

Say What?

Understanding Health Information

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After a few days of coughing, Mary bought over-the-counter cough medicine at a drugstore. However, she overdosed and fainted because she couldn't understand the label. "I didn't know it would make me sick," she said. "I thought it was safe."

Mary's experience illustrates the dual challenge to effective health communication. Health information is increasingly complex. Yet many people lack the skills to understand and act on the health information they receive.

As our health care systems and treatment options have become more varied and complex, people face more difficult decisions. To use cough medicine safely, Mary must understand precautions, dose recommendations, and drug interactions. She must know where to go with her questions and how to ask them. Many people are not well prepared for this challenge. A focus group participant, in a study done by the California Health Literacy Initiative, said, "I just have to trust the doctor. I put a huge amount of trust into the medical staff. I just sign forms without really understanding them." She was a native English speaker, but had limited reading skills.

Like this woman, many native English-speakers have limited literacy and numeracy skills. Many others have limited proficiency in the English language. And others, including many seniors, have vision, hearing, or cognitive limitations. Differences in cultural experiences can be an additional challenge to communication.

Often, those whose job it is to communicate about health—providers, educators, and administrators—have not been trained to present information in ways their patients understand. As one physician said, "I am unable to adequately explain my directions, and my patients are unable to process large volumes of written materials."

Why do these issues matter? Health information can save lives—if it is communicated effectively. And health communication must improve if we as a society are to reduce health disparities and improve population health.

The need to improve health communication has led to the new field of study called "health literacy." Health literacy is commonly defined as the ability to understand and act on health information.



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Literacy and Health Literacy

In a study of the literacy level of consumer information materials from California’s 11 largest commercial health maintenance organizations (HMOs), researchers at the University of California, Los Angeles (UCLA) found that 94% of the materials were written at college and graduate-school levels. Yet it is estimated that the majority of adults in the United States read between the 7th to 9th grade levels, and that 20% of adults read at the 5th grade level or lower. (Adults frequently read about 3 to 5 grades lower than the highest grade of school that they have completed, according to Davis and others in *Pediatrics*.)

Many adults in the United States do not meet the basic criteria of literacy: the ability to use “printed and written information to function in society, to achieve one’s goals, and to develop one’s knowledge and potential” (from *The Health Literacy of America’s Adults*).

Health problems associated with low literacy are estimated to affect “nearly half of all American adults—90 million people,” according to the Institute of Medicine. Low literacy leads to poor understanding of health and medical information, misdiagnosis due to poor communication between patients and doctors, and low rates of treatment compliance and preventive care. It costs billions of dollars annually in longer hospital stays, unnecessary emergency room visits, and increased doctor visits.

The seriousness of these issues and their effect on quality of care and health disparities have been recognized in recent years by the Institute of Medicine, the American Academy of Family Physicians Foundation, Pfizer, Inc., the American Medical Association Foundation, Kaiser Permanente, and many other public and private organizations. A number of initiatives are now under way to address health literacy issues, and the Harvard School of Public Health has a program in health literacy studies.

Finding Out What Works

Good health communication goes beyond addressing literacy levels. Historically, many efforts to educate people about health have had limited impact because they haven’t engaged their audiences and motivated people to act on what they learn. For more than 20 years, Health Research for Action (HRA), a center at UC Berkeley’s School of Public Health, has developed health communication resources based on research and evaluation with intended audiences. This development process seeks answers to the following questions:

- What do people want and need to know?
- What do they understand and not understand?
- How do they want to receive information?
- How can this information be made relevant and useful to peoples’ cultures and situations?

Both research and evaluation are important to developing effective health communication. Research with intended audiences during development can improve the relevance of health communication and the usability of materials. Evaluation of the acceptability, usefulness, and impact of materials helps to improve future efforts.



HRA worked with California’s Department of Managed Health Care to develop a website that explains health plan regulations in language consumers can understand. Visit the site at www.dmhc.ca.gov.

What Do People Want?

Patient self-management is key to diabetes care, but requires sophisticated understanding and skills. HRA worked with a regional medical center and its affiliated clinics to assess the educational needs of its diabetic patients, particularly those who were most vulnerable because of low incomes and limited language skills. Overwhelmingly, in a series of focus groups, patients said that they needed better basic information, consistent messages from health providers, and information more relevant to their daily lives—such as knowing which foods to eat, rather than just which foods to avoid.



Patients also talked about the economic and cultural factors that reduced their ability to manage their diabetes. One said, “I find that . . . you almost have to be rich to buy all that food you wanted to buy.” Another noted, “It’s hard with money. You’re cooking for your family, and you can’t afford to cook multiple meals, so it’s tough.”

A Latina patient said there should be “classes for spouses, because they just don’t get it. They think that diabetics look normal and therefore must be making it up.”

Mien patients were at a particular disadvantage with written information: there is no written Mien language and most had limited English skills. They wanted facilitated group discussions, in addition to individual meetings with the doctor. Such discussions could provide peer support as well as medical information. They also requested video information, “with explanations and examples to teach”—or, as another patient said, “so that we can replay it over again so we may understand.”

Reducing Knowledge Gaps

In 2000, as a result of managed care reforms, California established two new offices that work together to help health plan members. The Department of Managed Health Care (DMHC) was charged with making sure that health plans comply with California managed care laws. It also provides direct assistance, including an independent medical review process, for health plan members who are having problems with their plans. The Office of the Patient Advocate (OPA) was charged

with educating consumers about their rights and responsibilities in managed care.

Because of these mandates, effective consumer communication is an important goal for both departments. However, explaining the health care system is difficult. In general, people just want to get care. They do not want to read complex documents about how to get it, and they do not want to think about it before they need it. So OPA and DMHC had a challenge: motivating people to understand their health plans and use services before they are sick.

According to the National Center for Education Statistics, 59% of people 65 years of age or older are estimated to have “basic” or “below basic health literacy”—the lowest of four levels.

Soon after it was established, OPA began working with Health Research for Action to develop a guide to give HMO members basic information about how to choose a primary care doctor, use their benefits, exercise their rights and responsibilities, and find more help and information.

California’s HMO Guide and the Spanish version, *La Guía de los Planes de Salud HMO de California*, were created in collaboration with OPA, consumers, advocates, and HMOs. The guides feature:

- Telephone and website resources for consumers.
- An 8th grade reading level.
- Consistent design elements to increase readability and usability.
- Introductory information on a broad range of topics.
- Photographs and captions to model ways people can use the information.
- A colorful cover.

Both versions of the guide were launched in late 2002 and distributed by OPA, health plans, and consumer advocacy organizations. HRA conducted focus groups throughout California to assess the guide’s use and effectiveness, and found that it was

very well received. Participants liked its broad scope and many resources, its attractiveness, and easy-to-use format. One woman stated, “Everything you ever wanted to know about health is right here.” Another participant said, “I was amazed at how much information is in here that you can utilize right now.”

Overall, participants thought the guide would help them be better advocates for their health care. Spanish-speakers in particular were enthusiastic—“This is a primer for you to get comfortable with whatever issues you are dealing with at the time. Being comfortable with this book might make you more comfortable to deal with the actual HMO’s literature.”

The positive response to the Spanish guide corroborates HRA studies that the guide model can help reduce the knowledge gaps between English and Spanish speakers in the United States. Research indicates that low health literacy is more pronounced in the Spanish-speaking U.S. population, due to language barriers and the lack of background information.

Seniors also had positive feedback on the guide, but wanted something more tailored. As a result, OPA and HRA developed *California HMO Guide*

for Seniors and the Spanish version, *La Guía de los Planes de Salud HMO para Personas Mayores en California*. This version had larger print and simpler language to meet the needs of a population with more limited health literacy. According to the National Center for Education Statistics, 59% of people 65 years of age or older are estimated to have “basic” or “below basic health literacy”—the lowest of four levels.



Partnering to Improve Communication

The UCLA study mentioned earlier (page 2) concluded that many health plans lack the training, resources, and organizational buy-in to develop materials that their members can readily understand and use.

As a result of this study, OPA and HRA collaborated on a statewide project to help health organizations improve the materials they give to their members and clients. Through this project, HRA provided consultation and training to health plans, providers, consumer advocacy organizations, and county, state, and regional agencies. Among the materials that HRA assessed and revised were lab test reports, denial letters, grievance forms, newsletter articles, and patient self-care instructions.

Although this project helped organizations solve many communication problems, a number of barriers to effective communication must be addressed at a systemwide level. One is the generation of jargon by the many different entities involved in providing health care: federal, state, regional, and local, for-profit and not-for-profit. HRA's current work with the California Department of Health Care Services (DHCS) is addressing this issue. The goal of the effort is to inform seniors and people with disabilities about their benefits under Medi-Cal, California's Medicaid program, which DHCS administers.

Although Medi-Cal must, by law, provide materials in low reading levels and in threshold languages, HRA identified numerous areas of confusion for beneficiaries. For example, many beneficiaries thought their clinic or medical group was a managed care plan. They also thought they would have to pay for Medi-Cal managed care, because they knew people in HMOs who paid for care. Even nomenclature is confusing: fee-for-service Medi-Cal is also known as Straight and Regular Medi-Cal.



Another barrier, identified repeatedly by health care providers, is the prevalence of legal language and the reluctance, at many levels of the health care system, to change such language. No matter how well we explain the workings of the health care system, there are legal mandates and other complexities that communication improvements alone cannot fix.

Influencing Policy

California law mandates that HMOs provide specific information to their members about member rights and responsibilities. The wording and format of such information is mandated by the state's Knox-Keene Act, which regulates HMOs. However, the wording is typically legal language and the format is often all capital letters, a style that is notoriously difficult to read. Health plans and medical groups complained repeatedly about the mandated language: "The health plans make much of an effort to bring materials to the appropriate level. [We] are contractually asked to do so; however, regulatory language/writing is not at that level."

The California legislature must authorize any revisions to these mandated passages. The Department of Managed Health Care, which is responsible for regulating health plans, began

Selected Tips for Creating Clear Health Content

- Present the main message in the title.
- Focus on 2–3 main messages.
- Use headings to organize information and guide the reader through the document.
- Order sentences, paragraphs, and sections in a clear and logical way.
- Group similar information together.
- Relate each sentence to the ones around it.
- Break up complex topics into manageable parts.
- Use bullets, numbered lists, and pictures or graphics to clarify action steps.

Conduct a Communication Audit

- Who are our audiences?
- What are our main messages?
- What tools, venues, and media do we use to communicate?

A communication audit should examine all activities, such as hotlines, websites, press releases, brochures, health insurance policies, newsletters, forms, regulations, hearings, and face-to-face interactions.

working with HRA to improve selected passages. Working closely with DMHC to maintain fidelity to the legal intent of the language, HRA revised the passages using best practices in health literacy and health communication and conducted one-on-one usability testing with HMO members of varying age, income, race, gender, and educational background (from 3rd grade to postgraduate).

Such testing reveals what participants do or do not understand about a passage, how they relate to it, and how it affects them. Based on the results, further revisions were made. Overall, reading levels significantly decreased and user comprehension greatly increased.

Currently, DMHC is examining different ways to propose revisions to the mandated passages and facilitate continued improvements in the future. This project has led to additional efforts by DMHC and HRA, including the development of an easy-to-read Evidence of Coverage template for commercial HMOs in California. The Evidence of Coverage is the plan's contract with the member. It explains the member's benefits, fees, rights, and responsibilities, and is the document that would be cited in an appeal or grievance. It is usually long, dense, and difficult to read.

Increasingly, legislative bodies and government agencies are recognizing literacy and language barriers. As a result of California Senate Bill 853 (Martha Escutia, 2003), DMHC announced regulations in March 2007 to require health plans under its jurisdiction to translate standard communications, such as notices of membership requirements, benefit denials, and appeal rights into the languages of California HMO members.

In announcing the regulations, Cindy Ehnes, Director of the DMHC, said that "These new regulations will allow millions of Californians with limited or no English-speaking ability to have equal access to health care treatment."

Prescription for Change

Communicating effectively with culturally, educationally, and linguistically diverse audiences is not an easy goal to achieve. Government agencies and other organizations often need to devote significant resources to changing the way they communicate. Following are some important steps in the process:

- Clarify main messages and identify the actions to be encouraged. For example, is your message, "Call us with all your questions," or is it "Call us as a last resort"? Is it, "Make sure your baby sleeps on her back," or is it "Never put your baby to sleep on her face"?
- Identify preferred language. (One employee benefits department used the following terms interchangeably: indemnity plan, fee-for-service Medicare, Traditional Medicare, and Original Medicare.)
- Test current approaches.
- When undertaking a new initiative, involve consumers and stakeholders in the development of communication messages and methods.
- Periodically re-test. Public knowledge, interests, needs, and audiences change. Create an ongoing process to keep learning from desired audiences.

Clear Communication for Better Health

Improving the way health information is communicated is an important step toward better health care. The field of health literacy attempts to address the challenge of communicating increasingly complex health care information to audiences diverse in literacy, language, and culture.

Effective health communication requires ongoing feedback from the audiences to be reached. This feedback helps us develop resources that meet the audiences' health literacy needs and are also more relevant to an individual's situation and culture. Developing and testing information resources with end users provides a critical "reality check."



Effectiveness of a Multimedia Approach

California's *Kit for New Parents** includes DVDs, a parents' resource guide, brochures, a book to read to children, and other materials. The kits are developed and tested—in five languages—in close collaboration with parents and providers, and are now distributed to 500,000 families per year. The kit improved parents' knowledge and practices in a broad range of areas related to child development, health, nutrition, and safety. The success of this model has led to its replication in four other states.

*Developed and distributed by First 5 California, also known as the California Children and Families Commission. HRA developed the kit's *Parents Guide*.

For example, recently, Spanish-speaking parents who received *California's HMO Guide (La Guía de los Planes de Salud HMO de California)* from the Office of the Patient Advocate have asked for information about attention deficit hyperactivity disorder (ADHD). An increasingly frequent diagnosis, ADHD is becoming, like diabetes, a widely recognized health issue. This topic is under consideration to be added to the next version of the guide.

Those who wish to communicate health information effectively with diverse audiences must be prepared to change the way they communicate. Organizations should consider using a variety of communication strategies. One strategy may be better than another at reaching a specific audience, and most people learn better if they learn in more than one way.

Improvement of consumer communications requires organizational, regulatory, and policy-level changes. And it highlights the need to clarify and simplify our health care system itself.

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About DMHC and OPA

For information about California's Department of Managed Health Care and Office of the Patient Advocate, see their websites: www.dmhca.gov and www.opa.ca.gov.

About Health Research for Action

Health Research for Action is located in the UC Berkeley School of Public Health. Our mission is to conduct research and translate findings from that research into policies, resources, and programs that reduce health disparities and create healthier, more empowered communities. All of our work is conducted in partnership with the people living in these communities.

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