursing.* May 1999;15(2):124-137.
- Miller C, et al. Comprehension and recall of the informational content of the informed consent document: an evaluation of 168 patients in a controlled clinical trial. *J of Clin Res and Drug Development.* 1994;8:237-248.
- Paasche-Orlow MK, Taylor HA, Brancati FL. Readability standards for informed-consent forms as compared with actual readability. *N Engl J Med.* 2003 Feb 20;348(8):721-6.
- Philipson S, et al. Effectiveness of a writing improvement intervention program on the readability of the research informed consent document. *J of Investigative Med.* Nov 1999;47(9):437-445.
- Raich P, Plomer K, Coyne C. Literacy, comprehension, and informed consent in clinical research. *Cancer Investigation.* 2001;19(4):437-445
- Ratzan SC, Parker RM, 2000. Introduction. In *National Library of Medicine Current Bibliographies in Medicine: Health Literacy.*
- Sugarman J, Lavori PW, Boeger M, Cain C, Edson R, Morrison V, Yeh SS. Evaluating the quality of informed consent. *Clinical Trials,* Feb 2005; 2: 34 - 41.
- Titus S and Keane M. Do you understand?: an ethical assessment of researchers' description of the consenting process. *J of Clin Ethics.* Spring 1996; 7(1):60-68.
- White L, et al. Informed consent for medical research: common discrepancies and readability. *Academic Emerg Med.* August 1996;3(8):745-750.
- Wolf MS, et al. Health literacy and health risk behaviors among older adults. *Am J Prev Med* 2007;32(1):19-24.
- Williams MV, et al. Inadequate literacy is a barrier to asthma knowledge and self-care. *Chest.* 1998.

We're happy to update this list with other references or resources you may come across.

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