Panel 3: Toward an Informed and Engaged Public

Topics covered in Panel 3:

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

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

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

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

Patient Activation Measure

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

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

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

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

Health Literacy and Activation Both Contribute to Health Outcomes

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

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

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

Measuring Activation: Recommendations for the Field

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

Advancing Health Literacy: A Framework for Understanding and Action

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

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

Moving Beyond the "Deficit Model"

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

A Multi-Dimensional Model of Health Literacy

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

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

Meeting the Health Literacy Needs of the Population

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

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

- Contextualization
- Reinforcement
- Evaluation
- Subsequent revisions

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

Toward an Informed Public: A Communication Perspective

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

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

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

Closing the Knowledge Gap

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

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

- Source of the information
- Health message being conveyed

- Dissemination channels
- Receivers or target audience.

Role of the Source of Information in Communication

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

Creating Effective Health Messages

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

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

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

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>
> *Vicki Freimuth, Ph.D.*

Channels of Communication

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

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

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

Understanding the Target Audience

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

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

Translating Health Literacy Research into Large Scale Public Action

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

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

A Translational Research Model

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

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

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

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

User Collaboration in Health Communication

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

> "User-centered design improves communication for the participating groups, including persons with low health literacy."
>
> *Linda Neuhauser, Dr.P.H.*

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

Case Study: MyPyramid.gov

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

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

Health Literacy Standards and Participatory Methods to Improve Communication

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

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

Case Study: *First 5 Kit for New Parents*

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

Need for a National Plan to Improve Health Literacy

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

The ideal national plan would include:

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

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

Discussion: Panel 3

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

Limited Health Literacy: Not Just an Individual Problem

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

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

An Ecological Perspective

> "Communication deficits exist at all levels—including healthcare providers, healthcare systems, educators, policymakers, and the public."
>
> *Linda Neuhauser, Dr.P.H.*

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

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

Health Information on the Internet

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

Positive Versus Negative Health Messages

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