Authors:

Sarah Bauerle Bass, Ph.D., MPH, Associate Professor of Public Health, Temple University, Department of Public Health

Rachel Gallo, BS, Health Communications and Health Disparities, Fox Chase Cancer Center

Danielle M. Crookes, MPH, Health Communications and Health Disparities, Fox Chase Cancer Center

Theresa Berger, MBE, Health Communications and Health Disparities, Fox Chase Cancer Center

Principal Investigator:

Linda Fleisher, MPH, PhD (c) Health Communications and Health Disparities, Fox Chase Cancer Center

This project was funded by the Pennsylvania Department of Health, Edward G. Rendell, Governor.

July 29, 2008

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Table of Contents

I. How to Use this Guide ................................................................................................................. 4

Section II. Background .................................................................................................................. 7
  What is Health Literacy and What is the Extent of the Problem? ........................................... 7
  What are the Health Implications of Low Health Literacy Levels? ....................................... 8
  How is Health Literacy Measured? ............................................................................................. 9
  Conclusion ............................................................................................................................... 10
  References ............................................................................................................................. 11

Section III. Literature .................................................................................................................. 16
  Must Read Articles ................................................................................................................. 17
  Further Reading List .............................................................................................................. 20
  Books and Technical Reports ................................................................................................. 21

Section IV. Considerations ......................................................................................................... 25

Section V. Tools and Resources ................................................................................................. 26
  Toolkits and Guides ................................................................................................................. 26
  Websites ............................................................................................................................... 29
  Presentations and Trainings ................................................................................................. 32
  Health Literacy Assessment Tools ....................................................................................... 33
  Readability Tools .................................................................................................................. 34

  Materials/Resources for Consumers ....................................................................................... 36

  Image References .................................................................................................................. 39
I. How To Use This Guide

Introduction

This guide is meant to assist those interested in health literacy understand how it impacts healthcare, health outcomes, patient safety and, ultimately, the public’s health. Ineffective communication, from a brief one-on-one dyad with a physician, to confusing health education materials or unclear hospital signage and directions, all make the consumer with literacy issues more passive in the care of his/her health. When this happens, we are all affected. Thus, this guide has been created to help those interested in addressing the health literacy problem by providing resources, tools and guidance on how best to address the problem, with hopes of ensuring a better informed and more health activated citizenry.

What is Health Literacy?

The risk of ineffective health communication is not a problem only for the illiterate. In fact, recent estimates show that half of the U.S. adult population has difficulty using text to accomplish everyday tasks (Kirsch, 2001). This number increases when you consider those who are not able to effectively use or understand numbers. Just 33 percent of U.S. adults are considered to have basic quantitative skills, including the ability to solve one-step arithmetic problems and another 22 percent are considered to have below basic quantitative skills that would include simple addition (U.S. Department of Education, 2003).

This becomes important to consider as U.S. adults are trying to navigate the healthcare system, understand public health directives or even comprehend risk information related to taking certain medications. It is this intersection in which the term “health literacy” becomes important. According to the National Library of Medicine (Selden et al., 2000) and Healthy People 2010 (USDHHS, 2000), health literacy is defined 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” (Ratzan & Parker, 2000). It should be noted that while many who have low levels of education also have issues with health literacy, studies have confirmed that there are also many with higher levels of education who still have poor health literacy.

Thus, it is estimated that at least 90 million adults have limited health literacy, many of whom cannot fully benefit from their healthcare. In some respects this is not hard to understand; the “medspeak” used by hospitals, healthcare providers and even public health institutions is often filled with medical terms, jargon and even fabricated words that many find difficult to understand or put in context.

Consider this in the following scenarios…

1. A patient information sheet, meant to help the patient understand risk for eye infections, says…“Therefore, patients should be monitored for extraocular CMV infections and retinitis in the opposite eye, if only one infected eye is being treated” (IOM, 2004).
Clearly, health literacy has a real impact on the ability of millions of Americans to take care of their health. Unclear communication can, in fact, become a danger to health and contribute to adverse health outcomes for many. Consider this: according to a report by the Joint Commission (2007) on improving health literacy “…among patients who sign an informed consent form, 44 percent did not know the exact nature of the operation to be performed, and most – 60 to 70 percent – did not read or did not understand the information contained in the form.” Because of this lack of understanding, health literacy must be a priority for those working in healthcare, public health or other ancillary industries that are involved with communicating health and risk information to the public.

2. Language from an actual over-the-counter product says, “Topical antiseptic bactericide/viricide for degemging skin and mucus membranes” (IOM, 2004).

3. A mother whose two-year-old daughter has an ear infection and has been prescribed antibiotics has trouble understanding the label on the bottle and because it doesn’t tell her how to administer the medicine, she fills a teaspoon and pours it into her daughter’s ear (Parker et al. 2003).

4. Language from an actual and recommended informed consent form says, “We are seeking your participation in a research project involving a study of the burden borne by persons providing home care to victims of an immobilizing stroke” (Abilene Christian University, 2007).

How Can This Guide Help You?

This guide provides the user with a number of tools to help address health literacy, including:

Section II. Background
This section provides users with an introduction to, definitions of and current knowledge on literacy and health literacy, including a brief review of current literature, how health literacy affects health outcomes, how health literacy is currently measured and why it is important to study. In this section you will find many references considered good background articles on health literacy.

Section III. Literature
This section includes a list of articles on health literacy and other literature that provide a background on the issues of addressing health literacy. This section provides users with the most current resources for professionals and consumers to address health literacy and includes a brief description of each source as well as where each source can be located. For your convenience, this section has been broken into four types of materials.

Must Read Articles. These articles include those that have been recently published or have been cited several times in the literature. Annotated bibliographies have been provided.

Further Reading. These are articles that further describe the research on health literacy. Some of these articles provide a more detailed background for the must read articles, while others help to give a different perspective on issues of health literacy.

Books and Reports. This includes some of the most pertinent technical reports and books on health literacy so the user can further research and delineate major issues and problems.
Section III. Considerations
This section includes a brief overview of the implications of health literacy discussed in the background. Included are a few recommendations and things to think about when making changes to the literacy environment.

Section IV. Tools and Resources
This section provides a listing and description of toolkits, guides, websites, trainings and other resources that you can use to help continue making changes to the literacy environment. In addition, the current readability and health literacy tools are presented and described, including where they can be purchased or obtained. Finally, a section of internet resources and other resources for consumers is presented to illustrate locations for easy-to-read health materials on a number of different health topics.

Conclusion:
We hope that this guide provides the user with a “one stop shopping” experience. As our nation ages and demographically changes, it becomes even more important to address health literacy and understand its impact on the public. We hope that the guide encourages you to begin thinking about, or rethinking, how health literacy can be approached in your own setting and that the resources provided help you develop literacy appropriate materials to ensure all people can access the healthcare and health information they need and deserve.

References:


II. Background

What is Health Literacy and What is the Extent of the Problem?

The National Literacy Act of 1991 defined literacy as “an individual’s ability to read, write and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society, to achieve one’s goals, and to develop one’s knowledge and potential” (1991). Low literacy, however, is common in the United States. It is estimated that the majority of U.S. adults read below the 11th grade level, with fully 46% reading below the 7th grade level (Kirsch, 2001).

Health literacy is further defined as the ability of an individual to have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions (Ratzan & Parker, 2000). According to estimates from the 2003 National Adult Literacy Survey, 90 million people, nearly half of all American adults, have difficulty understanding and acting on health information (Kirsch, 2001; Kirsch et al., 2002) given to them by their doctors, in decision aids developed by public health educators or even the direction labels on their medications. As healthcare and avenues to deliver health information have become more sophisticated, using technology not thought imaginable even a decade ago, the health consumer is asked to keep up and assume new roles. For example, he/she must be able to maneuver the Internet to find health information, use phone commands to request prescriptions, use computer touch-screens to find where to go in the hospital, sign informed consent forms filled with medical jargon about procedures and, ultimately, make complex decisions about the treatment of disease or about undergoing screening tests and procedures.

Unfortunately, the majority of the American public is unable to understand or have the skills necessary to complete these tasks. More than 47% of adults, in fact, have difficulty locating, matching and integrating information in written texts with accuracy and consistency (Kirsch, 2001; Kirsch et al., 2002). While many of these adults may be able to perform simple and routine tasks using uncomplicated materials, most would find it very difficult to perform tasks or make a decision when other distracting information and complex text is present. Unfortunately, accessing healthcare and health information in the 21st century has become very complex, which has serious implications for the health sector. The Institute of Medicine (2004), in its report, “Health Literacy: A Prescription to End Confusion”, states that over 300 studies have been conducted over the past 30 years assessing various health-related materials, such as informed consent forms and medication package inserts and that the majority of these studies have shown that the reading skills of the intended audience did not match the level of the materials. In fact, most of the assessed materials exceeded the reading skills of the average high school graduate (IOM, 2004; Rudd et al., 2000). This is despite studies that indicate that even people with college degrees prefer medical information written at the 7th grade level (Davis, Crouch, Willis et al., 1990). In addition, over 600 studies have been conducted since 1980 to assess the relationship between low literacy and health outcomes (Berkman et al., 2004), most of which have shown a positive relationship between low literacy and adverse health outcomes.
For many years, it has been accepted knowledge that health disparities are more profound in those with the lowest levels of education (Pincus, Callahan & Burkhauser, 1987; Villaire & Mayer, 2007). And while the correlation between years of education and literacy is imperfect, there is a significant relationship that indicates that those with low health literacy (as measured by current measures such as the TOFHLA – Test of Functional Health Literacy in Adults), despite their level of education, also have poor health outcomes (Parker, Baker & Williams, 1995).

According to a systematic review by the Agency for Healthcare Research and Quality (Berkman et al., 2004), low literacy is positively associated with the increased incidence of chronic illness, poorer disease markers, low levels of health knowledge and low use of preventive health services. For example, a number of studies have indicated that patients with limited health literacy who also have chronic illness such as diabetes or heart disease have less knowledge of illness management and have worse health outcomes compared to those with higher health literacy (Cohen, Vittinghoff & Whooley, 2008; Knight et al., 2007; Kalichman et al., 2000; Schillinger et al., 2002; Williams et al., 1998).

There is also evidence that those with low health literacy do not participate in decision-making with their healthcare providers at the same level as those with higher literacy. This has been seen in a number of health-protective behaviors, such as cancer screening (Reyes-Ortiz et al., 2007; Kim et al., 2001; Scott et al., 2002), as well as STD screening (Fortenberry et al., 2001) and immunization (Scott et al., 2002). This relationship has also been documented in a number of health behaviors that are related to negative health outcomes, such as smoking (Hawthorne, 1996; Arnold et al., 2001; Fredrickson, et al., 1995), alcohol use (Hawthorne et al., 1996), and not breast feeding (Kaufman et al., 2001; Fredrickson et al., 1995), as well as adherence to treatment protocols in diseased populations, such as those with asthma (Williams et al., 1998), HIV (Paasche-Orlow et al., 2006; Golin et al., 2002; Kalichman et al., 1999; Miller, 2003), breast cancer (Li et al., 2000), and cardiovascular disease/stroke (Smith et al., 2006; Lasater, 2003; Win & Schillinger, 2003).

Health literacy’s relationship to negative biochemical or biometric health measures has also been observed. For example, a number of studies have shown that those with diabetes who also have low health literacy have elevated glycemic levels (Ross et al., 2001; Williams et al., 1998) and diabetes complications (Schillinger et al., 2006; Schillinger et al., 2002). Similar studies have shown those with hypertension (Battersby et al., 1993; Williams et al., 1998), HIV (Kalichman & Rompa, 2000; Kalichman, Benotsch & Suarez, 2000) and cancer (Hahn et al., 2007) have documented worse control and health outcomes in those with low health literacy.

Finally, health literacy also has been shown to have a profound effect on the use of health care services, which mitigates many of the negative health outcomes discussed above. For example, many studies have documented the relationship between literacy levels and knowledge of the use of health care services, including knowledge about preventive health services (Pippens, Algeria & Haas, 2007; Davis et al., 1996; Lindau et al., 2002; Moon et al., 1998; TenHave, 1997), understanding of informed consent and advance directives.
(Sudore et al., 2007; Woloshin, Schwartz & Welch, 2007; Miller et al., 1996), hospital discharge papers (Spandorker et al., 1995) or medication dosing instructions (Yin et al., 2007). Those with low health literacy have also been found to have more hospitalizations (Baker et al., 1998; Baker et al., 2002). This obviously can have significant financial consequences. One study by Weiss and Palmer (2004) showed that a sample of Medicaid patients in Arizona who had reading levels at or below the third grade had mean Medicaid charges $7500 higher than those who read above the third grade level.

How is Health Literacy Measured?

Because health literacy refers to an individual’s facility with or knowledge about health related issues, there are a number of validated tools that most researchers have used to assess literacy levels in populations. Instruments most commonly used to measure health literacy include the Wide Range Achievement Test (WRAT) reading subtest (Wide Range Inc., 1993), the Rapid Estimate of Adult Literacy in Medicine (REALM) (Davis et al., 1993) and the Test of Functional Health Literacy in Adults (TOFHLA) (Parker et al., 1995). The newest instrument, currently being tested for validity and reliability, is the Newest Vital Sign (NVS) (Weiss et al., 2005).

The WRAT and REALM are word recognition tests that assess whether an individual can correctly pronounce a series of words listed in order of increasing difficulty. Both instruments have been validated as instruments of reading ability and are highly correlated (Davis et al., 1993). The REALM is more specific to healthcare, however, and uses words that are commonly seen in healthcare directions or in the health care setting, such as “pill” or “allergic”. A high correlation (r=.88) between the WRAT and REALM, however, indicates that the information tested by the instruments is not substantially different. The WRAT takes approximately 10 minutes to administer; the REALM just 1-2 minutes.

The TOFHLA, its shorter version called the S-TOFHLA, and the NVS, take a different approach to assess health literacy. In the TOFHLA and S-TOFHLA, subjects read passages in which every fifth to seventh word has been deleted and there is a blank space; subjects are then asked to insert the correct word from a choice of four (Parker et al., 1995). In addition, the longer version of the test has subjects respond to prompts, such as pill bottle instructions and appointment slips, in an attempt to measure the subject’s ability to use basic numerical information. TOFHLA scores range from 1 to 100 with higher scores indicating better health literacy. Scores of less than 60 represent inadequate literacy and 60 to 74 represent marginal literacy. The TOFHLA is highly correlated to the REALM (r=.84) and the WRAT (r=.74) (Parker et al., 1995). The TOFHLA takes more than 20 minutes to administer; the S-TOFHLA approximately 5 to 10 minutes.
NVS is similar to the TOFHLA in that it attempts to assess both reading and numeracy skills. The instrument uses a nutrition label and asks six questions related to the label (Weiss et al., 2005). A score of less than 4 correct questions indicates the subject is at risk for limited health literacy. How the NVS’s accuracy compares to the other, more established measures, however, is still being tested. Current research indicates the NSV has a lower correlation with the TOFHLA than the other tests (r=.49), but it does seem to have a higher sensitivity than the other tests in identifying those with marginal health literacy (Weiss et al., 2005; Osborn et al., 2007). It has, however, been found to be less effective than the S-TOFHLA for predicting health outcomes (Osborn et al., 2007). The NVS takes approximately 3 minutes to administer.

It should be noted that none of these measures may accurately evaluate a person’s “health literacy” when discussed in the specific context of a health problem. For example, because these measures essentially assess reading ability, a person who reads at a high school level but knows nothing about a particular disease, such as diabetes, may be much more likely to score higher on these measures compared to a person who reads at a lower level but who has diabetes. Because of the experience of having diabetes, these patients may be well versed on how to perform effective self-care and thus are highly “health literate” in that particular context. Currently, no instrument adequately addresses this more global concept of health literacy (Berkman et al., 2004).

Addressing health literacy issues is the responsibility of a number of people and organizations. Those providing healthcare services are certainly at the forefront of dealing with patients and effective communication is one of the most important aspects of a beneficial patient-provider relationship. Health literacy is also the responsibility, however, of healthcare policymakers, insurance companies, accreditation and regulatory bodies, the public health system and even the consumers themselves.

In the end, no matter how many billions of dollars are spent for healthcare in the United States every year, if access to good care is unevenly distributed, the entire country suffers, whether it’s from lost wages, lost days of life or overall quality of life. As Rudd, Kirsch and Yamamoto (2004) point out, however, the United States’ overall performance in addressing health literacy and health disparities is mediocre at best and we are in fact one of the leaders in the degree of inequality between those with the highest and lowest rates of literacy. This inequality, it could be argued, is in proportion with the degree of health disparity between groups in the U.S. The poor, ethnic minorities, those who speak English as a second language, the elderly and those from rural areas of the country are all more likely to suffer from chronic diseases, have poorer health outcomes and participate in negative health behaviors such as cigarette and alcohol use. These populations are also more likely to be most at risk for health illiteracy. Thus, literacy is an important issue if we are to address the disparity in health that also occurs.

This link between literacy and health outcomes seems to now be on the national
agenda. As evidenced in this background, a number of researchers are now trying not only to understand how health literacy affects health and healthcare access, but also trying to develop tools and strategies to address this correlation. While most health related materials are still written at literacy levels above those of most Americans, inroads are being made as healthcare and public health institutions become aware of the problem and change information, policies and procedures to ensure understanding of a broader swath of people. It is our hope that this guide will help provide the resources and strategies to help continue making changes so that in the end, all people are able to make informed decisions about their health.

References


Davis, T.C., Arnold, C., Berkel, H.J., et al. (1996). Knowledge and attitude on


Pincus, T., Calahan, L.F., & Burkhauer, R.V. (1987). Most chronic diseases are reported more frequently by individuals with fewer than 12 years of formal education in the age 18-64 United States population. *Journal of Chronic Disease, 40*(9), 865-74.


In this section of the guide you will find articles and reviews as well as books and reports to help you better understand the issues health literacy has brought about. All of the resources in this section have been carefully selected and will make your understanding of health literacy even greater. Below are the sections that they have been broken into.

**Must Read Articles**
The articles include those that have been recently published, report experimental trials, or have been cited several times in the literature. Annotated bibliographies have been provided.

**Further Reading**
These are articles to help further describe the research on health literacy. Some of these articles provide a more detailed background for the must read articles, while others help to give a different perspective assessing the literacy environment.

**Books and Reports**
We have included some of the most pertinent technical reports and books on health literacy so the user can further research and delineate major issues and problems.

“Research shows that an increased organizational awareness to health literacy has an impact on patients’ learning and compliance, patient safety and access to care.”

This article explores the relationship of literacy with culture and language and how they intersect. The authors explore results from the 2003 NAAL and conclude that strategies to improve health literacy for low literate individuals are distinct from strategies for individuals who are culturally diverse or have limited English proficiency. This lack of integration, it is argued, results in unresponsive health care to the needs of vulnerable groups. The authors then present a vision for integrated care.


This article discusses the meaning of health literacy, the current measures of health literacy and questions whether the current measures used in current research are really measuring what should be measured. The author discusses different types of literacy (oral, print) and how issues such as individual capacity, prior knowledge, complexity and difficulty of messages and cultural factors can all affect measuring actual literacy level. The author then discusses the current measures, what measures are still in need of development and calls for the need for more research to understand the gap between capacities and current demands to educate the public about health.


This article is a meta-analysis to review the relationship between literacy and health outcomes. Using studies found in a systematic search of the literature from 1980 to 2003, the authors reviewed 73 articles that met inclusion criteria. Results show that patients with low literacy had poorer health outcomes, including knowledge, intermediate disease markers, measures of morbidity, general health status, and use of health resources. Patients with low literacy were generally 1.5 to 3 times more likely to experience a given poor outcome. The authors point out, however, that the average quality of the articles was fair to good, with most studies cross-sectional in design and many failing to address confounding variables adequately. The authors conclude that while low literacy does seem to be associated with several adverse health outcomes, future research, using more rigorous methods, will better define these relationships and guide developers of new interventions.


Health numeracy has often been overshadowed by health literacy, either ignored completely or identified simply as a subset of health literacy. Only now are researchers beginning to realize the importance of health numeracy as a
separate entity. One of the first steps in this evolution is to establish a distinct definition for health numeracy, something that has not been addressed in the literature to date. This paper proposes such a definition, as well as a set of clarifying categories in hopes of helping researchers both to advance the field of health numeracy and to focus their topics within the realm of health numeracy.


This article assesses the effects of pictures on health communications, based on a systematic literature review. The authors found that pictures closely linked to written or spoken text can, when compared to text only, markedly increase attention to and recall of health education information. They also found that all patients can benefit, but patients with low literacy skills are especially likely to benefit when pictures are used. The authors conclude that health educators should: (1) ask "how can I use pictures to support key points?", (2) minimize distracting details in pictures, (3) use simple language in conjunction with pictures, (4) closely link pictures to text and/or captions, (5) include people from the intended audience in designing pictures, (6) have health professionals plan the pictures, not artists, and (7) evaluate pictures' effects by comparing response to materials with and without pictures.


This article aims to provide an evidence-based review of plausible causal pathways that best explain associations between limited health literacy and negative health outcomes. The authors review the current literature to derive a causal model, showing that health literacy should be viewed as both a patient and system phenomenon. The authors then suggest three points on a continuum of healthcare that health literacy intersects: (1) access and utilization of healthcare, (2) patient-provider relationships and (3) self-care.


This article outlines the findings from the Educational Testing Service’s report that predicts that the U.S. is at great risk as a result of declining adult literacy, shifting demographics and a changing economy. They describe what a formative public health response should include, including seeking out new strategies for health systems to increase health literacy and strengthening the educational system to better equip younger generations with knowledge and skills to navigate health care.

This article examines adults’ literacy in multiple health contexts. It presents results of 191 health-related items drawn from all large-scale adult literacy surveys before 2003. Authors present results that show which demographic variables are associated with lower health literacy skills. They conclude that the distribution of health literacy is not independent of general literacy skills at population or subpopulation levels.


This article discusses how limited access to public health information certainly curtails knowledge and awareness but may also hamper action and civic involvement. A growth in published assessments of health materials indicates an increased interest in the mismatch between the reading level of most health materials and the reading ability of the average adult. However, while several guide books offer suggestions for developing new materials, little attention has been given to the process of rewriting materials and grappling with bureaucratic language. The authors thus describe a process to assess and then rewrite a federally mandated report to consumers about the quality of their water to illustrate how public health information can successfully be rewritten to address the needs of all people.


This article discusses how the prevalence of limited literacy and limited health literacy skills among adults creates a major policy challenge on how to create text-based health information that is accessible to the public. The authors argue that “Plain Language” is a logical, flexible response, however adoption and promotion of plain language standards and skills in health-focused organizations have lagged. The article discusses barriers to more rapid diffusion of plain language, including myths perpetuated by critics. These myths are refuted. The article concludes that while plain language is only one of many broad-based solutions needed to address low health literacy, the benefits to everyone demand increased use by health organizations.


   ![Image](http://www.ets.org/research/pic)

   This report provides an overview of current knowledge about the state of literacy and health literacy in the U.S. as well as a demographic picture of who is most at risk for low literacy. The report also discusses lapses in the research and what should be done next to ensure all populations have access to appropriate health information.


   ![Image](http://www.hsph.harvard.edu/healthliteracy/doak.html)

   A sentinel book that discusses how to develop effective health communication materials for patients with low literacy. It is currently out of print but can be accessed via the above website.


   ![Image](http://www.nci.nih.gov/pinkbook)

   One of the first comprehensive guides to creating effective health communication messages and programs, this book is still a valuable document that provides clear suggestions and templates for producing readable, culturally appropriate and effective messages for all populations.


   ![Image](http://nces.ed.gov/naal)

   These reports outline findings from the National Assessment of Adult Literacy surveys and are the basis for much health literacy work and focus. Each report has a slightly different focus. You can find past reports on the “archives” tab.
5. **The Joint Commission.** *What did the doctor say? Improving health literacy to protect patient safety.*


This report was developed to help clinicians and hospitals better improve communication, from the exam room to the waiting room, for low literacy patients.


Available at: [http://www.ncsall.net/?id=522](http://www.ncsall.net/?id=522)

This important chapter examines the medical and public health literature regarding links between health and literacy and identifies trends in research and practice. The authors also call for more research on the relationship between levels of health literacy and health outcomes, the intermediate factors that influence health outcomes, and health care costs. They stress the need for continued efforts to develop strategies to address the special needs of those with low health literacy. The authors close by describing some exemplary projects that illustrate the potential for effective collaboration between professionals in education and health in seeking to meet the needs of less literate populations.


This book, aimed at news reporters, provides information needed to understand, analyze and explain statistics in health science and related areas. It can also help those developing materials strategies to explain statistics and concepts such as risk and probability to a low literacy population.


This comprehensive assessment report presents an exhaustive review of all published studies on health literacy through 2003. It reviews and synthesizes the research so the reader is able to see what the research tells us about health literacy and its relationship to health outcomes, healthcare accessibility and a number of health disparities.


This book is a comprehensive look at the issue of health literacy, including its origins, consequences and solutions. It provides excellent depth to understanding the problem and how it effects health and healthcare in the United States.


This book focuses on effective communication between patients and providers. Osborne focuses on providing practical suggestions to health providers who communicate health information. She discusses how to communicate with patients with special needs, effectively understand culture and language, how to use photographs, plain language, signs and stories when communicating, as well as website design and effective word choice.


This book addresses the crisis in health literacy in the United States and around the world, examining the critical role of literacy in public health and outlining a practical, effective model that bridges the gap between health education, health promotion, and health communication using a public health perspective. This comprehensive resource includes the history of health literacy, theoretical foundations of health and language literacy, the role of the media, and a series of case studies on important topics including prenatal care, anthrax, HIV/AIDS, genomics, and diabetes. The book concludes with a series of practical guidelines for the development and assessment of health communications materials.


This comprehensive book on health literacy research seeks to improve understanding of health literacy and stimulate research focused on reducing or eliminating the literacy barrier to effective medical diagnosis and treatment.

Available at: [http://www.etsliteracy.com/Media/Research/pdf/PICSTORM.pdf](http://www.etsliteracy.com/Media/Research/pdf/PICSTORM.pdf)

This report, while not specifically about health literacy, discusses three forces that will severely impact the American population. These forces (divergent skill distribution among U.S. population groups, a changing economy, and demographic trends of a growing, more diverse population), they argue, will impact the nation in the next 25 years. Literacy is discussed as a consequence of these forces, putting the nation at risk. The report is an important complement to the more practical health literacy guides, in that it helps place the context of literacy in a large societal picture.
IV. Considerations

The background section of this guide has provided you with information about the role health literacy plays in health outcomes. More than other factors such as age, socioeconomic status, education level, and racial or ethnic group, health literacy is the strongest predictor of an individual’s health status. This section will provide a short summary of some steps you can take when making changes to the literacy environment of your organization.

Education

Education and awareness play an important role in effecting change to the literacy environment within an organization. This guide provides a number of tools to help prepare you for this step. Providing education and tools to staff through guest speakers, trainings and seminars on health literacy, are all ways to begin implementing change.

Research indicates that increased awareness of and sensitivity to health literacy can enhance learning, increase appointment keeping and compliance with regimens, improve patient safety, remove access barriers, and reduce costs (Rudd, 2006). Getting buy-in from your organization or a champion that can help facilitate change is important.

Another important consideration in making changes to the literacy environment is to look at the policies of your program or organization. You may need to make changes to policies or procedures before you are able to make organizational changes.

Assessment

Assessing the literacy environment includes looking at different areas of your organization. Two important considerations are communication (print, oral and web), and navigation, or the physical environment (including maps, signs, etc.). This guide offers different tools to help facilitate this process. For looking at print communication a number of readability tools are listed such as the SMOG readability formula. For assessing the whole literacy environment, refer to Dr. Rima Rudd’s tool, “The health literacy environment of hospitals and health centers. Partners for Action: Making your healthcare facility literacy friendly.” There are also health literacy assessment tools that can help you assess the health literacy level of the patients or clients that you serve, such as the TOFHLA or Newest Vital Sign.

The purpose of this guide has been to show you different resources available to help you examine your literacy environment. These tools should help you be more aware of the materials you provide, the language you use, or the overall health literacy environment you create for populations you may be working with.

References

V. Tools and Resources

Toolkits and Guides
All resources are current as of July, 2008


   Available at: [Link]
   Cost: $35 but DVDs can be viewed free of charge at: [Link].

   This provides a kit that includes two DVDs, a manual and other tools that could be used in a clinician’s office. The kit provides suggestions for clinicians to help their patients, including offering an open and shame-free environment, having an attitude of helpfulness and providing a place where patients feel safe and comfortable to ask questions.


   Available at: [Link]

   This guide is meant to help simplify complicated medical and scientific information put out by CDC in easy-to-read, accessible information for the public. Helps the reader learn how to effectively translate information and provides examples to follow.

3. Center for Health Care Strategies, Inc.
   Health literacy fact sheets, 1-9.

   Available at: [Link]

   These easy-to-use fact sheets cover the range of topics, from “what is health literacy” to preparing health education materials. All nine fact sheets are easily downloaded from the Center’s website and provide a good place to start with developing or revising materials.


   Available at: [Link]

   This guide gives health care providers information on how to select, write, and design health communications materials that will meet the needs of their patients, regardless of their health literacy level.

Available at: http://healthliteracy.worlded.org/docs/family/fhl.pdf

This guide is geared towards educators in health or community based organizations on how to incorporate easy-to-read materials in curricula with families and children. Includes materials, templates and sample lesson plans.


Available at: http://cancer.gov/aboutnci/oc/clear-and-simple/allpages

This guide is one of the first to address developing materials for a low-literacy population. Taking a marketing approach, this guide helps the reader understand how to pilot and test messages in populations to ensure understanding and appropriateness.


Available at: http://cccm.thinkculturalhealth.org/

This guide includes cultural competency curriculum modules designed to equip family physicians with awareness, knowledge and skills in cultural competency to better treat the increasingly diverse U.S. population.

8. Plain Language.gov. Plain Language: Improving communication from the federal government to the public.

Available at: http://www.plainlanguage.gov/howto.

This guide is designed to improve communication from the federal government to the public. The report contains excellent tools and examples of plain language, and provides a “how to” section for providers to re-write materials for low literacy users.


Available at: http://library.nymc.edu/PHInformatics/hltoolkit.cfm.

This toolkit is from a conference held May 30, 2007 at New York Medical College. The goal was to provide health professionals and hospital staff an opportunity to develop awareness of health literacy issues. The toolkit offers links to websites that promote health literacy skills.

Available at: www.ncsall.net and www.hsph.harvard.edu/healthliteracy.

This guide is geared specifically for hospitals and health centers to help them assess the accessibility of their institutions to all populations. This includes not only written materials but signage, policies and protocols, and websites. The guide has step-by-step instructions that institutions can take to make themselves more accessible to low-literacy populations.


Available at: www.ncsall.net.

This guide provides suggestions and materials for the development and implementation of a Health Literacy Forum to be coordinated by a local, county, or state Department of Public Health. It provides step-by-step instructions for public health departments just as the “Health Literacy Environment of Hospitals and Health Centers” guide did for hospitals and health centers.


Available at: http://www.valrc.org/

This guide provides suggestions and materials for the development and implementation of a Health Literacy Forum to be coordinated by a local, county, or state Department of Public Health. It provides step-by-step instructions for public health departments just as the “Health Literacy Environment of Hospitals and Health Centers” guide did for hospitals and health centers.


Available at: http://coveringkidsandfamilies.org/resources/docs/stylemanual.pdf

This booklet has suggestions for developing and improving print materials related to government programs. Strategies include writing and formatting specifically for clients, many of whom have limited literacy skills.

Available at: http://www.health.gov/communication/literacy/quickguide/Quickguide.pdf.

This guide contains a basic overview of key health literacy concepts and techniques for improving health literacy through communication, navigation, knowledge-building and advocacy. It provides the information needed to become an effective advocate for improved health literacy.


This bibliography covers information on health literacy primarily from online databases and the Internet.


Available at: http://www.nlm.nih.gov/medlineplus/etr.html

This report provides suggestions for writing comprehensive, easy-to-read materials for all populations.


Available at: http://healthliteracy.worlded.org/docs/comp/

This is a comprehensive resource guide on literacy. Includes not only resources around health but other issues such as law.
Websites

1. **Agency for Health Care Research and Quality. Health literacy and cultural competency.**

   **Sponsor:** U.S. Department of Health and Human Services  
   **URL:** [http://www.ahrq.gov/browse/hlitix.htm](http://www.ahrq.gov/browse/hlitix.htm)

   Online resources, consumer decision aids, clinical information and suggestions for improving healthcare delivery.

2. **Ask Me 3.**

   **Sponsor:** Pfizer Clear Health Communications  
   **URL:** [http://www.npsf.org/askme3/](http://www.npsf.org/askme3/)

   This website is for both consumers and providers to learn how to communicate with each other. Printable materials are available.

3. **Harvard School of Public Health. Health Literacy Studies.**

   **URL:** [http://www.hsph.harvard.edu/healthliteracy/index.html](http://www.hsph.harvard.edu/healthliteracy/index.html)

   Resources include a slide presentation, video and visual displays about health literacy, and available literature and information on how to create and access print materials.

4. **Health and Literacy Special Collection.**

   **Sponsor:** World Education with support from the National Institute for Literacy  
   **URL:** [http://healthliteracy.worlded.org](http://healthliteracy.worlded.org)

   Information includes sample health lessons, easy-to-read materials, multilingual health information and health literacy research. Can be used by both consumers and professionals.

5. **Health Resources and Services Administration.**

   **Sponsor:** U.S. Department of Health and Human Services  
   **URL:** [www.hrsa.gov/servicedelivery/language.htm](http://www.hrsa.gov/servicedelivery/language.htm)

   This website gives directions for creating more readable HIPAA privacy notices.


   **Sponsor:** National Library of Medicine  
   **URL:** [http://nnlm.gov/outreach/consumer/hlthlit.html](http://nnlm.gov/outreach/consumer/hlthlit.html)

   This website defines health literacy, lists health literacy organizations and websites and provides access to a number of resources.

7. **NIFL-HEALTH listserv.**

   **Sponsor:** National Institute for Literacy  
   **To subscribe go to:** [http://www.nifl.gov/mailman/listinfo/healthliteracy](http://www.nifl.gov/mailman/listinfo/healthliteracy)

   Fill out the form and click on the ‘subscribe’ button at bottom of the form.

   This is a listserv for health educators, literacy providers, clinical providers, researchers, policy developers and others interested in exploring links between health and literacy issues.
8. **NIFL-HEALTH listserv.**

   **Sponsor:** National Institute for Literacy  
   To subscribe go to: [http://www.nifl.gov/mailman/listinfo/healthliteracy](http://www.nifl.gov/mailman/listinfo/healthliteracy). Fill out the form and click on the ‘subscribe’ button at bottom of the form.

   This is a listserv for health educators, literacy providers, clinical providers, researchers, policy developers and others interested in exploring links between health and literacy issues.


   **Sponsor:** Plain Language Action and Information Network (PLAIN)  
   **URL:** [http://www.plainlanguage.gov/populartopics/health_literacy/index.cfm](http://www.plainlanguage.gov/populartopics/health_literacy/index.cfm)

   This site was created to promote the use of ‘plain language’ in all government communications. Site provides resources to help put text into plain language. Sponsored by the National Center for Education Statistics, the 2003 National Assessment of Adult Literacy (NAAL) is a nationally representative assessment of English literacy among American adults over 14. Webcasts are available on such topics as addressing low literacy and defining the goals and research behind the NAAL.

10. **Usability.gov.**

    **Sponsor:** U.S. Department of Health and Human Services  
    **URL:** [http://www.usability.gov](http://www.usability.gov)

   This website is a good resource to use when developing websites. It helps identify what a usable, useful and accessible website should look like. It contains information, guidelines and checklists for conducting usability testing and user-centered design.
Presentations and Trainings


Available at:

Sponsored by the National Center for Education Statistics, the 2003 National Assessment of Adult Literacy (NAAL) is a nationally representative assessment of English literacy among American adults over 14. Webcasts are available on such topics as addressing low literacy and defining the goals and research behind the NAAL.


Available at:

Stableford focuses on the need for plain language and argues that health literacy is critical to lowering health disparities. Using real world examples, she helps the student understand the importance of writing clearly and utilizing layout and design for reading ease.


Available at:

This CD helps the user critique, rewrite and create materials that get health and wellness information across quickly and clearly. The user is also provided with brochures, examples, SMOG and REALM tests, a webliography and links to other trainings.


Available at:

This online tutorial is designed for health and literacy educators interested in getting more involved in health literacy work. Users learn about the challenges associated with low health literacy, meet some of the new health literacy practitioners in the field, hear about successful strategies and practices and apply what they have learned to a challenging health literacy scenario. The tutorial was developed by World Education and funded by the National Network of Libraries of Medicine New England Region.
Health Literacy Assessment Tools

1. **WRAT-R – Wide Range Achievement Test Revised**

   Available at: [www.addwarehouse.com](http://www.addwarehouse.com) or [http://www.hsrdr.search.va.gov/for_researchers/measurement/instrument/overviews/co_literacy.cfm](http://www.hsrdr.search.va.gov/for_researchers/measurement/instrument/overviews/co_literacy.cfm)

   The WRAT offers two equivalent alternate test forms, to be used individually or in combination, for comprehensive test results. It can be used for persons aged 5 to 75 years. It assesses skills in reading, spelling and arithmetic. In health settings, the person reads aloud from a list of words. When 10 consecutive words are mispronounced, the test concludes and a score is calculated. Standard scores and percentiles compare individual performance with that of others of the same age or can be converted to a grade equivalent score. Takes approximately 10 minutes to administer.

2. **REALM – Rapid Estimate of Adult Literacy in Medicine**


   The REALM is designed to be used in public health and primary care settings to identify patients with low reading levels. It provides reading estimates for patients who read below a ninth grade level. It is a medical word recognition and pronunciation test arranged in order of complexity by the number of syllables and pronunciation difficulty. Patients read down the list, pronouncing aloud as many words as they can. They then are scored according to how many words they can pronounce correctly and put into one of four categories that approximately grade level. It takes approximately 1-2 minutes to administer. The entire REALM sample kit (instruction manual, laminated patient word lists, scoring sheets) is available for purchase from Terry C. Davis, PhD (LSU Medical Center, 1501 Kings Highway, Shreveport, LA 71130-3932, tdavis1@lsuhsc.edu).


   Funded by: The Robert Wood Johnson Foundation

   Available at: [http://www.peppercornbooks.com/](http://www.peppercornbooks.com/)

   Cost: $50.

The TOFHLA is used to measure functional health literacy, both numeracy and reading comprehension, using real health-related materials, including patient education, prescription bottle labels, registration forms and instructions for diagnostic tests. Users are classified by their ability to read and interpret health texts. The form is available in both Spanish (TOFHLA-S) and English.
and takes approximately 20 to 25 minutes to administer.

4. **S-TOFHLA – Short Form Test of Functional Health Literacy in Adults (see above)**

See TOFHLA for purchase information.

The S-TOFHLA is the short form of the TOFHLA that only uses two reading comprehension passages. It takes approximately 5 to 10 minutes to administer.

5. **The Newest Vital Sign (NVS)**

**Sponsor:** Pfizer Clear Health Communication  
**Available at:**  

The NVS is a test of numeracy. This test has 6 items and tests the ability to read and comprehend information on a nutrition fact label.

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### Readability Tools

1. **(plain•word)™**

   **Available at:**  

   Developed by the Canadian Public Health Association’s National Literacy and Health Program, this tool provides an interactive way to replace a “hard” word with a “plain word”. The software program operates as a “game” and will provide users with words or phrases that can be used in low-literacy materials.

2. **SMOG: A readability assessment tool**

   **Available at:**  
   [http://www.harrymclaughlin.com/SMOG.htm](http://www.harrymclaughlin.com/SMOG.htm)

   The SMOG is a useful tool for doing quick reading level assessments of written materials. It takes into consideration (1) the total number of sentences, and (2) the number of words of three or more syllables. The more polysyllabic words there are in the text, the higher the reading level will be. Since SMOG readability formula aims for 100% comprehension, its grade level scores are usually higher than any of the other formulas, most of which target between 50% and 75% comprehension.
3. **Flesch-Kincaid Formula**

Similar to the SMOG formula, this index computes readability based on the average number of syllables per word and the average number of words per sentence. The score in this case indicates a grade-school level. For example, a score of 8.0 means that an eighth grader would understand the document. This formula can be used when using Microsoft Word through the spelling function. Its reading level scores are usually slightly lower than SMOG scores as they do not target for 100% comprehension.

4. **Fry Readability Graphs**

The Fry Readability Graphs provide a visual, quick way to assess the reading level of written materials. The grade reading level (or reading difficulty level) is calculated by the average number of sentences (y-axis) and syllables (x-axis) per hundred words. These averages are plotted onto a specific graph; the intersection of the average number of sentences and the average number of syllables determines the reading level of the content.

5. **SAM: A suitability of materials assessment tool**

Instead of testing reading level, the SAM addresses other important aspects of written materials such as organization, layout and design, as well as readability. It has also been adapted to be used with video and audio-taped instructions to patients. It is, however, a subjective instrument and it can sometimes be difficult to achieve consistent scoring with multiple reviewers. It uses 22 scoring factors looking at content, literacy demand, graphics, layout and typography, learning stimulation and motivation and cultural appropriateness.

6. **PMOSE/IKIRSCH:**

**A document literacy assessment tool**

The PMOSE / IKIRSCH is the first and only tool available to assess the difficulty of written documents, especially as it relates to charts and tables. It does not address readability level, vocabulary or complexity of phrases. It does, however, look at structure of text, number of labels and number of items that a reader has to interpret in the text. These factors are then used to calculate the complexity of a chart or table, with scores ranging from Level 1 (grade 4 reading level; equivalent to eight years or less of school) to Level 5 (range including 16 years or more of schooling).
Materials/Resources for Consumers


Sponsor: Federal Drug Administration
Available at: http://www.fda.gov/opacom/lowlit/7lowlit.html.

The FDA provides easy-to-read health brochures in English and Spanish. Brochures are available in both HTML and PDF formats and topics include keeping food safe, diabetes, losing weight safely, giving medications etc.


Sponsor: Medical Library Association
Available at: http://www.mlanet.org/resources/medspeak/index.html.

These brochures help consumers translate ‘medspeak’, the language health professionals use. Written in English and Spanish, these brochures address a variety of health topics, including HIV/AIDS, stroke, eye disease, heart disease, diabetes and breast cancer.

3. MedlinePlus Easy-to-Read

Sponsor: NIH and National Library of Medicine
Available at: http://www.nlm.nih.gov/medlineplus/easytoread_a.html

Medline Plus helps consumers find up-to-date, quality information about health topics, herbs and drugs. Information is available in English, Spanish and Easy-to-Read versions.

4. NIH Senior Health.

Sponsor: National Institute on Aging and the National Library of Medicine
Available at: http://nihseniorhealth.gov

This website has easy-to-read health information and videos for senior citizens on a variety of topics.


Sponsor: National Institute of Diabetes and Digestive and Kidney Diseases
Available at: http://diabetes.niddk.nih.gov/dm/ez.asp

These easy-to-read materials are written in English and Spanish. Topics include information about diabetes and how it relates to medication, physical activity and nutrition.

Sponsor:
American Academy of Family Pediatrics
Available at: http://www.aap.org/bst/showdetl.cfm?
&DID=15&Product_ID=4391&CatID+13

This website has easy-to-read information on a number of pediatric issues, including vaccination, SIDS and parenting.

7. What to Do Series…

Sponsor:
Institute for Healthcare Advancement
Available at: www.iha4health.org or call 1-800-434-4633.

This series includes five easy to read soft cover books in both English and Spanish. They include:
1. What to do when your child gets sick
2. What to do when you’re having a baby
3. What to do for teen health
4. What to do for senior health
5. What to do for healthy teeth.


Available at: www.Healthwise.org.
Cost: $10
Accurate, easy to read and use family guide to know how to treat common health and medical problems and when to call the doctor.


Available at: www.ProLiteracy.org

This website provides literacy reports and resources as well as easy to read health information for consumers.


Available at: http://www.cancer.gov/cancertopics/wtk/index

NCI provides access to 12 easy to read one page fact sheets about cancer, treatments and how to manage side effects.

11. Healthy Roads Media.

Available at: http://www.healthyroadsmedia.org

This site offers health information about a variety of topics in many languages and in both audio and printed formats.

**Sponsor:**
U.S. Department of Health and Human Services

**Available at:**
www.healthfinder.gov

This portal website provides access to health information created by all federal agencies. Consumers can search by topic and can also access the website in Spanish.

**Image References**

**Cover Page**

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**Page 4**

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**Page 9**

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**Page 11**

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**Page 15**

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**Page 16**

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**Page 24**

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