Measures of Health Literacy: Workshop Summary

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Lyla M. Hernandez, Rapporteur; Roundtable on Health Literacy; Institute of Medicine

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MEASURES OF HEALTH LITERACY

WORKSHOP SUMMARY

Lyla M. Hernandez, *Rapporteur*

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

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> *"Knowing is not enough; we must apply.*
> *Willing is not enough; we must do."*
> —Goethe

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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in memoriam

This workshop summary is dedicated to
Dr. Sabra Woolley,
an accomplished researcher and advocate in the field of
health communication, health literacy, and health disparities,
a valued sponsor and founding member of the
Roundtable on Health Literacy,
and an irreplaceable colleague and friend.

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The Roundtable wishes to express its appreciation to the expert speakers whose presentations illuminated the ongoing work in developing measures of health literacy. These speakers were Marin Allen, Lisa Chew, Carolyn Clancy, John DuMoulin, Julie Gazmararian, Elizabeth Hahn, Amresh Hanchate, Nicole Lurie, Kathleen Mazor, Lauren McCormack, Ruth Parker, Andrew Pleasant, Sandra Smith, Beverly Weidmer Ocampo, Barry Weiss, and Amy Wilson-Stronks.

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Introduction

Health literacy, "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 and Parker, 2000) is being increasingly recognized as important to health and health outcomes (Berkman et al., 2004). Although research on health literacy has grown tremendously in the past decade, both in terms of assessing the level of health literacy of individuals and examining the relationship of health literacy to various health outcomes, a concern is that there is no widely agreed-on framework for health literacy as a determinant of health outcomes. Furthermore, existing measures do not adequately capture the data that are necessary to understand how health literacy works to affect outcomes (Pleasant, 2009) and what can be done to improve health literacy.

The only national health literacy assessment tool is the National Assessment of Adult Literacy (NAAL) supplement conducted by the Department of Education in 2003. The NAAL identifies four levels of health literacy: below basic, basic, intermediate, and proficient.

Several other instruments are used for assessing the health literacy of individuals, including the frequently used Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA). One problem with these instruments, however, is that they largely measure reading ability or print literacy. This makes it difficult to differentiate between health literacy and basic literacy. Another difficulty is assessing health literacy of those with limited English proficiency. Several of the health literacy assessment tools discussed in the following report attempt to address this difficulty.

Population-based assessments of health literacy focus on the health literacy of populations rather than individuals. Two of these approaches, the Demographic Assessment of Health Literacy (DAHL) and a geomapping approach, are discussed in Chapter 4. The DAHL imputes limited health literacy from sociodemographic indicators and estimates the association of imputed limited health literacy with indicators of health status. The geomapping approach uses Census data and the NAAL data to map mean health literacy by Public Use Microdata Area.

However, most currently available instruments focus on assessing an individual's health literacy, yet health literacy is broader than an individual's skills and abilities. Health literacy occurs in the context of the health care system, and it is increasingly recognized that measures of health literacy must assess not only patients' skills and abilities, but also the demands and complexities of the health care systems with which patients interact. For example, measures are needed to determine how well the system has been organized so that it can be navigated by individuals with different levels of health literacy and how well health organizations are doing at making health information understandable and actionable.

The Institute of Medicine Roundtable on Health Literacy serves to educate the public, press, and policy makers regarding issues of health literacy. To examine what is known about measures of health literacy, the Roundtable convened a planning committee (see Appendix A) to develop a workshop agenda that would address the following issues:

- The current status of measures of health literacy, including those used in the health care setting;
- Possible surrogate measures that might be used to assess health literacy; and
- Ways in which health literacy measures can be used to assess patient-centered approaches to care.

The following pages summarize the workshop presentations and discussions. Chapter 2 presents an overview of the field of health literacy measurement, describing current measurement tools and their strengths and weaknesses, measurement needs, and proposed principles for developing health literacy measures. In Chapter 3 several new approaches to assessing health literacy are presented, including new measures of written and oral health literacy, a bilingual assessment of health literacy, self-report measures of health literacy, a functional approach to assessing health literacy, and an approach to measuring whether people understand what they hear. Chapter 4 explores two population-based approaches to assessing health literacy—the DAHL and geographic coding of health literacy. Chapter 5 explores health system responses to health literacy, including development of two new health literacy supplements to the Consumer Assessment of Healthcare Providers and Systems (CAHPS). Chapter 6 summarizes the presentation and discussion, which focused on reflections of the entire workshop as well as a vision for the future.

2

An Overview of Measures of Health Literacy

HEALTH LITERACY MEASUREMENT: MAPPING THE TERRAIN

Carolyn Clancy, M.D.
Agency for Healthcare Research and Quality

Several publications have raised awareness of the importance of health literacy to health and health care and have drawn attention to the need for measures of health literacy. For example, the Agency for Healthcare Research and Quality (AHRQ) supported a systematic review of evidence about the relationship of health literacy and health outcomes. That report found that adults with lower health literacy have worse health care and poorer health outcomes. It also found that well-conceived interventions can improve the outcome of knowledge for those with both higher and lower literacy levels (Berkman et al., 2004). At approximately the same time the AHRQ report was released, the Institute of Medicine (IOM) published a report of a study that assessed the problem of limited health literacy and considered next steps that should be taken in this field.[1]

In 2007, the AHRQ *National Healthcare Disparities Report* included, for the first time, findings on health literacy. These findings show that nearly

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[1] Among the findings of that report was that adults with limited health literacy "have less knowledge of disease management and of health-promoting behaviors, report poorer health status, and are less likely to use preventive services." Another finding was that health literacy measures are indicators of reading skills and that no current measures include oral communication or writing skills and "none measure the health literacy demands on individuals within different health contexts" (IOM, 2004).

9 out of 10 adults may lack the skills needed to manage their health and prevent disease. Hispanic adults were 4.5 times more likely than white adults to have below-basic health literacy, and African American, American Indian, and Alaskan Native adults were nearly 3 times more likely than white adults to have below-basic health literacy (AHRQ, 2007).

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 and Parker, 2000). This definition focuses on individual capability, although it does imply needed skills.

In the conceptual model shown in Figure 2-1, developed by Paasche-Orlow and Wolf (2007), health literacy, which is affected by socio-demographic characteristics as well as cognitive and physical abilities, is a determinant of health outcomes. As a determinant, health literacy affects a person's ability to access and use health care, to interact with providers, and to care for himself or herself. Health literacy measurement has generally followed this model, focusing on measuring an individual's capabili-

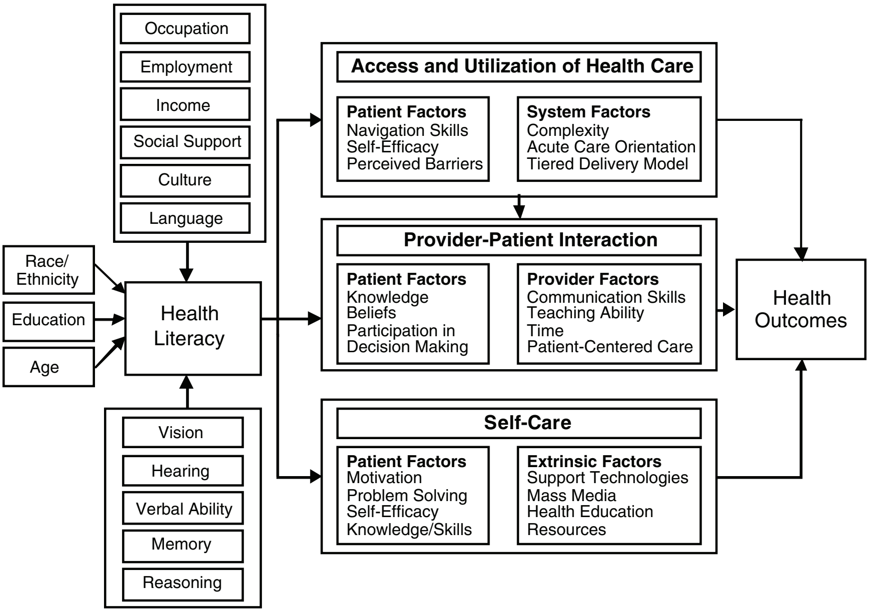

FIGURE 2-1 Causal pathways between limited health literacy and health outcomes.
SOURCE: Paasche-Orlow and Wolf, 2007. Reprinted by permission from PNG Publications, *American Journal of Health Behavior*, www.ajhb.org.

ties rather than actual skills and without reference to any interaction he or she may have with health information or the health care system.

Current Measurement Tools

The National Assessment of Adult Literacy (NAAL) was extremely important as the first national measure of literacy, providing systematic feedback to the education system and to the health care system about how literate American adults are. That feedback demonstrated that the level of information conveyed by these systems is not a good match with the abilities of most adults. The NAAL further identified substantial disparities associated with race and ethnicity, age, and insurance status.

While the NAAL provided an overall assessment of the level of literacy of American adults, various research measures have been used to establish the relationships among limited health literacy, health care, and health outcomes as well as the impact of interventions on individuals with limited health literacy. These measures include the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM). Researchers have used these measures to conduct studies that have shaped the field of health literacy. For example, as mentioned earlier, researchers found that those with lower health literacy have poorer health care and health outcomes (Berkman et al., 2004). Baker and colleagues (2007) used the TOFHLA to determine that inadequate health literacy independently predicts all-cause mortality and cardiovascular death among elderly persons and that health literacy is a more powerful variable than education.

In the clinical practice setting, clinicians commonly overestimate the health literacy of their patients (Ryan et al., 2008). Assessing the health literacy of a sample of patients can provide the clinician with information about his or her patients' average reading level, which then can be used as a guide in the selection and development of patient education materials. However, there is concern about universal testing. Some argue that such testing will alienate and stigmatize patients with limited health literacy. Others take the position that health care professionals must be aware of limitations in a patient's ability to read or understand instructions so that care can be tailored for each patient.

Measurement Needs

Several fundamental questions need to be answered when assessing the state of the art of health literacy measurement:

- How well do current approaches to measurement succeed in differentiating health literacy from literacy?
- How well do current measures capture an individual's ability to obtain, process, and use health information?
- Are these measures sensitive to health care and public health improvement efforts?
- Should disparities be included in the measures?

Baker (2006) developed a model that conceives of health literacy in the real world as a product of individuals' capabilities and the demands of health information messages delivered by the health care system (Figure 2-2). In this model, the health care sector shares responsibility for making sure that individuals can use health information effectively.

The Baker model highlights an important question for health literacy measurement: What is the role of the health system in addressing issues of low health literacy? The health system has a responsibility to communicate and identify the correct strategies for caring for patients. It must teach adults the health-specific knowledge they need to take care of themselves and to make decisions about their health care. The system must simplify written and spoken health communications, and it must be reengineered

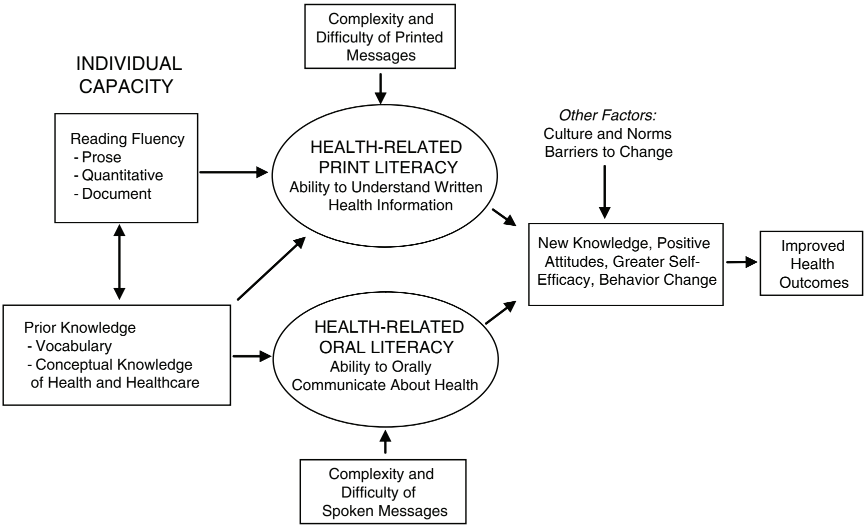

FIGURE 2-2 Conceptual model of the relationship among individual capacities, health-related print and oral literacy, and health outcomes.
SOURCE: Baker, 2006. Reprinted with kind permission from Springer Science + Business Media.

to reduce health literacy demands, from making the health system easy to navigate to making it easy to know how to avoid health risks and live a healthy lifestyle. Therefore, measures that would allow assessment of these responsibilities are key.

Yet if one thinks of health literacy as a determinant of health, then it is also important to improve individual capacity. To imagine that the problem of inadequate health literacy is solely a system problem ignores the fact that individuals engage with multiple systems in health care. Furthermore, efforts to improve health literacy have implications not only for solving patients' acute problems in delivery of care today, but also for anticipating difficulties that patients will have as they continue to traverse the health care system. In other words, for a patient with a chronic illness, limited health literacy is not only a problem now, but is also going to be a problem for nearly anything that happens later.

What, then, are the implications for health literacy measurement? Measures of health literacy must go beyond individual reading capability in order to capture how well Americans understand what they hear and what they are told. First, there is a need to measure the ability to use health information to attain and maintain good health. This includes assessment of the following factors:

- Oral understanding—how well individuals understand what they hear and what they have been told;
- Health knowledge—whether individuals have adequate knowledge about prevention, medication, and self-care; and
- Navigation skills—whether individuals are competent to access needed services, handle transitions, and find relevant information.

Second, health literacy measures need to guide quality improvement efforts. Such measures must be specific enough to provide information about the source of problems related to health literacy. They must also be sensitive enough to identify changes so that movement in the right direction can be detected. Third, measures are also needed to provide the information necessary to hold public and private health care organizations responsible for making health information understandable and actionable. No measures are currently available that can be used for accountability purposes. Finally, measures are needed that can be used with telephone surveys, thereby opening many research opportunities.

Promising Tools for Improving Health Literacy

There are promising approaches to improving health literacy. AHRQ and the National Heart, Lung, and Blood Institute funded a randomized trial at the Boston University Medical Center, Department of Family Medicine, that was designed to educate patients about their post-hospital care plans.[2] The program took about an hour of nursing time and about 30 minutes of pharmacy time. Results showed that patients assigned to the reengineered hospital discharge program (RED) had 30 percent fewer subsequent emergency visits and readmissions (Jack et al., 2009). Ongoing RED research is testing the automation of patient education through the use of an avatar. The challenge is integrating such programs into practice.

AHRQ is also testing several supplements to the ongoing Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys[3] that can be used to assess the health literacy friendliness of hospitals and physician practices. AHRQ has also developed some pharmacy literacy tools designed to help pharmacists better serve their low-health-literacy patients.[4] Another tool is a guide for developing and purchasing information technology that is accessible to populations with limited health literacy.[5] Finally, AHRQ has been working with the Ad Council to develop messages that inform individuals about what they can do to play a more active role in their own health and health care.[6]

Conclusion

Health literacy is not an individual problem, Clancy stated. It is a societal problem that should be addressed by making sure health information and services meet the needs of the public. To assess whether that is

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[2] The intervention included nurses working with in-hospital patients to make "follow-up appointments, confirm medication reconciliation, and conduct patient education with an individualized instruction booklet that was sent to their primary care provider. A clinical pharmacist called patients 2 to 4 days after discharge to reinforce the discharge plan and review medications. Participants and providers were not blinded to treatment assignment" (http://www.annals.org/cgi/content/abstract/150/3/178). Accessed April 5, 2009.

[3] "The Consumer Assessment of Healthcare Providers and Systems (CAHPS) program is a public-private initiative to develop standardized surveys of patients' experiences with ambulatory and facility-level care" (https://www.cahps.ahrq.gov/default.asp). Accessed April 5, 2009.

[4] Additional information can be found at http://www.ahrq.gov/qual/pillcard/pillcard.htm, http://www.ahrq.gov/qual/pharmlit/index.html, http://www.ahrq.gov/qual/pharmlit/pharmtrain.htm, and http://www.ahrq.gov/qual/callscript.htm.

[5] Additional information can be found at http://healthit.ahrq.gov/portal/server.pt?open=514&objID=5554&mode=2&holderDisplayURL=http://prodportallb.ahrq.gov:7087/publishedcontent/publish/communities/k_o/knowledge_library/features_archive/features/accessible_health_information_technology__it__for_populations_with_limited_literacy__a_guide_for_developers_and_purchasers_of_health_it.html.

[6] Additional information can be found at http://www.ahrq.gov/questionsaretheanswer/.

occurring requires accurate, meaningful health literacy measures. Characteristics of such measures are the following:

- The goals of every health literacy measure are very clear;
- Measures are developed in a way that enables movement upstream to levers of change;
- The system is responsive to specific literacy needs; and
- Measures provide information about quality or the "what to do."

Measuring health literacy is incredibly important. What must be done now is to identify the most practical and sensible way to move forward with developing and implementing important measures.

THE IMPORTANCE OF A NATIONAL DATASET FOR HEALTH LITERACY

Marin P. Allen, Ph.D.
Office of the Director, National Institutes of Health

Health Literacy: A Prescription to End Confusion (IOM, 2004) laid out the questions that have been raised in the field recently over the issue of how the needs and skills of the provider as well as the individual impact health literacy. That report stated, "Health literacy emerges when the expectations, preferences, and skills of individuals seeking health information and services *meet* the expectations, preferences, and skill of those providing information and services. Health literacy arises from a convergence of education, health services, and social and cultural factors. . . . Approaches to health literacy bring together research and practice from diverse fields" (IOM, 2004).

Increasing health literacy is one of the objectives of Healthy People 2010 (HP 2010), which is a multidecade national agenda for disease. The HP 2010 objectives provide a foundation for national research and action, including data collection. Currently, HP 2010 uses the NAAL assessment as its data source for information on health literacy. It is important to note that baseline and target data are expected for all objectives that will be included in the new Healthy People 2020. Without baseline and target data, there will be no objective.

Having the health literacy objective in HP 2010 has yielded several positive results. For example, there has been a Workshop on Improving Health Literacy organized by the Office of the Surgeon General, as well as Town Hall meetings on improving health literacy in several states including California, Missouri, and New York. There is a National Action Plan on Improving Health Literacy, and many professional societies (e.g., American Dental Association, American Academy of Pediatrics, American College of Physicians Foundation, and American Medical Association) have begun to focus on improving health literacy.

Additionally, a number of research efforts in health literacy have been funded in response to program announcements from the National Institutes of Health (NIH), AHRQ, and the Centers for Disease Control and Prevention. Sabra Woolley of the National Cancer Institute (NCI) and her postdoctoral student, Shaniece Charlemagne, examined NIH and AHRQ funding of health literacy and health disparities research. Interconnected health literacy and health disparities research funded through NIH and AHRQ grants is intended to involve health literacy as a key outcome, health literacy as a key explanatory variable for other outcomes, and prevention/intervention strategies that focus on health literacy. Woolley and Charlemagne found that more than half of the NIH and AHRQ grants primarily study the adult population. Race/ethnicity, gender, and special populations are more likely not to be specified within the abstract of grants funded. Of the grant abstracts that do specify population to be studied, African Americans, females, and low-literacy populations were the primary targets.

The NIH- and AHRQ-funded research projects are more likely to be supported through R01[7] and R03[8] funding mechanisms. Within the NIH and AHRQ, the NCI has provided more funding since 2006 to grants that address health literacy and health disparities than the other institutes and centers. Approximately 20 percent of the funded grants proposed use community-based participatory research or community-based research methods. However, only 6 percent of the abstracts identified a measurement methodology. In addition, special interest areas that have been funded primarily are "Cancer" and "Other" interest areas (i.e., risk behaviors, mental health, risk factors, child health and injury prevention, science education, etc.).

Woolley and Charlemagne concluded that grants funded by the NIH and AHRQ present various themes, patterns, and funding opportunities. The different ways in which the NIH and AHRQ afford researchers the opportunity to address health literacy issues ultimately will contribute to a reduction in health disparities among various populations. It was also

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[7] "The Research Project Grant (R01) is the original and historically oldest grant mechanism used by NIH. The R01 provides support for health-related research and development based on the mission of the NIH. R01s can be investigator-initiated or can be in response to a program announcement or request for application" (http://grants.nih.gov/grants/funding/r01.htm). Accessed April 6, 2009.

[8] "The R03 award will support small research projects that can be carried out in a short period of time with limited resources" (http://grants.nih.gov/grants/funding/r03.htm). Accessed April 6, 2009.

suggested that there is a need for researchers to specify, within the funded grant abstracts, the population studied (i.e., race/ethnicity, gender, etc.), measurement methodology, and research methodology used.

Healthy People 2010, in many ways, defined what is needed to move forward in health literacy. A key issue has been a data source that is national, provable, and demonstrable. According to HP 2010, individuals are *health literate* when they possess the skills to understand information and services and use them to make appropriate decisions about health. Without the NAAL data, there is no ability to track health literacy skills over time at a national level.

Of paramount importance is the need for a national, consistent dataset that provides information necessary to track changes in health literacy over time. The difficulty for measurement at the national level, however, has been to determine how big a picture is needed and what should be included in that picture. Numerous factors could be measured. Health literacy pervades health issues at all levels—prevention, diagnosis, intervention, and cure for both chronic and acute diseases. Health literacy also pervades social issues—disparities, cultural differences, language differences, and access issues. There is also economic strain, both on the individual and on the system, in terms of lost human capital, lost time, and money.

Information about the interactions of individuals with limited English proficiency (LEP) with the health care system is another area for measurement. Patients with LEP encounter difficulties as they attempt to interact with clinicians, but the extent and characterization of the problem are unknown. The 2000 Census counted 20 million people who speak English poorly and 10 million who speak no English (Newman, 2003). The White House Office of Management and Budget, in a 2002 report, estimated the number of patient encounters across language barriers each year at 66 million (Newman, 2003).

In terms of minorities, the Census projects that by 2042, more than 50 percent of the U.S. population will consist of minorities. For children, the figures are even more pronounced. Today, children who belong to a minority racial or ethnic group make up 44 percent of the U.S. population of children. By 2023 that figure will grow to more than half of America's children, and by 2050 that figure will be 62 percent (U.S. Bureau of the Census, 2008).

Considerations for health literacy measurement should include the capacity of people with LEP and the capacity of systems to respond to them. Currently there are no national data on health literacy for people who speak other languages or have LEP. This is a major gap.

Literacy is not a constant. It changes over time. Older adults who may have had fine reading, writing, and thinking skills in younger days may have difficulty reading and understanding information as they age. For people 65 and older, 66 percent have poor literacy skills. Vision problems, poverty, learning disabilities, immigration and minority status, and poor education also can contribute to low literacy. National data are needed that can track changes over time in multiple populations.

There is a need for national data to support a Healthy People 2020 objective. Furthermore, there is a need for population- and systems-based data. Some people have said that if there are no data, there is no problem. Without national data on the extent and characteristics of health literacy in America, Allen said, it will be impossible to develop effective interventions that lead to improving the health literacy of the 90 percent of the population who, the NAAL data show, do not have the skills necessary to understand information and services and use them to make appropriate health decisions.

NAAL DATA: TO USE OR NOT TO USE?

Barry D. Weiss, M.D.
University of Arizona College of Medicine

As mentioned previously, the NAAL database is currently the only database with national data about health literacy. But how easy is it to use this database, what kinds of problems do researchers encounter, and what suggestions might be offered for improvement?

If one accesses the National Assessment of Adult Literacy Data Files website (http://nces.ed.gov/NAAL/datafiles.asp), one finds a link to click in order to access the public use files. Clicking on that link, one then receives a message box asking, “Do you want to open this file?” When one clicks “open,” however, one receives a message box that says, “Windows cannot open this file.”

At this point one might turn to the Public Use Data File User’s Guide for instructions about how to access the public use files. This user’s guide is 882 pages long. For many people attempting to use the NAAL data, this is their interface experience—they get a file that will not open and if they want to find out what to do they have to read an 800-page book.

To prepare for this presentation, Weiss said, he sent an e-mail to 10 individuals whom he considers the top health literacy researchers in the country. He asked them the following questions: Have you used the NAAL data, and if so, tell me about your experience? How easy are they to use? Did you encounter any problems and, if so, what were they? The researchers’ responses follow.

Researcher #1

For the most part it is fairly easy to use. I've been using SAS [a computer program], but have used their interface tools to generate the code, which is a great resource. The documentation seems complete and has been very useful. We contacted NAAL to request a Census-tract crosswalk to the restricted-use dataset so we could use rural-urban commuting area (RUCA) codes for rural status designation (instead of the metropolitan statistical area [MSA] or non-MSA variable). They were responsive to our request for this information, and I don't recall that there were any "orphans"—all of the data had a corresponding Census tract. However, for our use considering rural literacy in Arizona, it became apparent that all of the Arizona data were collected only in Pima (Tucson) and Maricopa (Phoenix) counties. Seventeen states (including Arizona) did not have any non-MSA data. The rural data came disproportionately from the South and Midwest (only 8 percent of the records from the Northeast are "non-MSA"—from Pennsylvania, New York, Maine, Massachusetts—and from only 1 percent of Massachusetts's records). There were six records in the dataset that were apparently from California but classified as being from the Midwest.

Overall, then, researcher #1 had a positive experience with the NAAL data, with only minor comments about the rural data being collected in urban counties and the misclassification of some data from California as being from the Midwest. The same cannot be said for the other researchers who responded.

Researcher #2

The fact that they [NAAL] excluded people who are unable to read at all is problematic from the point of view of determining prevalence. Changing the categories/scaling from NAAL limits comparisons over time. But the biggest issue is the fact that they do not release individual-level data for investigation.

If one wants to find the prevalence of limited literacy, excluding people who cannot read from the sample is not a good idea. Changing the categories in the 2003 NAAL from those used in 1992 makes it difficult to compare trends and changes over time.

During the discussion period, one participant said the NAAL did not exclude people who could not read. Those excluded were people who could not communicate in English or Spanish. But other individuals who were able to complete the demographic information—either in writing or orally—were included, and they would have been put in the below-basic category if they could not complete the test. Another thing the NAAL did, for those who were clearly going to be unable to complete the standard questionnaire, was to use an easier test instrument. This was done to try to differentiate among people at the low end of the spectrum.

Researcher #3

Statistical analyses can only be reliably "run" using AM software. AM software is free, but only includes a small number of statistical tests. Because so few people have used or know how to use AM software, if you need help interpreting the output, you're pretty much stuck. The collection of health-related items is relatively small. There are questions regarding where one obtains health-related information and receipt of general screening (e.g., vision, dental, Pap tests). In the future, it would be great if NAAL data could be linked to robust health-related data (e.g., Medical Expenditure Panel Survey [MEPS], Behavioral Risk Factor Surveillance Survey [BRFSS], etc.).

Researcher #4

I did try [to use the NAAL data] shortly after it was released and ran into many difficulties with trying to get any answers/response to my inquiries about using/accessing the data. I also found it particularly troublesome to not be able to find out the exact wording of the questions. It seemed like NAAL was all operating with so many secrets and no interest in making the data available to advance our knowledge of health literacy. I have not since attempted to use/access the data.

Researcher #5

[We] need detail of what NAAL categories correspond to having limited literacy or health literacy. Having seen specific questions and data for a few NAAL items, my sense is that the data are not helpful and not credible. Health-services use items were flawed.

Researcher #6

I provide frequent health literacy/plain language trainings for health professionals, and I am always asked what "grade levels" are represented by the four NAAL reporting categories. I know that the concept of grade levels is not precise, to say the least, but people want a quick and easy way to grasp the magnitude of the literacy/health literacy problem. It would also allow us to use readability scores to more effect. Sometimes it's the ONLY way to get people to take action—to point out that all their materials are written at high school and college reading levels (which they usually are) and their patients read far below that level.

Conclusions

Of the 10 researchers from whom information was requested, 4 had not used the NAAL database. The remaining 6 provided information about their use of the database. One can conclude from these responses that the data are difficult to access or use, with the one exception being the response of the statistician (Researcher #1). A better option than what now exists is to house the database in a standard statistical program rather than an obscure program that few know how to use. Most attempting to use the database have not had the perseverance to find the data needed, even though those data might exist. Furthermore, a quick reference guide is needed, not an 882-page instruction booklet.

The responses also indicate a lack of confidence in the validity of the data. There is concern about sampling (rural, distribution across states). Additionally, it would probably enhance confidence in the validity of the survey if the questions were released so that researchers could see what was actually asked. Finally, the results are not translatable to education of health professionals because data are provided in a statistical database rather than in a form that people want to use—for example, by grade level.

In general, Weiss concluded, researchers find the data hard to obtain or use, and they do not trust the data.

HEALTH LITERACY MEASUREMENT: A BRIEF REVIEW AND PROPOSAL

Andrew Pleasant, Ph.D.
Rutgers University

Health literacy is an important and powerful tool for improving health. Yet health literacy measurement is incomplete. Adequate and accurate health literacy measurement is important because with such measures, appropriate attention to the importance of health literacy can be demonstrated. Furthermore, such attention can lead to funding of efforts to improve health literacy, and that can, in turn, lead to change in health systems. Health literacy can be both a theoretical and empirical guide to how, where, when, and why that change should occur.

A number of different tools are available that are meant to address health literacy. Yet these tools are incomplete. The tools include

- **NAAL:** National Assessments of Adult Literacy, health literacy component
- **HALS:** Health Activities Literacy Scale
- **REALM:** Rapid Estimate of Adult Literacy in Medicine; now REALM Spanish, REALM Teen
- **TOFHLA, S-TOFHLA, "Adapted" TOFHLA:** Test of Functional Health Literacy in Adults

- **NVS:** Newest Vital Sign
- The **single (or three) item** screeners
- **SAHLSA:** Short Assessment of Health Literacy for Spanish-speaking Adults
- **SIRACT:** Stieglitz Informal Reading Assessment of Cancer Text
- **MART:** Medical Achievement Reading Test
- **FHLM:** Functional Health Literacy Measure
- **ELF:** Health literacy screener

Although these are described as tools to measure health literacy, most are actually screening tools. There is a fundamental difference between screening and measurement. The goal of screening is to divide people into healthy and sick categories (have/have not). Screening does not tell what is actually wrong with the patient; it is both under- and overdiagnosis because what is required in screening in clinical contexts is a tool that is short, quick, and easy to use.

Measurement, on the other hand, is an attempt to explore in depth the structure and function of objects of interest. In fact, a true measure should establish the basis for a reliable screening tool. The purposes of measurement are to

- Advance knowledge—i.e., test hypotheses;
- Explore and explain structure and function;
- Monitor effectiveness and equity of interventions;
- Indicate major problems confronting society; and
- Contribute to setting policy goals.

When one thinks of measurement and health literacy, one often thinks of the capability of individuals. Yet there is another component to health literacy, which is the health care system as shown in Figure 2-3.

On the health care system side of Figure 2-3, current measurement is in terms of readability tools that assess level of difficulty in language. On the other side of the figure, the patients/public side, available tools are those in the long list above. None of these tools, however, measures health literacy in the *context* of both the health care system *and* the patient/public. This is a critically important issue, especially for attempts to self-report literacy or health literacy, which serve as both dependent and independent variables. Some people overestimate their literacy skills, when in fact they may just be avoiding challenges—for example, no traveling, no attempts to learn new things, no visits to a physician.

Another major difficulty with current measures is that, using data from any of the currently available tools, the data do not describe how health literacy *causes* improved health. There are data about what happens

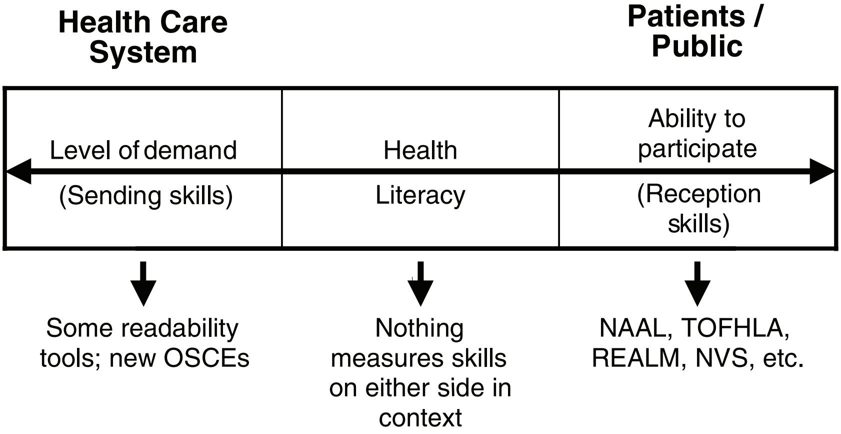

FIGURE 2-3 Health care system and patients/public.
SOURCE: Pleasant, 2009.

when health literacy is not present, there are correlational data, but the actual structure of the mechanism, how it is that health literacy leads to improved health, has yet to be shown.

A Comprehensive Measure of Health Literacy

There is currently no open-access (free/easily available) comprehensive measure of health literacy. But there should be. A comprehensive measure of health literacy does not mean a measure that includes everything. Comprehensive means showing extensive understanding. A comprehensive measure builds a foundation of knowledge that is needed to enable accurate screening and to advance health literacy as a tool to improve health and reduce inequities in health. A comprehensive measure is one that consists of items that test a theory, a framework, or a definition of health literacy.

To build a comprehensive measure of health literacy, those in the field must agree on exactly what should be measured. A commonly agreed-upon definition of health literacy is needed. Although the Ratzan and Parker definition promulgated in the IOM report *Health Literacy: A Prescription to End Confusion* (2004) is often used, there are many in the field, including some who served on that IOM committee, who believe this definition is insufficient. It was good for the time, but the field has progressed.

In arriving at a comprehensive measure of health literacy, the process is as important as the product. As the process for building the measure of health literacy proceeds, two things must be kept in mind. First, one must remember the broader context in which health literacy operates. This is important from a research perspective because when the point is reached that longitudinal studies can be conducted, measures must be able to demonstrate that change is due to change in health literacy, not a change in the larger context in which health literacy operates.

The second point to keep in mind is that health literacy is a social construction. It exists solely because of social interaction. Health literacy should not be treated, as it often has been, as a biomedical issue with social roots. Rather, it is a social issue with biomedical implications. Therefore, the tools of social research are required for measurement.

Eight Proposed Methodological Principles

Eight principles of social research are needed in the development of a new and comprehensive measure of health literacy. The comprehensive measure must

1. Be built explicitly on a testable theory or conceptual framework of health literacy;
2. Be multidimensional in content;
3. Use multiple methods;
4. Clearly distinguish health literacy from communication;
5. Treat health literacy as a "latent construct";
6. Honor the principle of compatibility;
7. Allow comparison; and
8. Prioritize social research and public health applications versus clinical use.

First, a comprehensive measure must be built explicitly on a testable theory or conceptual framework of health literacy. Currently, there are about five or six models, two of which were presented earlier. There are many points of agreement among these models and several points of disagreement. None of the current measurement tools, however, were built to actually test and advance any of the models, frameworks, or theories. There needs to be a renewed consensus about the theory or conceptual framework of health literacy in order to develop a comprehensive measure of health literacy.

Second, the conceptual framework of health literacy needs to be multidimensional in context. Most theories or conceptual frameworks define health literacy as a construct with multiple conceptual domains and multiple skills and abilities. Conceptual domains include fundamental, civic, science, culture, critical, and communicative. Skills and abilities include finding, understanding, evaluating, communicating, using, navigating, prose, document, quantitative, and speech. Furthermore, the elements of the underlying construct should be explicit in a measure.

Third, multiple measures must be used because there is a huge difference in the skills between recognizing and understanding a letter, a word, a sentence, a paragraph, or a document or narrative. Navigating information in the health care system requires a range of skills.

Fourth, health literacy must be clearly distinguished from communication. Communication is a symbolic transactional process. Most of the functional definitions of health literacy involve the use of skills and abilities. Communication and health literacy can and should be distinguished from one another, yet a number of the current attempts to evaluate and address health literacy make no distinction.

Fifth, health literacy should be treated as a latent construct.[9] Health literacy is not explicit, that is, one cannot "see" health literacy, and it varies across individuals and contexts. Therefore, health literacy should be considered a latent construct for measurement purposes. This means a new measure should contain items that sample from all the conceptual domains outlined by the underlying theory or conceptual framework.

Sixth, honor the principle of compatibility. A measure of health literacy that focuses solely on the clinical setting is inappropriate when researching public health behaviors and outcomes. For a hypothesized relationship among attitudes, behaviors, and knowledge to hold true, the three components must be measured at equivalent levels in regard to action, target, context, and time (Fishbein and Ajzen, 2005).

Seventh, allow comparison across contexts and languages including culture, life course, population group, and research setting. This implies that the measure be adapted or developed in parallel in different target languages and different contexts. One can think of a measure of health literacy as a core module with add-on modules to address specific states. The modules are all built on the same theory, so they are comparable across a multitude of different states. For example, one could have a health literacy module about diabetes, about aging, or about AIDs. As long as they are built on the same theoretical basis, they are comparable.

Eighth, prioritize social research and public health applications versus clinical use. It is time to dedicate resources toward building a complete measure of health literacy if the following factors are understood:

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[9] "The term 'latent' is used to emphasize that any set of measured observations, no matter how precise and elegant, is only an indirect approximation of an unobservable construct, and that all relevant observations are necessarily one step removed from the construct they are designed to measure" (Atkinson and Lennox, 2006).

- Health literacy is an important determinant of public and individual health;
- There is a risk of harm in labeling individuals as “low health literate” in a clinical setting;
- Several screeners already exist;
- The time burden on clinical settings limits ability to measure versus screen; and
- A simple tool is limited in its ability to advance knowledge of a complex social process.

To accomplish the task of building a comprehensive measure of health literacy, consensus, scientific methods, and leadership funding are needed. Social constructions are defined through a social process, through consensus. Health literacy is a relatively new idea and is being continually defined in words and actions. A great deal of progress has been made, but if a comprehensive measure is to be developed, it is time for a consensus about the theory and conceptual framework of health literacy.

A comprehensive measure of health literacy should use the scientific method, that is, the measure should explicitly test the definition of the social construct of health literacy. No current screening tool of health literacy was explicitly designed to test any of the more commonly accepted definitions of health literacy.

Finally, there must be research-funding leadership. A good deal of research has been conducted on health literacy, but those projects are using a variety of tools without an actual consensus on the depth and strength of health literacy. This could lead, further down the road, to an even more disjointed field than currently exists, with findings that are not comparable. Many screening tools are available, but what is needed is a comprehensive, usable, freely accessible measure of health literacy. Developing such a measure requires the kind of process described earlier. It is critical, Pleasant said, that funding organizations take the lead in funding a renewed consensus process about health literacy and support development of measures based on that process.

DISCUSSION

Moderator: George Isham, M.D., M.S.
HealthPartners

National Assessment of Health Literacy

One person drew attention to the fact that the Healthy People 2020 process is ongoing and is being conducted by the U.S. Department of

Health and Human Services (HHS). For that process, national-level data on health literacy are needed. However, the NAAL, which is managed by the Department of Education (DOE) and is currently the only source of national data on health literacy, is not slated to be implemented again until 2015. These two processes are out of synchronization. Therefore, at the very least, there is a need for coordination between HHS and DOE.

Another participant raised the issue that the fact that the NAAL data are collected by and housed in DOE creates some difficulties. Several other efforts to measure and collect health literacy data are also under way. Is there a need for an ongoing data collection system for health literacy that is owned and operated within HHS? Would this help move the issue forward?

Clancy said that what is clearly needed is a strategy. Whether that strategy is solely owned by HHS or shared with others is not clear. The *American Recovery and Reinvestment Act of 2009*, Public Law 111-5, 111th Congress, 1st session (February 17, 2009), has brought many new demands and opportunities. Language in the Act provides for new resources for health information technology and federal investment in collection of data on patient race, ethnicity, and primary language. Should health literacy measures be built into what is being developed in electronic records or as part of information collected on quality measures, or should health literacy be treated more as a vital statistic? There is no answer to that question as yet. But there is a unique opportunity for clinical care and public health to be thinking together about what might be a joint approach.

One participant said that what was particularly troubling about the comments on the NAAL were the questions regarding the validity of those data. She asked whether Weiss had a prescription for remedying the problems with the NAAL. Weiss responded that there was mistrust of the sampling methods and great concern over the fact that the survey questions are not available. Why not release the questions on the survey? Some of the researchers' concerns might evaporate if the information was released. Then they could make judgments about what to use, or, with the information in hand, they might think that their concerns were overblown. But refusing to release the questions induces cynicism in the users.

Another participant asked what Weiss would like to see in terms of national data and what would help in his research. Weiss said what is needed is a measure of health literacy that is known to be reliable and valid when used with the same people over and over across time. The TOFHLA, REALM, NVS, and all other current health literacy instruments are all meant for one-time assessments of individuals' health literacy skills. But conducting research that shows that improving health literacy improves outcomes requires a reliable and valid measure of health literacy that can be used longitudinally.

The NAAL questions offer that potential. The NAAL was implemented in 1992 and 2003, and could be implemented again. Many believe there are reliable and valid questions in the NAAL that can be used to assess *literacy* over time to see if there are changes. This may be the only set of questions that has that characteristic. If there are valid questions regarding *health* literacy, this could be a very powerful tool. But we do not know what the questions are, and the data are very difficult to access and use.

Weiss said if that is the case, then researchers such as those who responded to his simple questionnaire are misinformed. Such misinformation raises the question of the need for better communication between the NAAL and researchers. Different researchers have different understandings of what data were collected and what are available. The information about what the survey was about and what is actually in the survey has not been transmitted effectively.

One participant said the complexity of the NAAL does not seem too dissimilar from that of other large national datasets where it is important to have available assistance from someone who really knows how to navigate that dataset. However, the secrecy over the health literacy questions is a serious problem because it prevents more specific analyses on the implications of health literacy. Weiss agreed and said there is no reason the questions should not be released.

Another participant suggested that one of the problems with a database such as the NAAL is that it is isolated from health outcomes and other health information. Someone else stated that one other factor missing in the NAAL is the ability to measure quality of care and relate that to health literacy and health outcomes. The federal government, he continued, has an opportunity to begin to focus on a meta-organization of its various databases in ways that are usable, not only to researchers, but to the general public and to care delivery systems across the country. Weiss agreed that such linkage would be valuable because then one could examine health literacy data in relationship to known health outcome data.

One participant concluded the discussion with a series of questions. If the NAAL data are not adequate, and if the DOE implemented the health literacy supplement as an add-on to its original assessment of adult literacy, what happens next? Where should the locus of decision making be to create the data that the field believes are necessary? What are reliable and valid measures of health literacy? How can the data be made accessible and transparent? What is needed to facilitate economic analyses of the impact of low health literacy?

Accountability

One participant referred to the portion of Clancy's speech where she talked about the need for health system accountability in health literacy. For example, what are the barriers to including health literacy as a component of all federal research grants, just as is done now for minorities? Are there other approaches to these new comparative effectiveness activities that would make health literacy fundamental to the activities? Clancy said she did not think the issue is one of barriers; rather it is an issue of knowing what should be measured. For example, having a way to measure what patients hear in their interactions with providers rather than what the providers do is very complex.

Another participant asked Clancy, given the importance of health literacy to quality, how effective has The Joint Commission been in embracing health literacy and health literacy measurement? Clancy responded that The Joint Commission has been acutely aware of this issue and has sponsored a number of policy roundtables on it. As one thinks about how health literacy relates to quality measurement, it is important to identify next steps that could be taken with both The Joint Commission and other potential stakeholders.

One participant asked what would be involved in including health literacy in the required Joint Commission quality measures. Clancy responded that the supplements to CAHPS are a starting point. Amy Wilson-Stronks of The Joint Commission said the Commission is continuing work in the area of health literacy through the IOM Roundtable on Health Literacy and the continuing emphasis on culture and language.

Other Issues

A participant asked whether the relationship between behavioral health issues and health literacy has been examined. The participant's health system has a large proportion of patients who are older and who have multiple chronic conditions as well as behavioral health diagnoses. The participant asked how health literacy measures and interventions could be designed to address such patients.

Clancy said it is logical to assume there is an interaction between behavioral health issues and health literacy. AHRQ has an initiative that has focused on the needs of complex patients, defined as people with multiple chronic illnesses. If one of those illnesses is a behavioral health issue, a situation becomes much more complicated in terms of factors such as the ability to cope with health care demands and the information needed to care for oneself.

One area of AHRQ's focus in the development of the hospital CAHPS instrument in health literacy is the patient's ability to care for himself or herself after leaving the hospital. Hopefully, some of those measures will capture when a patient is not able to care for himself or herself and determine what supports are in place for both mental and physical health.

One participant referred to the new push for comparative effectiveness research. She said that one fear is that such research will be interpreted in a narrow way. How can one think of the comparative effectiveness of different approaches to health literacy, both within the health care system and in communities? How can those involved in the issues of health literacy communicate better about the serious research needed to understand the approaches to health literacy and comparative effectiveness research?

Part of the AHRQ mandate, Clancy said, is to produce information that is accessible to a broad number of audiences. There is a center that tests a variety of modes for effective communication, with a particular focus on audiences with limited health literacy. They have made a fine start, but have a way to go. Sufficient resources have not been available to evaluate different approaches. One of the sections of the American Recovery and Reinvestment Act of 2009 directs that the IOM make recommendations about national priorities for comparative effectiveness research.[10] The IOM will hold a public hearing on this issue. It would be important to get health literacy on the agenda of this meeting early.

Health literacy is not constant over one's lifetime, one participant said. It will vary with factors such as the level of stress and health conditions. This is a real problem from a measurement perspective. If one is collecting national-level data, then one would expect these variations to even out—that is, some are having a bad health literacy day while others are having a good health literacy day. But implementing health literacy measurement for an individual in order to tailor care presents a different measurement challenge.

Weiss agreed that it is definitely more difficult at the individual level. The finding that people with low health literacy have worse health indicators and higher costs has been established. The big question is, if an individual's health literacy is improved, are the health outcomes better? Unless it can been shown that health literacy has improved, it can never be shown that health outcomes have improved as a result of improved health literacy. Therefore, an instrument is needed that can be used to show

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[10] "That the Secretary shall enter into a contract with the Institute of Medicine, for which no more than $1,500,000 shall be made available from funds provided in this paragraph, to produce and submit a report to the Congress and the Secretary by not later than June 30, 2009, that includes recommendations on the national priorities for comparative effectiveness research to be conducted or supported with the funds provided in this paragraph and that considers input from stakeholders" (http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_bills&docid=f:h1enr.pdf). Accessed April 5, 2009.

health literacy changes over time, an instrument that can be depended on as valid and reliable for what it is intended to measure.

Developing such an instrument, Weiss said, might simply be a matter of validating some of the existing tools. Perhaps the NAAL has the best potential, but that is unknown because the questions remain unavailable and data remain difficult to access and use.

Another participant said that many standardized tests, such as the NAAL, are essentially a knowledge-deficit model of assessment. In other words, they measure what people do not know rather than what they do know. As a replacement, some people advocate standardized tests that measure engagement or interest in, for example, one's own health care. Other measures could be included that indicate an individual's intention or proclivity to learn more.

Weiss said he was familiar with the concept of empowerment, which is what the questioner seemed to be suggesting. For example, there are those who assert that low health literacy is consistent with a low sense of self-empowerment and an external locus of control. Those with low literacy tend not to be those who believe they can take charge of their lives or have the ability to do so. The question is, what does one measure? Maybe the test of health literacy is to measure this proclivity for self-empowerment. There are scales of empowerment. There are scales of locus of control. These things do exist, and they might be incorporated into a health literacy measure to make it more comprehensive.

One participant asked how one could tie health literacy tools to self-management training for prevention efforts. For example, the Centers for Medicare & Medicaid Services (CMS) has entered into an agreement to provide training and education for those who have chronic kidney disease and diabetes. As CMS looks to expand its training efforts, could a health literacy assessment tool be used to increase the effectiveness of the CMS action plans and, thereby, hopefully improve health outcomes? Allen replied that adding a health literacy assessment tool would be an exciting opportunity for research, an opportunity to assess—both at the beginning of the project and at the end—what actually has been accomplished.

Another participant added that AHRQ is developing a universal precautions health literacy tool kit to help clinicians in their practices. Once a clinician understands that there is a health literacy problem, this collection of tools, with brief guidance on how to use them, can help integrate health literacy work into clinical practice. The tool kit is now being pilot tested with a number of practices and should be out within the year.

One participant asked Pleasant about his vision of what a comprehensive, multimethod health literacy measure looks like. What is the practicality of administering such a measure, and how could it be done? Is the comprehensive measure something just for researchers, or could this be a population measure? Pleasant responded that it is critically important to use a consensus process to develop an agreed-on theory and framework around which measures are developed. There should be a core module of health literacy and then, depending on the context that one is addressing (e.g., chronic disease, health literacy of physicians, health literacy of patients, etc.), add-on modules would be developed. If measures for these were based on an agreed-on framework, comparisons could be made across modules and contexts. It should be possible, Pleasant continued, to develop a telephone assessment of health literacy.

The issue of measurement for research versus measurement for improvement versus measurement for what might be called accountability was raised by one participant. It is hoped that the comprehensive measure under discussion will have components that can accommodate all needs. It seems important that one identify the various needs for measurement. Pleasant responded that a number of measures, such as the REALM and the TOFHLA, are used. But questions have been raised about their validity and whether they address the scope of health literacy. The way to resolve these issues is to develop a consensus approach to the theory and framework of health literacy and then to develop a new set of measures, based on that consensus, that will fill the needs of a variety of audiences.

3

Approaches to Assessing Health Literacy

WHAT IS HEALTH LITERACY AND HOW DO WE MEASURE IT?

Lauren McCormack, Ph.D., M.S.P.H.
RTI International

RTI International is developing and testing a new measure of health literacy. The objective of this R01 project funded by the National Institutes of Health (NIH) is to create a publicly available health literacy instrument that can be used for population-based surveillance and for measuring an individual's health literacy in intervention and research studies. In addition to the research team, there is an external panel advising the project. Specific project tasks include developing a conceptual framework, developing health literacy items, cognitively testing these items, pilot testing the items in a survey, and conducting psychometric analyses of the pilot data.

As discussed previously, existing measures of health literacy have limitations. For example, a major limitation of the Test of Functional Health Literacy in Adults (TOFHLA), the Rapid Estimate of Adult Literacy in Medicine (REALM), the Wide Range Achievement Test (WRAT), and the Ask-Me-3 is that these instruments largely measure reading ability or print literacy. The National Assessment of Adult Literacy (NAAL), as has been discussed, is not publicly available, and there is uncertainty about when the next round will be fielded.

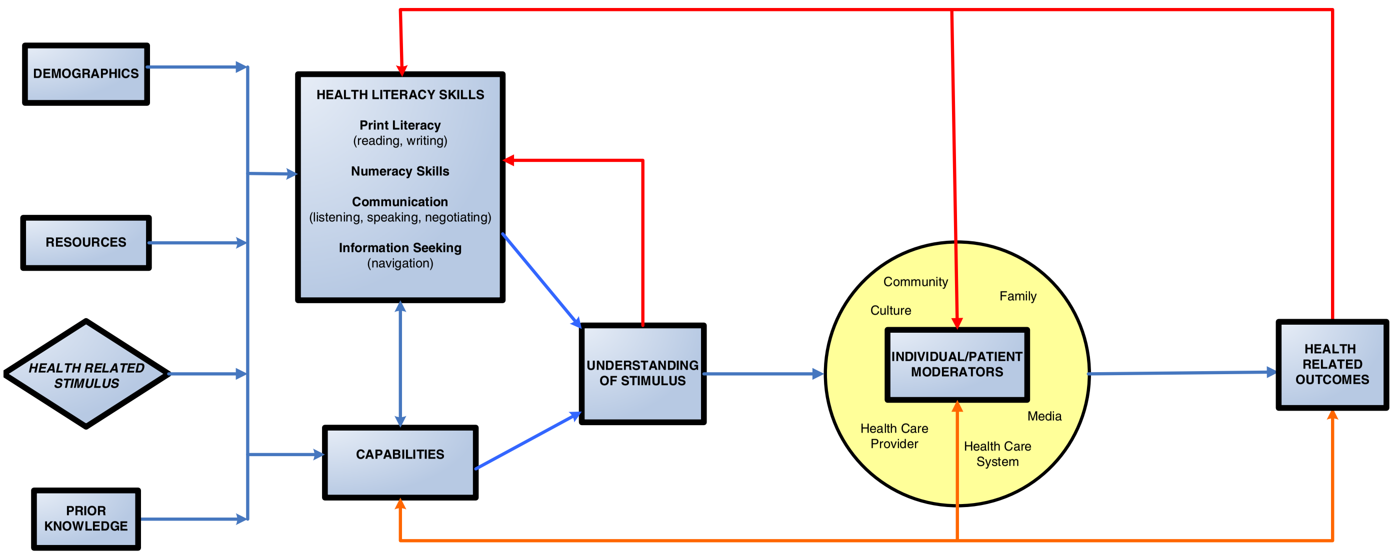
The project team began by reviewing existing definitions of health literacy. The Office of Disease Prevention and Health Promotion defines health literacy as not simply a function of basic literacy skills, but as "dependent on individual and system factors, including communication skills of lay persons and professionals, lay and professional knowledge of health topics, culture, the demands of the healthcare and public health systems, and the demands of the situation/context" (http://www.health.gov/communication/literacy/quickguide/ factsbasic.htm). "Health literacy varies by context and setting and is not necessarily related to years of education or general reading ability," according to the National Network of Libraries of Medicine (http://nnlm.gov/outreach/consumer/hlthlit.html). The Institute of Medicine (IOM) states that, "Even well-educated people with strong reading and writing skills may have trouble comprehending a medical form or doctor's instructions regarding a drug or procedure" (2004). Thus, the literature review supports an increasing recognition of the importance of context and setting when assessing health literacy. The project team adopted a slightly modified version of the Ratzan and Parker (2000) definition.

Conceptual Framework and Skills-Based Approach to Measurement

The next step in the project was to develop a conceptual framework (see Figure 3-1). As Pleasant said earlier, a conceptual framework is critical as a foundation of measurement. An important component of this framework is the feedback loop from health-related outcomes back into skills; people learn from their experiences, and that affects their skills for the future.

There is an increasing call in health care for consumer activation, consumer empowerment, and consumer involvement. Under these circumstances a skills-based approach to measuring health literacy is warranted. Therefore, the approach under development will include assessments of people's ability to use different types of health information to make informed decisions as well as the skills needed across the life course in periods of health and periods of illness. Issues addressed range from disease prevention to treatment and self-management. The assessment will be based on the U.S. health care system, which means that the measurement process reflects current health insurance issues and care provided in public and private systems. One challenge in creating a skills-based approach in which data are collected via a computer is keeping up with technological advancements and changes in health-related materials that are used in the measurement process.

The measures will cover several health literacy domains, including print (both prose and document), numeracy skills, communication (including listening, speaking, and negotiating), and information seeking or navigation. A hierarchical approach was taken to determine the measures. First the skill or task was identified. Second, stimuli that enabled



CONSTRUCTS

DEMOGRAPHICS: age, race, ethnicity, income, gender
HEALTH RELATED STIMULUS: educational brochure, conversation with doctor
RESOURCES: occupation, employment, income, social support, culture, language, education, literacy
PRIOR KNOWLEDGE: vocabulary, conceptual knowledge of health/health care
CAPABILITIES: vision, hearing, verbal ability, memory, cognitive/reasoning/processing
INDIVIDUAL/PATIENT LEVEL MODERATORS: motivation, self-efficacy, perception of outcome/behavior, attitude toward outcome or behavior, coping strategies, social support, emotions, behavioral intention, trust in information/source/stimulus, decision making skills, fatalism, knowledge, decision making)

STIMULUS CONSIDERATIONS

Health literacy demand: complexity and difficulty of stimulus, one vs. many stimuli
Channel: print, mass media
Message: health promoting vs. disease preventing, fear appeals, narrative vs. non-narrative
Messenger: relationship of messenger to recipient, credibility of/trust in messenger/source, communication skills of messenger

FIGURE 3-1 Conceptual framework for individual health literacy.
SOURCE: McCormack, 2009.

measurements of the skill or task were selected. Finally, the mode of administration was chosen. Although some of these questions could be conducted over the telephone or in person, a web-based approach is the preferred mode at this time. The following criteria were used to identify the skills to include in the measures:

- Understanding health-related concepts and terms (in writing and verbally);
- Interpreting tables, charts, symbols, maps, and other visuals;
- Making inferences based on available data;
- Applying information to new situations; and
- Using arithmetic manipulations.

Criteria used for selection of stimuli included

- Sufficiently related to the health of the public;
- Widely applicable, balanced content;
- Accessible to many subgroups (gender neutral, culturally sensitive);
- Clinically important and not controversial;
- Appropriate length of content;
- Mixture of public- and private-sector materials;
- Likely to stand the test of time;
- Variety of formats/channels;
- Wide range of difficulty; and
- Has face validity.

In developing criteria for the survey items themselves, the project team determined that prior knowledge should not be required to answer the questions. Another criterion is that there must be only one correct response, but there also have to be reasonable distractors (alternatives) that are neither too obvious nor too difficult. The questions must be independent of each other, that is, respondents should not have to get the first question correct in order to get the second question correct. Finally, the questions must include a range of difficulty and must cognitively test well.

Survey Items

The following are examples of stimuli and survey items that the project team is considering for the assessment. Final decisions about the stimuli and items will be based on the pilot work and assuming approvals are granted from the organization that created the stimuli. One possible stimulus is “Signs of a Stroke” (Figure 3-2). A few survey questions are associated with each stimulus.

EASY: Which of the following is NOT a sign of a stroke?

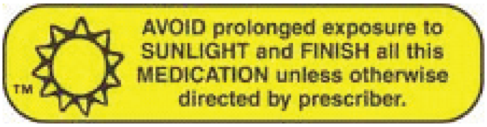
a) Difficulty breathing *(correct response)*
b) Blurred vision
c) Bad headache
d) Numbness on one side

MEDIUM: Which of the following is a true statement?

a) Someone who is having a stroke will have all of the signs.
b) Someone who is having a stroke may have only two or three signs. *(correct response)*
c) Everyone who has a stroke dies if they are not treated right away.

FIGURE 3-2 Signs of a stroke.
SOURCE: McCormack, 2009.

Other items in the survey require reading an article to obtain information and then answering questions based on information provided in the article. Other questions are based on short videos such as the public service announcement *The Faces of Influenza*, sponsored by the American Lung Association and posted on YouTube.com. There are also questions about symbols. For example, the question appearing in Figure 3-3 is about medication adherence.



Bill is at the beach and taking this medicine. He should

a) Continue his outdoor activities without any changes
b) Not take his medicine for now
c) Take the medicine before going outdoors in the morning
d) Sit in the shade if he is going to be outdoors *(correct response)*

FIGURE 3-3 Caution symbols on medication bottles.
SOURCE: McCormack, 2009.

Conclusion

A number of issues and challenges remain as health literacy measures are developed, including identifying skills that can be measured, selecting appropriate stimuli and items, and assessing the trade-offs associated with different modes of administration. Another issue is how emerging technologies will allow improvement in measurement of health literacy, especially oral literacy. Additional questions include, What are the advantages and disadvantages of using real-world stimuli versus stimuli developed for assessments? On which national surveys would health literacy items and scales best fit? How do we deal with the need for stimuli to be updated and/or changed over time?

DISCUSSION

Moderator: George Isham, M.D., M.S.
HealthPartners

One audience participant asked whether there is enough knowledge and new technology today (e.g., with the personal health record and the new health initiative measures) that one could develop a measure, be it of knowledge, skills, or function, that would take 5 minutes and that could be used to rapidly move the field forward. McCormack said many in the field would like to have a 5-minute short form instrument to measure health literacy, and one could be created eventually. A first step is creating a longer form of the instrument and using psychometric and other analyses to determine which items reflect the core of the instrument, then eliminating items that contribute less. One possible model for measuring health literacy is to take an approach like the Patient Reported Outcomes Measurement Information System (PROMIS)[1] for quality-of-care measurement. PROMIS uses a large bank of items that are rotated over time but still measure the same construct.

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[1] PROMIS "is an NIH Roadmap network project intended to improve the reliability, validity, and precision of PROs and to provide definitive new instruments that will exceed the capabilities of classic instruments and enable improved outcome measurement for clinical research across all NIH institutes" (http://aramis.stanford.edu/downloads/2005FriesCERS53.pdf). Accessed April 9, 2009.

REFINING AND STANDARIZING HEALTH LITERACY ASSESSMENT: ENGLISH AND SPANISH ITEM BANKS

Elizabeth Hahn, M.A.
Northwestern University

The bilingual assessment of health literacy project at Northwestern is funded by the National Heart, Lung, and Blood Institute of the NIH. The project has four goals:

1. Develop English- and Spanish-language item banks for reading-related health literacy skills;
2. Evaluate the feasibility, validity, and acceptability of computer-based methods for assessment of health literacy;
3. Develop computer-adaptive testing (CAT) of health literacy in clinical settings; and
4. Evaluate the associations among health literacy, sociodemographic/clinical characteristics, and health outcomes in primary care patients.

There is a continuum in health literacy that goes from low health literacy to high health literacy (Figure 3-4). The project intends to develop items that span the continuum and to make sure that for each English item on the continuum, there is a corresponding item in Spanish that sits at the same place on the continuum. To have equivalence across English and Spanish, the items must mean the same thing.

There will be a bank of questions that identifies the underlying trait to be measured. The definition of the trait and the meaning of each item will be the same across all participant characteristics. If that were not the case, differences due to measurement bias could be interpreted incorrectly as real differences between groups.

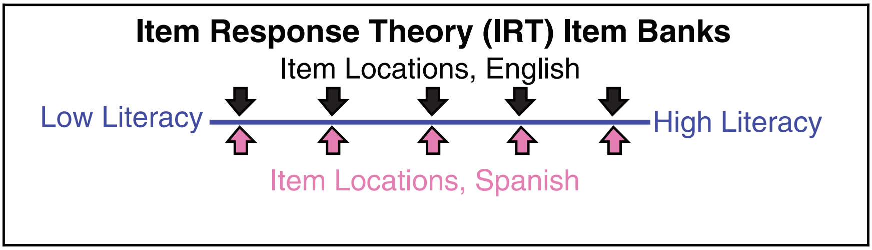

FIGURE 3-4 Item response theory.
SOURCE: Hahn, 2009.

Item Bank

A well-constructed item bank will enable development of computer-adaptive tests or creation of short forms of the test. In other words, individuals could answer different questions in the item bank but, because it is known exactly where on the continuum each question is located, it will still be possible to estimate a health literacy score for each individual with good precision. The Talking Touchscreen[2] (*la Pantalla Parlanchina*) will be adapted and used, providing those with low literacy an opportunity to self-administer questions by having some text on the screen read out loud.

The definition of health literacy used in this project has essentially two parts: capacity and application. First, an individual must have the capacity to process and understand health-related information. He or she must then be able to apply that information in the management of her or his own health. The capacity to *obtain* information, which is part of other definitions of health literacy discussed earlier, is a navigation skill that is not included in this health literacy tool. Instead, the focus is on comprehending and interpreting information provided and understanding what an appropriate health care decision based on that information *should* be. Whether the patient actually implements an appropriate health care decision and related behavior is also beyond the capability of this assessment tool.

The following are examples of items in this tool. All items are in English for this presentation, but there are comparable items in Spanish. Figure 3-5 shows a prose item. There is a short paragraph with text drawn from real-world documents. This is followed by a sentence with a missing word. Options are then given for the respondent to choose what to use to fill in the blank.

A second type of item included in this assessment tool is a document item. There is a stimulus (in Figure 3-6 a prescription label is the stimulus), followed by a question that asks about the stimulus. This particular item also has sound (the respondent would click on the "talking head" in the figure) so that information can be relayed orally.

The third type of item (Figure 3-7) involves a quantitative or numeracy skill. Again, the respondent can click to have the information delivered orally. All of the items have four response choices with only one correct answer.

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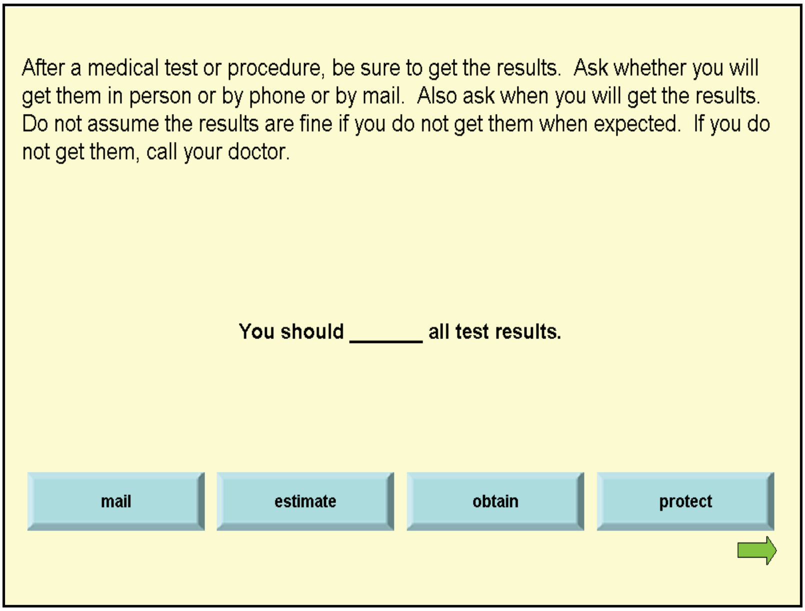
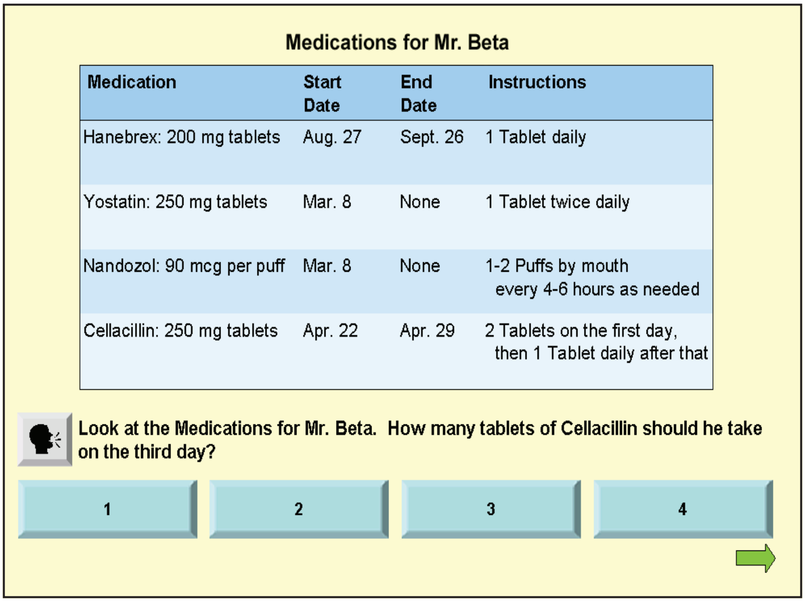
[2] "The TT [Talking Touchscreen] is a practical, user-friendly data acquisition method that provides greater opportunities to measure self-reported outcomes in patients with a range of literacy skills" (Hahn et al., 2004).



After a medical test or procedure, be sure to get the results. Ask whether you will get them in person or by phone or by mail. Also ask when you will get the results. Do not assume the results are fine if you do not get them when expected. If you do not get them, call your doctor.

You should ______ all test results.

FIGURE 3-5 Prose item.
SOURCE: Hahn, 2009.

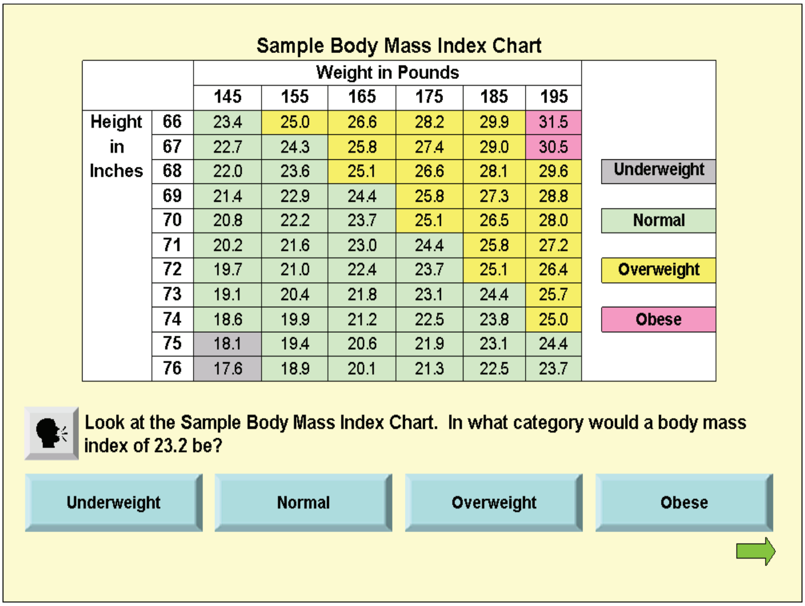


Medications for Mr. Beta

Medication	Start Date	End Date	Instructions
Hanebrex: 200 mg tablets	Aug. 27	Sept. 26	1 Tablet daily
Yostatin: 250 mg tablets	Mar. 8	None	1 Tablet twice daily
Nandozol: 90 mcg per puff	Mar. 8	None	1-2 Puffs by mouth every 4-6 hours as needed
Cellacillin: 250 mg tablets	Apr. 22	Apr. 29	2 Tablets on the first day, then 1 Tablet daily after that

Look at the Medications for Mr. Beta. How many tablets of Cellacillin should he take on the third day?

FIGURE 3-6 Medications for Mr. Beta.
SOURCE: Hahn, 2009.



Sample Body Mass Index Chart

		Weight in Pounds					
		145	155	165	175	185	195
Height in Inches	66	23.4	25.0	26.6	28.2	29.9	31.5
	67	22.7	24.3	25.8	27.4	29.0	30.5
	68	22.0	23.6	25.1	26.6	28.1	29.6
	69	21.4	22.9	24.4	25.8	27.3	28.8
	70	20.8	22.2	23.7	25.1	26.5	28.0
	71	20.2	21.6	23.0	24.4	25.8	27.2
	72	19.7	21.0	22.4	23.7	25.1	26.4
	73	19.1	20.4	21.8	23.1	24.4	25.7
	74	18.6	19.9	21.2	22.5	23.8	25.0
	75	18.1	19.4	20.6	21.9	23.1	24.4
	76	17.6	18.9	20.1	21.3	22.5	23.7

Look at the Sample Body Mass Index Chart. In what category would a body mass index of 23.2 be?

FIGURE 3-7 Sample body mass index chart.
SOURCE: Hahn, 2009.

Item Testing

All of the items were pilot tested with 97 English-speaking participants and 134 Spanish speakers. The characteristics of the pilot test participants can be seen in Table 3-1.

Most of the testing was done with paper and pencil, but the printed paper looked just like the Talking Touchscreen view will look when those components are completed. There were also research assistants present who could read the questions out loud for participants. Cognitive interviewing was conducted with some participants, who were shown the different types of items and then asked to describe how they would go about answering the questions.

The participants were recruited mainly in primary care clinics, which are also where the ultimate calibration testing is being conducted. To obtain sufficient numbers for the pilot test, some testing was conducted at community-based organizations that provide general education development (GED), literacy tutoring, or job training.

The pilot test showed that nearly all (>90 percent English, 100 percent Spanish) correctly described the steps needed to answer each type of ques-

TABLE 3-1 Characteristics of Pilot Test Participants

	English Speaking (n = 97)	Spanish Speaking (n = 134)
% Female	65%	75%
Mean age	44.0	38.7
Hispanic ethnicity	91%	99%
Race		
African American	60%	—
White	7%	22%
Other	33%	78%
Education		
< High school	43%	53%
High school/GED	31%	25%
College	26%	22%
Not available	(n = 27)	—
Method		
Paper and pencil	74%	100%
Talking Touchscreen	26%	—

SOURCE: Hahn, 2009.

tion. Participants were also asked if they felt anxious, nervous, or uncomfortable completing this health literacy test. Only one English-speaking participant and three Spanish-speaking participants were uncomfortable or anxious.

Once the participants completed the computer-based test, cognitive interviews were conducted with 25 English-speaking participants. Most reported that the test was easy to use and commented favorably on the screen design and the availability of audio. Some evidence shows that even people with high literacy skills found comprehension was aided with sound as well as the visual prompt. Participants also commented favorably on the items, even when acknowledging that some of them were difficult to answer.

A large number of items are needed for a good bank of items. Ultimately, people will answer only a small number of items, but the pilot tested 98 English items and 127 Spanish items. Some items were eliminated, such as those that everyone completed correctly. Such items are not useful for measurement. The items that were left have a range of difficulty. A small number of items are at the easy and difficult ends of the range, and the bulk of the items are in the middle.

A 10-item short form was developed for the pilot test and is being used in other ongoing projects. Calibration testing is under way for the final set of 90 English items and 90 Spanish items. Those items are being tested with 600 English speakers and 600 Spanish speakers who are primary care patients. The analysis plan is to accomplish the following:

- Examine the extent to which items measure a single latent trait;
- Calibrate items on the health literacy continuum using the most parsimonious model that displays a good fit;
- Evaluate the possibility of differential item functioning (DIF) across language, gender, age, education, and health care experience;
- Convene an expert advisory panel to create ability classifications; and
- Develop an algorithm for the CAT.

Conclusion

In conclusion, Hahn said, these new health literacy items have good content validity and cover a variety of topics relevant to primary care patients and their health care providers. The Talking Touchscreen (*la Pantalla Parlanchina*) is easy to use and acceptable for self-administration of a health literacy test. A computer could be placed in the waiting room of a clinic, and people coming in for an appointment could fill out the assessment and immediately receive a score. That score could then be used in the same clinical encounter.

A bilingual, computer-adaptive test of health literacy will enable clinicians and researchers to more precisely determine at what level low health literacy begins to adversely affect health and health care use. This tool will also provide better opportunities to determine the independent effects of limited English proficiency and limited health literacy. By using novel computer-based methods for health literacy assessment in clinical settings, the tool could also increase the access of underserved populations to new technologies and contribute information about the experiences of diverse populations with new technologies.

DISCUSSION

Moderator: George Isham, M.D., M.S.
HealthPartners

Scott Ratzan, one of the authors of the definition of health literacy used in the IOM report (2004), clarified the way in which that health literacy definition was developed. It was not a consensus project, Ratzan said. The National Library of Medicine (NLM) conducted a review of some 6,000 abstracts and articles to see if the definition would be inclusive for all kinds of research. That definition was then published through the NLM NIH process.

What is important, Ratzan continued, is that the field today does not become too epistemological or ontological on the issue of the definition of health literacy, resulting in the perfect becoming the enemy of the good. Most health literacy research does aim to help America become a more health-literate society.

One participant asked for clarification on the conceptual framework being used to develop the bilingual assessment of the health literacy tool. A portion of the presentation suggested that the project was using an information gain-type model—that is, what somebody knows now that he or she did not know before. But another part of the presentation suggested that the model being used is far more comprehensive.

Hahn said the framework is for the purpose of understanding the big picture. When work began it was assumed that the framework would be a framework just for health literacy. However, the framework that the project ended up using is more of a continuum of what health literacy can impact, taking it all the way to health outcomes. That is where one sees some of the blending of the information gain and the skills.

Another participant said that the tools Hahn is developing are going to be very useful because there is little information on Spanish-language literacy among Spanish speakers in the United States. The few data that do exist indicate that the average literacy level may be lower among Spanish speakers than among English speakers. Has the project considered those who speak English as a second language and how appropriate the English-language instrument is for measuring those people's English literacy?

Those taking the assessment will choose which language they want to use, Hahn said. There will also be a short acculturation scale that asks questions such as, When you are talking to your family, what language do you usually use? When you are talking to your friends, what language do you usually use? What is your country of origin? What languages do you speak at home? Using the answers to these questions, psychometric analyses will be conducted to determine whether items are working differently for those who are fully acculturated in English and those who are not.

One participant asked whether Hahn has considered bilingualism as a language. For example, many Latina mothers obtain information in English as well as Spanish. Their knowledge about medical issues is a mixture of English and Spanish. So information may be given in both languages in a pediatrician's office. However, when testing for health literacy, the test is usually given in one language or the other. Furthermore, when looking at health literacy in children, it has been found that testing in both languages actually provides a better picture of what the children understand.

Hahn said it would be great if the resources were available to conduct testing in both languages; that is certainly something the project could consider for the future.

Another person said that more rigorous definition is needed for what a Spanish speaker is. This participant's group conducted an assessment of the quality of Spanish translations and found that there is a difference between what monolingual Spanish speakers understand and what those who also speak English understand from the same document. The participant went on to say that the translator is only half of the equation. The other half is the introduction of the use, purpose, and context for the materials.

Hahn replied that the project has had a very rigorous translation methodology. A team of people from multiple countries and regions who speak Spanish have been involved in translation for 15 years. The project recognizes that one cannot just translate the words but must also capture the meaning that would be understandable and appropriate for people who speak Spanish across the United States.

A participant said one concern she has is that people can often parrot back the correct response but cannot actually demonstrate what needs to be done. For example, when patients are given the instruction "take two tablets by mouth twice daily," most patients might say that means they should take two pills two times a day. But in one study, only about a third could actually demonstrate what that meant—that is, only about a third could actually count out four pills (Davis et al., 2006).

As another example, the participant continued, one might be able to read the ideal body weight chart, he or she might be able to say what is ideal, but can that person stand on a scale, read his or her own weight, and then tell whether it is within the acceptable range? Has Hahn's project considered developing test items that would determine whether participants could demonstrate the skill needed?

Hahn replied that with item response theory item banks, once one has a well-calibrated bank and knows where the continuum is and whether the items are on that continuum, it is possible to add items at any time. One can add other languages too. If this assessment works as intended and has a unidimensional construct, then it will be possible to add other item types to it and to add other languages.

Hahn said she is currently engaged in another project (in addition to the one described in her presentation) that is using the Talking Touchscreen to administer questionnaires that measure health literacy and deliver patient education materials to newly diagnosed cancer patients. All of that technology can be fed into the electronic medical record. The challenge is that none of the settings in which this project is being conducted has a true electronic medical record.

One participant asked Hahn how long the assessment takes, how easily it can be modified, and whether community health workers could use this tool. Hahn replied that participants currently take 30 to 45 minutes to answer the 30 questions, which is too long. But this stage of testing is for calibration purposes. Once the instrument testing phase is completed, one can customize the test by adding items or expanding it to other languages.

SELF-REPORT MEASURES OF HEALTH LITERACY

Lisa D. Chew, M.D., M.P.H.
University of Washington

Persons with limited health literacy are those individuals who read at a sixth-grade level or less. They often misread the simplest materials, including medication bottles and appointment slips. Persons with marginal health literacy are those individuals who read between a seventh- and eighth-grade level. They are able to perform better on simple tasks than those with limited health literacy, but they have difficulty reading and understanding more complicated materials such as educational brochures and informed consent documents. Persons with adequate health literacy are those individuals who read at a ninth-grade level or above and who are able to complete successfully more tasks required to function in the health care setting.

Approximately 90 million American adults have limited health literacy and lack the needed literacy skills to navigate the health care environment (IOM, 2004). Growing scientific evidence has shown an association between limited health literacy and poorer health outcomes, such as high rates of medication nonadherence (Kalichman et al., 1999), higher hospitalization rates (Baker et al., 1998, 2002), and poorer self-reported health (Baker et al., 1997; Weiss et al., 1992).

Despite the important implications of limited health literacy for patient care, health care providers are often unaware of patients' reading abilities (Bass et al., 2002). Concerns about the implications of limited health literacy on the care of patients have led some experts to advocate for screening for limited health literacy.

Two commonly used formal health literacy assessment instruments are the TOFHLA and the REALM, both of which have been discussed previously. The TOFHLA is a comprehension test that has a short version and a full version. Its administration time ranges from 7 to 22 minutes. The REALM is a word recognition test with average administration time of 2 to 3 minutes. The TOFHLA and the REALM are often used for research purposes.

Despite the existence of these health literacy assessment instruments, there are major barriers to routine screening. Patients are sometimes ashamed of their limited health literacy, and many will attempt to conceal their reading impairments from others. In addition, the length of the formal health literacy instruments limits their clinical use. Finally, although there is an association between educational attainment and literacy level, certain questions that simply ask patients about their reading ability and educational attainment do not always accurately predict reading ability. Therefore, a self-report measure that could quickly and accurately screen patients for limited health literacy would help increase the feasibility of assessing a patient's health literacy in busy settings.

An ideal self-report measure for health literacy would, Chew said, have the following characteristics:

- Quickly identify patients with limited health literacy;
- Be easy to administer so that it could be routinely integrated into busy settings;
- Be acceptable to patients and not cause shame and embarrassment; and
- Accurately identify patients with limited health literacy.

In evaluating the performance of any measure used to screen for a certain condition, whether it is limited literacy, colon cancer, or alcohol use, one often looks at sensitivity and specificity. Sensitivity is the true-positive rate. The higher the sensitivity, the better the measure or question is able to identify patients with this condition. Specificity is the true-negative rate. The higher the specificity, the better the measure or question is able to rule out patients with this condition.

An initial effort at self-report measures of health literacy included three questions: (1) Can you read a newspaper? (2) Can you read forms and other written materials obtained from the hospital? (3) Do you usually ask somebody to help you read materials you receive from the hospital? (Williams et al., 1995). Each of these questions had a dichotomous response of yes or no. Although the specificity was high, the sensitivity—being able to identify the portion of patients with limited health literacy—was low.

A separate study was conducted to determine if one could develop questions that better detect patients with limited health literacy. This study involved 332 patients seeking care at a Veterans Administration (VA) preoperative clinic. The gold standard to determine if a patient had limited health literacy was a Short Test of Functional Health Literacy in Adults (STOFHLA). Of the 332 participants, the mean age was 58.2 years. Participants were mostly men and white. Thirty-eight percent had 12 years or less of education. Some 4.5 percent of patients had limited health literacy, and another 7.5 percent had marginal health literacy (Chew et al., 2004).

The content of the questions was based on important domains identified in a prior qualitative study of patients with limited health literacy.

That study (Baker et al., 1996), which involved using focus groups in one-on-one interviews, reported five problem areas that patients with limited health literacy experienced when interacting with the health care system:

- Navigating the health care system;
- Completing medical forms;
- Following medication instructions;
- Interacting with providers; and
- Reading appointment slips.

In addition, previous studies reported the frequent use of a surrogate reader as a common coping mechanism for patients with limited health literacy. These six domains guided the development of the health literacy screening questions.

In anticipation of the underreporting of reading difficulties due to the shame associated with limited health literacy, several methods were used to attempt to increase patient reporting. Questions were developed for other sensitive areas, such as alcohol use, and were phrased as "how often" or "how confident" the patient was in each domain rather than asking if he or she had problems. Second, response options were scaled from 0 to 4 to allow patients to report even rare problems with reading. Finally, to avoid restrictions in patient reporting, no time frame or visit setting was specified for reading difficulties.

Of the 16 questions included in this study, the three strongest screening questions for detecting limited health literacy were the following:

- How often do you have someone help you read hospital materials? (*Help Read*) (five possible responses ranging from never to always)
- How confident are you filling out medical forms by yourself? (*Confident with Forms*) (five possible responses ranging from not at all to extremely)
- How often do you have problems learning about your medical condition because of difficulty understanding written information? (*Problems Learning*) (five possible responses ranging from never to always)

The graph in Figure 3-8 represents the Receiver Operating Characteristic (ROC) curves of these three screening questions for detecting limited health literacy. The ROC curves plot the sensitivity versus 1 minus the specificity and allows us to graphically portray the trade-offs involved between improving a question's sensitivity or its specificity. The area

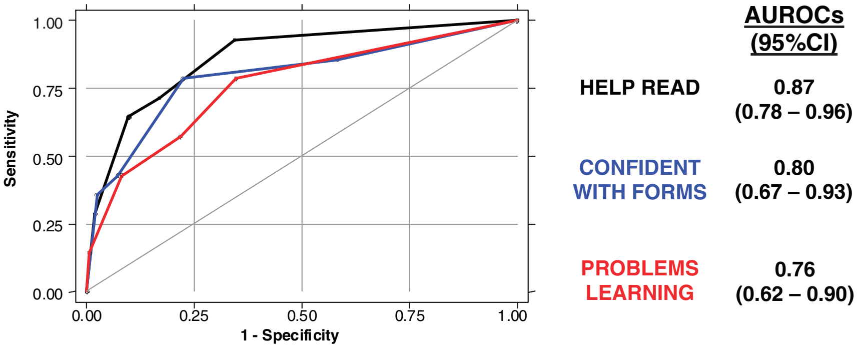


FIGURE 3-8 Receiver Operating Characteristic curves for detecting limited health literacy.
SOURCE: Chew, 2009.

under the curve is a useful summary of the overall accuracy of a question and can be used to compare the accuracy of two or more questions. An ideal question is one that reaches the upper left corner of the graph with an Area Under the Receiver Operating Characteristic (AUROC) of 1.0. A poor-performing question is one that follows the diagonal from the lower left to the upper right corner with an AUROC of 0.5. The difference in the performances of these questions was not statistically significant.

In identifying patients with limited health literacy, the *Help Read* question had a sensitivity of 93 percent and a specificity of 65 percent at the threshold of the occasionally or greater response. The self-report screening questions were less effective in identifying patients with marginal health literacy. Combining the questions did not improve the screening performance of detecting limited health literacy or limited marginal health literacy.

Results of this study show that each of the three health literacy screening questions listed above was effective in identifying VA patients with limited health literacy, potentially offering a practical, inexpensive, and unobtrusive method to identify those at risk for reading difficulties.

There have been three studies validating the performance of these three questions in other populations. Wallace and colleagues (2006) conducted a study among 305 English-speaking adults at a university-based primary care clinic and found a 17.7 percent prevalence of limited health literacy. Another study (Wallace et al., 2007) among 100 English-speaking adults at a university-based vascular surgery clinic found an 18 percent prevalence of limited health literacy. More recently, a study of 1,796 English-speaking adults at four VA medical centers found a 6.8 percent prevalence of limited health literacy (Chew et al., 2008). In all three validation studies, the question "how confident are you filling out medical forms by yourself?" appeared to be the strongest-performing question.

Another recent study conducted in a primary care clinic among 225 patients with diabetes found a 15.1 percent prevalence of limited health literacy (Jeppesen et al., 2009). The responses to the three questions were combined with demographic information (highest education attained, sex, race) into one predictive model. The three questions were

- How would you rate your reading ability?
- On a scale of 1 to 10 where 1 is "not at all" and 10 is "a great deal," how much do you like reading?
- How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?

The raw data were not presented, so it is not possible to determine the screening performance of these questions.

There have been conflicting opinions about whether the performance of these self-report health literacy questions is better than demographic information (e.g., education level, age) alone in detecting limited health literacy. Preliminary and unpublished data from the Minneapolis VA show no differences in the two measures of self-reported education attained and the *Confident with Forms* question. This suggests that further research may be needed to determine whether education level and other demographic characteristics in certain populations may perform as well as the self-report measures discussed here.

The strengths of the self-report measures include the finding that limited health literacy may be detected with a single question. The measures are easy to administer and can be administered by anyone with minimal training. These measures may also be more acceptable to patients than a formal test, causing less shame and embarrassment. Because the measures are quick and easy to administer, they are practical to use in different settings. The measures may be a useful tool for identifying patients who may need more formal health literacy testing and for allocating resources to those patients at highest risk.

The weakness of these measures is that their generalizability is unknown. The development and validation studies were conducted at either a VA health care center or at university-based clinics, where the prevalence of limited health literacy is lower than what would be anticipated at a public hospital. It may be that different questions produce varying results in different populations.

What is also unclear is how these measures would perform in other languages. Furthermore, although these questions are able to detect patients with limited health literacy, the ability to detect marginal health literacy was less optimal. Finally, more studies are needed to determine whether the predictive value of these questions is better than demographic variables alone for limited health literacy.

In conclusion, Chew said, future research is needed to answer additional questions about the use of these measures. First, how do these questions perform in populations and languages other than those studied? Second, do self-report measures perform better than demographic variables, and could combining demographic characteristics and self-report measures improve screening performance? Third, how can these measures be integrated into systems of care and what are appropriate, practical, and feasible interventions for patients who screen positive? Finally, do screening and interventions improve the health outcomes of patients with limited health literacy?

DISCUSSION

Moderator: Cindy Brach, M.P.P.
Agency for Healthcare Research and Quality

One participant asked Chew how much of the work she has done has spread throughout the VA. Is there any uptake in using the tool and applying it to change interventions for individuals identified as having marginal health literacy? Chew said one of the challenges is how to integrate health literacy questions into systems of care. Some small pilot studies have been conducted with pharmacy care management of patients with chronic illness. Also, an electronic record system called MyHealth*e*Vet is an online tool for VA patients to use. It was developed with a consumer focus and guided by the belief that knowledgeable patients are better able to make informed health care decisions, stay healthy, and seek services when needed than those without adequate knowledge.

One participant, Dr. Cecil Garcia from Harlingen, TX, said he used Chew's study to conduct research on health literacy in Spanish-speaking patients. According to the Dartmouth Atlas data, this area of Texas has high costs but a low quality of care. Garcia translated Chew's questions into Spanish and examined 116 patients. The prevalence of inadequate literacy was 45 percent in these Spanish-speaking patients. Questions were asked orally because the reading level was at the third- or fourth-grade level. If patients are given information that is above their reading levels, the information is not going to help.

MEASURING THE FUNCTION IN FUNCTIONAL HEALTH LITERACY

Sandra Smith, M.P.H.
University of Washington School of Public Health

A very different approach to assessing health literacy from those discussed previously is one that focuses on function. The *National Literacy Act of 1991*, Public Law 102-73, 102nd Congress, 2nd session (July 25, 1991), marked a significant evolution in the understanding of literacy in America. That legislation aimed to broaden the concept of adult literacy and to differentiate it from the concept of basic literacy skills. The Act defined literacy as the "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 develop one's knowledge and potential."

Hourigan (1994) used the term "academic literacy" to differentiate students' mastery of cognitive skills from adults' functional literacy. Academic literacy is focused on reading, writing, and arithmetic. Functional literacy, however, involves putting into real-world practice a wide range of cognitive and noncognitive problem-solving communications, interpersonal, and lifelong learning skills. Functional literacy is about what adults do rather than what they are capable of doing.

Academic literacy skills are considered to be individual, static, and transferable across settings. In contrast, functional literacy skills are social, evolve over time, and are content specific. An adult may, therefore, have many functional literacies. For example, computer literacy enables a person to use a computer but not necessarily to read the manual or understand programming language. Similarly, functional health literacy enables people to use the health care system and take care of themselves but not necessarily to read insurance documents and understand medical terminology.

Academic literacy becomes apparent in reading and comprehension test scores. A good score suggests capability to function in other settings. Functional literacy, however, is about social practices instead of individual abilities. It manifests in actions, behaviors, and relationships. Functional literacy requires authentic assessment, which means assessment of performance or practice in the real world.

Measures matter because they drive intervention. What is measured and how it is measured determines what is discovered about what works and what is worth doing. Researchers and policy makers have dropped the function from functional health literacy and have switched the focus back to academic skills and reading tests. Nearly all studies have operationalized health literacy as reading skills in a medical setting and measure those skills by standardized reading tests. The focus has been on understanding information. As a result, interventions primarily have been aimed at making information easier to understand by reducing the cognitive demand.

Such work is important and must continue, but it does have its limitations. What has been learned from intervention studies is that improved information does improve knowledge for readers with both higher and lower reading skills. However, skilled and unskilled readers alike still struggle to use their acquired knowledge. Reading and understanding information are important parts of functional health literacy, but they offer an incomplete picture and they are insufficient to promote appropriate use of health services, good self-care, and improved health.

The problem with focusing on academic skills and information is that, like money, one needs it. But what one really needs is not the money itself, but what the money enables one to do. Similarly, it is not really the information that patients need for health, it is what the information enables them to do and how it enables them to function, and that is the function in health literacy.

A number of literacy scholars characterize types of levels or layers of literacy. Donald Nutbeam (2000, 2008) applied the work of Freebody and Luke (1990) to characterize three types of health literacy. One type is functional health literacy, defined as reading and writing *associated* with tasks. In this usage it is associated with literacy tasks—read the list of words, then pass the comprehension test. This is the stage of the field in its measurement of health literacy. Nutbeam also refers to functional health literacy as fundamental or basic literacy that is associated with everyday tasks.

Interactive literacy is another type of literacy. It requires social skills such as listening and speaking to complete more complicated interactive tasks. Such tasks might be making an appointment, getting to the appointment, describing symptoms, and listening to treatment instructions. This type of health literacy is analogous to oral health literacy.

Critical reflection is the third and higher level literacy that is needed to manage one's health. As an example, a mother goes to the pediatrician and hears that her baby should sleep on his back to avoid Sudden Infant Death Syndrome. She hears from her grandmother that the baby should sleep on his stomach to avoid aspiration. She needs critical literacy, reflective literacy, to differentiate the sources of information to reconcile the conflicting advice, to manage the power differentials, to control the sleep position for her son, and to thereby manage his health.

The current conceptualization and measures of health literacy miss much of this deeper meaning and purpose of literacy for health.

What does this conceptualization have to do with measurement?

One might infer from the use of the term "functional" in this model that interactive health literacy and reflective health literacy are not functional. That is not the case. It is possible to extend the idea of function to all three types of health literacy. Functional health literacy, then, becomes a concept that describes the practical application of a wide range of cognitive and noncognitive skills in real life, rather than a single literacy skill in a clinical setting. Functional health literacy is the outcome of intervention rather than the independent variable. It captures how people use literacy for health as patients and also as family members, workers, and citizens. It captures social capital.

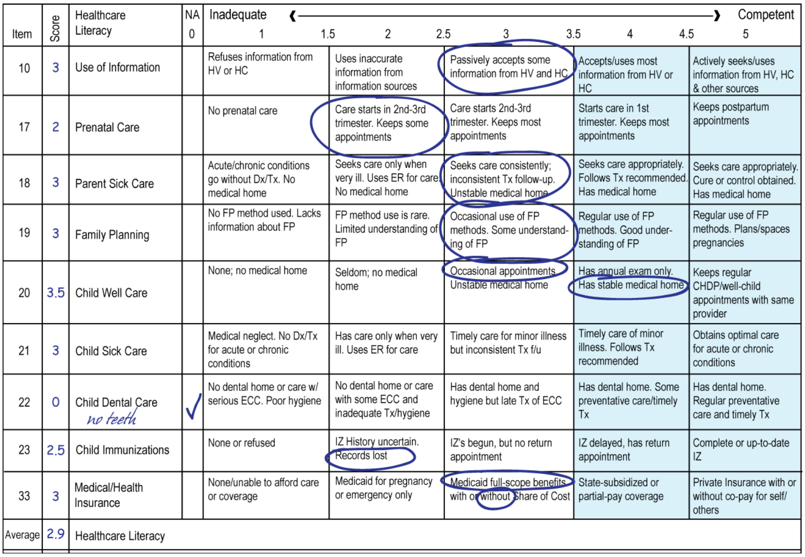
Measurement

How can one measure the function in functional health literacy? A good example of promoting many aspects of family functioning can be found in the work of public health nurses in maternal and child health home visitation programs. These visiting nurses link disadvantaged parents to health care services and community resources. They provide social support, practical assistance, information, and health education. Many of these programs use an instrument called the Life Skills Progression^{TM} (Wollesen and Peifer, 2006) to monitor parents' progress toward higher levels of functioning.

To measure functional health literacy, two scales were derived from the Life Skills Progression instrument: a Functional Healthcare Literacy Scale (Figure 3-9) and a Functional Selfcare Literacy Scale (Figure 3-10). The Functional Healthcare Literacy Scale rates parents' use of health information and services for both parent and child. Each of the items is a Likert scale that identifies behaviors, practices, and characteristics that indicate progressive levels of function that range from dysfunction to optimal functioning. Scores greater than 4 indicate adequate to optimal functioning. One might think of this scale as a map and the items as pathways toward optimal functioning in a health care system.

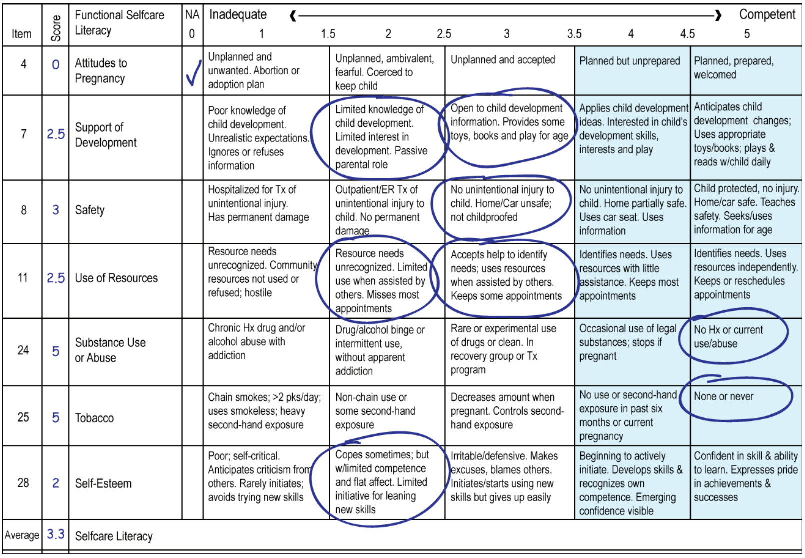
Both of these assessments function in the same manner. To monitor progress, a home visitor completes the instrument on a parent at intake, every 6 months, and at end of service. The comparison of these sequential measures allows one to track progress over time and to see points of regression. The data are immediately available for intervention planning.

The elegance in measuring function is that it provides for solutions along with the identification of problems. One can choose to intervene on a need, which would be indicated by a low score on the left in Figure 3-10. One can also choose to intervene by building on a strength, which is indicated by a high score on the right. Subsequent measurement allows one to see the impact of the interventions.



Item	Score	Healthcare Literacy	NA	Inadequate				Competent
			0	1 1.5	2 2.5	3 3.5	4 4.5	5
10	3	Use of Information		Refuses information from HV or HC	Uses inaccurate information from information sources	[✓ Passively accepts some information from HV and HC]	Accepts/uses most information from HV or HC	Actively seeks/uses information from HV, HC & other sources
17	2	Prenatal Care		No prenatal care	[✓ Care starts in 2nd-3rd trimester. Keeps some appointments]	Care starts 2nd-3rd trimester. Keeps most appointments	Starts care in 1st trimester. Keeps most appointments	Keeps postpartum appointments
18	3	Parent Sick Care		Acute/chronic conditions go without Dx/Tx. No medical home	Seeks care only when very ill. Uses ER for care. No medical home	[✓ Seeks care consistently; inconsistent Tx follow-up. Unstable medical home]	Seeks care appropriately. Follows Tx recommended. Has medical home	Seeks care appropriately. Cure or control obtained. Has medical home
19	3	Family Planning		No FP method used. Lacks information about FP	FP method use is rare. Limited understanding of FP	[✓ Occasional use of FP methods. Some understanding of FP]	Regular use of FP methods. Good understanding of FP	Regular use of FP methods. Plans/spaces pregnancies
20	3.5	Child Well Care		None; no medical home	Seldom; no medical home	[✓ Occasional appointments] Unstable medical home	Has annual exam only. [✓ Has stable medical home]	Keeps regular CHDP/well-child appointments with same provider
21	3	Child Sick Care		Medical neglect. No Dx/Tx for acute or chronic conditions	Has care only when very ill. Uses ER for care	Timely care for minor illness but inconsistent Tx f/u	Timely care of minor illness. Follows Tx recommended	Obtains optimal care for acute or chronic conditions
22	0	Child Dental Care no teeth	✓	No dental home or care w/ serious ECC. Poor hygiene	No dental home or care with some ECC and inadequate Tx/hygiene	Has dental home and hygiene but late Tx of ECC	Has dental home. Some preventative care/timely Tx	Has dental home. Regular preventative care and timely Tx
23	2.5	Child Immunizations		None or refused	IZ History uncertain. [✓ Records lost]	IZ's begun, but no return appointment	IZ delayed, has return appointment	Complete or up-to-date IZ
33	3	Medical/Health Insurance		None/unable to afford care or coverage	Medicaid for pregnancy or emergency only	[✓ Medicaid full-scope benefits] with or [✓ without] Share of Cost	State-subsidized or partial-pay coverage	Private Insurance with or without co-pay for self/others
Average	2.9	Healthcare Literacy						

FIGURE 3-9 Functional Healthcare Literacy Scale.
SOURCE: Wollesen and Peifer, 2006. Reprinted by permission from Paul H. Brookes Publishing Co., Inc.



Item	Score	Functional Selfcare Literacy	NA	Inadequate				Competent
			0	1 1.5	2 2.5	3 3.5	4 4.5	5
4	0	Attitudes to Pregnancy	✓	Unplanned and unwanted. Abortion or adoption plan	Unplanned, ambivalent, fearful. Coerced to keep child	Unplanned and accepted	Planned but unprepared	Planned, prepared, welcomed
7	2.5	Support of Development		Poor knowledge of child development. Unrealistic expectations. Ignores or refuses information	[✓ Limited knowledge of child development. Limited interest in development. Passive parental role]	[✓ Open to child development information. Provides some toys, books and play for age]	Applies child development ideas. Interested in child's development skills, interests and play	Anticipates child development changes; Uses appropriate toys/books; plays & reads w/child daily
8	3	Safety		Hospitalized for Tx of unintentional injury. Has permanent damage	Outpatient/ER Tx of unintentional injury to child. No permanent damage	[✓ No unintentional injury to child. Home/Car unsafe; not childproofed]	No unintentional injury to child. Home partially safe. Uses car seat. Uses information	Child protected, no injury. Home/car safe. Teaches safety. Seeks/uses information for age
11	2.5	Use of Resources		Resource needs unrecognized. Community resources not used or refused; hostile	[✓ Resource needs unrecognized. Limited use when assisted by others. Misses most appointments]	[✓ Accepts help to identify needs; uses resources when assisted by others. Keeps some appointments]	Identifies needs. Uses resources with little assistance. Keeps most appointments	Identifies needs. Uses resources independently. Keeps or reschedules appointments
24	5	Substance Use or Abuse		Chronic Hx drug and/or alcohol abuse with addiction	Drug/alcohol binge or intermittent use, without apparent addiction	Rare or experimental use of drugs or clean. In recovery group or Tx program	Occasional use of legal substances; stops if pregnant	[✓ No Hx or current use/abuse]
25	5	Tobacco		Chain smokes; >2 pks/day; uses smokeless; heavy second-hand exposure	Non-chain use or some second-hand exposure	Decreases amount when pregnant. Controls second-hand exposure	No use or second-hand exposure in past six months or current pregnancy	[✓ None or never]
28	2	Self-Esteem		Poor; self-critical. Anticipates criticism from others. Rarely initiates; avoids trying new skills	[✓ Copes sometimes; but w/limited competence and flat affect. Limited initiative for leaning new skills]	Irritable/defensive. Makes excuses, blames others. Initiates/starts using new skills but gives up easily	Beginning to actively initiate. Develops skills & recognizes own competence. Emerging confidence visible	Confident in skill & ability to learn. Expresses pride in achievements & successes
Average	3.3	Selfcare Literacy						

FIGURE 3-10 Functional Selfcare Literacy Scale.
SOURCE: Wollesen and Peifer, 2006. Reprinted by permission from Paul H. Brookes Publishing Co., Inc.

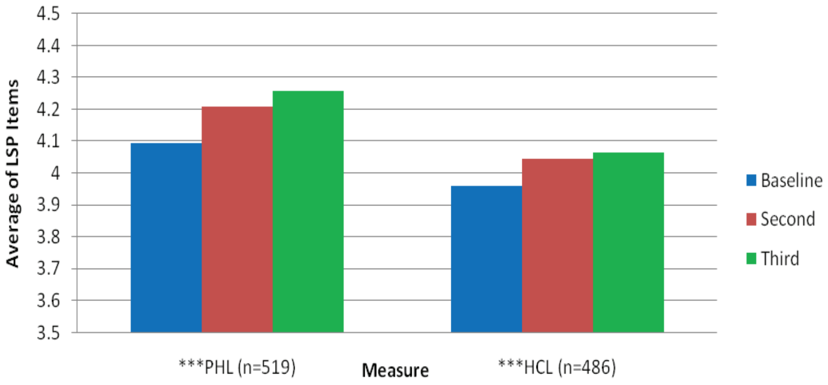
These scales demonstrated good reliability. Validity testing is under way.

Results

This project was a 2-year, quasi-experimental, multicohort intervention study with multiple waves of measurement. The total database from seven home visitation programs has 2,532 parents. The data below are on about 1,800 of those parents. One can see in Figure 3-11 that the intervention worked quickly in the first six months. Parents demonstrated statistically significant linear stepwise progress over time, regardless of their reading level.

Conclusion

Measuring function is important in assessments of health literacy, Smith said, because measuring function captures the impact of efforts to reduce the risk of low literacy skills as well as the efforts to promote functioning directly. It allows the integration of the social determinants of health, it guides interventions, it informs practice, and it is patient centered. The Life Skills Progression method presented here could be



*** Time: p<.001

N = 1,808 Time in service = 36 mo P < 0.001

Change in Health Care Literacy and Personal Care Literacy Over Time with Home Visitation

FIGURE 3-11 Home visitation promotes parental functional health literacy.
SOURCE: Smith, 2009.

adapted for clinical use, particularly for adults with chronic conditions that require frequent visits, clinical encounters, and significant self-care.

Is the instrument clinically feasible? It takes an experienced user about 5 minutes to complete both of the scales, and the data are immediately available for intervention planning. There is a limitation in that the assessments were implemented in home visitation programs, a hallmark of which is that the visitor and the family build a relationship over time. Therefore, the degree to which the clinical practice environment limits relationship development could affect use of the instrument.

In conclusion, Smith said, focus on function.

HEALTH LITERACY AND CANCER PREVENTION: DO PEOPLE UNDERSTAND WHAT THEY HEAR?

Kathleen Mazor, Ed.D.
University of Massachusetts Medical School

The focus of this R01-funded project is on understanding spoken communication. The project team was multidisciplinary, and the research was carried out within the Cancer Research Network (CRN). The CRN is a consortium of 14 health plans around the country that cover approximately 10 million enrollees (about 4 percent of the population).

Not much attention has been paid to oral communication in the health literacy field. It is often said that if people cannot read, one needs to speak with them or let them listen to an audio version of the information. But do people actually understand even if they hear information? It is not just a question of hearing the words—the listener must know what the words mean and the context within which the words are spoken and be able to act on the information provided. Better measurement of oral communication is important in improving health literacy.

The project has three aims, although this presentation will discuss only the first aim, which is to develop and validate a psychometrically sound test of oral health literacy. The project also aims to investigate the relationship between oral health literacy and cancer prevention behaviors by comparing scores from the instrument with actual health behaviors. The third aim is to develop and test recommendations for improving oral communication about cancer prevention and screening.

Measurement

The first step in developing the measures for assessing oral health literacy was to specify the test blueprint. Because the assessment was administered in the CRN, the focus was on common cancers (breast, cervical, colorectal, general, lung, prostate, and skin), cancer prevention, and screening. Not included were factors such as diagnosis, treatment, follow-up, and survival. The blueprint also specified the context within which messages are received (e.g., media or clinical), the style of the communication (i.e., narrative, statistical or numeric, factual), the purpose of the communication (i.e., instruction, information, or query), and the content of the information (i.e., prevention, screening methods, or risk factors).

The next step was to collect and examine messages about cancer that one might receive from different media, including television, radio, the Internet, and patient education materials. Of great importance was the need to include only those clips that contained accurate information. Furthermore, a variety of clips that represented the kinds of thing one might encounter in everyday life were included.

The selected clips of oral communication varied in content. Some clips showed a person describing his or her cancer experience, or the experience of quitting smoking. These personal stories were identified as *narratives*. Another set of clips presented factual information such as the type of cancer or the stage of the cancer. Such information can be delivered in three different ways: (1) One can simply provide information, (2) one can potentially provide information and then ask something about it, or (3) one can give someone an instruction with the intention that the person take action related to that information.

The third step was to develop some clinical vignettes. To construct such vignettes, physicians agreed to participate in role playing, which would be audiotaped and then transcribed. A professional writer helped create the scripts, which clinicians then reviewed and revised. After that, the project team conducted its own review and revisions. The project team then produced videos of those vignettes.

The next step was to construct the items for the test. Unfortunately, while there is literature on different approaches to use in developing items, there is not a great deal of literature on how to measure comprehension. The approach the team chose to use is the sentence verification technique (SVT).[3] This is a method that is used to examine comprehension of text messages. The first step is to select a portion of the transcript that contains what one is trying to measure. Next, the sentence(s) is paraphrased so that the wording is changed but the meaning remains

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[3] "The Sentence Verification Technique (SVT) is a procedure that non-psychometricians can use to develop reading and listening comprehension tests that can be based on a wide variety of text materials" (http://www.readingsuccesslab.com/publications/Svt%20Review%20PDF%20version.pdf). Accessed April 12, 2009.

constant. The information is also rewritten so that the wording is similar to the original sentence(s) but with a different meaning.

For example, an original sentence said "overall HPV [human papillomavirus] prevalence among females in the United States, ages 14 to 59 years of age, was 26.8 percent, and that means one in four women are infected with HPV." When the original material was paraphrased, the result was written as, "A quarter of women ages 14 to 59 are infected with HPV." When the material was rewritten for a meaning change, the sentence read, "One in four women in the United States are infected with cervical cancer," which is not true because only certain HPV strains develop into cervical cancer.

A respondent would hear the original statement and then hear either the paraphrase or the changed-meaning statement. Then the respondent would be asked, "Is the meaning of the statement about the same as the content of the original sample, or is it different?"

Testing

Pilot testing is currently under way. The test is administered using a touchscreen laptop. No reading is required; everything is spoken. Instructions are given at the beginning, and the test takes about an hour. Currently, the test has 16 videos and 66 questions. It is in English only, which is a limitation imposed because of resources available.

Participant feedback on the test is that it is user friendly, even for those unfamiliar with a computer; it is engaging and informative; it has clear instructions; and participants are not fatigued at the conclusion of the test. Once pilot testing is completed, the items will be revised and the test will then be administered to about 1,000 adults at four sites.

Conclusion

Results to date have shown that the comprehension of spoken measures is variable, Mazor said. Measuring comprehension of spoken messages is challenging because many factors affect comprehension and all of those factors cannot be evaluated fully in a single study.

DISCUSSION

Moderator: Cindy Brach, M.P.P.
Agency for Healthcare Research and Quality

One participant said it appears that what both the assessment of functional health literacy described by Smith and the assessment of oral health literacy described by Mazor are attempting to do is to develop more authentic health literacy measures. For the future, in terms of functional health literacy, what are some of the factors that may predict whether people score high or low on a functional scale? Smith said that major predictors are likely to be self-efficacy, confidence, and social support. Sometimes having a child will galvanize one's motivation and interest, and parents become very ready to learn and to change.

Another participant commented that Smith's measure has not focused on prediction, but rather on intervention and how one moves forward with that. It is very exciting to think about obtaining information that one can use to intervene and improve health outcomes.

One participant stated that in terms of what had been presented as measures for health literacy, what was missing was a focus on measurement specifically related to either parents or children. The way in which health literacy is measured in adults is very different from what parents understand about taking care of their children's health. Furthermore, measuring health literacy in children, from young children through adolescence, is exceedingly complex. The main social support for a child is the parent or caregiver. But as the child moves from childhood through adolescence to adulthood, there is dynamic change in whose knowledge and whose management determines health actions.

Smith responded that the functional health literacy measure is designed specifically to address literacy in parents and how it affects children's health. Ratzan suggested that a framework for health literacy could follow a life course determinant model. One of the things such a model would do is address the issue raised earlier about the lack of measures of parent and child health literacy.

One participant referenced the levels of intervention in the health care system discussed in the report *Crossing the Quality Chasm* (IOM, 2001). The discussion describes opportunities to intervene at different levels, such as at the level of the individual patient, the team, the organizational level, and the specific context or environment. These different approaches to measuring health literacy appear to be moving back and forth among these levels. At some point, it might be helpful to develop a table or graph that sets out the domains of activity and organizes the measures at different levels within these domains. Developing such a table might help clarify which factors contribute to problems in health literacy at different levels. On the other hand, such a table might help determine which interventions are likely to work at different levels.

Smith responded that the Life Skills Progression Instrument and the functional health literacy measure derived from it are used at all levels. The data are rich with information for the individual level, the particular practice level, and the organizational level. The assessment looked at seven different programs with a number of visitors in each one. Analysis of differences among sites is ongoing. Not every site achieves the same progress. Differences in program emphasis and differences in individual visitor practices create different levels of progress for the families.

One participant said he appreciated the focus on functionality, which is important to incorporate into the testing of health literacy. Also important are constructs from behavioral science, such as the self-efficacy construct used by Smith. Were there other constructs from behavioral theories that could be suitably incorporated into measurement of functional health literacy? Smith said health belief model theories can be incorporated.

One participant said Mazor appeared to be looking at oral health literacy in a static way rather than taking advantage of the simple ability in an interpersonal situation to ask a question for clarification. Is that being factored into the analysis? Mazor responded that it is not because of the resource limits and constraints of the testing situation—administering a test that did not require someone to score it. It is an important piece missing from the study, but there is still value in learning whether people understand information when they hear it the first time.

If one could get at the interaction effect, the participant continued, there is an opportunity to weave health literacy into the care model. The care model[4] is a systems approach to health care that involves productive interactions among activated patients and informed providers. If one could weave health literacy into that model, it could be a very important way to evaluate whether those interactions have been productive.

Mazor said that one will probably find that people do not understand a lot of what are fairly simple bits of interactions. It is important to know that what is said in interactions is not understood in the same way that print literacy is understood.

Another participant from Health Literacy Consulting said that her experience has shown that difficulty in understanding is increased at the moment of encounter when the provider speaks English but the patient speaks English as a second language. Assessment of oral health literacy would benefit from looking at this issue.

One participant asked whether there is any assessment that observes what happens during an interaction between the patient and clinician, either with a peer observation of the process, a patient exit interview, a

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[4] "The Care Model is a population-based model that relies on knowing which patients have the illness, assuring that they receive evidence-based care, and actively aiding them to participate in their own care. . . . Effective outpatient chronic illness care is characterized by productive interactions between activated patients (as well as their family and caregivers) and a prepared practice team. This care takes place in a health care system that utilizes community resources" (http://www.tachc.org/HDC/Overview/CareModel.asp). Accessed April 12, 2009.

doctor exit interview, or another method. Cindy Brach responded that John Hopkins University has a project where interactions are videotaped in order to study the nature of the interaction.

One participant asked, for the assessment of oral health literacy taking place in the CRN, are there any plans to study people's ability to understand information under distressing conditions? For the most part, it appears these assessments are being conducted under ideal conditions. But how will patients perform when they have just been given distressing news, such as that they have cancer or that they need to come back for a second mammogram?

Mazor said that issue is very important, but it is not something that is covered by the study described. An assessment conducted under stressful conditions would require different measurement questions from the kind of standardized instrument being tested in the assessment of oral health literacy.

Another participant said it appears that for each of the items included in the assessment described by Mazor, one can examine the difference in difficulty of each of the messages as well as the performance of individual participants. There are informed providers (i.e., the messages) and activated patients (i.e., participants). One should be interested not only in the performance of the participants—the test takers—but also the performance of the items that represent the context.

Mazor said she agreed completely. Looking at how difficult the items are—the items within a clip and the individual items associated with each clip—is important. It is planned that during the final year of the project work can focus on modifications to messages that allow one to test whether it is easier to give a message in one way versus another. That would, hopefully, lead to recommendations to providers as well as public health communication personnel about how better to construct messages.

One participant said that the study under discussion is measuring both the understanding of the stimulus and the understanding of the question. But is the study trying to match these in terms of level of difficulty? Mazor said that each of the demonstrations will have a number of restatements associated with it. One could conceivably write easy ones or hard ones. One does not want everything to be too easy because that would not allow discrimination of levels of health literacy. The level of difficulty is really a function of both the original statement and the item associated with that statement.

Another participant said that one of the differences between oral communication and print communication is that the printed material can be taken home while the oral communication exists in the interaction only. Additionally in terms of the immediacy of measurement, there is also the delay factor. Has thinking been given to exploring not only what is understood in the office, but what is understood once the patient returns home?

Mazor said that one of the reasons print materials are valuable is because one can take them and review them later. Patients want materials to take home. This underscores the fact that attention must be paid to print material. In the study of oral health literacy, there are measures of cognitive function as well as memory.

4

Population-Based Approaches to Assessing Health Literacy

DEMOGRAPHIC ASSESSMENT FOR HEALTH LITERACY

Amresh Hanchate, Ph.D.
Boston University School of Medicine

The approach described here is based on work described in a recent article published in the *Journal of General Internal Medicine* (Hanchate et al., 2008). This approach uses a different method for assessing health literacy, not in-person questions or even phone questions, but an indirect way of imputing health literacy based on patient sociodemographic indicators such as age, education, etc. Miller and colleagues (2007) proposed a similar measure based on social demographics. The main difference is that the Demographic Assessment of Health Literacy (DAHL) has been tested for external validity by applying it to population-representative samples from other surveys.

The DAHL is not used to make individual-level assessments of health literacy. Instead, it is for use in population-level analysis. The objectives of the DAHL are as follows:

- To impute limited health literacy from sociodemographic indicators; and
- To estimate the association of imputed limited health literacy with indicators of health status and compare findings with those from a measured indicator of limited health literacy (Short Test of Functional Health Literacy in Adults, or S-TOFHLA).

A number of recent studies have examined the association of health literacy with poor health status, health outcomes, and health care utilization. Most of these studies have small samples, which is understandable because in-person health literacy assessment is time-consuming and costly. But the representativeness of these samples to the general population is unknown.

As has been discussed previously, health literacy is a social construct. It is intimately connected with the socioeconomic environment and with demographics. Health literacy is also complex. A few sociodemographic measures will not account for all individual differences in health literacy. For example, some people with substantial schooling may still have inadequate health literacy, and such cases will be captured only by direct measurement.

However, when one is examining population-level interrelationships such as the extent to which limited literacy is correlated with poor health status, sociodemographic factors may drive a majority of differences in health literacy. A derived measure would allow easy quantification of this relative contribution.

The potential gains of a demographic assessment could be substantial. The derived health literacy measures would be applicable to nationally representative survey data such as those obtained in the National Health Interview Survey (NHIS), the Medical Expenditure Panel Survey (MEPS), and the Medicare Current Beneficiary Survey (MCBS). Using the derived measure, one could then exploit the richness of such datasets, examining the relationship of health literacy with health outcomes (especially rare events that are harder to investigate in small datasets) and with health care utilization.

Methods

Two main steps are involved in deriving the DAHL. First, one obtains the imputed measure of health literacy using a dataset that has a direct measure of health literacy, in this case the Prudential Survey data. The Prudential Survey includes an individual measure of health literacy based on the short-form TOFHLA instrument. It is one of the largest such health surveys, with a sample of about 3,000, and is representative of a number of regions around the country. The sample frame for the survey was all new enrollees to a Medicare health maintenance organization plan in four locations (Cleveland, OH; Houston, TX; South Florida; and Tampa, FL) during the 9 months from December 1996 to August 1997. The survey excluded those not living in the community, those with severe cognitive impairment, and those who were not comfortable speaking in either

English or Spanish. The effective response rate for the survey was 41 percent. Data from the Prudential Survey have been the source for a number of published studies evaluating the association between inadequate health literacy and health status.

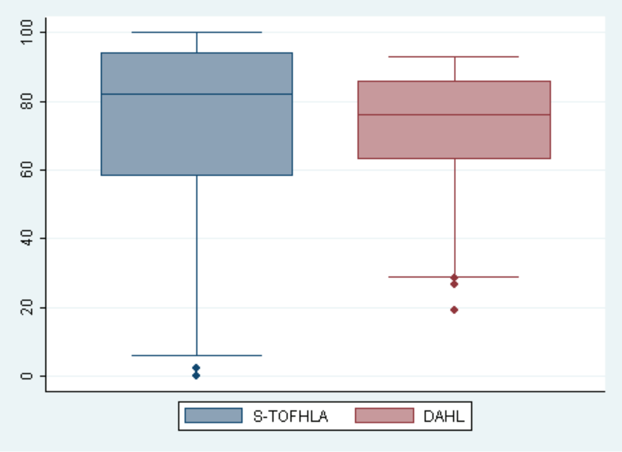
Data from the Prudential Survey was used to estimate the linear statistical relationship between the measured S-TOFHLA health literacy score and the four selected sociodemographic indicators (age, highest educational achievement, sex, and race/ethnicity). The estimates—that is, the coefficients of the regression model—were then used as scoring weights for obtaining the imputed measure of health literacy. The Prudential data were used to evaluate the concordance between the DAHL and the S-TOFHLA.

The second step of the analyses applied the imputed scoring method to external data using two nationally representative health surveys: the 1997 NHIS and the Health and Retirement Study (HRS). The NHIS population chosen was the subset of those 65 or older, with a resulting sample of about 7,000. The HRS sample size of elderly was about 10,000. Neither of these surveys has a validated measure of health literacy.

The main analyses performed for external validation compared the association of limited health literacy with health status measures. Four health status measures were identically defined in all three surveys examined, that is, in the internal data source (Prudential) and the two external data sources (NHIS and HRS). These four measures are general health (poor or fair), hypertension, diabetes, and difficulties with activities of daily living (ADL). Logistic regressions of the health status measures were estimated as a function of the indicator of limited literacy, household income, marital status, and geographic location. This was done separately using each of the three data sources.

Results

Figure 4-1 compares the distribution of the original measures of health literacy score in the Prudential Survey using the S-TOFHLA with the imputed scores of the DAHL. An important difference is that the imputed scores have a more compact distribution because the imputed scores are derived from only a few factors; the measures' scores range from 0 to 100, but the imputed scores range from 19 to 93. A sizable portion of measured scores are above 80; nevertheless, as the imputed scores are squeezed in, the median score decreases from 83 to 76. In terms of the ability to discriminate relative differences in health literacy, the DAHL does fairly well, that is, the Area Under the Receiver Operating Characteristic (AUROC) curve is 81 percent. Typically the bottom 25 percent is classified as those



AUROC = 0.81 % correctly classified = 79%

(Prudential Medicare Study; N = 2,842)

FIGURE 4-1 Results: Comparison of S-TOFHLA and DAHL scores.
SOURCE: Hanchate, 2009.

with limited literacy. If that is also done for the DAHL, then 79 percent of the observations are correctly classified into those with limited literacy and others.

Results of applying the DAHL and comparing the association of limited health literacy with health status outcomes from the NHIS can be seen in Table 4-1.

Results show that those with measured inadequate literacy using the S-TOFHLA were 77 percent more likely to report their general health to be fair or poor. If the derived indicator of inadequate literacy is used, then for the same data, the association was virtually identical. If one looked at the NHIS data and used the derived measure, the estimate was very similar.

There is concordance for hypertension, too, although of a different sort. That is, in none of the cases was the association sizable or statistically significant. For diabetes, the estimate using NHIS data was similar to that for general health. For difficulty with ADL, there is a consistently large association with inadequate literacy.

Applying the DAHL and comparing the association of limited health literacy with health status outcomes from HRS found similar results, as shown in Table 4-2.

TABLE 4-1 Association (Odds Ratio) of Inadequate Literacy with Self-Reported Health and Chronic Conditions (Comparing NHIS 1997)

Data Source →	*Prudential Medicare*		*NHIS 1997*
Health Literacy Measure →	*S-TOFHLA*	*DAHL*	
Poor/fair general health	1.77	1.78	1.70
Hypertension	1.08[a]	1.15[a]	1.07[a]
Diabetes	1.37	1.08[a]	1.29
Difficulty with ADL	1.91	2.57	2.47

[a]Denotes lack of statistical significance ($p > 0.05$).
SOURCE: Hanchate, 2009.

TABLE 4-2 Association (Odds Ratio) of Inadequate Literacy with Self-Reported Health and Chronic Conditions (Comparing HRS)

Data Source →	*Prudential Medicare*		*HRS*
Health Literacy Measure →	*S-TOFHLA*	*DAHL*	
Poor/fair general health	1.77	1.78	1.92
Hypertension	1.08[a]	1.15[a]	1.19
Diabetes	1.37	1.08[a]	1.30
Difficulty with ADL	1.91	2.57	1.94

[a]Denotes lack of statistical significance ($p > 0.05$).
SOURCE: Hanchate, 2009.

Conclusion

Results of this analysis support use of the DAHL as a proxy for identifying subgroups with limited literacy in nationally representative surveys. The four determinants of the DAHL appear to capture the important variation in health literacy as far as its impact on health status is concerned. However, it is important to remember that the DAHL is not designed for individual assessment of health literacy and it is not designed for health literacy assessment of a nonrepresentative cohort of patients.

MAPPING HEALTH LITERACY

Nicole Lurie, M.D., M.S.P.H.
The RAND Corporation

A population measure of health literacy can be developed for several reasons. Individual assessments of health literacy are time-consuming and expensive, and they rely largely on contact with the health care system. But they are good at supporting individual-level interventions, and probably facility-level interventions. If one could conduct population-level assessment, it would be fast, it would be inexpensive, and it might begin to support population-level interventions that may conserve resources, such as pharmacy-based intervention or deployment of navigators.

A project with the National Health Plan Collaborative (a group of 12 insurers that covers about 90 million people) served as an impetus for developing a population-level assessment of health literacy. The project identified specific Census tracts in the Los Angeles area where the quality of diabetes care was particularly low, and then asked what factors might explain the pattern of performance. A major factor seemed to be that the areas with low quality of care seemed to be linguistically isolated. A number of the plans were working on health literacy, so it was decided to draw a health literacy map to compare with the map showing low quality of diabetes care.

Methods

The question then became, how would one develop a health literacy map? Several things were needed, including a population-based model and national data on health literacy. One also would need to develop a multivariable predictive model of health literacy using Census variables. One would need to apply those model coefficients to Census data. Finally, one would need to map estimates at the relevant level of aggregation.

The decision was made to develop a predictive model based on the 2003 National Assessment of Adult Literacy (NAAL). The NAAL is restricted to an English-speaking sample, and the project restricted analysis to a household sample (N = 18,541) and did not include the incarcerated population.

The NAAL uses the incomplete block-test design where each respondent answers a subset of questions. Predicted scores are based on item response theory. The NAAL tests a series of functional health literacy items (e.g., reading a prescription label, interpreting a body mass index table). Scores are on a scale of 0–500 points.

The variables in the predictive model are age, gender, education, language spoken at home, marital status, race, income, time in the United States, and metropolitan statistical area (MSA). Other than time in the United States and MSA, all of the variables were significant because they contributed to the model. Two models were constructed, one to predict mean score and one, basically, to see if one could predict the percentage or the probability of health literacy above basic level (i.e., intermediate or proficient).

The adjusted r-squared for the linear model was 0.298. Interestingly, the r-squared for education alone was only a little more than half that at 0.16. This demonstrates that the model does substantially better than any of the individual predictors alone. The predictive capacity did not vary by age group or by region of the country. Because NAAL oversampled populations in six states, the project built six predictive models with those larger populations to determine if the model performed differently on those different states. It did not.

The next issue to address was how to use Census data in the model. There are two sources of Census data. One of the sources is the 2000 Census (the census is conducted every 10 years), which aggregates data at the Census-tract level. Each Census tract has between 1,500 and 8,000 people in it. Because of the concern about information being identifiable, the Census provides only aggregated information, such as percentage of population at different ages and percentage of different races and ethnicities.

Working with 2000 data presents a problem because significant changes have occurred since the data were collected; it would be better to capture more recent data. The American Community Survey (ACS), which is a new way in which the Census is collecting data, has a rolling sample. After 5 years of data collection, the ACS will release Census-tract estimates based on the ACS. Those data should be out some time in 2009.

Results

The ACS aggregates individual-level data at the Public Use Microdata Area (PUMA) level. Each PUMA has 100,000 people. Figure 4-2 is the PUMA-level map of the mean health literacy scores for Missouri. As the figure shows, certain areas of St. Louis and Kansas City have the biggest “hot spots” for low health literacy. One can also see that there are a number of other areas (in yellow) where the average health literacy score is marginal.

This kind of population-level assessment helps one think about where one might focus a health literacy intervention. These maps also can be produced for the percentage of the population with above basic health literacy.

What happens, however, if one maps education on one map and health literacy on another? The maps in Figure 4-3 use tract-level data. If one examines the map of average health literacy, one finds that there are a few pockets where average health literacy is low. But if one looks at the map of educational attainment, the percentage without a high school diploma is very low in certain parts of the state, but not all of those parts are at the worst level of health literacy.

One analysis, not reflected on these maps, showed that in the average

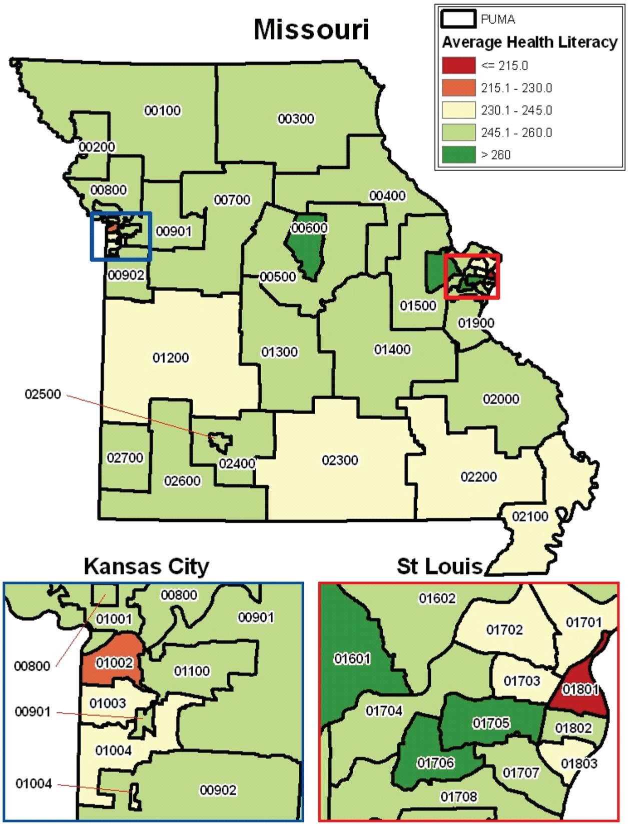


FIGURE 4-2 Mean health literacy by Public Use Microdata Area (PUMA) for Missouri.
SOURCE: Lurie, 2009.

Census tract in Missouri, between 25 and 40 percent of people have basic or below basic literacy. In some areas, the situation is much worse than that. This raises the following question: If one has limited resources to focus on health literacy, should one use just the level of education or just the level of income as a measure with which to target resources, or might one want to use a more precise measure?

This population-based assessment approach has limitations. First, the method has yet to be validated. How to conduct this validation is unclear because a large-scale, population-based assessment of health literacy has not been conducted using any of the other measures available. Furthermore, the validation needs to be conducted in a resource-efficient way in

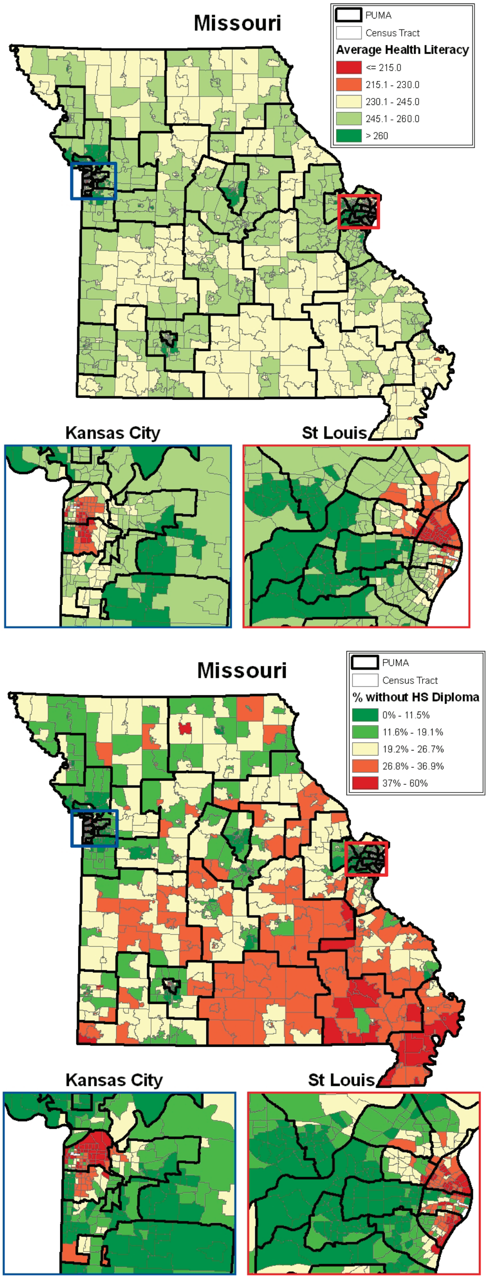


FIGURE 4-3 Model and single variable estimates produce different area-level estimates.
SOURCE: Lurie, 2009.

different geographic areas. Another challenge is that the standard errors of tract-level estimates are larger than those of PUMAs.

Conceptually there are some important issues. One is that the optimal level of community health literacy is not known. Is there a point at which the percentage of community members with low health literacy is large enough that it has a negative effect on health outcomes? Or, conversely, is there a protective effect if a certain percentage of the community has adequate health literacy? If a community has a high percentage of individuals with low health literacy, does it risk losing those members with higher health literacy levels to other communities? Finally, whether maps of population-based assessments of health literacy will help stakeholders take action is unknown.

Conclusion

The next step probably will be to look more closely at the relationship between health literacy areas and quality of care. The idea is to identify the "hot spots" of low literacy and the hot spots of low quality to see if they relate to one another. Depending on what those maps look like, perhaps all the stakeholders—such as community organizations, philanthropy, pharmacies, and health plans—will come together to think about pilot testing some geographically focused interventions in the areas of need.

DISCUSSION

Moderator: Cindy Brach, M.P.P.
Agency for Healthcare Research and Quality

One participant asked two questions: first, whether Lurie had the kind of data for the entire country that were available for Missouri, and second, whether those data could be correlated with the Dartmouth Atlas[1] data on quality. In other words, how might the methodology she described correlate with existing measures of quality, and how might they align with geographic subdivisions?

Lurie said the goal of the project is to produce a publicly available and easily usable model with programming language that anyone could use. RAND is currently attempting to determine the costs of constructing

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[1] "For more than 20 years, the Dartmouth Atlas Project has documented glaring variations in how medical resources are distributed and used in the United States. The project uses Medicare data to provide comprehensive information and analysis about national, regional, and local markets, as well as individual hospitals and their affiliated physicians" (http://www.dartmouthatlas.org/). Accessed April 11, 2009.

these maps for the country and updating the maps as the new Census data become available. The positive thing about using Census data is that one can aggregate those data to any level desired. Developing the data at a county level should be possible.

Correlating this work with the Dartmouth Atlas is a great idea, Lurie continued. What can be done is limited only by the resources available. Obtaining access to the NAAL data took 3 years, and gathering support for carrying out the project in Missouri took even longer.

Another participant addressed the theoretical frameworks for health literacy that are used to develop measures. Those frameworks treat health literacy as an individual issue when more ecological forces are at play. Perhaps the individual models should incorporate a component that addresses social capital. The participant described his grandmother as a person with an eighth-grade education and very low health literacy. She has very good health outcomes, however, in part because of her broad array of social capital supports. Incorporating social capital into the frameworks might enable one to determine whether the outcomes for those with low health literacy and high social capital are different from those with low health literacy and low social capital.

Lurie agreed and said if one looks at work in health literacy or community health education in developing countries, where large numbers of people may not be able to read, the concept of health literacy includes social networks. Hanchate added that an entire field of social epidemiology examines contextual factors.

The Agency for Healthcare Research and Quality (AHRQ) has funded some research that demonstrates the point just made, said Cindy Brach of AHRQ. When one takes social support into account, health literacy drops in terms of its predictive abilities. The problem is that researchers have a difficult time capturing social support on large datasets for population-level measurement.

One participant who identified himself as being from Kaiser asked what some effective population management interventions might be. Lurie said the interventions she can think of may not be specific to health literacy, but would be likely to help people with low health literacy. For example, the Asheville Project[2] in North Carolina paid pharmacists a bit

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[2] "The Asheville Project began in 1996 as an effort by the City of Asheville, North Carolina, a self-insured employer, to provide education and personal oversight for employees with chronic health problems such as diabetes, asthma, hypertension, and high cholesterol. Through the Asheville Project, employees with these conditions were provided with intensive education through the Mission-St. Joseph's Diabetes and Health Education Center. Patients were then teamed with community pharmacists who made sure they were using their medications correctly" (http://www.aphafoundation.org/programs/Asheville_Project/). Accessed April 11, 2009.

more to help educate people about how to take their medicines, why they are taking them, and how to be adherent. The investment resulted in a seven-to-one return in a short time period. The important thing is to think about how to focus limited resources in the most effective way.

When problems are identified in particular geographic areas, one must look carefully at what is going on in that community. For example, the National Health Plan Collaborative has data on Los Angeles, where Hispanic/Latino enrollees identified low quality of care for diabetes. The first idea for intervention was to send a letter with low-literacy levels of information in Spanish and English to thousands of members who had diabetes and Spanish surnames. But after looking at other variables, it was decided to focus the intervention on the linguistically isolated areas. In developing interventions, Lurie said, one must think much more comprehensively about the underlying drivers for health care and outcomes.

Another participant said the two presenters have both developed predictive models using demographics. Hanchate benchmarked his model to the TOFHLA, and Lurie used the NAAL. How might one decide which model would be more useful to use in certain situations? If one desires a health literacy measurement for a community, what results might be obtained using the different models? What would make one choose one model over the other?

Hanchate said the DAHL was an attempt to achieve balance between making the model as rich as possible without making it so complicated that it could not be replicated with other datasets being used for comparison.

Lurie said if one wants to look at the contribution of predictive health literacy to outcomes available in a secondary dataset, one is limited to data that exist in those datasets. The set of variables used in the RAND project is used in most datasets. The set of variables used in the DAHL is a smaller set and is available in the NHIS and others.

Dr. Angela Mickalide of the Home Safety Council said the project on health literacy mapping has implications for injury prevention as well. In Montgomery County, MD, for example, the fire department worked with literacy teachers to develop a map of literacy in the county. They overlaid that map with a map of the fire incidents, deaths, and injuries and found nearly a one-to-one perfect match, thereby identifying where efforts should be targeted. The Home Safety Council developed a home safety literacy project in which literacy teachers are provided with tools to teach students to read by using materials on fire safety, disaster preparedness, and poisoning prevention.

5

Measuring Health System Responses to Health Literacy

AMERICA'S HEALTH INSURANCE PLANS' RESPONSE TO HEALTH LITERACY

Julie Gazmararian, Ph.D., M.P.H.
Emory University Rollins School of Public Health

Why should health plans care about health literacy? In addition to the general complexity of the current health care system, the Institute of Medicine report on health literacy (IOM, 2004) identified several emerging themes or issues that are important aspects of the health system context with respect to health literacy. These include chronic disease care and self-management, patient-provider communication, patient safety and health care quality, access to health care and preventive services, provider time limitations, consumer-directed health care, and health care expenditures. The bottom line for all these issues is that health plan members who do not understand and cannot act on the medical information and instructions they are given are more likely to have poor health status that results in unnecessary costs.

Several years ago America's Health Insurance Plans (AHIP) created a Task Force on Health Literacy that included individuals from a variety of backgrounds, including health communication experts, physicians, health educators, marketers, and AHIP staff who are also involved with work in health disparities and cultural competency.

The Task Force recently began discussions with the American College of Physicians Foundation on areas of possible collaboration. Furthermore, as part of their monthly conference calls, the Task Force is scheduling case study presentations from member organizations to share information on major issues related to health literacy, thereby providing an opportunity to learn what is working and to make available different resources and tools in health literacy improvement.

In April 2008, the Task Force, along with AHIP's personal health records task force, evolved a checklist of reader- and user-friendly web design for health plans (http://www.ahip.org/content/default.aspx?docid=22865) and held a web seminar on the topic. More than 200 individuals participated. These participants included individuals responsible for health literacy efforts in health plans as well as web designers, information technology specialists, and those responsible for personal health records.

The Task Force also sponsored an all-day training session in June 2008 that attracted 100 individuals from health plans across the country who are starting or building health literacy programs in their organizations. The 6-hour program included case studies providing background information about issues in health literacy reported by various member plans.

AHIP also recently transformed that training session into a series of three webinars to extend its reach. The faculty for this series includes a nationally renowned health literacy expert and professionals from a variety of disciplines and health insurance plans who have helped build capacity for clear health communication organizations. The three-part virtual seminar on health literacy can be found on the AHIP website (http://www.ahip.org/virtual/healthliteracy). It includes a session that provides a health literacy overview and steps for implementing a program, a session on starting up and advancing a company health literacy program, and a session on health literacy campaigns that provides case studies from national health insurance plans.

The AHIP board proposed four key steps toward creating a culture of clear health communication. AHIP recently surveyed its member companies to determine the current level of adoption of these four key steps. Results of that survey should be available in late spring of 2009. The four steps include the following:

1. Create responsibility for health literacy at an appropriate level in the organization;
2. Adopt a consistent approach to clear health communication;
3. Provide training in clear health communication for staff who prepare written communications for members and interact with members directly; and
4. Adopt a target reading level for written consumer communications

and review the content of documents to ensure that they meet the target.

Finally, AHIP is collaborating with Emory University on developing, piloting, and evaluating a health literacy friendliness assessment. This project was funded by the Agency for Healthcare Research and Quality (AHRQ) and The Robert Wood Johnson Foundation. The contributions of the project officer, Cindy Brach from AHRQ, have been of particular importance.

The Pharmacy Intervention for Limited Literacy Study

The study, the Pharmacy Intervention for Limited Literacy (the PILL study), tested a three-pronged approach: a phone reminder call for prescription refills, clear health communication training for pharmacists who counsel patients on their medications, and pill cards given to patients when they pick up their medication. The pill cards include pictures of pills, information about what the medication is for, when to take the medication, and possible side effects.

The primary question of interest is the effect of the intervention on program medication refill adherence and cost. Secondary outcomes of interest include self-reported adherence, understanding of medication instructions, patient satisfaction, and pharmacist satisfaction. The study also assessed the effect of health literacy on the intervention.

The study was conducted in two different pharmacy settings affiliated with Grady Hospital in Atlanta that fill 5,000 prescriptions per day. Patients in these settings have a high burden of comorbidities.

The first phase of the study was the pharmacy health literacy assessment. Why conduct such an assessment? Because a pharmacy or other organization can improve the quality of services offered to patients or clients of limited literacy by raising awareness of health literacy issues among the organization staff; by identifying barriers that may prevent individuals with limited literacy from accessing, comprehending, and taking advantage of health information; and by identifying areas where improvements can be made and focusing on these areas first.

The three components of the pharmacy assessment tool are complementary and designed to be completed together. The first component of the assessment tool is a pharmacy assessment tour that is designed to be completed by trained assessors who evaluate the pharmacy environment from an objective perspective. These assessors do not work for or receive services from the pharmacy.

The second component is a survey of pharmacy staff that is completed by pharmacy members, including pharmacists, pharmacy technicians, administrative personnel, and supervisors. The third component of the assessment is patient focus group discussions with members of the pharmacy population. The assessment guide is available on the AHRQ website (http://www.ahrq.gov/qual/pharmlit/).

The Pharmacy Assessment

During the first phase of the pharmacy assessment, the pharmacy assessment tour, assessors observe both the physical environment of the pharmacy as well as staff interaction with the patients. The assessors identify existing barriers that inhibit clear communication of health information to patients with limited literacy skills, including promotion of services, print materials, and verbal communication. Because it is important that assessors observe the pharmacy in different situations, one assessor may conduct the assessment on a busy day and another on a slower day. Additionally, to avoid bias, the pharmacy staff should not be aware that the assessments are being conducted so that they do not act differently because they know they are being observed. Each assessment takes 20 to 30 minutes.

To minimize bias in the results, the pharmacy assessment tour should be conducted by at least two people who are trained together to promote consistent assessment techniques. The assessors should be familiar with principles of clear health communication, should not be pharmacy staff or patients, and should be able to blend in with patients who use the pharmacy.

All pharmacy staff are surveyed in the second phase of the pharmacy assessment because pharmacy staff members help create the environment within the pharmacy. Their choices and interactions with patients determine the health literacy friendliness of the pharmacy environment. Pharmacy staff have a unique perspective on the strengths and weaknesses of the pharmacy in serving patients with limited health literacy that may or may not be consistent with the viewpoints of outside assessors and patients. The pharmacy staff survey evaluates staff opinions of pharmacy sensitivity to the needs of limited-literacy patients in three areas: print materials, clear verbal communication, and sensitivity to health literacy. This survey takes about 20 to 30 minutes.

The third component of the pharmacy assessment is the focus group discussions with pharmacy patients. This is an effective way to collect detailed feedback directly from patients about their personal experiences with and impressions of pharmacy services. Four areas are discussed: the physical environment, care process and workforce, paperwork and written communication, and culture. The perceptions of focus group patients help to identify physical and institutional barriers in the pharmacy that might prevent those with limited literacy from fully understanding pharmacy instructions and assessing pharmacy services.

Results

Results of the pharmacy assessments showed that although the pharmacies had a number of strengths, they needed to improve in several areas, including

- Literacy-sensitive counseling;
- Pharmacy flow, signage, and wait times;
- Take-home materials available;
- Services for limited English proficiency; and
- Printed information not easy to understand.

Health Plan Assessment

The pharmacy assessment project has led to a new project that is broadening the application of the pharmacy assessment tool kit. The goal of the new project is to modify the PILL assessment tool and its applicability to the needs of health insurance plans throughout the country. The PILL assessment tool will be adapted and tested in a variety of health plan organizations and disseminated for widespread use in assessing health literacy friendliness of health insurance plans. There is incredible enthusiasm from AHIP member plans; plans are volunteering to be part of the pilot project. Pilot testing of the adapted tool is scheduled for spring 2009 with a report ready in late summer or early fall.

The project is currently in the early stages of adapting the assessment tool for use with health plans. Several areas have been identified in which questions will be developed to examine the health literacy friendliness of the health plans, including member information, member services/communication personnel, web navigation, forms, nurse call line, and nurse case/disease management.

Parallel to adapting the assessment tool, the project conducted an assessment of health literacy activities in health plans. Forty-one plans were invited to complete by e-mail a 10-minute web-based survey in January and February 2009. As of the time of the workshop, 27 of the 41 plans had completed the survey. Of those who responded, 100 percent said they had heard of health literacy. Sixty-nine percent of the plans indicated they have a policy or program in place to assess health literacy.

One question asked who is responsible for the health literacy program and activities within the respondent's company. The responses were

- Media, Public Affairs, Communications, Marketing, Editing – 7;
- Health Education, Promotion, Cultural, Health Equity – 6;
- Management – 6;
- Project, Program Coordinator, Manager (vague) – 3;
- Quality/Health Care Improvement – 2; and
- None, N/A – 3.

When asked how they would rate company-wide support for health literacy policies and programs, 10 percent of respondents indicated excellent and 59 percent indicated good, while 28 percent indicated support was fair and 3 percent indicated it was poor. In terms of funding for health literacy programs and policies, a large percentage (43 percent) indicated funding came from sources other than the categories specified (categories were "health literacy department," "each department," "not sure," and "other").

When asked how responsibility for carrying out health literacy programs and policies was distributed, 4 percent of respondents indicated responsibility rested with the health literacy department, 32 percent said it was the responsibility of each department, 11 percent were not sure, and 54 percent responded by checking the "other" category. In terms of the focus of health literacy efforts, 50 percent of respondents said the focus was on universal health precautions, 14 percent indicated health literacy efforts were targeted at plan members with low health literacy skills, 14 percent indicated they were not sure of the focus, and 21 percent indicated the "other" category.

Examples of programs for plan members with low literacy skills included specific reading levels for all materials, staff training, simplified consent forms, simplified health education materials, a plain language tool kit, a revised enrollment form, and interpreter translation of materials.

In response to a question that asked if the plan had conducted any activities that assess whether plan members understand materials distributed by the health plan, 11 respondents said yes (surveys, focus groups, informally at member benefit education classes), 4 respondents indicated "sort of" through a health plan satisfaction survey or advertising understanding, and 9 said no or that they did not know.

For the future, Gazmararian said, efforts at measuring and improving health literacy must infuse clear health communication into all prevention and chronic disease management programs, integrate disciplines and approaches within organizations, collaborate with other health care partners and communities, and document success.

AN ACCREDITOR'S EFFORT TO PUSH THE PUBLIC POLICY AGENDA FORWARD

John P. DuMoulin, M.S.
URAC

URAC is a nonprofit, independent organization whose mission is to promote continuous improvement in the quality and efficiency of managed health care through processes of accreditation and education. URAC was established in 1990 to accredit utilization review services. Currently, URAC offers more than 25 distinct accreditation and certification programs across the continuum of care and accredits more than 400 organizations operating in all 50 states. URAC programs are now recognized by 39 state governments, the District of Columbia, and 4 federal agencies (Center for Medicare & Medicaid Services, Office of Personnel Management, Department of Defense, and Department of Veterans Affairs).

The accreditation programs include programs in health care management; workers compensation, property, and casualty management; pharmacy quality management; core organizational quality; vendor certification; health care operations; and health information technology. URAC accreditation is recognized as a "seal of approval" because the accreditation standards are

- Set and enforced by an independent group of experts representing all stakeholders;
- Current with market conditions;
- The intersection of health policy goals and health service delivery reality; and
- Built with performance measures to ensure there are data to support a continuous quality improvement cycle.

In terms of health literacy, URAC began working in this area with consumer-directed health care plans in the early 2000s. Following publication of the *National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health Care: Final Report* (HHS, 2001), URAC focused on making sure its efforts addressed areas highlighted in that report. Currently, URAC is engaged in promulgating health literacy requirements for managed health care organizations. An early effort in this area was the URAC Consumer Education and Support (CES) Accreditation Standards of 2005. The focus of this effort was twofold: to make sure that health plans communicate with consumers in such a way that the consumers understand the information, and to make sure sufficient information is made available to consumers so that they can make good decisions about their health care.

Standard CES 2, a nonmandatory standard, addresses pre-enrollment consumer information requirements and requires descriptions of the processes the *organization* uses to provide information and support to *consumers* for whom English is not the primary language, who are from different cultural backgrounds, or who have special needs, such as cognitive or physical impairments.

The nonmandatory standard addressing health literacy communication (Standard CES 13) requires that the *organization* provide information that meets the following goals:

- Lowers, to the extent practicable, the cognitive effort required to use the information;
- Helps consumers understand what effect a health care decision may have for their daily lives; and
- Displays the information in a way that highlights information important to the *consumer*.

There is also a nonmandatory standard (CES 14) that addresses cultural sensitivity communication. The requirement is that information be presented and delivered in ways that are sensitive to the diversity of the *organization*'s enrollment, including literacy levels, language differences, cultural differences, and cognitive and/or physical impairment.

URAC has continued to be active in the area of health literacy. In 2007 the Health Standards Committee (HSC) agreed to address "Health Literacy/Diversity" as a topic for all its accreditation program standards (with the exception of the health information technology standards). Additionally, URAC worked with the Center for Information Therapy (Ix Center) to draft health information therapy standards for its disease management accreditation program. These new standards were developed and approved by the URAC board in 2008. Health literacy is now addressed in all URAC health care accreditation programs.

The core health literacy standards state the *organization* will implement written policies and/or document problems addressing *health literacy* that

- Require *consumer* materials to be in *plain language*;
- Assess the use of *plain language* in *consumer* documents; and
- Provide relevant information and guidance to *staff* who interface directly with, or write content for, *consumers*.

Additionally, in 2008 URAC launched a five-part educational web seminar series on health literacy topics for its accredited companies, in partnership with the Northern Virginia Area Health Education Center.

However, health care organizations can still achieve accreditation without meeting this core health literacy standard.

URAC is committed to continuing its work in the area of health literacy, DuMoulin stated. The standards are becoming more granular and specific, and are being applied more broadly to the majority of managed care accreditation programs. The key thing has been to embed these standards (performance measures) in the accreditation programs so there is a scoring system to capture where organizations stand at any point in time. With such a system, URAC can provide feedback to the industry about the status of health literacy in the organizations with the goal of continuing to improve over time as an industry.

DEVELOPING AND TESTING A CAHPS® HEALTH LITERACY ITEM SET

Beverly Weidmer Ocampo, M.A.
The RAND Corporation

The Consumer Assessment of Healthcare Providers and Systems (CAHPS), which is funded by the AHRQ, is a set of standardized, evidence-based surveys for assessing patient experiences with their health care encounters. The CAHPS project not only develops survey instruments, but also provides reports that consumers can use to make decisions about their choices in health care. The project has also started to develop provider reports that can be used by providers to identify areas for quality improvement.

CAHPS has a number of surveys. There is the CAHPS Hospital Survey (the H-CAHPS), the CAHPS Health Plan Survey, the CAHPS In-Center Hemo-Dialysis Survey for dialysis facilities, the Experience of Care and Health Outcomes (ECHO) Survey of behavioral health services, a dental plan survey, and an ambulatory survey instrument for health plans (the CAHPS Clinician & Group Survey). A survey instrument for assessing nursing home care is in the final stages of development.

Each CAHPS survey includes a core set of items that can be supplemented with additional items. Each survey has its own set of supplemental items. For example, there is a supplemental item set for children with chronic diseases and people with mobility impairment that can be added to the CAHPS Health Plan Survey. Two new supplemental item sets are in development—one that assesses health literacy issues and one that is for health information technology issues.

In developing CAHPS instruments, strict design principles must be followed. The items emphasize collection of information from the perspective of the consumer and patient. The focus is on things for which the patients are the best source of information. For example, if information is best collected from records or physicians, then that item is not included in the survey.

Furthermore, the survey instrument must report on actual experiences, not just patient satisfaction. The surveys include ratings from 0 to 10. The survey instruments are standardized across the board, input is sought from stakeholders, there is extensive testing and validation of the surveys, and the surveys are publicly available.

For health literacy, two different supplemental item sets are being developed: one for H-CAHPS and one for the CAHPS Clinician & Group Survey. They both cover the same broad range of concerns, but because two types of settings are involved, the items are slightly different. These surveys are designed as supplements to the core surveys and are not intended to be stand-alone surveys. The intent is to develop a set of items that can be used to measure patients' perspectives on how well health care professionals communicate health information. The goal of these supplements is to gather data to help health providers improve communication skills and patients' health literacy. The supplements are being developed by all CAHPS grantees under RAND leadership.

The instrument development process for the health literacy supplements adheres to the same instrument development protocol used for the other CAHPS instruments. Preliminary survey development work on the health literacy supplemental item set for the Clinician & Group Survey involved identifying domains and subdomains of health literacy through review of an environmental scan of the literature and a call for input through the *Federal Register,* through discussions with key information sources in the area of health literacy, and through a stakeholders' meeting. Stakeholders included health plan representatives, government agencies, health literacy advocates, researchers, and clinicians.

In conducting the environmental scan, existing measures in the public domain were reviewed to identify items that could be included in the supplemental item set. In addition, existing CAHPS instruments were reviewed to identify domains that could be expanded to include a health literacy measure. New survey items were written for each of the proposed health literacy domains that are not currently addressed by CAHPS or other existing instruments. Twenty-nine health literacy items were developed to cover four health literacy domains. English and Spanish versions of the items were developed in parallel. The health literacy domains targeted in this item set included

- Oral communication regarding health problems and concerns, medications, tests, health promotion, and forms;

- Written communication regarding medications and tests;
- Techniques utilized by health providers to ensure patient comprehension of health information (commonly referred to as "teach back methods"); and
- Patient-provider relationship.

The instrument development team included several researchers who are completely bilingual and bicultural and are experienced in developing, translating, and testing CAHPS surveys. Although English served as the official "carrier" language in the development process, making sure that survey items in both Spanish and English were both conceptually and linguistically equivalent was a top priority. When necessary, English items were modified to better convey the concept in Spanish. In addition, English-language wording was modified as necessary for easier translation into Spanish. In some cases, the item was rewritten in Spanish first, then translated into English to ensure comparability of the two items. The item set for the Clinician & Group Survey includes 29 items that fall within 6 item clusters as follows:

1. Patient-provider communication (10 items);
2. Communication about health problems or concerns (2 items);
3. Disease self-management (5 items);
4. Communication about medications (6 items);
5. Communication about tests (2 items); and
6. Communication about forms (4 items).

Two rounds of cognitive testing in both English and Spanish were conducted, followed by a field test to evaluate the reliability and validity of the item set. Affinity Health Plan and the University of Mississippi Medical Center participated in the field test. Six hundred patients were randomly selected from each site to participate. The field test was conducted by mail, with telephone follow-up. Approximately 54 percent of English speakers and 57 percent of Spanish speakers completed a survey.

Analysis of the field test data is nearing completion. Results will be used to make final decisions about survey items. The final set will include approximately 25 items, with a recommendation to have both a short version of the item set and a longer version. The goal is to have the item set publicly available during the summer of 2009. (Please see Appendix C for the CAHPS® Clinician & Group Survey Health Literacy Item Set.)

The developmental work for the health literacy supplement for the H-CAHPS is just beginning. It will go through the same overall process as was followed in the development of the health literacy supplemental item set for the CAHPS Clinician & Group Survey. The domains will include patient-provider communication, shared decision making, communication about care or treatment, communication with nurses, communication about medications, discharge planning and coordination, communication about test results, and communication about forms. The plan is to field test the item set in the fall or winter of 2009 with an expected release date of spring 2010.

PROMOTING EFFECTIVE COMMUNICATION: THE JOINT COMMISSION'S EFFORTS TO ADDRESS CULTURE, LANGUAGE, AND HEALTH LITERACY

Amy Wilson-Stronks, M.P.P.
The Joint Commission

The Joint Commission accredits about 88 percent of the nation's hospitals. It also accredits other facilities such as ambulatory care and long-term care organizations. The emphasis of this discussion is primarily on what is occurring in the hospital setting. The key question for The Joint Commission regarding health literacy is the following: What accreditation standards will move hospitals in a manner that better meets the needs of patients who present with health literacy issues, but also patients who present with other issues and concerns that affect communication?

The Joint Commission has had standards that stress that every patient has the right to effective communication, thereby addressing the concept of effective communication and, less directly but also importantly, health literacy. There are also standards that address patient education and the need for that information to be provided to patients in a manner they understand. Historically, the standards reflected communication as a patient rights issue, but that thinking has evolved: Effective communication is not just a patient rights issue but is critical to patient safety.

The focus on health literacy has come primarily through a focus on issues related to culture and language and their impact on racial and ethnic health disparities. In 2003 The California Endowment funded The Joint Commission to conduct a cross-sectional qualitative study examining three questions:

1. What are the challenges hospitals face in providing care to diverse patient populations?
2. What are hospitals doing to address these challenges?
3. Are there any promising practices that can be replicated to improve care?

The first report of this project identified many challenges. One major challenge is related to time—not having enough time to address some of the things that need to be done. Another major challenge is availability of resources, such as sufficient workforce, bilingual staff, language services, and money. Another major challenge is lack of training and awareness. It was also found that in some instances the resources were available but not being used by the hospitals.

Sixty hospitals were included in the study (Wilson-Stronks and Galvez, 2007). Forty-seven percent of those hospitals indicated that executives have direct responsibility for cultural and linguistic competence, 8 percent have direct responsibility for linguistic competence only, 43 percent do not have executives with direct responsibility for either area, and 2 percent did not answer the question. Sixty percent of the hospitals indicated they had developed plans to meet the cultural needs of patients, and 77 percent had developed plans to meet patients' linguistic needs. Figure 5-1 shows how funds are allocated for cultural and linguistic services.

The study resulted in 32 recommendations for hospitals, researchers, and policy makers. The recommendations addressed the areas of leadership, quality improvement and data use, workforce, language services,

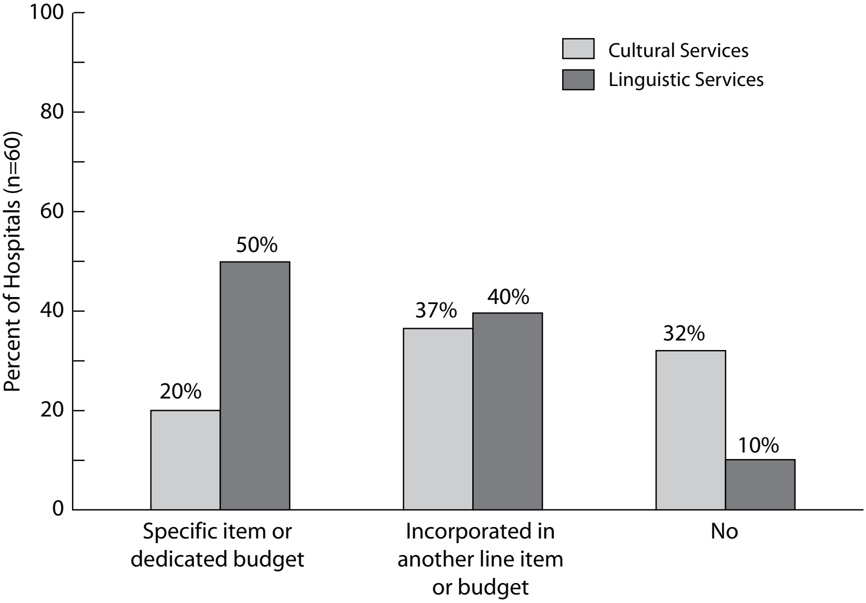

FIGURE 5-1 Operating funds allocated to cultural and linguistic services.
SOURCE: Wilson-Stronks and Galvez, 2007. Reprinted by permission from The Joint Commission.

provision of care/patient safety, and community engagement. One of the recommendations was to examine The Joint Commission standards more closely.

While this study was under way, The Joint Commission convened a public policy roundtable to address the issue of health literacy. Recommendations include

- Recommendation 1: Make effective communications an organizational priority to protect the safety of patients.
- Recommendation 2: Incorporate strategies to address patients' communication needs across the continuum of care.
- Recommendation 3: Pursue policy changes that promote improved practitioner-patient communications.

The common theme for addressing health literacy, cultural competence, and language issues is the need to address communication between the patient and the provider within the context of the health system. Support for this position can be found in examining The Joint Commission sentinel event data. These data have been voluntarily reported by accredited hospitals for more than 10 years. Since July 2005 hospitals have reported 1,400 sentinel events. For 843 of these events, detailed information on the root causes of the events was collected. Communication was identified as the primary root cause for 533 of these sentinel events.

Given the results of these investigations, The Joint Commission is considering how best to move toward creating standards for communication with vulnerable populations. Many patients are vulnerable, and access to direct communication can be inhibited by hearing impairment, visual impairment, speech impairment, cognitive limitation, intubation, disease, language, culture, health literacy, and health care proxy. Accurate information is needed for providers, practitioners, and patients. For example, practitioners need to be able to communicate and obtain accurate information to assess patient needs in order to determine a diagnosis, make a prognosis, provide treatment, obtain consent, and provide education and information.

Unfortunately, sometimes the health system hinders effective communication. For example, there is no standardized system in place to identify when a patient may have a communication need. Frequently there is a lack of supporting resources. Sometimes the resources are available, but the training needed for using the resources has not been conducted. Furthermore, there is a lack of evidence about which things work best to address which communication difficulties.

Given the findings, The Joint Commission has developed and is in the process of reviewing a Call to Action for communication (Patak et al., in review). The goals of the Call to Action are as follows:

- Improve clinical practice to incorporate a systematic and methodological approach to patient-provider communication;
- Optimize institutional availability and use of auxiliary services and increase frequency of referrals to specialists for "communication" purposes;
- Educate health care providers; and
- Revise health care policy and standards to set performance expectations for heath care providers on patient-provider communication.

The Joint Commission has a national patient safety goal concerning patient engagement. With a grant from The Commonwealth Fund, it is now in the process of developing culturally competent patient-centered care standards. The project will explore how diversity, culture, language, and health literacy issues can be better incorporated into current Joint Commission standards or drafted into new requirements. The standards will build on previous studies and projects, including the research framework from the Hospital, Language, and Culture Study and evidence from the current literature. Finally, a multidisciplinary Expert Advisory Panel, representing a broad range of stakeholders, will provide guidance regarding the principles, measures, structures, and processes. The standards are expected to address three main areas: effective communication, data collection and use to improve care, and meeting the special needs of different populations.

The Joint Commission developed a publication titled *"What Did the Doctor Say?" Improving Health Literacy to Protect Patient Safety* (The Joint Commission, 2007). In addition, The Joint Commission developed the Speak Up™ Initiatives, which are

- **S**peak up if you have questions or concerns. If you still don't understand, ask again. It's your body and you have a right to know.
- **P**ay attention to the care you get. Always make sure you're getting the right treatments and medicines by the right health care professionals. Don't assume anything.
- **E**ducate yourself about your illness. Learn about the medical tests you get and your treatment plan.
- **A**sk a trusted family member or friend to be your advocate (adviser or supporter).
- **K**now what medicines you take and why you take them. Medicine errors are the most common health care mistakes.
- **U**se a hospital, clinic, surgery center, or other type of health care organization that has been carefully checked out. For example, The

Joint Commission visits hospitals to see if they are meeting The Joint Commission's quality standards.

- **P**articipate in all decisions about your treatment. You are the center of the health care team.

In conclusion, Wilson-Stronks said, The Joint Commission is committed to developing standards and programs that will help health care organizations improve communication and, thereby, health literacy.

DISCUSSION

Moderator: Carolyn Cocotas, R.T., M.P.A.
F.E.G.S. Health and Human Services System

One participant raised a caution and a question. The caution is not to confuse health communication with health literacy because, he said, they are different. The question for DuMoulin is, how does one convince organizations to adhere to standards if there are no consequences for not doing so?

DuMoulin responded that URAC seeks to set the minimum necessary and attempts to raise that minimum. Susan Pisano, vice president of communications for AHIP said AHIP is attempting to work with member health plans to make sure training programs and policies are in place for communication with patients either orally, in written form, or through the Internet. The approach taken is an operational approach.

Another participant said it was laudable that many groups have stepped forward to engage in the issue of health literacy. The accreditation organizations are wrestling with describing the problem, producing reports, and developing standards. But at this point the uptake is not large because there is a great deal to learn about how to incorporate health literacy into health care organizations. What needs to happen next to involve all the organizations engaged in health literacy in a more substantive manner, the participant asked?

Wilson-Stronks said it is early in the process of incorporating health literacy. One of the struggles is how to separate communication from health literacy. What kinds of programs can an organization put in place to address things we do not fully understand? How can systems be set up to support the patients who are the ultimate recipients of care? As a first step, this lack of understanding needs to be addressed.

Gazmararian said that in working with AHIP over the past 6 months, she has seen a great deal of enthusiasm from the plans to become involved in health literacy issues and programs. However, a careful assessment of the barriers to plan engagement needs to be conducted. Pisano said one of the reasons AHIP has measured what its member plans have done is so that it can develop a plan to engage its members that is based on where the plans currently are.

Another participant said it is terrific that organizations are acknowledging that there is an issue with health literacy and want to do something about it, particularly when there is not a large science base to support interventions. There is, however, a knowledge base regarding levels of health literacy and interventions to improve health literacy that can be used to move forward. We have many disparate pieces, but is it possible to pull together what we have to develop a core health literacy set of indicators?

Gazmararian said she has become less certain over time about the possibility of developing one composite measure for health literacy. Perhaps the question is whether the one composite measure is the way to go or whether one should develop measures for the separate pieces that fit together.

Isham responded that he thinks there are tremendous opportunities at various levels. At the federal level, for example, there is a marvelous opportunity and challenge to develop measures that more effectively characterize health literacy, health, and quality in ways that fit together—much the way Lurie presented the mapping of health literacy with other indicators. At the organizational level, different measures may well be called for to use with health plans, hospitals, and ambulatory care organizations, and it is encouraging to see the development of the different CAHPS measures. There is also a need for patient-level data and data that can be used in research.

The challenge, Isham said, is to develop a framework for measures of health literacy that includes information necessary for research, for quality improvement, and for accountability. Perhaps what is needed is not a single metric, but rather a family of information at different levels—national, organizational, and individual.

6

Measuring Health Literacy: What? So What? Now What?

Ruth Parker, M.D.
Emory University School of Medicine

Seven years ago the Institute of Medicine Committee on Health Literacy set out to define the scope of health literacy and to develop a set of basic indicators that could be used to assess the extent of problems in health literacy at the individual, community, and national levels. Although that committee's report set the base for future direction, not enough was known at that time to develop measures at these various levels. Much, however, has been learned in the intervening years.

The presentations in this workshop have demonstrated that health literacy is linked to quality, to decreasing disparities, to decreasing costs; we will not make strides in any of these areas if we do not simultaneously do something about health literacy. This means that health literacy is fundamental to health reform in this country.

The definition of health literacy first proposed by Ratzan and Parker (2000) has generated much discussion, both in the literature and in this workshop. It is not perfect, but it was a start, a start at broadening the idea that communication is more than the information that is put out—it is also about what individuals take in. Health literacy reflects the dual nature of communication: what information is being disseminated and how people understand the information given to them. Looking at health literacy in this way enables a focus on making systematic improvements rather than blaming those with low health literacy skills.

Another point mentioned several times in this workshop is reflected in the saying, "What gets measured gets done." This is very important. To develop interventions that improve health literacy means that health literacy has to be measured. There is a developing science for health literacy, but it is not yet robust. One might think of health literacy as one thinks of medicine. Medicine may be a science, but it is practiced as an art. That is what needs to happen with health literacy. There must be a science of health literacy, but it must be artfully practiced.

One must align skills and abilities with the demands and complexity of the system. When that is accomplished, one has health literacy (see Figure 6-1).

What is known about measures of skills and abilities? Measures of individual skills and abilities such as the Rapid Estimate of Adult Literacy in Medicine (REALM) and the Test of Functional Health Literacy in Adults (TOFHLA) are used to describe prevalence and association. These measures have been around for more than 15 years. But measures at the community level, such as the geocoding measures presented earlier by Lurie, are new and exciting. Such community-based modeling allows one to take a population health approach to the measurement of skills and abilities and the development of interventions. With such measures, one can identify areas of greatest need and align resources with those needs at the population level.

Other measures are used to determine the demands and complexity of the system. More than 300 studies have documented that health material demand exceeds the ability of those who need to use the material. The new Consumer Assessment of Healthcare Providers and Systems

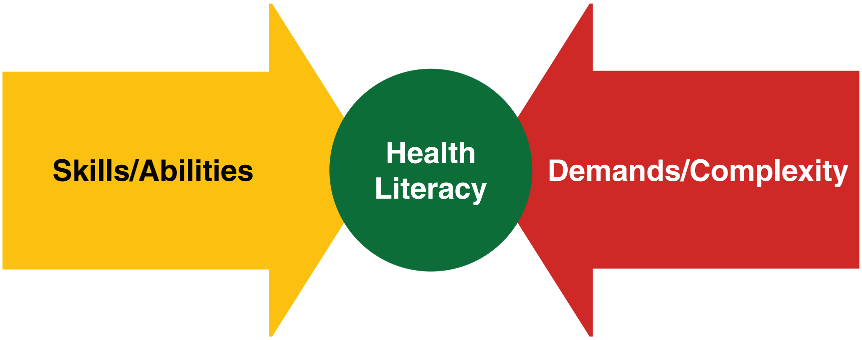

FIGURE 6-1 Health literacy framework.
SOURCE: Parker, 2009.

(CAHPS) surveys described earlier by Weidmer Ocampo will measure system demands and complexity.

But do we know what essential skills are needed, across the lifespan, to successfully navigate and engage in health? What do people need to know and understand to take care of their health? What about health systems—do health systems reflect health literacy within their organizational infrastructure? What does a literate medical home look like? Has someone defined a vision for that?

Currently we are out of alignment. The demands and complexity of the system overwhelm the skills and abilities, and health literacy, the green circle in the middle of Figure 6-1, is not as large as it should be. We should be concerned about this; balance is incredibly important.

But how can balance be achieved—how can skills and abilities match the demands and complexities? To achieve balance requires knowing the goal and figuring out how to get there. The medication label on a pill bottle provides a good example of achieving health literacy by balancing skills and abilities with demands and complexity. The National Assessment of Adult Literacy (NAAL) data provide us with information about skills and abilities, that is, about how many people can pick up a label on a pill bottle and understand what it means. Only one-third of people surveyed have the skills and abilities to read, understand, and demonstrate what is meant by a pill bottle label that says take two tablets by mouth twice a day (Davis et al., 2006). That is, only about a third could actually count out four pills. Then there is the question of *when.* Does twice a day mean the morning and the evening? Are 8:00 a.m. and 5:00 p.m. the same as morning and evening?

What about the demands and complexity of the pill bottle label? Is the pill bottle label navigable? Might there be a system change or changes that could better align the system demand and complexity with what we know about the skills and abilities? Actually a great deal of work has been done on this question. For example, the U.S. Pharmacopeia has established a task force to advance label standards, and a team of investigators is researching a new approach to labeling using a universal medication schedule developed by Alastair Wood (2007). With efforts such as these, greater balance between skills and abilities and the demands and complexities of the system is obtained, and health literacy is achieved.

What gets measured gets done. Putting health literacy on the agenda builds demand for measurement and action. Allen said earlier in her presentation, “If there are no data, there is no problem. If there is no problem, there is no action.” Health literacy measures must be implemented if there is to be balance and health literacy in the system. Health literacy must be an important agenda item within the organizational infrastructure—with assigned responsibility and funding to carry out activities.

What is needed in the field of health literacy? There is a need for a broad agreement across the field that health literacy occurs when skills and abilities are aligned with demands and complexity. Also needed are measures that reflect a dual nature—skills and abilities plus demands and complexity.

The goal is for all to be health literate. Indicators are needed that reflect progress toward the goal of aligning skills and abilities with demands and complexities. Her wish list for measures of skills and abilities, Parker said, includes the following:

- There should be an ongoing national data repository of health literacy measures of skills and abilities within the U.S. Department of Health and Human Services, using what was learned from the NAAL that is housed in the Department of Education.
- The data need to be accessible, usable, and transparent with the ability to be used in conjunction with other datasets.
- Census tract-level data are needed so that the entire country can be mapped down to the local level. With such community mapping, one can begin to explore what is known about those communities and where resources are needed for improvement.
- In clinical practice, one should promote "universal precautions" rather than individual skill testing. Not enough is known about individual skill testing in health literacy, so the outcomes of such testing are not ready to be placed in patients' records and charts.

Parker also has a wish list for measures of demands and complexities. The Centers for Medicare & Medicaid Services and health plans need to develop meaningful metrics of health-literate care and service providers. Models and demonstrations are needed for what a health-literate doctor looks like, what a health-literate person in the front office is like. What do these health-literate people do when talking on the telephone with a patient, when helping people navigate the system? Incentives are also needed for the early adopters, as are prods such as standards for accreditation. Also important is that the various institutes of the National Institutes of Health and individual professional societies need to define the essential basics, the "need to know to do" for health.

Parker concluded by saying that health literacy needs to be part of Healthy People 2020. Furthermore, measures of health literacy must be linked to health quality, disparities, and costs. The report *State of the USA Health Indicators* (IOM, 2009) listed health literacy as an important indicator, and it is. It is a very important indicator for the country.

DISCUSSION

Moderator: George Isham, M.D., M.S.
HealthPartners

Knowledge

Brach from the Agency for Healthcare Research and Quality (AHRQ) raised the point that all of the measures of individual health literacy have excluded prior knowledge and instead measure skills that are assumed to be constant. To some extent this is overwhelming in terms of measurement, trying to determine what individuals know about how their body works and other basic items.

Ratzan suggested that what might be needed are some core competencies in health literacy. What does a 4th-grader, an 11th-grader, a young adult need to know? Is there a health literacy base? Could competencies be developed for different populations?

Health Literacy in Organizations

One participant asked how health literacy can be embedded in the conceptual model for health care. Brach said that AHRQ recently published a tool kit for business strategies in chronic care. The tool kit is for physicians and practices trying to implement the chronic care model, specifically with safety net practices in mind. One of the components of the tool kit is health literacy tools.

Is health literacy an enabler, one participant asked, or is it an add-on burden or an extra cost? It would be good to start thinking about these questions. Parker said this is very important. From her perspective health literacy is not in and of itself the ultimate path to a solution for health care problems, but rather a prime layer that cuts across many areas including quality, safety, and cost. Developing measurements that allow linkage with these important variables is timely and critical.

Wilson-Stronks said that when she thinks of incorporating health literacy into organizations, she thinks of practical ways this can be done. One of these might be through the use of an advocate. Is such an approach considered when one is measuring individual health literacy? Can the individual patient be considered more broadly to include the use of advocates?

Brach responded that the individual measures considered do not take advocates into account, but that is an important point. What is needed are measures that can tell us how each person can do and what coping mechanisms they have developed, such as bringing a family member or someone else along to facilitate understanding.

Health Literacy Frameworks

Isham said the presentations and discussion at the workshop generated some thoughts about the figure Parker presented (Figure 6-1). On one side of the figure are the individual skills and abilities (the yellow arrow) that, in Parker's presentation, reflect what the individual brings to the interaction. Although the presentation referred only to the skills and abilities of an individual patient or consumer, one might think of these individual skills as being composed of three different sets. The first set has the skills the individual patient or consumer brings to the contact with the health care system, the skills that enable activity on his or her own behalf. A second set of individual skills and abilities are those that the individual provider of care brings to the interaction at the point of contact with an individual patient. A third set of skills on this side of the figure is that of the community or population. This last set could be thought of in relation to the presentation by Lurie regarding geomapping of health literacy with other indicators.

Smith asked where the determinants of health fit in the figure presented by Parker (Figure 6-1). Parker said the model of health literacy presented in the report *Health Literacy: A Prescription to End Confusion* (IOM, 2004) included social determinants. Certainly those are important and affect skills and abilities. A complete framework for viewing health literacy would necessarily have to include social determinants. Past measurement efforts have focused primarily on individual skills and abilities, Parker said. The intent of Figure 6-1 is to encourage a broader view of what needs to be measured to determine health literacy. That is, measurement of health literacy involves more than individual skills and abilities; it also must take into account the demands and complexities of the systems with which individuals must interact.

Isham said this issue had arisen earlier in conversations regarding the need for close coordination at the national level among many federal agencies. Health and health care are affected by the policies and activities of many federal agencies. For example, what the Environmental Protection Agency decides to do can have a great impact on health. Policies and activities of the Department of Education also impact health because it is known that educational attainment is a major social determinant of health. In thinking about health and health literacy, it is important to keep this overlap in mind.

The need to think beyond simple measures of health literacy, isolated from other factors, is illustrated by Lurie's presentation, Isham said, and by the report *State of the USA Health Indicators* (IOM, 2009). Both of these efforts illustrate the need to pay attention to numerous factors or determinants and how they interact to produce health.

One participant said many people see health as a linear process where care is delivered to people and a health outcome is experienced. But health exists also within families and communities and is affected by socialization, by the popular culture and the media. If one is going to create an overall conceptual framework for health literacy, the participant continued, that framework should be dynamic and demonstrate how health literacy is a process created by the society and culture within which people live.

Another participant suggested that measurements for health literacy need to include collection of data that would enable research on the return on investment for the health care system and society. The information Clancy and others presented indicates that health literacy does affect health outcomes. Such effects most likely impact costs, but the relationship has not been shown. This is an important issue, especially in these times when efforts at health reform are under way.

One participant, who identified himself as working in the area of shared decision making, suggested that the newly appropriated money available for studies of comparative effectiveness should include a greater focus on the side of Figure 6-1 that lists skills and abilities. Apparently the vast majority of those dollars will be devoted to the red arrow or right side, which is the side one might call the supply side of health care services, devices, and drugs. It appears that little will be spent for research on the yellow arrow, or consumer side. There is a great deal of disequilibrium between the knowledge of the supplier and the knowledge on the demand side.

Parker agreed that supply and demand has a great deal to do with the imbalance of the system represented in Figure 6-1. There is a supply and demand problem.

International Efforts in Health Literacy

Ratzan said there is international interest in health literacy. The Organisation for Economic Co-operation and Development is developing measures of health literacy. The United Nations is promoting health literacy, and a meeting in April in China is expected to discuss what health literacy means for the millennium development goals. How do U.S. health literacy rates compare with those in other countries? There is an opportunity to put forth a measure or some indicators that would allow the United States not only to measure progress in health literacy at home, but to measure the U.S. communities against international communities.

One participant who identified herself as being from Canada urged the group to think about the importance of measuring health literacy not only for the United States, but for many other countries. The Canadian Center for Learning has developed numerous materials on health literacy, and a number of other countries are beginning to move into this area. Much of what has been presented could be of great value to these international efforts.

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Appendix A

Workshop Agenda

ROUNDTABLE ON HEALTH LITERACY
WORKSHOP ON MEASURES OF HEALTH LITERACY
Thursday, February 26, 2009
8:30 am–5:15 pm
Room 100
Keck Center of The National Academies
500 Fifth Street, NW
Washington, DC 20001

WORKSHOP AGENDA

Objectives

- To review existing approaches for measuring health literacy
- To review health system level approaches to assessing health literacy
- To provide a vision for what could be done in population-based measurement of health literacy

7:45-8:30 am	Registration
8:30-8:45	Welcome and Introduction to the Workshop George Isham, M.D., M.S. Chair, Roundtable on Health Literacy

8:45-9:00	Health Literacy Measurement: Mapping the Terrain Carolyn M. Clancy, M.D. Agency for Healthcare Research and Quality
9:00-11:15	**Panel: Testing Individual Health Literacy** George Isham, M.D., M.S., *Moderator* HealthPartners
9:00-9:15	Health Literacy Measurement: A Brief Review and Proposal Andrew Pleasant, Ph.D. Rutgers University
9:15-9:30	The Importance of a National Dataset for Health Literacy Marin P. Allen, Ph.D. National Institutes of Health
9:30-10:00	Discussion
10:00-10:15	**BREAK**
10:15-10:30	What Is Health Literacy and How Do We Measure It? Lauren McCormack, Ph.D., M.S.P.H. RTI International
10:30-10:45	Refining and Standardizing Health Literacy Assessment Elizabeth Hahn, M.A. Northwestern University
10:45-11:15	Discussion
11:15 am-12:30 pm	**Panel: Other Approaches to Health Literacy Measurement** Cindy Brach, M.P.P., *Moderator* Agency for Healthcare Research and Quality
11:15-11:30	Self-Report Measures of Health Literacy Lisa D. Chew, M.D., M.P.H. University of Washington

11:30-11:45	Demographic Assessment for Health Literacy Amresh Hanchate, Ph.D. Boston University School of Medicine
11:45-12:00	Mapping Health Literacy Nicole Lurie, M.D., M.S.P.H. The RAND Corporation
12:00-12:30	Discussion
12:30-1:30	**LUNCH**
1:30-1:45	NAAL Data: To Use or Not to Use? Barry Weiss, M.D. University of Arizona College of Medicine
1:45-2:00	Discussion
2:00-3:00	**Panel: Other Approaches to Health Literacy Measurement, *continued*** Cindy Brach, M.P.P., *Moderator*
2:00-2:15	Measuring the Function in Functional Health Literacy Sandra Smith, M.P.H. University of Washington School of Public Health
2:15-2:30	Health Literacy and Cancer Prevention: Do People Understand What They Hear? Kathleen Mazor, Ed.D. University of Massachusetts Medical School
2:30-3:00	Discussion
3:00-4:30	**Panel: Measuring Health System Responses to Health Literacy** Carolyn Cocotas, R.T., M.P.A., *Moderator* F.E.G.S. Health and Human Services System
3:00-3:15	America's Health Insurance Plans' Response to Health Literacy Julie Gazmararian, Ph.D., M.P.H. Emory University Rollins School of Public Health

3:15-3:30	An Accreditor's Effort to Push the Public Policy Agenda Forward John P. DuMoulin, M.S. URAC
3:30-3:45	Developing and Testing a CAHPS® Health Literacy Item Set Beverly Weidmer Ocampo, M.A. The RAND Corporation
3:45-4:00	Promoting Effective Communication: The Joint Commission's Efforts to Address Culture, Language, and Health Literacy Amy Wilson-Stronks, M.P.P. The Joint Commission
4:00-4:30	Discussion
4:30-4:45	**Measuring Health Literacy: What? So What? Now What?** Where do we want to go in terms of measuring health literacy? Measurement of health literacy requires measurement of skills (individual, community, and population level) as well as measurement of demands related to health and health care. Ruth M. Parker, M.D. Emory University School of Medicine
4:45-5:15	Discussion
5:15	**ADJOURN**

Appendix B

Workshop Speaker Biosketches

Marin P. Allen, Ph.D., is deputy associate director for communications and director of the Public Information Office in the Office of Communications and Public Liaison (OCPL) in the Office of the Director of the National Institutes of Health (NIH). OCPL is responsible for all phases of internal and external communication, including press relations, public information, outreach about NIH programs and responses to public inquiries, the NIH website, the NIH radio service including the podcast news services, and public liaison activities. Dr. Allen has been involved in transagency efforts in health literacy, cultural competency, and health communication. She is the NIH representative to the U.S. Department of Health and Human Services (HHS) working group on Health Literacy, and the Health Communications and Health Literacy working groups for Healthy People 2010. Additionally, she serves on the NIH Nanotechnology Task Force Executive Committee and chairs the working group on Communication, Public Trust, and Public Engagement. She recently presented on health literacy at the NIH Health Disparities Summit titled "What Does the Government Want?"

Prior to 2004, Dr. Allen was the communication director and public liaison officer for the National Institute on Deafness and Other Communication Disorders (NIDCD). She led the NIDCD communications program since its inception. Before joining NIH, she directed public relations for Gallaudet University and was also a tenured full professor and chair of the Department of Television, Film, and Photography in the School of Communication at Gallaudet University. Before going to Gallaudet, Dr. Allen was a media specialist with the White House Conference on Aging. Prior to that, she was a faculty member in communications at the University of Maryland, College Park, for nearly a decade. Dr. Allen received two Emmy awards for programs she produced that aired for 5 years on the Discovery Channel and PBS.

Cindy Brach, M.P.P., is a senior health policy researcher at the Agency for Healthcare Research and Quality (AHRQ). She conducts and oversees research on health literacy, cultural and linguistic competence, system design innovations, Medicaid, and the State Children's Health Insurance Program (SCHIP). Ms. Brach spearheads AHRQ's health literacy activities, coordinating the Agency's work in developing measures and improving the evidence base. She has served on the National Cultural Competence Conference Advisory Group since 2001. Her recent publications include *Integrating Literacy, Culture, and Language to Improve Quality of Health Care for Diverse Populations* and *Integrating Health Literacy into Patient Safety Partnerships*.

Before coming to AHRQ, Ms. Brach was the associate director for research and analysis at the Mental Health Policy Resource Center, where she directed mental health and health policy research projects with an emphasis on managed care. Her earlier health and human services experience includes serving as a welfare reform consultant and provider of technical assistance, a state-level administrator, and a municipal policy analyst. Ms. Brach received her master of public policy from the University of California, Berkeley, where she is a Ph.D. candidate.

Lisa D. Chew, M.D., M.P.H., is medical director of the Adult Medicine Clinic at Harborview Medical Center and assistant professor of medicine at the University of Washington. Dr. Chew's primary interest is in issues of health literacy, particularly in the development of a brief screening measure for limited health literacy. As medical director, her administrative interests lie in quality improvement in the areas of access, chronic disease management, and patient safety. She is also leading efforts to develop a quality improvement curriculum for the University of Washington Medicine Residency Program. Dr. Chew received her M.D. at the University of California, San Francisco, and completed a residency at the University of Washington, where she also earned her M.P.H. and certificate in medical management.

Carolyn M. Clancy, M.D., was appointed director of AHRQ in February 2003. Prior to her appointment, she had served as AHRQ's acting director since March 2002 and previously was director of the Agency's Center for Outcomes and Effectiveness Research. Dr. Clancy's major research interests include various dimensions of health care quality, including women's health, primary care, access to care services, and the impact of financial incentives on physicians' decisions.

Dr. Clancy, who is a general internist and health services researcher, is a graduate of Boston College and the University of Massachusetts Medical School. Following clinical training in internal medicine, she was a Henry J. Kaiser Family Foundation fellow at the University of Pennsylvania. She was also an assistant professor in the Department of Internal Medicine at the Medical College of Virginia in Richmond before joining AHRQ in 1990.

Dr. Clancy holds an academic appointment at George Washington University School of Medicine as clinical associate professor in the Department of Medicine and serves as senior associate editor of *Health Services Research*. She has served on multiple editorial boards and has current positions with the *Annals of Family Medicine*, *American Journal of Medical Quality*, and *Medical Care Research and Review*. Dr. Clancy has published widely in peer-reviewed journals and has edited or contributed to seven books. She is a member of the Institute of Medicine (IOM) and was elected a master of the American College of Physicians in 2004.

Carolyn Cocotas, R.T., M.P.A., is senior vice president of Quality and Corporate Compliance at F.E.G.S. Health and Human Services System, one of the largest voluntary, not-for-profit health, education, and human services organizations in the country. Previously, she was director of Community Health Innovation at Affinity Health Plan, where she directed innovation work in care delivery to the Medicaid population. Ms. Cocotas's career spans over three decades, during which she has held progressively responsible positions in the health care industry, including at HHS, the U.S. Government Accountability Office, U.S. House of Representatives, National Committee for Quality Assurance, Community Health Plan of the Rockies, Performance Measurement Coordinating Council, and Kaiser Permanente. Ms. Cocotas has a master's degree in public and health administration from the University of New Mexico.

John P. DuMoulin, M.S., is vice president of government relations, product development, and education at URAC, a managed health care accreditation agency located in Washington, DC. In this position, he leads health policy federal and state affairs strategy and is also responsible for all URAC product development and educational programming for managed care and health management programs.

Mr. DuMoulin served for more than 10 years as lead regulatory and managed care/private-sector lobbyist and policy director for the American College of Physicians and the American Society of Internal Medicine.

He led the Departments of Regulatory and Insurer Affairs and the Physicians' Practice Management Education Center. Additionally, he served as the lead congressional and regulatory lobbyist and policy director for all health information technology and reimbursement issues. Prior to working for not-for-profit organizations, Mr. DuMoulin was a provider relations and network management professional for Prudential HealthCare in the greater Washington, DC, region.

Julie Gazmararian, Ph.D., M.P.H., is associate professor in the Department of Epidemiology at Emory University Rollins School of Public Health. Her primary research interests include issues in underserved populations, particularly related to reproductive health and health literacy. She has served as an editor of the American Medical Association (AMA) book on health literacy and has contributed to the IOM report on health literacy and is currently leading a multidisciplinary health literacy workgroup at Emory University.

Dr. Gazmararian has an undergraduate degree in business administration from the University of Michigan and an M.P.H. (health education) from the University of South Carolina. After receiving her master's degree, she worked at the American Public Health Association in Washington, DC, as scientific programs coordinator, where she was involved in a broad range of public health issues. She then received her doctorate in epidemiology at the University of Michigan and entered the Epidemic Intelligence Service program at the Centers for Disease Control and Prevention (CDC). While at the CDC, she worked in the Division of Reproductive Health and was involved in a variety of projects examining the occurrence of physical violence during pregnancy, race differences in cause-specific fetal mortality, the measurement of socioeconomic status among reproductive-age women, and the occurrence of epiglottitis among presumptive Sudden Infant Death Syndrome. In addition to her work in this country, Dr. Gazmararian has an interest in international health and has worked in Jamaica, Brazil, Bangladesh, and Armenia.

Elizabeth Hahn, M.A., is a medical sociologist whose research primarily involves patient-reported outcomes in chronic illnesses, with a focus on underserved populations and health disparities. She developed a bilingual, multimedia Talking Touchscreen (*la Pantalla Parlanchina*) that allows patients with varying literacy levels and computer skills to self-administer questionnaires and to access patient education information. It has also been adapted for self-administration of a health literacy measure. She is associate professor of preventive medicine at Northwestern University, director of the Outcomes Measurement and Survey Core for the Robert H. Lurie Comprehensive Cancer Center of Northwestern University, and director of biostatistics at the Center on Outcomes, Research, and Education at NorthShore University HealthSystem.

Amresh Hanchate, Ph.D., is a research assistant professor in the Health Care Research Unit of General Internal Medicine at Boston University School of Medicine. His research has spanned the fields of health economics and health services research, with specific interest in the relationship between health disparities and health quality. His recent research covers measurement of health literacy, racial and ethnic disparities in insurance access and demand for inpatient care, and risk adjustment for inpatient mortality using clinical data. Dr. Hanchate has considerable experience in the use of large administrative and survey data. He earned a Ph.D. in economics from the University of Wisconsin, Madison, specializing in the application of econometric and statistical techniques for analyzing individual decision-making models.

George Isham, M.D., M.S., is medical director and chief health officer for HealthPartners. He is responsible for quality and utilization management, chairs the Benefits Committee, and leads Partners for Better Health, a program and strategy for improving member health. Before his current position, Dr. Isham was medical director of MedCenters Health Plan in Minneapolis. In the late 1980s, he was executive director of University Health Care, an organization affiliated with the University of Wisconsin, Madison.

Dr. Isham received his master of science degree in preventive medicine/administrative medicine at the University of Wisconsin, Madison, and his doctor of medicine from the University of Illinois. He completed an internship and residency in internal medicine at the University of Wisconsin Hospital and Clinics in Madison. His experience as a primary care physician includes 8 years at the Freeport Clinic in Freeport, IL, and 3 years as clinical assistant professor in medicine at the University of Wisconsin.

HealthPartners is a consumer-governed Minnesota health plan that formed through the 1992 affiliation of Group Health, Inc., and MedCenters Health Plan. HealthPartners is a large managed health care organization in Minnesota, representing nearly 800,000 members. Group Health, founded in 1957, is a network of staff medical and dental centers located throughout the Twin Cities. MedCenters, founded in 1972, is a network of contracted physicians serving members through affiliated medical and dental centers.

Nicole Lurie, M.D., M.S.P.H., is senior natural scientist and Paul O’Neil Alcoa Professor of Policy Analysis at The RAND Corporation. She is also associate director for public health at the RAND Center for Domestic and International Health Security. Prior to joining RAND in early 2002, she had a long affiliation with the University of Minnesota, where she was professor of medicine and public health and, most recently, medical adviser to the commissioner at the Minnesota Department of Health. From 1998 to 2001, she took a leave of absence to serve as principal deputy assistant secretary of health in HHS. Dr. Lurie has a long history in the health services research field, primarily in the areas of access to and quality of care for disadvantaged populations, managed care, mental health, prevention, and health disparities.

Dr. Lurie's recent publications include *Variation in Racial and Ethnic Differences in Consumer Assessments of Health Care, The Public Health Infrastructure: Reinvest or Redesign?, Does Medicare Managed Care Provide Equal Treatment for Mental Illness Across Races?,* and *Measuring Disparities in Access to Care*, which was prepared for the IOM. Dr. Lurie completed undergraduate studies and medical school at the University of Pennsylvania and earned her residency and M.S.P.H. at the University of California, Los Angeles, where she was also a Robert Wood Johnson Foundation clinical scholar.

Kathleen Mazor, Ed.D., is a psychometrician and researcher with a strong interest in health literacy. A primary focus of her work has been to investigate the patient's perspective on both spoken and print health messages. She has led and collaborated on numerous studies investigating the impact of alternative strategies for communicating health-related information to patients and the public. She is an associate professor of medicine at the University of Massachusetts Medical School and a senior research associate at the Meyers Primary Care Institute. Dr. Mazor received her doctorate in education from the University of Massachusetts, Amherst.

Lauren McCormack, Ph.D., M.S.P.H., has 17 years of professional experience in health communication and health services research. She joined RTI International in 1997 as a senior research associate and has directed RTI's Health Communication Program since its inception in 2002.

Dr. McCormack is responsible for overseeing the program's portfolio of public health communication and social marketing research projects. Her research focuses on promoting informed health decision making and understanding the effects of health communications on individual knowledge, beliefs, and behaviors. Her expertise spans the health communication process from initial exploratory research and audience identification to comprehensive evaluation of communication interventions. Dr. McCormack has designed evidence-based messages and materials, quantitatively analyzed small- and large-scale survey datasets, and employed a variety of qualitative research techniques as part of numerous multiyear health promotion projects for various federal clients, including AHRQ, CDC, National Cancer Institute (NCI), and Centers for Medicare & Medicaid Services.

Currently, Dr. McCormack leads an NIH R01 to develop and test a skills-based measure of health literacy and an AHRQ DEcIDE Center study to facilitate the measurement of patient-centered communication based on an NCI monograph. Dr. McCormack has presented her findings at national conferences and in peer-reviewed professional journals, including *Health Services Research*, *Medical Care*, *Health Affairs*, *Health Care Financing Review*, and the *Journal of Health Communication.*

Ruth Parker, M.D., is professor of medicine at the Emory University School of Medicine. Her primary research interests are in medical education and health services of underserved populations. Dr. Parker has focused extensively on the health care issues of underserved populations, particularly health literacy. As principal investigator in the Robert Wood Johnson Literacy in Health Study, she developed a measurement tool to quantify patients' ability to read and understand health information. The tool is used in a number of surveys and studies to understand the relationship between poor health literacy and health outcomes.

Dr. Parker is widely published in health literacy and coedited the complete bibliography of medicine on health literacy for the National Library of Medicine. She is chair of the AMA Foundation steering committee for the National Health Literacy Program and former chair of the AMA expert panel for the Council of Scientific Affairs. Dr. Parker received her medical degree at the University of North Carolina, Chapel Hill.

Andrew Pleasant, Ph.D., works in the areas of health literacy; science, health, and environmental communication; and social marketing. He is currently an assistant professor at Rutgers University in the Department of Human Ecology and the Extension Department of Family and Community Health Sciences. Dr. Pleasant has published a number of peer-reviewed journal articles and has a decade of experience at daily newspapers in the United States. He received graduate degrees from Cornell University and Brown University.

Sandra Smith, M.P.H., is principal investigator and health education specialist at the University of Washington Center for Health Education and Research, Seattle, and clinical instructor in the Health Services Department of the School of Public Health and Community Medicine. She is a graduate fellow of the Zero to Three National Center for Infants, Toddlers and Families. Ms. Smith is author of the *Beginnings Pregnancy Guide* (1989-

2008) and *Beginnings Parents Guide* (1999-2007) for low-skills readers, and their Spanish editions. She is coauthor of the Beginnings Life Skills Development Curriculum and training for home visitors (2004-2008), which aims to promote health literacy and reflective functioning in disadvantaged parents and school readiness in their children during the prenatal to preschool period. Currently, she is investigating home visitation as a channel to promote health literacy; developing a method of measuring the function in functional health literacy; and writing a dissertation on health literacy concepts, measurement, and intervention. She earned an M.P.H. at the University of Washington and a Ph.D. (cand.) in social policy and leadership at the Union Institute & University in Cincinnati.

Beverly Weidmer Ocampo, M.A., is a survey director at The RAND Corporation. She has more than 20 years of experience in both quantitative and qualitative survey research methodology and has directed data collection for large multisite studies at RAND. Ms. Weidmer Ocampo is experienced in all aspects of survey design and management and in qualitative research methods, including focus groups and in-depth interviews, and in methods for assessing the validity of survey instruments, including cognitive interviews and usability testing. She has special expertise in translation, in the design of culturally appropriate survey instruments, and in testing instruments and diagnostic tools for cultural competence.

Ms. Weidmer Ocampo has been a member of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) grantee team since 1995 and has participated in developing and testing various CAHPS surveys and supplemental items. She leads the CAHPS Cultural Comparability team and was the RAND lead in the development and testing of the CAHPS Clinician and Group Survey Health Literacy Item Set. She is currently leading the development of a Health Literacy Item Set for the Consumer Assessment of Healthcare Providers Systems and Hospital Survey (H-CAHPS). She has managed the translation into Spanish of many of the CAHPS instruments developed to date and the translation of the H-CAHPS Survey into Chinese, Vietnamese, and Russian. She has also participated in the cognitive testing in Spanish of various CAHPS instruments and reporting tools.

Barry D. Weiss, M.D., is a tenured professor in the Department of Family and Community Medicine at the University of Arizona College of Medicine and an affiliate professor of public health in the College of Health Sciences at the University of Alaska, Anchorage. He has been involved in the fields of health literacy and patient-physician communication for much of his professional career. His writings on these topics have been published in *New England Journal of Medicine*, *Journal of the American Medical Association,* and a variety of other medical journals and books.

Dr. Weiss wrote the AMA's *Health Literacy Manual for Physicians* and a chapter for the AMA's health literacy textbook. He has served on health literacy advisory committees for the American College of Physicians, the AMA Foundation, NCI, The Joint Commission, the American Academy of Family Physicians (AAFP), and other organizations. Dr. Weiss was a consultant to the IOM Committee on Health Literacy and wrote a portion of the IOM's health literacy report. He is also the developer of the *Newest Vital Sign* health literacy screening instrument.

Dr. Weiss is the editor of *Family Medicine*, the national journal of the Society of Teachers of Family Medicine, and he is also editor of *FP Essentials,* one of the AAFP's largest continuing medical education programs. He is series editor of McGraw-Hill's *20 Common Problems* textbook series, which includes his texts on *20 Common Problems in Primary Care* and *20 Common Surgical Problems and Procedures in Primary Care.* Dr. Weiss is board certified in family medicine and holds a certificate of added qualification in geriatric medicine.

Amy Wilson-Stronks, M.P.P., is project director of the Division of Standards and Survey Methods at The Joint Commission and the principal investigator for the study Hospitals, Language, and Culture: A Snapshot of the Nation. She is the coauthor of *Hospitals, Language, and Culture: A Snapshot of the Nation Report of Findings,* published in March 2007, and *One Size Does Not Fit All: Meeting the Healthcare Needs of Diverse Populations,* published in April 2008.

Ms. Wilson-Stronks is a member of several national advisory panels, including the Advisory Committee for the National Council on Interpreting in Health Care, Institute for Diversity's Diversity Leadership Benchmark Study Expert Panel, Hastings Center's Professional Chaplaincy and Quality Improvement Working Group, Association of Professional Chaplains Quality Commission, Advisory Committee for the National Conference Series on Quality Care for Culturally Diverse Patients, and Hablamos Juntos Translation Quality Assessment Advisory Group. Ms. Wilson-Stronks earned her M.P.P. in health policy and a graduate certificate in health administration and policy from the University of Chicago and is a certified professional in health care quality.

Appendix C

CAHPS® Clinician & Group Survey: Health Literacy Item Set

Version: Supplemental Item Set for the Adult Primary Care Questionnaire 1.0
Language: English
Response Scale: 4 points
File Name: Final HL Item Set_4pt
Last Updated: September 10, 2009

This item set was developed as a supplement to the CAHPS Clinician & Group Survey: Adult Primary Care Questionnaire 1.0. This survey is available with a 4-point and 6-point response scale.

Note regarding the Never-to-Always response scale: This questionnaire employs a four-point response scale – "Never/Sometimes/Usually/Always" – which is the standard scale for CAHPS surveys. An alternative six-point scale adds "Almost never" and "Almost always" to the response options. Questionnaires with the six-point scale are available for downloading at https://www.cahps.ahrq.gov/cahpskit/CG/CGChooseQX6p.asp.

A version of the questionnaire with the six-point scale has been used by several early adopters of the survey; it is also the version that was endorsed by the National Quality Forum. The CAHPS Consortium is examining the performance of the two response scales in the context of this survey.

The CAHPS Clinician & Group Survey and Reporting Kit contains complete information on preparing, fielding, analyzing, and reporting the CAHPS Clinician & Group Survey. The Survey and Reporting Kit can be accessed at https://www.cahps.ahrq.gov/cahpskit/CG/CGChooseQX.asp.

HEALTH LITERACY ITEM SET

Insert HL1 – HL4 after core question 14.
Please note that HL1 was formerly C3. C3 was part of the Communication supplemental items but has been updated as part of the Health Literacy Item Set.

HL1. In the last 12 months, how often were the explanations this doctor gave you hard to understand because of an accent or the way the doctor spoke English?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL2. In the last 12 months, how often did this doctor use medical words you did not understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL3. In the last 12 months, how often did this doctor talk too fast when talking with you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL4. In the last 12 months, how often did this doctor use pictures, drawings, or models to explain things to you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL5 – HL9 after core question 15.
Please note that HL5 was formerly C5.

HL5. In the last 12 months, how often did this doctor ignore what you told him or her?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL6. In the last 12 months, how often did this doctor interrupt you when you were talking?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Please note that HL7 was formerly C7.

HL7. In the last 12 months, how often did this doctor show interest in your questions and concerns?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL8. In the last 12 months, how often did this doctor answer all your questions to your satisfaction?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL9. In the last 12 months, how often did this doctor give you all the information you wanted about your health?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL10 before core question 16.
Please note that HL10 was formerly C1.

HL10. In the last 12 months, how often did this doctor encourage you to talk about all your health problems or concerns?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL11 – HL15 after core question 18.

HL11. In the last 12 months, did you see this doctor for a specific illness or for any health condition?

1☐ Yes
2☐ No➔ If No, go to core question 19

HL12. In the last 12 months, how often did this doctor give you easy to understand instructions about what to do to take care of this illness or health condition?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL13. In the last 12 months, how often did this doctor ask you to describe how you were going to follow these instructions?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL14. Sometimes doctors give instructions that are hard to follow. In the last 12 months, how often did this doctor ask you whether you would have any problems doing what you need to do to take care of this illness or health condition?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL15.In the last 12 months, how often did this doctor explain what to do if this illness or health condition got worse or came back?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL16 after core question 19.
Please note that HL16 was formerly C6.

HL16. In the last 12 months, how often did this doctor use a condescending, sarcastic, or rude tone or manner with you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL17 – HL24 after core question 20.

HL17. In the last 12 months, how often did you feel this doctor really cared about you as a person?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL18. In the last 12 months, did this doctor prescribe any new medicines or change how much medicine you should take?

1☐ Yes
2☐ No➔ If No, go to core question 21

HL19. In the last 12 months, how often did this doctor give you easy to understand instructions about how to take your medicines?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL20. In the last 12 months, did this doctor explain the possible side effects of your medicines?

1☐ Yes
2☐ No➔ If No, go to #HL22

HL21. In the last 12 months, how often did this doctor explain the possible side effects of your medicines in a way that was easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL22. In the last 12 months, other than a prescription, did this doctor give you written information or write down information about how to take your medicines?

1☐ Yes
2☐ No➔ If No, go to #HL24

HL23. In the last 12 months, how often was the written information you were given easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL24. In the last 12 months, how often did this doctor suggest ways to help you remember to take your medicines?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL25 after core question 22. Core items 21-22 must be used prior to HL25.

Core question 21. Did this doctor order a blood test, x-ray or other test for you?

1☐ Yes
2☐ No→ If No, go to core question 23

Core question 22. When this doctor ordered a blood test, x-ray or other test for you, how often did someone from this doctor's office follow up to give you those results?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL25. In the last 12 months, how often were the results of your blood test, x-ray or other test easy to understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Insert HL26 – HL30 after core question 23.

HL26. In the last 12 months, did you have to fill out or sign any forms at this doctor's office?

1☐ Yes
2☐ No→ If No, go to core question 24

HL27. In the last 12 months, how often did someone explain the purpose of a form before you signed it?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL28. In the last 12 months, how often were you offered help in filling out a form at this doctor's office?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

HL29. In the last 12 months, how often were the forms that you got at this doctor's office easy to fill out?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

Please note that HL30 is only included in the Spanish version of the Item Set

HL30. In the last 12 months, how often were the forms that you had to fill out available in Spanish?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always