

Improving Health Literacy for Older Adults



Expert Panel Report 2009



**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
CENTERS FOR DISEASE CONTROL AND PREVENTION**



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Background

Improving health literacy is increasingly critical as information, choices, and decisions about health care and public health have become more complex. *Healthy People 2010*, the nation's public health agenda, recognizes limited health literacy as an issue of national significance and set objectives and targets for improvement.¹

Limited health literacy has been linked to increased health disparities, poor health outcomes, increased use of health care services, and several health care safety issues, including medical and medication errors.²⁻⁴ Improving health literacy for all Americans has been identified as one of the 20 necessary actions to improve health care quality on a national scale.⁵

In the past, patients and consumers were often restricted to a small number of medical information sources, most of them written



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*

for health professionals. Today, a wide variety of health information is available because of recent trends in society, which include technological advances such as the Internet and the need for patients to be informed “consumers” of health care services.⁶ Consumers are expected to be savvy about quality, cost, and effectiveness, which requires access to accurate and actionable information.

Greater access to reliable health information can provide tangible benefits to patients and consumers who routinely must make minor and major health decisions. At the same time, access to information is only part of the process.

Patients must sort through large amounts of often confusing or conflicting information to make choices about unfamiliar treatment options. Consumers must make sense of numerous—and often unclear and conflicting—recommendations, warnings, and guidelines to protect and promote their own health and the health of their families and communities. They also must be actively involved in ensuring that they receive health care services that are safe and appropriate.

The challenges of making sense of health information are especially great for the increasing proportion of people aged 65 years and older in the United States.⁷ By 2030,

there will be 71.5 million U.S. adults aged 65 years or older, which is more than twice their number in 2000.⁸ Older adults have more chronic illnesses and use more health care services than other segments of the population, and they face unique issues related to physical and cognitive functioning that can make it difficult for them to find and use appropriate health information.⁹

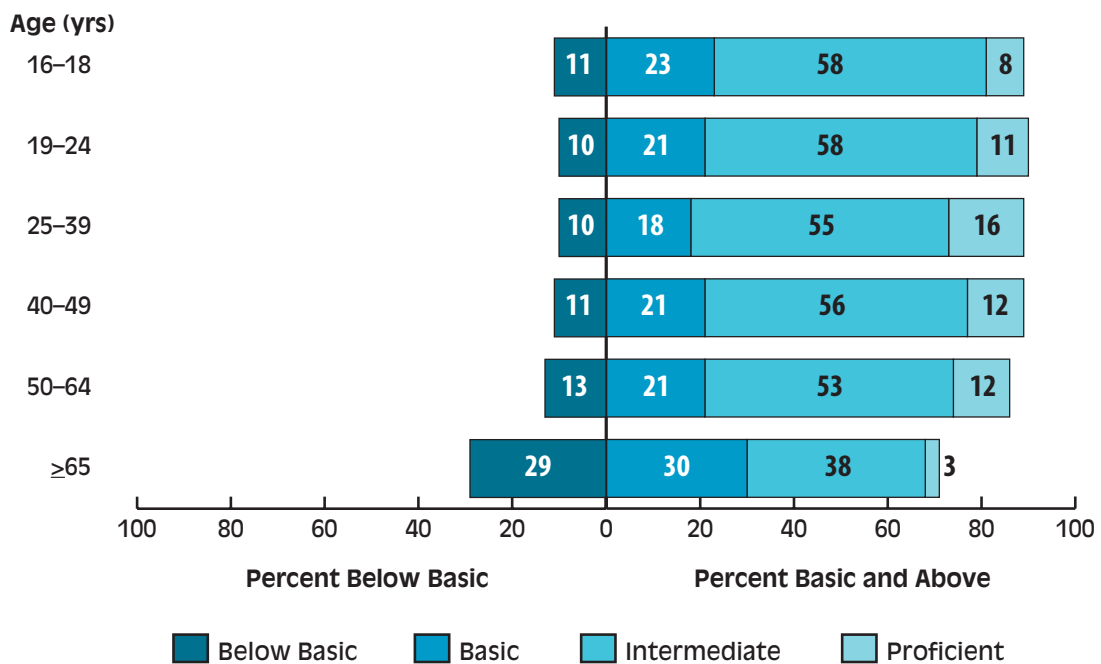
Research studies and data from the 2003 National Assessment of Adult Literacy (NAAL) demonstrate the importance of focusing on older adults and their health literacy challenges. Among adult age groups, those aged 65 and older have the smallest proportion of persons with proficient health literacy skills.¹⁰ This group also has the highest proportion of persons with health literacy defined as “below basic.”

CDC Convenes Expert Panel

To address concerns about the barriers for older adults to understand and use health information, the Centers for Disease Control and Prevention (CDC) convened an Expert Panel on Improving Health Literacy for Older Adults on December 6–7, 2007, in Atlanta, Georgia. The panel’s deliberations and conclusions are a critical component of efforts by CDC’s Division of Health Communication and Marketing, which is part of the National Center for Health Marketing (NCHM), to develop an agenda to improve health literacy for all U.S. population groups.

The meeting was designed to assess health literacy issues among older adults and to identify opportunities for health professionals at CDC and other organizations to better meet the health communication needs of older adults.

Figure 1. Health Literacy Skills of U.S. Adults, by Age Group, 2003



Source: Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America’s Adults: Results from the 2003 National Assessment of Adult Literacy*. Washington, DC: U.S. Department of Education, National Center for Education Statistics; 2006. Publication no. 2006-483.

Panelists were asked to

- Review and discuss the need for health literacy improvement as a critical issue for serving older adults.
- Identify research gaps related to older adults and health literacy.
- Integrate experiences from the field with research findings.

At the end of the meeting, the expected outcome of the panel's work was to

- Develop key questions and identify issues to inform a research agenda to improve health literacy among older adults.
- Identify public health priorities for improving health literacy among older adults.
- Consider a preliminary set of best practices to guide CDC and the U.S. Department of Health and Human Services (HHS) in their efforts to communicate health information to older adults.

The presentations and discussions were intended to enhance understanding of the scope and scale of health literacy issues among older adults and to suggest options for creating and delivering more accessible and appropriate health information to older adults and those who serve them.

This report summarizes the presentations and discussions of the expert panel convened by NCHM. The 12 panelists, all of whom came from outside CDC, were selected because of their expertise in the health


The expert panel convened by CDC brought together a diverse group of researchers, social service providers, and public health and medical practitioners to connect research and practice.

information needs, preferences, and capacities of older adults. See Appendix A for a list of the panelists and their professional profiles; see Appendix B for a copy of the meeting agenda.

Day 1 of the meeting included presentations by 9 of the 12 panelists that addressed different aspects of health literacy among older adults. One panelist served as the moderator, while two panelists served as commentators on the presentations.

Day 2 consisted of discussions between the panelists and invited guests, including staff from CDC and other HHS agencies. The panelists were asked to use the *Healthy People 2010* definition of health literacy as





the starting point for their presentations and remarks (see definition on page 1).

Day 1 opened with NCHM Director Jay Bernhardt, PhD, MPH, welcoming the panel and affirming NCHM's interest in health literacy as an important area of research and practice for health communication and marketing. Dr. Bernhardt stressed CDC's commitment to improving health communication with all populations, especially older adults, and encouraged the panel to consider new ideas that would help guide future agendas.

Cynthia Baur, PhD, director of NCHM's Division of Health Communication and Marketing, also welcomed the panel and reiterated that the panel's work will help

develop research priorities and best practices in health communication. She explained the *Healthy People 2010* definition of health literacy in greater detail, highlighting the links between the key actions in the definition—“obtain, process, and understand . . . and . . . make appropriate health decisions.”

Dr. Baur noted that research and discussion often focus on how people process and understand health information rather than on how and why people obtain information and use it to make appropriate decisions. She asked the panel to give equal weight to all four actions and to consider what public health agencies can do to make these actions easier for older adults.

Presentation 1. Overview: Low Health Literacy Among Older Adults

Rima E. Rudd, ScD, MSPH
Senior Lecturer on Society, Human
Development, and Health
Department of Society, Human Development,
and Health
Harvard University, School of Public Health

Dr. Rima E. Rudd provided a brief overview of the problems of limited health literacy among older adults in the United States. Recent studies have indicated that a majority of U.S. adults do not have the literacy skills needed to use health-related print materials and tools with accuracy and consistency.

Dr. Rudd noted that, although very few adults are illiterate, many do not understand what they read. Literacy involves reading, writing, speaking, doing basic math, and listening. The best predictor of literacy skills is the use of these skills on a daily basis. Literacy influences a person's ability to access information, navigate the highly literate environments of modern society, and engage in work and civic activities.

In 1992 and 2003, national surveys assessed the literacy proficiency of the U.S. population. These surveys were not merely reading tests, but instead focused on key issues related to access and navigation—that is, a person's ability to use commonly available print materials to accomplish mundane tasks. Findings from the 1992 National Adult Literacy Survey (NALS)¹¹ and the 2003 National

Assessment of Adult Literacy (NAAL)¹⁰ indicated that significantly large numbers of U.S. adults have low literacy skills. In general, older adults have more limited literacy skills than do adults in other age groups. Findings from the 2003 NAAL indicated that 71% of adults older than age 60 had difficulty in using print materials in prose form, 80% had difficulty using documents such as forms or charts, and 68% had difficulty with quantitative tasks.¹⁰

At the same time, an in-depth analysis of literacy proficiencies for health-related materials and tasks indicated that older adults with access to resources and more than a high school education had strong literacy skills, stronger than those of adults living in poverty at any level of education.¹²

Literacy Demands of Health Information and Health Care

In spite of the data on adult literacy skills, Dr. Rudd pointed out that analyses indicate that the skills required to use the health care system effectively exceed the skills of adults who graduated from high school.



“We have the audacity to say people have low literacy skills when our material is poorly designed.”

—Rima E. Rudd, ScD, MSPH

Three decades of research studies have consistently found that health materials exceed the reading ability of the intended audiences.¹³

Dr. Rudd also discussed the significance of oral communication and math skills in health literacy. Oral communication includes the vocabulary that people use when they speak, the length of their sentences, how quickly they speak, and if they take turns talking and listening.

People’s ability to understand and perform basic math is often overlooked in health management. For example, to effectively manage a health condition, a person needs to be able to follow instructions about medication dosage and understand concepts of risk and probability.

Finally, Dr. Rudd noted that there are specific skills required to use the Internet to obtain health information. Older adults may have problems with technical jargon, scientific terms, and search engines that do not return suitable results. They may not be able to discern the quality of the information presented.

Dr. Rudd suggested that innovative technologies such as touch screens and voice activation could help older adults use the Internet to get health information.

Suggestions to Improve Health Literacy Among Older Adults

Dr. Rudd had two overarching observations. First, research—particularly data on literacy skills—should guide how we provide information to older adults. Second, public health professionals should apply what already is known about how to communicate health information in everyday language.

Dr. Rudd concluded with a call for health professionals to

- Adjust their expectations and demands.
- Consider the literacy environment.
- Improve their written and oral communication skills.
- Apply greater rigor to the development of materials and tools designed for older adults.



Presentation 2. Aging, E-Health Tools, and Health Literacy

Sara J. Czaja, PhD, MS
Professor

Department of Psychiatry and Behavioral
Sciences, Center on Aging
University of Miami, Miller School
of Medicine

Dr. Sara J. Czaja discussed the emerging use of e-health tools for health information and management, the challenges that e-health tools pose for older adults, and the disparities that can be reinforced by new technologies. Current evidence suggests that the effectiveness and use of many e-health tools are low for many population groups, particularly older adults.

The ability of older adults to find and use e-health tools is a critical issue, according to Dr. Czaja, because this population is more likely to want and need medical care that could be enhanced by the use of these tools. Dr. Czaja opened her presentation with the following question: Given age-related changes in functional abilities and lower

E-health Tools

Digital resources designed to help patients, consumers, and caregivers find health information, store and manage their personal health information, make decisions, and manage their health. Most e-health tools are available on the Internet.

Some have interactive features that allow people to contact their health care providers directly or share information with other consumers and patients.

“As people age, cognitive changes affect the ability to use technology.”

—Sara J. Czaja, PhD, MS

levels of health literacy, will older adults be able to adapt successfully to the e-health environment? To help answer this question, Dr. Czaja reported the results of usability research that she and her team have conducted on older adults and their use of online health information resources.

E-Health Tools Can Be Difficult for Older Adults to Use

The use of e-health tools requires many cognitive abilities, including the ability to comprehend highly technical language. Information seeking on the Internet is especially complex because it requires a general knowledge of the topic of interest (e.g., diabetes), basic knowledge of hardware and software operations, information-seeking skills (e.g., knowledge of how the Internet or a Web page is organized and how links, search boxes, and search histories work), and the ability to judge whether information sources are credible.

Dr. Czaja’s research found that reasoning, working memory, and perceptual speed were significant predictors of performance on health-related Internet searches.¹⁴ The data indicated that older adults who performed better had higher cognitive abilities than those who performed at a lower level. The participants in this study were mostly literate and well-educated. Dr. Czaja also noted that data from the 2007 Health and Retirement Survey showed that people with lower cognitive

abilities were less likely to enroll in the Medicare Part D program and less likely to use the Internet for enrollment.¹⁵

More Research Is Needed

As noted in a recent HHS report, if the vision of e-health benefits for all Americans is to be realized, much more information is needed about users' acceptance of and ability to understand and use these tools.⁶

Dr. Czaja stated that more research is needed to understand the role of health literacy in the use of e-health tools. This research should involve the development of

- More comprehensive and diagnostic measures of health literacy.

- Systematic data on factors that influence health literacy.
- Systematic data on the relationship between health literacy and a person's ability to use e-health tools.

Understanding these issues is particularly important if we want to improve the health and health literacy of older adults. Dr. Czaja predicted that unless the needs of diverse user groups are considered in the development and implementation of e-health tools, the emergence of these tools will increase health care disparities among U.S. population groups.



Presentation 3. Older Adults and the Practice of Obtaining Health Information

Michelle Eberle, MSLIS
Consumer Health Information Coordinator
National Network of Libraries of Medicine,
New England Region
University of Massachusetts, Medical School

Ms. Michelle Eberle discussed her work and experience with online and face-to-face health information outreach to older adults at the community level. She provides education and training on consumer health resources such as MedlinePlus.gov and NIHSeniorHealth.gov, which are online resources of the National Library of Medicine (NLM) and the National Institutes of Health (NIH).

Ms. Eberle noted that her organization, the National Network of Libraries of Medicine (NN/LM), has traditionally focused on outreach to librarians and health professionals. In recent years, services have been extended to older adults, their caregivers, and community-based organizations as health care professionals have shifted their thinking about who should have access to health information.

Historically, medical information was provided to patients at the doctor's discretion. In 1972, the American Hospital Association created A Patient's Bill of Rights, which states that, "The patient has the right to and is encouraged to obtain from physicians and other direct caregivers relevant, current, and understandable information concerning diagnosis, treatment, and prognosis."

"It used to be that patients got information at the doctor's discretion. Now, patients are empowered to get information themselves."

—Michelle Eberle, MSLIS

Patients now are asked to be consumers of health care services and to partner with health care professionals to make decisions about their health. Older adults who grew up in a culture where the doctor made critical decisions are now living in a "consumer-centric" world where people are expected to be informed participants in their own health care. Contrary to stereotypes of older adults who think the doctor always knows best, Ms. Eberle has found that older adults are eager to learn, and they want to be in control of their own health.

Research on who uses the Internet for health information has found that the majority of older adults are "truly disconnected," a term coined by the Pew Internet and American Life Project to describe older adults who have never used the Internet and have no one to access online information for them.¹⁶

Older adults often are embarrassed by their lack of familiarity with computers and the Internet, and they try to hide their discomfort. The fact that a majority of older adults are not using the Internet for health information has important implications for understanding how this age group obtains health information. Family members, friends, caregivers, health care providers, and print resources are the most sought-after sources for older adults, according to Ms. Eberle.

Public health workers—whether they are consumer health librarians, home health aides, or case workers—also can play an important role in ensuring that older adults obtain the health information they need and, more importantly, that they understand and act on it.

Direct Outreach to Elder Care Providers

Ms. Eberle's first attempt to offer training on how to use online health resources to older adults was through group sessions at senior centers. Although the classes were held in hands-on computer labs, enrollment was limited. She soon realized that she could be more effective if she reached out directly to elder care providers. This approach allows her to provide health information for hundreds of patients through one provider with a train-the-trainer approach.

Many of the elder care providers who attend Ms. Eberle's training sessions are unfamiliar with the authoritative, current, and free health information available from NLM and NIH. They are usually enthusiastic and eager to learn about these resources. However, they often voice concern that their clients would not be savvy enough to use such resources, even the "senior-friendly" NIHSeniorHealth.gov site.

To address this concern, elder care providers have found unique ways to use the NIHSeniorHealth.gov resource. For example, a regional director for a long-term care facility asked Ms. Eberle to speak to case workers during monthly sessions that address different senior health topics. When the director learned about the

NIHSeniorHealth.gov site, she was quick to share this information with her staff.

Now, rather than create customized presentations, staff members highlight a different health topic on NIHSeniorHealth.gov each month and print customized handouts from the site. Ms. Eberle now highlights the customizable, printable information about health topics on the NIHSeniorHealth.gov site when she speaks to other groups.

Older Adults Face Many Challenges

Ms. Eberle concluded her presentation by noting that the "digital divide" between older adults and other age groups and the concept of the "truly disconnected" are not the only factors that make accessing health information difficult for older adults. This population is faced with other physiological challenges of aging, including changes in vision, hearing, and cognition.

Public health workers can play important roles in ensuring that older adults get needed health information, understand it, and can act on it.



Presentation 4. Health Literacy in Aging: Processing Health Information

Katharina V. Echt, PhD
Assistant Professor
Emory University, School of Medicine
Research Health Scientist
Atlanta VA Rehab R&D Center of Excellence
on Geriatric Rehabilitation

Dr. Katharina V. Echt's presentation summarized her research on sensory factors and cognition and how they affect the health literacy skill of older adults. Dr. Echt's research team conducted formative research with older adults who have limited health literacy skills. She gave an overview of age-related changes in vision, hearing, and cognition; their interrelation; and emerging evidence on their associations with health literacy and health management performances among older adults. Dr. Echt suggested that cognition is likely a better predictor of health literacy among older adults than educational level.

Sensory and Cognitive Abilities

Sensory, perceptual, and cognitive abilities work together to help people process information. Dr. Echt noted that few empirical data exist to guide interventions intended to improve health knowledge and comprehension, and that past studies of these types of interventions have found mixed results.¹⁷

Although a great deal is known about the prevalence and consequences of limited health literacy and the principles of effective health communication, few researchers have specifically examined the underlying processes, antecedents, or determinants that contribute to declining health literacy as people age.

“The processing of health information is intimately tied with sensory processes. Sensory intervention and rehabilitation may have made a difference earlier in life, but they are not easily changed later on.”

—Katharina V. Echt, PhD

To guide informed, targeted, and ultimately cost-effective interventions, a better understanding of which processes contribute to limited health literacy in older adults is critical. Researchers also need to identify when decline in sensory and cognitive processes begins, as well as the rate of decline.

This knowledge will give health communicators the information they need to design specific tools and strategies to support, train, or retrain older adults. It also can guide the design of health materials that account or compensate for health literacy disparities among older adults.

Dr. Echt concluded that sensory processes are a critical link in information uptake because the senses are the mode by which information is obtained from the external environment. When people have even mild vision or hearing loss, the extra effort needed to see or hear information may cause measurable failures in processing of what would otherwise be understandable.¹⁸

The ability of older adults to process and later recall and apply spoken or printed information—such as medication instructions from a health care provider—depends on their ability to fully hear the spoken message¹⁸ or see the printed or graphical information presented.¹⁹

Formative Research with Older Adults

Dr. Echt's research was conducted initially with focus groups of older adults with limited health literacy skills who were asked about their experiences with health information.

Transcripts from these focus groups included some of the following quotes:

"Sometimes I get nervous and I can't read as good, but I can look at the pictures all right . . ."

"One time I took an overdose of medicine . . . when I got my new prescription I saw the word Tegretol but I didn't see 400, you see, so I took too much . . . there's really nothing wrong with my eyes, it's just I don't know what."

"You look at something and you read it—but you just can't comprehend—you can't get it in your head straight—it's like a picture that's out of focus."

These statements highlight that the processing of health information is intimately tied to sensory processes, particularly vision and hearing, that are prone to age-related declines.

Suggestions for Action

Dr. Echt reiterated that much is known about how to design health texts and instructions, both print and electronic, for greater accessibility by older adults. However, many of the guidelines available have not been tested. Dr. Echt proposed that health literacy interventions be introduced at three levels—for patients, for health care providers, and for the overall health care system.

Older adults can be trained to compensate for age-related declines. Providers can be trained to be effective communicators and to work with older adults' abilities. Systems can be redesigned to provide accessible, interactive, and user-centered information.

In the future, researchers need to develop a better understanding of which processes and determinants predict limited health literacy in aging, identify at what point declines begin, and identify the rate of decline. Addressing these issues will provide evidence that will allow health communicators to develop specific approaches to address health literacy disparities in older adults.



Presentation 5: Improving Health Literacy for Older Adults: A Provider Perspective

Linda H. Miller, MA
Community Services Coordinator
Centralina Area Agency on Aging
Charlotte, North Carolina

In her presentation, Ms. Linda H. Miller spoke about her experiences as a services advocate for older adults in her community. She also provided an overview of the demographics of the people living in the Charlotte, North Carolina, area in order to provide a contextual background.

Ms. Miller went on to discuss the health literacy challenges of this region and how she and her colleagues work to improve the quality of life for older adults. She included information about how to reach older adults in various settings to provide effective education and promote changes in behavior.

Frontline Workers Contribute to Health Literacy

In her work, Ms. Miller noted that nearly all of the concerns, problems, and questions that older adults share with her relate to their health and quality of life. Getting them the information and resources they need to make good decisions is a constant challenge for her department. Information must be reliable and accurate, but it also must be in a format that can be understood.

Ms. Miller offered numerous lessons from the field about how to present information to older adults in ways they can process and understand.

“Many older adults still react best with person-to-person contact. Health care workers who are knowledgeable about aging issues and aging professionals who are well-informed about health issues should be able to make a significant difference in improving the lives of older adults.”

—Linda Miller, MA

These lessons include the following:

- Keep information focused.
- Repeat as needed.
- Allow people time to process the information.
- Use face-to-face communication and make the information personally relevant.
- Highlight the short-term benefits of taking a specific action.
- Provide sufficient follow up for each person you contact.

According to Ms. Miller, staff members in community service departments are frontline workers who are often more likely to be the main source of information for older adults than doctors or other health workers. In this role, they have found that many older adults respond best to person-to-person contact. If these workers had more access to training and materials, they could use their frontline experience to help improve health literacy among older adults.

Resources, Support, and Training

Ms. Miller noted that older adults and their caregivers get health information from a variety of sources. Most of the older adults

she works with are very frail and the “old” old (older than age 80) who have yet to embrace technology. Their adult children and the “young” old (younger than age 65) are more open to online resources.

Other potential sources of information for older adults are local programs designed to promote health, prevent disease, and manage chronic diseases. These programs are helping to raise awareness and provide resources, but not enough health care providers are trained to use these programs, and some programs are not appropriate for older adults.

Older adults and their caregivers also are using the existing network of professionals and volunteers that serve them to learn about health issues. To ensure access to accurate and consistent information, the people who serve these populations need more support and training.

Aging and Disability Resource Centers, which are increasing in number throughout the country, are another source of health information for older adults. These one-stop information, resource, and referral centers can connect older adults and their caregivers to needed services and provide assessments, case management, and counseling. Ms. Miller noted that people working in these centers will need training to be able to work properly and successfully with older adults.

Most older adults continue to report that doctors do not spend adequate time with them at office visits,

nor do they provide educational materials to refer to later. Follow up is especially poor, and there is little to no support provided by the health care team. These problems are reported regardless of where older adults reside in the community, but they are worse when they live in long-term care or assisted living facilities. Ms. Miller emphasized that all older adults deserve to have good care and to be participants in their care, no matter where they live.

A Challenge to the Health Community

Ms. Miller concluded with a challenge to the health community to improve training and access to resources for the health care providers and community workers who serve older adults. Both groups need to understand what the other can do to support this vulnerable population. Health care workers who are knowledgeable about aging issues and health professionals who are well-informed about age-related health issues will be able to make a significant difference in improving the lives of older adults if they work together and receive the training and support they need.



Presentation 6: Functional Understanding of Medical Information Among Older Adults

Michael Scott Wolf, PhD, MA, MPH
Associate Professor
Director, Center for Communication in
Healthcare
Northwestern University, Institute for
Healthcare Studies

Dr. Michael Wolf discussed the importance of both cognitive and psychosocial skill sets and their effect on the ways older adults make informed medical decisions. Cognitive skills include basic reading ability and math skills. Psychosocial factors include self-efficacy and communication skills, as well as the expectations and experiences that people bring to their encounters with the health care system. The path to making informed medical decisions involves being able to obtain information and then to process, understand, and act on that information.

Dr. Wolf discussed several health topics—health promotion, preventive services, chronic disease management, self care, medication use, and treatment decisions—that have been examined in terms of the relationship between health literacy and patient understanding of a particular topic.

For example, one study showed that more than 90% of older adults with adequate health literacy knew the symptoms of hypoglycemia (low blood sugar), but fewer than 75% knew the correct action to take for these symptoms.²⁰ Among adults with limited health literacy, approximately 50% knew the symptoms, while fewer than 40% knew the correct action to take.

“The disparity between health literacy, older age, and medical understanding may be based on generational as well as cognitive differences.”

—Michael Wolf, PhD, MA, MPH

Factors that Affect How Older Adults Process Information

Dr. Wolf noted that older adults typically have more comorbidities, complex care regimens, limited literacy, and decreased cognitive function. This group is clearly at risk for inadequate functional understanding of health concepts and roles.

Dr. Wolf presented a “comprehension failure model” that described both patient and system factors that influence comprehension of health information. Patient factors include mental state, cognitive abilities, prior knowledge, self efficacy, and social support. System factors include complexity, structure, modality (verbal or print), and whether the atmosphere is instructional. Any one of these factors—or a combination of factors—is a potential failure point for a patient’s understanding of health information.

Summary

Dr. Wolf concluded that health literacy and understanding of health information can decline with age and that the inherent complexity of the health care system contributes to this problem. Some solutions may be found in cognitive factors research, but psychosocial factors also influence aging. Dr. Wolf proposed that the panel look for ways to redesign the health care system and pursue research that validates the health literacy agenda.

Presentation 7: Health Literacy: Ingredient for Better Health

Jorge J. Lambrinos, MA
Director, Edward R. Roybal Institute for
Applied Gerontology
University of Southern California, Leonard
Davis School of Gerontology

In his presentation to the expert panel, Mr. Jorge Lambrinos provided a brief overview of the problem of limited health literacy in the United States, and then focused specifically on the challenges in older adult and minority communities.

Language and Cultural Barriers

Older adults in minority communities who are not native English speakers present health care workers with unique challenges for service delivery. Health literacy issues are compounded by differences in language and the specialized vocabulary used both in written and spoken form to convey health information. Frequently, words or their underlying concepts have little meaning or a different meaning for those who are not native speakers.

Limited health literacy associated with a poor understanding of the English language will affect a person's understanding of written or oral medical advice and directives, as well as the person's ability to navigate the health care system.

One recent study of older Latin American and Caribbean adults found that cancer screening information may be ineffective with people who are less literate because they do not understand or have limited knowledge of cancer screening concepts, health vocabulary, and anatomy.²¹ Mr. Lambrinos suggested that

“Web site health information is easy, economical, and requires little effort, but Hispanics need trust built by personal relationships. That can't happen with a computer.”

—Jorge Lambrinos, MA

there is also a relationship between cancer screening, literacy, and cultural barriers. Focus groups conducted by the Edward R. Roybal Institute for Applied Gerontology with Latina women across the country showed that many did not understand etiology and did not have the anatomical knowledge necessary to comprehend health information.²² For example, the terms *utero* (uterus) and *matriz* (womb) were often confused in Spanish and described as distinct reproductive parts.

Eliminating Cultural and Personal Barriers

Many cultural and individual barriers can be eliminated, Mr. Lambrinos argued, with a thorough understanding of common cultural and health beliefs among Latinos/Hispanics. Examples include the belief that disease is related to hot and cold principles, a reliance on folk remedies, the concept of a hex, the belief that treatment requires consulting a *santero* (healer), and a belief in the *mal de ojo* (evil eye).

Some common cultural characteristics among Latinos/Hispanics include the following: *simpatía* (positive interpersonal interactions), *familismo* (a heightened concern with family), *fatalismo* (the belief that there is little a person can do to alter fate), *respeto* (respect for authority figures), *personalismo* (importance to personal as opposed to institutional relationships), and

confianza (trust in the developing provider-patient relationship). Mr. Lambrinos noted that the Latino value of *familismo* and its positive influence on health care interventions and behavioral change in individual Hispanic patients is well-documented.

He also emphasized that understanding the cultural, institutional, personal, emotional, and knowledge barriers faced by minorities and older persons is an important step toward improving health services to these populations. The use of community health workers or *promotoras* has been found to be an effective intervention in minority communities.

Promotoras are neighborhood volunteers associated with a local organization or clinic. They are known and trusted by the community and provide health education on topics such as disease prevention, medicine management, diabetes, and high blood pressure.

Another way to improve health literacy among minority populations, according to Mr. Lambrinos, is to train health professionals in communication skills and the use of new communication technologies. The National Library of Medicine's MedlinePlus en Español Web site is an example of this technology. Focus groups conducted by the Edward R. Roybal Institute for Applied Gerontology found the Web site to be well accepted in the Latino community as a source of health information.

Mr. Lambrinos also proposed that health information campaigns be developed by people with specific knowledge of the cultural characteristics, media habits, and language preferences of the intended audiences, and that these campaigns be coupled with culturally appropriate marketing.



Presentation 8: The Aging, Health Literacy, and Decision-Making Research Milieu

Jeffrey W. Elias, PhD
Director/Manager
Grant Facilitation Service
University of California Davis,
School of Medicine

Dr. Jeffrey W. Elias began his presentation by discussing self-management as an important component of aging and describing how aging influences self-management. Factors that significantly affect older adults and their ability to make health care decisions include how they process information, the burdens of chronic illness for themselves and their significant others, reduced mobility and access to health care services, and changes in household economics.

Much of the current scientific understanding of limited health literacy indicates a risk for cognitive decline with age. However, the interaction between health literacy,

literacy, and cognitive vulnerability, as well as potential protective factors, is unknown. The research agenda, according to Dr. Elias, is set by the need to know the buffers between health literacy, literacy, and cognition; the cognitive biases that people have; the heuristic environment for health care decisions; and the developmental nature of limited health literacy.

Cognition is a critical factor because of the multiple elements involved in processing information. Cognitive factors that link directly to health literacy skills include changes in memory capacity, processing speed, and mental shortcuts used to handle new information. However, cognitive processing and change are not the complete picture. Decision-making processes also appear to have a strong effect on health literacy.

Age, Health Literacy, and Health Decision Making

Dr. Elias noted that research on general decision making has shown that when decision options are described in terms of gains, people tend to prefer the “sure thing” option. When information is presented in terms of losses, people are more likely to choose a riskier option.²³ These rules are more likely to be followed when gains and losses are relatively clear.²⁴

According to Dr. Elias, decisions regarding health do not follow the same patterns. In some cases, a person will make a decision that supports one aspect of health but puts another aspect at risk. For example, Elias and his colleagues have found that some decisions about diet or medications can improve a person’s heart function but increase the risk for impaired cognitive function.²⁵



“We make health decisions based on the way we see options.”

—Jeffrey W. Elias, PhD

Another example of a trade-off is moderate alcohol consumption, which can reduce risk for heart disease but increase the presence of brain neuropathological biomarkers.²⁶

Dr. Elias noted that health decisions often are made as trade-offs between one aspect of health or another—or between financial viability and health. Economists present these kinds of decisions within the perspective of the *personal utility* of a decision and the consideration of the *probability or odds* of outcomes related to the decision.²⁷ Understanding health information in terms of numerical odds and risk is very difficult, and it is one of the most difficult concepts of health literacy.²³

Risks and Buffers for Health Literacy

Comprehension and retention of information may have little to do with health literacy, according to Dr. Elias. Expanding the research agenda to include decision making, the factors that affect decision making, and other complex cognitive factors will provide a more complete picture of health literacy skills.

Dr. Elias recommends future research to better identify the buffers between health literacy, literacy, and cognition; people’s cognitive biases; the heuristic environment for health care decisions; and the developmental nature of limited health literacy.

Presentation 9: Health Literacy and Health Decision Making in Practice

Joanne G. Schwartzberg, MD
Director, Aging and Community Health
American Medical Association

Dr. Joanne G. Schwartzberg addressed the challenge of helping older adults translate health care information into action. Specifically, her concerns are for older adults who have to “do the work” required to manage their health and be a patient. Older adults face many challenges when they try to follow care plans developed by their providers. These plans may not be consistent with what older adults need to reach their own desired goals and make it through the constant changes of daily living.

According to Dr. Schwartzberg, health professionals tend to think only in terms of what they as professionals need to do to communicate more clearly. They assume that if a patient with limited literacy understands and decides to follow the doctor’s recommendations, he or she will be able to do so.

Dr. Schwartzberg argues that this assumption ignores the complexity facing the patient and the difficulty in safely completing the tasks required. The patient must do the work at home, alone, without the health care team or organization, in a natural, undesigned, and often chaotic environment. Patient confusion and fear can be paralyzing, resulting in nonadherence to prescribed therapies and poor outcomes.

“Patients need help setting up reliable, sustainable systems at home.”

—Joanne G. Schwartzberg, MD

Meeting the Needs of Older Adults

Dr. Schwartzberg discussed the concept of *human factors*, which is the understanding of how humans perform work and interact with systems. These systems can be physical (e.g., musculoskeletal), cognitive (e.g., mental workload), and organizational (e.g., communication).²⁸ A patient’s level of confidence or confusion can influence his or her understanding and action. For example, does the patient know what work needs to be done, does he want to do it, and does he have what is needed to do the work?

Dr. Schwartzberg also discussed the influence of distractions—such as environmental, emotional, social, and physical factors—that can lead to confusion, error, and loss of confidence.

A Therapeutic Alliance


Dr. Schwartzberg recommended that providers help patients set up a reliable, sustainable system at home, including a safe physical environment with emotional support and built-in error management. Clinicians should work with patients to carefully evaluate the work that needs to be done, and then design step-by-step materials and ways to monitor the patient’s success in using the system at home.

Best practices for patients with limited literacy include a brief

intervention with the physician followed by a 1-hour, intensive, one-on-one session with a nurse or pharmacist; a series of weekly telephone calls to provide additional education; and interactive follow-up sessions.

Through this approach, clinicians would provide a therapeutic alliance that meets patients’ need for trust and emotional support to complete the complicated work they have to do. This alliance would rely on interactive education with clear materials, coaching in basic navigational and organizational skills, repetition and reinforcement, and enough time for the support to be provided. In addition, Dr. Schwartzberg recommends that the self-care system use pictograms and plain language materials for instructions.





Self-Care: Example of a Successful Program

Dr. Schwartzberg concluded her remarks by discussing a study that showed patients with limited literacy achieving better outcomes than those with adequate literacy when they used a reliable, sustainable self-care system.²⁹

This study involved patients with heart failure whose doctors helped them organize the information they needed to manage their condition into a few simple directions. The resulting booklet included simple, clear graphics, easy-to-follow steps, daily instructions, and charts to fill out. Although the doctor meets with the patient first to explain the importance of the program,

the actual training is done one-on-one with a nurse. This training is followed by telephone contact and regular visits in which the doctor reviews the patient's written information. Although all patients improved and cut their rehospitalization rates by almost 50% (when compared with controls), patients with limited literacy did better than those with adequate literacy.

Even when older adults lack a high degree of literacy skills, Dr. Schwartzberg concluded, they can be successful in achieving health care goals when they are offered a reliable, sustainable self-care system that is useful in their everyday environment.



Summary of Panel Presentations

On Day 1 of the Expert Panel on Improving Health Literacy for Older Adults, panelists made their presentations. On Day 2, they focused on achieving the expected outcomes of the expert panel, which were to

- Develop key questions and identify issues to inform a research agenda to improve health literacy among older adults.
- Identify public health priorities for improving health literacy among older adults.
- Consider a preliminary set of best practices to guide CDC and HHS in their efforts to communicate health information to older adults.

Day 2 began with a discussion of what the panelists and invited guests had learned on Day 1. Julie Gazmararian, PhD, MPH, an associate professor in Emory University's Rollins School of Public Health, served as facilitator for the discussion. She summarized the presentations on health literacy, Internet use, why older adults are an important group to focus on, and the role of aging in health literacy.

Dr. Gazmararian also summarized the following overarching topics:

- The *Healthy People 2010* definition of health literacy is the most commonly used definition in the field.
- There is no good measure of comprehensive health literacy skills, particularly one that could be administered over the telephone.

- Health literacy is consistently related to people's ability to manage their own care; use health care services and e-health tools; access health information and services; and make informed decisions about health protection, health promotion, and health care services.
- Many people do not have the necessary literacy skills to interact effectively with the health care system.
- Most health materials are written at too high of a reading level and are not formatted or presented well.
- Health professionals often do a poor job of educating patients and consumers.
- Our fragmented health care delivery system can be even more challenging for people with limited health literacy skills.

Another major topic of discussion was Internet use by older adults. Some older adults do not have the awareness, access, or skills to use a computer to access the Internet, and some do not know how to use e-health tools.



Whether the current generation of older adults will be able to access and successfully adapt to and actually use e-health tools is unknown. Several panel members asked if our focus should be on training the current generation of older adults to access and successfully adapt to using e-health tools, since the next generation of older adults is likely to be more Internet savvy.

Internet Challenges for Older Adults

- Many Web sites use technical jargon and scientific terms that are not familiar to lay audiences.
- Many search engines do a poor job of identifying appropriate and accurate information.
- Consumers often have trouble knowing which information is accurate.
- Few computers have innovative features such as touch screens or voice activation systems that would make computers easier for older adults to use.
- Many older adults have limited access to the Internet because they have older computers or less-expensive, slower connections.
- Many older adults have limited access to newer technologies and fewer technological skills.
- Some computer functions, such as mouse “double clicks,” are difficult for people with arthritis in their hands.
- The screen flicker inherent to many computer systems makes online information difficult for older adults to read.

Panel members agreed that focusing on older adults is important for many reasons. Older adults exhibit the following characteristics that are relevant to efforts to improve their health literacy and health status:

- Lower rates of Internet use compared with other adult age groups.
- Higher rates of comorbidities and chronic diseases.
- Less mobility and access to health care services.
- Higher rates of use of health care services.
- Limited literacy and declines in cognitive function.
- Decreases in financial resources.

Panelists and invited guests devoted a great deal of attention to the issue of motivating and engaging health professionals to apply what is already known about effective communication and information delivery with older adults. Several tools and guidelines already exist. For example, the Spry Foundation published a report on how to accommodate the communication and learning needs of older adults that includes 19 research-based factors to consider.³⁰ This information has been available for several years, but it is not being used routinely to guide interventions.

Panelists agreed that health professionals need to radically change the way they currently communicate with older adults. They recommended that health professionals follow existing guidelines and create innovative collaborations—for example, between researchers, cognitive scientists, librarians, end-of-life and elder abuse coalitions, and linguists—to support the use of interventions already proven effective and to identify new ones.

Panel Members Agree on Key Issues

The panel members ended their meeting by agreeing on the following general points:

- There is a high rate of the “truly disconnected” (those not using the Internet) among older adults, and many people in this age group receive their health care information from family members, friends, and print resources.
- Several age-related issues—such as vision, hearing, and cognition—influence the ability of older adults to process health information.
- Cognition is an important predictor of health literacy among older adults, even more so than years of education.
- Other characteristics related to health literacy include psychosocial skills, self-efficacy, communication, expectations, and experiences.
- Older adults want health information.
- Many older adults have difficulties with routine tasks of daily living.
- Literacy practices change over the lifespan.
- Health literacy should not be equated to reading ability. Health literacy has many dimensions, only one of which is comprehension of text.
- The ability to understand numerical and risk information and to perform calculations is becoming increasingly important in health care and must be a central part of health literacy.

Summary of Discussion

As a final step, panel members and invited guests discussed research opportunities, suggestions for public health action to improve health literacy, and potential next steps.

Research Opportunities

Panelists did not agree on the need to invest more time and resources in measuring health literacy in the general population or among older adults. Health literacy as a term continues to confuse health professionals, educators, and the public. Some panelists felt that older adults would benefit more immediately if health professionals applied what is already known about clear communication. The concept of health

literacy has too many components to allow the development of a single measure of health literacy, according to Dr. Rudd.

Past research on health literacy emphasizes reading skills and tasks, but key leaders in the field also want to include a broader range of skills and tasks, such as listening, speaking, seeking, viewing, and analyzing information. However, this broader definition adds to the difficulty of developing acceptable measures and makes it difficult for policy makers to see the scope of the problem and progress when it occurs. Russell E. Morgan, Jr., PhD, MPH, president of the SPRY Foundation and an invited guest to the discussion, stated that health literacy metrics are necessary to inform policy makers about health literacy issues.

Studies Needed to Identify Difficulty of Tasks

Dr. Schwartzberg advocated research that uses the methods of human factors analysis to identify and understand the tasks that older adults must do to find and use health information. She posed the following question: How does a person interact with the environment to do the “job” of being a patient or health care consumer? She stated that health professionals do not always understand the complexity of the tasks they ask their patients to do.

Dr. Schwartzberg also pointed out that health literacy researchers have shown how medication labeling and instructions are confusing to patients. Subsequent research and task analysis have produced suggestions of how medication labeling and instructions

can be improved. Dr. Schwartzberg called for more research that uses task analysis to identify how the process and products of health care could be reengineered to make them more user-friendly.

Dr. Rudd supported this position, noting that no research has been done on the demands placed on people by the public health system. For example, environmental and community conditions can influence people’s health and health outcomes, but public health officials have not done a good job of making information about these factors easy to understand.

Health Information Must Consider Age-Related Changes

Several panel members noted the importance of conducting research to understand how cognitive functioning and literacy practices change over time. They rejected the idea that either health literacy skills or cognitive functioning is static. Even though people are aging and experiencing changes in their bodies and cognitive functioning, they still want health information, but information is not being designed to accommodate these changes. Panelists also noted the importance of changes in hearing and vision as factors that can affect a person’s health literacy skills.

Research on and experience with older adults and their learning styles and preferences was highlighted as an important source of information for understanding the needs of this population, as well as an area for future research. Studies have shown that older adults are self-directed in what and how they learn, yet they like to learn as part of a group.



Panelists noted that the high cost of changing how information is presented and disseminated is often given as a reason for why even minor changes cannot be made.

They dislike a lot of technical information, and they need time for reflection to process what they have heard or read. They want information that is appropriate and easy to understand. More research into how people's learning styles and preferences change as they age could help to guide how health professionals communicate with older adults.

Most health literacy research (basic and applied) has been conducted in the areas of chronic disease management, self-care, medication, and treatment. Limited attention has been paid to the relationship between people's health literacy skills and how they access health promotion and preventive services or how health literacy affects behavioral change.

The panelists agreed that these areas need more research. Other gaps in research include the need for systematic data on factors that influence health literacy and the relationship between health literacy and a person's ability to use e-health tools.

Suggestions for Public Health Action to Improve Health Literacy

The panelists were charged with identifying steps that public health organizations can take to make it easier for older adults to find and use health information and services. The majority of the panelists' suggestions focused on information presentation and

dissemination. Some of these suggestions were directed specifically at CDC, whereas others were directed more broadly at public health and health care organizations.

Panelists noted that the high cost of changing how information is presented and disseminated is often given as a reason for why even minor changes cannot be made. However, the cost of not making the changes must be considered as well.

If older adults cannot get the information they need to manage their illness, take their medications properly, respond to public health recommendations and warnings, and use health care services effectively, then both individuals and public health systems bear significant costs in wasted resources and time. Individuals also pay an even higher cost in lower quality of life and poorer health status.



Use Plain Language

The panelists agreed that uniform application of plain language principles to public health information would be of great benefit to the public, especially older adults. Several federal guidelines on plain language exist, including CDC's *Simply Put* and the National Cancer Institute's *Making Health Communications Work*. Despite these guidelines, CDC's materials for the public do not reflect plain language principles.

Panel members agreed that if CDC and other government agencies would systematically apply the guidelines they already have, they could improve health information easily and quickly. They also agreed that CDC and other agencies should be role models for how to implement clear communication practices.

One audience member suggested that CDC's associate directors of science (ADSs) should be enlisted to help explain to subject matter

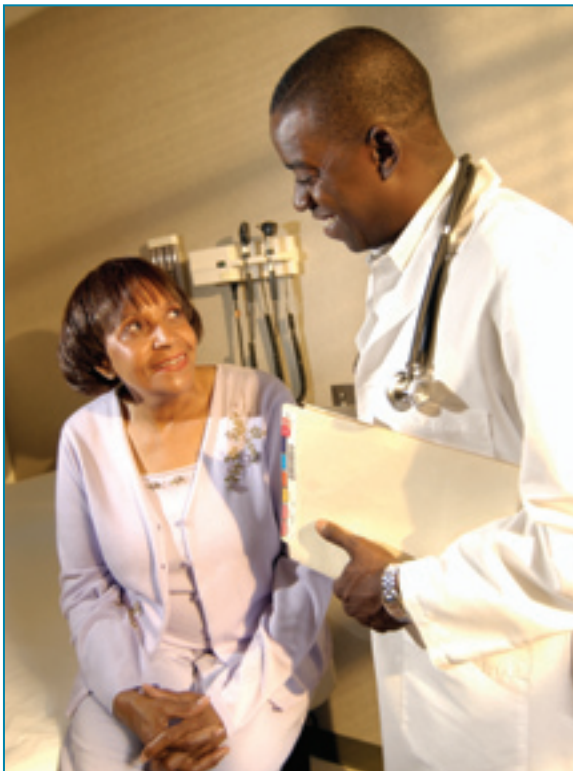
experts the difference between communication among scientists and communication with the public. She suggested that if ADSs became advocates for clear communication with the public, then subject matter experts would be more likely to accept scientific concepts and recommendations being rewritten in plain language.

The panelists agreed that information for the public should not be written from the perspective of the scientist or use scientific jargon if CDC wants the public to use the information. One panelist noted that CDC scientists should be educated about the state of literacy skills in the population so they can appreciate how many people would benefit from simple, clearly written materials.

Bundle Messages to Avoid Clutter

Panel members noted that government agencies often put out multiple, simultaneous messages that contribute to information clutter rather than understanding. They expressed concern that people cannot make sense of the many recommendations presented to them by the government. Based on an analysis of health information products and reviews of the literature, Dr. Rudd found that public health messages often are disorganized, poorly written, and unclear about the required action.

Panelists discussed the idea of bundling messages from various government programs and channels and coordinating their dissemination as a way to address information overload and clutter. They encouraged further exploration of CDC's proposed approach to grouping messages by life stage or age. They also encouraged CDC and other public health agencies to use structured formats to provide consistency in information presentation.





Panelists encouraged CDC to ensure that all health information disseminated by the agency is appropriately directed at the intended audience. Several panelists and audience members said that a consolidated data resource on the communication needs and issues of vulnerable populations, including older adults, is needed, and that CDC could provide an important service by creating or sponsoring such a resource.

One panelist cautioned against proceeding without a solid definition for vulnerable populations. Some panelists suggested participatory research with older adults as a way to build knowledge about what older adults want and engage them in the process of creating more effective messages and materials.

Use Information Layering and Multiple Channels

Panelists also discussed the concepts of information layering and structuring as ways to improve information presentation. Panelists stated that older adults prefer

structured information that is intuitive because it is easier to understand. Information should be repeated to aid comprehension. Information layering makes the most important, basic information available first, then adds additional information and detail in layers or stages so that people can select what is most relevant to them.


Using multiple channels to reach audiences is a fundamental principle of good communication, and panel members reinforced the importance of using this practice to reach older adults. They agreed that many older adults will not use the Internet as a first choice for health information, and they encouraged continued use of mass media channels such as television and radio to reach older adults.

Find Ways to Bridge the Digital Divide

Panel members expressed concern about the ongoing digital divide for older adults and the assumption that most older adults are active seekers of health information. They suggested that public health agencies design information delivery systems that do not rely primarily on older adults using the Internet themselves.

Dr. Rudd questioned how many older adults would go to CDC's Web site during an emergency such as a pandemic. To reach this population, CDC should provide local public health workers with plain language materials that they can disseminate directly to older adults in their communities.

Panelists encouraged CDC to be proactive in letting older adults know that the agency does more than investigate and report on infectious diseases. CDC should promote its work in prevention, as well as in infectious disease and emergency response, to help interest older adults in its health information resources.



Libraries and senior centers were identified as important venues for older adults to find health information and access the Internet. Rural and poor residents are particular beneficiaries of library-based Internet access. Libraries also offer literacy classes that can support efforts to improve health literacy. For example, the National Library of Medicine (NLM) has supported initiatives to provide Internet access in tribal regions.

Dr. Morgan noted that organizations such as the Bill & Melinda Gates Foundation are already providing Internet access at the community level, and these groups should be included in discussions about health information access.

Improve Quality of Web Sites and Add E-Health Tools

However, access is only part of the picture. Web site content needs to be improved to make it more usable. For example, the panelists agreed that government Web sites need more plain language content. They noted that many government Web sites are collections of links, not content designed to answer people's questions.

Invited guest Robert A. Logan, PhD, MA, who is on the senior staff of the NLM, also noted that government Web sites such as MedlinePlus are important because they serve as reliable clearinghouses of information.

The panel agreed that ensuring the quality of information on Web sites should be a priority. In addition, the panel proposed that Web sites devoted to health issues include tools designed to help people make decisions, which could, in turn, prompt people to take action to improve their health.

Collect Data on Populations with Special Needs

Panelists also considered the role of families and culture in improving health literacy. Dr. Rudd noted that many older adults did not have access to advanced schooling, and their current resources are limited. Lack of schooling also may be an important factor for older adults who were born and grew up outside the United States and whose first language is not English.

Mr. Lambrinos noted that many people who immigrate to the United States have limited literacy skills in their native languages as well as in English. Although children often help older adults find and use health information, they should not be the sole resource for older adults or serve as interpreters during health care visits. Panelists agreed that more data are needed to understand the nature of vulnerabilities in older adult populations, especially immigrant populations.

Mr. Lambrinos suggested that technical innovations intended for one population could be used for others as part of a health literacy intervention. For example, a pill bottle reader developed for people with vision impairment could be useful for all older adults with reading challenges. He encouraged public health workers to engage the business sector in discussions of how to improve health literacy.

In addition, Internet-based learning tools could be designed for use by older adults to help them understand health information and motivate them to make positive behavior changes. Existing best practices in health communication and technology use could be used to develop tools that provide new types of personal feedback. Research has shown that the “baby boomer generation” will be very focused on self-directed learning, and Internet-based tools can be used to support this approach.

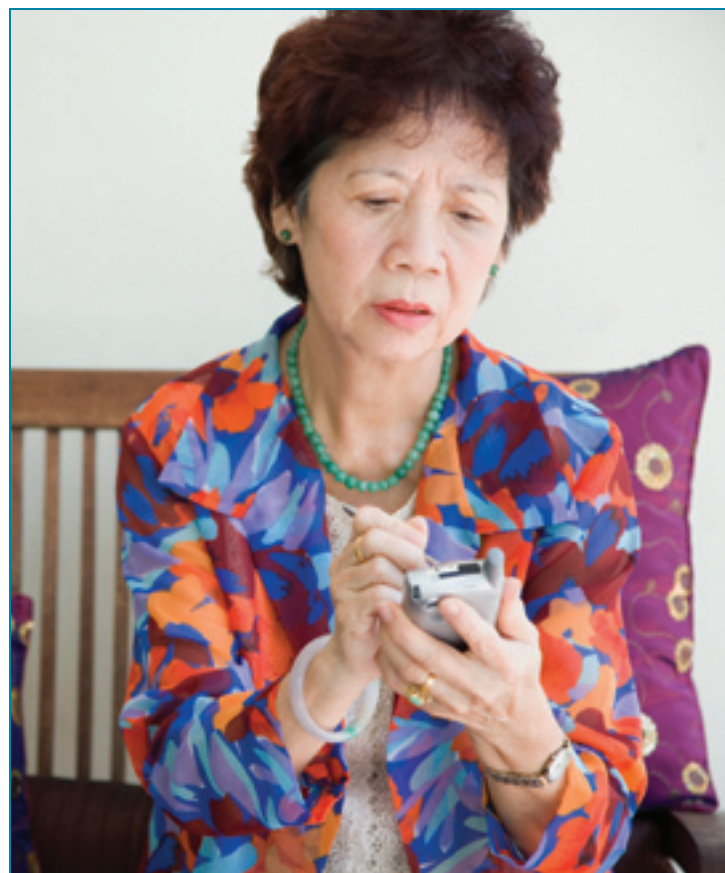
Finally, panelists suggested partnerships with scientific groups, such as science museums or organizations that sponsor touring educational exhibits, as a way to reach the public and build scientific and health literacy. Interactive exhibits could be designed and promoted to the public to engage people in learning about basic concepts of health.

Next Steps and Conclusions

Panelists identified several next steps to ensure that the work of the expert panel will have a positive and lasting effect. They proposed a follow-up meeting to assess which of the panel's suggestions had been adopted. They also suggested that the next meeting include consumer and patient perspectives. Participants agreed that discussing the same issues from the perspectives of researchers and practitioners was very helpful, and several panelists said that it would affect their approach to the subject in the future.

In addition, participants wanted the panel's work to be summarized into a printed report, and they called for the report to be widely disseminated to other researchers, health care and public health practitioners, educators, funding organizations, and policy makers. Panel members agreed that changing the way government agencies design and deliver health information will require an investment of time and money. However, the cost of not making these improvements will be even greater for older adults and our society as a whole.

Agencies waste resources when they create materials that older adults do not understand and use. When older adults do not make optimal decisions about their health and have poor health outcomes because they do not have appropriate, usable information, they are less productive and need more medical care, which increases costs for society.



Panelists were optimistic that if the findings and suggestions of their meeting were uniformly adopted by public health organizations, we could make rapid and significant improvements in the health and health literacy of older adults. As in many areas of medicine and public health, the challenge is not a lack of knowledge about the nature of the problem or ideas about what to do; it is the inconsistent and spotty translation and implementation of simple measures that could reduce or eliminate the problem.

The panelists encouraged CDC to continue to make issues related to health literacy and older adults better known in the public health community and to lead the way in creating and delivering usable, appropriate health information for all Americans.



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Participant Profiles for the Expert Panel on Improving Health Literacy for Older Adults

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Rima E. Rudd is a member of the faculty in Society, Human Development, and Health at the Harvard University School of Public Health. She teaches courses on health education strategies, health literacy, and theory. She is a visiting senior associate at Johns Hopkins University's Bloomberg School of Public Health and a visiting professor in the London South Bank University's Faculty of Health and Social Care. Dr. Rudd's research and program work focus on health disparities; barriers to health information, programs, and services; and health literacy policy.

Dr. Rudd has served on many national and international committees and advisory boards and written several reports that are shaping the research agenda in health literacy. These reports include the health literacy action plan for the U.S. Department of Health and Human Services' *Healthy People 2010* (2003) and the Educational Testing Services report, *Literacy and Health in America* (2004). She served on the Institute of Medicine's Committee on Health Literacy, the National Research Council Committee on Measuring Adult Literacy, and the Joint Commission Advisory Committee on Health Literacy and Patient Safety.



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Sara J. Czaja has a BS in Psychology and an MS and PhD in Industrial Engineering from the State University of New York at Buffalo. She is currently a professor of Psychiatry and Behavioral Sciences and Industrial Engineering at the University of Miami. She is also the director of the Center for Research and Education for Aging and Technology Enhancement (CREATE) and the co-director of the Center on Aging at the University of Miami Miller School of Medicine. CREATE is a collaboration between the University of Miami, the Georgia Institute of Technology, and Florida State University, and it is funded by the National Institute on Aging. Before joining the University of Miami faculty in 1990, Dr. Czaja was a member of the Engineering faculty at the State University of New York at Buffalo.

Dr. Czaja has extensive experience in aging research and a long commitment to developing strategies to improve the quality of life for older adults. Her research interests include aging and cognition, e-health, caregiving, human computer interaction, and functional assessment. She is currently the principal investigator on a project that is examining how or if older adults use e-health information, and she is involved in ongoing research related to the usability of patient portals of electronic medical records.

Dr. Czaja has published extensively in the field of aging, with numerous book chapters and scientific articles. She also actively promotes aging research at the national level. She is a fellow of the American Psychological Association, the Gerontological Society of America, and the Human Factors Society. She is also a member of the National Academy of Science's National Research Council Committee on Human Factors in Home Health Care.



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Michelle Eberle is the consumer health information coordinator for the National Network of Libraries of Medicine, New England Region (NN/LM NER). In her position, she travels throughout New England educating librarians, health professionals, and consumers about National Library of Medicine (NLM) resources, specifically MedlinePlus.gov, PubMed.gov, and NIHSeniorHealth.gov.

Over the past 5 years, Ms. Eberle has made more than 150 presentations. Her outreach to elder care providers includes presentations at the Massachusetts Council on Aging, the Case Managers Society of New England, local councils on aging, the Massachusetts Council for Home Health Care Aide Services, and regional consortia of elder care providers. She chairs the Outreach Review Subcommittee and the Consumer Health Advisory Board of the NN/LM NER.

Ms. Eberle earned an MS in Library and Information Science from Simmons College in 2000. While earning her undergraduate degree in social work from the Sacred Heart University in Fairfield, Connecticut, she interned at the Norwalk Senior Center. Before working at the NN/LM NER, Ms. Eberle worked as a medical librarian at Somerville Hospital, which is part of the Cambridge Health Alliance. She served on the Patient Education Committee and provided instruction on medical databases for clinical staff. Ms. Eberle's professional interests include health literacy, patient education, consumer health, complementary and alternative medicine, and mental health.



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Katharina V. Echt is a research health scientist at the Atlanta VA Rehabilitation Research and Development Center of Excellence; an investigator and the director for education at the Atlanta Site of the Birmingham/Atlanta VA Geriatric Research, Education and Clinical Center; and an assistant professor in the Division of Geriatric Medicine and Gerontology of the Emory University School of Medicine. She received her MS and PhD in Life-Span Developmental Psychology with a focus on Cognitive and Sensory Aging from the University of Georgia, and she holds a Certificate in Gerontology.

Dr. Echt's primary research focus is to identify and to develop strategies to accommodate the sensory and cognitive mechanisms that contribute to older adults' losses in health management capacity, including medication management and health literacy.

Dr. Echt's research also has involved the development of directives for the production and evaluation of usable technologies and texts for health promotion with older adults. Her areas of expertise include visual and auditory aging, cognitive aging, and human factors. She is a member of Emory University's Health Literacy Workgroup, the American Psychological Association, the Gerontological Society of America, and the Sigma Xi Scientific Research Society.



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Linda H. Miller is the community services coordinator for the Centralina Area Agency on Aging (CAAA). CAAA is the largest Area Agency on Aging in North Carolina, serving the most adults older than age 60 in the state and overseeing more than 16,000 long-term care beds in facilities throughout the state. It serves the nine counties surrounding Charlotte. Hired initially as a regional long-term care ombudsman, Ms. Miller has been with CAAA for 12 years. She graduated from Eckerd College in Florida with a BA in Anthropology and from the University of South Florida with an MA in Medical Anthropology.

Ms. Miller's background includes extensive experience in long-term care and specialized dementia care. With more than 20 years of experience in the aging field, she has worked with two Alzheimer's Associations and has a strong background in education, programs, in home services, respite care, and volunteer training. Ms. Miller currently supervises the Chronic Disease Self-Management Program (CDSMP) grant for the Centralina region and the Health Promotion Disease Prevention Program. She serves as a master trainer for the following evidence-based health programs: CDSMP, Diabetes Self-Management, and A Matter of Balance: Managing Concerns About Falls. She is certified as a master trainer with the Adult Communications and Training program sponsored by the SPRY Foundation, and in October 2009, she will be certified as a national lead trainer for A Matter of Balance.

Ms. Miller has served as a presenter at local, state, and national conferences, including the National Alzheimer's Association Education Conference, the National Association of Area Agencies on Aging, the Southeast Association of Area Agencies on Aging, the American Society for Aging, the National Association of Nutrition and Aging Service Providers, the Carolinas Center for Hospice and End of Life Care, the North Carolina Director of Nursing Association.



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Michael S. Wolf is an associate professor of Medicine and director of the Center for Communication in Healthcare at the Feinberg School of Medicine at Northwestern University. Dr. Wolf is a behavioral scientist and health services researcher with primary interests in adult literacy and learning, cognitive factors, and the management of chronic disease. He was one of the first recipients of the Pfizer Health Literacy Initiative Scholar Award and has received numerous national awards for his work in the field of health literacy and medication safety.

Dr. Wolf has written 84 peer-reviewed publications, many of which address the problem of limited health literacy. He currently serves on advisory committees for the U.S. Food and Drug Administration, U.S. Pharmacopeia, the American Dental Association, and the Agency for Healthcare Research and Quality. He has served as a consultant on health literacy issues to the Institute of Medicine, the American College of Physicians Foundation, the American Medical Association, the American Pharmacists Association, and the Centers for Disease Control and Prevention.

Dr. Wolf is currently the principal investigator on grants from the National Institute on Aging, the National Cancer Institute, the Agency for Healthcare Research and Quality, the Target Corporation, the Foundation for Informed Decision Making, and the Missouri Foundation for Health. Dr. Wolf also led an Institute of Medicine white paper on health literacy and medication safety, and he is the principal investigator of a trial to test enhanced drug labeling and the use of visual aids to improve patient processing and understanding of medication instructions.



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Jorge J. Lambrinos is the executive director of the Edward R. Roybal Institute for Applied Gerontology at the University of Southern California (USC). Mr. Lambrinos has directed the health promotion and disease prevention projects of the Roybal Institute, with a focus on eliminating health disparities through education and training of consumers and service providers. His research interests include adult immunization, fall and injury prevention, and breast and cervical cancer. He collaborated with the National Library of Medicine to measure the accessibility and acceptability of its MedlinePlus en Español program and related educational materials.

Mr. Lambrinos served as chief of staff to Congressman Edward R. Roybal (CA) from 1985 to 1993 and staff director of the House Select Committee on Aging from 1982 to 1985. Before going to Capitol Hill, Mr. Lambrinos served as special assistant to the Commissioner on Aging and director of the Executive Secretariat at the Administration on Aging. Mr. Lambrinos was appointed by the governor to the California Commission on Aging, where he served as chair during 2005–2006. He currently serves on the California Policy Council for AARP.

In 1989, Mr. Lambrinos was named one of the Top 100 Most Influential Hispanics in the U.S. by Hispanic Business Magazine. Mr. Lambrinos has been actively involved in the field of aging for more than 30 years in various capacities at local, state, and federal levels. He is a decorated (Bronze Star) veteran of the 1991 Gulf War. Mr. Lambrinos is pursuing a PhD in public policy from Claremont Graduate University.



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Jeffrey W. Elias is the current director/manager of the Grant Facilitation Service of the University of California Davis School of Medicine, and he publishes and develops research in the area of aging. He is the editor of the journal *Experimental Aging Research* and is a fellow of the Gerontological Society, the American Psychological Association, and the American Psychological Society.

Before coming to UC Davis in May 2007, Dr. Elias served as scientific review administrator for the Center for Scientific Review (in the Adult Psychopathology and Disorders of Aging Section) and chief of the extramural Cognitive Aging Program in the Behavioral and Social Research division at the National Institute on Aging (NIA). During his tenure at NIA, Dr. Elias was particularly active in promoting the areas of cognitive interventions, human factors, translational research, decision making, and health literacy.

Before his tenure at NIA, Dr. Elias was director of research at the University of Nevada's Sanford Center on Aging. Before that, he spent 25 years in academics at Texas Tech University's Department of Psychology, where he was associate chair of Psychology and director of the Experimental Psychology Program. Dr. Elias also worked with the Texas Tech University Health Sciences Center Neurology and Psychiatry Department and at St. Mary's Hospital in Lubbock, Texas, where he specialized in developing fall prevention programs and studying executive function in Parkinsonian patients.

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Joanne G. Schwartzberg is director of Aging and Community Health at the American Medical Association (AMA). She received her BA from Harvard University and her MD from Northwestern University. She is a clinical assistant professor of Preventive Medicine and Community Health at the University of Illinois at Chicago's College of Medicine. She is a past-president of the Institute of Medicine of Chicago, the Illinois Geriatrics Society, and the American Academy of Home Care Physicians.

In 1995, Dr. Schwartzberg served as co-chair of the Illinois Delegation to the White House Conference on Aging, Caucus on Health and Social Services. She also served on the Advisory Committee of the 2005 White House Conference on Aging. She currently directs AMA initiative on aging and long-term care, with projects on medical education and geriatric competencies, older driver safety, medical management of the home care patient, health literacy, safe communication, and patient self-management.

Dr. Schwartzberg has been working in the field of health literacy and clinician-patient communication since 1997. She organized the AMA ad hoc committee of experts that developed *Health Literacy: Report of the Council on Scientific Affairs*, organized physician awareness campaigns based on the AMA's Health Literacy Introductory Kit, and later developed the Health Literacy: Help Your Patients Understand self-study program. She has led the AMA Foundation's Training of Trainers program for the last 6 years, which with 29 teams around the country has reached over 30,000 health professionals.

In 2005, Dr. Schwartzberg was an editor of the first textbook in the field: *Understanding Health Literacy: Implications for Medicine and Public Health*. She has recently been working on patient safety and health literacy, leading to the 2007 monograph and current CME program on *Reducing the risk by designing a safer, shame-free health care environment*. She is also the 2001 recipient of the Henry P. Russe, MD, Citation for Exemplary Compassion in Healthcare awarded by the Institute of Medicine of Chicago and the Rush-Presbyterian-St Luke's Medical Center.



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Julie A. Gazmararian has an undergraduate degree in business administration from the University of Michigan and an MPH in health education from the University of South Carolina. After receiving her MPH, she worked as scientific programs coordinator at the American Public Health Association in Washington, DC, where she was involved in a range of public health issues. She received her doctorate in Epidemiology at the University of Michigan, and then entered the Epidemic Intelligence Service (EIS) program at the Centers for Disease Control and Prevention (CDC). Dr. Gazmararian worked in CDC's Division of Reproductive Health, where she was involved in a variety of projects that examined physical violence during pregnancy, race differences in cause-specific fetal mortality, socioeconomic status among reproductive-age women, and the occurrence of epiglottitis among presumptive cases of sudden infant death syndrome.

In addition to her domestic work, Dr. Gazmararian has an interest in international health and has worked in Jamaica, Brazil, Bangladesh, and Armenia. During 1994–2001, she worked at the USQA Center for Health Care Research (formerly the Prudential Center for Health Care Research), where she served as director for scientific research and center director. During this time, she was the lead researcher on several studies, including one that examined health literacy among Medicare enrollees.

Dr. Gazmararian is currently an associate professor in Emory University's Department of Epidemiology, and she leads the university's multidisciplinary health literacy workgroup. Her primary research interests include issues in underserved populations, particularly related to reproductive health and health literacy. She served as editor of a book on health literacy published by the American Medical Association, and she contributed to the Institute of Medicine's report on health literacy.



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Russell E. Morgan, Jr., is president of the Maryland-based SPRY Foundation, which conducts research and education programs to improve people's quality of life as they age. The foundation focuses on wellness and health, mental health, financial security, and intellectual connectivity. Emphasis is placed on translating outcomes of new scientific research and using new communication technologies and principles of adult and multigenerational learning. The foundation also works to help older adults understand and become creatively involved with personal decisions about volunteerism, life-long learning, and personal employment.

Dr. Morgan brings more than 30 years of experience in the areas of health care and policy to the SPRY Foundation. During 1992–1996, he served as president of the Institute for Advanced Studies in Immunology and Aging in Washington, DC. He was also the first president of the Global Health Council (formerly the National Council for International Health), holding that position for 13 years. He has held senior positions with the American Public Health Association and was secretary general of the World Federation of Public Health Associations.

Dr. Morgan received his BS in Biology and Chemistry from Moravian College. He has an MS in Public Health from the University of Pittsburgh and a doctorate of Public Health from the University of Texas. He was also a Visiting Takemi Fellow at the Harvard University School of Public Health.



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Vicki S. Freimuth is director of the Center for Health and Risk Communication at the University of Georgia, where she holds joint appointments as a professor in the Department of Speech Communication and the Grady College of Journalism and Mass Communication. She received her BS from Eastern Illinois University, her MA from the University of Iowa, and her PhD from Florida State University.

Before joining the faculty at the University of Georgia, Dr. Freimuth served as director of communication at the Centers for Disease Control and Prevention (CDC). Her research focuses on health communication, specifically the role of communication in health behavior change programs, and she has received research grants from CDC and the National Cancer Institute. She is author of *Searching for Health Information*, co-editor of two books on HIV/AIDS and communication, and author of chapters in several major books on health communication.

Dr. Freimuth's 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 also has served on the editorial boards of several journals, including the *Journal of Communication*, *Human Communication Research*, and *Journal of Health Communication*. Dr. Freimuth 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 she was named the Woman of the Year at the University of Maryland in 1990.

Agenda for the Expert Panel on Improving Health Literacy for Older Adults

Thursday, December 6, 2007

7:00 am Room 1022 open, CDC Executive Park Meeting Center

7:30 am Coffee

8:00 am **Introductions**

Julie A. Gazmararian, PhD, MPH

8:15 am **Overview: Low Health Literacy Among Older Adults**

Rima E. Rudd, ScD, MSPH

Panel discussion

9:15 am **Break**

9:30 am Obtaining Health Information

The Evidence: Sara J. Czaja, PhD

The Practice: Michelle Eberle, MSLIS

Panel discussion

11:00 am **Processing Health Information**

The Evidence: Katharina V. Echt, PhD

The Practice: Linda H. Miller, MA

Panel discussion

12:30 pm **Lunch in Room 4052**

1:15 pm **Understanding Health Information**

The Evidence: Michael Scott Wolf, PhD, MA, MPH

The Practice: Jorge J. Lambrinos, MA

Panel discussion

2:45 pm **Break**

3:00 pm **Health Decision Making**

The Evidence: Jeffrey W. Elias, PhD

The Practice: Joanne G. Schwartzberg, MD

Panel discussion and wrap-up

4:30 pm **Adjourn**

6:00 pm **Optional networking: panelists meet for dinner**



Friday, December 7, 2007

8:00 am

Coffee

8:30 am

Recap of Day 1

Facilitator: Julie A. Gazmararian, PhD, MPH

9:00 am

Discussion

Develop key questions and identify issues to inform a research agenda to improve health literacy among older adults.

Identify public health priorities for improving health literacy among older adults.

10:00 am

Break

10:30 am

Discussion

Consider a preliminary set of best practices to guide CDC and the U.S. Department of Health and Human Services in their efforts to communicate health information to older adults.

Facilitator: Julie A. Gazmararian, PhD, MPH

12:00 pm

Panel Adjourned

