

# Bringing Health Literacy Research to Practice

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Andrew Pleasant & Sabrina Kurtz-Rossi

# The LINCS Health and Literacy Special Collection

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<http://www.worlded.org/us/health/lincs>

The LINCS Health & Literacy Special Collection provides support to professionals interested in health and literacy education in adult literacy and health care settings. The site will link you to easy-to-read health information websites and materials, including:

Health and literacy research and technical reports

Guides for integrating health and literacy education

Health information in plain English, or in languages other than English

Health information tutorials with sound, text, and illustrations in English and Spanish

Links to health literacy organizations and initiatives

The site is maintained by World Education, with support from the National Institute for Literacy (NIFL) Literacy Information and Communication System (LINCS).

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## WHY RESEARCH?

Research is the best tool for understanding what works and what doesn't. Research is how we learn from the programs that are effective and improve those that are less effective. There are a number of very specific ways health literacy research can be useful to practitioners. When you're looking for funding, research that documents the effectiveness of combining health and literacy education is very useful. If you're looking to develop or modify a health and literacy curriculum, you may find it helpful to read studies that describe what others have done in order to learn from their experiences.

Evidence-based: the integration of professional wisdom with the best available empirical evidence in making decisions about how to deliver instruction.

Professional wisdom: the judgment individuals acquire through experience.

Empirical evidence: scientifically-based research that is rigorous, systematic, objective and peer-reviewed.

\*Whitehurst, U.S. Department of Education's (DOE) Institute of Education Sciences (IES), 2002.

## WHAT IS EVIDENCE-BASED?

In the health and education fields, the use of evidence-based approaches and material is increasingly emphasized. Through research, we can gather "evidence" that a program or material is successful. One way to think about evidence is to consider what it is not. The following is a list of examples of what is not considered credible evidence (Perkins, 1999).

### EVIDENCE IS NOT

- A set of morals
- Casual conversations
- A brainstorming session
- Continuing the status quo
- Arguments in defense of past actions
- An opinion or value
- Something only a Ph.D. can do
- A new idea that seems good

But what constitutes evidence? Findings that result from well-designed and implemented randomized control trials are often considered the 'gold standard' for evidence. For many literacy programs, however, a randomized control trial can be impractical, ineffective, or even unethical. This places health literacy researchers in a potential bind between the 'gold standard of evidence and the reality of program implementation and evaluation.

Observational studies are very different from randomized control trials. Observational studies are descriptive studies using methods like focus groups or in-depth interviews. Observational studies answer questions such as, how was the intervention used, what did people think of the intervention, and how can the intervention be improved? Reports of expert committees and opinions based on experience are often considered observational.

Some argue that observational studies produce weaker evidence. Others argue that observational studies produce comparable results to randomized control trials. A debate continues on the strength of evidence produced by the different approaches. The more important point is to select a research approach that delivers relevant and useful information.

Increasingly, researchers are combining qualitative research methods used in observational studies with quantitative research methods used in randomized controls. In this way researchers hope to provide a more complete picture of which approaches are effective and why.

Randomized control trials are studies that randomly assign people to an intervention group or a control group. The intervention group receives an intervention, which could be a new curriculum, medicine, or program, and the control group does not. If those in the group that received the intervention change more than those who do not receive the intervention, we can begin to say that the intervention had an effect. Many influences may have made the effect, however, so researchers need to carefully account for all possible sources of the change.

Quantitative research methods generally express findings in numbers and rely upon statistical methods of analysis. If the participants are a representative random sample, quantitative data can be used to draw conclusions that apply to a larger group of people with similar characteristics, sometimes called the “target population.” Quantitative research is useful for measuring the extent to which an intervention changes people’s knowledge, attitudes or behaviors.

Qualitative research methods, like focus groups or individual interviews, are used to gather in-depth reactions and impressions among participants. Results are often not described numerically or used to make generalizations about the larger population. Qualitative research is useful for determining why people react the way they do and how to make changes to better meet users’ needs or to better understand their ideas, issues, and concerns.

## USING HEALTH LITERACY RESEARCH

One way to learn about health literacy research and how it might impact your work is to read some of the articles with your colleagues and discuss them. For example, you could form a study circle. In study circles, practitioners come together as a group to develop their knowledge and skills. You can form a study circle to read and discuss research on any topic. For more information on study circles on various issues in adult literacy, visit the Website of the National Center for the Study of Adult Learning and Literacy (NCSALL) [www.ncsall.net](http://www.ncsall.net) and look for their teaching and training materials. For general information about study circles, visit the Study Circles Resource Center’s Website at [www.studycircles.org](http://www.studycircles.org).

Below is an annotated bibliography of selected key research articles on health literacy. We organized these research articles by setting: Adult Basic and Literacy Education, Public Health and Clinical Investigation. Read through the annotations to choose those that interest you. Then get a copy of the entire article to read for further study and discussion. For more information on how to get a copy of the articles that interest you, please contact Tina White, [twhite@worlded.org](mailto:twhite@worlded.org).



Association for the Advancement of Health Education, (1995). National health education standards: Achieving health literacy. Washington, D.C., Association for the Advancement of Health Education: 90.

These standards outline what students (K-12) are expected to learn and be able to do with regard to their health and the health of their friends and family.

Freire, P. (1980). Education for Critical Consciousness. New York, NY, Continuum.

Freire's core argument is that traditional education models that treat learners as passive and dependent receivers of information reinforce existing social inequalities. He proposed that participatory learning processes empower individuals to better related and reflect on their own experiences, improve problem-solving skills, and make more effective and thoughtful actions.

Grosse, R.N. and C. Auffrey (1989). Literacy and health status in developing countries. Annual Review of Public Health. 10: 281-297.

Grosse and Auffrey review the literature and data (quantitative and qualitative) on the relationship between literacy and health in developing countries. The authors conclude that "strong and consistent" associations of literacy and mortality are independent of culture or level of economic development.

Hohn, M.D. (1997). Empowerment health education in adult literacy: A guide for public health and adult literacy practitioners, policy makers, and funders. U.S. National Institute for Literacy. Available at: <http://www.nifl.gov/nifl/fellowship/reports/hohn/HOHN.HTM#org>

Based on a participatory action research project in Massachusetts, this report explores the introduction of health content into an adult literacy program.

Kirsch, I., Jungeblut, A., Jenkins, L. & Kolstad, A. (1993). *Adult Literacy in America: The First Look at the Results of the National Adult Literacy Survey (NALS)*. Washington, D.C.: U.S. Department of Education, 1993.

The results of the 1991 National Adult Literacy Survey (NALS) in the United States, this research project set the stage for much of the later work on health literacy.

Kurtz-Rossi, S., Coyne, C., Titzle, J. (2004). Using Research to inform health and literacy program development: Results from the HEAL:BCC evaluation study. *Literacy Harvest* 11(1): 35-39.

This study evaluates the impact of integrating breast and cervical health content into adult basic education classes. Researchers used a quasi-experimental design administering pre- and post-surveys and conducting focus groups. The study found increases in knowledge about breast and cervical cancer and in the proportion of women learners who went for Pap tests post intervention. The article also provides a detailed description of the HEAL:BCC Curriculum and what teachers and learners thought about the program.

Mukherjee, A. & Vasanta, D. Eds. (2002). *Practice and Research in Literacy*. New Delhi, Sage Publications India.

Reviews theories of literacy underpinning initiatives to improve literacy in India since the early 1980s. Includes chapters focusing on theories of literacy and numerous case studies of applied projects.

Rudd, R. E., C. Zacharia, et. al. (1998). Integrating health and literacy: Adult educators' experiences. Boston, MA, NCSALL/World Education: 20. Available at: <http://www.ncsall.net/fileadmin/resources/research/rep5.pdf>.

Presents the findings of a qualitative and exploratory research project into the experiences of teachers at adult learning centers in Massachusetts who introduced health projects into the classroom.

Street, B. (Ed.) (2001). *Literacy and Development: Ethnographic perspectives*. New York and London. Routledge.

Discusses the understandings and practices of literacy in several informative case studies. A chapter by Anna Robinson-Pant (pp. 152-170) focuses on health and literacy, in particular the tensions that can emerge when using qualitative ethnographic research practices in literacy program evaluation to produce policy recommendations.



Cleveland J.G. and J.K. Van Ginneken, (1988). Maternal Education and Child Survival in Developing Countries: The search for pathways of influence. *Social Science and Medicine* 27(12): 1357-68.

This is one of the earlier studies to link education and health status, in particular the connection between mothers' education level and the mortality rates of children under five in low-income countries. The article includes an assessment of what the actual reasons for the link are, assessing several possible advantages occurring from education that could improve the chance of young children to survive.

Davis, T.C., R. Michielutte, E. Askov, Williams, M., & Weiss, B. (1998). Practical assessment of adult literacy in health care. *Health Education & Behavior* 25(5): 613-624.

This article provides an introduction and overview of the main methods of assessing English and Spanish literacy, including the Rapid Estimate of Adult Literacy in Medicine (REALM), Slosson Oral Reading Test-Revised (SORT-R), Wide Range Achievement Test (WRAT-3), the Test of Functional Health Literacy in Adults (TOFHLA), and the Instrument of Diagnosis of Reading or Instrumento para Diagnosticar Lecturas (IDL).

Doak, L., C. Doak, et al. (1996). *Teaching patients with low literacy skills*. Philadelphia, PA, Lipincott.

A classic in the field. This is essentially a manual full of practical tips and strategies for making materials easier to read and understand.

Gazmararian, J.A., Baker, D.W., Williams, M.V., Parker, R.M. Scott, T.L., Green, D.C., Fehrenbach, S.N., Ren, J., & Koplan, J.P. (1999). Health literacy among Medicare enrollees in a managed care organization. *JAMA: Journal of the American Medical Association*, American Medical Association. 281(6): 545-551.

This article reports on the first use of the Short-TOFHLA to assess health literacy in over 3,000 elderly Medicare enrollees in a national managed care plan. Over 1/3 of the English speakers and 1/2 of the Spanish-speaking participants in this research were found to have inadequate or marginal health literacy.

Kickbusch, I.S. (2001). Health literacy: addressing the health and education divide. *Health Promotion International* 16(3): 289-297.

This is a discussion of health literacy as an approach to addressing health status and health inequities. The authors argue that health literacy should play an important role in the global alliances to combat disease and health inequities. Overall, the argument is based on a theory of health literacy as a source of empowerment and social capital.

Meade, C.D. & Byrd, J.C. (1989). Patient literacy and the readability of smoking education literature. *American Journal of Public Health* 79(2): 204-206.

This article reports on a comparison of participants' ability to read and the readability of anti-smoking materials. The researchers conclude there is a wide gap between the reading ability of their participants, and that it is necessary to read and understand the anti-smoking materials. They also found that the number of years of education was not a good predictor of reading ability.

Nielsen-Bohlman, L., A.M. Panzer, et al., Eds. (2004). *Health literacy: A prescription to end confusion*. Washington, D.C., Institute of Medicine of the National Academies.

A consensus report on health literacy, this book contains specific sections addressing health literacy in the contexts of culture and society, the educational system and the health system.

Nutbeam, D. (2000). Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century. *Health Promotion International* 15(3): 259-267.

This article connects health literacy with health education and health promotion as well as theorizes connections between health literacy and outcomes related to social, environmental, and health conditions. Additionally, this article develops a theory of health literacy that includes levels of basic/functional, communicative/interactive, and critical literacy.

Osborne, H. (2005). *Health literacy from A to Z*. Sudbury, MA, Jones and Bartlett Publishers.

Written primarily for health care providers, this is a collection of short descriptions and recommendations of a wide variety of health literacy issues and practices.

Perrin, B. (1990) Literacy and Health: Making the Connection: The Research Report of the Literacy and Health Project, Phase One: Making the World Healthier and Safer for People Who Can't Read. Toronto: Ontario Public Health Association.

This report from Canada explores the relationship between literacy and health. The authors look at what is being done to help people with limited literacy skill to be healthier and safer; and makes some recommendations for future efforts.

United States Department of Health and Human Services (USDHHS). (2000). Healthy People 2010: Understanding and improving health and objectives for improving health. Washington, D.C., U.S. Department of Health and Human Services.

Healthy People 2010 outlines the priority areas for improving health in the United States, including health literacy, for the first time.

Van Servellen, G., J. Brown, et al. (2003). Health literacy in low-income Latino men and women receiving antiretroviral therapy in community-based treatment centers. *AIDS patient care and STDs* 17(6): 283-298.

Reports on creation of a health literacy assessment tool targeting HIV/AIDS knowledge and the connection between health literacy and the treatment of HIV/AIDS. This study also identifies factors in individuals and the health care system that lead to poor functional health literacy, whereas most studies focus on the effects of functional health literacy.

Zarcadoolas, C., Pleasant, A., & Greer, D. (2005). Health literacy: Can the public be healthy without it? *Health Promotion International*. 20:195-203.

Using the anthrax threat in the United States as a case study, this article outlines an expanded model of health literacy that includes fundamental, scientific, civic, and cultural domains.

Baker, D.W., R.M. Parker, et al. (1997). The relationship of patient reading ability to self-reported health and use of health services. *American Journal of Public Health* 87(6): 1027-30.

This research found that functional health literacy as measured with the Test of Functional Health Literacy in Adults (TOFHLA) was a stronger predictor of how healthy people said they were (self-reported health status) than was years of education.

Baker, D.W., M.V. Williams, et al. (1999). Development of a brief test to measure functional health literacy. *Patient Education and Counseling* 38(1): 33-42.

This article reports the development of a shorter version of the Test of Functional Health Literacy in Adults. While the short TOFHLA (S-TOFHLA) is quicker to take than the TOFHLA, the authors acknowledge that there is no gold standard to measure health literacy.

Baker, D.W. Gazmarian, J., Williams, M., Scott, T., Parker Ruth, Green, D., Ren, Junling, & Pell, J. (2002). Functional Health Literacy and the Risk of Hospital Admission Among Medicare Managed Care Enrollees. *American Journal of Public Health*, 92(Aug 2002): 1278-1283.

This article reports on a study investigating the relationship between functional health literacy and the risk of being admitted to a hospital among over 3,000 Medicare managed care enrollees. The hypothesis tested is that inadequate functional health literacy is an independent risk factor for hospital admission. After accounting for the impact of ("controlling for") factors such as age, sex, race/ethnicity, education, income, smoking, alcohol use, chronic disease, and self-reported physical and mental health, the researchers found that participants with "inadequate" functional health were more likely to be admitted to a hospital.

Davis, T.C., R. Michielutte, E. Askov, Williams, M., & Weiss, B. (1998). Practical assessment of adult literacy in health care. *Health Education and Behavior* 25(5): 613-624.

This article provides an introduction and overview of the main issues and methods of assessing English and Spanish literacy available to health care providers. The article summarizes the main strengths and weaknesses of the Rapid Estimate of Adult Literacy in Medicine (REALM), Slosson Oral Reading Test-Revised (SORT-R), Wide Range Achievement Test (WRAT-3), the Test of Functional Health Literacy in Adults (TOFHLA) and the Instrument of Diagnosis of Reading or Instrumento para Diagnostico de Lecturas (IDL).

Doak, C., Doak, L., Friedell, G. & Meade, C. (1998). Improving comprehension for cancer patients with low literacy skills: Strategies for clinicians. *Ca-a Cancer Journal for Clinicians* 48(3): 151-162.

This article offers a series of easy-to-do steps for health care providers when communicating with patients about cancer. The goal is to improve patients' understanding, particularly those with low health literacy. The main recommendations include providing organizing information before the message, focusing on behavior and actions, presenting context first then information, using examples, tailoring information to the individual, underlining key points, and asking questions to get feedback and check comprehension.

Kalichman, S.C., Benotsch, E., Suarez, T., Catz, S., Miller, J., Rompa, D. (2000). Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventative Medicine* 18(4): 325-331.

Based on research in a community health setting with small sample sizes, Kalichman and colleagues report that low literacy and education independently relate to poorer health status and misperceptions about HIV/AIDS.

Kalichman, C., Ramachandran, B., & Catz, S. (1999). Adherence to combination antiretroviral therapies in HIV patients of low health literacy. *Journal of General Internal Medicine* 14: 267-273.

Working with a relatively small sample of individuals taking a triple-drug combination of anti-retroviral therapy for HIV in a community-based health service setting, researchers found that education and health literacy were significant and independent predictors of treatment adherence. The study also found that individuals with low health literacy were more likely to have missed treatment doses because of confusion, depression, or a desire to cleanse their body, than those with high health literacy.

Parker, R. M., D. W. Baker, et al. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. *Journal of General Internal Medicine* 10(10): 537-41.

This article reports on the initial development of the Test of Functional Health Literacy in Adults (TOFHLA). The TOFHLA consists of a 50-item reading comprehension and 17-item numerical ability test.

Roter, D.L., R. Stashefsky-Margalit & R. Rudd. (2001). Current perspectives on patient education in the U.S. *Patient Education and Counseling* 44(1): 79-86.

The authors discuss the evolution of patient education from a biomedical model to, in their view, its current embrace of empowerment and participation themes. Using selected diabetes education research as a case study, they propose future research be directed at priority areas of empowerment and quality of life, and secondly, disparities in health and access to health services.

Schwartzberg, J., VanGeest, J., & Wang C. (Eds.) (2005). *Understanding Health Literacy: Implications for medicine and public health*. Chicago, IL, AMA Press.

A fairly technical review of health literacy, this book is primarily focused on clinical implications of health literacy for health care providers, health literacy researchers, and patients.


Williams, M., R. Parker, et al. (1995). Inadequate functional health literacy among patients at two public health hospitals. *Journal of the American Medical Association* 274(21): 1677-1682.

One of the most cited studies of health literacy. Williams et al. conducted a large study with over 2,500 participants drawn from emergency room patients at hospitals in California and Georgia. They found over 35 percent of English speaking and over 61 percent of Spanish speaking patients had "inadequate" or "marginal" levels of functional health literacy.


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## ABOUT THE AUTHORS...



Andrew Pleasant is an assistant professor in the Department of Human Ecology at Rutgers University. He works to better understand and improve the communication of science within society, issues of health literacy, and how communities can create positive change to protect and improve human health and the environments we live in. He has worked with the World Health Organization's Health Inter Network India project to place information and communication technologies in the health care system. Andrew is also part of a new global certificate program in science communication. Dr. Pleasant earned a masters degree in Environmental Studies from Brown University and a Ph.D. in Communication from Cornell University, and he has worked for over a decade at daily newspapers in the



Sabrina Kurtz-Rossi is a project director for World Education's Health and Literacy Initiative. She offers professional development training on a variety of health literacy topics, including: integrating health and literacy education, developing low literacy health education materials, using Web-based health literacy resources, and reaching limited-literacy audiences. She joined World Education, a non-profit adult literacy organization, in 1994 to develop programs and approaches to improve access to health information and health care services for adults with limited literacy skills. Ms. Kurtz-Rossi earned a masters degree in Health Education from Boston University's School of Education and has worked in a variety of community-based settings developing health information outreach programs.

