



## Organizational Change to Improve Health Literacy: Workshop Summary

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Melissa French and Lyla M. Hernandez, Rapporteurs; Roundtable on Health Literacy; Board on Population Health and Public Health Practice; Institute of Medicine

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# Organizational Change to Improve Health Literacy

WORKSHOP SUMMARY

Melissa French and Lyla M. Hernandez, *Rapporteurs*

Roundtable on Health Literacy

Board on Population Health and Public Health Practice

INSTITUTE OF MEDICINE  
*OF THE NATIONAL ACADEMIES*

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Willing is not enough; we must do.”*

—Goethe



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**MARY ANN ABRAMS**, Health Literacy Medical Advisor, Iowa Health System

**CINDY BRACH**, Senior Health Policy Researcher; Center for Delivery, Organization, and Markets, Agency for Healthcare Research and Quality

**BENARD P. DREYER**, Professor of Pediatrics, New York University School of Medicine, and Chair, American Academy of Pediatrics Health Literacy Program Advisory Committee

**PAUL M. SCHYVE**, Senior Advisor, Healthcare Improvement, The Joint Commission

**RICARDO WRAY**, Associate Dean for Graduate Education and Research and Associate Professor of Behavioral Science and Health Education, Saint Louis University College for Public Health and Social Justice

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<sup>1</sup> The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants, and are not necessarily endorsed or verified by the Institute of Medicine, and they should not be construed as reflecting any group consensus.

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University of Albany
- CINDY BRACH**, Senior Health Policy Researcher, Center for Delivery,  
Organization, and Markets, Agency for Healthcare Research and  
Quality
- GEMERALD DAUS**, Public Health Analyst, Health Resources and  
Services Administration Office of Health Equity, Department of  
Health and Human Services
- DARREN DEWALT**, Associate Professor of Medicine, University of  
North Carolina at Chapel Hill
- BENARD P. DREYER**, Professor of Pediatrics, New York University  
School of Medicine, and Chair, American Academy of Pediatrics  
Health Literacy Program Advisory Committee
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Oregon Primary Care Association
- MARTHA GRAGG**, Board Member, Health Literacy Missouri
- LORI HALL**, Consultant, Health Education, Eli Lilly and Company
- LINDA HARRIS**, Team Leader, Health Communication and eHealth  
Team, Office of Disease Prevention and Health Promotion,  
Department of Health and Human Services
- BETSY L. HUMPHREYS**, Deputy Director, National Library of  
Medicine, National Institutes of Health
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- PATRICK MCGARRY**, Assistant Division Director, Scientific Activities,  
American Academy of Family Physicians
- RUTH PARKER**, Professor of Medicine, Emory University School of  
Medicine
- TERRI ANN PARNELL**, Vice President, Health Literacy and Patient  
Education, North Shore–Long Island Jewish Health System
- KIM PARSON**, Consumer Experience Center for Excellence, Humana,  
Inc.
- KAVITA PATEL**, Managing Director for Clinical Transformation and  
Delivery, The Brookings Institution
- CLARENCE PEARSON**, Consultant, Global Health Leadership and  
Management

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**SUSAN PISANO**, Vice President of Communications, America's Health Insurance Plans

**ANDREW PLEASANT**, Health Literacy and Research Director, Canyon Ranch Institute

**SCOTT C. RATZAN**, Vice President, Global Health, Johnson & Johnson

**LINDSEY ROBINSON**, President, California Dental Association

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**RIMA RUDD**, Senior Lecturer on Health Literacy, Education, and Policy, Harvard School of Public Health

**STEVEN RUSH**, Director, Health Literacy Innovations Program, United Health Group

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**PATRICK WAYTE**, Vice President, Marketing and Health Education, American Heart Association

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*IOM Staff*

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**MELISSA FRENCH**, Associate Program Officer

**ANDREW LEMERISE**, Research Associate

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**ROSE MARIE MARTINEZ**, Director, Board on Population Health and Public Health Practice





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This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published workshop summary as sound as possible and to ensure that the workshop summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this workshop summary:

**WILMA ALVARADO-LITTLE**, Director, Community Engagement/  
Outreach, Center for the Elimination of Minority Health Disparities,  
University of Albany

**SHARON E. BARRETT**, Principal, SEB and Associates

**DEBRA KELLER**, San Francisco Department of Public Health

**DEBRA ROTER**, Professor, Health, Behavior, and Society, Johns Hop-  
kins Bloomberg School of Public Health

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the workshop summary before its release. The review of this workshop summary was overseen by **Harold J. Fallon**, Medical University of South

Carolina. Appointed by the Institute of Medicine, he was responsible for making certain that an independent examination of this workshop summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this workshop summary rests entirely with the rapporteurs and the institution.

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# 1

## Introduction

The Board on Population Health and Public Health Practice of the Institute of Medicine (IOM) established the Roundtable on Health Literacy to foster dialogue and discussion to advance the field of health literacy and improve the translation of research findings to health care, education, and policy. The roundtable strives to enhance mutual understanding of health literacy among the health community and the general public and to provide a mechanism that fosters collaboration among stakeholders. To accomplish its purpose, the roundtable brings together leaders from academia, industry, government, foundations, and associations and representatives of patient and consumer interests who have an interest and role in improving health literacy. It also commissions papers and conducts workshops to inform its meetings.

Although health literacy is commonly defined as an individual trait, there is a growing appreciation that health literacy does not depend on the skills of individuals alone. Health literacy is the product of the interaction between individuals' capacities *and* the health literacy-related demands and complexities of the health care system. System changes are needed to better align health care demands with the public's skills and abilities.

In early 2012, members of the roundtable published a discussion paper that focused on the attributes of a health literate health care organization or system. That paper detailed 10 attributes of a health literate health care organization, along with references and suggestions on how

**BOX 1-1****Ten Attributes of a Health Literate Health Care Organization**

1. Has leadership that makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.

SOURCE: Brach et al., 2012.

to achieve those attributes<sup>1</sup> (see Box 1-1). Achieving those attributes requires not only knowledge about health literacy but also a focus on systems and organizational change.

To examine what is known about implementation of the attributes of a health literate health care organization, the roundtable held a workshop on April 11, 2013, to

1. discuss implementation approaches (e.g., how to overcome resistance/obstacles, how to garner resources);
2. share tools that are useful in implementing specific health literacy strategies;
3. create a network of health literacy implementers who can share information about health literacy innovations and problem solving;

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<sup>1</sup> The full text of the discussion paper “Ten Attributes of Health Literate Health Care Organizations” can be found online at <http://www.iom.edu/Global/Perspectives/2012/HealthLitAttributes.aspx>.

4. establish lines of communication between health literacy implementers and roundtable members; and
5. inform the roundtable and its members about the needs of health literacy implementers in order to inform future roundtable activities.

The workshop (see Appendix A for the agenda) was organized by an independent planning committee in accordance with the procedures of the National Academy of Sciences. The planning committee comprised Mary Ann Abrams, Cindy Brach, Benard Dreyer, Paul Schyve, and Ricardo Wray. The role of the workshop planning committee was limited to planning the workshop. Unlike a consensus report, a workshop summary may not contain conclusions and recommendations, except as expressed by and attributed to individual presenters and participants. Therefore, this report has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop.

Those invited to present were identified as health literacy implementers, that is, they were individuals who had responsibility for implementing health literacy across their organizations; were involved as leaders or champions for health literacy within their organizations; or were involved in implementing health literacy in a “real-world” setting, that is, dealing with competing priorities, resource constraints, and organizational politics. Each speaker was asked to address the following five questions:

1. What generated interest in improving health literacy in your organization?
2. What general strategies did you use to move health literacy forward? For example, did you recruit leadership support? Did you first focus on small projects and then use the successes of those projects to convince others of the importance of health literacy?
3. What factors facilitated implementation of changes to improve health literacy?
4. What factors were barriers to implementation of changes to improve health literacy?
5. How will the implementation of changes to improve health literacy in your organization be maintained over time?

Three panels of speakers addressed the questions above. During the planning phase of the workshop, it became clear that there was not a clear organizing principle for the groupings of speakers. In practice, the lines between different attributes are often blurred, and the presentations reflected this reality. As a result, the first three panels of speakers were ordered at random with no topical or organizational theme. In addition,

there is little implementation research available for interventions related to the attributes. Although some of the presentations report the results of research and trials conducted in organizations, others are anecdotal in nature and have no evaluative component. The workshop planning committee believed that it was important to hear about a range of experiences from implementers. The final panel of speakers was asked to identify key points that emerged from the presentations and discussions. The following chapters of the workshop summary are organized by panel presentations. The workshop was moderated by George Isham, roundtable chair.

## REFERENCE

- Brach, C., D. Keller, L. M. Hernandez, C. Bauer, R. Parker, B. Dreyer, P. Schyve, A. J. Lemerise, and D. Schillinger. 2012. *Ten attributes of health literate health care organizations*. Discussion Paper, Institute of Medicine, Washington, DC. <http://www.iom.edu/Global/Perspectives/2012/HealthLitAttributes.aspx> (accessed September 7, 2013).

## 2

# Panel 1: Implementing Attributes of a Health Literate Organization

**BRIDGET McCANDLESS, M.D.**

*Medical Director and Cofounder, Shared Care Free Clinic  
Jackson County, Missouri*

The following is a summary of the presentation given by Bridget McCandless. It is not a transcript.

The Shared Care Free Clinic in Jackson County, Missouri, cares for adults who are uninsured, whose incomes are below 200 percent of the federal poverty level, and who already have a diagnosed chronic illness. This population is most likely to need medications, and one of the strengths of the program is that the clinic is able to provide people with necessary medications. Education levels for the clinic's patients range from third grade to college degrees, although the average level of education is high school. The patients generally have complex multiple chronic illnesses, and 72 percent take six or more medications. The one thing that the clinic's patients have in common is that they are going through hard times, said McCandless.

Effective communication is an issue for patients at the Shared Care Free Clinic, especially because complicated ideas about conditions and treatments are being conveyed to people who often have low health literacy. Health literacy, for those working at the clinic, is defined as "understandable and two-way communication about wellness and illness for you and those you care about," which helps ensure that the two-way

aspect of communication is not forgotten. McCandless said she believes that the most important message is not the message at the end of the visit but rather the tone and style of interaction established from the beginning, which encourages patients to be receptive to the messages at the end of the visit.

Knowing about the patient's living environment is very important, according to McCandless. For example, the provider needs to know about special circumstances, such as whether the patient lives in a car, because it is very difficult to manage insulin levels when living in a car. Does a patient have access to refrigeration, a telephone, and a stable place to live? These things have to be taken into account to be sure that information given to a patient is relevant to his or her circumstances. The patient's emotional state is also very important, regardless of his or her education level. When an individual is stressed or tired, he or she is less able to receive and understand information. Providers must communicate differently with those patients.

One of the greatest needs at the clinic, McCandless said, is to simplify complex patient regimens and to segment the treatment plan into smaller pieces that a patient could process a little bit at a time. Sometimes providers are concerned that a patient may not return, so their tendency is to give too much information at one time. A treatment plan for diabetes (see Box 2-1) shows how much is expected of a patient. McCandless noted that it would be difficult for her patients to find time for a regular workday after complying with the treatment regimen.

A clinic team composed of the director of the clinic's medication program, the front office clinic coordinator, and McCandless worked on simplifying complex regimens and developing treatment plans to help patients adhere to intensive lifestyle interventions and increase their abilities to engage with health care providers. The team also included four patients who acted as advisers.

The clinic serves a population that can be shy when dealing with a physician because of the substantial wealth and power differential. This differential needs to be taken into account when setting goals for providers and patients as they engage in the new approach to treatment. The goals for providers are to simplify vocabulary and promote recognition that style and demeanor affect the progress of the patient. One of the challenges in reaching these goals is giving constructive feedback to physicians, particularly when they are volunteers. The clinic does not have any tools to enforce behavior change among providers and must rely on their willingness to volunteer.

The goals for the patients are that they know and understand their diagnosis, that their understanding of and adherence to medication improves, that they feel they can ask questions, and that they come pre-

**BOX 2-1**  
**Diabetes Treatment Plan**

Get up after 8 hours of sleep  
Brush and floss your teeth  
Shower and check your feet  
Check your sugar and write it down  
Take insulin and other morning medications  
Eat a balanced breakfast  
Check 2-hour postprandial (PP) glucose  
Do your meal planning  
Grocery shop  
Check sugar and record  
Eat a balanced lunch and take insulin  
30 minutes of aerobic exercise  
Prepare a healthy dinner  
Check your sugar and write it down  
Check 2-hour PP glucose  
Practice stress reduction techniques  
Take bedtime insulin

pared for office visits. McCandless said that preparation for the visit was a concern, because often patients had not given any thought to what they needed from their time with the physician. In response to this concern, the clinic staff developed some tools to help patients be better prepared.

The first tool used in the new approach to treatment is a notebook, which every patient is given. On the front of the notebook is information about how to reach the patient's provider. Even more important, McCandless said, is that inside the notebook is information about patient responsibilities, provider responsibilities, and how to use the notebook. The patient's job is to ask questions; take medicines and call if there is a problem with them; and do his or her best with following the diet and being active. The provider's job is to give good explanations about the patient's condition, medicine, and blood tests; be available to give good advice; and help the patient be successful. The notebook helps alleviate the problem of patients leaving without their instructions. Prior to using these notebooks, patients would frequently leave their instructions at the front desk, in the chair on the way out, or somewhere else in the clinic. The notebook gives patients a place to keep their notes together.

The notebook also serves as a place for written instructions. McCandless said that she and a patient negotiate together what changes the patient will



work on before the next visit and record them in the notebook. Treatment changes can also be recorded. This approach assisted in identifying a major problem—patients did not understand why medications were stopped, which can be more crucial information than why a medication was added. That information is now recorded in the notebook and is important both to help the patient adhere to the medication plan and to inform the next provider who sees the patient.

Another strategy used at the clinic is to choose the most important pieces of information to communicate to the patient. McCandless said she found that patients will read only one piece of paper. As a result, almost all patient education material at the clinic has been shortened to one page. In addition, providers are using the teach-back<sup>1</sup> method, so that now, following a discussion, the patient explains to the provider in his or her own words the treatment plan and how to accomplish it, and agrees to the plan.

McCandless explained that at the clinic they have had to change their perspectives on patients' illnesses to match those of the patients themselves. She said that the population served by the clinic does not plan on a 30-year horizon. Rather, they exist in a 2-week cycle that revolves around paychecks. For example, instead of discussing the long-term effects of diabetes, such as amputations and blindness, McCandless said that she has found greater success in discussing short-term effects, such as infections, because these things have an immediate impact on patients' lives. An infection means that a patient cannot go to work the next day.

Teach-back becomes more than a tool for understanding; it also forms a social contract, a promise, between patient and provider. It is not just that the patient understands what he or she has been told but also that the patient agrees with the plan and sees the relationship with the provider as a partnership.

With this health literate approach to treatment, the clinic's patients now have exceptional adherence rates to very complicated treatment regimens. They have a much higher rate of screening than patients with health insurance. The clinic's diabetes and hypertension outcomes are better and, most important, patient medication adherence is exceptional. At the clinic, patients are instructed when they come in that if they have any questions or if they decide they need a change in their medication, they should call their provider. This practice has been very helpful, McCandless said.

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<sup>1</sup> "Teach-back is a way to confirm that you have explained to the patient what they need to know in a manner that the patient understands. Patient understanding is confirmed when they explain it back to you" (<http://www.nchealthliteracy.org/toolkit/tool5.pdf> [accessed June 3, 2013]).

Another successful mechanism implemented to encourage patients to engage in their care and with their provider is the patient preparation sheet. The sheet, which was designed by staff in collaboration with patients, gives the patients something to think about while they are waiting for the provider. Some examples of questions and statements are as follows: "Are you having a hard time taking your medication?" "What is it that you need in patient education?" "I am having difficulty with this part of my care plan." McCandless said they have found that the most important statement for sparking conversation and learning what is happening in people's social lives is "I have exciting news to share."

When the form was created, the questions and statements were numbered, but patients were answering only the first question. When asked why, one patient said, "I cannot believe you are giving me a test!" The numbers were intimidating to patients. Once they were removed from the form, people began to fill it out completely.

Terminology can also get in the way of good communication with patients. McCandless related an anecdote that while making rounds with her team, she mentioned that one patient probably had Graves' disease. On returning to the patient, McCandless found her in tears. The patient said that she could not believe her provider told all of those people that she was going to die and go to her grave. So, McCandless noted, even words that one thinks are benign can cause trouble. This was a lesson in the importance of hearing through the patient's ears.

One strategy that has worked at the clinic is to put students in the room with providers and ask them to grade the providers on how well they communicate with the patient. This invests everyone in modeling good behavior, and the students learn language and listening skills, so it is win-win. The students are asked if the encounter passed the "grandma test," that is, could your grandmother have understood the directions?

All the forms at the clinic were reviewed to determine their helpfulness to patients. The feedback received from patients was that it was not the form that was a problem, but the lack of explanation as to why the information was necessary. Patients wanted an explanation on every single page. For example, they wanted to know why they were asked for demographic and financial information and how this information would be used. McCandless noted that when dealing with a vulnerable population, it is important to provide those explanations. She then showed a copy of the clinic's HIPAA (Health Insurance Portability and Accountability Act) consent form, which is one page long. She said that it was taken from the Privacy Rights Clearinghouse with its permission, and she recommends looking to outside sources for helpful ideas and information.

One idea that did not work well, McCandless said, was putting

together a patient advisory committee that included only the patients with the strongest literacy skills. The patients would give good grades and approve all the forms. So, McCandless said, she took the forms to her most marginal patients and asked, “Does this picture make sense to you?” and “Does this form have too many words?” A clean copy would not produce any feedback, but when the form was already marked up, she would get a better response from the patients.

Volunteers are a great blessing to an organization like the clinic, but they can also be a challenge to implementing organization-wide efforts. First, because volunteers are not present all the time, the clinic needs to reinforce the message of health literacy. Therefore, the day after they volunteer, the providers are sent a reminder. The reminder lists the health literacy efforts the clinic expects them to make while there and asks for feedback. So far, this method has worked well.

Measuring success is always a difficult thing, McCandless said. The clinic has been tracking diabetes, hypertension, and asthma outcomes for the past 10 years. There has not been a substantial change in numbers, but there has been great receptivity from the patients. The clinic has done well on pre- and post-care surveys. It has seen an improvement in communication skills in its post-care surveys. McCandless noted that it is always difficult when changes are made to an entire organization. It is hard to know which changes are attributable to health literacy and which are attributable to doing a better job with medicine. McCandless said she believes health literacy is an integral part of the clinic’s hypertension and diabetic messaging.

To promote sustainability of the changes, the clinic has embedded teach-back in the provider progress notes, so that every time a provider leaves the room, he or she has to check off that teach-back was performed and that the patient received written instructions. McCandless noted that it is important to make sure something is recorded in a patient’s notebook because it is a reward to the patient for remembering to bring the notebook to every visit. Sometimes, McCandless said, all she writes is “great job” or “I love that you quit smoking.”

McCandless concluded by saying that she thinks that teaching people about language will always be sustainable. She believes that it is like a physical examination scale or differential diagnosis scale—that is, when health literacy becomes embedded in the entire program, it is easy to sustain.

**KAREN ROGERS, M.S.N., R.N.-B.C.**

*Director of Education  
Western Maine Area Health Education Center,  
Franklin Memorial Hospital*

The following is a summary of the presentation given by Karen Rogers. It is not a transcript.

Franklin Memorial is a small community hospital in west-central Maine with about 50 beds and 14 office practices. The hospital's coverage area is about 1,000 square miles, but the population is only 29,000. The population is not racially or ethnically diverse, but a large segment of the population has low socioeconomic status. The hospital's health literacy steering committee has six consistent members who include occupational therapists, social workers, behavioral health specialists, the Health Community Coalition, physician's assistants, nurses, and, occasionally, physicians. For certain projects, the team also includes representatives from the hospital lab, billing, radiology, facilities, and maintenance. The team has focused on general awareness, environment navigation, and patient education and has developed a literacy volunteer program, implemented teach-back education, and instituted plain-language document preparation.

Rogers said that her organization exhibits most of the attributes of a health literate organization. First, there is great support from the hospital's leadership. Rogers is the director of the education department and is given wide latitude in her duties. In addition, the hospital's leadership recognizes that health literacy has an impact on the financial bottom line. Any intervention that helps to prevent readmissions will save the hospital money. Health literacy efforts also help Franklin Memorial compete with other hospitals. Maine has some of the highest-rated hospitals in the nation, and patient satisfaction and hospital quality are areas where hospitals are competitive. Because Franklin Memorial is competing in a high-level group, its leadership is supportive of health literacy activities.

Rogers's team conducted an organizational assessment and found that only 15 percent of the clinical staff used the teach-back method. After training, participation is 66 to 89 percent, with the best performance occurring in obstetrics and physical rehabilitation because the method is well integrated into those systems. There is also a program for emergency medical services in the community that calls patients and follows up with them at home. They also use teach-back and follow through to make sure that what patients learned in the office is carried on in the home setting as well. Rogers' team prepares the workforce by teaching awareness and

education about health literacy and how it impacts patients, the hospital's bottom line, and hospital workers' jobs.

Health literacy efforts at Franklin Memorial involve various strategies, many of which are free and available online, such as the Agency for Healthcare Research and Quality (AHRQ) *Health Literacy Universal Precautions Toolkit*.<sup>2</sup> The hospital is focusing on overall patient safety, safety with medication, and its core measures.<sup>3</sup> Rogers noted that another accomplishment is a patient education policy, which is revised every 3 years and is based on what the hospital has learned from prior years' experience.

The hospital has a very large volunteer population. Most of the volunteers are elderly, and the hospital has a system in which individuals can pay off their hospitals bills by volunteering their time. Volunteers can also bank hours toward future medical bills for themselves or their families. The volunteer workforce is 25 percent of the size of the paid employee workforce, and it is very useful for testing health literacy and patient education materials. The hospital also has incorporated chaplains and groups of chaplain students into the health literacy program because these individuals have a great deal of patient contact.

Rogers noted that the hospital, which includes the only behavioral health services unit in the area, has a large population of patients with mental health needs. The health literacy team works to include this population in its focus groups for testing materials.

High-risk topics the health literacy team has chosen to address include congestive heart failure (CHF), medications such as anticoagulants, diabetes, stroke, and certain procedures. CHF is of great interest because of the penalty imposed by the Centers for Medicare & Medicaid Services if patients are readmitted within 30 days of their release from the hospital's care. The team searched for existing programs and materials that were health literate but often had to develop their own. The team has been learning more about plain language and teaching others in different departments to prepare letters to patients, for example, letters about how to access services and information by phone. Nevertheless, legal issues can be a barrier

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<sup>2</sup> The AHRQ "toolkit is designed to help adult and pediatric practices ensure that systems are in place to promote better understanding by all patients, not just those you think need extra assistance. The toolkit is divided into manageable chunks so that its implementation can fit into the busy day of a practice" (<http://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit> [accessed June 3, 2013]).

<sup>3</sup> Core measures were developed by The Joint Commission. According to the Baylor Health Care system, core measures "have been shown to reduce the risk of complications, prevent recurrences and otherwise treat the majority of patients who come to a hospital for treatment of a condition or illness. Core measures help hospitals improve the quality of patient care by focusing on the actual results of care." See <http://www.baylorhealth.com/ABOUT/FACTSSTATS/QUALITYDATA/Pages/Default.aspx> (accessed June 3, 2013).

to using plain language to create documents and forms, especially consent forms. In addition, user testing is an important and ongoing activity.

Bills are a major source of patient dissatisfaction because, Rogers said, they are difficult for patients to understand. The health literacy team is working on a better way to format bills and to explain charges, payment options, and Medicare coverage. Rogers' team has also worked on improving ease of navigating the hospital environment. Finding that many people were getting lost in their system, the team conducted a "secret shoppers"-type exercise, sending people to various parts of the hospital to see if they could find their way. One problem discovered by the team was that signage was not consistent. For example, if a patient needed an X-ray, he or she had to have a prior understanding that "radiology" and "computed tomography (CT) scan" meant "X-ray," because the hospital's signs used all those terms. There were also no icons on the hospital signs, making it difficult for patients with low literacy skills to find even the cafeteria. These problems were corrected.

The team used patient tracer methodology<sup>4</sup> to evaluate the patient's experience from the time he or she arrives on the hospital campus through the duration of the stay. For example, the team asked, do patients know where to park? The hospital has elderly patients walking all over a large campus, getting lost and tired and not knowing where to go. The team worked on signage and followed the patients from the entrance of the hospital to the office practices, discharge, and billing. The team looked at every area the patient might be visiting, Rogers said.

As part of a patient education campaign, the team created a library-on-wheels program to provide needed information resources. Eight portable carts with computers are now available for use. Staff can show patients how to surf the Internet and where to find useful, valid, and reliable information. The carts also allow nurses and certified nursing assistants to show a DVD of patient education material.

Rogers said the team conducted needs assessments, implemented the teach-back method, evaluated the videos used, and conducted many education sessions. Assessments showed, for example, that in teaching about medications, the staff was strong in imparting knowledge such as what a medication was for, but was weak in communicating why it was important to take the medications. The staff did well in teaching certain skills, such as how patients should weigh themselves, but did less well

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<sup>4</sup> Tracer methodology allows for the evaluation of an organization's continuum of care, infection control, and medication management, among other things. Tracer methodology calls for the use of "surveyors" who select active patients and trace their progress and care through departments or services of the hospital or care organization. See [http://www.hcmarketplace.com/supplemental/6209\\_browse.pdf](http://www.hcmarketplace.com/supplemental/6209_browse.pdf) (accessed June 4, 2013), p. x.

in teaching patients how to remember to do it every day. The facility has since implemented and been using questions from the Ask Me 3 program.<sup>5</sup> Rogers thinks of “ask” as an acronym standing for “attitude, skills, and knowledge.” It is easy for the nurses to remember and has been easy for them to continue teaching. Rogers said the team also has done quite a lot of work with the hospital lab because during their education programs they found that there were a lot of recalls and refusals of samples. The office practices were not giving patients who needed laboratory tests the correct information. By following through on different departments’ issues, Rogers said, her team ended up teaching more than 400 people in the organization about health literacy.

Rogers said that the health literacy team found a good book on CHF from the University of North Carolina at Chapel Hill that they initially reviewed with patients and gave them to read. However, they found that this was not the best approach because the patients would look at it once and never again. To get patients to use the book as a reference, they decided, with permission from the author, to take the pictures out of the book and make a one-page plan that was more effective for reinforcing the concepts the patients needed to know. One of the physicians actually used the one-page sheet for a research project. Keeping information to one page has worked extremely well and has been the most important thing that the hospital has done in CHF education, Rogers said.

The hospital set a goal to decrease emergency department admissions for mental health patients by getting them help earlier, Rogers said, and the health literacy team is working in this area. Figure 2-1 shows the material the hospital is using to prompt people to seek help at the first sign of trouble. The team had created the material with input from patients, their families, and hospital staff.




Interest in health literacy has been generated in several hospital departments by health literacy audits. The departments want to hear about problems such as missed appointments, noncompliance, readmissions, repeat labs, and issues with the learning management systems. If the departments do poorly on a health literacy audit, they work hard to improve, she said.

Rogers said that the organization’s attempts to integrate health literacy into other programs are under way. For example, health literacy was integrated into a customer service program that was already being

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<sup>5</sup> Ask Me 3 is a patient education program with the goal of improving provider-patient communication. The patient is encouraged to ask these three questions of their health care providers: What is my main problem? What do I need to do? Why is it important for me to do this? See <http://www.npsf.org/for-healthcare-professionals/programs/ask-me-3> (accessed August 1, 2013).



Know the Signs: Develop your Personal Safety		
 <b>Green Light OK</b>	 <b>Yellow Light Warning</b>	 <b>Red Light Get Help</b>
<ul style="list-style-type: none"> <li>• You are managing life</li> <li>• Taking your medications</li> <li>• Thinking clearly</li> <li>• Sleeping well</li> <li>• Eating well</li> </ul>	<ul style="list-style-type: none"> <li>• Managing life is getting harder</li> <li>• Missing medications, forgetting</li> <li>• Harder to think</li> <li>• Not sleeping well</li> </ul>	<ul style="list-style-type: none"> <li>• Can not manage life</li> <li>• Not taking medications</li> <li>• Can not think</li> <li>• Sleeping all the time or not at all</li> </ul>
<p>List other ways you know that you are doing well:</p> <hr/> <hr/>	<p>List other warning signs:</p> <hr/> <hr/>	<p>List your Get Help signs:</p> <hr/> <hr/>
<p><b>KEEP UP THE GOOD WORK!</b></p>	<p><b>What to do?</b></p> <p>Call your counselor or doctor</p> <p>Name: _____</p> <p>Tel: _____</p>	<p><b>Get immediate help!</b></p> <p>Call Evergreen Behavioral Services 779.2843   1.888.568.1112</p> <p>If you need help with this personal safety plan please call us at 779-2843. We would be happy to meet with you.</p>
	<p><b>CALL WARM- LINE</b> 1.866.771.9276</p>	

**FIGURE 2-1** Emergency mental health form.  
SOURCE: Rogers, 2013.

implemented. Health literacy has also been hardwired into clinical and information technology (IT) documentation. The team is currently working on a health literate approach to reduce smoking among the Medicaid population.

Rogers also noted that the Clinician and Group Consumer Assessment of Healthcare Providers and Systems (CG-CAHPS)<sup>6</sup> provides patient satisfaction scores for physicians on how effectively they communicate. This is an incentive for physicians to engage with health literacy. In addition, the organization is further engaging leadership by continuing with their interdisciplinary team collaboration. Franklin Memorial is also collaborating with the Geriatric Education Center at the University of New England and with four other teams in the state to share ideas and combine initiatives.

One barrier the health literacy efforts have confronted is an entrenched way of thinking or acting. For example, physicians resist health literacy tools because they do not see teaching as part of their role but rather as that of their medical assistants. Rogers and her staff tell these physicians that explaining and obtaining consent is also a teaching role. Provider acceptance of health literacy efforts varies and is an area of continuing work.

<sup>6</sup> CG-CAHPS is a tool developed by the Agency for Healthcare Research and Quality that measures the patient's perception of care.



Other examples of entrenched thinking can be found in both the marketing and legal departments. Although the marketing department has received some training in health literacy, it continues to produce materials with shadowing, complicated fonts, and formatting that is difficult to read. There has also been resistance to simplifying consent forms. Rogers said that occasionally the nurses will say that they don't have time to teach, but, from the organizational perspective, part of the nurse's role is to find and take advantage of the teachable moment.

Rogers noted that trust is very important and is something that the hospital works to build between patients and staff. The health literacy team has also been working with hospital employees, people who work in the kitchen, in maintenance, and in the laundry. Many of them have low health literacy, and the organization has been reaching out to them in a learning management system, making use of plain language to convey information. For example, health literacy is integrated into hospital orientation programs, so every new employee learns about the importance of health literacy. Teach-back has been hardwired into the hospital's electronic records. Rogers said that they have also developed a reading coach program with hospital volunteers. The volunteers have been trained in literacy programs, and they serve as reading coaches to help people complete their forms and refer them to literacy programs if necessary.

Other health literacy efforts include working with dental and other practices in the community. Because the hospital and the other practices share the same patient population, it is beneficial to include everyone, from dentists to nursing homes, in the health literacy effort.

Hospital policies need to be updated every 3 years, Rogers said, and this provides an incentive to review and update information. Some financial support for patient education materials has been received from the local Oddfellows group, which donated money specifically for patient education.

Health literacy efforts at Franklin Memorial have been under way for 6 years, and there has been a shift in culture. The nurses and medical assistants have adopted teach-back communication, even among themselves. The hospital has begun to use plain language even for other types of training, such as fire safety.

The hospital's accreditation requirements and rating systems make health literacy necessary and are additional incentives to support and sustain health literacy efforts. Rogers concluded by saying that the rules changes for Medicare and Medicaid are making health literacy even more important, thereby adding additional incentives to continue to work on this issue.

**LAURA NOONAN, M.D.**

*Director, Center for Advancing Pediatric Excellence  
Carolinas HealthCare System*

The following is a summary of the presentation given by Laura Noonan. It is not a transcript.

The Carolinas HealthCare System is one of the nation's largest public not-for-profit health care systems, with close to 60,000 employees, 38 hospitals, 7,500 licensed beds, and 900 care locations. It serves more than 3 million patients and has more than 9 million patient encounters each year. The system continues to grow. It began as a single community hospital that was also an academic hospital with community-based residency programs and a strong educational component. Now it has developed into a fully integrated health care delivery network, working to deliver value in three important ways—through patient experience, through high-quality outcomes and delivery processes, and through cost savings and efficiency. However, she noted, achieving success is a journey for any organization.

Noonan explained that her presentation would describe the Carolinas HealthCare System's health literacy efforts while answering five questions:

1. What generated interest in improving health literacy?
2. What general strategies did you use to move health literacy forward?
3. What factors facilitated implementation of changes to improve health literacy?
4. What factors were barriers to implementation of changes to improve health literacy?
5. How will the implementation of changes to health literacy in your organization be maintained over time?

In answer to the first question, Noonan said that in 2009 the new chief medical officer at the system level, Roger Ray, recognized the role of health literacy in patient safety and outcomes. He created a task force of experts, including roundtable member Darren DeWalt, to build a case and persuade the hospital governing board of health literacy's importance. Noonan was asked to chair the task force, not because she was an expert in health literacy but because the system's leadership wanted to use an improvement science framework and data-driven change.

Over the next year, the task force designed a change package. This effort coincided with the development of the Agency for Healthcare Research and Quality (AHRQ) toolkit, which was incorporated into the system's work. The task force identified three drivers: (1) patient com-

munication, (2) provider education, and (3) patient experience, which included more than just patient satisfaction. The task force was involved in testing the AHRQ *Health Literacy Universal Precautions Toolkit* in one of the system's clinic settings.

To answer the second question concerning strategies to move health literacy forward, Noonan said the first thing the task force did was create a collaborative. They used an Institute for Healthcare Improvement<sup>7</sup> collaborative model that used learning sessions to bring teams together. Teams from 25 facilities across two states participated in two face-to-face learning sessions with action periods, and communication occurred between sessions with coaching, content experts, and improvement science experts. Work centered around data-driven change.

The teams' immediate goal was not implementation. Noonan said that, in her view as an improvement science expert, implementation is at the end of the journey rather than the beginning. The facility teams used quality improvement methodology to test and use data in order to determine which ideas worked and which did not. The teams had to commit and submit their monthly data on a regular basis, and the data were used to provide feedback and drive the improvement. A customized database was built to manage monthly data reporting.

The learning sessions included work prior to the session. During the sessions, there were health literacy expert presentations and use of quality tools and improvement methodology. The process allowed flexibility of specifics depending on local conditions and each site's strengths and opportunities. During action periods, teams communicated using conference calls, monthly reports, an online content and document management site, and a listserv.

Noonan said that a collaborative dashboard with run charts<sup>8</sup> was used to indicate whether the facility teams were making improvements and achieving their goals. Using such a format is often helpful for seeing the interactions between efforts. One of the goals involved the use of teach-back. The goal was not only to train staff in the use of teach-back but also to observe them using the method. Over time, the teams increased the use of teach-back and surpassed the goal of successful use of teach-back 75 percent of the time. Noonan noted that the teams were also able to increase the successful use of Ask Me 3 to more than 75 percent. Never-

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<sup>7</sup> "The Institute for Healthcare Improvement (IHI), an independent not-for-profit organization based in Cambridge, Massachusetts, is a leading innovator in health and health care improvement worldwide." See <http://www.ihl.org/about/Pages/default.aspx> (accessed June 3, 2013).

<sup>8</sup> "A run chart is a line graph of data plotted over time. By collecting and charting data over time, you can find trends or patterns in the process." See [http://www.pqsystems.com/qualityadvisor/DataAnalysisTools/run\\_chart.php](http://www.pqsystems.com/qualityadvisor/DataAnalysisTools/run_chart.php) (accessed June 3, 2013).

theless, she said, there was not much change in achieving the sixth goal, a 75 percent patient feedback rating of “excellent” regarding physician communication. Although the task force had not been targeting physicians in their efforts, they did want to track progress on this measure for the next phase of the project, she said.

Some of the measures for determining effectiveness included how well the collaborative was working together as a team and how the teams rated their own effectiveness. By synthesizing this information, the collaborative’s leadership helped provide feedback and coach and drive the teams.

The collaborative included long-term care facilities, post-acute care facilities, private practices, and faculty and residency practices—all within the same learning collaborative as acute-care hospitals. At the end of the process, the collaborative’s leadership believed that a third learning session should be added to obtain the greatest benefit. Furthermore, the leadership noted, content expertise in health literacy was needed for the entire collaborative. Teams need strong leadership, organization, data, and management involvement from the beginning, Noonan said.

The participants indicated that they valued the learning environment, wanted more role-playing experience, and desired more help understanding data collection and analysis. At the end of this collaborative process, the teams had been successful and received a great deal of positive feedback. The next question they tackled was how to disseminate or spread these changes throughout the organization.

The task force spent the following 6 to 10 months figuring out how to spread the changes. Different models were explored to disseminate the change package of 28 change items. A key question was whether to spread the entire change package to each facility and run miniature collaboratives on the basis of the 2010 systemwide project, or to send the change package to everyone and allow each facility’s senior leaders to determine the best implementation approach. The decision was to implement a smaller change package, focused on teach-back and Ask Me 3, using video and employee orientation to raise awareness and to spread those changes across the system with one targeted audience.

The task force then needed to ask itself what problem it was trying to solve. Noonan said that the task force believed that one of the most critical factors in improving patient outcomes was to help patients understand and be involved. For this reason, teach-back and Ask Me 3 were confirmed as top priorities for the next phase of spread. This led to the decision to develop the next project—a program called TeachWell. The program was named TeachWell because its implementation coincided with the interactive patient system GetWell, which the hospital had bought and was beginning to implement.

The goal of the TeachWell program was to ensure that all 10,000 Carolinas HealthCare System nurses were trained in and using the two evidence-based health literacy strategies by December 31, 2012. In order to accomplish that goal, implementation would have to be quick, economical, and sustainable, and it would need to be spread across a single unified enterprise.

An example of the toolkit Noonan's team assembled can be found in Figure 2-2; the toolkit features Ask Me 3 and teach-back. Noonan's team surveyed the staff to determine how often teach-back was currently used. They discovered that the initial collaborative teams had been very successful within their teams, but encountered barriers in disseminating the programs beyond their teams into the facilities. Noonan said they learned that rollout of the programs was not continued at the facilities, which was a significant barrier. Also, there was a lack of observation after training because of time constraints, and there was also a lack of training on how to phrase questions.

Given these findings, the task force knew that there was still a lot of work ahead to improve on the initial gains from the collaborative. In response, they tried a new approach that incorporated design strategy,

## Established Evidence-Based Best Practices

### ASK ME 3™

An educational program to help patients and their families be better informed about their medical care.

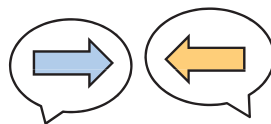


#### THE 3 QUESTIONS TO ASK:

- What is my main problem?
- What do I need to do?
- Why is it important for me to do this?

### TEACH BACK

Asking patients to explain or demonstrate understanding of information after it is explained to them.



A method to check patients and caregivers understanding of health information explained to them

...Nationally recognized, CHS innovated.



Carolinas HealthCare System

FIGURE 2-2 Established evidence-based best practices.

SOURCE: Noonan, 2013a.

improvement science, and a group called a Business Innovation Council. This process brought frontline stakeholders together to design the next steps.

Some of the elements of the toolkit are online, so staff can download content. The toolkit contains quiz cards, tracking metrics, and a storytelling worksheet, among other things. Implementation at the Carolinas HealthCare System began with a TeachWell steering committee, then moved to champions within each business unit and facility and project advisory teams. The program was then rolled out to small team leaders, then small teams, and then to the nurses (see Figure 2-3).

Although the Carolinas HealthCare System did not reach the goal of 10,000 nurses by the end of 2012, it did reach 9,100 nurses, and the project is still operating. The project was led by the Nursing Division. Noonan said that a chief nurse executive who joined the project served as a champion and was able to spread the project to the rest of the chief nurse executives in the system.

Nevertheless, one of the challenges Noonan noted is that although the system has spent a lot of time and money on training, more is now being invested in accountability. Employees must see health literate practices as “the way we do business.” These practices must be recognized as a requirement, not a choice. Monitoring and follow-up are necessary to ensure consistent use. A cultural change needs to take place that starts with raising awareness, teaching, training, and remediation. Ultimately, if

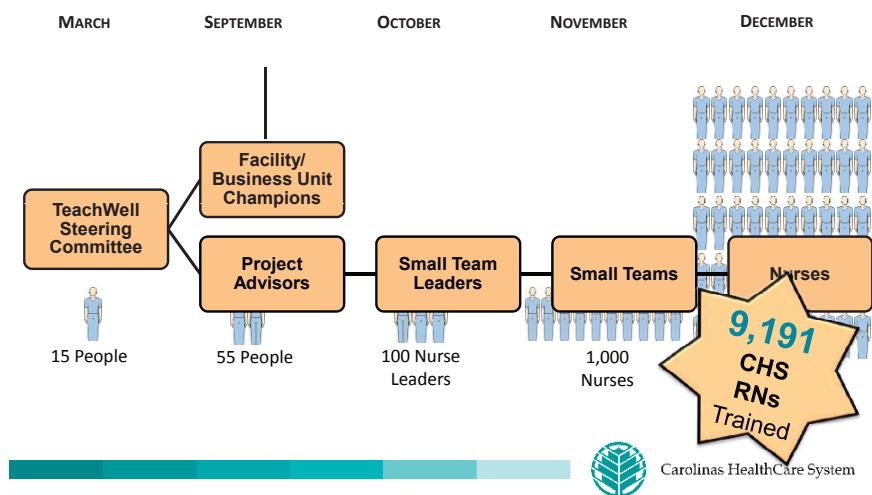


FIGURE 2-3 TeachWell spread.  
SOURCE: Noonan, 2013b.

an individual does not participate, there will be consequences, no matter how competent his or her clinical skills. That individual will not be able to work in the Carolinas HealthCare System. This is one of the accountability pieces that are under discussion, said Noonan.

The system incorporated innovative design methodology with change management and improvement science, and, as a result, the package was deliberately left unfinished so that people could adapt it to their own situations. An acute-care facility has different needs from a residency clinic, which has slightly different needs from a long-term care facility or home health services. The project was designed to allow the participants, through testing and data, to make it their own and to involve frontline staff in planning and implementation.

Noonan said that they relied on the Nurse Knowledge Exchange<sup>9</sup> concept and a program developed by Kaiser Permanente using the P3D3 Innovative Pathway, a design thinking method for improvement created by members of Carolinas HealthCare System's internal management company. The package consists of an overview, a playbook, and a toolkit, all of which are customizable. Noonan also noted that reaching out to nurses helped move the project along. There were champions, project advisers, and small team leaders. The goal was to increase awareness first and then to help change and teach the behaviors.

In addressing the third question—"What factors facilitated implementation of the changes to improve health literacy?"—Noonan said that system leadership was a key factor. The project had support from the highest level of leadership, which acknowledged that low health literacy is a problem and decided to do something about it. Another facilitating factor was the use of improvement science methodology and the use of data to drive change, along with shared learning. Finally, the success of the project also rested on the fact that staff did not have to create a change package on their own. They were given a packaged step-by-step process that could be adapted.

In terms of the fourth question, regarding barriers, Carolinas HealthCare System faced time constraints, competing priorities, and limited resources. Noonan said it was estimated that 10,000 nurses participating in a 2-hour workshop would result in a cost of \$4 million. Therefore, the objective was to embed the program into the daily workflow so that the nurses did not have to leave work to participate in training. The

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<sup>9</sup> Nurse knowledge exchange incorporates "proactive measures and a reliable workflow to support nurses during the essential, and often chaotic, time of shift change." See <http://xnet.kp.org/innovationconsultancy/downloads/NKEplus%20PG.pdf> (accessed June 20, 2013).



project was designed in such a way that it could be completed onsite. As a result, the predicted \$4 million cost did not materialize.

With regard to the fifth question, that is, how the implementation of changes will be maintained over time, Noonan said that change has been incorporated into employee orientation. The marketing and communication departments are getting involved in the project as well, and it is being incorporated into the GetWell network design and workloads. TeachWell is also being integrated into work standards. The health system is creating a standard that people have to meet after they are trained, and there will be no choice but to follow the program.

The system is moving the program to an operational home, overseen by a chief patient experience officer, so that it will maintain a systemwide focus and not become just another initiative that fades away once attention has shifted. Noonan said that the third stage of the effort will focus on maintaining accountability, training new people, managing the long-term veterans (especially physicians), and spreading the program to staff beyond the nurses.

Noonan noted that the Carolinas HealthCare System has some of the attributes of a health literate organization, including leadership support. The system has identified a chief patient experience officer; it has a chief diversity officer and a patient experience team or health literacy team at the highest levels of the organization. The patient experience and quality and safety leadership teams are now well aligned and working together in this area. Also, the organization is engaged in workforce preparation in its orientation programs. Noonan said that the TeachWell program is mandatory, and use of the skills is observed. Leadership and supervisors are also engaged in coaching and feedback because the data show that this drives behavior change.

Noonan closed her presentation by saying that it is a journey to become a health literate organization, but that the term “journey” sounds slow to her. She asserted that many in the audience are as passionate as she is and that she views the journey with urgency. She believes that progress toward health literacy has to be made quickly and not over the next 20 years.

## DISCUSSION

*George Isham, M.D.*  
*Chair, Roundtable on Health Literacy*  
*Moderator*

Cindy Brach, roundtable member, thanked the panelists for their interesting and stimulating presentations. She asked the presenters to



address the issue of measurement. For example, was there any measurement of the extent to which the nurses in the Carolinas Healthcare System who were trained in the use of teach-back actually use teach-back in their practice? How does one measure actual practice, as opposed to seeing that a box was checked? How does one achieve accountability at both the individual practitioner level and the organizational level? What measures are needed for accountability?

Rogers responded that caregivers at Franklin Memorial are used to having people watching what they do. For example, there are frequent audits for hand washing. Measurement is blended with the system. Information is collected by staff members working on the floor who are relieved for an hour or two to conduct the audits. The IT system is also used—with electronic documentation in both the office practices and the hospital, reports are easier to prepare. Now that the assessment questions for office practices and patient education are embedded in the system, it is much easier to generate reports. This is one way in which nurses can be held accountable. Patient experience is also examined using satisfaction questionnaires, readmission rates for particular populations, and emergency room (ER) use for particular populations. The hospital is supporting health literacy and patient education efforts because the staff realize those efforts can affect the bottom line.

McCandless said that it is easy for a provider to check a box, and, using that method, 90 percent of providers in her organization document using teach-back. But there are other ways to measure whether teach-back is being used. For example, patients are asked to “teach back,” that is, to record in their notebooks, that they should bring their medications on their visits. About 65 percent of patients do bring their medicines, which is great for the population served. Teach-back was also found to be effective with telephone interventions, especially for high-risk medications such as Coumadin and its dose adjustment. One of the things the patient is asked to do and to “teach back” is to return a provider’s call to see whether his or her dose needs adjusting. The chart remains out until the patient calls back.

Noonan said that although she is a strong supporter of the use of data in improvement science, measurement does not have to be a big data burden. In her health care system it would take about 18 months to get a report-out of the electronic medical record (EMR) system. Therefore, the organization still conducts chart audits using small, frequent samples. In this manner, over time one can get large sample sizes. Using the correct statistics, one can then find out whether improvements are being made, and the results can be quickly reported to the unit. Data collection needs to be built into the toolkit, Noonan said, and used to drive change and

improvement, but should not be used for judgment or given to some governing body.

A checkmark showing that one has done teach-back is an easy approach, Noonan said. But it is not a guarantee that teach-back has actually been done. That is why observed use is so important. Initially, there was tremendous pushback from the nursing staff when they were told they were going to be observed. But they have ultimately accepted observation of their practice; it is part of what they do, and it is a culture change in the organization.

Will Ross, roundtable member, asked the presenters to describe how, in their organizations, health literacy data collection and analysis relate to their quality improvement departments. McCandless responded that her extremely small organization does not have a quality improvement department. But it does relate to local hospitals, which have been willing to share expertise. Rogers said that the small quality improvement department in her organization has been very helpful in analyzing the data it collects on health literacy efforts. Noonan said that, in her opinion, everyone needs to learn to collect and analyze data, not just those involved in quality improvement.

Laurie Francis, roundtable member, asked the presenters whether they had taught staff about using data in the improvement process. She said she was also curious about whether declines have been achieved in readmissions and ER use.

McCandless responded that it is difficult in a very small clinic to show reduced ER use because the clinic does not have ER data. It does, however, have patient reports. Measurement includes accumulation of new medical debt, which, for the clinic's patients, may occur in many systems and in many places. This turns out to be the best measure to use, she said, and results show a gradual improvement over time. Questions include whether the patient has seen a provider outside of the clinic and how much medical debt he or she has. Some patients respond that they don't know, that they cannot count that high. For the patients who do report medical debt, there has been an 82 percent reduction in new medical debt and a 50 percent reduction in hospitalization and ER use. The community hospital is very pleased. It is important to note that this reduction is not due simply to implementing health literacy efforts; it is something the clinic has worked on for a very long time.

Noonan said it is important to measure, simply and easily, the effect of health literacy efforts in a way that can be repeated over time. If readmission rates have decreased, it is difficult to say the extent to which they decreased because of the health literacy strategies or because of care management.

Rogers said her hospital is looking very closely at visits to the ER

because of the cost involved. The mental health brochure, developed with a focus group, has had an impact on reducing visits to the ER. A strategy being explored is whether one of the ER triage options should be referral to a care physician. With funding from a grant, a nurse navigator will follow up with patients to find out their concerns and why they are using the ER as a source of care.

Susan Pisano, roundtable member, said that the presenters had highlighted major barriers related to the marketing and legal departments. She recalled Noonan's comment that in her system, employment will be at risk if employees are not on board with health literacy. She asked whether that risk would be extended to include the IT, marketing, and legal departments as well as other departments that impact performance but may not be direct caregivers.

Noonan said that marketing and legal departments have to be involved in health literacy efforts. In her system, marketing and legal representatives are now sitting on the systemwide health literacy committee and patient experience committee. They are beginning to ask what they can do differently, whether it is changing fonts or using plain language. Noonan said a significant challenge is finding and hiring health literacy experts who know how to create health literate materials. The question then becomes whether and to what extent to outsource development of materials. If one examines material developed by some of the people who advertise that they use health literate principles, one often finds that the material is still written at the twelfth-grade level, Noonan said.

Rogers said her institution conducts health literacy education with every employee, including the legal and marketing staff and those answering the telephone. Although there is still difficulty, forms and materials are being revised and made easier to understand.

Clarence Pearson, roundtable member, said that the University of North Carolina School of Public Health has a course in patient advocacy, and he wondered whether the speakers' institutions encourage patients to have an advocate when they get their exams. Noonan responded that, as a pediatrician, she has a parent in the room with the patient most of the time. The hope is that the parent acts as an advocate. Although her system is not yet patient-centered in that way, it does encourage one to bring an advocate and to ask questions.

McCandless said that in her clinic the initial consent-to-treat form asks patients to list the person to whom they would like information to be given and to indicate if they would like to bring that person with them when they make clinic visits. They are also asked to list all contact information for that individual and to indicate whether the clinic can leave messages for and give medical information to that individual. This is all part of the intake process. There are at least 25 patients for whom all

information is filtered through the listed individuals, and those individuals hold the notebooks for those patients, McCandless said.

Rogers said that her institution also asks patients who should be given information and who to talk with on the telephone, and includes those individuals during discharge. Patients receiving mental health care have built-in patient advocates who can be provided by state caseworkers.

Wilma Alvarado-Little, roundtable member, asked how the needs of those with limited English proficiency, the deaf, and the hard-of-hearing community are addressed. "Have your organizations identified these populations within your organizations?" she asked.

Rogers said that there is a large deaf population in the service area and that her organization arranges for an in-person interpreter during visits as well as provides written information. There is not a large population of patients with limited English proficiency, so the organization uses online resources to address their needs. The small population of Somalis usually brings interpreters with them. This is an area that needs further work, Rogers said.

McCandless said that her clinic used to ask whether English was the patient's first language, but in 5 years no one indicated a language other than English, so that question was dropped. The people who come to the clinic have self-selected a place that serves them well. Those with limited English proficiency select other sources of service.

Noonan said that, like many other organizations, hers is working on improving in this area. When she first started practice at the Carolinas HealthCare System, she was one of the few physicians who spoke Spanish and was frequently called to interpret for others. Over the past 10 years the interpreter service has grown, however, and there are now three full-time interpreters in certain clinics. The population has changed during this time, from less than 1 percent Spanish-speaking to 67 percent Spanish-speaking. There is also a Nepalese community, and an interpreter has been contracted to assist with these patient visits. But it is more difficult for the private practices. Additional work is needed, Noonan said.

Noonan also said that her system uses Culture Vision, an online tool for health-related cultural information, to raise awareness about different cultures, but, again, this is a work in progress, and even the interpreters could benefit from such learning and become cultural mediators rather than just interpreters. The interpreters also need to learn how to express things properly, Noonan said. When the clinician asks the patient, "What questions do you have?," the interpreter will often translate that as, "Do you have any questions?" That is not the correct way to pose the question, and training has begun for interpreters.

Cynthia Demarest, a workshop participant from Aetna, said that the presentations were fabulous and that it was exciting to hear about

progress in the field of health literacy. She said she was curious to know what kinds of strategies the speakers used as opening gambits to establish health literacy. For example, did they provide people with the results of an exercise in health literacy or with evidence from research findings? What was the strategic argument to convince leadership? Is there in-house evidence of change? Did the strategy shift as things got under way?

Noonan said her organization used a collaborative style for its first strategy. The opening argument was delivered by content experts—Darren DeWalt and Toni Cordell—as well by patients. The idea was that one needs to speak both to the head with statistics and to the heart with stories. For statistics, the experts described what the literature had to say about why things needed to be done differently. Then, patients spoke about the harm they suffered because of a lack of health literacy, helping show why it is so important. The continuing strategy uses both ethnography and videos to share the voice of the patient and provide the facts.

McCandless said that in her very small organization not a great deal of persuasion was needed. Most came to the conclusion that health literacy was needed because of the things that had gone wrong. Everyone had an example of how health literacy could have improved things. Rogers said they related health literacy to the monetary bottom line. That convinced the administration.

Benard Dreyer, roundtable member, echoed others' comments about the excellence of the presentations. An issue of concern, he said, is whether what one communicates to the patient is actually actionable, as opposed to informational. McCandless responded that her clinic providers try very hard to be specific. It does not help the patient much to say, "Eat better." The focus at first is not on what patients will subtract from their diets, but rather on what they can add. For example, the patient might be asked, "Can you buy three fruits and eat them by the time that you are worried that they are going to expire?" Then, gradually, the less-healthy foods are pulled from the diet. The patient writes in his or her notebook what has been agreed to, even if the agreement is to stand up during commercials and jump up and down.

McCandless said her organization involves children when possible, for example, asking, "Will you take your mother for a walk twice a week?" Or the patient might be asked if he or she can take a pet for a walk. For cigarettes the question might be, "By the time I see you next week, you need to be down to 16 cigarettes. Can you do that?" The idea is to set actionable goals that the patient negotiates with the provider.

Rogers said she agreed with McCandless. It is crucial to look at the patient's goals and see what is important to the patient and what fits into his or her life. The idea is to take one step at a time. What can the patient do to make a difference in his or her lifestyle or health? Rogers said her

organization uses motivational interviewing and incorporates the family as much as possible.

Noonan agreed with Rogers and McCandless and said her system also uses shared motivational interviewing. The patient is asked what is most important to him or her—control, convenience, or cost. In a sense, no matter what the patient’s situation, those are three things that one can work from. So, for example, the goal might be to walk to the mailbox once a day. In the inpatient setting, parents might be asked what single goal they have for their child—should the providers help the child get off oxygen, or should they cuddle him and hold him when he is concerned or crying? That goal is then written on the board in the family-centered rounds. The same thing is done in the neonatal intensive care unit and the pediatric intensive care unit.

The AHRQ *Health Literacy Universal Precautions Toolkit* is extremely helpful, Noonan said. The toolkit action plan is simple and straightforward, and although it is designed for primary care, the Carolinas HealthCare System has tested it and found it useful in the pediatric intensive care unit, the inpatient unit, and specialty centers. There is still a great deal to be learned, but when the researchers find something that works, the staff will try to implement it.

Ricardo Wray, a participant from the Saint Louis University College for Public Health and Social Justice, said he was intrigued that both the health system in Maine and the one in North Carolina highlighted the important role nurses play in the implementation of health literacy. He wondered if the presenters could talk about the role of different staff in successfully implementing the attributes of a health literate organization.

Rogers said that nurses have the most direct contact and spend the most time with patients. Nursing is still the most trusted profession, she said, and trust is essential in developing a relationship with patients. Nurses and medical assistants in office practices play a tremendous role in educating patients.

Noonan said that for the inpatient setting, the nursing staff and medical assistants interact with patients at many points. They can provide teach-back throughout the entire hospital stay—from explaining treatment to helping exhausted parents navigate the hospital and find the cafeteria. The nurses now understand that these little pieces, these many interactions throughout the process of care, are opportunities for teach-back.

Andrew Pleasant, roundtable member, asked whether the presenters had suggestions for what would help sustain and expand current efforts in health literacy and if there was something the roundtable could do to support that. Noonan responded that many things could be done but of great importance is the need for health literate education materials that are easily accessible from a centralized location. McCandless said that helping

people know what to look for and modify in their own materials is important. Perhaps a video showing the process of revising some material would be a good learning tool, she suggested. Rogers added that incorporating health literacy and its principles into professional schools' training curriculums is needed in order to make it part of the culture of each profession.

Ruth Parker, roundtable member, asked whether there was anything in the discussion paper "Ten Attributes of Health Literate Health Care Organizations" that the presenters found particularly useful or any addition that should be made. Noonan responded that it was a very helpful document. She incorporated all 10 attributes (which she designated as high-leverage changes or change concepts) into her improvement science framework. She then broke them down into what they might look like at the actionable, testable level in different settings.

Rogers said the attributes document was a good guide to developing a plan of action. The attributes allowed her to see in greater detail the areas in which she needed to focus her efforts. McCandless agreed that it was a good guide that allowed her clinic staff to see how they were doing in their efforts to become a health literate organization.

Patrick Wayte, roundtable member, asked how the presenters were balancing what the providers thought were the most important things to address versus what patients were most willing to change. Then, he asked, how do you document the choices made? McCandless said that one can find success at every visit regardless of whether that success is just that the patient showed up. One builds on small successes to reach the treatment agenda the provider is concerned about. For example, it is important to engage in physical exercise. Therefore, if a patient is worried about developing Alzheimer's—tell him or her to go for a walk. If the patient wants his or her diabetes to get better—go for a walk. If a patient is having a hard time controlling his or her depression—go for a walk.

In terms of documentation, McCandless said the goals set are recorded in the notebook and are then tracked by a chronic disease manager. If the goal is to quit smoking, did the patient do that? Did the patient make good food choices? Did the patient meet with the diabetes educator? Is the patient bringing the glucose log with him or her to the visit?

Rogers said that documentation has been incorporated into the care planning process. Noonan said there is still a substantial gap in training physicians, medical students, and nursing staff about the importance of patient-centered care. If one has 7 minutes to see a patient, one tends to focus on one's own agenda, not the patient's.



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### 3

## Panel 2: Implementing Attributes of a Health Literate Organization

**THOMAS BAUER, M.B.A.**

*Director, Research Development and Implementation of Health Literacy,  
Patient Empowerment, and Cultural Competence Initiative  
Novant Health*

The following is a summary of the presentation given by Thomas Bauer. It is not a transcript.

Novant Health is actively pursuing implementation of the 10 attributes of a health literate organization. The first attribute is that the organization has leadership that makes health literacy integral to its mission, structure, and operations (Brach et al., 2012). An indication that Novant Health has such leadership is that health literacy was included in the organization's 5-year strategic plans for 2010 and 2015. That decision was the result of research and discussion with stakeholders, including patient partners, physicians, and providers, who indicated that health literacy was an issue.

Health literacy is also included in Novant Health's corporate dashboard (which measures key corporate goals visually) through behavioral assessments and HCAHPS<sup>1</sup> outcomes. One of the areas added to the

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<sup>1</sup> HCAHPS stands for Hospital Consumer Assessment of Healthcare Providers and Systems. It is a national, standardized, publicly reported survey of patients' hospital care experience. See <http://www.hcahpsonline.org/files/HCAHPS%20Fact%20Sheet%20May%202012.pdf> (accessed June 5, 2013).

dashboard in 2013 will be the results of patient surveys measuring health literacy. Patients will be asked randomly throughout the year if they can explain their main health problem, what they need to do, why it is important, and if someone has asked them to repeat back some of the instructions that they have been taught. The results will be reported at the corporate level and to the board of directors. In addition, health literacy is included in patient education, communications, patient experience, and safety policies and procedures and is built into the design of Novant's electronic health records system, the Epic Health Information System (EPIC). In 2009, Novant Health hired Bauer as the corporate director of Voice and Choice to lead the health literacy effort.

To meet the second and third attributes—integrating health literacy into planning, evaluation measures, patient safety, and quality improvement and preparing the workforce to be health literate and monitor progress—Novant Health has trained 19,000 providers and clinical staff throughout the organization. Following the training, each staff member was required to take a test. The organization then conducted staff assessments on the ability to apply the training. The result was that 96 percent of staff were able to use the skills they had been taught. Novant Health's patient education standards also require that all patient education materials be written at a fifth-grade level, and clear communication is an important part of Novant's safety initiative. This concept is interwoven throughout all of the organization's policies, procedures, and the mainframe of Novant Health.

The fifth attribute of a health literate organization is that it meets the needs of populations with a range of health literacy skills while avoiding stigmatization. To do this, Novant Health applies the universal precautions methodology<sup>2</sup> to address health literacy issues. The staff have also been trained to use simplified language, a modified Ask Me 3, and teach-back. Bauer explained that the organization had modified the Ask Me 3 method in a manner that worked better in the organization's clinical context. He stressed that the organization is working toward a goal of 100 percent staff use of these programs.

The use of the modified Ask Me 3 and teach-back has also been important in achieving the sixth attribute, using health literacy strategies in interpersonal communications and confirming understanding at all points of contact. Novant Health also uses a method called "chunking

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<sup>2</sup> For information on the universal precautions methodology as it applies to health literacy, see Agency for Healthcare Research and Quality (AHRQ), *Health Literacy Universal Precautions Toolkit*, <http://www.ahrq.gov/legacy/qual/literacy/healthliteracytoolkit.pdf> (accessed September 7, 2013).

and checking,"<sup>3</sup> which was a challenge to put in place but has proved successful.

Novant Health has also become more adept at using interpreters. The interpreter services area was moved to a corporate function, and the organization has conducted extensive training so that people understand when and how to access an interpreter. There has been a lot of progress in that area in the past year. Interpreters are trained to be advocates for the use of Ask Me 3 and teach-back. Not only are they interpreting, Bauer said, they are teaching the patients about Ask Me 3 and teach-back. Patient education materials are now available in up to 15 languages. In addition, the organization is now using the Ask Me 3 questions to format written patient education materials. Novant Health created patient education materials called focus sheets, which are one-page documents that answer the three questions of Ask Me 3 for the condition being presented: What is my main problem? What do I need to do? Why is it important for me to do this? This innovation has been very successful, said Bauer. He also noted that these activities are important to the eighth attribute—designing and distributing print, audiovisual, and social media content that is easy to understand and act on.

Novant Health is in the process of installing MyChart, a patient portal that provides controlled access to individual health information, as a part of EPIC. This tool will promote the seventh attribute—providing easy access to health information and sources of navigation. MyChart is a powerful tool for communication between patient and provider. Novant Health has also implemented electronic patient scheduling in some of its clinics and continues to expand this service.

Novant Health has also been working aggressively to achieve the tenth attribute, communicating clearly what health plans cover and what individuals will have to pay for services. As of April 17, 2013, all of the health system's registration materials will be written at a fifth-grade level. Bauer said they converted a five-page document that included financial responsibilities in the informed consent material into a two-page document with a lot of white space. There will also be a tool to estimate out-of-pocket expenses. Easy 3, a modification of Ask Me 3, was developed by and has been implemented in the business office to explain benefits.

Novant Health's transformation into a health literate organization began with research. The health system covers four states: Georgia, North Carolina, South Carolina, and Virginia. It was important for the organization to ask, "What did those communities need from Novant Health? What did the patients, insurers, providers, and clinicians want? What

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<sup>3</sup> In this approach, information is broken down into small pieces, and once each piece is delivered, the recipient is asked to show that he or she understands the information.

were the driving forces?" Figure 3-1 shows some of the research that was undertaken.

After Novant analyzed the research and information that had been gathered, Bauer said, four themes emerged:

1. Making things easy. Easy For Me takes into account that health care is complex, difficult to navigate, and difficult to understand. People need easy access and easy understanding.
2. Authentic personalized relationships. People are looking for authentic personal relationships with their health care providers.
3. Safety. People are looking for quality and safety.
4. Voice and choice. This theme includes health literacy, patient empowerment, and patient activation.

Novant Health hired coaches for each one of the four themes, including Bauer as the coach for voice and choice.

In 2009, Bauer began extensive research on health literacy and what the organization could do to improve health literacy among patients and providers and at the system level. Out of this research, Ask Me 3 and teach-back emerged as the possible methods to address low health literacy, so a pilot program using these methods was begun. The pilots were implemented in four hospital units and in four different physician



FIGURE 3-1 The beginning of the journey: Extensive research.  
SOURCE: Bauer, 2013.

practices. They included different geographical areas, rural and urban, and different types of practices. The implementation and testing occurred over the course of a year. The pilot programs showed that Ask Me 3 and teach-back worked well when modified to better fit the context of the situation. In the office setting, when patients were prompted to ask questions, often they did not, and at times they became irritated. As a result, Bauer said, Novant Health has backed away from that strategy.

The elements of the modified Ask Me 3 program focused on framing the conversation using the three essential questions of Ask Me 3. In addition to focusing on defining the problem and a course of action, the provider also learned to communicate why it was important. Once a person understands this, he or she is much more likely to follow the plan of care, be more active in the conversation, and make a joint decision, Bauer said. In addition, teach-back was implemented along with using simplified language and asking providers to sit and make eye contact with patients in order to form a personal relationship.

At Novant Health, there is a program called the Senior Leadership Academy. In response to the results of the research, that academy began work on health literacy, which helped garner support for the effort as a whole. The organization engaged Darren DeWalt to help work on health literacy efforts in congestive heart failure at Presbyterian Hospital in Charlotte, North Carolina. Eventually, physician leaders emerged, and those physician champions began to excite the rest of the organization. As the work continued, it gathered more physician leaders and nursing leaders, and then, because of the results, a number of presidents of hospitals became very interested. This interest led to some healthy competition among parts of the organization that wanted to be the first to implement health literacy measures.

As the implementation spread systemwide, the success of the initiative led to a corporate mandate that Ask Me 3 and teach-back be used throughout the organization. The corporate mandate indicated a culture change, and health literate behaviors became an expectation. Bauer said that a key lesson from the experience was that when an action is expected it becomes more accepted at all levels.

The results of implementing Ask Me 3 and teach-back in the clinical realm were significant. To measure the impact of the programs, the organization asked patients in a stroke center who were not cognitively impaired and who had not been exposed to Ask Me 3 or teach-back to describe what had happened, what they needed to do, and why. Prior to implementing health literacy measures, the first two questions could be answered with heavy prompting and the third question hardly at all. After exposure to Ask Me 3 and teach-back, patients displayed full recollection of the information they had been given. Terminology also played

a role, according to Bauer, in that providers are not always consistent, sometimes referring to strokes as “small bleeds” or “aneurysms.”

In one of the original studies to determine the need for health literacy, patients with congestive heart failure were administered a test. If they could pass the test, then it was assumed that they could manage their disease. The average score on the test, when it was originally administered, was 38.5 percent. After the use of Ask Me 3 and teach-back, the score rose to 85 percent, where it has remained for more than 2 years. The result was a reduction in preventable readmissions of about 44 percent. There was also a significant increase in patient satisfaction. Everywhere that Ask Me 3 and teach-back were implemented, patient satisfaction levels rose, particularly in the area of explanation of treatment. There was also a rise in reported joint decision making at every site.

There were several barriers to implementation. First, system capacity for change was limited. Health care evolves quickly, and the ability to change is an issue for the entire field. Providing consistent training for almost 20,000 people is difficult, and sometimes people do not realize that they have not communicated effectively throughout their career.

Sustaining change is also a challenge. Bauer said that Novant Health is committed to health literacy and to remaining a health literate organization. The organization has dedicated points of contact in each of the facilities to help hardwire the change into the system. The organization is embedding health literacy in its best practices and in systems and processes. Health literacy is a part of the patient-centered medical home, and the patient education process is contained within those systems.

Bauer concluded his presentation by saying that the organization’s next steps are implementing the AHRQ *Health Literacy Universal Precautions Toolkit* and assessing and determining what tools are necessary for the practices. That process will begin as part of the patient-centered medical home. Novant Health expects that, in the coming months, 28 practices will have completed assessments, and implementation plans will be developed as a result of those assessments.

**KAREN KOMONDOR, R.N.**

*Director of Education and Health Literacy Institute  
St. Vincent Charity Medical Center*

The following is a summary of the presentation given by Karen Komondor. It is not a transcript.

St. Vincent Charity Medical Center is a 250-bed urban not-for-profit teaching hospital in the heart of downtown Cleveland, Ohio. It is one of

five hospitals in the Sisters of Charity Health System, which has three hospitals in the Cleveland and Akron areas and two in South Carolina. St. Vincent has been working in health literacy for 6 years. In 2007, the hospital was awarded a grant from the Sisters of Charity Foundation in collaboration with Project Learn, an adult learning center located in Cleveland. At that time, Komondor was director of education and was brought in to be a part of the project. The hospital held community discussions and met with other grantees from the foundation. Komondor said that she was not familiar with the term “health literacy” when the project began, but she saw that it gave a name to an issue that she had often thought about.

One of the hospital’s first initiatives was to form a health literacy team and combine it with the patient education committee. This team has been meeting monthly for 6 years, Komondor said. There are 12 members, with each member representing a different discipline in the hospital. The disciplines include pulmonary, radiology, diabetes education, mission and ministry, nursing, pharmacy, rehab services, quality, deaf access, information technology, community outreach, and marketing.

Initially, the hospital’s efforts focused on training, and over the years, the team has found that training needs to be ongoing, Komondor said. The first health literacy task was to increase awareness, because not many people realized that health literacy was an issue. Although a patient education team had been in place for many years, the team needed to be trained on health literacy principles. The health literacy team leadership was able to attend the American Medical Association’s Train the Trainer Program and returned to the hospital to spread lessons learned to other members of the team. Nurses and medical residents were two other important target groups identified for increased awareness. The initial focus was on raising awareness and sharing tools, such as plain language and teach-back. Training has evolved considerably since those initial efforts, Komondor said.

In 2007, the health literacy focus was on the low-literacy population, but as more tools (such as the *Health Literacy Universal Precautions Toolkit*) became available, the hospital incorporated many different techniques into its training. Every caregiver at the department level has been trained, and there is support from all of the department directors. Members of the health literacy team have been invited to different staff meetings in every hospital department to share health literacy principles. St. Vincent defines health literacy as not only the patient’s ability to understand and act on health information, but also the provider’s ability to share that information in a way the patient can act on.

The hospital has incorporated health literacy into new employee orientation, which takes place monthly, so every caregiver beginning work at St. Vincent receives about an hour of training in health literacy. The



training has been expanded to include annual health literacy competencies along with clinical competencies for every caregiver.

The hospital is also working toward achieving the eighth attribute of health literate organizations—designing and distributing print, audiovisual, and social media content that is easy to understand and act on. One of the first objectives was to assess current patient education materials. A random sampling of patient education materials used at the hospital showed that the average reading level was about twelfth grade. The hospital also did an assessment of patient education materials provided by a vendor and found that those materials were at an even higher level. Most of the materials were very lengthy; one set of discharge instructions was 17 pages long. As a result, Komondor said, the hospital stopped using that vendor's materials.

Now all of the in-house patient education materials have been revised to a fifth- or sixth-grade reading level. The new vendor provides materials that are at the same level. All the materials are available in Spanish because Spanish speakers make up the largest percentage of the minority population that uses St. Vincent, and many of the sheets are also available in multiple other languages.

The hospital also wants to improve interpreter services and has decided to go with a vendor that uses a video system. Because the hospital serves a large deaf population, the ability to interpret for American Sign Language is necessary. The hospital has also purchased health education videos that are available in every inpatient room, along with a content guide. All of the nurses have been trained to encourage patients to look at the guide, Komondor said. For example, a patient admitted for a cardiac catheterization will receive information from the nurse and be encouraged to view the appropriate videos.

Another major effort has been to involve the adult learner students from Project Learn in different focus groups. The adult learners are brought in to assess the print materials developed in house, and the materials are revised until they make sense to them.

The hospital has also used the adult learners as navigation tracers. On three different occasions, the adult learners were brought to the lobby of the hospital and asked to find a particular location, such as CT (computed tomography) scan or radiology. They were asked about their experience in navigating the hospital. Findings were that although the caregivers were happy to help when asked for directions, the signage in the hospital was not clear. With the support of senior leadership, the health literacy team held further focus groups with these adult learners. The students were given a list of all the hospital departments and asked for input on terminology used. On the basis of what was learned, the hospital's signs were changed. Instead of "Radiology," for example,

the sign now reads “X-ray.” The new signage is also in Spanish as well as English.

Sometimes language can seem benign but still prove to be a barrier, Komondor said. For example, the department where patients check in for tests was called “Admitting,” but patients were not being admitted to the hospital in that area. The name has since been changed to “Patient Check-In.”

The hospital was also interested in addressing high-risk populations and high-risk procedures. One target area for improvement was the process for education about heart failure. The information booklet *Caring for Your Heart: Living Well with Heart Failure* from the North Carolina Program on Health Literacy is a great tool, and the response from patients is that it is working well, Komondor said. The hospital has revised the way questions are asked and incorporated changes into the computer documentation. Nurses now follow a guide to assessing knowledge, skills, and attitude. For example, on the first day, the nurses address teaching knowledge. On the second day, the questions are reformatted to cover the same information, but the focus is now on skills. Finally, on day three, the questions are reframed to emphasize attitude.

In another effort, clinical pharmacists are now involved in education about heart failure. The clinical pharmacists visit patients in their rooms and teach them about medication. They are also present at discharge to go over medication reconciliation with the patients, and they perform follow-up calls with the patients.

When patients were questioned about the barriers they face in following a treatment plan, many reported that they did not have scales at home. Now, the hospital provides a scale to patients who do not have one at home.

Another focus area for the hospital is informed consent. The health literacy team has developed an informed consent document that covers everything in plain language.

Leadership support for health literacy has been enormous at St. Vincent, said Komondor. There is a health literacy institute that sets its own team goals and has its own budget. Health literacy measures have been incorporated into hospital policies, including the use of plain language, universal precautions, and a teach-back technique.

Beginning in 2007, the primary goal of the organization was to develop a program model that would institutionalize health literacy at St. Vincent. Komondor said that she thinks they have made good progress. The administrative leadership at St. Vincent has changed several times since the program’s inception, but sharing the personal stories and results of the research has convinced senior leadership of the importance of health literacy and ensured continued support.

One of the main barriers to health literacy is finding adequate staff time. The health literacy and patient education department is small and has a number of duties. Another barrier is a lack of buy-in from attending physicians. This will be the next target audience for building awareness and support.

To sustain the changes within the organization, the team has included them in new employee orientation and mandatory annual competencies. The health literacy team has also held conferences and workshops. In 2012, they hosted a conference series and four different short workshops on writing for easier reading. This effort culminated in the October Health Literacy Month Inaugural Ohio Health Literacy Conference, which had about 200 attendees, including physicians, nurses, and others from a wide array of disciplines.

The hospital has also sponsored several annual health literacy month events that involved community members. Since the conference in October, the hospital has initiated a blog on its website to continue the conversation. St. Vincent is committed to collaboration and partnership and is reaching out to other institutions to broaden its work.

Finally, to illustrate a model of its work, the health literacy team devised a graphic that incorporates five steps to better health literacy (see Figure 3-2). This graphic has been laminated and is posted in every department and in all of the organization's health care clinics as a daily reminder for health care providers to incorporate these principles in all of their communications.



FIGURE 3-2 Health literacy 101: Your role as a health care provider to better health literacy.

SOURCE: Komondor, 2013.

**TERRI ANN PARNELL, D.N.P., M.H.A., R.N.**

*Vice President, Health Literacy and Patient Education  
North Shore–Long Island Jewish Health System*

The following is a summary of the presentation given by Terri Ann Parnell. It is not a transcript.

North Shore–Long Island Jewish Health System (North Shore–LIJ) consists of 16 hospitals with more than 44,000 employees, almost 10,000 nurses, and nearly 10,000 physicians. The system also has 400 ambulatory physician practices, a number of skilled nursing facilities, an ambulatory transport system, a laboratory system, and a research institute. In 2011, it launched a medical school. One of the hospitals is located in the New York City borough of Queens, which is one of the most diverse regions in the world. The populations served by North Shore–LIJ speak more than 176 languages, which offers many opportunities to address health literacy.

North Shore–LIJ leadership makes health literacy integral to its mission, structure, and operations, the first of the 10 attributes of a health literate organization. In June 2010, the system established the Office of Diversity Inclusion and Health Literacy as a corporate office for all of the system's facilities—ambulatory, hospital, and long-term care. The chief diversity inclusion officer, Jennifer Mieres, reports directly to the chief executive officer and president, Michael Dowling. Dowling also receives monthly updates on office activities, initiatives, and plans.

The health system has a patient education policy and procedure process, a systemwide patient education committee, and a systemwide language and communication access committee. Beginning in May 2013, the patient education and language and communication access committees will be combined because there are a number of synergies across those subject areas. The system also launched a Diversity, Inclusion and Health Literacy Council with members representing all of its sites. The council's mission is to share best practices that representatives can modify for their own patient population and for the resources they have available.

The health system is working to integrate health literacy into the various service lines, such as orthopedics, that cut across departments rather than taking a facility-by-facility approach. Parnell said this is intended to integrate a health literate approach across all the system's hospitals and facilities.

North Shore–LIJ conducted an initial health literacy assessment at several sites for planning purposes. The assessment uncovered many gaps in knowledge and literacy that the health system needed to address. Assessments continue as efforts expand to new hospitals and as demo-

graphics change. Health literacy is also integrated into the organization's annual mandated topics for all employees, as well as new employee orientations, at both corporate and individual site locations.

North Shore–LIJ also monitors its patient experience and HCAHPS scores. There are other health literacy–focused programs that operate throughout the system as well. For example, Patient Safety Fridays is a program in which the organization offers education and training on patient safety every Friday. Often, health literacy or a component of health literacy is the topic. Patient Safety Fridays are for every discipline, from maintenance to security to the executive director's office. Parnell said that her team has also collaborated with the system quality and informatics departments to help staff with monitoring, compliance, and documentation.

The health system has an onsite training facility called the Center for Learning and Innovation (CLI) that is very helpful in educating and preparing the workforce in health literacy. CLI offers classes and workshops for staff. There is also a Patient Safety Institute, where staff can role-play in different scenarios and obtain feedback on their performance. Some of the lessons learned from these sessions have been incorporated into online modules. The system offers other educational resources, such as toolkits from the Office of Diversity, Inclusion and Health Literacy, monthly tips that go out across the organization, and references to materials and other aids.

One of the early efforts was aimed at raising awareness, addressing cultural competency, and communicating across cultural lines. Sometimes a health care provider does not realize that he or she might be acting in a disrespectful manner. To address this problem, the organization launched the Dignity and Respect Campaign, which was adapted from a program in place at the University of Pittsburgh Medical Center. One of the challenges for this program was convincing people that the initiative involved more than basic courtesy, Parnell said. The campaign includes a video of senior leaders in the organization talking about dignity, respect, and inclusion and their importance to the organization.

The North Shore–LIJ Health System uses a universal precautions approach to health literacy in which one's health literacy level is never assumed, and the patient is always asked for his or her preferred language. Individual learning needs are assessed, and staff members use plain language and incorporate teach-back methods into communication. The organization also uses the AHRQ *Health Literacy Universal Precautions Toolkit* and will soon launch a health literacy competency program for nursing staff.

The electronic medical record (EMR) is one strategy used to improve communication at North Shore–LIJ. An effort is under way to include

language preference as part of the EMR on the top banner of the record along with allergies and other key information. The hospitals have language-access coordinators at each site. The coordinators receive a daily limited-English-proficient patient report so that they can visit and assess those patients. The coordinators ensure that interpretation services are being used properly, and they confirm understanding by using teach-back methods, which have also been integrated into the EMR. The system also has a language-access audit tool for concurrent monitoring.

Parnell's team has an ongoing collaboration with the marketing and public relations departments. Collaboration has been productive, and processes are now in place to promote the development of health literate materials. The departmental teams meet and communicate regularly and have developed a process to review the creation and translation of in-house materials. Closed-captioning services are available on all the televisions in inpatient and ambulatory facilities. North Shore–LIJ has also been working with transitional care and patient consent and education documents to improve health literacy in high-risk situations. The health system has completed some projects related to informed consent, medication safety, and the discharge process.

For North Shore–LIJ, interest in health literacy was prompted by the growth of the system and the changing patient population. Senior leadership learned that health literacy strongly correlates with patient safety and patient outcomes. The leadership believes that improving health literacy is an integral part of providing high-quality care, Parnell said. In addition, patient satisfaction scores are tied to value-based purchasing, and the organization is always trying to improve those scores. Also, training new physicians at the medical school brings a different perspective and heightens the awareness of health literacy.

The ongoing support of senior leadership is a key component to continued progress in health literacy. The creation of the corporate Office of Diversity, Inclusion and Health Literacy, which is devoted to enhancing health literacy and providing ongoing education, was also very helpful because the office provides a visible presence, a resource for leadership, and a place to which people needing assistance can be referred. Parnell's team is also identifying health literacy champions at each of the system's many sites. People who are passionate about health literacy help drive the process at their organization, she said.

Incorporating health literacy into every system function possible, from internal and external publications to the screensavers that are on the computers in every office and department, also facilitates the spread of health literacy throughout the organization. The hope is that health literacy practices will become automatic behaviors, like hand washing.

Parnell noted that, as she mentioned earlier in her presentation, there

is an initiative to move health literacy from an individual facility-based effort to a service-line approach, which will promote sustainability. The organization views health literacy as a necessary service line, just like a clinical service line. It is helpful to tie health literacy to the interests of particular groups, from finance to clinical specialties. The health literacy team always has to make sure the message is meaningful to the audience in order to gain support for its efforts. One way to do this is to ensure that health literacy is incorporated in current work rather than treated as something extra. Standardizing policies, expectations, and accountability across the health system will help continue to move these goals forward.

Comparing the results of the current effort with the baseline assessment is helpful in facilitating and implementing health literacy, according to Parnell. Every year, the health literacy strategy is reexamined to see if it is still relevant to the current situation. It is important to provide to senior leadership a concise but complete overview of what is occurring, because their time is very limited.

One of the key barriers to implementing health literacy efforts is the amount of time it takes. Currently, nurses are the front line of health literacy, but they cannot do everything. Parnell said that she is trying to develop a team approach so that the effort does not rely solely on the nurses. However, getting physician participation can be a challenge.

Another barrier is that no one “owns” health literacy because it applies to everybody. This can lead to everyone thinking health literacy is someone else’s issue. The culture of the system must reinforce the belief that health literacy is everybody’s responsibility and eliminate the assumption that someone else is going to solve the problem.

Parnell said that it is encouraging that her office continues to grow. Ongoing awareness, education, integration, and accountability across the system are essential. She concluded by saying that health literacy is an essential component of excellent patient care.

## **H. SHONNA YIN, M.D., M.Sc.**

*Assistant Professor, Department of Pediatrics  
New York University Langone Medical Center/Bellevue Hospital Center*

The following is a summary of the presentation given by H. Shonna Yin. It is not a transcript.

Yin discussed a project aimed at reducing medication errors through the implementation of a health literacy intervention called HELPix. Her presentation focused on local champions engaged in implementing HELPix and the following 8 of 10 attributes of a health literate organization:



- Has leadership that makes health literacy integral to its mission, structure, and operations.
- Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
- Prepares the workforce to be health literate and monitors progress.
- Includes populations served in the design, implementation, and evaluation of health information services.
- Meets the needs of populations with a range of health literacy skills while avoiding stigmatization.
- Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
- Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
- Addresses health literacy in high-risk situations, including care transitions and communications about medicines.

Two of the main organizations involved in the HELPiX initiative were the New York University (NYU) School of Medicine/NYU Langone Medical Center and Bellevue Hospital Center. They are located within a few blocks of each other in New York City. Bellevue is considered to be the flagship hospital of the New York City public hospital system, which is known as the Health and Hospitals Corporation. The families served by Bellevue are largely Latino and of low socioeconomic status.

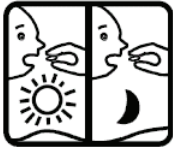




The HELPiX intervention came about as the result of the efforts of two key local champions within the Department of Pediatrics, Yin said. The first champion was Linda van Schaick, an educator in Bellevue's Pediatric Clinic who founded Bellevue's Health Education and Literacy for Parents (HELP) project. HELP is a waiting-room intervention designed to support the health literacy needs of parents while they are waiting to see their pediatrician. While van Schaick was developing the HELP project, it became clear to the staff how hard it was for parents to understand how to correctly give medicines to their children, said Yin. In addition, medical providers were struggling with how best to communicate instructions about medicine and did not think they had resources to help families with low health literacy. The second key local champion was Benard Dreyer, the director of pediatrics at Bellevue. He supported the idea of developing an intervention to address the issue of health literacy and parent errors in administering children's medication.

The intervention was named HELPiX because it grew out of the HELP program and involves use of pictograms. As a first step, medication instruction sheets were developed. These sheets are patient-specific, are available in English and Spanish, and use plain language. Pictograms are used to illustrate concepts such as preparation (e.g., shake well), route



and frequency of administration, storage, how long to take the medication, and who to call when there are questions (see Figure 3-3).

There is also a medication reminder and tracking sheet, which contains a dosing diagram to help parents know exactly how much medication to give. The prescribed dose is shown within a dosing instrument for liquid medications (see Figure 3-4). The tracking sheet indicates when the medication course should begin and what the total number of doses should be, and it also has a log to help parents keep track of the medica-

<b>Name:</b> <u>Alexander</u>	<b>Nombre:</b> <u>Alexander</u>	
Information on your prescription for:	Información sobre su receta para:	
<b>Amoxicillin</b> 250MG/5ML	<b>Amoxicillin</b> 250MG/5ML	
To treat an infection of the ear	Para tratar una infección en el oído	
<b>2 capsules by mouth</b> <b>2 times a day for 10 days</b>	<b>2 cápsulas por la boca</b> <b>2 veces al día por 10 días</b>	
		
<u>Take 2 times a day by mouth</u> Tome 2 veces al día por la boca	<u>Take by mouth with a glass of water</u> Tome por la boca con un vaso de agua	<u>Keep out of reach of children</u> <u>Keep at room temperature</u> Mantenga fuera del alcance de los niños y a temperatura ambiente
		
<u>Give this medicine for 10 days, even if your child is feeling better</u> Dé esta medicina por 10 días, aunque su niño se sienta mejor	<u>If you have questions call (212) 562-5524 day or night</u> <u>Si tiene preguntas llame (212) 562-5524 día o noche</u>	

Read the instructions that come with your medicine. Lea las instrucciones que vienen con la medicina.

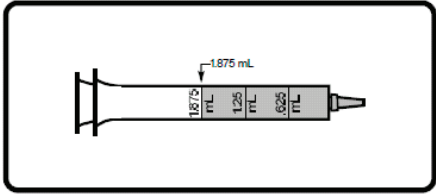
The H.E.L.P. Project Bellevue Hospital Pediatric Clinic (212) 562-5524  
© 2008 New York University School of Medicine \* Modified with permission from the USP Pictogram Library

FIGURE 3-3 HELPix concepts.

SOURCE: Yin, 2013.

Keeping track of Mary's  
Infants' Ibuprofen Drops (Advil/Motrin)

Your child's dose is 1.875 mL by mouth  
on March 11, 2008.



**Important**

- ★ Only give this medicine if it has been **6 hours or more** since the last dose.
- ★ Only give this medicine if your child has a fever or does not feel comfortable.

**Instructions**

Write the exact time that you give the medicine.  
You may not need to use all the boxes.

Day 1	Day 2	Day 3

The H.E.L.P. Project Bellevue Hospital Pediatric Clinic (212) 562-5524  
© 2008 New York University School of Medicine

**FIGURE 3-4** Example of HELPix tracking sheet for as-needed medications.  
SOURCE: Yin, 2013.

tions. Providers use this log to talk to parents about specific times that are convenient for the family to give the medicine and to indicate when to start and end the course of medication. Instruction sheets have also been developed for tablets and capsules, as well as for as-needed medications.

Yin explained that the complete HELPix intervention does not involve the instruction sheets alone. HELPix is a five-step intervention. The pictogram-based sheets are the first step and are intended to serve as a framework for providers to use when counseling families about how to

give medications. The second step involves the physician showing the parent the dosing diagram and demonstrating how to give the dose using an oral syringe (in the case of a liquid medication). The third step involves the physician using teach-back to make sure that parents demonstrate understanding. Next, the provider reviews with the family the log for tracking medication. For liquid medications, the provider then gives the family an oral syringe to take home. The intervention takes 1 to 2 minutes on average.

A number of partners helped in the development of the HELPix intervention. Feedback from parents was particularly critical, Yin said. Feedback was obtained from both English- and Spanish-speaking families and the HELP program was used as a way to reach potential participants. Many health care providers were also consulted and the New York City Poison Control Center became a key community partner. Overall, there was extensive pilot testing of materials, especially with parents, to find out how well the sheets worked as a whole and how well pictograms and phrases worked individually.

There was recognition of the importance of evaluating HELPix in a rigorous way because evidence showing that the intervention helps improve parents' ability to follow medication instructions was needed to get the support of hospital leaders and staff. As part of her fellowship, Yin undertook the task of conducting a randomized controlled trial of HELPix in the Bellevue Hospital Pediatric Emergency Department.

English- and Spanish-speaking families with children who were prescribed short-course liquid medicines were enrolled in the trial. Families were randomized to receive the HELPix intervention or standard medication counseling. In terms of dosing accuracy for as-needed medicines, trial results showed that about 40 percent of caregivers who received standard medication counseling made dosing errors compared to about 16 percent of caregivers exposed to the HELPix intervention. For every four families who received the intervention, one family was prevented from making a dosing error. Yin reported that findings with daily dose medicines were even more dramatic, with about 48 percent of caregivers who received standard medication counseling making errors compared to about 5 percent of caregivers who received HELPix. For every two families exposed to HELPix, one was prevented from making an error. In terms of adherence, about 38 percent of caregivers in the control group were found to be nonadherent compared to about 9 percent of intervention caregivers.

The findings were published in the *Archives of Pediatrics and Adolescent Medicine*. HELPix was also featured as a case study in The Joint Commission's 2009 publication *Addressing Patients' Health Literacy Needs* and received the grand prize at the 2009 Patient Safety and Quality Expo of the New York City public hospital system. This recognition helped garner

support for the development of technology that would allow for HELPiX dissemination, specifically, a Web application that would give providers the ability to generate medication instruction sheets as part of their routine patient care.

The results of the trial led to support from senior leadership within the NYU Langone Medical Center, including information technology leadership, which made a commitment to create the Web application (see Figure 3-5). Using the Web application, a provider can generate instruction sheets for more than 50 liquid and pill-form medications, with more than 300 variations, for as-needed and daily dose medicines. The instruction sheets are available in English and Spanish. The application sits on the NYU Langone Medical Center server.

Yin said that senior leadership from Bellevue Hospital also agreed to allocate resources to create a link between the stand-alone Web application from NYU and the EMR system at Bellevue Hospital, which is called Quadramed. This link is key to facilitating provider use of HELPiX because when providers use the application, patient information can be prepopulated into the HELPiX system. This makes the system easier to use, as providers do not need to manually enter patient and medication information into a separate system.

Yin said that her team is currently working closely with providers to encourage them to use the application. Parents are also being encouraged

**HELPIx**  
Medication Instruction Sheets

**REQUIRED FIELDS**

**Patient Information:** Antoinette Test 1742

**Medication Name:** Amoxicillin

**Form:** oral suspension

**Strength:** 125MG/5ML

**Rx Information:** Daily Dose

**Take:** 05:00 ml 2 times a day by mouth for 10 days

**Dosing Instrument:** 5 ml Syringe With cup? No

**Start Date:** Today

**Language(s):** English & Spanish

**OPTIONAL FIELDS**

**Indication:** To treat Please select one

**RESET FORM** **GET PICTOGRAM**

The HELP Project © 2011 New York University School of Medicine HELPIx.med.nyu.edu CONTACT US

**FIGURE 3-5** HELPiX Web application, medication instruction sheet.  
SOURCE: Yin, 2013.

through the HELP program to ask their doctors for the instruction sheets. The HELPiX team is working closely with the information technology teams at both Bellevue and NYU on troubleshooting challenges that arise during the implementation process.

One of the key parts of the implementation process has been provider training. Several short training modules have been developed to focus on the practical issues of how to generate instruction sheets, how to counsel using the sheets, and how to conduct teach-back. Training has been conducted in groups and in one-on-one sessions, and there are modules available on computers in clinical areas for providers to access at any time.

The goal of the implementation effort is to help providers use HELPiX as part of a universal precautions approach to counseling families about medicines. The HELPiX implementation process is also being evaluated at two hospitals. As part of the evaluation, they will be examining the effectiveness of HELPiX, including whether the use of HELPiX improves parent dosing accuracy and adherence and whether HELPiX decreases return visit rates. This evaluation is different from the original study, which was done under research conditions in which study staff performed the intervention. The providers are now using HELPiX as part of their clinical care, and it is important to evaluate the program's effectiveness under these conditions.

HELPiX began with local champions who recognized that there was a problem and decided to take action. Work on HELPiX was also spurred by the growing national focus on health literacy issues. Hospital system support was obtainable because health literacy was recognized to be a patient safety issue that is especially important in the population the system serves, which is composed largely of immigrant families with low socioeconomic status.

Evaluation of HELPiX was considered to be a key part of moving the HELPiX project forward, because showing the impact of HELPiX on dosing errors and adherence was important to getting support for the project from hospital leadership as well as providers. This began with a small quality improvement project, followed by the randomized controlled trial in the emergency department. A pre-/post-implementation study of HELPiX is now in progress. Outside grant funding was obtained to support HELP and HELPiX-related development, evaluation, implementation, and dissemination. Identifying local provider champions was important for increasing rates of HELPiX utilization. Other strategies that facilitated HELPiX implementation included establishing the reputation of HELPiX through scientific publications and recognition from local and national authorities such as The Joint Commission.

Barriers to HELPiX implementation included the amount of time it took to obtain support and resources from senior leadership, particularly

with regard to development of HELPiX information technology. Initially, the HELPiX team thought it would take a few months to obtain support and resources to develop HELPiX information technology, but it actually took years. The HELP project began in 2001. The idea for the HELPiX instruction sheets was conceived in 2002, and the development of the Web application began in 2007. The work on the EMR link began in 2011, and HELPiX was finally implemented at the end of 2012. Competing demands on provider time have been another barrier to implementation.

HELPiX will be sustained by the continued commitment of local champions and ongoing support from senior leadership. Much of the infrastructure for HELPiX has been built, Yin said, and she anticipates that there will not be too many resources needed to maintain it. There will be a need to continue to identify and obtain commitment from provider champions to encourage HELPiX use, as well as a need for continued monitoring and evaluation of HELPiX.

Yin said that the next steps include enhancing HELPiX technology and functionality. This includes making it easy for users to add/edit medication information as well as new languages. There is also interest in developing instruction sheets for different types of medicines, such as for chronic illnesses, and adapting HELPiX for use with adult medications. The team plans to explore further dissemination of HELPiX locally, statewide, and nationally.

## DISCUSSION

*George Isham, M.D.*  
*Chair, Roundtable on Health Literacy*  
*Moderator*

Isham pointed out that Bauer had talked about using MyChart and that earlier in the day McCandless had described how each patient is given a spiral notebook in which important information is recorded so that it can be easily accessed. Isham asked whether the notebook idea could be incorporated in MyChart. Bauer said he thinks the two approaches could coexist very well. Some individuals are technically inclined, whereas others are not, so it is important to have both approaches. He said he hopes the two could eventually be integrated into one system. The Josie King Foundation, for example, has journaling that can be done in written or electronic form, he said.

Kavita Patel, roundtable member, asked Yin if she had thought about marketing and exporting the HELPiX system because it is Web-based and vendor-agnostic. In this time of medication adherence problems, it would seem that everyone could benefit from this system, she said. Yin

responded that they are very interested in disseminating the HELPiX system. The initial approach was to try to develop a stand-alone Web application that could be accessed by everyone in the country. However, such an approach is a real barrier for providers because in addition to writing the prescription in the EMR or on paper, providers would need to log in to the application and create specific sheets. The idea of linking HELPiX to the EMR is very exciting, Yin said, but there are so many different EMR systems that it would be difficult to figure out how to do this. She said they are trying to find funds and identify common pathways so that HELPiX could be linked to multiple and different EMRs.

Winston Wong, roundtable member, asked about the role of technology in accelerating change. Various speakers touched on this issue with module training, electronic health records, and HELPiX form generation. How can technology accelerate and catalyze some of the changes? he asked.

Bauer responded that technology plays a very important role in training and education. How people are trained to maintain their accreditation, for example, has changed significantly over the years with the use of distance learning. A great deal can be learned from how this is done. A lot also can be learned about how to educate people from entities such as the Kahn Academy,<sup>4</sup> Bauer said. He believes the concept of “chunk and check” can be applied successfully. For example, rather than a person having to take 3 days off to attend a course, material could be provided online in chunks or segments with feedback scheduled for specific times.

Yin said that she believes technology is important for accelerating change. It is a great way to “hardwire” health literacy into an organization so that providers can easily access health literate instruction sheets for a range of disease processes and issues. One of the difficulties is working within the silo of an organization’s EMR. It would be great if there was a way to share all the promising health literacy work across EMR systems, including items such as revised consent forms, registration forms, and financial forms, she said.

Patel noted that leadership buy-in and timing were themes throughout the presentations. We are now in a time of health care change because of the Patient Protection and Affordable Care Act, she said. The focus is on patient-centered medical homes and accountable care organizations. How could these attributes be thought of in the context of financing delivery system changes? she asked.

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<sup>4</sup> The Kahn Academy is a not-for-profit organization “with the goal of changing education for the better by providing a free world-class education for anyone anywhere.” Materials and interactive opportunities are available for free online. See <https://www.khanacademy.org/about> (accessed June 20, 2013).



Bauer said that one impact is on clinic physicians. In the past year, clinic physicians have been making more requests for assistance in health literacy than ever before. It is not uncommon, he said, to get a telephone call from a provider who has concerns about his or a partner's Clinician and Group CAHPS scores. On the financing side, the ability to reduce preventable readmissions is a driving force. But another major force is that providers are caring people, Bauer said. When they see that patients are not following their treatment plans, they want to know why, and they are pleased to have new tools such as Ask Me 3 and teach-back to help them be more effective.

Parnell said that when health literacy efforts at North Shore–LIJ first started, it was a challenge to get people to ask for help. Now calls for assistance come all the time. Whether the heightened awareness is due to accountable care organizations, value-based purchasing, or worry about readmissions and patient outcomes, the organizational culture is changing. Health literacy is thought of at the beginning of projects rather than at the end.

Komondor added that value-based purchasing and patient experience as reflected in the HCAHPS helped in obtaining leadership buy-in, and the calls for assistance are growing. For example, about 4 or 5 years ago, she said, an attempt was made to promote health literacy in one of the suburban hospitals. The hospital's comment at that time was, "Oh, we don't have that problem here. You only have to worry about that downtown." Since that time, however, the hospital has called for assistance, and health literacy work has begun there.

Ricardo Wray, a participant from the Saint Louis University College for Public Health and Social Justice, asked presenters to speak about the larger policy and regulatory environment. He said it sounds as if these larger forces are encouraging the work being done in health literacy. To what extent does the policy environment facilitate the enhancement of organizational health literacy and to what extent does it hinder such work? he asked.

Parnell responded that the policy environment both facilitates and hinders health literacy work. Regulatory standards encourage health literacy work, but the resources to carry out the work are not always available. Translation of materials into languages other than English, for example, is very costly, and the system is now required to provide vital documents in 18 different languages.

Bauer said that they do not look at regulations as a driver of their efforts because all the work they do is based on what they call the "remarkable patient experience." The focus is on making sure each person gets what he or she needs. Regulation has probably had some impact on the translator services, but the real driver is the remarkable patient experience, he said.



Yin said that she thinks the policy and regulatory environment is helping rather than hindering because it puts pressure on leadership to make changes. If there is a mandate to disseminate information in specific languages, then that is good leverage to translate instruction sheets into those languages.

Rima Rudd, roundtable member, said that hospital health systems throughout the industry are very concerned about their financial situation and their budget challenges. At the same time, they are being asked to improve quality. Most chief executive officers are looking at return on investments. What are compelling arguments that could be presented to executive leadership to encourage them to implement health literacy programs? she asked.

Parnell said a rationale to present to executive leadership is that health literacy is foundational for patient safety, improved patient outcomes, and patient satisfaction, all of which ultimately tie into reimbursement. Administrators understand the need for patient-centered care.

Komondor said that every hospital is interested in the patient experience as well as meaningful use requirements and readmission rates. Data and examples of how health literacy affects these areas of interest are extremely useful when talking with leadership.

Isham observed that the reduction in readmission rates is a compelling argument for hospitals, given the new Medicare policy.

Wilma Alvarado-Little, roundtable member, said she was interested in learning about language access in the various organizations. How is information or feedback from the non-English-speaking and the deaf and hard-of-hearing communities being captured? she asked. How are those data influencing the organization's processes and policies?

Parnell said that providing health literate materials in multiple languages and for special populations is a work in progress. Of major importance is educating staff who are the first point of patient contact in the organization. Conversations between registrars and patients can be difficult. Some registrars do not understand that race, ethnicity, and preferred language relate to patient outcomes and patient safety. And sometimes there is pushback from the patient, who says, "You can't ask me that. It's illegal." Some patients think they are going to be treated differently on the basis of their answers.

The organization is looking at a systemwide approach instead of working with one vendor at a time, Parnell said. It is possible that services might need to be provided by region or by several different vendors to meet the language needs of different populations of patients, she noted.

Bauer said they had proceeded in a similar way, educating all the registration staff about how to gather needed information appropriately and sensitively. The organization has hired a director of interpreter and transla-

tion services and has formalized a corporate structure for that activity. All staff have been made aware of the services and when and how to use them. All patient surveys are available in English and Spanish. An examination of which other languages might be added is being conducted, Bauer said.

Komondor said that her organization has also trained all of the registrars in health literacy. They are required to attend a training that includes instructions about asking questions on preferred language. The deaf-access coordinator is an active member of the health literacy team, and she conducts health literacy training with the American Sign Language interpreters.

Yin said that when they are training providers about the instruction sheets, they tell them to use the interpreter line for communicating with patients who do not speak English. Currently, the instruction sheets are in English and Spanish only. But they have translated many of the instruction sheets into Chinese, French, Polish, and Russian. The difficulty is incorporating these in the Web application.

Kim Parson, roundtable member, asked Bauer to talk a bit more about financial literacy and explanation of benefits. What mediums are used, when are the conversations held, and how is patient understanding measured? she asked.

Bauer responded that it was a great day when the leader of the organization's registration process e-mailed him and said he would like to talk about health literacy in the business office. He said he thought they could use the Ask Me 3 approach during registration. A new registration package using best practices in health literacy was launched on April 17, 2013. Many items are in the package because of Joint Commission requirements. But the information is in easy-to-understand terms. For example, all legalese has been eliminated from the financial consent form. Medical terminology has been simplified, as has discussion of insurance coverage. That now moves along the lines of "you have X insurance, which means that you have a deductible of Y, and this is what you need to do, and here is why it is important." Financial counseling can occur prior to admission by telephone, during the admission process, and as part of the follow-up counseling process.

The process is audited by the patient registration team, Bauer said, but he does not know the measurements used. What he finds impressive is that these people saw health literacy as an opportunity to increase financial literacy. The same kind of thing happened on the legal side, and all forms are now at a fifth-grade reading level with simplified language.

Gemirald Daus, roundtable member, asked Yin if they had considered pictograms and other information that would convey information about medication safety, that is, how home remedies or complementary and alternative medicines might interact harmfully with prescribed medica-

tions. Yin responded that there is definitely potential for development in this area. It would be great to be able to tailor messages and include questions about home remedies when generating instruction sheets. At the moment, however, only basic information is given—information parents really need to know to give medications correctly.

Daus said he was pleased to see that North Shore-LIJ had put diversity and health literacy together and asked Parnell to discuss why this was done. Parnell replied that they believed that if health literacy was not included in the name of the department, it might not be recognized as separate from, although related to, culture and diversity. The organization viewed health literacy as an overarching area, with culture and diversity as one of its components. If one cannot communicate and help patients navigate the system, all other components will not work well, she said.

Benard Dreyer, roundtable member, asked whether it is more important to have a separate office for health literacy, or whether it is better to integrate health literacy into patient safety, quality improvement, or regulatory issues.

Komondor said that in her organization there is a separate health literacy committee, but it is composed of people from different disciplines. When they reach out to other hospital committees, such as the patient safety committee, that is where health literacy becomes integrated and institutionalized. And members of the health literacy team sit on virtually every hospital committee, whether it is patient safety or infection control. So health literacy is involved in all ongoing policy revisions and policy developments.

Bauer said he believes there must be a person or group to serve as a focal point and driver for health literacy. However, that person or group cannot be successful without being integrated and inspiring others. Parnell agreed that there must be someone to drive change and be accountable, but if health literacy efforts are not integrated into the system, then nothing is accomplished.

Will Ross, roundtable member, said that health literacy needs to be “hardwired” into the system in order to get provider buy-in. A mature institution understands that health literacy is a key component of corporate culture and embeds it in performance appraisals. But how does one walk the line between embedding health literacy in everything so that it is institutionalized versus highlighting it as a separate and key component? he asked.

Komondor responded that the greatest challenge has been engaging attending providers. Just recently, an attending physician has agreed to be the physician champion on the health literacy team. What is key, she said, is to have physician-to-physician communication about the importance of health literacy. The attending physician who heads up the

residency program has encouraged health literacy efforts and has asked that ongoing health literacy training be added to the curriculum. As a result, medical residents are supportive. It will be a long process, however, to have health literacy fully institutionalized in her medical center, Komondor said.

Bauer said he found that there are early physician adopters and that there are others who are slow to use new techniques. And there are surprises, he said. For example, one physician practice that had strong leadership support refused to adopt Ask Me 3 and teach-back. Although there was a strong physician proponent, there was equally strong resistance from a physician who took the position that communicating with patients was not a problem. In that practice, other staff members were taught to use these tools, and patients are encouraged to use them through wall placements, written material, and videos that play in the office.

Following pilot tests of these techniques in 10 practices, Bauer said he randomly selected four providers and asked if they would share their experiences on video. He conducted documentary-style interviews with each. On the basis of these interviews, a 16-minute video was developed. Its title is *What Is the Main Problem, What Do I Need to Do About It, Why Is It Important, and Teach Back*. The video is extremely powerful and has resonated with clinicians because it shows their peers being very candid about their experiences, and, in the end, that is what will drive adoption, Bauer said.

Parnell said that there are many physician champions, and they are building support, but currently it is easier to reach the fellows and residents. The chief medical officer of North Shore–LIJ introduces the online module for health literacy and talks about how important it is, and the physicians at the medical school are supportive. Health literacy is gaining momentum, Parnell said, but it will take some time to reach and convince all the attending physicians.

Patrick McGarry, roundtable member, said that he finds it disconcerting that physicians are perceived to be barriers to implementing health literacy. Would health literacy efforts be more palatable if they were couched in terms of patient self-management? he asked.

Bauer said that physicians are not always a barrier. At Novant, physicians were a driving force for establishing health literacy efforts. They can be strong leaders in health literacy. As with any change, however, there are early and late adopters, and this is true of physicians, nurses, and others in medical care.

Isham said that it sounds as if physicians can be a barrier or they can be an asset. When physicians are a barrier, there are special challenges if the person attempting to implement health literacy efforts is not a physician.

Yin said that physicians work within a system. If the system is not conducive to practicing in a health literate manner, then it is not just the physician who is the problem, it is also the system, she said.

Cindy Brach, roundtable member, said that one of the things that concerns her is that even with the use of health literacy tools such as Ask Me 3 and teach-back, there may not actually be shared decision making about treatment plans. She asked whether shared decision making is part of health literacy. She also asked Bauer to describe how he measures whether shared decision making takes place.

Bauer responded that when a patient is educated, he or she is able to be part of a conversation. Encouraging questions and joint decisions is part of that conversation, and health literacy techniques such as Ask Me 3 facilitate the conversation. Patient-centered care is the goal, and talking about the diagnosis and treatment options and jointly arriving at a decision about the best way to proceed is what we strive for. When that approach is used, measures of patient satisfaction increase.

Komondor said that shared decision making depends, to some extent, on the population with which one is working. All staff members have been trained to encourage patients to ask questions, to become involved in their own care, and to share in decision making. A short time ago, Komondor said, she conducted a focus group with some women in the community who were asked about their struggles with health and getting health information. The main thing she learned was that the women were too intimidated to ask questions. They said things like “The doctor doesn’t have time,” or “We don’t want to appear stupid,” or they figured the doctor would tell them what they needed to know, and if they didn’t understand, the doctor would tell them again at the next visit. This kind of population presents a huge challenge to shared decision making.

Andrew Pleasant, roundtable member, said that although the presenters had described cost as a barrier to implementation, no one had included an assessment of cost savings associated with the interventions implemented. Was that because the assessment has not been done, or no effect was found, or because it was impossible to tease out the effect of health literacy from other factors? he asked.

Bauer said that they saw a large decrease in readmissions for congestive heart failure after health literacy efforts were implemented. But, he added, it is very difficult to show that health literacy was the driving factor, given the many variables involved. Parnell agreed that isolating the impact of health literacy from other factors is very difficult.

Isham observed that when implementing programs in real-world systems as opposed to a research trial, it is difficult to identify what is responsible for change. It would be helpful to learn about methods that can be used to evaluate impact in such situations. Are there more robust

analytic abilities within the systems that can help with a complex evaluation? he asked.

Parnell responded that they have a research institute that helps with evaluation. Komondor said her organization does not have help, but they have set a major goal to measure outcomes. They would, she said, appreciate input on how to do this. Bauer said Novant has a very sophisticated evaluation department, but the question is complicated and they have not yet taken the time to address it fully.

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## 4

### Panel 3: Implementing Attributes of a Health Literate Organization

**PALOMA IZQUIERDO-HERNANDEZ, M.S., M.P.H.**

*President and Chief Executive Officer  
Urban Health Plan, Inc., New York, New York*

The following is a summary of the presentation given by Paloma Izquierdo-Hernandez. It is not a transcript.

Izquierdo-Hernandez said that Urban Health Plan was founded in 1974 by her father, Richard Izquierdo, a local physician who grew up in the neighborhood and believed in the community. The health center was founded on community-based grass-roots principles, and in 1999 the center became a federally qualified health center (FQHC). Currently, Urban Health Plan has a staff of 730 and operates 8 health care practices, 8 school health programs, and 3 part-time programs for at-risk populations. They have had a fully implemented electronic medical record system since 2006, with health education and counseling fully integrated into the templates.

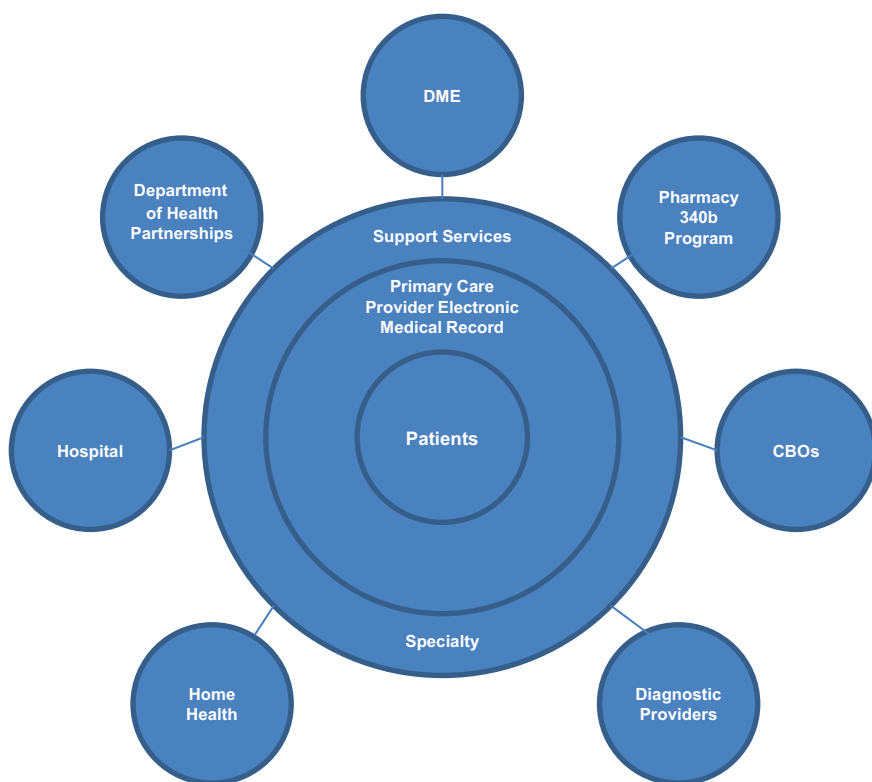
Urban Health Plan serves a predominantly Latino population. Much of the organization's health literacy efforts are focused around health educators, nutritionists, patient navigators, care coordinators, case managers, and volunteers. Most of Urban Health Plan's health literacy work occurs in the community and not during the doctor-patient visit. The organization does a great deal of outreach work, including community health fairs and waiting-room presentations. Another type of outreach is



preceptorships, in which medical students come to the facilities to work with patients on health literacy.

Urban Health Plan uses a patient-centered home model of care (see Figure 4-1). According to Izquierdo-Hernandez, much of its health literacy work is focused around support services provided through the outreach health educators or some other mechanism.

Izquierdo-Hernandez said that she believes that Urban Health Plan has all of the attributes of a health literate organization, although not always in a traditional manner. For example, Urban Health Plan's leadership has made health literacy a priority from the beginning. The center was also an active participant in the health disparities collaborative that the Health Resources and Services Administration (HRSA) put forth and, through that activity, learned about self-management. Health educators were brought in as a way to address health management through quality



**FIGURE 4-1** Patient-centered home model from Urban Health Plan.  
SOURCE: Izquierdo-Hernandez, 2013.

improvement efforts. The organization started with 1 health educator and now has 18.

Urban Health Plan has integrated health literacy into performance improvement and trains its workforce to be health literate. There is a staff learning center for professional and personal growth, with classes on how to conduct motivational interviews, how to deal with difficult patients, and how to develop a curriculum for certain chronic illnesses. The learning center was created because, in order to continuously improve health care, the organization has to continuously train its staff. In addition, a director of health literacy was recently hired to coordinate efforts and further integrate health literacy into the organization.

Educational and other materials are standardized to meet the needs of the entire population. Staff also use health literacy strategies and are encouraged to always be aware of how they communicate with patients. The organization hires from the community, which helps build linguistic proficiency into the culture. Easy access to health information and navigation assistance is also provided. One way this is done is through employing greeters to help patients navigate their way through the health centers.

Urban Health Plan's interest in improving health literacy comes from its history and culture as a community-centered organization. Urban Health Plan's mission and core values include cultural proficiency, innovation, and performance improvement. Izquierdo-Hernandez noted that working with the HRSA health disparities collaborative brought about an awareness of the need to go beyond the community and also work within the provider setting.

One strategy to move the organization toward a health literate model was to include health educators in performance improvement teams. The organization has also invested in staffing. In addition to health educators, there are patient advocates, nutritionists, care coordinators, and case managers. The entire care team is integrated into the clinical units so that patients do not have to move around the building to see different care providers. These positions have been built into the budget, so they are incorporated into the system, which is important for sustainability. Unless there is a financial catastrophe, the health literacy positions will stay as they have for the past 10 years.

Urban Health Plan also collaborates with some valued partners on health literacy initiatives. For example, a partnership with the Canyon Ranch Life Enhancement Program has allowed Urban Health Plan to take a program from Canyon Ranch and duplicate it in the South Bronx with good results. The program focuses on giving health information to people when and where they need it. One example of success is the significant drop in depression scores for approximately 100 people who have

completed the program. Another important partner is the New York City Department of Health and Mental Hygiene, which provides appropriate health information, in forms such as pamphlets and brochures.

The role of stability in an organization is often overlooked in creating and sustaining health literacy efforts, Izquierdo-Hernandez said. A community health center may be especially vulnerable, either financially or operationally. Thus, stability is fundamental because an organization that is in flux or has financial problems will have to use resources for things other than health literacy.

Izquierdo-Hernandez said that it was very important that the board of directors of the center supported health literacy efforts. As an FQHC, the board is at least 51 percent patients. Therefore, it was important for the patients to agree that the organization should be doing this work. The chief medical officer was also supportive of these efforts, which helped ensure provider support as well.

Urban Health Plan has had successful and sustainable performance improvement projects. For example, a program called Shop Healthy Bronx sends nutritionists into supermarkets to conduct food demonstrations. The goal is to increase the use of fresh vegetables and produce and make healthier options available to the community.

There are several barriers or challenges to implementing health literacy in the organization. One of the barriers has been standardization of key messages across the entire network. Finding the right staff, individuals who are linguistically and culturally competent, can also be a challenge, as is finding the right leader. But, Izquierdo-Hernandez noted, the new health literacy director is making progress.

Another major challenge is ensuring continued funding to support this work. Izquierdo-Hernandez said that she thinks health literacy will be supported by payment reform as organizations move from volume to value and start to see some savings that come back to the health centers. Currently, Urban Health Plan is not part of a formal health system but rather is an independent FQHC. It has been able to negotiate some shared savings that help pay for health literacy, and, she believes, as health care reform and payment reform move toward prevention, health literacy work will be more sustainable. In addition, she said, the center will continue to seek outside funding.

Izquierdo-Hernandez concluded her presentation by saying that a knowledgeable community becomes a healthier community.

**AUDREY RIFFENBURGH, M.A.**

*Senior Health Literacy Specialist  
Office of Diversity, Equity, and Inclusion  
University of New Mexico Hospitals*

The following is a summary of the presentation given by Audrey Riffenburgh. It is not a transcript.

University of New Mexico (UNM) Hospitals is a health system with a 630-bed hospital and 24 offsite health clinics with about 500,000 ambulatory visits per year. UNM Hospitals is the only medical academic center in New Mexico and the region's only Level 1 trauma center. The system has about 6,000 employees, and about half of the population it serves lives in poverty. About half of the region's population self-identifies as Hispanic or Latino, about one-quarter as white or Anglo, and about 10 percent as Native American (from a variety of different tribes). Other, smaller populations make up the other 15 percent.

Health literacy is relatively new in the organization, and it is currently placed in an office that is also relatively new, Riffenburgh said. In 2010, the Office of Diversity, Equity, and Inclusion was created for the purpose of ensuring that all patients received the safest, most effective, and most sensitive care regardless of their race and ethnic identification or their health knowledge or literacy. Riffenburgh's position was created in 2012 to help achieve those goals.

UNM Hospitals is working most intensively on the sixth and eighth attributes of a health literate organization: interpersonal communications and printed materials. One of the system's greatest successes in interpersonal communication has been a strong and vibrant interpreter language service program. There are 20 onsite interpreters—16 Spanish, 3 Vietnamese, and 1 Navajo. The program also serves about 23 other language groups through video and telephone interpreting. This is a vibrant community of dedicated people, Riffenburgh noted.

Another component of efforts to improve interpersonal communication is raising awareness across the organization of the different ways that providers and patients use language and the importance of plain or "living room" language. To further that awareness, Riffenburgh said, she has made a plain-language thesaurus available. It is based on a Centers for Disease Control and Prevention document, to which she added the thesaurus she had been developing for 20 years as part of her workshops. The thesaurus is publicly available on the Internet. The organization is also just beginning a teach-back initiative.

The system is also focusing on making printed materials easier to understand. This means not just making them available in different lan-

guages, but also writing them in a way that allows for better understanding. The system has provided resources to hire professional plain-language editors and a graphic designer who has special training and expertise in readability. Riffenburgh said that although she is also working to build systemwide change, she also has been given the task of editing patient documents, and this has taken a great deal of time because there are so many.

One of the projects under way with the graphic designer is to create a new style for all of the organization's documents—a new look for standardization and branding. This will culminate in a template of the new style and a "gallery" of sample materials available on the system's Intranet so that people in the organization can see what plain language looks like. Riffenburgh said that she found that providers and hospital staff have often misunderstood what plain language is, and that has proven to be a barrier.

She is also designing a more formalized system for document approval to be implemented in the future. Currently, submitting documents for review of readability and usability is voluntary, but the goal is to make it mandatory, at least for all new documents. Riffenburgh said she is training a team of people to be document reviewers. She has also created some tip sheets to help people as they review, write, and format their own documents.

Printed materials are all supposed to be translated into Spanish and Vietnamese, according to Riffenburgh. That effort is in progress. Ensuring that the English versions are more focused and actionable will help, because when something is written at a difficult level in English, it will not get better when it is translated.

Turning to the first and second attributes, leadership and measurement, Riffenburgh said that she believes these are strengths of the UNM program. Key leaders at the organization are supportive of the effort, although some still need to be convinced, she said. She has received support for editing documents even when providers have resisted, and resources have been provided for this and other work. Early in the effort, an organizational self-assessment was conducted, which provided some very good data about what needed to be done.

Preparing the workforce is a major area the organization is addressing, Riffenburgh said. She, on the hospital side, and a key physician who works on the medical school side give presentations to people within their respective spheres of influence to raise awareness.

Riffenburgh also teaches a 2-day intensive workshop that she taught for years around the country when she was a consultant. Seventy people were trained in the first year, which she believes is a good start. There is also an online competency unit on health literacy that all employees must complete.

The health sciences center library has put up an entire website on health literacy. Riffenburgh gave the library an extensive bibliography, and it includes links to a wide variety of information, making it a clearinghouse. It is available publicly and contains direct links to a number of health literacy information resources.

UNM Hospitals is working hard to improve the overall environment as far as ease of navigation and accessibility are concerned. Improving signage is a challenge, but the effort is under way. Riffenburgh serves on the way-finding committee, but it is difficult to implement health literacy measures because many decisions have already been made.

The patient financial services department does an excellent job helping patients navigate and get the help they need, Riffenburgh said. There is also a special Office of Native American Health Services, which does an outstanding job helping Native American patients navigate the system. In addition, there is a new patient portal, but unfortunately most of the information on it is not very readable for many of the patients the hospital serves. Riffenburgh has edited some of the text so that it is at an eighth-grade level, but other text has been declared off-limits to editing.

To address health literacy in high-risk situations, Riffenburgh said she is working with a palliative care doctor to revise the advanced directive forms. She is also working to make consent forms and medical intake forms easier to understand. A team of doctors inside the system created a simpler consent form, which has been approved; however, some physicians choose not to use the form.

According to Riffenburgh, the interest in health literacy at UNM Hospitals was generated by key leaders who became aware of the communication problems. At the same time, the national forces for change—the reports, the standards, and The Joint Commission—were gaining momentum. This prompted some of these leaders to begin speaking to colleagues to encourage change. Probably the most significant factor, however, was a lawsuit filed in 2005 demanding language access because the hospital was not doing enough to provide services for speakers of languages other than English.

Strategies that have moved health literacy efforts forward at UNM Hospitals include gaining the support of key leaders and champions and linking health literacy to safety, quality, patient satisfaction, and cost savings. By consistently making these links, health literacy champions in the organization are able to keep this work a priority. These leaders continue to challenge people across the organization at all levels, saying, “We can do better than this.” They have provided commitment, tenacity, and focus. The lawsuit facilitated the change, but leadership has kept it going.

Implementation of national health reform is expected to bring new patients in to the system. UNM Hospitals is the system that best serves

low-income patients in the area. This fact, coupled with new Medicare readmission policies, has provided incentives for the system to continue to make progress in health literacy.

One barrier to implementing health literacy has been resistance to using plain language. Many people do not believe or do not understand that there is really a mismatch between what the system demands and what patients can navigate. Riffenburgh related an anecdote that at a meeting with a provider, she showed a video of speaker and health literacy activist Toni Cordell talking about her own experiences as a low-literacy patient. When the video was over, the provider said that he did not believe it could be true. He had trouble believing there could be such a gap in understanding between doctor and patient.

Competing priorities have also proved to be a barrier. In the past year, there have been system evaluations by the Department of Health and Human Services/Centers for Medicare & Medicaid Services and The Joint Commission. Those visits generated a huge amount of work. In addition, the organization was implementing some changes to its electronic health record and combining four disparate parts of the UNM Hospitals system into a single health system. The people who worked in the system already had a lot of work to do. It is a challenge to get people to take the extra time to attend classes and focus on health literacy, Riffenburgh said.

At the same time, some people are beginning to see and understand the need for health literacy efforts, and they have a great deal of enthusiasm. This brings its own challenges, Riffenburgh noted, as the volume of work has outpaced her single position. There is concern that this lack of resources will lead to waning enthusiasm if people think they are not getting responses or results.

Another challenge is resistance to change in general. As an example, Riffenburgh said that she had created a consent form that was in use for a while. The Joint Commission evaluators called it a best practice, but the providers said they were not comfortable with it. It used the word "die" instead of "mortality," and some patients were reacting to that. So, now, the old form, written at college level, is back in use.

Riffenburgh concluded her presentation by saying that it will be a challenge to continue and to maintain the changes but that support from leadership remains strong, and she will continue to promote health literacy at UNM Hospitals.



**LORI HALL, R.N.**

*Consultant, Health Education  
Eli Lilly USA, LLC*

The following is a summary of the presentation given by Lori Hall. It is not a transcript.

Eli Lilly is a global pharmaceutical company headquartered in Indianapolis, Indiana. It has offices in Puerto Rico and 17 other countries, with a portfolio of products sold in approximately 125 countries. The company was founded in 1876 by Colonel Eli Lilly, a pharmaceutical chemist and a veteran of the U.S. Civil War. Many know Lilly from its diabetes portfolio; it was the first to bring commercial insulin to the market. The company still has a very strong presence in diabetes care, which remains central to the company's mission. Overall, Hall said, Lilly's mission is to provide answers through medicines and information for some of the world's most urgent medical needs.

Hall said Lilly's journey toward becoming a health literate organization began on the front lines, that is, in the health education department, rather than in the executive office. The health education department has a vision to provide foundational knowledge and skills to engage, educate, and empower patients to be active in the management of their own health care. Its mission is to create and deliver nonbranded, nonpromotional patient education materials aligned with health literacy principles in the areas where Lilly has presence and expertise. Hall stressed that the area of the company in which she works has nothing to do with products but rather is focused on patients and education. In fact, she said, there is a firewall between what her group does and what the marketing teams do.

The health education department is a customer-facing team of health care professionals focused on delivering positive experiences for patients. In addition to the consultants who work in the Indianapolis office, there is a field team of 10 health education professionals who have advanced-practice nursing and pharmaceutical experience. They interact with national health plans, which include UnitedHealth, Humana, and Aetna as well as many smaller regional plans. The consultants do not talk about Lilly's medicines, but about patient resources. They try to understand unmet patient-related needs and to match those needs with the portfolio of patient education resources available at Lilly.

Health literacy is a new initiative for Lilly. The effort is still in its infancy at the company, with a small group of people actively engaged in it. Lilly is conducting health literacy pilots in the areas of clinical trial management and informed consent, the medical call center, medical education grants, and brand marketing. These activities align with the



health education department's overall vision of engaging, educating, and empowering patients to be more active in their health care.

Hall said that in addition to internal activities, Lilly also engages in health literacy activities in the broader community, for example, making health literacy presentations during employee wellness series. Lilly also sponsors events called Lilly Neighbor Nights, because although it is a large corporation, it is also a neighbor to a large residential community. Once a year, Lilly invites the community to come and see what they do. One of the most recent events was focused on health literacy. Lilly has also partnered with Indy Reads, an adult literacy program, and has made presentations at the Marion County Public Health Department.

Lilly is supporting educational grants to a number of regional medical education programs, Hall said (see Table 4-1). The intent is to educate primary care physicians in the area of health literacy, and attendance was very good at the Pri-Med South and Pri-Med Houston conferences. Various other events are planned for the rest of 2013.

On a national level, Lilly recently won the Institute for Healthcare Advancement's Health Literacy Award in the published materials category. Hall said that she and her colleagues are very proud of that honor, but, more important, it helped to legitimize Lilly's corporate health literacy initiative—so that it is not seen as just the passion of certain individuals. Experiences such as winning an award help health literacy gain support in the organization.

**TABLE 4-1** Regional Medical Education Programs (Supported by Educational Grants from Eli Lilly and Company)

Region	Program
Pri-Med South and Pri-Med Houston	Improving Health Literacy and Patient Provider Communication: A Call to Action for Healthcare Providers
Primary Care Network	Health Literacy and Patient Safety: A Primary (Care) Concern
CME INCITE/ Virtual Rounds™	Addressing the Health Literacy Epidemic: Prescribing Toward Better Patient Outcomes
Pri-Med West	Health Literacy—The Whole Patient in Primary Care
Integritas Communications/ Web-based	Improving Health Literacy in Primary Care: Identifying Deficiencies and Promoting Shared Decision Making
Illinois Academy of Family Physicians/Ed Track	Keep It Clear: Developing Communication Skills to Work with Patients with Limited Health Literacy
Boston Medical Center	Annual Health Literacy Research Conference (HARC)

SOURCE: Hall, 2013.

With regard to the 10 attributes of a health literate organization, Hall said that Lilly has accomplished the eighth—designing, developing, and implementing patient education resources that meet health literacy principles. She said they are working to master the other attributes, but are still early in the process.

At Lilly, interest in health literacy began in 2009 with the efforts of a small group in consumer marketing. They commissioned the Health Research for Action center at the University of California, Berkeley, School of Public Health to conduct an assessment of how health literacy and clear communication issues were addressed at Lilly. It was a very small assessment, consisting of interviews with 20 key staff at Lilly and selected agencies that work with Lilly.

The key findings were both interesting and a cause for concern. The interesting parts were that most of the key informants believed that health literacy is important, that it is something Lilly should be involved in, and that it is something that could be better understood by those in the organization. The interviewees thought that understanding health literacy would help Lilly better comply with Food and Drug Administration (FDA) regulations and guidance.

But the assessment also identified challenges, according to Hall. First, the interviewees said that Lilly simply did not have adequate knowledge and expertise in health literacy. Because Lilly outsources the creation of its materials, the limited pool of affordable contractors who have health literacy expertise was a challenge. Identifying agencies that have the necessary expertise was a further challenge.

The assessment also identified a lack of sufficient standards and protocols, which led to inconsistency in materials. Constraints on staff time were also an issue, as is the case in many organizations. Lack of trust and communication among departments was an additional barrier at Lilly. Hall said that at times FDA regulatory requirements and health literacy best practices are in conflict. And, finally, Hall noted, there is always some resistance to change.

Hall said that when she heard a presentation on the findings of the assessment, it inspired her to take up health literacy work at Lilly. She realized that to be effective, any efforts to create a health literate organization had to support Lilly's business plan and build on efforts that were already under way, so that health literacy is not a separate workstream, but instead is integrated into the work that everyone is already doing. Efforts also need to be anchored in quality, safety, and patient-centered care.

To create the necessary momentum for health literacy efforts to succeed at Lilly, the organization needed evidence-based tools and resources and a multidisciplinary approach. Support from senior leadership was

also needed, and, most important, awareness of the need for health literacy efforts.

Hall created a team of advocates from many of the major consumer and patient touch-points within the organization. This team calls itself Health Literacy Matters. It consists of representatives from consumer marketing, clinical project management, the medical call center, labeling, and global patient safety, among others. The team focuses on raising corporate awareness of how better health communications help improve patient adherence and, therefore, help achieve better outcomes. Although none of the members of the team has advanced credentials in health literacy, it is a frontline group of people who care passionately about patients.

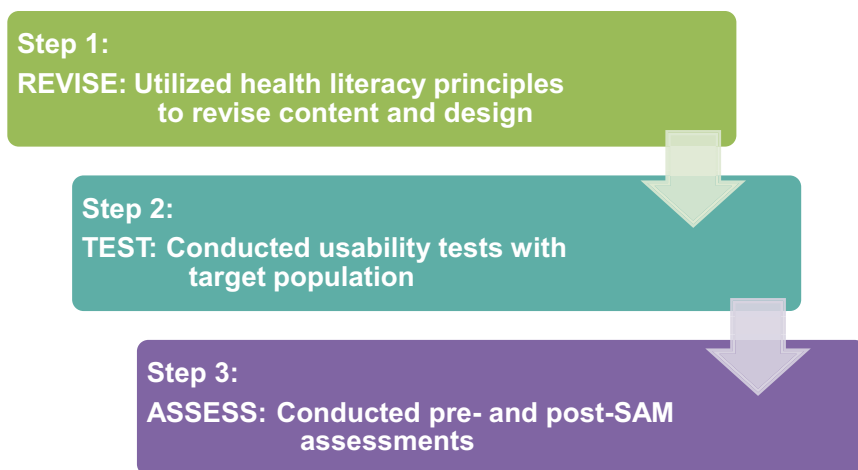
The team organized activities around Health Literacy Month in October. They began with making presentations throughout the organization that were designed to raise awareness. They also created an internal online collaboration site with facts, tips, tools, and resources. The team developed a multimedia internal communication plan that included putting Health Literacy Matters on television screens throughout the organization and in the internal newsletter. Efforts culminated in October when, once each week, a different national thought leader in health literacy came to speak at Lilly. This gave the effort some momentum and generated more interest within the organization.

Other efforts have begun as well, Hall said. A small health literacy pilot project involved developing patient education materials that are not branded or disease-state specific. The existing materials were tested and rewritten to follow health literacy principles. Usability tests were conducted with patients and consumers, and pre- and post-Suitability Assessment of Materials<sup>1</sup> (SAM) tests were conducted. But the real test, Hall said, is the reaction of the health plans.

Customer requirements are practical requirements; for example, material must fit into a number-10 envelope. However, when Lilly could demonstrate the effectiveness of the revised materials, they were allowed to bend the requirements. Now, the revised brochures titled "Feel Your Best" are among Lilly's most widely used patient brochures. As a result of this success, the approach taken by the health education department (see Figure 4-2) is now serving as a role model pilot program for the rest of the organization. For example, Hall said, there is a pilot that will take a more holistic approach to training key stakeholders, including legal, medical

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<sup>1</sup> The SAM instrument "offers a systematic method to objectively assess the suitability of health information materials for a particular audience in a short time." It was developed in 1993 by Leonard and Cecilia Doak and Jane Root. See <http://aspiruslibrary.org/literacy/SAM.pdf> (accessed June 20, 2013).



**FIGURE 4-2** Three-step approach.

NOTE: SAM = Suitability Assessment of Materials.

SOURCE: Hall, 2013.

and regulatory, and marketing. The goal is engage these stakeholders, who will then become role models for others in the organization.

Hall concluded her presentation by saying that her team will continue to share its successes and will not be discouraged by setbacks. Lilly has a number of health literacy champions within the organization that make her team's efforts possible. Hall said that she intends to keep the conversation about health literacy alive at Lilly and to keep moving forward in making Lilly a health literate organization.

### **MARY ANN ABRAMS, M.D., M.P.H.**

*Health Management Consultant  
Iowa Health System*

The following is a summary of the presentation given by Mary Ann Abrams. It is not a transcript.

The Iowa Health System has been engaged in health literacy efforts for almost 10 years. Abrams focused her presentation on a reader-friendly consent for surgeries and procedures and described its development in the context of the attributes of a health literate organization.

Although health literacy work at the Iowa Health System originates in the Department of Clinical Performance Improvement, development of the new consent materials was a crosscutting, systemwide quality initia-

tive that incorporated health literacy. The immediate goal was to develop standardized, reader-friendly consent forms in both English and Spanish, to use throughout the informed consent process and within the framework of plain language, teach-back, and other health literacy principles.

Still, this project was not just about revising forms. The wider organizational goal was to use the project as a strategy to

- educate staff and providers about health literacy concepts;
- promote patient understanding through plain language and teach-back;
- optimize perioperative consent communication; and
- encourage adult learners, risk managers, health care providers, and the law department to work collaboratively with the health literacy team.

The product of this effort, that is, the consent form, was to be made available for use throughout the Iowa Health System's affiliated hospitals, clinical sites, and physician offices, consistent with their individual policies and applicable state and federal laws.

The original consent form was written at the college level and was not very visually inviting. The revised consent form has a reader-friendly format and wording along with space for teach-back, where the patient describes procedures in his or her own words. Box 4-1 shows how complicated phrasing was modified using plain language.

#### **BOX 4-1**

##### **Consent Form Text—Old and New**

###### **Old Text**

"I authorize \_\_\_\_\_ Hospital to retain, preserve and use for scientific, teaching or commercial purposes, or to dispose of at their discretion, any specimens or tissues removed from my body. I release to \_\_\_\_\_ Hospital all of my ownership interests or other rights to these specimens, tissues or other materials."

###### **New Text**

"I understand that the doctor may remove tissue and body parts during this surgery or procedure. If it is not used for lab studies or teaching, it will be disposed of as the law requires."

SOURCE: Abrams, 2013.

The revised consent form (see Figure 4-3) is a one-page, two-sided document, with a readability level of seventh to eighth grade. It has good spacing, careful use of bullets and numbering, selected use of bold text, and directions, said Abrams. It incorporates the key elements of informed consent and includes plain-language descriptions of other pieces of the consent process, such as the taking of photographs, what happens to tissue, and a final reminder to ask questions before signing the form. The revised form is part of an overall health literacy-based consent process that includes surgeon-patient discussions conducted in plain language.

The health literacy team began revising the old consent form with input from a number of individuals, including the New Readers of Iowa, a group of adult learners. Multiple revisions were made until the form was deemed functional. Key leaders, both formal and informal, were involved from the start and helped guide the early pilot work. A small pilot test was conducted at one hospital with one surgeon, and revisions were made as necessary. Abrams said it was important that the hospital and the team working on the pilot documented all the steps of the development process so that it could be replicated at other sites. That process evolved into one that included informational meetings, written communication, and further training before an individual hospital would begin to use the new consent process.

The pilot test included evaluating whether the success of the new form differed by patient demographics and whether the amount of time taken to complete the process increased because patients were actually reading it, Abrams said. And, if so, she added, was that a problem? They were also interested in general feedback. Did the staff like it? Did the patients?

Evaluation results showed a marked increase in the number of patients and family members who actually read the consent form (from 25 to 90 percent), an increase in the proportion of patients who were able to describe their surgery in their own words, and increased patient comfort with asking questions. There had been some concern that providers might not like the new form and might find the new process disruptive, but this turned out not to be the case. Patients, families, and nurses were very pleased with the new procedure, noted Abrams.

The initial work was completed about 8 years ago. Each affiliate hospital is continuing to implement the program, adapting the process as necessary. There is an implementation checklist for individual organizations that identifies important stakeholders who must be involved before changes are made. The training focuses not just on health literacy and teach-back, but also on the consent form as a tool to verify patient understanding.

Even with years of experience in implementing the health literate

### Consent for Surgery or Procedure

- Please read the form.
- Ask about any part you do not understand.
- **Be sure you have your questions answered before you sign this form.**
- When you **sign** it, you are giving us permission to do this surgery or procedure.

I, \_\_\_\_\_ (patient's name) agree for Dr. \_\_\_\_\_ along with any assistants the doctor may choose, to do this surgery or procedure on me at \_\_\_\_\_ (facility):

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Name of surgery or name of procedure in medical words – including left, right or level  
(Doctor or health care worker fills this out)

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\_\_\_\_\_ Name of surgery or name of procedure in my own words  
(What the patient or family says back to the doctor or health care worker – quote patient or family)

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1. I understand that my doctor may find other medical conditions he/she did not expect during my surgery or procedure. I agree that my doctor may do any extra treatments or procedures he/she thinks are needed for medical reasons during my surgery or procedure.
2. I understand I may be given medicine to put me to sleep, make parts of my body numb, or help control pain. People with special training will give this medicine. These people may be an anesthesiologist, a nurse anesthetist (CRNA), a nurse, or the doctor doing my surgery or procedure.
3. I understand the doctor may remove tissue or body parts during this surgery or procedure. If it is not used for lab studies or teaching, it will be disposed of, as the law requires.

Turn Page Over  
Do Not Write Here

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Page 1 of 2

4. I understand pictures or video of my surgery or procedure may be taken, if my doctor thinks it is needed for medical reasons.
5. I understand someone may watch or help with my surgery or procedure for medical teaching. These people are usually medical or nursing students. A technical advisor may watch if my doctor thinks one is needed.
6. I understand that if my doctor thinks I need **blood** for medical reasons, **it will be given**.

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**I understand and my doctor has told me:**

- What I am having done and why I need it.
- The possible risks to me of having this done.
- What might happen to me if I don't have it done.
- What other choices I can make instead of having this done.
- What can happen to me if I choose to do something else.
- What can happen to me if I choose no treatment.
- That there is no guarantee of the results.

**Be sure you have your questions answered before you sign this form**

I give my permission for this surgery or procedure.

Sign Here →

\_\_\_\_\_ Date/Time

\_\_\_\_\_ Patient's Signature

\_\_\_\_\_ Witness to Signature

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Section for a Patient who is a minor, or is not legally able to sign. Signature is from a person who has legal rights to consent for the Patient.

\_\_\_\_\_ Signature of Person

\_\_\_\_\_ Legal Consent Relationship

\_\_\_\_\_ Date/Time

\_\_\_\_\_ Witness to Signature

Page 2 of 2

**FIGURE 4-3** Consent for surgery or procedure form.  
SOURCE: Abrams, 2013.

consent process, individual hospitals are encouraged to do small tests of change to see what might not work well in their settings and to allow some time to allay concerns or fears. It is important to make sure that the process is adapted to each hospital, because even though the organization is a system, each affiliate has a great deal of independence.

The Iowa Health System has achieved 9 of the 10 attributes of a health literate system, Abrams said. Interest in the consent project within the context of the health literacy effort was generated when people noticed that the original form was very hard to read. For example, the director of risk management, who is a member of the law department and serves on the health literacy collaborative, identified case law concerning communication of risk in which claims were filed due to lack of informed consent. Lack of understanding of informed consent is also a patient safety issue.

The evaluation of the form led to the questions, If the form is too difficult to understand, is a patient's signature meaningful? Are patients undergoing surgery without fully understanding the procedures, their risks, their benefits, and the alternatives? Could a simpler, more effective tool be developed?

The law department was very supportive of this initiative, Abrams said, on the basis that the doctrine of informed consent holds that patients have the right to participate in decisions about their own care. The national focus on health literacy also helped lend credibility to this initiative, as did the growing number of standards and best practices in the field, for example, the National Quality Forum's Safe Practices for Better Health Care, which calls for use of teach-back and for improving the quality of consent documents.

In addition to having the support of the health system leaders and the law department, the health literacy team held a 2-day workshop to build health literacy team skills, knowledge, and understanding of plain language. The goal of the workshop was to help people recognize plain language and understand its importance. The involvement of the adult learners was also critical to the success of the project. Their involvement helped overcome concerns about readability.

Work in this area is ongoing, Abrams said. The health literacy team at each hospital affiliate identifies key participants to include in implementing the new process. The health literacy teams build tools, prepare educational materials, conduct training, and contribute to a library of readable consents on the internal website. They have also been able to expand health literacy efforts to other procedures.

Existing health literacy teams that could test and implement the new process were a major facilitating factor, according to Abrams. Also, because the process was not viewed as external to regular responsibilities,



the support of people with appropriate knowledge and expertise was forthcoming.

Steps in the development process were as follows: (1) articulate health literacy as a system goal; (2) engage in multiple rounds of feedback and input from consumers, particularly those with low health literacy; (3) underscore the value of teach-back; (4) monitor and report back on impact; and (5) relate the initiative to quality, safety, patient-centered care, risk management, and the transformation of the health care system.

Barriers included inertia as well as competing priorities that take time and resources, Abrams said. Although she found that resistance to change and legal issues were minimal barriers, there were some “turf” issues over the branding on the forms. And, finally, the affiliates are independent and cannot be forced to use the new form. There were some early adopters, and there are some who are just beginning the process of implementation.

Maintaining changes over time will, Abrams said, be facilitated by a documented, structured approach that can be replicated. This approach also helps the changes spread to additional hospitals and allows expansion to other areas, such as radiology, consent for treatment, and consent for blood transfusion. The effort is sustainable because it has become part of routine operations and because it benefits hospital operations. For example, one of the hospitals had more than 100 condition-specific forms. For them this was an efficiency issue; they were able to retire hundreds of forms and replace them with a generic one.

Abrams said many key factors led to the program’s success. First, leadership was very important, especially from the law department. A second key factor was integrating health literacy into planning, quality, and patient safety, and coupling that effort with evidence and resources from national organizations in support of health literacy. Another factor was having expert training to help jump-start the effort, as well as ongoing training and resources to prepare the workforce. Abrams said that she thinks the increase in the number of patients reading the form showed that the consent process is a navigational issue. The revised process and form improve patients’ ability to navigate that aspect of care.

In high-risk situations, the new form helps address doubts that the patient is giving true informed consent. Abrams ended her presentation by thanking the people who have led and facilitated health literacy work at her organization.

## DISCUSSION

*George Isham, M.D.  
Chair, Roundtable on Health Literacy  
Moderator*

Isham said that the presentations reminded him that the passion and commitment to do public good began, for many organizations, with being responsive to patients and patient care in the community. He said he thinks it is very important that people's work is aligned with a purpose and a true commitment to helping others.

Robert Logan, representing roundtable member Betsy Humphreys, noted that the National Library of Medicine (NLM) was founded on the singular efforts of one person 160 years ago, John Shaw Billing, and that it is amazing what one committed person can do. The NLM has a special interest in Native American health. The library has an exhibition, a website, and an iPad application called NLM Native Voices dedicated to those issues and the many perspectives on health among Native Americans, including Alaska natives and native Hawaiians. Logan asked Riffenburgh if her organization had any special health literacy strategies or initiatives for the Native Americans.

Riffenburgh said that it is a challenging area. UNM Hospitals has had a Native American Health Services unit for some time. The hospital is located on Indian land, which is leased by the hospital for \$1 per year. The hospital has made a special commitment to people of Native American heritage. Native Americans have specific patient navigators and advocates to help them in the system. The health literacy efforts that Riffenburgh has initiated are not focused on that population specifically, however, because every population the hospital serves has the same level of need. Riffenburgh said that much of the assistance provided to Native Americans is related to health literacy, but there is no formal connection. She said that she and the director of Native American Health Services are in the same organizational unit, but their work does not yet overlap.

Darren DeWalt, roundtable member, observed that most of the efforts presented involve intensive organizational change. Health literacy is not something that can be picked up and simply dropped into place. Many people and organizations say they can and do develop health literate products that can be applied anywhere, but the presenters suggested that it is difficult and time consuming to implement organizational change to improve health literacy. DeWalt then asked Izquierdo-Hernandez to describe what she meant when she talked about standardizing key messages and how she does it.

Izquierdo-Hernandez said that her organization's health educators have key messages that are developed jointly with patients and the director of health literacy. They are focused around specific health conditions and consist of a series of topics to be covered by the health educators. There is standardization among the topics and messages, and everyone across the organization is aware of those key messages. Although a lot of health literacy material is being created by individual organizations for the communities they serve, that material can be shared with other organizations and communities and adapted as needed. Dissemination can be a challenge, she said.

DeWalt then asked what in health literacy can be borrowed or adapted from other organizations and what needs to be developed within each organization.

Riffenburgh said that a number of resources, such as the *Health Literacy Universal Precautions Toolkit* and the TeachBackTraining.org website, can be helpful to any organization undertaking health literacy initiatives. But, she said, there is another category of tools that need to be developed within an organization because they have to be context-specific for the politics and structure of the specific organization.

Hall said that at Lilly she has used many tools developed outside the organization, particularly ones that have been evaluated for effectiveness because, as a pharmaceutical company, her organization is very data-driven. But she also adapted tools so that they were appropriate for Lilly, even changing materials for use in different parts of the organization. It is important to use the language of one's audience and to understand specific motivations and incentives to engage in health literacy, Hall said.

Abrams agreed that there are great tools available that can be adapted for particular situations. Each tool needs to be evaluated for its usefulness and effectiveness in the specific context in which it will be used. One cannot simply download a form that claims to be written in plain language and call that health literacy. Abrams said she has seen a lot of progress in the past 5 or 10 years with organizations taking a more thoughtful approach to the development and use of materials. There are also changes taking place within the culture of medicine and health care that encourage linking quality and performance improvement efforts with health literacy. These linkages and integration should become part of the way a health literate organization does business, Abrams said. She emphasized that a very important thing to remember when developing health literacy initiatives within an organization is the voice of the patient. Engaging with patients and adult learners in a respectful, mutual partnership is very important to developing programs.

Margaret Loveland, roundtable member, said that her organization, Merck, has developed a training program for everyone involved in creat-

ing consumer materials, including outside contractors and vendors, to ensure that their materials meet the same standard. She said a great deal of effort was required to achieve minimal participation in health literacy activities until a new global marketing leader who was passionate about medication adherence started working at the company. This focus on adherence led to a focus on health literacy, and that was the beginning of leadership support. Loveland said that initially the Merck department of health literacy had only one employee, but it is a much more active entity now. She said that although Merck is more active in health literacy, it still is not part of the culture, and there are issues with both the legal and marketing departments. She asked if Hall faced any of the same issues in her work.

Hall said she had faced some of those same issues. She said that her background included work in marketing, sales training, and leadership development, which gave her a better understanding of their perspective. Although a great deal of work remains to be done, she said, she is working with the marketing department to help them understand that engaging in health literacy could give the organization a competitive advantage. As a result, they have begun assessments of a few of the marketing materials to see how they can be improved from a health literacy standpoint.

Isham said the roundtable had engaged in work related to clarity of communication about drug dosing and other issues and has presented workshops on the topic in the past. He noted that several speakers mentioned regulatory and legal issues related to pharmaceutical patient education materials and said this might be a topic the roundtable should take up again. Addressing the challenge of communicating clearly with regard to medication and drug dosing in the context of the regulatory environment is an important issue, he said.

Wilma Alvarado-Little, roundtable member, asked Abrams and Riffenburgh about translation of consent forms into languages other than English. What kind of guidance did the translators receive regarding health literacy and plain language? she asked. Are health literacy and plain language considered when dealing with outside vendors?

Abrams said that Iowa Health Systems has a team of translators within the system, and the health literacy team works with them. She said it is very important to translate from plain-language English to plain language in the new language, because the original document needs to be a health literate document. She said they also commission two translations for each document to be sure that they are getting the best product. They also perform a small test with the translated document to further validate that it is well written.

Riffenburgh said the issue of plain-language translation is something she is still working on, particularly building a relationship with inter-

preters. She is working to help them understand what they can do to make information more readable even if the document in English is very difficult to read. One of the challenges is the perception that translators are legally or ethically bound to produce the same document in the new language—that everyone should be given the same unreadable document. The translators are also concerned that if they change a document, then they will get in trouble for it. The translators and interpreters have not had any training with the consent forms, and it is a conundrum, Riffenburgh said, because they are stuck with the materials they are given. Riffenburgh said that in response to this issue, she has focused on improving the English-language documents so that the translators and interpreters have better material to work with.

Hall said that once they have created patient education materials in English that follow health literate principles, they translate them into other languages, and then a separate group translates the material back into English. This is one way to check that the health literacy principles are maintained in the documents, she said.

Susan Pisano, roundtable member, said she was glad to hear presentations from such a geographically diverse group because it meant good work was being done across the country. She said that a common complaint of members of her organization, American's Health Insurance Plans (AHIP), is that even when an organization is doing well with health literacy internally, when they need to contract work externally they run into a problem. She wondered if contracting with other health literate organizations could be considered an aspect of being a health literate organization.

Riffenburgh said she is a specialist in materials development with a background in adult literacy and special education. A short time ago she conducted a research study to find out whether an online search for easy-to-read health materials identified materials that met any kind of health literate guidelines. The answer is no, they did not. Many organizations and individuals claim they are creating materials that are easy to read, and the materials are posted in a variety of places, but they are not health literate materials. The difficulty is finding vendors who do use health literacy principles. She said she used to be able to go to the adult literacy community to conduct field tests of materials. But, now, many of those communities in her state say she cannot conduct tests to receive feedback because of the Family Educational Rights and Privacy Act.

Abrams said that when requests for proposals are issued to develop educational materials, the application guidelines should specify that the materials adhere to a checklist for reader-friendly print materials.

Pisano said AHIP has developed such a tool to assist health plans. Izquierdo-Hernandez asked if there is a dialogue about health literacy

in the health plans. Pisano said yes. She staffs a health literacy task force that has representatives from 65 of AHIP's member companies. There are monthly programs on health literacy, and they develop tools and resources for companies to start and advance health literacy programs.

Rima Rudd, roundtable member, said that when we look at organizational change, we focus on process. Everett Rogers, an expert in the diffusion of innovations, said that organizations do not adopt an innovation, they adapt it. The articulation of the change, the modifications, and the adaptations are incredibly informative. They build knowledge, and that is how we can move on, she said. So, instead of trying to package and distribute a health literate consent form, one should package the process so that others can understand how to develop the form.

Brach said she coauthored a paper several years ago that had nothing to do with health literacy called "Will It Work Here?" The paper is about looking at innovations to determine whether they can be adapted to one's organization. Brach then recalled Izquierdo-Hernandez's comment about negotiating shared savings and asked her to talk about what kinds of shared savings were negotiated, with whom they were negotiated, and what was included in the calculation of costs.

Izquierdo-Hernandez said they negotiated shared savings with a health plan. Her organization was clearly the lowest-cost provider in the plan network. If the center does well, it shares in the savings, but if it does not do well, it shares in the risk. For the past 18 months, the center had done well, and the shared savings enabled the organization to reinvest in its system to expand health education and care coordination.

Isham concluded the discussion session by thanking the panel.

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## 5

# Concluding Panel

**SABRINA KURTZ-ROSSI, M.Ed.**

*Principal, Kurtz-Rossi and Associates*

The following is a summary of the presentation given by Sabrina Kurtz-Rossi. It is not a transcript.

Kurtz-Rossi said she would be presenting her perspective on the workshop presentations. First, she said, the field has come a long way. Titles such as “director of health literacy,” “health literacy coordinator,” “director of education and health literacy,” and “senior health literacy specialist” did not exist a short time ago. Health literacy has become a respected field of study, with its own group of professionals, and that indicates how far the field has come. Yet, most people who work in health literacy have other credentials before they enter the field, and that, Kurtz-Rossi said, is significant.

A lot of new people are entering the field of health literacy, and those people really make a difference, Kurtz-Rossi said. Every speaker identified having the support of leadership as critical to moving an initiative forward. But the people who are passionate about health literacy work, who really believe in equity and making sure that people understand and are able to act on information for themselves, are who really make change happen. Kurtz-Rossi said that she believed that this was something that needs to be remembered in order to support those doing the work.



Another theme Kurtz-Rossi identified throughout the presentations was that people need health literacy tools to be successful. There are a number of tools out there—teach-back, confirming understanding, plain language, and now something new, HELPix. In addition, there is the *Health Literacy Universal Precautions Toolkit* from the Agency for Healthcare Research and Quality.

One thing Kurtz-Rossi said she did not hear about was any organized professional development for people in the field. There are a number of tools, but there needs to be a place to bring them together so that new people in the field know where to go to get them. Evaluation is another area in which health literacy professionals need more support. It is important to provide technical assistance, training, and resources for evaluation. It is important both to plan the evaluation while designing the program and then to actually conduct the evaluation. These are basic things, like measurable objectives and logic models. There is a strong and growing research base, which has helped develop the field, although there is still work to do.

Kurtz-Rossi said the health literacy field has to do a better job of engaging the community. Medical care cannot solve all health problems. Patients need to be educated, to be engaged in a dialogue, and to participate in decision making. Health literacy could use community partners that may or may not be health oriented, such as social service programs.

Related to that point is the issue of culture, literacy, and language, Kurtz-Rossi said. A number of speakers talked about how critical it is to link these elements. Health literacy work must pay attention to language issues and language access. This needs to be emphasized more and could be a topic for a future roundtable meeting. One component often missing in the training of health professionals is how to work with interpreters. Training interpreters in health literacy is important, but health professionals also need to be trained to work effectively with interpreters.

Technology was an issue mentioned by a number of speakers, Kurtz-Rossi said. Social media and new technologies might be approaches to use to increase information access and build health literacy skills in the community. Knowing how to access information, evaluate that information, and use that information to make decisions are real skills. If people don't have those skills from the outset, they will not learn them during the patient-provider interaction. Working with the community might help with that.

Kurtz-Rossi said that the way in which the roundtable supports the development, growth, and sustainability of the field is key. For example, with regard to standards, how do people in the field know they are doing the right thing? The roundtable might be a leader in this discussion. There is also discussion in the field about establishing a health literacy associa-

tion, which, Kurtz-Rossi said, is needed for health literacy professionals to take themselves seriously as a profession.

Kurtz-Rossi also noted that everyone in the room was a health literacy expert with a lot of experience to pass on to new people coming into the field. That could be a role for a health literacy association—to mentor and pass on experience, she said.

**RICARDO WRAY, Ph.D., M.S.**

*Associate Dean for Graduate Education and Research  
Saint Louis University*

The following is a summary of the presentation given by Ricardo Wray. It is not a transcript.

Wray noted that the roundtable members, presenters, and participants were an early adopter group in health literacy. The challenge for this group is to codify and document successes. Some of the key lessons he learned from the presentations were the importance of

- leadership,
- integrating health literacy across systems and departments, and
- using evidence both to begin a conversation about health literacy and then to maintain efforts in health literacy.

Wray said that a common theme of the presentations was that the policies coming out of The Joint Commission and health care reform serve as an impetus for organizations to move forward with health literacy efforts. Rather than hindering efforts, these policies are helping move the conversation forward. Another common theme, he said, is that the habit of looking for best practices and standards is an attribute or characteristic of an organization that has success in sustaining and maintaining these efforts.

Cost is a common concern for administrators and leadership, who ask, “Will the program cost money?” Wray said he thought there was a lot of good material at the granular or tactical level, such as creative strategies that people employed to keep their efforts from becoming too expensive for their organizations. For example, rather than spending \$4 million to train all of the nurses in the Carolinas HealthCare System, the health literacy team spent much less creating the materials and disseminating them. They spread the effort through the organization using an on-the-job training modality. Many others used community partners and volunteers as a resource, Wray said.

Wray noted that another critical factor is having a team approach across departments and using a multipronged approach, which are also strategies identified to gain the support of physicians. If the patients are engaged and acting on their knowledge and if the support systems are in place, then, before long, the doctors will join in because it becomes a matter of course. Culture and leadership also are important, he said.

Wray said that he found it interesting that most of the speakers were from large health systems. One of the questions is how to replicate these efforts in smaller, independent organizations.

For research and evaluation, evidence is important, and a number of metrics were identified, Wray said. He hoped that these could be codified to develop common, validated methods of study design and metrics for measurement that are appropriate. This is also a time to begin to think about conceptual frameworks, said Wray. A number of theoretical and conceptual approaches are very consistent and align with these efforts. Some of these approaches were mentioned by the speakers—quality improvement, organizational behavior and change, and diffusion of innovations—and the extent to which this thinking is integrated into health literacy efforts is important. Wray said that he thinks this effort of establishing conceptual frameworks for health literacy is in the early stages, but it is progressing.

Evidence is also important to dissemination and implementation. In thinking of ways to make programs easy for organizations to adopt, the nature of the evidence has to be considered in terms of what is appropriate and acceptable for different audiences. For example, in smaller organizations, there might not be the expertise or the resources to conduct randomized controlled trials, but there might more pragmatic study designs that are appropriate. Wray said that the organizations he has worked with have designed their own studies for their own contexts.

Implementation science is also a key framework for health literacy programs, Wray said. Implementing health literacy programs is often more adaptation than adoption. Each organization must identify key ingredients of the interventions that can serve its needs. Strategies for marketing and distributing knowledge, tools, and resources are going to be important areas of work. A number of speakers had introduced resources that they have made available to the public. It is a challenge to provide standardized education materials because an item will not work for all populations, he said. However, if the health literacy community can identify some strategies for sharing the resources, starting with the resources that are available across the organizations represented at the workshop, then that is a good starting point. It is important to make sure that the materials that are shared emphasize the system's sensibility.

Wray noted that the attributes that seemed to be discussed less over

the course of the day were the fourth attribute (includes populations served in the design, implementation, and evaluation of health information and services), the fifth attribute (meets needs of populations with a range of health literacy skills while avoiding stigmatization), the seventh attribute (provides easy access to health information and services and navigation assistance), and the tenth attribute (communicates clearly what health plans cover and what individuals will have to pay for services).

Wray concluded his remarks by asking which of the attributes of a health literate organization should come first. Are there foundational attributes that set the stage for the others? Over the course of the presentations, it seemed that leadership and training may fill the role of foundational attributes, he said.

## DISCUSSION

*George Isham, M.D.*  
*Chair, Roundtable on Health Literacy*  
*Moderator*

Isham called on former roundtable member Sharon Barrett to start the discussion. Barrett said that as a founding member of the roundtable, she has seen health literacy grow and spread over the years as resistance to implementing health literacy interventions decreases. As she listened to the presentations, she wondered, what got each of these people interested in health literacy? Was it the growing number of publications. Is it the information coming from the roundtable? What, she asked, engaged the presenters?

Bauer said he supported his grandparents as they aged and saw the need for clear communication and partnering, so he became an advocate, and this is his passion.

Rogers said seeing patients readmitted time and again to the hospital because they didn't understand how to take care of themselves motivated her.

Riffenburgh said she was working in adult basic education and special education. But when she had to begin taking care of her father, who had leukemia, and her mother, who had dyslexia, she realized there was a mismatch between what they could understand and what she could.

McCandless said she had to complete a maintenance-of-certification module in order to stay board-certified for internal medicine, and she found health literacy.

Parnell said a major component of her nursing training was patient education and health literacy (although she didn't have a name for it then), and it has been a labor of love ever since.

Komondor said she also did not know what it was called, but her passion came from years in nursing and personal experiences with siblings with chronic illnesses, trying to interpret what was going on. But the American Medical Association (AMA) videos were the igniting force when she realized the depth of the struggle that some people have.

Yin said her interest began when she realized how often patients were confused about what was happening. Then she met and heard health literacy champions—Benard Dreyer, Linda van Schaick, Ruth Parker, and Rima Rudd—and they inspired her to get into the field.

Izquierdo-Hernandez said that she came to health literacy through working with the community over many years, which increased her understanding of the value of formalizing performance improvement within an organization.

Hall said personal experience brought her to health literacy, although, like many others, she did not have a name for it. She worked with parents who were grieving over the loss of a normal pregnancy. In an attempt to try to meet them where they were, she would try to help them understand what was going on with the complicated situation of monitors and ventilators and IVs and noises. The AMA videos were the final motivating factor.

Abrams said what motivated her was finding a name for something that was of lifelong interest, hearing a couple of key people eloquently describe the importance of health literacy, having tools available, and getting to hear the eloquent voices of new readers and adult learners who put a real face on the issue.

Noonan said she came to health literacy because she was tapped by a senior leader to lead health literacy, about which she knew nothing, from a quality perspective. But as she dived into the content, she quickly became a zealot, she said, thanks to Cindy Brach and Darren DeWalt.

A meeting participant said that as an immigrant she experienced communication barriers, difficulties accessing care, and trouble understanding health information given to her. Health literacy empowered her, she said. Now she wants to be a health literacy champion, teaching providers what patients go through and helping patients become their own advocates.

Wray said he heard that the passion for health literacy comes from personal experience, particularly for the clinicians in the room. For himself, Wray said, he comes from the field of communications, so it is all about health communication to him.

Kurtz-Rossi said that a focus on adult learners and adult literacy brought her to the field—working with adult learners who talked about their struggles.

Scott Ratzan, roundtable member, said he entered the field when he first worked with Ruth Parker to define health literacy for a National Library of Medicine bibliography.

Cindy Brach, roundtable member, said she thinks measurement is another theme heard throughout the day, that is, measurement for quality improvement, for marshaling support, and for performance rewards or saving. Perhaps it is time to focus more effort on health literacy measurement, she said.

Rima Rudd, roundtable member, observed that early measurement in health literacy focused on attributes of the patient, that is, ability to read, to comprehend, to recognize words, to read instructions, and to deal with numbers. Nothing had been said about measures of a health care professional's ability to present information in a clear, logical order without jargon, she said. Why is it that discussion of measures of professionals has focused on whether they use specific health literacy tools? There are measures of systems, but missing are measures of how well those in the health care and public health systems communicate, she said.

Andrew Pleasant, roundtable member, said that a common and validated measure of health literacy is needed. Tools do exist to evaluate the health literacy skills of the medical team, he said, and many different tools are used to evaluate patient health literacy skills. But there is no single agreed-upon tool in either case. Only one of the definitions of health literacy explicitly states that it is not only the patient's problem but also the health care professionals' problem, and that is the Calgary Charter on Health Literacy.<sup>1</sup> But now is the critical time to examine where we are in health literacy and where we need to go, he said. One way to do that would be to revisit the 2004 Institute of Medicine (IOM) report *Health Literacy: A Prescription to End Confusion*. The opportunity to advance health literacy has never been more embedded into the regulatory structure of the United States, he said, and now is the time to act.

Linda Harris, roundtable member, said that in terms of health literacy measurement, when she thinks of a unit of analysis, it is either the patient or the provider. One of the things that is appealing about the chronic care model is the emphasis on productive interaction, which is about whether two people together produce a positive outcome. Perhaps productive interaction can be measured through teach-back, which invites feedback as its fundamental element. In the giving and requesting of feedback, there is real conversation. If patients and clinicians can have conversations where there is reciprocation of feedback, each has the opportunity to adjust to the other. If that could be evaluated, she said, it could move the field forward. It also has implications for training, she said. How does one train somebody to engage in that kind of conversation?

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<sup>1</sup> The Calgary Charter is a document that identifies core principles for developing health literacy curricula. See [http://www.centreforliteracy.qc.ca/sites/default/files/CFL\\_Calgary\\_Charter\\_2011.pdf](http://www.centreforliteracy.qc.ca/sites/default/files/CFL_Calgary_Charter_2011.pdf) (accessed June 21, 2013).

Wray said he thinks it is important to identify strategies for measuring provider communication skills. If health professionals are trained in health literacy skills while they are in school, then that would also be a good place to develop evaluation measures.

Alice Horowitz, University of Maryland, College Park, said that placing health literacy on board examinations, whether national, state, or regional, is a major incentive to teach health literacy in health professional schools. She urged people to focus effort on doing this.

Will Ross, roundtable member, said that medical students in his school must complete a clinical skills examination that assesses their ability to communicate effectively. And this idea is spreading to other schools. What is missing in the field are trained and certified health literacy experts. We need experts who understand the literature and can monitor the training of other health care professionals, he said.

Kurtz-Rossi said that Cliff Coleman from Oregon Health and Science University has begun to develop some health literacy competencies for health care professionals, but noted that it is true that we have not yet identified what the competencies are for those communicating information.

Patrick McGarry, roundtable member, suggested that motivational interviewing could be a key communication tool.

Horowitz pointed out that neither oral health nor dentistry was mentioned during the meeting, although the conference organizers tried to find a dental health literacy implementer to speak. Yet, oral health is of prime importance, she said. Beyond that, however, Horowitz said, she thinks it may be time for another crosscutting, state-of-the-art IOM consensus report on health literacy. It has been 10 years since the first report, and much has changed, she said.

Benard Dreyer, roundtable member, said he identified four major themes throughout the presentations. First, organizations that are successful at implementing health literacy have a person whose job is to move health literacy forward and whose title reflects that. Yet, health literacy also needs to be integrated into safety, quality, regulation, value purchasing, and so on for it to be sustainable. Second is the need for supportive and engaged leadership even if competing priorities sometimes result in fewer resources than necessary to mount a successful health literacy effort. Third is the bidirectional relationship of health literacy and limited-English-proficiency efforts—each needs to inform the other. Finally, there is a need for general processes and tools that can be used anywhere, but also needed is the opportunity to tailor these processes and tools to particular settings, Dreyer said.

Kurtz-Rossi said that the majority of those who work in health literacy come from a number of different fields—nursing, dentistry, physical



therapy, and education, for example. It is important to be as inclusive as possible as the field of health literacy moves forward, she said. In terms of measurement, there is a lot to be learned from the literacy field. Finally, there are a number of best practices out there that are not research based. There needs to be a place to house those practices so that people have easier access. It also would be great to have a health literacy research journal, she said.

Wray said that one thing that struck him is that the successes described by the presenters took years to develop. Many had been on the job for a decade or more. Yet, it is still not clear how to begin efforts in an organization that does not recognize the importance of health literacy, and work is needed on this question, he said.

Isham said that broad social changes take time and that the momentum for health literacy is growing. In terms of organizational change, one might learn from models in the health care quality improvement field.

Ratzan said he agreed with earlier statements that it is important to include health literacy in board-certification examinations because that will be an incentive to learn. We also need tools, including health literacy tools, for mobile health, he said. Another area of need is how to sustain advocacy for health literacy, not only at the local level but also nationally and internationally, with corporations and governments. We need to look for new ways to incorporate health literacy in public health and medical institutions. We need to work together in partnerships to advocate, develop competencies, develop population measures, and figure out how to sustain and expand health literacy efforts, he said.

Darren DeWalt, roundtable member, said that the spread of innovation is facilitated by an innovation's adaptability and ease and simplicity of use. Several speakers said they took concepts from health literacy and boiled them down to simple things they could use. Several people said they focused on Ask Me 3 and teach-back, yet there are many tools for health literacy, and it is important to remember that, DeWalt said. Feedback on the *Health Literacy Universal Precautions Toolkit* is that it is too lengthy and complicated. But health literacy groups should choose items from the toolkit that work for each situation. One does not need to use the entire kit, he said.

Steven Rush, roundtable member, pointed out that organizational change in an organization with more than 100,000 employees is difficult. Rush said he was impressed by successful efforts to reduce the reading grade level of materials, but it is important to note that, by itself, materials written at a lower level are not necessarily health-literate materials. Another important point, he said, is the idea that health literacy is related to social justice and to the social determinants of health. There are millions of people who will soon have access to medical care under the provisions



of the Patient Protection and Affordable Care Act. Many will not have any idea how to access and use health care, he said. This is a major opportunity to demonstrate health literacy's importance. Finally, in the spirit of sharing health literacy tools, Rush said that UnitedHealth Group has created a plain-language English-Spanish glossary of more than 1,600 health and health insurance terms, including dental health, which everyone is welcome to use.

Lori Hall, roundtable member and speaker, said that she often gets inspiration for health literacy efforts from outside the field. For example, she recently watched a TED Talks<sup>2</sup> episode about the golden circle, that is, about what differentiates successful efforts from less successful ones. Successful efforts focus on why the effort is important. That is what she is trying to communicate in her organization—why health literacy is important. Similarly, an article she read about shared values described how businesses come together with academia and communities to solve social issues. This may be something that health literacy needs to focus on, she said. When she talks with her corporation's senior leaders, the focus is on corporate responsibility. Only after having that conversation is health literacy woven in, she said.

Laurie Francis, roundtable member, said health literacy is part of patient-centered care and communication. The patient-centered health home approach is growing in community health centers around the country. With the implementation of the Affordable Care Act, these centers can expect to serve millions more people who will be able to get health insurance and access to care, she said. But health literacy is not fully embedded in those centers even though there is some good work under way on patient-centered communication. She said she agrees with Rush that health literacy is connected to social justice and social determinants and that this should be an area of focus.

Wilma Alvarado-Little, roundtable member, said that it is important to think about teaching health literacy early in schools.

Kurtz-Rossi said she would emphasize the attribute of preparing the workforce and think about the characteristics of a learning organization. A learning organization changes on the basis of its people, and changing the way people view and engage in health literacy changes the organization. Ratzan was correct, she said, when he spoke of the importance of advocacy. Currently, no organization is an advocate for health literacy, but that could be an important role for a health literacy association, she said.

Isham said that as he listened to the presentations about successful implementation of the attributes of a health literate organization,

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<sup>2</sup> TED Talks are conferences on different topics that are available for free online viewing at [www.ted.com](http://www.ted.com).

he began thinking about systems theory and adaptive systems and the rules that promote change. He asked Wray to comment about the character of changes, that is, about driving change in the system that would lead to more effective provision of information to low-literacy populations. To what extent do systems theory and complex adaptive systems inform us about the kinds of things that would be useful at a national level or to an industry, as opposed to things that might not be as helpful?

Wray said that what comes to mind are earlier comments about how the policy environment has simplified the impetus for organizations to engage in this kind of work. The benefit of the roundtable, he said, is that it includes representatives from private-sector companies, from the insurance industry, from education, from health care organizations, and from academia. There can be conversations about the extent to which intersectoral system demands can be synchronized. Such conversations could, he said, find areas where there is agreement. Wray said that Ruth Parker made a presentation in which she said that health literacy is a “primer coat” in that it is essential to quality of care, patient safety, and patient-centered care, but it is not the whole thing. Much of the resistance from administrators is that they think health literacy is elective, that it is gilding. But if the system can establish health literacy as an essential part of the health care system, that is a major step, Wray said.

It is fascinating, Wray said, that the field has transformed and changed from one that focused initially on serving individuals with low literacy to one in which the emphasis is on system demands. An article by Koh and colleagues (2013) in *Health Affairs* said that if 88 percent of people are not proficient in health literacy, then people are not the problem, the problem is the system.

Isham concluded the workshop by once again thanking all presenters for their stimulating and fascinating presentations and everyone for their active participation in discussion sessions.

## REFERENCE

- Koh, H. K., C. Brach, L. M. Harris, and M. L. Parchman. 2013. A proposed “health literate care model” would constitute a systems approach to improving patients’ engagement in care. *Health Affairs* 32(2):357-367.



# Appendix A

## Workshop Agenda

### Organizational Change to Improve Health Literacy April 11, 2013

**Thursday, April 11**

**OPEN SESSION**

**Lecture Room and Room 125**

- |                |   |
|----------------|---|
| 8:30-8:40 a.m. | Welcome and overview of day<br><i>George Isham, Chair</i> |
| 8:40-8:45      | Introduction of first panel                               |
| 8:45-9:30      | Three 15-minute presentations                             |
| 8:45-9:00      | <i>Bridget McCandless, Shared Free Clinic</i>             |
| 9:00-9:15      | <i>Karen Rogers, Franklin Community Health Network</i>    |
| 9:15-9:30      | <i>Laura Noonan, Carolinas HealthCare System</i>          |
| 9:30-10:15     | Discussion  |
| 10:15-10:30    | BREAK   |
| 10:30-10:35    | Introduction of second panel                              |

10:40-11:40	Four 15-minute presentations 10:40-10:55 <i>Tom Bauer, Novant Health</i> 10:55-11:10 <i>Karen Komondor, St. Vincent Charity Medical Center</i> 11:10-11:25 <i>Terri Ann Parnell, North Shore–Long Island Jewish Health System</i> 11:25-11:40 <i>H. Shonna Yin, New York University Medical Center/Bellevue Hospital Center</i>
11:40 a.m.- 12:30 p.m.	Discussion
12:30-1:30	LUNCH
1:30-1:35	Introduction of third panel
1:35-2:35	Four 15-minute presentations 1:35-1:50 <i>Paloma Izquierdo-Hernandez, Urban Health Plan, Inc., South Bronx</i> 1:50-2:05 <i>Audrey Riffenburgh, University of New Mexico Hospitals</i> 2:05-2:20 <i>Lori Hall, Eli Lilly and Company</i> 2:20-2:35 <i>Mary Ann Abrams, Iowa Health Systems</i>
2:35-3:30	Discussion
3:30-3:45	BREAK
3:45-3:50	Introduction of final panel
3:50-4:10	Two 10-minute presentations identifying important points learned 3:50-4:00 <i>Sabrina Kurtz-Rossi, Kurtz-Rossi and Associates</i> 4:00-4:10 <i>Ricardo Wray, Saint Louis University College for Public Health and Social Justice</i>
4:10-4:30	Comments from the roundtable members
4:30-5:00	Comments from the audience

## Appendix B

### Speaker Biosketches

**Mary Ann Abrams, M.D., M.P.H.**, spearheaded the development of Health Literacy Iowa, the statewide center for health literacy, and leads Iowa Health System's health literacy quality initiative. Her focus is on implementing and sustaining health literacy-related interventions in real-world clinical settings, including the development of a reader-friendly consent form for surgery/procedures, the *Always Use Teach-Back! Toolkit*, online modules on geriatrics and health literacy, and a reader-friendly shared decision-making tool. She co-chaired the American Academy of Pediatrics Health Literacy Project Advisory Committee, served on the American College of Physicians Foundation Health Literacy Programs Committee, and was twice selected as the Pfizer Visiting Professor in Health Literacy. She is coeditor and contributing author to the American Academy of Pediatrics' *Plain Language Pediatrics* guidebook and has publications on implementing health literacy-based interventions, fostering pediatric health literacy, and partnering with patients and adult learners. Through Reach Out and Read, she links health literacy to promoting early literacy and school readiness. Dr. Abrams is board-certified in pediatrics and preventive medicine and has worked at the clinical/public health interface at national, state, and local levels.

**Thomas Bauer, M.B.A.**, is the corporate director of Remarkable Patient Experience at Novant Health. Novant Health is a 13-hospital system serving patients in Virginia, North Carolina, South Carolina, and Georgia with more than 26,000 employees, including a 1,100-plus physician medical

group. Mr. Bauer leads the research, development, and implementation of health literacy, patient empowerment, and cultural competence initiatives at Novant Health. He is a passionate leader in empowering patient partners through enhanced health literacy. Research conducted at Novant Health has resulted in increased patient understanding, reduced preventable readmissions, and enhanced patient satisfaction. As a result of the research findings, 26,000 clinicians, providers, and professional staff were trained in a modification of Ask Me 3 and teach-back.

Mr. Bauer is the 2011 recipient of the Eagle Award from the North Carolina Alliance for Health Communities. The Eagle Award is presented to an individual or organization that has demonstrated compelling vision, leadership, and excellence in their commitment to improving health outcomes in North Carolina communities. Mr. Bauer is a contributing author of the "Health Literacy Toolkit for Cardiology" and the "Health Literacy Toolkit for Rheumatology" with the health literacy researchers at the University of North Carolina at Chapel Hill. His research has been presented in numerous journal articles and at the International Stroke Symposium, Institute for Healthcare Improvement, International Health Literacy Researcher Conference, and numerous venues in his home state of North Carolina.

**Lori Hall, R.N.**, is a health education consultant with Eli Lilly and Company, with almost 30 years of health care experience, including direct patient care as well as experience in the diagnostics and pharmaceutical industries. Throughout her career, her focus has been in the areas of training and leadership development, adult learning, and coaching. Lilly's health education department develops and delivers nonbranded, nonpromotional, patient-focused education materials aligned with health literacy principles in the areas where Lilly has presence and expertise. Ms. Hall played an integral role in Lilly's entry in the Eleventh Annual Institute for Healthcare Advancement Health Literacy Awards, "Feel Your Best: Patient Education Brochures," which was selected as the winner in the published materials category, thus giving national recognition to the company's commitment to health literacy principles.

Ms. Hall is also spearheading an effort to raise corporate awareness on how better health communications help to improve patient adherence and, therefore, achieve better health outcomes. Through her work with a grass-roots initiative of Lilly advocates from other major patient "touch points," health literacy pilots are being conducted in the areas of clinical trial management and informed consent, the medical call center, medical education grants, and brand marketing. Each of these pilots aligns with the overall vision to help engage, educate, and empower patients to be more active in their own health care.

Ms. Hall has a bachelor of science degree in nursing from Purdue University. Currently residing in Indianapolis, she dedicates her spare time as a mentor in Big Brothers Big Sisters of Central Indiana.

**Paloma Izquierdo-Hernandez, M.S., M.P.H.,** is the president and chief executive officer of Urban Health Plan, Inc. (UHP), a network of community health centers located in the South Bronx and Queens, New York. Led by her efforts, UHP has grown from a one-site facility to a network of federally qualified community health centers that includes eight sites, eight school health programs, three part-time sites at facilities for at-risk populations, two large Special Supplemental Nutrition Program for Women, Infants, and Children sites, and multiple other grant-funded programs, serving 54,000 individual patients in 2012 through 320,000 visits. Ms. Hernandez spearheaded the development and implementation of an organization-wide health literacy and education strategy that has gained UHP national recognition. Its asthma management program has received the National Exemplary Award from the U.S. Environmental Protection Agency for the work it has done in reducing asthma-related hospitalization rates in the South Bronx. UHP has been named 1 of the top 20 community health centers in the country by the Bureau of Primary Health Care and received the Nicholas E. Davies Award for Excellence from the Health Information Management Systems Society for excellence in the use of electronic health records. UHP has a Level 3 recognition as a Physician Practice Connections–Patient-Centered Medical Home from the National Committee for Quality Assurance. Ms. Izquierdo-Hernandez is the immediate past president of the board of directors of the Community Health Care Association of New York State. She also serves on multiple professional and community boards and organizations, including the National Hispanic Medical Association, the National Association of Community Health Centers, the Primary Care Development Corporation, Affinity Health Plan, and the Dr. Richard Izquierdo Charter School for Health and Sciences.

**Karen Komondor, R.N.,** is the director of education at the Health Literacy Institute at St. Vincent Charity Medical Center, a 200-bed urban teaching hospital in the heart of downtown Cleveland, Ohio. As director, she is responsible for all aspects of staff and program development and patient education. Ms. Komondor has more than 30 years of experience as a registered nurse in a variety of roles, including as a critical care staff nurse, fixed-wing air transport nurse, and critical care educator. From her many years of experience with patients, she has recognized the importance of health literacy's relationship to patient care and was the first to coordinate a systemwide program that served to promote health literacy



awareness. Funded by the Sisters of Charity Foundation of Cleveland, St. Vincent Charity Medical Center began its health literacy initiative in 2007 in collaboration with Project Learn, Greater Cleveland's premier adult literacy center. Since that time, Ms. Komondor has led the initiative with a goal to promote health literacy across the continuum of patient care. Ms. Komondor has conducted health literacy training at more than 30 health care facilities and conferences. She is currently working on strategies to build a regional and statewide collaborative in Ohio.

**Sabrina Kurtz-Rossi, M.Ed.**, is principal of Kurtz-Rossi and Associates, a women-owned business providing health, literacy, education, and evaluation services. She is a member of the Clear Language Group, a consortium of women-owned health literacy consultants, and is a nationally known health literacy professional development specialist. Her work supports integrating health and literacy education, enhancing patient and provider communication, developing plain-language health education materials, and using Web-based consumer health resources. Recent projects include developing a health literacy curriculum for computer training classes taught in Spanish for the Zufall Community Health Center, the Morris County Organization for Hispanic Affairs, and the National Network of Libraries of Medicine–New England Region and conducting an implementation and evaluation project to increase access to reliable health information via the Internet among older adults in rural Maine. She is coauthor of *Building a Health Literate Organization: A Guidebook to Achieving Organizational Change* (in press). Ms. Kurtz-Rossi is an adjunct clinical instructor at Tufts University School of Medicine, where she teaches health literacy and adult learning theory. She is also course director of the Health Literacy Leadership Institute.

**Bridget McCandless, M.D.**, is a board-certified internal medicine specialist with an interest in chronic disease management and poverty medicine. She serves as the medical director and cofounder of the Shared Care Free Clinic, which serves uninsured, low-income adults with chronic illness. She provides direct patient care and directs a care team of diabetes educators, pharmacists, nurses, mental health providers, ophthalmologists, podiatrists, and primary and specialty care physicians. Their outcomes-driven program has produced diabetes and hypertension outcomes that beat benchmarks for commercially insured patients. She continues her work in the areas of health care reform, patient advocacy, and health literacy.

Dr. McCandless currently serves as the co-chair of the Infrastructure Committee of the Safety Net Coalition, as a board member of the Missouri Chapter of the American College of Physicians, and as a member of

the Missouri Medicaid Oversight Committee. She served as president of the Metropolitan Medical Society, president of the Missouri Association of Free Clinics, and chair of the Healthy Independence Coalition and was a past member of the Health Care Foundation board of directors.

**Laura Noonan, M.D.**, joined the Department of Pediatrics at Carolinas Medical Center in 1994. In addition to her educational role on the faculty, she continues to practice medicine in the ambulatory, inpatient, and newborn nursery settings. She is a founding organizer and current director of the Center for Advancing Pediatric Excellence (CAPE) in the Department of Pediatrics at Levine Children's Hospital at Carolinas Medical Center. CAPE was established in 2007 to implement a longitudinal, project-based quality improvement (QI) curriculum for pediatric residents. In addition to QI education, CAPE provides QI project management and QI data management.

For the past 16 years, Dr. Noonan's focus has been on the health care QI methodology and framework across the care continuum. She is a Charlotte Area Health Education Center senior improvement advisor. She teaches courses in QI methods to health care providers at the local, regional, and national levels. She is currently involved in either QI teaching or coaching roles for a variety of collaboratives. Dr. Noonan's most recent publication is as a contributor to *Quality Improvement: Methods, Principles, and Role in Healthcare*. Dr. Noonan also has extensive experience teaching and advising about health literacy. She was the collaborative director for Carolinas HealthCare System's QI-based health literacy initiative for 24 facilities across the third largest nonprofit health care system in the United States. She is currently an adviser for the next phase of this project, an initiative to educate 10,000 nurses across two states in health literacy strategies. She frequently lectures on this topic locally and nationally.

Prior to joining the Carolinas HealthCare System, Dr. Noonan practiced in the greater Charlotte area. From 1987 to 1990 she completed a pediatric residency at the University of North Carolina at Chapel Hill, as well as a chief residency from 1990 to 1991. From 1991 to 1992 she was a clinical instructor in the Department of Pediatrics at the University of North Carolina at Chapel Hill. Dr. Noonan received her medical degree from the University of Arizona at Tucson.

**Terri Ann Parnell, D.N.P., M.H.A., R.N.**, is the vice president of health literacy and patient education for the North Shore–Long Island Jewish (North Shore–LIJ) Health System. She is also an assistant professor of population health at the Hofstra North Shore–LIJ School of Medicine. Dr. Parnell is responsible for having established a diversity, inclusion, and

health literacy strategic plan and is implementing initiatives that support the mission of the office across the 16-hospital health system, its communities, and the Hofstra North Shore–LIJ School of Medicine. She has provided health literacy leadership and consultation for all departments across the health system and is integrating concepts of health literacy, cultural awareness, and patient-centered care into core activities of the organization.

With more than 30 years of experience in nursing and health care administration, Dr. Parnell is well known for innovation in the area of health literacy. Her accomplishments include the development of an online educational module titled “Health Literacy: Partnering for Patient-Centered Care.” She received second place in the champion category of the Leonard G. Doak Health Literacy Innovator Award for demonstration of commitment to excellence in health literacy within an organization. She has also received numerous nursing awards for excellence in research, patient and family education, and community service. Her expertise and passion for health literacy have made her a frequent presenter at local, national, and international conferences. She currently serves as a member of the steering committee of the American Nurses Association Care Coordination Quality Measures Panel. In addition, Dr. Parnell is widely published in the areas of women’s health and heart disease, patient education, and health literacy. As author of *Heart Smart for Black Women and Latinas: A Five-Week Program for Living a Heart-Healthy Lifestyle*, Dr. Parnell incorporated her familiarity with the importance of community, culture, and lifestyle.

**Audrey Riffenburgh, M.A.**, is the senior health literacy specialist at University of New Mexico (UNM) Hospitals, New Mexico’s only academic medical center and the region’s only Level 1 trauma center. UNM Hospitals has more than 600 beds and 24 offsite clinics. Ms. Riffenburgh manages systemwide changes for meeting the communication and access needs of patients with a wide range of health literacy skills. She conducts training and education of staff and leadership and consults at the organization, unit, and individual leader levels on strategies and processes to become a more health literate organization.

From 1994 to 2012, Ms. Riffenburgh was the president of Plain Language Works (formerly Riffenburgh and Associates), a health literacy and plain-language consulting firm. Her firm specialized in helping health care providers, public health professionals, government agencies, researchers, and others communicate information clearly and effectively. Clients of Plain Language Works included the American Academy of Pediatrics, the Centers for Medicare & Medicaid Services, the Indian Health Service, the Iowa Health System, the National Cancer Institute, and the Navajo nation

and other tribal communities. Ten publications created or edited by Plain Language Works received awards in the plain language competition sponsored by the National Institutes of Health. Ms. Riffenburgh is a founding member of the Clear Language Group, a national consortium of health literacy, plain-language, and cross-cultural communications specialists. She is on the faculty of the nationally recognized Health Literacy Institute. Ms. Riffenburgh is working on a Ph.D. in health communication at UNM.

**Karen Rogers, M.S.N., R.N.-B.C.**, is the director of the Western Maine Area Health Education Center and the director of education of the Franklin Community Health Network at Franklin Memorial Hospital in Farmington, Maine. She has 36 years of experience in nursing, with a B.S.N. degree from the University of Connecticut, an M.S. degree in nursing from the University of Pittsburgh, and a postgraduate certificate from Kent State University. She is board-certified as a nursing professional development specialist and is active in many state and national associations. Besides overseeing and delivering education to all employees, she works closely with patients and their families for their educational needs. She is chairperson of her organization's health literacy committee and collaborates with the Geriatric Education Center at the University of New England on a number of projects, including health literacy. Her passion for patient education and health literacy has led her to deliver multiple presentations at several statewide and national conferences over the past few years.

**Ricardo Wray, Ph.D., M.S.**, is associate dean for graduate education and research and associate professor of behavioral science and health education at the Saint Louis University College for Public Health and Social Justice in St. Louis, Missouri. He has dedicated his career to the study of how communication processes can promote informed choices and healthy behaviors, support the diffusion and adoption of innovative evidence-based practices by organizations, and enhance population health. As associate dean, Dr. Wray supports faculty, staff, and students in the development and management of externally funded grants and contracts. For more than 20 years, Dr. Wray has contributed to the design, implementation, and evaluation of health communication programs promoting reproductive health, emergency preparedness, and the prevention of violence, cancer, and chronic and infectious disease. His current research explores change management strategies to promote health literate organizations among health care systems serving poor, underserved, and rural populations. His research has been funded by the National Cancer Institute, the National Immunization Program, the Office of Smoking and Health and the Emergency Communication Branch at the Centers for Disease Control

and Prevention, the Illinois Department of Public Health, the Missouri Department of Health and Senior Services, the Missouri Foundation for Health, Emerson Electric, Express Scripts Foundation, Ascension Health, and other sources. In recent years he has taught health communication, the application of theory in research and practice, and intervention research.

**H. Shonna Yin, M.D., M.Sc.**, is a general pediatrician and an assistant professor of pediatrics in the New York University (NYU) School of Medicine/Bellevue Hospital Center. Her research interest centers on the issue of health literacy and its implications for child health. A large focus of her work involves examining the intersection between health literacy and medication safety, including the development and evaluation of low-literacy strategies to improve parent understanding of medication instructions. Some of her work is featured in The Joint Commission book *Addressing Patients' Health Literacy Needs*. Dr. Yin is a key member of the Centers for Disease Control and Prevention's (CDC's) PROTECT (Prevention of Overdoses and Treatment Errors in Children Taskforce) initiative and served as co-chair of the subcommittee focused on the standardization of dosing instructions for pediatric medications.

Currently, Dr. Yin is principal investigator of a newly awarded multi-site research grant to develop and evaluate a low-literacy medication labeling and dosing strategy for pediatric prescription liquid medications, as well as co-principal investigator of a multisite research grant to develop and test a low-literacy and numeracy-focused intervention for early childhood obesity prevention; both grants are funded by National Institutes of Health/National Institute of Child Health and Development. Dr. Yin was a Robert Wood Johnson Foundation Physician Faculty Scholar (2009-2012) and a recipient of the Pfizer Fellowship in Health Literacy/Clear Health Communication (2007-2009).

Dr. Yin is a graduate of the Massachusetts Institute of Technology and the University of Rochester School of Medicine. She completed residency training in pediatrics at the NYU School of Medicine and received her master of science degree in clinical investigation through the CDC-sponsored Medicine and Public Health Research Fellowship Program at the NYU School of Medicine.