

# Discussion: Creating a Vision for the Future

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Discussion topics:

- Health literacy standards
- Opportunities for future research and collaboration
- Working with schools to address health literacy
- How widespread is low health literacy in America?
- Is there significant data linking health literacy to health outcomes?
- Do we know how to change health literacy and make it better? How rich is the evidence in this area?

Dr. Smith facilitated a discussion session entitled “Creating a Vision for the Future” intended to provide workshop coordinators, speakers, and audience members the opportunity to discuss possible conclusions and next steps that would appear in the Workshop Summary Report.

## Health Literacy Standards

Panelists and audience members identified various opportunities for future research and collaboration on health literacy improvement. Dr. Freimuth noted that in early 2006, JCAHO issued a directive on communication, requiring that healthcare organizations rely on communication standards that meet the needs of their patients. It may be useful to work with JCAHO to incorporate some of the health literacy research into these standards. A representative from JCAHO suggested that strategically linking health literacy with patient safety might broaden the base of support and the potential for forward movement on this health issue. Audience members highlighted additional standards related to health literacy, including the National Standards on Culturally and Linguistically Appropriate Services, developed by the Office of Minority Health, and the National Standards for Medical Interpreters developed by the National Council on Interpreting in Health.

## Areas for Future Research

Workshop participants unanimously agreed that enough data exist to substantiate limited health literacy as a major public health problem in America.

An audience member from the National Institutes of Health stressed the importance of encouraging interdisciplinary research, so that we might benefit from a broad base of scientific work that is relevant to the advancement of health literacy. Another audience member stressed the importance of considering learning style as an important component of health literacy.

Several participants commented on the need for additional research on special populations, particularly persons with communication disorders. In response to a question from an audience member, several workshop participants commented on health literacy challenges for persons affected by communication disorders, such as those with autism, aphasia, stuttering, hearing loss, or deafness.

It is estimated that more than 46 million people in the United States suffer some form of disordered communication that can impair or prohibit clear spoken or written communication with medical professionals or the understanding of medical information (National Institute of Deafness and Other Communication Disorders, 2006). The approximately one in six individuals with communication disorders may constitute a significant subgroup, who if recognized, would have an impact on health literacy numbers. More importantly, recognizing these and other special populations—such as persons with physical disabilities or behavioral health disorders—would allow for the creation of communication strategies that would better address their needs.

## Working with School Systems to Address Health Literacy

Audience members remarked on the importance of working with school systems to address health literacy. One participant emphasized the need to teach children as well as adults how to be informed patients. A representative from the American School Health Association commented that schools are under pressure to increase overall literacy, which may have the effect of leaving other types of literacy, such as health literacy, behind. However, there is evidence that health education programs can contribute to an improvement in reading and math rather than detract from test scores in these subject areas.

In follow-up, a representative from the Department of Education reiterated that interdisciplinary methods are effective in teaching children. She emphasized, however, that school systems are structured at the local level, i.e. the state or local government mandates the curriculum. We must, therefore, work with state and local officials to improve health education. She added that many school systems are creating policies on health and wellness and that there may be opportunities to work with local school districts to incorporate health literacy into these policies.

Next, the moderator asked panelists and audience members to respond to a set of key questions for the field of health literacy.

**Question 1: How widespread is low health literacy in America? Do we have convincing data that this is a problem?**

Audience members unanimously agreed that enough data exist to substantiate health literacy as a major public health issue in America.

**Question 2: Is there sufficient data linking health literacy to health outcomes?**

Participants largely agreed that there was evidence that literacy is related to some health outcomes, although there are gaps in the research. Dr. Rudd remarked that we are at an exciting moment in the study of health literacy. There is a substantial evidence base supporting a relationship or an association between health literacy and a variety of health outcomes; this evidence will serve as the foundation for future studies and hypothesis testing. Dr. Baker concurred, adding that because people use the term health literacy differently, it is important to begin with current science. Tests of reading comprehension and the TOFHLA show increased hospitalization and mortality with lower levels of literacy.

However, we need to be able to understand why the association exists, i.e., what are the causal pathways. Dr. Pignone cautioned that there is still no measure of health literacy as a broad construct, and without a global measure it is hard to draw conclusions between literacy and health outcomes. Several audience members addressed the notion that health literacy may be a mediator of cognitive function. This remains an unresolved issue.

Dr. Flores argued against the cognition hypothesis, noting that research shows that, regardless of cognition, associations exist between language barriers and adverse health outcomes.

**Question 3: If there is some evidence that limited health literacy is widespread, and that it is related to poor health outcomes, do we know how to change health literacy and make it better? How rich is the evidence in this area?**

There appears to be more anecdotal evidence on this issue; the intervention studies to date have been relatively small in scale. A representative from AHRQ noted that there were few intervention studies to evaluate several years ago during the development of the AHRQ evidence report, *Literacy and Health Outcomes* (Berkman, et al., 2004). Although the number of such studies has increased since the publication of the report, more intervention studies are needed. Much of the evidence on interventions comes from the "teach back" method, the simplification of written materials, and the use of video or other supplementary materials—all showing somewhat mixed results. There is concern that the intervention studies, some of which were described during the workshop, might be difficult to replicate on a larger scale.

A discussion of research methods and study design followed. Dr. Keil suggested that the next step might be to tackle longer-term interventions, possibly with children, to untangle

the causation question and to address whether we can improve health literacy. He also suggested that more studies are needed that compare more than one intervention.

Dr. Pignone argued that the study design will depend on the kind of question being asked. For example, if the intervention hopes to have an impact on the healthcare system, then the control should be as real as possible. Dr. Zarcadoolas added that there needs to be more of a multi-disciplinary approach to health literacy research. She cautioned against research that gives priority to quantitative over qualitative studies.

Finally, audience members raised the issues of cost and reimbursement. One participant observed that there has been little mention of the costs associated with interventions to improve health literacy. She emphasized that as we call upon the healthcare system to change, we must also consider associated costs. A representative from JCAHO commented that reimbursement policies will need to be reviewed to support such interventions. Participants concurred, noting that costs associated with interventions to improve health literacy should be evaluated against the estimated and often hidden costs to the system of ignoring limited health literacy.