

Surgeon General's Workshop on

Improving Health Literacy



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Surgeon General's Workshop on Improving Health Literacy

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Executive Summary

On September 7, 2006, Acting Surgeon General Kenneth Moritsugu held a Surgeon General's Workshop on Improving Health Literacy. The goal of the workshop was to present the state of the science in the field of health literacy from a variety of perspectives, including those of health care organizations and providers, the research community, and educators. During the course of the one-day workshop, participants identified the public health consequences of limited health literacy and established an evidence base for taking action.

Limited Health Literacy: A Public Health Problem

People make choices about their health everyday, such as what they eat or how they exercise. In order to stay healthy, Americans must know how to read the labels on food and medicine, describe symptoms, or use a map to locate the closest health center. The ability to read, understand, and act on health information is called health literacy.

Health literacy impacts Americans of all ages, races, incomes, and education levels. It affects our ability to search for and use health information, adopt healthy behaviors, and act on important public health alerts.

Workshop Highlights

The Surgeon General's Workshop on Improving Health Literacy was divided into three expert panels. Key findings from each panel are summarized below.

Panel 1: Health Literacy, Literacy, and Health Outcomes

- According to the National Assessment of Adult Literacy, only 12% of Americans have proficient health literacy skills. The majority of adults may have difficulty completing routine health tasks like understanding a drug label or vaccination table.
- There is a strong, independent association between health literacy and health outcomes. These outcomes include emergency department use, hospitalization, self-reported physical health, and mortality.
- In order to understand and improve health literacy, we must examine both sides of the issue: 1) the demands of our health care system; and 2) the skills of individuals who use it.
- Communication characteristics of the health care system—such as lack of time and reliance on only written or verbal communication—contribute to poor health care, particularly for those with limited literacy. There is growing research to suggest that restructuring the health care system may improve the reach and effectiveness of care for persons with limited health literacy.

- Interventions to mitigate the effects of low literacy in patients with chronic conditions have been shown to improve health outcomes. In some cases, the interventions appear to be more effective for low literacy users compared with higher literacy users.

Panel 2: Meeting the Health Literacy Needs of Special Populations

- To ensure that improvements in health literacy result in improved quality of life and reductions in health disparities, we must marry health literacy improvement with appropriate access to recommended health care.
- Quality of care is compromised when patients with limited English proficiency do not have access to interpreters or use untrained, ad hoc interpreters such as children.
- Much of today's health information exceeds the cognitive capabilities of older adults, even those who are well-educated. Older adults have particular problems with medical issues when they must assimilate new information or make complex decisions about treatments.
- Despite large gaps in their understanding, research strongly suggests that children of all ages have the potential to understand a great deal about health and about how to access health information.

Panel 3: Toward an Informed and Engaged Public

- The ability to understand health information is dependent on multiple factors, including: difficulty of the information; skill of the user; and motivation of the user. Even when people have a high degree of skill, they may not expend the effort necessary to understand written text. For people with lower literacy skills, increased motivation can lead to greater understanding.
- Health literacy, like any competency, is a continuum. A health literate person is able to use health concepts and information generatively—applying information to novel situations. This is critical to our efforts to prepare the public to react to complex public health emergencies.
- Simply increasing the volume of health information will not improve health literacy. Information must be adapted to the following elements of communication: source, message, channel, and receiver.
- There is strong evidence that participatory or user-centered design improves communication for the participant groups, including persons with low health literacy. Communication designed by and for persons with low health literacy is often preferred by all readers since it is written in a clear and concise style.

Conclusions

Based on the evidence presented at the workshop, Acting Surgeon General Moritsugu made the following conclusions:

- First, public health professionals must provide clear, understandable, science-based health information to the American people. In the absence of clear communication and access to services, we cannot expect people to adopt the health behaviors we champion.
- Second, the promises of medical research, health information technology, and advances in health care delivery cannot be realized without also addressing health literacy.
- Third, we need to look at health literacy in the context of large systems—social systems, cultural systems, education systems, and the public health system. Limited health literacy is not an individual deficit but a systematic problem that should be addressed by ensuring that health care and health information systems are aligned with the needs of the public.
- Lastly, more research is needed, but there is already enough good information that we can use to make practical improvements in health literacy.

Introduction

Health literacy is increasingly recognized as a necessary element of all efforts to improve health. Health literacy is critical for people's search for and use of health information; adoption of healthy behaviors; and decision-making about health issues in the workplace, community, and society. Furthermore, health literacy is central to people's ability to access the public health and healthcare systems, communicate with health professionals, and engage in self-care and chronic disease management.

There is mounting evidence that the complex demands of modern health systems do not match up with people's knowledge and skills. Many Americans have limited health literacy, affecting their ability to locate providers, fill out medical forms, understand food or drug labels, or act on important public health alerts (Kutner, Greenberg, Jin, & Paulsen, 2006). This, in turn, impacts health outcomes, healthcare costs, and quality of care.

Concern about the scope and implications of limited health literacy in the United States led the Office of the Surgeon General to convene the "Workshop on Improving Health Literacy" on September 7, 2006 in Bethesda, Maryland.

The goal of the workshop was to identify the most important public health issues and research needs in health literacy from a variety of perspectives, including those of health care organizations and providers, the research community, and educators. The workshop was structured to compile the best evidence from experts in the field to enhance understanding of the public health consequences of limited health literacy.

Workshop Proceedings

This document summarizes the scientific research, views, and issues addressed by invited speakers and discussants at the Surgeon General's Workshop on Improving Health Literacy. The speakers were selected because their research and experience have important health literacy applications.

In preparing their presentations, the speakers were asked to include broad health literacy implications, rather than to focus exclusively on individual research or studies. They were asked to address the following questions:

- What does your research suggest about the barriers to health literacy improvement;
- What does your research suggest about the types of changes that are needed;
- How does your research or study translate into action steps for health literacy improvement;
- Which sectors, organizations or groups should contribute to health literacy improvement?

The views expressed in these proceedings reflect the opinions of the individual participants at the Workshop and do not necessarily reflect the official position of the Office of the Surgeon General, the Department of Health and Human Services (DHHS), or other federal agencies.

Welcome

*RADM Penelope Slade Royall, P.T., M.S.W.,
Deputy Assistant Secretary for Disease Prevention and Health Promotion,
Office of Disease Prevention and Health Promotion,
U.S. Department of Health and Human Services*

The Surgeon General's Workshop on Improving Health Literacy was called to order on September 7, 2006 by Rear Admiral (RADM) Penelope Slade Royall. RADM Royall welcomed participants and spoke of the challenges of the day's Workshop—to review the large body of scientific evidence in support of health literacy improvement and to identify gaps in information that need to be assigned priorities. RADM Royall then introduced the Acting Surgeon General, RADM Kenneth P. Moritsugu, who reviewed the charge and goals for the Workshop.

Charge and Goals

*RADM Kenneth P. Moritsugu, M.D., M.P.H.,
Acting U.S. Surgeon General*

RADM Moritsugu emphasized the important role health literacy plays in efforts to improve the public's health. When people have accurate, understandable information about a public health issue, they are better able to take action to maintain or improve their health. The Office of the Surgeon General focuses on three major health priorities: prevention, public health preparedness, and eliminating health disparities. Health literacy is a critical underpinning to each of these priorities.

Definition of Health Literacy

RADM Moritsugu began with the definition of health literacy first developed in the National Library of Medicine bibliography on health literacy and adopted by *Healthy People 2010* and the Institute of Medicine (IOM). Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. The 2004 IOM report, *Health Literacy: A Prescription to End Confusion*, builds on this definition and conceptualizes health literacy as a shared function of cultural, social, and individual factors. According to the report, both the causes and remedies of limited health literacy rest with our cultural and social frameworks, the health and education systems that serve them, and the interactions between these factors and individuals.

Limited Health Literacy: A Public Health Problem

Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.

Healthy People 2010

The Acting Surgeon General encouraged those in attendance to challenge their assumptions about health literacy research and practice. He urged participants to look at health literacy from every angle—from the perspectives of health professionals and those they serve. People of all ages, races, incomes, and education levels are affected by limited health literacy. Even the seemingly simple things that we can all do to stay healthy and safe, such as getting recommended screenings and eating healthy foods, can be difficult for some people. The reality is that to be able to make healthy choices, people must have a basic understanding of how to find and use health information. And they must also understand why these choices are important.

Several recent events have drawn attention to the challenge of limited health literacy. In early 2000, *Healthy People 2010* identified limited health literacy as a public health problem and set national objectives for its improvement. In 2004, the IOM released its health literacy report, finding that nearly one-half of American adults may lack the

needed literacy skills to use the U.S. health care system. At the same time, the Agency for Health Care Research and Quality (AHRQ) released its evidence report on literacy and health outcomes (Berkman, et al., 2004). This report was the result of a thorough scientific review of the evidence related to the effect of low literacy on a wide variety of health outcomes.

A Public Health Approach to Health Literacy Improvement

RADM Moritsugu emphasized the importance of taking a public health approach to health literacy improvement. He noted that over the past 100 years, thanks largely to public health efforts, we have successfully prevented the spread of infectious diseases, increased the life expectancy of Americans, protected against environmental hazards, and reduced accidents and injuries. As threats to America's health shift, so too do our public health efforts. The public health approach allows us to address new challenges such as limited health literacy by defining the problem; identifying its causes and protective factors; developing and testing intervention strategies; implementing interventions; and evaluating and refining those interventions.

Goals for the Workshop

RADM Moritsugu presented the three major goals for the workshop:

- Identify the latest scientific data on the scope and public health consequences of limited health literacy.
- Review and discuss the research needs and identify areas where information is lacking.
- Based on the body of health literacy research, establish an evidence base for taking steps to improve health literacy.

The purpose of the meeting is to present a critical analysis and understanding of the state of the science in the field of health literacy. He emphasized that this workshop is not the end point, but rather, the beginning of a series of activities that the Office of the Surgeon General is undertaking to move this issue forward.

Moderator Opening Remarks

*William Smith, Ed.D.,
Executive Vice President,
Academy for Education Development*

William Smith, Ed.D., Executive Vice President, Academy for Educational Development
Dr. Smith, a member of the IOM Committee on Health Literacy, described health literacy as a cultural phenomenon. In order to be a truly health literate society, we have to be aware of how culture shapes our understanding of health. We are accustomed to thinking of health literacy as an *individual* competency or deficit, and asking the question, is she or he literate? But a more appropriate question is, are we a health literate *nation*?

He reminded attendees that there are thousands of professionals and educators who are working hard to improve the health literacy of adults, and he urged participants to help those in the field evaluate their efforts.

The day's presentations address the scope and the public health consequences of limited health literacy. Dr. Smith noted that the research presented at the workshop has already been through rigorous scientific review. Participants' job is not to analyze the validity of the results but rather the relevance of the conclusions and their implications for public health practice.

Panel 1: Health Literacy, Literacy, and Health Outcomes

Topics covered in Panel 1:

- National Assessment of Adult Literacy health literacy results
- Health literacy in everyday life
- Literacy in the clinical care setting
- The association between health literacy and health outcomes
- Improving health outcomes for patients with low health literacy

The National Assessment of Adult Literacy: Health Literacy Results

*Russ Whitehurst, Ph.D.,
Director, Institute of Education Sciences,
U.S. Department of Education*

Dr. Whitehurst, Director of the Institute of Education Services at the U.S. Department of Education, opened the panel with an overview of health literacy data from the National Assessment of Adult Literacy (NAAL).

About the National Assessment of Adult Literacy (NAAL)

The NAAL is a nationally representative assessment of English literacy among American adults. The survey sample included over 19,000 adults ages 16 and older in homes and over 1,000 inmates in state and Federal prisons across the country. In 2003, for the first time, the NAAL included a health literacy component which assessed respondents' skills for locating and understanding health-related information and services.

The Health Literacy Scale

The NAAL assessment measures health literacy on a scale of 0 to 500, using four literacy levels:

1. *Proficient*—Able to perform complex activities such as searching a document to define a medical term or other information.
2. *Intermediate*—Capable of conducting moderately challenging tasks such as finding the age range for a particular vaccine from a childhood vaccination chart.

3. *Basic*—Able to complete simple tasks such as giving two reasons why a person should be tested for a specific disease, based on information in a clearly written pamphlet.
4. *Below Basic*—Demonstrates the lowest levels of performance such as identifying what is permissible to drink before a medical test, based on a set of short instructions.

There is also a fifth category, *Nonliterate in English*, which includes adults at the bottom of the *Below Basic* level and those adults who could not take the test because they did not speak English or Spanish.

The NAAL health literacy tasks encompassed three domains of information:

- *Clinical*—such as filling out a patient form.
- *Prevention*—such as following guidelines for age-appropriate preventive health services.
- *Navigation of the health care system*—such as understanding what a health insurance plan will pay for.

To perform the health literacy tasks, individuals need to:

- Be familiar with everyday health-related words.
- Have experience with the type of written material (such as a drug label).
- Have knowledge of how the health care system works.

The health literacy scale did *not* measure the ability to obtain information from nonprint sources, such as interactions with a health care provider. It also did not measure knowledge of health issues or assess understanding of medical terms.

“Those who are most in need of health literacy are the ones with the poorest reported health.”

Russ Whitehurst, Ph.D.

Results of the 2003 NAAL

Based on the survey findings, Dr. Whitehurst provided the following interpretation of the NAAL data:

- The majority of adults (53 percent) had *Intermediate* health literacy.
- An additional 12 percent had *Proficient* health literacy.

- Among the remaining adults, 22 percent (corresponding to 47 million adults) had *Basic* health literacy and 14 percent (30 million adults) had *Below Basic* health literacy (see Table 1).
- 5 percent (11 million adults) were found to be *Nonliterate in English*. This includes 7 million adults at the bottom of the *Below Basic* level who did poorly on the easiest test questions and an additional 4 million adults who could not participate in the study at all because of language barriers.

Table 1: Percentage and Number of Adults in Each Level: Health Literacy Component 2003 National Assessment of Adult Literacy

Health literacy level	Percentage of adults in each health literacy level	Number of corresponding adults in millions
Below Basic	14	30
Basic	22	47
Intermediate	53	114
Proficient	12	25

NOTE: Detail may not sum to totals because of rounding. n = 19,000 adults. Adults are defined as people 16 years of age and older living in households or prisons. Adults who could not be interviewed because of language spoken or cognitive disabilities (3 percent in 2003) are excluded from this figure. From: Kutner, Greenberg, Jin, & Paulsen, 2006.

Adults who spoke only English before starting school had higher health literacy scores than did adults who spoke another language alone or other languages plus English. Adults who spoke only Spanish before starting school had the lowest mean health literacy score. Demographic data show how adults with *Below Basic* health literacy are different from the adult population as a whole. For example, 51 percent of adults with *Below Basic* health literacy did not graduate from high school, as opposed to 15 percent of the total population.

About 76 percent of adults who reported that their overall health was excellent had *Intermediate* or *Proficient* health literacy. In contrast, 69 percent of adults who reported their health was poor had *Basic* or *Below Basic* health literacy. Dr. Whitehurst concluded that the data indicate that those who are most in need of health literacy are the ones with the poorest reported health. More detailed information about the NAAL health literacy report, as well as other reports on the study, is available at www.nces.ed.gov/naal.

Functional Health Literacy: Health Information in Everyday Life

*Rima Rudd, Sc.D., M.S.P.H., Sc.D.,
Senior Lecturer on Society, Human Development, and Health,
Harvard School of Public Health*

Dr. Rima Rudd, Senior Lecturer on Society, Human Development, and Health at the Harvard School of Public Health, provided a brief history of the growing interest in

health literacy over the past several decades and gave an overview of the literature on the topic to date.

There are now more than 1,000 peer reviewed articles on health literacy. Early studies in education and adult literacy set the stage for future research with evidence that literacy influences one's ability to access information, use print materials, and participate in society. According to Dr. Rudd, leadership in the early days of the health literacy movement came from medicine, with a strong focus on patient-provider communication.

A New Focus: Functional Health Literacy

Patient-provider encounters are less frequent than other health-related situations that occur at home, at work, and in the community. Individuals must make daily choices about what they eat, how they exercise, whether to put on sunscreen, or how to take over-the-counter medications. For this reason, Dr. Rudd's research has focused on functional health literacy—the ability to read, understand, and act on health information in everyday life. She and her colleagues established a project to clearly define functional health literacy and to derive a set of provisional estimates of the distribution of health literacy in the United States. Their report, *Literacy and Health in America*, is an analysis of health literacy skills based on health-related materials and tasks from national and international surveys of adult literacy conducted before 2003 (Rudd, Kirsch, & Yamamoto, 2004).

"We need to look at both the demand side (the health care system) and the skill side (individual capacities) in order to make improvements in health literacy."

Rima Rudd, M.S.P.H., Sc.D.

Dr. Rudd and colleagues found that as many as one-half of adults lack the skills needed to accomplish health-related tasks such as following directions on medicine labels, reading nutrition labels, describing symptoms, or using a map to locate health facilities. They also found that general literacy skills and health-related literacy skills are related; those with more general literacy skills will also be more likely to have stronger health literacy skills (Rudd, et al., 2004).

Improving Health Literacy: A Two-Sided Approach

Dr. Rudd emphasized a two-sided approach to improvement in health literacy. Researchers and others concerned with health literacy must examine both:

- The demand side—what the health care system requires
- The skill side—individual capacities to respond to system demands.

Toward this end, Dr. Rudd has begun to deconstruct health activities by delineating the specific tasks associated with each health activity and assessing the skills needed to complete the tasks. For example, in order to enhance and maintain their health,

individuals are expected to read nutrition labels and purchase healthy food, prepare a dish from a recipe, understand charts and graphs such as the Body Mass Index, and/or plan an exercise routine. For many people, there is a mismatch between the demands of the activity and their skill level.

In response, Dr. Rudd and her colleagues have developed an in-depth training protocol for adult educators to help them increase health literacy skills among their students. The resulting three Health Literacy Study Circle guidebooks have been peer-reviewed and piloted (Rudd, Soricone, & Santos, 2006a, 2006b, 2007). They have been implemented in the State of Louisiana, New York State, New York City, and Boston.

Advice to Researchers and Practitioners

Dr. Rudd concluded by emphasizing the need for researchers to develop testable hypotheses related to the link between literacy skills and health, thereby clarifying the pathways from health literacy to health outcomes. Findings can then inform practice, which, in turn, must include rigorous evaluation studies. As a result, the health sector can eliminate literacy-related barriers to health promotion and access to care.

At the same time, health researchers and practitioners must work closely with colleagues in education to clearly define the needed skills associated with access to healthcare services, management of chronic disease, and participation in disease prevention activities and early screening. Adult education professionals must then work to develop these skills among members of the general public to improve health literacy.

Literacy, Chronic Disease Care, and Public Healthcare Systems: A Focus on Communication

*Dean Schillinger, M.D.,
Director of the Center for Vulnerable Populations,
University of California, San Francisco*

Dr. Dean Schillinger, Director of the Center for Vulnerable Populations at the University of California, San Francisco (UCSF), summarized the research that has been underway over the last six years at the UCSF/San Francisco General Hospital. The research includes studies evaluating the effects of limited literacy on communication, decision-making, self-care, and health outcomes such as access to care, self-rated health, and morbidity. Major findings from these studies provide good evidence that the “communication characteristics” of the health care system (described below) contribute to suboptimal care, particularly for those with limited literacy.

Limited Literacy and Health Outcomes: An Association

In one community-based prospective study of elderly English-speaking adults, limited literacy was associated with:

- Less self-rated access to care (i.e., whether patients had a regular doctor or regular place of care, had obtained a flu shot in the last 12 months, or had supplemental insurance that covered medications);
- Lower self-rated health (classified as excellent, very good, good, fair, poor);
- Higher rates of some chronic diseases; and
- Higher adjusted mortality (Sudore, Yaffe, et al., 2006).

In a separate study of public hospital patients with diabetes, limited literacy was associated with higher rates of health complications (Schillinger, et al., 2002).

Dr. Schillinger presented four hypotheses to explain these associations:

1. *Confounding*: In this hypothesis, limited literacy is a marker for a number of sociodemographic and behavioral factors or experiences that directly or indirectly lead to morbidity and mortality.
2. *Reverse Causation*: Limited literacy is a *consequence* (not a cause) of high disease burden or poor disease control, and this is associated with a worse health trajectory.
3. *Mediation*: Limited literacy affects health through a number of behavioral and exposure-related factors at the individual and community-level that directly or indirectly lead to morbidity and mortality.
4. *Effect Modification at the System Level*: The predominant hypothesis Dr. Schillinger addressed in his intervention research is that limited literacy leads to poor quality of care, which results in illness and premature death. According to Dr. Schillinger, the health care system places inappropriate demands on the patients and population groups with the greatest needs. This hypothesis suggests altering the context of care is a possible remedy.

Communication Characteristics of the Health Care System

There is good evidence that the communication characteristics of the healthcare system contribute to suboptimal health care, particularly for people with limited literacy.

*Fang et al., 2006;
Schillinger et al., 2004, 2006;
Sudore, et al., in press*

Studies have shown that limited literacy affects both written and verbal communication. Ineffective communication can impair shared decision-making and impede understanding of technical information and explanations of self-care (Sudore, Landefeld, et al., 2006).

Dr. Schillinger cited several examples from studies involving heart disease, diabetes, and end-of-life care that demonstrate these findings (Fang, Machtinger, Wang, & Schillinger, 2006; Schillinger, Bindman, Stewart, Wang, & Piette, 2004; Sudore, et al., in press). For example, diabetes patients with limited literacy were more likely to report that their doctor used words they did not understand (Schillinger, et al., 2004). In addition, limited literacy impairs medication communication, jeopardizing patient safety (Schillinger, Machtinger, Wang, Rodriguez, & Bindman, 2006).

These studies from UCSF/San Francisco General Hospital suggest a number of characteristics of the U.S. health care system that exacerbate the communication difficulties experienced by patients with limited literacy:

- Lack of time and incentives
- Over-reliance on “activated patients”
- Reliance on single modes of communication (written or verbal)
- Provider/population mismatch across language and culture
- Unprepared health professional workforce with respect to communication
- Underdeveloped technology platforms to support communication

Improving the Reach and Effectiveness of Health Care

In response to these findings, Dr. Schillinger and his colleagues recently completed a three-arm randomized trial (the IDEALL Project) that compared automated telephone diabetes management to nurse follow-up, monthly group medical visits, and usual care among public hospital patients with diabetes (Schillinger, Hammer, & Wang, in press). The study was designed to challenge the "inverse care law" which states that the availability of good medical care tends to vary inversely with need among the population served.

Preliminary analyses show that the extent of engagement was five times higher for those patients participating in the automated telephone diabetes management program than for those participating in the group medical visits. Moreover, the greatest reach of the automated telephone diabetes management program was among patients with limited literacy and limited English proficiency. More detailed analyses will be forthcoming in the near future.

Limited Literacy and Health Outcomes: A Complex Issue

In conclusion, Dr. Schillinger noted that the mechanisms by which limited literacy affects health are complicated and likely multiple. Although it is apparent that improving literacy levels of the population can achieve important public health objectives, there is strong evidence that the communication characteristics of the health care system, such as lack of time, reliance on single modes of communication, and provider/population

mismatch across language and culture, contribute to suboptimal health care, particularly for those with limited literacy. There is limited but growing research to suggest that restructuring the health care system can improve the reach and effectiveness of health care, improving quality, promoting safety, and possibly saving lives (Davis et al., 2006; Kripalani et al., 2006; Paasche-Orlow, Schillinger, Green, & Wagner, 2006; Sentell & Halpin 2006; Sudore, Landefeld, et al., 2006; Weiss, Francis, Senf, Heist, & Hargraves, 2006). It is likely that such restructuring would have greater benefit for those with limited literacy.

The Associations Between Health Literacy and Health Outcomes: Self-Reported Health, Hospitalization, and Mortality

*David W. Baker, M.D.,
Chief of the Division of General Internal Medicine,
Northwestern University Feinberg School of Medicine*

Dr. David Baker, Chief of the Division of General Internal Medicine at Northwestern University's Feinberg School of Medicine, discussed his research, which demonstrates a strong, independent connection between health literacy and health outcomes. These outcomes include emergency department use, hospitalization, self-reported physical health, and mortality. Dr. Baker seeks to demonstrate a causal association, though by which means in particular (knowledge, self-management skills, use of preventive care, medication errors, access, or cognitive function) is not clear.

Health Literacy and Health Outcomes: A Strong Association

One of Dr. Baker's earliest studies examined the relationship between health literacy* and self-reported health among patients presenting to the emergency department at one of two urban public hospitals. Patients rated their overall health as excellent, very good, good, fair, or poor. Those with inadequate health literacy skills were more than twice as likely to self-report poor health (Baker, Parker, Williams, Clark, & Nurss, 1997). After 2 years of follow-up, those with inadequate literacy had a 52 percent (95% confidence interval 1.11 to 2.06) higher adjusted risk of hospital admission compared to those with adequate health literacy (Baker, Parker, Williams, & Clark, 1998).

Multiple studies show there is a strong, independent connection between health literacy and health outcomes, including emergency department use, hospitalization, self-reported physical health, and mortality.

*Baker et al., 1997, 1998;
Wolf et al., 2005 2006*

*To measure the reading fluency of participants in their studies, Dr. Baker and colleagues used the Test of Functional Health Literacy in Adults (TOFHLA) or the short-TOFHLA. The TOFHLA classifies people as having *adequate*, *marginal*, or *inadequate* literacy.

Another study, the Literacy and Health of Medicare Managed Care Enrollees, followed 2,923 new Medicare managed care enrollees to evaluate the association between health literacy and functional health status (Wolf, Gazmararian, & Baker, 2005). Outcome measures included scores on the physical and mental health functioning subscales of the Medical Outcomes Study 36-Item Short Form Health Survey (SF-36), difficulties with instrumental activities of daily living and activities of daily living, and limitations because of physical health and pain.

The study found that individuals with inadequate health literacy reported significantly lower mean physical function (67.7 vs 78.0, $P < .001$) and mental health (76.2 vs 84.0, $P < .001$) scores on the SF-36 compared to those with adequate and marginal health literacy. Individuals with inadequate health literacy were more likely to report difficulties with instrumental activities of daily living and activities of daily living, limitations in activities because of physical health, and pain that interferes with normal work activities (Wolf et al., 2005).

A recent study of health literacy and mortality among the elderly revealed that the risk of death was 50 percent higher for those with inadequate literacy compared to those with adequate literacy (Baker, et al., 2007). This was true for cardiovascular death but not cancer death. Dr. Baker concluded that inadequate health literacy, as measured by reading fluency, independently predicts all-cause mortality and cardiovascular death among elderly persons. Interestingly, in contrast to health literacy, years of school completed were not associated with higher mortality (Baker et al., 2007). According to Dr. Baker, reading fluency is a more powerful variable than education for examining the association between socioeconomic status and health.

The Roles of Reading Fluency and Cognitive Abilities in Health Outcomes

Dr. Baker and his colleagues have begun investigating the independent associations between reading fluency, cognitive abilities, and mortality. They have proposed two specific domains—memory and the ability to follow commands—that may affect health communication and patients' ability to adhere to recommended treatment plans. Using the Mini Mental State Exam, Dr. Baker is investigating whether individuals with inadequate health literacy are less likely to be able to recall three items and to follow a three-step command than individuals with adequate health literacy (Baker, 2006). Individuals' performance on the items used to measure these domains is unlikely to be biased by educational experience or literacy. Ongoing analysis has shown that performance on measures of cognitive function predict mortality (Baker, 2006). According to Dr. Baker, cognitive function may explain a significant portion of the increased risk of mortality among patients with limited health literacy.

It remains unclear whether individuals with inadequate literacy have worse outcomes than individuals with adequate health literacy because of their poor reading fluency, their poor background knowledge of health-related issues, or their lower cognitive abilities. Further work using more detailed measures of reading fluency and cognitive function is needed to understand these relationships and to identify which individual capacities most strongly influence patients' ability to acquire and use new knowledge and gain new skills.

Interventions to Improve Health Outcomes for Patients with Low Literacy

*Michael Pignone, M.D., M.P.H.,
Associate Professor of Medicine,
University of North Carolina—Chapel Hill School of Medicine*

Dr. Michael Pignone, Associate Professor of Medicine at the University of North Carolina—Chapel Hill School of Medicine, provided an overview of existing literature on intervention studies to improve health outcomes for patients with low literacy. To date, such interventions can be categorized into three main types:

1. Interventions that make written health information easier to understand;
2. Interventions that attempt to change or re-organize the care system to mitigate the effects of low literacy; and
3. Interventions that attempt to directly improve patient literacy.

Intervention Studies: A Review of the Literature

Dr. Pignone and colleagues conducted a systematic review of the literature between 1980 and 2003 to assess the relationship between literacy and health outcomes, as well as interventions to improve outcomes for individuals with low literacy (Berkman, et al., 2004). Of the 20 studies included in the review, only 5 stratified their results by literacy level. Stratification by literacy level is key to understanding and closing the disparity gap between high and low level literacy. Most of the studies measured knowledge as their main outcome. Based on the results of the evidence review, Dr. Pignone and colleagues concluded that future research is required to better understand the factors that mediate the relationship between literacy and health outcomes.

Accommodating Patients with Low Literacy

Subsequent intervention trials have been published since the systematic literature review in 2003 (Berkman, et al., 2004). One intervention study by Dr. Pignone, Dr. Darren DeWalt, and colleagues involved a 12-month randomized trial to test the efficacy of a heart failure self-management program designed to accommodate patients with low literacy (DeWalt, et al., 2006).

The intervention included an education session and booklet written below the 6th grade reading level, a digital bathroom scale, and scheduled follow-up calls. Special attention was paid to barriers to care. Results showed improved knowledge, self-efficacy, and self-care behavior for those in the intervention group as compared with the control group. Self-efficacy, defined as an individual's judgment of his/her ability to succeed in reaching a specific goal, was measured with an 8 item scale developed for the behaviors needed in this trial. The intervention reduced incidence of hospital admission or death.

Patients with low literacy showed even greater improvements than those with higher literacy.

Providing Literacy Education

In a separate intervention study cited by Dr. Pignone, the authors investigated literacy education as an adjunct treatment for depression. In addition to receiving standard treatment for depression, patients in the intervention group were also referred for literacy training at an adult education program. Learning was facilitated through computer-assisted instruction, traditional text-based instruction, and/or self-paced study modules. The literacy program also offered employment-skill training.

Results of the small, randomized study of 70 patients suggested that literacy education can beneficially supplement the effects of depression treatment in primary care settings (Weiss, et al., 2006). It is unknown whether these results can be replicated for other health outcomes.

Suggestions for Future Intervention Studies

In conclusion, Dr. Pignone noted that relatively few studies have examined interventions to mitigate the effects of low literacy on health outcomes. Future studies should include participants with a wide range of literacy levels and stratify results by literacy level. Pignone also suggested that in addition to outcome measures like knowledge, future studies should identify the behaviors required for effective self-care and measure the ability of patients to learn those tasks. For example, rather than asking only asthma knowledge questions, researchers could analyze the effect of interventions on the ability to correctly use inhalers. Finally, more studies are needed that examine the effect on health outcomes by improving the reading skills of persons with low literacy.

Discussion: Panel 1

Panel 1 elicited a wide variety of comments from audience members and panelists.

Self-Efficacy versus Knowledge Building in Improving Health Literacy

One researcher in the audience asked whether there were scientific studies investigating causal influence interventions (i.e., teaching people more generally about how the body works and the nature of disease so that they may act more appropriately when faced with symptoms). Panelists noted that much of the work to date concerns self-efficacy building rather than knowledge building. Dr. Baker expressed concern that causal models can sometimes create excessive cognitive demand, noting that it may be useful to begin with a simple causal model, then build on that knowledge. He emphasized the importance of efforts to determine how we can effectively create learning situations that promote the long-term retention of information.

Participants discussed the role of knowledge versus skills in improving health literacy. Dr. Rudd noted that what is taught in kindergarten through 12th grade (K-12) varies so widely that few assumptions can be made about the knowledge base of children and

adults with regard to understanding the human body and its systems. A representative from the American School Health Association responded that national health education standards for K-12 emphasize skills, such as how to access health information and the ability to set goals and make decisions, rather than content or knowledge. There appears, however, to be a large disparity in the content taught and no clear definition of what content people should have in order to say that they are health literate. Dr. Pignone agreed with the need to improve health and science instruction, but he expressed concern about the tendency to overemphasize pathology and physiology. He commented that at a basic level, people need non-health-specific skills related to empowerment and self-efficacy, such as how to ask questions during a medical appointment.

The Relationship Between Literacy and Health Literacy

Panelists and audience members had varying views on the relationship between literacy and health literacy. Dr. Rudd noted that the IOM Committee on Health Literacy had concluded that there is a significant overlap between the two concepts, but that there are strong content-specific demands in the area of health literacy that distinguish it from general literacy. The skills may be the same, but the applications differ.

“Although there is significant overlap between literacy and health literacy, there are strong content-specific demands in the area of health literacy that distinguish it from general literacy.”

Rima Rudd, M.S.P.H., Sc.D.

Dr. Whitehurst added that the correlation between literacy scores and health literacy scores in the NAAL is quite high.

Dr. Baker agreed that there were commonalities, but argued that there was a need for greater precision in discussing general literacy. He noted that background conceptual knowledge may be key to understanding the distinction between literacy and health literacy. Dr. Pignone cautioned participants against calling the measures described at the workshop health literacy measures, when in fact they are literacy measures that use health terms. He stated that a measure of health literacy as a broad construct has yet to be developed.

Improving the Communication Skills of Health Care Providers

A representative from the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) raised the issue of changing the communication practices of healthcare providers, noting that good communication practices need to be introduced in provider education and training. An audience member from the American Medical Association (AMA) echoed these concerns and announced that the AMA would be launching an initiative linking health communication and patient safety. Dr. Schillinger pointed out that nursing, medical, and pharmacy students are very receptive to learning these skills, but noted that skills training needs to continue into the residency phase/clinical context. The positive effects of communication skills training can be

displaced by the demands of residency. He commented that medical student associations can often drive curricular change, making them excellent points of intervention.

Dr. Pignone noted that system changes such as team-based care, information technology infrastructure, and reimbursement practices can also improve patient-provider communication. Dr. Rudd added that, while it is important to look at communication between health professionals and patients, we must also work with writers of health education materials to ensure that they rely on formative research. She noted that we do not approve new drugs without formative research, so we should not produce written materials without comparable research.

Methodological Issues in Health Literacy Research

An audience member remarked that much of the study of health literacy has been quantitative in nature and asked how much ethnographic research, particularly research models that involve people with low literacy in the design of materials, has been conducted. Dr. Baker pointed out that qualitative studies as early as 1991 have included interviews and focus groups designed to record the opinions, questions, and experiences of persons with low literacy. Dr. Schillinger described a study in which clinicians and patients were videotaped in order to assess shared decision-making (Saba et al., 2006). Results did not show a strong correlation between the effective communication behavior of the provider and the positive experience of the patient. The researchers concluded that relationship dynamics such as trust between provider and patient mediate the patient's perception of shared decision-making. Efforts to enhance patient-physician communication, especially among disadvantaged populations, must include improvements in effective communication behavior and affective relationship dynamics (Saba et al., 2006).

An adult education advocate in the audience asked how much research has been done on oral literacy, commenting that we are largely an oral society. Dr. Rudd replied that there is not much in the literature to date, but a number of studies on the topic are underway. She noted that the NAAL collected information on oral skills such as fluency and pronunciation, but that information had not been analyzed at the time of the workshop. There is a good deal of literature on oral communication in the communication field, and more knowledge-sharing on this topic would be useful.

Interpreting the NAAL Health Literacy Data

A representative from the Indian Health Service asked if the NAAL accurately reflects the health literacy of minority populations. Dr. Whitehurst replied that the NAAL was a very large national study, with a sufficient sample size to accurately report on population differences. He added that because the assessment was in English, there would be some differences in literacy skills when nativity is analyzed.

The moderator commented that prior to the 2003 NAAL data, most people cited the 1992 National Adult Literacy Survey figure used in the IOM report that 90 million Americans would have trouble understanding health information. He asked whether the NAAL data

give us a more concrete number. Dr. Whitehurst replied that they did not categorize the data in that way. According to the NAAL, there are approximately 30-34 million adults in the lowest levels of health literacy (30 million adults in Below Basic and an additional 4 million adults who could not participate in the survey due to language barriers); it is reasonable to presume that they will have trouble understanding and using health information (Kutner, et al., 2006). An audience member from AHRQ pointed out that the 30-34 million figure does not include those from institutionalized populations (other than prisons) and homeless people. Therefore, she suggested that the figure was likely artificially low.

Panel 2: Meeting the Health Literacy Needs of Special Populations

Topics covered in Panel 2:

- Language barriers, literacy, and communication in health care
- The role of health literacy in reducing health disparities
- Health literacy needs of older adults
- Health literacy needs of young children

Lost in Translation: Language Barriers, Literacy, Communication, and Quality in Health Care

*Glenn Flores, M.D., F.A.A.P.,
Director of the Center for the Advancement of Underserved Children,
Medical College of Wisconsin and the Children's Hospital of Wisconsin*

Dr. Glenn Flores, Director of the Center for the Advancement of Underserved Children at the Medical College of Wisconsin and the Children's Hospital of Wisconsin, began by emphasizing the rapid growth in the United States of those speaking a language other than English at home and those with limited English proficiency (LEP). Specifically, 52 million people in this country speak a language other than English at home, and 23 million have LEP.

Mismatch in Language between Provider and Patients: A Barrier to Health Care

Although Title VI of the Civil Rights Act of 1964 protects LEP individuals' rights to medical care, there continue to be barriers, particularly in the availability of medical interpreter services. At one inner-city primary care clinic, 26 percent of mothers of Latino children cited language problems as the single greatest barrier to health care (Flores, Abreu, Olivar, & Kastner, 1998). A study of patients seen in an urban emergency department revealed that no interpreters had been used for 46 percent of the LEP patients, and when interpreters were used, 39 percent had had no training in medical interpreting (Baker, Parker, Williams, Coates, & Pitkin, 1996). In a separate study by Flores and colleagues of 175 pharmacies, 47 percent never or only sometimes printed prescription labels in a language other than English and 64 percent never or only sometimes could orally communicate with LEP patients (Bradshaw, Tomany-Korman, & Flores, in press).

“Quality of care is compromised when LEP patients do not have interpreters or use untrained, ad hoc interpreters such as children.”

Glenn Flores, M.D., F.A.A.P.

The Dangers of Using Ad Hoc Interpreters

Quality of care is compromised when LEP patients do not have interpreters or use untrained, ad hoc interpreters such as children. Language problems have an impact on many aspects of health care, including access, health status, use of services, patient-physician communication, satisfaction with care, and patient safety. There are many examples in the literature that cite interpreter problems, such as omissions or erroneous information, that demonstrate that lack of quality interpretation leads to poor health outcomes for LEP patients (David & Rhee, 1998; Flores, 2003; Launer, 1978).

The hazards of using ad hoc interpreters (e.g., family members, friends, strangers from the waiting room) are numerous. In these instances, interpretation errors are more likely to have potential clinical consequences than those caused by professional interpreters. Examples of interpreter error of clinical consequence include:

- Omitting questions about drug allergies
- Erroneously adding that hydrocortisone cream must be applied to a baby’s entire body, instead of solely to a rash on the arm
- Omitting instructions about antibiotic dose, frequency, and duration
- Instructing a mother not to answer personal questions about STDs and drug use (Flores, 2003).

One study found that family members of LEP patients misinterpret 23 to 52 percent of questions asked by physicians (Ebden, Bhatt, Carey, & Harrison, 1988).

Increasing Language Access in Health Care: Recommendations for Action

Based on his body of research, Dr. Flores outlined several areas where action is needed in order to increase language access in health care, including:

- Increasing the number of bilingual health care providers
- Increasing the level of foreign language study available to children in school
- Ensuring clinicians’ access to information regarding free or low-cost English classes in order to refer LEP patients
- Ensuring comprehensive language access from intake to discharge

- Enforcing Title VI requirements
- Creating centralized banks of trained interpreters
- Providing third-party payer reimbursement for medical interpreter services for all 50 states.

A Call to Action: The Role of Health Literacy in Reducing Health Disparities

*Harold P. Freeman, M.D.,
Medical Director,
Ralph Lauren Center for Cancer Care and Prevention, New York*

Dr. Harold Freeman, Medical Director at the Ralph Lauren Center for Cancer Care and Prevention, began by encouraging participants to marry efforts to improve health literacy with access to recommended health care. If patients can neither comprehend needed health information nor access the recommended care, attempts to improve the quality of care, increase survival, and reduce health disparities will inevitably fail. According to Dr. Freeman, this linkage must be achieved at the community level and must include not only patients, but also community health care providers and systems of care.

The Persistence of Health Disparities

It is well known, Dr. Freeman observed, that disparities exist in health care for the poor and medically underserved, especially in minority communities. The interaction of three major factors—low socioeconomic status, social injustice, and culture—causes disparities in health to persist in these communities. The current health system does not adequately address these disparities. Furthermore, there is a disconnect between scientific discovery and delivery. By developing strong alliances between literacy and access, Dr. Freeman proposed, we can have an impact on closing the delivery gap in this country, a key determinant, for example, in the unequal burden of cancer.

“We must marry efforts to improve health literacy with access to recommended health care.”

Dr. Harold Freeman, M.D.

When he was President of the American Cancer Society, Dr. Freeman conducted a series of hearings with testimony from poor Americans who had been diagnosed with cancer. He found the principal barriers to care for this group were related to:

- Cost
- Communication and information
- Medical system

- Fear and other emotional aspects
- Geographic concerns
- Cultural concerns
- Unequal treatment

The Patient Navigation Program

Based on his experience as President of the American Cancer Society, Dr. Freeman created the first "Patient Navigation" program, conceived and initiated in 1990 at the Harlem Hospital Center (Freeman, 2006). The program provided patients with a navigator to help them make their way through the complex health care delivery system and promoted access to timely cancer care, from diagnosis through treatment. Evidence of the program's success was observed in the early diagnosis and higher survival rates for women with breast cancer (Oluwole, et al., 2003).

As a result of the Harlem experience, patient navigation is being evaluated widely. The National Cancer Institute (NCI) has awarded nine grants to examine the effectiveness of patient navigation programs in various settings across the country, particularly in communities with an unequal burden of cancer.

By augmenting the role of patient navigators in developing health literacy, and by providing resources to train patient navigators in health literacy, Dr. Freeman hopes to be able to accelerate progress and expand the reach of health literacy efforts. Dr. Freeman emphasized that patient navigators could play a major role in promoting community-based health literacy efforts across all populations.

Recommendations for the Field

To ensure that improvements in health literacy effectively result in improved quality of life, increases in survival, and reductions in health disparities and costs, Dr. Freeman outlined several steps health professionals should take. These include:

- Marry the improvement of health literacy with access to recommended health care.
- Target geographic areas with excessive mortality with an intense approach to providing culturally relevant education, screening, diagnosis, treatment, and network of social support.
- Enhance patient navigation programs to improve health literacy and promote strong community involvement.

Meeting the Health Literacy Needs of Older Adults

*Denise C. Park, Ph.D.,
Director of the Center for Healthy Minds,
University of Illinois at Urbana-Champaign*

Dr. Denise Park, Director of the Center for Healthy Minds at the University of Illinois, began with three main points:

- Healthy older adults experience cognitive decline;
- This decline affects their ability to comprehend medical information and follow treatment regimens; and
- It is much more feasible to restructure materials and messages than it is to improve cognition to enhance health literacy in the elderly.

Old Age and Cognitive Decline

Older adults are vulnerable. Very old age (over age 80) is a particular risk factor for poor health literacy. Data suggest that this increased vulnerability is the result of decreased efficiency in information processing, declines in working memory function, and difficulty remembering context or learning, all of which can create confusion (Brown and Park, 2003). Older adults may have problems when facing new medical issues as they have to learn about a new disease or disorder and make complex decisions about treatments. These tasks may tax the capabilities of a declining cognitive system. In one study, lower literacy scores in a sample of older adults predicted increased hospitalization and poorer health, even in the well-educated, affluent population (Baker et al., 2002).

The Illusion of Truth

Given the changing cognitive systems of older adults, Dr. Park and her colleagues became interested in a memory effect called "the illusion of truth" which holds that familiar information, even when false, feels true, particularly to older adults who forget where they learned or heard something. The researchers asked older adults to study medical phrases, some of which were designated as false. They varied how often they presented the same statements as true or false. They found that the more often participants had been told a medical statement was false, the more likely they were later to believe that it was true (Skurnik, Yoon, Park, & Schwarz, 2005). Dr. Park noted that information presented as health "myths" also encourages the illusion of truth effect.

"Familiar information, even when untrue, feels true, particularly to older adults who forget where they learned or heard something."

Denise Park, Ph.D.

Recommendations for Action

She concluded that many health laws, programs, conditions, and consent forms exceed the cognitive capabilities of a significant proportion of older adults, even those who are well-educated. Dr. Park cited Medicare Part D as one example. Cognitive scientists can play an important role in engineering effective and memorable health materials and Web sites for older adults that will help them process medical information accurately and increase their ability to follow medical instructions. Policymakers can help by consulting with experts on designing elder-related government programs that are compatible with the cognitive systems of older adults.

Meeting the Health Literacy Needs of Young Children

*Frank C. Keil, Ph.D.,
Professor of Psychology and Linguistics,
Yale University*

Dr. Frank Keil, Professor of Psychology and Linguistics at Yale University, provided an overview of his research concerning the way children learn and how that learning relates to health literacy.

Children, along with most adults, have large gaps in their understanding of health-related issues (Eva, Cunningham, Reiter, Keane, & Norman, 2004; Hayes, Hulleat, & Keil, 2004; Kriz & Hegarty, 2004; Rozenblit & Keil, 2002; Simons & Keil, 1995). But it is also clear that children have surprisingly rich ways of making sense of the living world (Inagaki & Hatano, 2002). Taken together, the body of research strongly suggests that children of all ages have the potential to understand a great deal about health and about how to access health information. In particular, more attention should be paid to the ways in which children can grasp cause-effect relationships in the world around them and how they can use these relationships to reason in more powerful and effective ways, both about health and about providers of health information (Sigelman, Rinehart, Sorongon, Bridges, & Wirtz, 2004).

Illusions of Understanding

On one level it appears that children are severely limited in their ability to understand health and illness. In addition, there is substantial evidence that both children and adults have little understanding of just how limited their knowledge is (Eva, et al., 2004; Hayes, et al., 2004; Kriz & Hegarty, 2004; Rozenblit & Keil, 2002). In fact, people of all ages systematically mislead themselves into thinking they have far more mechanistic knowledge than they really do. Children show the same illusions of understanding. They also hold dramatic misconceptions about the biological world. In one study by Dr. Keil and colleagues, large numbers of kindergartners were unable to correctly choose bottles of bodily organs as the appropriate insides of animals in comparison to bottles of pebbles and bottles of gears (Simons & Keil, 1995).

Cause-effect explanations are powerful in maintaining knowledge about disease, thinking about new situations, and forming negative views of health risks.

Sigelman, et al., 2004

Very young children know a good deal in the way of abstract patterns, while being quite ignorant about concrete details—a notion contrary to classical views. For example, by the preschool years, children know that food gets transformed after it enters the body and that the transformed version is critical for helping the body grow—even though they may have incorrect knowledge about the specific details of digestion (Inagaki & Hatano, 2002).

Cause-Effect Explanations

Keil and his colleagues also found that children are interested in cause-effect explanations and these explanations are powerful in maintaining knowledge about disease, thinking about novel situations, and forming negative views of health risks. For example, teaching children about the effects of drug actions is much more effective in making them good judges about risk in novel situations than simply teaching them a list of behavioral dos and don'ts (Sigelman, et al., 2004).

Evaluating the Quality of Health Information

A second and more recent development concerns children's potential ability to seek out health-related information and evaluate its quality. Children appear to have a good basis for learning about appropriate domains of expertise. Studies by Dr. Keil and colleagues show that young children are inclined to doubt claims made by an adult who has previously been mistaken and are more inclined to doubt the truth of a message if it coincides with the speaker's self-interests (Mills & Keil, 2004). While this work has largely been done outside the health arena, there is reason to believe that similar results will occur with regard to health messages. This research suggests that providing children with information about the people making health-related claims will make them better able to evaluate those claims.

Dr. Keil argued that from preschool years onward, there are tremendous benefits to be gained from teaching health-related concepts in ways that connect that information to coherent causal biological accounts. However, a key challenge lies in pruning these explanatory messages down to a developmentally appropriate level.

Discussion: Panel 2

Much of the discussion that followed the second panel centered on the potential influence of language, ethnicity, culture, and belief systems on health literacy and health outcomes.

The Relationship between Culture, Language, and Health Literacy

Audience members offered a variety of examples illustrating the lack of adequate communication on the part of healthcare providers in response to differences in ethnicity, culture, and belief systems between providers and patients. They expressed interest in learning about the research on ethnicity, health perception, and culture, as well as cultural taboos and their role in health literacy. In response, panel members described a number of studies that demonstrate that either cultural or linguistic concordance leads to positive health outcomes. Moreover, panel members agreed that communication must be tailored and framed to take into account the patient's language, culture, and illness representation.

Two members of the audience highlighted the problem of false fluency errors created by physicians, i.e., physicians who believe that they can speak a second language, but who in fact make errors that may affect patient safety. Dr. Flores noted that there is not much research on this area and that the evidence is largely anecdotal. In response to this discussion, a representative from the Office of Minority Health stressed the need to increase the bilingual capability of health professionals, noting that there is a severe under-representation of minorities in the health professions. Dr. Flores agreed that to effectively bridge language barriers, efforts must be made to increase the number of health professionals from minority populations.

Trust and the Patient-Provider Relationship

Several speakers also commented on patient-provider communication. Dr. Baker expressed interest in the notion of probabilistic thinking highlighted during Dr. Keil's presentation, and asked whether current communication by physicians who follow the "don't do this, or this will happen" format might lead to a general distrust of the physician. Dr. Keil was not aware of any specific data on this topic, but agreed that physicians need to be sensitive about their presentation of health information.

Dr. Freeman commented on the issue of distrust of providers and the legacy of the Tuskegee experiment, particularly in poor Black communities. He noted that the trust barrier seems to disappear when programs that promote health literacy are developed with involvement from the people who will use them. One audience member asked whether there were data to support the use of *promotoras*, or community health workers, as a way of meeting the cultural and linguistic needs of patients. Dr. Flores explained that the research consists largely of case studies and anecdotal evidence that show the success of case managers, similar to *promotoras*, in reaching out to diverse communities.

Persons with Limited Literacy as a Special Population

One participant remarked on what she observed to be a general theme of the day—the need for additional research to document the extent and associations of limited health literacy. She commented that despite the recommendation in the 1999 IOM report *The Unequal Burden of Cancer: An Assessment of NIH Research and Programs for Ethnic Minorities and the Medically Underserved* to define low literacy groups as a special

population, large national studies typically do not measure or identify health literacy levels among their sample populations.

Defining the Problem: Limited Health Literacy or Poor Quality Health Care?

Panelists and participants had varying opinions on the role of the individual versus the system in improving health literacy. An adult education advocate in the audience questioned whether the problem is low health literacy on the part of the patient, or rather, poor quality health care. Dr. Flores commented that the issue is primarily about communication, though it is confounded by cultural, literacy, and language barriers.

Dr. Keil stated that the more health literate people are, the more likely they are to communicate effectively with their doctor; thus, communication and literacy go hand in hand. Dr. Freeman stressed that doctors cannot solve the problem of limited health literacy, given their time constraints, and that there needs to be systemic solutions such as the navigator concept. Finally, Dr. Park suggested that future research should explore technological solutions to limited health literacy.

Panel 3: Toward an Informed and Engaged Public

Topics covered in Panel 3:

- Patient activation and health literacy
- Health literacy, preparedness, and public health
- Health literacy: a communication perspective
- Translating health literacy research into action

Both Health Literacy and Patient Activation Contribute to Consumers' Ability to Manage Their Health

*Judith Hibbard, Dr.P.H.,
Professor of Health Policy,
University of Oregon*

Dr. Judith Hibbard, Professor of Health Policy at the University of Oregon, began by emphasizing that patient activation and health literacy, while only moderately correlated, both make independent contributions to health behaviors, health choices, and health outcomes. To focus on one and not the other is to miss a major contributor to health outcomes.

Patient Activation Measure

Patient activation refers to the ability to manage one's own health and health care. The Patient Activation Measure (PAM) is a 22-item measure that assesses patient knowledge, skill, and confidence for self-management. The measure was developed using Rasch analyses and is an interval level, uni-dimensional, Guttman-like measure. Research findings indicate that the PAM predicts healthy behaviors, disease-specific self-management behaviors, and consumer behaviors (Hibbard, Mahoney, Stockard, & Tusler M, 2005; Hibbard, Stockard, Mahoney, & Tusler, 2004; Hibbard & Tusler, 2007; Mosen, et al., 2007). Findings from a longitudinal study conducted by Dr. Hibbard and her colleagues showed that activation levels are not fixed, and that positive changes in activation are followed by improved health behaviors and improved functioning (Hibbard, Peters, Dixon, & Tusler, 2007).

Empirical evidence suggests that there are four stages of activation that patients go through in the process of becoming fully competent managers of their health:

- The patient does not yet believe that they have an active and important role in their health;
- The patient lacks the confidence and knowledge to take action;

- The patient begins to take action; and
- The patient maintains behaviors over time (Hibbard, et al., 2005).

Health Literacy and Activation Both Contribute to Health Outcomes

Findings from two separate studies indicate that health literacy and activation both contribute to health outcomes (Hibbard, Greene, & Tusler, 2005, 2006). Health literacy contributes more to choices and the use of information; activation contributes more to health behaviors. When it comes to being able to understand health information, three factors come into play:

- Difficulty of the information and how it is presented
- Skill of the user
- Motivation of the user.

Even when people have a high degree of skill, they may not expend the effort necessary to understand written text. For people with lower literacy skills, motivation can make a difference, with those putting more effort into trying to derive meaning from a document typically achieving higher comprehension. In Dr. Hibbard's studies, results indicated that activation may help to compensate for lower literacy skill, increasing comprehension among those with lower literacy (Hibbard, et al., 2007).

Measuring Activation: Recommendations for the Field

Dr. Hibbard concluded by stressing the need to tailor health information and messages to both health literacy and patient activation levels. By measuring activation, we can both tailor care for individual patients and have a metric to know whether patients are gaining in their ability to self-manage. Focusing on improving materials to support patients with lower literacy and strategies to increase activation may contribute to improved health outcomes.

Advancing Health Literacy: A Framework for Understanding and Action

*Christina Zarcadoolas, Ph.D.,
Associate Clinical Professor,
Mount Sinai School of Medicine*

Dr. Christina Zarcadoolas, Associate Clinical Professor at Mount Sinai School of Medicine, opened by remarking that human beings are skilled communicators. There is a large body of literature—in anthropology, linguistics, and sociology—that demonstrates this (Zarcadoolas, Pleasant, & Greer, 2006).

Moving Beyond the “Deficit Model”

She emphasized that work on the issue of health literacy has operated largely on a deficit model to describe the gap between the complexity of health information coming from the medical, scientific, and policy-making communities and the comprehension abilities of the public. As a result, the field of health literacy has adopted a dominant strategy to tackle low health literacy: simplifying health information. Dr. Zarcadoolas’ research demonstrates that the focus on simplifying surface level language (vocabulary and sentences) downplays important socio-cultural aspects of people’s understanding and minimizes the intricate, efficient, and inefficient strategies people have for understanding health messages and making health decisions (Zarcadoolas, et al., 2006).

A Multi-Dimensional Model of Health Literacy

Dr. Zarcadoolas defines health literacy broadly as the wide range of skills and competencies that people develop over their lifetimes to seek out, comprehend, evaluate, and use health information and concepts to make informed choices, reduce health risks, and increase quality of life. Health literacy, like any competency, is on a continuum. A health literate person is able to use health concepts and information generatively—applying information to novel situations. This is critical to our efforts to prepare the public to react to complex public health emergencies.

“A health literate person is able to use health concepts and information generatively—applying information to novel situations. This is critical to our efforts to prepare the public to react to complex public health emergencies.”

Christina Zarcadoolas, Ph.D.

This definition of health literacy is the foundation for a multi-dimensional model developed by Dr. Zarcadoolas and her colleagues, built around four central literacy domains: fundamental, scientific, civic, and cultural literacy. Literacy skill in one domain can contribute to the development of literacy skill in other domains, and competency in one area can compensate for a lack of competency in another. This model provides a broad construct for creating tools and communication strategies that ultimately can improve health literacy.

Meeting the Health Literacy Needs of the Population

In outlining areas for action, Dr. Zarcadoolas emphasized the need to create information that is appropriate to the health literacy needs of the specific population. This end can be accomplished through the following strategies:

- Use of an elaborated model of health literacy
- Collaboration with the target audience
- Revision and simplification

- Contextualization
- Reinforcement
- Evaluation
- Subsequent revisions

She stressed the need to look for richness in what people *can* do with language (rather than what they cannot do) to avoid stigmatizing people for using health information in ways we have yet to understand.

Toward an Informed Public: A Communication Perspective

*Vicki Freimuth, Ph.D.,
Professor of Health and Risk Communication,
Grady College, University of Georgia*

In order to illustrate that mass media are common and heavily used channels of health information, Dr. Vicki Freimuth, Professor of Health and Risk Communication at the University of Georgia, opened with the following statistics. Each year in the United States, the average person is likely to spend:

- 84 hours reading magazines
- 165 hours reading newspapers
- 480 hours accessing the Internet
- 1,248 hours watching television
- less than 1 hour in a doctor's office (Kline, 2003).

Closing the Knowledge Gap

Dr. Freimuth went on to describe the knowledge gap hypothesis (Tichenor, Donohu, & Olien, 1970) which predicts that as mass media information is infused into a social system, members with more education will acquire knowledge faster than do those with relatively less education. Consequently, the gap in knowledge between social groups will increase. Simply increasing the volume of health information will not improve health literacy.

To help eliminate this knowledge gap, Dr. Freimuth suggests, health communication must be adapted to four primary elements:

- Source of the information
- Health message being conveyed

- Dissemination channels
- Receivers or target audience.

Role of the Source of Information in Communication

The source of information is critical to the way the public receives and uses health information. Source credibility has two dimensions: expertise and trust. The 2005 Health Information National Trends Survey (HINTS), conducted by NCI and available at <http://cancercontrol.cancer.gov/hints/>, found that the lowest income group reported a lower level of trust for all sources studied (health professionals, family and friends, newspapers, magazines, radio, internet, and television).

Creating Effective Health Messages

There is extensive science around what creates an effective health message. Some of the principles include the following. The message should be:

- clear and simple;
- positive rather than negative;
- include emotional appeals as well as logical ones; and
- be as tailored to the receivers' individual characteristics as possible.

In addition, there are common theoretical variables across health behavior change models that should be considered in crafting health messages, such as fear and perceived susceptibility, self-efficacy, and social norms (Andreasen, 1995; Backer, Rogers, & Sopory, 1992; Centers for Disease Control and Prevention, 2001; Maibach & Parrott, 1995; National Cancer Institute, 2001; Siegel & Doner, 1998).

“Simply increasing the volume of health information will not improve health literacy.”

Vicki Freimuth, Ph.D.

Channels of Communication

Channels of communication traditionally have been classified as mass media or interpersonal (Reardon & Rogers, 1988). Mass media channels such as television, radio, newspapers, and magazines are typically considered the most effective in creating awareness of a new issue or setting a public agenda and for imparting knowledge (McCombs & Shaw, 1973). However, it is the interpersonal channels (family, friends, coworkers, and health professionals) that are more trusted and more persuasive. A multi-step flow of information from mass media to opinion leaders to the general public has been widely documented (Katz & Lazarsfeld, 1955; Rogers, 1983; Tichenor, Donohue,

& Olien, 1980). Additionally, the Internet has increasingly become the channel of choice for health information seekers, regardless of income.

Mass media campaigns have frequently been used to promote healthy behaviors. Traditionally, these campaigns have relied on public service advertising, making it difficult to target specific audiences or achieve much exposure. Still, there is evidence of their effectiveness. Dr. Freimuth cited two examples: the Truth anti-smoking campaign achieved a 22% reduction in prevalence of youth smoking (Farrelly, Davis, Haviland, Messeri, & Healton, 2005); and the VERB campaign to promote daily physical activity among children ages 9-13 achieved 74% awareness of its brand and messages after one year and increased levels of free-time physical activity in its target population (Huhman, et al., 2005).

Understanding the Target Audience

The final element—the receivers—involves understanding the target audience. The public cannot be considered a homogenous group but must be segmented by demographics, behaviors, health status, or psychographics (attributes relating to values, attitudes, or lifestyle). Formative research using qualitative techniques should be used to learn about the audience before designing a message.

Dr. Freimuth concluded by recommending that researchers explore how communication interventions could be used to improve health literacy directly. The concept of health literacy itself could be raised on the public's agenda with more mass media coverage, and skill-building messages could be disseminated as part of other health communication campaigns.

Translating Health Literacy Research into Large Scale Public Action

*Linda Neuhauser, Dr.P.H.,
Clinical Professor
University of California, Berkeley School of Public Health*

Dr. Linda Neuhauser, Clinical Professor at the University of California, Berkeley School of Public Health, addressed the challenge of translating what is known about health literacy improvement into public health action on a large scale. She presented a translational research model to provide important guidance in meeting this challenge.

A Translational Research Model

The model consists of five steps necessary to translate health literacy research into action:

- Basic research
- Creation of evidence-based guidelines
- Testing of interventions among diverse groups

- Creation of large-scale action
- Development of policies and mandates based on these results.

While there is much work being done in the first three areas, most of this academic research has not been translated into large-scale action or policies.

User Collaboration in Health Communication

Dr. Neuhauser recommended two ways to improve health communication for low health literacy groups: (1) involve low health literacy groups in the user-centered design of health communication; and (2) apply proven health literacy design principles and standards derived from usability testing. User collaboration is critical in both approaches.

“User-centered design improves communication for the participating groups, including persons with low health literacy.”

Linda Neuhauser, Dr.P.H.

User-centered design is a structured process to engage intended users in the development of a product. Usability testing is an essential part of user-centered design; it evaluates representative users’ performance and satisfaction with a product. These processes are described on the DHHS website: www.usability.gov. There is strong evidence that when users participate in designing and testing communication, outcomes are more successful, including those for persons with low health literacy (Cooper, Beach, & Clever, 2005; Davis, Holcombe, Berkel, Pramankik, & Divers, 1998; Gustafson, et al., 1999; Jibala-Weiss, et al., 2006; Neuhauser & Krepps, 2003; Neuhauser, 2001; Nielson, 2000; Taub, Baker, & Sturr, 1986; Vaiana & McGlynn, 2002; Zarcadoolas, Pleasant, & Greer, 2006).

Case Study: MyPyramid.gov

Too often, Dr. Neuhauser noted, mass communication is produced without the adequate participation of low health literacy user groups or adherence to user-centered design principles. For example, the U.S. Department of Agriculture developed MyPyramid.gov, an important resource to promote healthy eating and activity for the U.S. population (Hentges, 2006). Site content was targeted at a 7-8th grade reading level, but an assessment of the Website found that its readability averaged 9-11th grade (Haven, Burns, Herring, & Britten, 2006; Neuhauser, Rothschild, & Rodriguez, 2007).

Moreover, even though the site was intended to be consumer-friendly, it met only half of the usability design criteria recommended by DHHS and other sources (Koyani, Balley, & Nall, 2006; Lynch & Horton, 2002; Neuhauser, Rothschild, et al., 2007; Nielsen, 2000; Vaiana & McGlynn, 2002; Zarcadoolas, Blanco, & Boyer, 2002). Although focus groups and usability testing were part of the design process, low health literacy was not a specific criterion for selecting participants (Haven et al., 2006; Juan, Gerrior, & Hiza, 2006; Neuhauser, Constantine, et al., 2007).

Health Literacy Standards and Participatory Methods to Improve Communication

There is significant guidance regarding health literacy standards and participatory methods to improve communication for low literate groups (U.S. Department of Health and Human Services (USDHHS), 2006a; USDHHS, 2006b; Neuhauser, 2001; Nielson, 2000; Vaiana & McGlynn, 2002; Koyani, et al., 2006). Methods include:

- Identification of the key user groups by language, literacy, disability, culture, health conditions, and other factors
- Involvement of members of the user groups as collaborators
- Use of multiple and intensive participatory methods
- Involvement of other key stakeholders in the participatory process
- Adherence to tested health literacy and communication standards
- Iterative testing for user engagement, usage, comprehension, motivation, and behavioral outcomes.

Case Study: *First 5 Kit for New Parents*

These methods and the steps in the aforementioned translational research model were used in the development of the successful *First 5 Kit for New Parents*, which is distributed to 500,000 new parents in California each year. The *Kit* is a low-literacy multi-media health and parenting resource. Hundreds of parents and providers were involved in the 1-year design and testing process. A longitudinal study showed positive outcomes, and results were used to further refine the *Kit* (Neuhauser, Constantine, et al., 2007). Furthermore, participatory design was used to adapt the kit for four Asian language groups.

Need for a National Plan to Improve Health Literacy

Dr. Neuhauser concluded by emphasizing the need for a national plan to improve health literacy. She specifically highlighted the lack of cross-agency leadership at the federal level to apply guidance from health literacy research to the work of all agencies and departments.

The ideal national plan would include:

- National evidence-based health literacy standards and guidelines.
- Federal, state, and organizational leadership and commitments to advance health literacy.
- Specific objectives and approaches for large-scale health literacy action.

- Indicators to measure improvements in health literacy efforts.
- National mandates and policies.
- Milestones for health literacy progress.

Discussion: Panel 3

This panel elicited a number of questions and comments from audience members, largely related to how best to define and approach the issue of limited health literacy without labeling or stigmatizing a segment of the population.

Limited Health Literacy: Not Just an Individual Problem

Discussion addressed the conviction that communication about limited health literacy ought to be presented in a manner that would preclude dividing the nation into “literate” and “nonliterate” people. Dr. Hibbard pointed out that there were many evidence-based strategies to effectively reduce the cognitive burden of health information without “dumbing down” the material. These techniques help everyone, no matter what their literacy level.

Dr. Neuhauser remarked that there are deficits at all levels—including providers, health care organizations, and educators—and that we can benefit from identifying all of these deficits, rather than focusing on individuals with limited health literacy skills. An audience member from AHRQ commented on the usefulness of Dr. Rudd’s work in this area, including new tools she designed, such as an audit to help organizations assess the demands they are placing on patients and clients (Rudd & Anderson, 2007).

An Ecological Perspective

“Communication deficits exist at all levels—including healthcare providers, healthcare systems, educators, policymakers, and the public.”

Linda Neuhauser, Dr.P.H.

One audience member suggested that we need to look at health literacy from an ecological perspective. He asked whether there was any research underway to study health literacy in a broad context, including family literacy, institutional health literacy, and organizational health literacy. An audience member from the Centers for Disease Control and Prevention pointed out that their agency is making an effort to approach public health issues as “syndemics” rather than epidemics; they are looking at how epidemics and other public health issues interact synergistically in a population. A representative from AHRQ commented on the lack of literature on family health literacy, calling this a significant research gap.

In response to a question about how to operationalize the definition of health literacy, Dr. Zarcadoolas commented that language is generative and productive—we learn to recombine it in new ways and create meaning in response to novel situations. We must take a similar approach to health information—if we are working toward the acquisition of health facts alone, we are not going to improve health literacy.

Health Information on the Internet

Commenting on Dr. Freimuth's presentation, Dr. Keil noted that the number of people accessing health information via the Internet appears to have risen substantially and wondered whether there had been any progress in teaching people to filter Internet content. An audience member questioned this assumption, remarking that the NAAL suggested that people with the most limited health literacy skills do not use the Internet for health information.

Positive Versus Negative Health Messages

With regard to health marketing campaigns, an audience member from the National Library of Medicine noted that much of the literature demonstrates that positive health communication messages are more effective than messages framed in a negative context. Yet many commercial marketers frame their messages negatively. Panelists agreed there were a number of negative techniques, such as fear, that are commonly used in health communication. They stressed the importance of conducting formative research to determine if a negative approach would work in a particular context. Dr. Baker referred to research indicating that people prefer to be confronted with fear first, so that they become aware of the risk; after that, however, they want to hear good news. Dr. Pignone remarked that there was evidence that fear reduces prevention behaviors such as screening.

Discussion: Creating a Vision for the Future

*Moderator: William Smith, Ed.D.,
Executive Vice President,
Academy for Educational Development*

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.

Closing and Action Steps

*RADM Kenneth P. Moritsugu, M.D., M.P.H.,
Acting U.S. Surgeon General*

Acting Surgeon General Moritsugu closed the workshop with his impressions of the day's presentations and discussion. He stated that the scientific evidence presented at the workshop indicates a need for health literacy improvement. RADM Moritsugu highlighted a number of themes he heard over the course of the workshop:

- First, that we must provide clear, understandable, science-based health information to the American people. In the absence of clear communication and access, we cannot expect people to adopt the health behaviors we champion.
- Second, the promises of medical research, health information technology, and advances in healthcare delivery cannot be realized if we do not simultaneously address health literacy.
- Third, we need to look at health literacy in the context of large systems—social systems, cultural systems, education systems, and the public health system. Limited health literacy is not an individual deficit but a systematic problem that should be addressed by ensuring that healthcare and health information systems are aligned with the needs of the public and with healthcare providers.
- Lastly, more research is needed. But there is already enough good information that we can use to make practical improvements in health literacy.

RADM Moritsugu reiterated the need to engage the public in health literacy improvement, stimulate change in the nation's health care system, and motivate health professionals to educate themselves about the health literacy problems in this country and what can be done to improve our communication with the public. He noted that many key stakeholders were in the room, such as the Centers for Medicare and Medicaid Services and other agencies in DHHS, as well as the AMA, JCAHO, and others. Working together, these organizations can change the healthcare system, from reimbursement to communication practices, to improve health literacy. The problems that are associated with limited health literacy are complex and far-reaching. A simple one-size-fits-all solution will not work.

The next steps for the Office of the Surgeon General will be the issuance of proceedings from the Workshop. Based on the evidence presented at the Workshop, a Surgeon General's Call to Action may be an appropriate next step. RADM Moritsugu remarked that the Workshop and proceedings represent the beginning of a long-term strategy to improve health literacy. Part of this strategy is to make linkages to other high priority public health topics such as patient safety.

RADM Moritsugu closed the Workshop by thanking the participants for their contribution and commitment, and for bringing an oft-overlooked issue to the forefront of public health practice and policy.

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Appendix A: Speaker Biographies

Surgeon General's Workshop on Improving Health Literacy

David W. Baker, M.D., M.P.H.

Dr. Baker is Professor of Medicine, Chief of the Division of General Internal Medicine, and Associate Director of the Institute for Healthcare Studies at the Feinberg School of Medicine, Northwestern University in Chicago. Dr. Baker's research activities have focused on healthcare delivery for underserved populations and improving quality of care for chronic medical conditions. He was one of the Principal Investigators for the Literacy in Health Care Study, the first major study examining how often patients are unable to accurately read pill bottles, appointment slips, and the other written materials they encounter when they come to see a doctor. He was also the Principal Investigator for a large study of literacy, health status, and use of health care services that included over 3000 Medicare managed care enrollees in four cities in the United States. He was one of the developers of the Test of Functional Health Literacy in Adults, and he has published over 30 articles on the measurement of health literacy and the consequences of inadequate health literacy. His current work focuses on the relationship between literacy and mortality and the use of multimedia and other strategies to improve health communication between health care providers and patients.

Glenn D. Flores, M.D., F.A.A.P.

Dr. Flores is Professor (with tenure) of Pediatrics, Epidemiology and Health Policy at the Medical College of Wisconsin. He is also Director of the Center for the Advancement of Underserved Children and Director of the Pediatric Primary Care Research Fellowship in the Department of Pediatrics at the Medical College of Wisconsin and Children's Hospital of Wisconsin. He is on the editorial boards of *Ambulatory Pediatrics* and the *Journal of Health Care for the Poor and Underserved*. He is a member of the National Advisory Committee of the Robert Wood Johnson Amos Medical Faculty Development Program, and a member of the Committee on Pediatric Research for the American Academy of Pediatrics. He is a member of the Expert Panel for the Department of Health and Human Services Health Care Language Services Implementation Guide, recently provided a Congressional Research Briefing, and he has testified in the U.S. Senate on Latino health and the Hispanic Health Improvement Act. He has served as a consultant and national advisory committee member for the American Medical Association, National Hispanic Medical Association, Sesame Street Workshop, and the Centers for Disease Control and Prevention. He received the 2006 American Academy of Pediatrics Outstanding Achievement Award in the Application of Epidemiologic Information to Child Health Advocacy. He has published 74 articles and book chapters on a variety of topics in such journals as *JAMA*, *the New England Journal of Medicine*, *Pediatrics*, and *the Lancet*, including many papers that address racial/ethnic and linguistic disparities in children's health and healthcare.

Harold P. Freeman, M.D.

Dr. Freeman is president, founder, and medical director of the Ralph Lauren Center for Cancer Care and Prevention in New York, New York. Dr. Freeman is also senior advisor to the director of the National Cancer Institute in Bethesda, Maryland. He is responsible for strategies to achieve NCI's 2015 goal to eliminate cancer health disparities. He is a professor of clinical surgery at Columbia University College of Physicians and Surgeons, also in New York. From 1974 to 1999, Dr. Freeman was director of surgery at Harlem Hospital in New York and, for a 2-year period ending in 2001, Dr. Freeman served as the president and CEO of North General Hospital in New York. Dr. Freeman is a diplomat of the American Board of Surgery and a fellow of the American College of Surgeons. He has been medical director of the Breast Examination Center of Harlem, a program of Memorial Sloan-Kettering Cancer Center, since 1979. He was elected to membership in the Institute of Medicine of the National Academy of Sciences in 1997. Dr. Freeman served as national president of the American Cancer Society from 1988-1989. He pioneered the "Patient Navigation Program" which addresses disparities in access to treatment, particularly among poor and uninsured people. Based on this model, the Patient Navigator and Chronic Disease Prevention Act was signed into law by President Bush in June 2005. Dr. Freeman is past chairman of the President's Cancer Panel, to which he was appointed for four consecutive three-year terms, first by President Bush in 1991 and subsequently by President Clinton in 1994, 1997, and 2000.

Vicki S. Freimuth, Ph.D.

Dr. Freimuth is the Director of the Center for Health and Risk Communication and a Professor in the Department of Speech Communication and the Grady School of Journalism at the University of Georgia. Her major research interests center on health communication, specifically studying the role of communication in health promotion. Before joining the faculty at the University of Georgia, she served as Director of Communication at the Centers for Disease Control and Prevention for seven years. Prior to that position, she was Professor and Director of the Health Communication program at the University of Maryland. She is author of *Searching for Health Information*, co-editor of *AIDS: Communication Perspectives*, and author of chapters in several major books in health communication. Her research has appeared in such journals as *Human Communication Research*, *Journal of Communication*, *Journal of Health Communication*, *American Journal of Public Health*, *Social Science and Medicine*, and *Journal of Emerging Infectious Diseases*. She won a Distinguished Career Award from the American Association of Public Health in 2003. She was selected as the first Outstanding Health Communication Scholar by the International Communication Association and the National Communication Association and was selected as the Woman of the Year at the University of Maryland in 1990.

Judith Hibbard, Dr.P.H.

Dr. Hibbard is a Professor of Health Policy in the Department of Planning, Public Policy and Management at the University of Oregon. Her work focuses on consumer decision-making and consumer roles in the care process. Recent work includes an assessment of

the degree to which consumer driven health plans influence consumer behavior. Patient activation, health literacy, and the impact of public reports on consumers and providers are other areas of current research. Professor Hibbard serves on several advisory panels and commissions, including The National Advisory Counsel for AHRQ, National Health Care Quality Forum, and United Health Group Advisory Panel. Her work appears in recent issues of: *Health Affairs*, *Medical Care*, and *Health Services Research*.

Frank C. Keil, Ph.D.

Dr. Keil is a Professor of Psychology and Linguistics at Yale University and Master of Morse College. Previously, he held the William R. Kenan, Jr. endowed chair in psychology at Cornell University. His research focuses on how people come to make sense of the world around them. Much of this research involves asking how intuitive explanations and understandings emerge in development and how they are related to notions of cause, mechanism and agency. These relations are linked to broader questions of what concepts are, how they change with development and increasing expertise, and how they are structured in adults. His work also explores how children and adults learn to navigate the division of cognitive labor that integrates both formal and informal scientific understanding. Dr. Keil received the NIH multi-year MERIT award in 2003 which provides long-term support for outstanding investigators. He has been a Guggenheim Fellow and a Fellow at the Center for Advanced Study in the Behavioral Sciences. He received his Ph.D. in Psychology, with an emphasis in developmental, from the University of Pennsylvania in 1977, an M.A. in Psychology from Stanford University in 1975, and a B.S. in Biology from MIT in 1973.

RADM Kenneth P. Moritsugu, M.D., M.P.H.

Rear Admiral Kenneth P. Moritsugu has filled the position of Deputy Surgeon General of the United States since October 1, 1998, serving as the principal assistant and advisor to the Surgeon General. From August 2006 to the present and from February to August 2002, he served as the Acting Surgeon General, in which he had responsibility to directly oversee nearly 6,000 Commissioned Corps medical personnel of the U.S. Public Health Service, and to function as the nation's top doctor. From December 1987 to September 1998, he was assistant bureau director and the medical director of the U.S. Department of Justice's Federal Bureau of Prisons.

Also an educator, Dr. Moritsugu is an adjunct professor of public health at the George Washington University School of the Health Sciences, and adjunct associate professor of preventive medicine at the Uniformed Services University of the Health Sciences. Dr. Moritsugu is board certified in preventive medicine and is a certified correctional health professional. He also holds fellowships in the American College of Preventive Medicine, the Royal Society of Health, and the Royal Society of Medicine. He received his Baccalaureate Degree with Honors in Classical Languages from the University of Hawaii in 1967, an M.D. from the George Washington University School of Medicine in 1971, and an M.P.H. in Health Administration and Planning from the University of California, Berkeley, in 1975.

Linda Neuhauser, Dr.P.H.

Dr. Neuhauser is a Clinical Professor of Community Health and Human Development at the University of California, Berkeley School of Public Health. Her research, teaching and practice are focused on translating research findings into improved health interventions, including mass communication. She is especially interested in leveraging participatory approaches to improve the relevance of communication to meet the literacy, linguistic, cultural and other needs of diverse audiences. She is principal investigator of the UC Berkeley Health Research for Action Center that works with users to co-design and evaluate multi-media health communication resources that have now reached over

10 million households in the United States and overseas. She is an advisor to UC Berkeley's (CDC) Center for Infectious Disease Preparedness on strategies to improve risk communication for issues ranging from emerging diseases to terrorist events. She is a frequent advisor to state, federal and international workgroups about health interventions and communication. She was previously a U.S. health officer in West and Central Africa.

Denise Park, Ph.D.

Dr. Park received her Ph.D. from the State University of New York at Albany in 1977. She is a professor in the University of Illinois at Urbana-Champaign, Department of Psychology and a research scientist at the Beckman Institute. She is Co-Director of The Center for Healthy Minds, sponsored by the National Institute on Aging. Her research has focused on understanding the role of age-related changes in memory function at the basic level (through functional neuroimaging techniques and behavioral studies) as well as the implications of these changes for society (in cross-cultural studies and work in medical information processing). Dr. Park is a Fellow of the American Association for the Advancement of Science as well as a number of other scientific organizations. She chaired the Board of Scientific Affairs for the American Psychological Association, and is a past member of the Board of Directors of the American Psychological Society. She received the Distinguished Contributions to the Psychology of Aging Award from Division 20 of the American Psychological Association. She recently completed a term as chair of the NIH Scientific Review Panel for Cognition and Perception.

Michael P. Pignone, M.D., M.P.H.

Dr. Pignone is an Associate Professor of Medicine in the Division of General Internal Medicine at University of North Carolina-Chapel Hill, Associate Chief of the Division of General Internal Medicine, and Director of the UNC Center for Excellence in Chronic Illness Care. He received his medical degree and residency training in primary care internal medicine from the University of California-San Francisco. He then completed fellowship training in clinical epidemiology and health services research through the Robert Wood Johnson Clinical Scholars Program at UNC. Dr. Pignone's research is focused on chronic disease prevention and physician—patient communication about risk in primary care settings. His main areas of interest include heart disease prevention, colorectal cancer screening, and disease management for common chronic illnesses such

as diabetes, depression, heart failure, and chronic pain. He has conducted research examining the role of literacy in physician-patient communication and its effect on health outcomes, including racial/ethnic disparities, in patients with chronic illnesses. He has developed and tested interventions to mitigate literacy-related disparities and to improve the use of appropriate preventive services.

RADM Penelope Slade Royall, P.T., M.S.W.

RADM Royall is the Deputy Assistant Secretary for Disease Prevention and Health Promotion, and Director, Office of Disease Prevention and Health Promotion, Office of Public Health and Science, U.S. Department of Health and Human Services. She is a Commissioned Corps Officer in the U.S. Public Health Service. RADM Royall leads prevention priorities for HHS and is a senior advisor to the Assistant Secretary for Health and to the HHS Secretary. Prior to this appointment, she was Acting Executive Director, President's Council on Physical Fitness and Sports and Senior Public Health Advisor, Immediate Office of the Assistant Secretary for Health. Before joining OPHS, she was the Chief of Physical Rehabilitation in the Physical Rehabilitation Department, Federal Medical Center, Butner, North Carolina. RADM Royall earned a degree in Physical Therapy and a Masters Degree in Social Work from the University of North Carolina at Chapel Hill.

Rima E. Rudd, M.S.P.H., Sc.D.

Dr. Rudd is Senior Lecturer on Society, Human Development, and Health at the Harvard School of Public Health. Her work centers on health communication and on the design and evaluation of public health community based programs. She teaches courses on innovative strategies in health education, public health program planning and evaluation, and health literacy. Dr. Rudd is focusing her research inquiries on literacy-related disparities and literacy-related barriers to health programs, services, and care. She is a research fellow of the National Center for the Study of Adult Learning and Literacy and serves as Principal Investigator for the Health and Adult Literacy and Learning [HALL]. She served on the National Research Council Committee on Performance Levels in Adult Literacy and on the IOM Committee on Health Literacy and wrote sections of both National Academies' reports. Dr. Rudd wrote several other reports that are helping to shape the agenda in health literacy research and practice. They include the health literacy objective action plan of the Health and Human Services book, *Communicating Health: Priorities and Strategies for Progress* (2003), and the Educational Testing Services report, *Literacy and Health in America* (2004).

Dean Schillinger, M.D.

Dr. Schillinger is an Associate Professor of Clinical Medicine in the UCSF Division of General Internal Medicine and is a practicing primary care physician at San Francisco General Hospital. He is nationally recognized for his translational, practice-based research with vulnerable populations. With a focus on health communication, chronic disease care, and literacy, he has carried out a number of studies in patients with diabetes and heart disease. He has published extensively on the relationship between literacy and

health; quality of care; decision-making; and patient safety, and received the 2003 Institute for Healthcare Advancement Research Award for this work. He was recipient of an Open Society Institute Physician Advocacy Fellowship to work with California Literacy, a state-wide adult education organization. Dr. Schillinger recently completed a 6-month tenure as Visiting Scholar at the University of Chile School of Public Health, where he developed research programs in socioeconomic disparities in chronic disease prevention and care, and tobacco control. He returns to UCSF as director of a research center whose focus will be communication and population health. Dr. Schillinger is co-editor of the just published textbook *Caring for Vulnerable and Underserved Patients: Principles, Practice, and Populations* (2006, Lange series, McGraw-Hill).

Dr. Schillinger is the proud father of twin 8 year old boys and is expecting a 3rd child in October (a girl... and only one!).

William A. Smith, Ed.D.

Dr. Smith is the Executive Vice President of the Academy for Educational Development, one of America's largest non-profit organizations. He is a co-author of the IOM report, *Health Literacy: A Prescription to End Confusion*. Dr. Smith is also a co-founder of the Social Marketing Institute, a columnist and editorial board member of the *Social Marketing Quarterly*, the *International Journal of Health Communication* and *Applied Environmental Education and Communication: An International Journal*. He authored a recent book entitled *Fostering Community Based Social Marketing* and has published widely on communication for social change.

Grover J. (Russ) Whitehurst, Ph.D.

Dr. Whitehurst was appointed in 2002 to a 6-year term as the first director of the Institute of Education Sciences, the research arm of the U.S. Department of Education. The Institute includes the National Center for Education Statistics, the National Center for Education Evaluation and Regional Assistance, the National Center for Education Research, and the National Center for Special Education Research. Dr. Whitehurst previously served as U.S. assistant secretary for educational research and improvement. Prior to beginning federal service, he was Leading Professor of Psychology and Pediatrics and Chairman of the Department of Psychology at the State University of New York at Stony Brook. During his academic career, Dr. Whitehurst published five books, and more than 100 research papers on language and reading readiness in children. He developed programs for enhancing children's language development that are widely used in preschool programs in the United States and other countries. Dr. Whitehurst received a Ph.D. in experimental child psychology from the University of Illinois, Urbana-Champaign, in 1970.

Christina Zarcadoolas, Ph.D.

Dr. Zarcadoolas is a sociolinguist working in the area of health and environmental literacy. Her research focuses on analyzing and closing the gaps between expert knowledge and public understanding of health and environmental issues.

Dr. Zarcadoolas joined Mount Sinai School of Medicine after spending 15 years on the faculty of Brown University's Center for Environmental Studies where she taught courses on public perception of the environment and environmental communications and doing applied, collaborative research with communities. She recently completed a textbook on health literacy—*Advancing Health Literacy: A Framework for Understanding and Action* (with Andrew Pleasant, PhD., and Dr. David S. Greer, Jossey-Bass/Wiley, 2006). The book develops an elaborated model of health literacy addressing the roles of fundamental literacy, science literacy, civic literacy and cultural literacy. She is presently writing a new book on communicating complex emergencies.

Appendix B: Participant List

Surgeon General's Workshop on Improving Health Literacy

Marin P. Allen, Ph.D.

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Appendix C: Acknowledgements

Surgeon General's Workshop on Improving Health Literacy

The Surgeon General's Workshop on Improving Health Literacy was co-sponsored by the Office of the Surgeon General and the Office of Disease Prevention and Health Promotion.

The Acting Surgeon General and the Deputy Assistant Secretary for Disease Prevention and Health Promotion expresses their sincere appreciation to all who contributed time, experience, and knowledge to support the development of the Surgeon General's Workshop on Improving Health Literacy and this report. The Acting Surgeon General and the Deputy Assistant Secretary for Disease Prevention and Health Promotion would especially like to acknowledge the following:

HHS Health Literacy Workgroup

The Department of Health and Human Services (HHS) Health Literacy Workgroup was formed in 2004 under the leadership of the Office of Disease Prevention and Health Promotion. The Workgroup fosters inter-agency collaboration to raise awareness of this issue, meeting bi-monthly to review progress, share information, and develop strategic plans and activities on health literacy. Members of the Workgroup formed a Steering Committee to develop a Surgeon General's Workshop on Improving Health Literacy. Their commitment to improve the health literacy of all Americans led to a robust presentation of the science and research base that supports the improvement of health literacy.

Workshop Attendees

Approximately 80 experts in the field of health literacy and related disciplines attended the invitation-only Surgeon General's Workshop on Improving Health Literacy. The participants provided valuable insights concerning the scope of the problem of limited health literacy, highlighting gaps in the knowledge base, and suggesting methods to improve health literacy. Their thoughtful contributions helped guide the development of this report.

Government Agencies

The Surgeon General's Workshop on Improving Health Literacy was sponsored by the following HHS Agencies and Offices:

- Agency for Healthcare Research and Quality
- Administration on Aging
- Centers for Disease Control and Prevention

- Food and Drug Administration
- Indian Health Service
- Office of HIV/AIDS Policy
- Office of Minority Health
- Substance Abuse and Mental Health Services Administration
- National Institutes of Health
 - National Cancer Institute
 - National Eye Institute
 - National Human Genome Research Institute
 - National Heart, Lung and Blood Institute
 - National Institute of Dental and Craniofacial Research
 - National Institute of Child Health and Human Development
 - National Institute on Drug Abuse
 - National Library of Medicine
 - Office of Communications and Public Liaison
 - Office of Disease Prevention

Health Literacy Workshop Steering Committee

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HHS Agencies and Offices

Lisa Adams

Neyal Ammary

Peter Bonner

Daniel Berch

Cindy Brach

Martin Dannenfelser

Elizabeth Goldstein

Sarah Gregory

Sandra Hilfiker

Megan Homer

Kimberly Kaphingst

Pamela Kelley

Jennifer Klocinski

Camha Le

Robert Logan

Carmela Lomonaco

Sheryl Massaro

Charlotte Neuhaus

Victor Olano

Nancy Ostrove

Guadalupe Pacheco

Toni Stifano

Martina Vogel-Taylor

Mary Wachacha

Maria White

Violet Woo

Sabra Woolley