UnityPoint Health

Building Health Literate Organizations:

A Guidebook to Achieving Organizational Change

Health Literacy Iowa

Mary Ann Abrams, MD, MPH
Sabrina Kurtz-Rossi, MEd
Audrey Riffenburgh, MA
Barbara Savage BS, MT(ASCP)

Author Affiliations

UnityPoint Health
Mary Ann Abrams, MD, MPH
Barbara Savage BS, MT(ASCP)
Kurtz-Rossi & Associates
Sabrina Kurtz-Rossi, M.Ed.
Plain Language Works, LLC
Audrey Riffenburgh, MA

Contributors

Michael Abrams
Ellen Anderson
Cynthia Baur
Brent Blum
Eileen Boggess
Nolan Boggess
Dr. Nathan Boonstra
Cindy Brach
Mark Burnham
Frank Burns
Dr. Ken Cheyne
Maria Collis
Robert Dickerson
Barb Earles
Javier Harris
Mike Hoenig
UnityPoint Health Health Literacy Teams
Megan Jones
Kanan Kappelman
Norma Kenoyer
Mary Mahoney
Sandy Mote
Gail Nielsen
Suzanne Rita
Barbara Rozenboom
Amanda Schill
The New Readers of Iowa
Laura Vonnamhe
Dr. Roberta Wattleworth
Archie Willard

Acknowledgement

Development of this guidebook was supported, in part, by the Community Responsive Grant Program through the Wellmark Foundation, Des Moines, Iowa.

Abstract

There are many tools to help you engage in organizational change to become a health literate health care organization. The challenge is to use them effectively and reliably, yet choose your own path—one that works for your organization. This guidebook includes background, resources, examples, and lessons learned to help you build a health literate health care organization.

Suggested Citation

Abrams MA, Kurtz-Rossi S, Riffenburgh A, Savage BA. Building Health Literate Organizations: A Guidebook to Achieving Organizational Change. 2014. Available at: http://www.HealthLiterateOrganization.org.

Table of Contents

Guidebook At-a-Glance

1 | Introduction

This chapter will help you:

- Recognize health literacy as key to quality, safety, and equity in health care.
- Identify key areas for health literacy improvement to build a health literate health care organization.
- Use this guidebook to effect organizational change and build a health literate health care organization based on the ten attributes of a health literate health care organization.

2 | Background

This chapter will help you:

- Recognize that health literacy is a factor of individual capacities and the demands and complexities of the health care system.
- Identify key health literacy research, policies, and guidelines, and incorporate that information into your work.
- Connect your work at the local level to national efforts to improve health literacy.

3 | Engaging Leadership

This chapter will help you:

- Teach leaders about health literacy and its importance.
- Give leaders tools to integrate health literacy throughout your organization.
- Collaborate with your leaders to achieve success.

4 | Preparing the Workforce

This chapter will help you:

- Make the case for all health care providers and staff to understand health literacy and use clear health communication.
- Identify and use patient and provider experiences as teaching tools, and recruit health literacy champions.
- Build capacity for clear effective health communication among all members of the health care team.

5 | The Care Environment

This chapter will help you:

- Understand what a shame-free care environment is and why it is needed.
- Make your health care setting more welcoming, safe, and patient-friendly by fostering dialogue and questions.
- Make it easier for patients to find, understand, and use your information and services to manage their health.

6 | Involving Populations Served

This chapter will help you:

- Understand the importance of patient and family involvement and benefit from the feedback you get.
- Appreciate the significant contribution that adult learners can make.
- Find ways to involve patients, family members, and adult learners in your health literacy work.

7 | Verbal Communication

This chapter will help you:

- Explain and demonstrate how to use health literacy tools like teach-back.
- Show how *all* staff can help with communication.
- Get providers started building new communication habits into their routine.
- Set up systems that make checking for understanding standard practice.

8 | Reader-Friendly Materials

This chapter will help you:

- Evaluate the materials you already have.
- Select new materials that match the literacy needs of your patients.
- Develop your own materials using plain language writing and design principles.

9 | Case Study

This chapter will help you:

- Describe how one health literacy initiative can help an organization become more health literate.
- Visualize success and apply the ten attributes of a health literate health care organization to improve the health literacy of your organization.

1 | Introduction

> "Under the stewardship of health care organizations that are committed to being health literate, everyone benefits from communication that is clear and easy to understand." (*Ten Attributes of Health Literate Health Care Organizations, 2012*)

High quality, safe health care depends on clear communication between patients, families, providers, and health systems. Increasingly, health care providers and organizations recognize this and are trying to address health literacy in their daily work. This guidebook is intended to complement the many excellent health literacy resources that already exist and are emerging every day, and to help organizations of any size use them to become health literate health care organizations. Health literate health care organizations "make it easier for people to navigate, understand, and use information and services to take care of their health."[1] A health literate health care organization supports patient-provider communication to improve health care quality, reduce medical errors, facilitate shared decision-making, and improve health outcomes.

The ideas and information in this chapter are designed to help you:

- Recognize health literacy as key to quality, safety, and equity in health care.
- Identify key areas for health literacy improvement to build a health literate health care organization.
- Use this guidebook to effect organizational change and build a health literate health care organization based on the ten attributes of a health literate health care organization.

The goal of this guidebook is to help you move your organization forward in becoming a health literate health care organization.

There are many tools, trainings, guidelines, and other resources to help you engage in organizational change to become a health literate health care organization; the challenge is to use them effectively and reliably.

What does *effectively and reliably* mean? It means that changes need to be tested and polished on a small scale before they are turned into policy. It means that change needs to reach beyond one provider or one department and take root in the organization itself. It means using key health literacy interventions the right way *every* time they are needed. It means using resources to change the behavior and culture of health care teams and organizations, and *embed* and *spread* these changes throughout the system, whether large or small. Organizational and individual behavior change is essential to effectively and reliably integrate and implement health literacy interventions.

What Is Health Literacy?

The most widely used definition of health literacy focuses on how well an individual can succeed at getting, understanding, and using health information and services.

> "Health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[2]

In practice, health literacy is the result of many things acting together at any given moment. These can include schooling, general literacy, culture, language, personal history, state of mind, illness, medication side effects, eyesight, stress, and degree of trust. Expanded definitions see health literacy more broadly:

> "More than just the ability to read and write, health literacy includes the ability to listen, follow directions, fill out forms, calculate using basic math, and interact with professionals and health care settings. It can also include making sense of jargon or unfamiliar cultural norms. Health literacy requires people to apply critical thinking skills to health-related matters."[3]

When we talk about doing health literacy work, or addressing health literacy needs, we really mean both what we are doing to improve communication with the people we serve *and* how we are helping people improve their skills and knowledge about their health.

What does it mean to address health literacy?

Addressing health literacy means improving the way we communicate with patients *and* helping people improve their own skills and knowledge.

What is a Health Literate Health Care Organization?

Participants in the Institute of Medicine (IOM) Roundtable on Health Literacy published a discussion paper on the *Ten Attributes of Health Literate Health Care Organizations*.[1] In this paper a health literate organization is described as easier for people to use, and critical to delivering patient-centered care. They note that anyone may experience low health literacy and have a hard time understanding and acting on health information when they are sick or confronted with a new diagnosis; and that literacy, language, and culture must all be addressed to reduce health disparities.

Reprinted with permission from *Ten Attributes of Health Literate Health Care Organizations*, 2012 by National Academy of Sciences, National Academies Press, Washington, DC.

To be a health literate organization, a health care organization must demonstrate the following:

1. Have leadership that makes health literacy a priority.
2. Integrate health literacy into planning, evaluation, safety, and quality efforts.
3. Prepare the workforce to be health literate, and monitor progress.
4. Include consumers in design, implementation, and evaluation efforts.
5. Create a shame-free care environment to meet the needs of patients with a range of health literacy skills.
6. Use health literacy strategies in interpersonal communication to ensure and check patient understanding.
7. Ensure easy access to health information and services and navigation support.
8. Design and use information that is easy to read, understand, and act on.
9. Address health literacy at high-risk points (eg, care transitions, medicines).
10. Communicate health insurance and health care cost information clearly.

How To Use This Guidebook

Becoming a health literate health care organization will not happen overnight, and it may seem overwhelming. So look at it as a process, recognizing that addressing health literacy in only one or two areas will limit your overall success. This is because providers and patients exchange information at every point of contact in the health care system. Communication can break down anywhere. And even a small error in communication can follow a patient throughout their interactions with the health care system, with the potential for harm.[4]

This guidebook, that originated from ongoing work of UnityPoint Health, formerly known as Iowa Health System, presents health literacy learning and examples from real-world settings and an adaptable approach to becoming a health literate health care organization. Use it as a guide as you address health literacy in *your* setting and to support your journey to better-quality, safer, and more equitable health care.

Key Areas for Improvement

UnityPoint Health's Health Literacy Collaborative identified key health literacy development areas that intersect with the attributes of a health literate health care organization. The guidebook contains the following content chapters and a case study:

- Engaging leadership
- Preparing the workforce
- The care environment
- Involving populations served
- Verbal communication
- Reader-friendly materials
- Case study

Addressing each of these interconnected areas will help as you move toward becoming a health literate organization. This is not a step-by-step process and there is not one correct starting point. You need to make progress in all areas for results you can sustain over time. As you begin, keep in mind that people learn from even small efforts. A small change in one area can be a big step forward. And small improvements encourage people to do more.

Form a Team

You don't have to do it alone. It helps to have a group of people with a variety of perspectives who can identify areas for improvement and the best approaches to take. Consider forming a health literacy team made up of key stakeholders, including patients, families, and community representatives. Once you identify your team members and get everyone up to speed, they will help identify your organization's health literacy priorities and establish aims and goals. The *Health Literacy Universal Precautions Toolkit* http://www.nchealthliteracy.org/toolkit/toollist.pdf contains a useful tool on how to form a health literacy team, along with a number of other tools, resources, tips, and testimonials.

Each Chapter Answers These Questions

We organized each chapter to answer these questions:

Why?	Why do you need to address health literacy issues in this area? Why is it important?
What?	What would success in this area look like? What are the target outcomes? Success may include changes to process, behavior, and attitudes, as well as health outcomes.
How?	What tools, resources, and actions will you use to reach the target outcomes? We include stories and real-world examples from UnityPoint Health and elsewhere.

Each Chapter Addresses These Attributes

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

Start with Any Chapter

After reading this *Introduction*, you may want to review the *Background* chapter for more about health literacy, UnityPoint Health, and the Model for Improvement. Or go straight to one of the six content chapters. The chapters all relate to one another, but each can stand alone. You may be further down the road in some areas than others. A good rule of thumb is to start where you can begin to build a pattern of early success.

Ideally, you should work in more than one area at a time. Eventually, you need to be working in all key areas. Each is necessary, but not sufficient, to bring about improvement. For example, the chapter on *Preparing the Workforce* talks about how awareness and engagement through education, training, and personal stories help providers understand why and how to communicate better with patients, but that is not an end in itself. It has to be coupled with permanent changes in behavior.

Health Literacy Basic Principles

Since beginning to address health literacy, UnityPoint Health has learned much and made advances among staff and doctors in health literacy-related knowledge, attitudes, and behaviors. We have done this in urban and rural hospitals, outpatient clinics, and home health. The following principles reflect some key learning.

Health Literacy is a Universal Issue

It's hard to tell which patients are at risk for not understanding. You don't need to test patients to find out though. According to a statement by new readers at the multi-state 15th Annual New Readers of Iowa Conference in 2004, "A doctor's office is no place for a reading test."[5] It is the duty of *all* health care providers to make sure *all* patients understand. This is not an add-on service. It is part of everyone's job.

Making sure patients understand is simply part of everyone's job.

Low health literacy can affect anyone. People may need extra help for various reasons, like trouble reading, language issues, mental state, or dealing with a complex health condition and its treatment. Being sensitive to health literacy concerns is *not* dumbing down information. *Everyone* benefits from clearer communication, no matter their background.[6]

Health Literacy Affects All Aspects of Care

In its report, *Priority Areas for National Action: Transforming Health Care Quality*, the Institute of Medicine (IOM) calls health literacy and self-management support "cross-cutting priorities for transforming the quality of health care in the U.S."[7]

Health literacy affects all dimensions of health care—preventive, acute, and chronic conditions—and people of all ages. It affects direct patient care, health care systems, and public health interventions. Addressing health literacy is everyone's responsibility, not just those charged with patient education. This includes clinical and non-clinical staff: doctors, nurses, physical and occupational therapists, dietitians, and social workers; it also includes those in laboratories, radiology, billing, public relations, and support services. Improving communication goes beyond improving written materials. It involves changing spoken and unspoken messages and the care environment itself.

What is self-management support?

Self-management support means providing education and help in a systematic way, to build patients' skills and confidence in managing their health problems. This includes regular checks on progress, goal-setting, and problem-solving.

Source: Institute of Medicine Committee on Identifying Priority Areas for Quality Improvement. *Priority Areas for National Action: Transforming Health Care Quality*, 2003.

Health Literacy is Part of Quality Care

> "Health literacy is fundamental to quality care, and relates to three of the six aims of quality improvement described in the *IOM Quality Chasm Report*..." (Institute of Medicine Committee on Health Literacy. *Health Literacy: A Prescription to End Confusion*, 2004)

Those three aims are safety, patient-centered care, and equitable treatment.[8] Here are some examples of how health literacy can relate to each.

Safety: Using plain language and teach-back during medication reconciliation with patients may help reduce medication errors and increase adherence.

Patient-centered care: Making sure patients understand their options and involving them in decision-making helps ensure they get the care they need and want. Understanding patients' lifestyles is important to making self-care information usable and helping them set personal action plans.

Equitable treatment: Clear communication is key to efforts to eliminate health disparities and build cultural and linguistic competence. This includes understanding and responding to cultural and language differences through interpretation and translation services.[9]

National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care

Principal Standard: Provide effective, equitable, understandable, and respectful quality care and services that are responsive to diverse cultural health beliefs and practices, preferred languages, health literacy, and other communication needs.

Source: U.S. Department of Health and Human Services. Office of Minority Health. *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice*, 2013.

Involve Health Care Consumers in Your Health Literacy Work

Involving patients, families, and adult learners is basic to health literacy work. They are the experts in knowing what they understand and need. They can guide you in communicating more clearly. Listening to and learning from their viewpoints, suggestions, and stories helps in many ways. It teaches you about their experiences of care. It builds passion in the organization for making improvement. And it suggests areas for testing and implementing changes to improve communication.

Some important ways in which patients, families, and adult learners can help you advance your organization's health literacy work are to:

- Review and critique written materials.
- Give input to policies and procedures.
- Do a clinical site walk-through.
- Co-present health literacy information.
- Act as liaisons to adult literacy and adult basic education programs.
- Model patient involvement for other organizations.

Help Employees Who Struggle with Literacy

Much of the focus so far has been on limited literacy among patients and families. But it's important to recognize that some employees, who are critical to the ability to deliver quality care, may struggle with reading problems or language barriers. Health care organizations, especially during orientation and training, may assume employees have a certain level of literacy or language skills. When there is a mismatch between what is presented and the employees' ability to understand, a door opens for possible harm to employees, other staff, and patients.

Employees who understand their roles and responsibilities are better able to:

- Protect patients' health and safety.
- Manage their own and their families' health and safety.
- Do their jobs and contribute to the organization.

So, in addition to using clear communication with patients, use it in important employee communications tools as well. For example, use plain language principles in policies, manuals, benefits information, and computer-based learning. Think about ways to develop the general literacy and English language skills of employees and staff. Contact local adult literacy and adult basic education programs to learn about services they provide, and find out how to make referrals to them.[10,11] Consider offering on-site reading, math, and English as a second language (ESL) programs.

Make Changes Last

Here are some recommendations for sustaining health literacy improvement:

- Educate staff and providers. But don't stop there. Education is not the same as behavior change. And changing behavior is key.
- Adapt your ways of delivering health literacy messages, as well as the messages themselves, for different audiences. Your audiences may include any or all of these: boards of directors, senior leaders, quality committees, medical staff, individual doctors, department managers, front-line patient care staff, non-clinical departments like billing, marketing, public relations, and non-clinical support staff like transportation, housekeeping, dietary, engineering services.
- Test your changes in varied settings with different people and at all times of the day, week, and year. Learn what works best and solve the problems before you move to widespread implementation.
- Integrate health literacy into organizational initiatives, policies, procedures, meeting agendas, and reports to senior leaders.
- Embed your improvements in standard operating procedures like competency assessments, job descriptions, and performance reviews. Use other strategies to be sure improvements will be sustained over time and continually improved.
- Spread your health literacy messages and interventions to strategic points throughout the organization. This will help you grow champions and build knowledge, skill, buy-in, and will. Involve patients in the process. Remember, they are the experts in what they understand and what they need to know.
- Collaborate with colleagues within and outside your organization.

- Assess your progress as you go. This is important to sustaining change beyond the single project or person phase. The complex nature of health literacy makes it hard to measure its direct impact on patient outcomes. You may find related measures useful, such as patient or staff satisfaction, and markers of understanding or adherence, like keeping follow-up appointments or procedure cancellation rates.

What We Did and How

UnityPoint Health uses the Model for Improvement,[12,13] with Plan-Do-Study-Act (PDSA) cycles, and coaching in its health literacy initiative. Some examples in this guide are based on these strategies. That doesn't mean you have to do the same. There are other useful approaches.

We do recommend you start with small steps—small tests of change—to build confidence and buy-in. For example, try using a new communication technique with the last patient of the day. This helps lessen concern about it taking too much time. As you gain confidence and comfort with this skill, expand to more patients, conditions, and settings. And then share it with colleagues.

Summary of Key Points

- Health literacy is basic to quality, safety, and equity in health care.
- To improve health literacy, we need to change how people and organizations behave. And we need to embed and spread those changes in the system.
- This book is laid out according to areas UnityPoint Health found useful in its health literacy work as they relate to the attributes of a health literate health care organization.
- Use this book as a guide, rather than a step-by-step manual. Begin where it makes sense to you and your organization, and move from there.
- Use whatever improvement or change strategy works best for you, but start small and build on your success.
- You need to make progress in all areas for results that will last.

1 Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington, DC: National Academy of Sciences; 2012. http://iom.edu/~/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH_Ten_HLit_Attributes.pdf. Accessed: September 23, 2013.

2 Ratzan SC, Parker RM. Introduction. In: *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*. NLM Pub. No. CBM 2000-1. Selden CR, Zorn M, Ratzan SC, Parker RM, eds. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services. 2000.

3 U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Quick Guide to Health Literacy. Available at: http://www.health.gov/communication/literacy/quickguide/. Accessed: October 16, 2012.

4 American Medical Association Foundation and American Medical Association. *Health Literacy and Patient Safety: Help Patients Understand: Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment*. Chicago, IL: 2007. Available at: http://www.ama-assn.org/ama1/pub/upload/mm/367/hl_monograph.pdf. Accessed: October 16, 2012.

5 Osborne H. *Health and literacy working together: A health literacy conference for new readers and health professionals*. 2004. Available at: http://www.healthliteracy.com/article.asp?PageID=7493. Accessed: October 16, 2012.

6 DeWalt DA, Callahan LF, Hawk VH, et al. *Health Literacy Universal Precautions Toolkit*. AHRQ Publication No. 10-0046-EF. Rockville, MD. Agency for Healthcare Research and Quality. April, 2010. Available at http://www.ahrq.gov/qual/literacy/healthliteracytoolkit.pdf. Accessed: October 18, 2012.

7 Institute of Medicine Committee on Identifying Priority Areas for Quality Improvement. *Priority Areas for National Action: Transforming Health Care Quality*. Adams, K, Corrigan, JM, eds. Washington, DC: The National Academies Press; 2003. Available at: http://www.nap.edu/openbook.php?record_id=10593&page=1. Accessed: October 16, 2012.

8 Institute of Medicine Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: The National Academies Press; 2001. Available at: http://www.nap.edu/openbook.php?record_id=10027. Accessed: October 16, 2012.

9 U.S. Department of Health and Human Services. Office of Minority Health. *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice*. Washington, DC: 2013. Available at: http://www.thinkculturalhealth.hhs.gov/pdfs/EnhancedCLASStandardsBlueprint.pdf. Accessed: June 25, 2013.

10 Literacy Information and Communication System, (LINCS). Available at: www.literacydirectory.org. Accessed: October 16, 2012.

11 ProLiteracy. Available at: http://www.proliteracy.org/our-solutions/referral/national-literacy-directory. Accessed: September 23, 2013.

12 Institute for Healthcare Improvement: *Model for Improvement*. Available at: http://www.ihi.org/IHI/Topics/Improvement/ImprovementMethods/HowToImprove/. Accessed: October 16, 2012.

13 Langley GJ, Moen RD, Nolan KM, et al. *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. 2nd ed. San Francisco, CA: Jossey-Bass; 2009.

2 | Background

> "Health literacy is ... the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions." (Ratzan SC, Parker RM, 2000)

This commonly-used definition of health literacy focuses on the individual.[1] Yet, health literacy is the product of individuals' capacities and the health literacy-related demands and complexities of the health care system.[2,3] So, addressing health literacy means not only improving the skills of individuals, but also the skills of the system in communicating with those individuals as patients, family members, employees, staff, and communities.[4] Improved health literacy comes as the result of an ongoing process of education and thoughtful give-and-take among health systems, providers, patients and families, and the community.

The ideas and background information in this chapter are designed to help you:

- Recognize that health literacy is a factor of individual capacities and the demands and complexities of the health care system.
- Identify key health literacy research, policies, and guidelines, and incorporate that information into your work.
- Connect your work at the local level to national efforts to improve health literacy.

Why is Health Literacy so Important?

Many Health Problems Are Linked to Low Health Literacy

Limited health literacy is associated with:

- Less use of preventive health measures (e.g., influenza vaccination[5,6] and pneumococcal vaccination[5], and mammography[6]).
- Less knowledge about one's own health conditions and self-care, especially for chronic diseases needing complex self-management (e.g., heart failure).[5]
- Less healthy behaviors (e.g., more smoking).[5]
- Poor ability to demonstrate taking medicines appropriately.[6]

- Poor ability to interpret labels and health messages.[6]
- Less understanding of treatment choices.[5]
- Greater use of emergency care.[6]
- More hospitalizations.[6]
- Increased mortality and poorer health status.[6]
- Higher health care costs.[7]

Low Health Literacy Is Very Costly

The 2007 report *Low Health Literacy: Implications for National Health Policy*[7] estimated yearly costs to the U.S. economy of $106 billion to $238 billion associated with low health literacy. These costs result from premature death (mortality), avoidable illness (morbidity), racial, ethnic, and socioeconomic disparities in health and health care, and many other avoidable costs.

Only 12% of U.S. Adults Have Proficient Health Literacy Skills

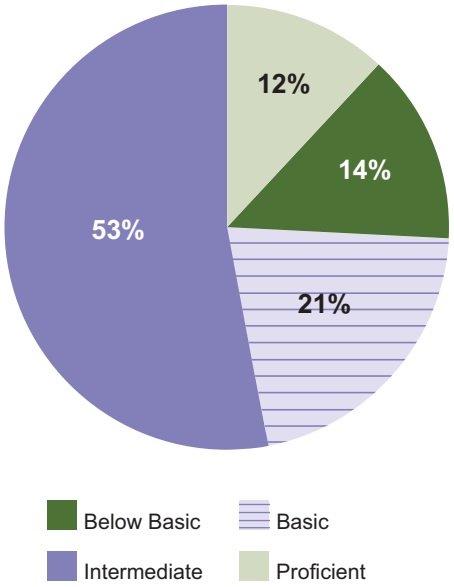
The health care system assumes, and often demands, a high level of literacy, making it very hard to use for many people. The 2003 National Assessment of Adult Literacy (NAAL)[8] was the first national survey of adult literacy to specifically look at health literacy by assessing the ability to perform health literacy-related tasks in three areas: clinical, prevention, and navigation of the health care system. Findings from this survey show that most U.S. adults have difficulty with health-related tasks:

- 14% have below basic health literacy. Sample task: Name what is OK to drink before a medical test, based on information in a clearly-written booklet.
- 21% have basic health literacy. Sample task: Give two reasons a person with no symptoms of a specific disease should be tested for the disease, based on information in a clearly-written booklet.
- 53% have intermediate health literacy. Sample task: Figure out what time a person can take a prescription drug, based on information on the label that relates the timing of the medicine to eating.

- Only 12% have proficient health literacy. Sample task: Calculate an employee's share of health insurance costs for a year, using a table that shows how the employee's monthly cost varies depending on income and family size.

The bottom line — 88% of U.S. adults find it difficult to handle the literacy-related tasks needed to manage their own or their family members' health.[8]

Adults' Health Literacy Level: 2003



Source: America's Health Literacy: Why We Need Accessible Health Information. An Issue Brief From the U.S. Department of Health and Human Services. 2008. Available at: http://www.health.gov/communication/literacy/issuebrief/.

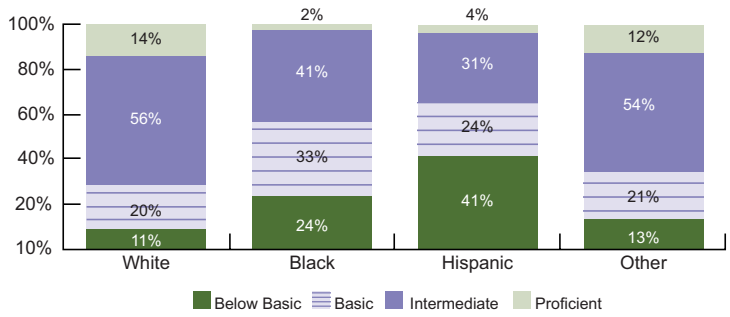
Limited Health Literacy Affects Certain Groups More than Others

The NAAL health literacy report found important differences in the risk for low health literacy among certain groups. Adults aged 65 years and older; those having Medicare, Medicaid, or no insurance; and those of Hispanic ethnicity or black race are among those with the highest percentages in the basic and below basic categories.[8]

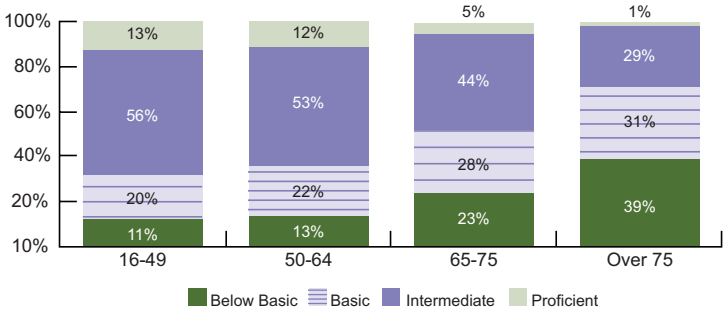
The IOM notes that inadequate health literacy may contribute to health disparities and is integral to cultural and linguistic competence.[9]

Percentage of U.S. Adults in Each Health Literacy Level

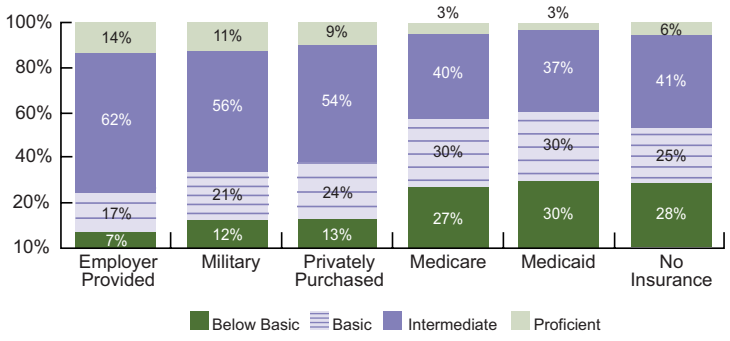
By Race/Ethnic Group



By Age



By Type of Health Insurance



Source: America's Health Literacy: Why We Need Accessible Health Information. An Issue Brief From the U.S. Department of Health and Human Services. 2008. Available at: http://www.health.gov/communication/literacy/issuebrief/.

Too Much Health Information is Too Hard to Understand

Health information comes from many competing sources, such as the media, the Internet, marketing, education, consumer protection groups, the health system, and informal networks. Yet most written health-related information far exceeds the average reading skill of most U.S. adults.[5]

Health Literacy Is an Ethical Issue

There is a relationship between health literacy and the ethical and legal foundation for safe medical practice and patient-centered care.[10] Health care providers have an ethical duty to address health literacy in their practice. The U.S. Supreme Court ruled as early as 1891 that the patient's right to determine what will or will not happen to his or her own body is a basic concept of American law. Later court decisions upheld the patient's right to understand conditions and risks before agreeing to treatment.

> "Patients have the right to understand health care information [they need] to safely care for themselves... Health care providers have a duty to provide information in simple, clear and plain language, and to check that patients have understood the information before ending the conversation."[11]

Stories of failed or near-failed communication between health care providers and patients can illustrate what might happen if patients and families don't understand. *Art's Story* is one of them.

Art's Story

Art was a 78-year-old retired parole officer with emphysema. He had recently developed recurrent throat cancer. His cancer surgeon recommended surgery to remove the cancer. Art asked for advice from his lung doctor, who had been treating Art for years. The doctor tried to explain what would happen during the surgery and some of the risks. The doctor used many terms, such as "laryngectomy," "hemi-laryngectomy," (later, simply "a hemi"), "palliative trach," "ventilatory problems," "bronchiectasis," and "purulent bronchitis."

"OK," said Art. "You've saved my life before. I think I better follow your advice. Let's do it."

Art's adult daughter was in the room, listening and taking notes. She sat next to her father and said, "Dad, what the doctor is saying is that with the surgery, you would have your voice box taken out. You wouldn't be able to talk anymore. You'd have a breathing hole through the front of your throat for the rest of your life. You'd have to keep the hole protected so germs couldn't go straight into your lungs. And you'd have a tube in your breathing pipe that you'd have to take care of every day."

Art's eyes got wide, then angry, and he asked, "What the hell do you mean … I won't be able to talk?"

Health Literacy Policy Can Do More for More People

Federal Policy Initiatives

Federal policy initiatives are advancing health literacy as an integral component of improving health outcomes, increasing quality, and controlling costs.[12,13] They are driving healthcare reform, patient-centered medical home initiatives, and development of accountable care organization, Medicare, and other payment structures to improve quality and outcomes and reduce health disparities. Each of these calls for accessible, actionable health information, effective patient-provider communication, improved patient satisfaction, and consideration of language and cultural issues. For example:

- Under the Affordable Care Act, newly-insured individuals need clear information to choose a health plan and interact with the health system.[14]

- Addressing cultural and linguistic competence can help reduce racial and ethnic health disparities.
- Strategies to improve health literacy can support practice transformation into patient-centered medical homes.
- Providers have incentives to work collaboratively to improve quality and patient satisfaction. Surveys like the Consumer Assessment of Healthcare Providers and Services (CAHPS) and Hospital Consumer Assessment of Healthcare Providers and Services (HCAHPS) have questions related to health literacy and cultural competence. Working to improve these patient experience survey scores, especially for communication with doctors and nurses, can lead to improvement in health communication.[15]
- National quality and safety goals include lowering unplanned readmissions and associated costs.[16] Ensuring patients understand what they need to do to manage their own and loved ones' health is fundamental to ensuring safe transitions home and optimizing self-care for increasingly prevalent chronic conditions.

Accreditation and Quality Improvement

Health literacy is increasingly recognized by accreditation and quality care programs. The Joint Commission states "…the safety of patients cannot be assured without mitigating the negative effects of low health literacy and ineffective communications on patient care."[17] The National Quality Forum endorses teach-back and reader-friendly documents during the informed consent process as best practices for universal use to reduce harm to patients.[18]

Professional Associations

The American Medical Association (AMA), AMA Foundation, and American College of Physicians Foundation have been leaders in physician and other health care professional education and training, highlighting the linkages between providers' responsibility for clear communication and patient safety and improved outcomes. Other professional associations, like the American Dental Association and American Academy of Pediatrics, play roles in raising awareness, providing training, tools, and resources, and evaluating health literacy-related strategies and interventions.

Improving Health Literacy Requires System Changes

Shift Your Focus to the Health Care System

It's easy to focus on the limited skills of millions of people in coping with health literacy tasks. But shift your focus to the health care system and you see a different picture. Perhaps the data do not suggest that nearly 90% of U.S. adults lack skills but, instead, that the health care delivery system is not easily used by 90% of the people it is supposed to serve.

How many poor outcomes occur because health systems are too hard for almost 90% of U.S. adults to use?

Health literacy is a dynamic systems issue reflecting the complexity of the health information being presented and care system being navigated.[19,20] Addressing the challenge of low health literacy requires system-level changes for both health professionals and organizations.[12]

Health Literate Health Care Organizations

System-wide organizational change is needed to stop what has been described as a cycle of crisis care where there can be a wide gulf between what providers mean to convey verbally and in writing, and what patients and families understand and do. A system-wide approach makes promoting health literacy an organizational responsibility and prepares and expects all employees, including health care providers, office staff, and hospital personnel, to address health literacy and patient understanding as a priority. Implementing health literacy strategies at the system level can help transform the ineffectiveness of crisis care, shift the focus to patient-centered care, and ultimately improve health access, quality, and cost management.[12]

At a system level, health literate health care organizations take into account that miscommunication and misunderstanding are common and that the ability of individuals to process and utilize health care information may diminish when they are sick, frightened, or impaired. They appreciate that language and culture are important

dimensions of health literacy.[21] They underscore that system changes are needed to better align with the skills and abilities of the public.[22,23] And they acknowledge that everyone benefits from clear communication. All health care organizations can become health literate, not just hospitals and health centers. Being health literate will benefit all health care professionals and a broad range of health care delivery-related organizations, including health plans and insurance providers.

Moving from a Cycle of Crisis Care to Health-Literate Care

The cycle of crisis care[12] is demonstrated when a sick patient seeks care and is asked to fill out complex forms, examined and given a diagnosis using technical language, offered a treatment plan and prescribed medications without confirming understanding, and sent home with no support or follow-up. This may lead to the patient taking their medicines incorrectly, altering or not following the treatment plan, and missing appointments. The sick patient then seeks care again, is perhaps given a new treatment plan, and the cycle continues.

In a cycle based on health-literate care, a sick patient is given simple forms and help filling them out. Explanations are given using easy-to-understand wording, questions are solicited and answered, and understanding is confirmed by asking the patient to explain the treatment plan back using their own words. Reader-friendly hand-outs are given and follow-up calls made to help the patient carry out the plan.[12]

The National Action Plan to Improve Health Literacy

The *National Action Plan to Improve Health Literacy*[24] reflects a national commitment to providing health information that is usable for all populations and promotes a vision of a health literate society that:

- Provides everyone with access to accurate, actionable health information.
- Supports life-long learning and skills to promote good health.
- Delivers person-centered health information and services.

The *National Action Plan* envisions a restructuring of the health care system and invites multi-sector participation. It has seven goals and offers evidence-based and best practice strategies for achieving a health literate society. The second goal specifically calls for promoting changes in the health care system that improve health information, communication, informed decision-making, and access to health services to meet the communication needs of patients and improve quality.

The National Action Plan to Improve Health Literacy

Seven Goals to Achieve a Health Literate Society

1. Develop and disseminate health and safety information that is accurate, accessible, and actionable.
2. Promote changes in the health care system that improve health information, communication, informed decision-making, and access to health care services.
3. Incorporate accurate, standards-based, and developmentally-appropriate health and science information and curricula in child care and education through university level.
4. Support and expand local efforts to provide adult education, English language instruction, and culturally- and linguistically-appropriate health information services in the community.
5. Build partnerships, develop guidance, and change policies.
6. Increase basic research and development, implementation, and evaluation of practices and interventions to improve health literacy.
7. Increase dissemination and use of evidence-based health literacy practices and interventions.

Source: U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. *National Action Plan to Improve Health Literacy*, 2010.

UnityPoint Health

UnityPoint Health is a large integrated health system. Its mission is to provide the "Best Outcome for Every Patient Every Time."[25] Through hospitals and clinics in metropolitan and rural communities throughout Iowa, Illinois, and Wisconsin, it provides care through more than 4 million yearly visits.

Implementing a Plan

UnityPoint Health incorporates health literacy as a cross-cutting, system-wide quality initiative. In 2003, UnityPoint Health established a multidisciplinary group called the Health Literacy Collaborative to implement improvements in health literacy. The Collaborative worked with hospital, outpatient clinic, and home health teams to develop communication tools and strategies to increase patient understanding and provide a better experience for patients and their families.[26,27] Teams were asked to:

- Test health literacy tools and techniques in busy real-world settings.
- Assess how easy, acceptable, and practical it is to introduce and adopt various health literacy approaches.
- Speed up use of evidence-based and best practice health literacy interventions.
- Identify strategies for sustaining and spreading improvements.

Health literacy interventions such as plain language, teach-back, and reader-friendly print materials were used to support understanding of discharge instructions, medication safety, informed consent, and navigation (finding your way around). Teams used strategies like staff training and coaching; competencies, policies, and checklists; and management incentives to promote long-lasting improvements.

Working with Partners

UnityPoint Health's Health Literacy Collaborative has worked with patients, families, and diverse public and private partners to address health literacy. One invaluable partner is the New Readers of Iowa, an organization run for and by people learning to read as adults, who help each other and advocate for adult literacy.

Health Literacy Collaborative Partners

- Adult literacy programs and community colleges
- Des Moines University
- Drake University College of Pharmacy
- Health Literacy Iowa
- Iowa Department of Education
- Iowa Department of Public Health
- Iowa Geriatric Education Center
- Iowa Healthcare Collaborative
- Iowa Hospital Association
- Iowa Medical Society (IMS)
- IMS Alliance
- Iowa Nurses Association
- New Readers of Iowa
- Pfizer
- Reach Out and Read Iowa
- The Wellmark Foundation
- University of Iowa Center for Disabilities and Development
- University of Iowa College of Public Health
- University of Northern Iowa Center on Health Disparities

Using the Model for Improvement

The Model for Improvement[28] is a simple yet powerful tool used by health care organizations to test and implement changes in real-world settings to improve health care processes and outcomes. Plan-Do-Study-Act (PDSA) cycles guide the tests of change to determine if there is improvement. The Model for Improvement helps answer three basic questions:

- What are we trying to accomplish?
- How will we know that a change is an improvement?
- What change can we make that will result in improvement?

Testing Changes

PDSA stands for:

- Plan—Develop a plan to test the change.
- Do—Carry out the test.
- Study—Observe and learn from what happens.
- Act—Decide what changes to make to the test for the next cycle.

PDSA cycles break down changes into a series of small tests that can be tried in real working settings. Multiple PDSA cycles in a quick series can lead to successful change that ultimately involves many stakeholders. They make it possible to:

- Learn how to adapt the change to the local environment.
- Allow failures without impacting performance.
- Predict how much improvement might come from the change.
- Increase belief the change will result in improvement.
- Minimize resistance to change.

Other advantages include the chance to evaluate costs and side-effects, refine the process before it becomes a done deal, and run multiple PDSA cycles in multiple areas at the same time.

To be considered a complete PDSA test, the following must apply:

- The test or observation was planned (including a plan for collecting data).
- The plan was attempted (do the plan).
- Time was set aside to analyze the data and study the results.
- The next action was based on what was learned.

The Model for Improvement is especially well-suited to addressing health literacy, since it can create a *pull* as much as a *push*. This pull represents the fact that organizational change can begin on the front lines, through people who work with patients and families, as well as a push from leadership.

Learning Collaboratives and the Model for Improvement

The Model for Improvement can be applied in any setting, from individual clinics, departments, or hospitals, to formal Learning Collaboratives. Learning Collaboratives focus on improvement using a philosophy of "all teach, all learn." They are comprised of health care organizational teams committed to making major, rapid changes and working together to identify improvement strategies and test changes.

A Learning Collaborative involves Learning Sessions that allow participants to come together to share, teach, and learn. Between Learning Sessions there are Action Periods for PDSA testing and conference calls to share progress, problem-solve, and report lessons learned. Testing leads to implementation—making changes part of the day-to-day operations of the organization, where support processes and resources become more important. Ultimately, testing leads to sustainability and spread. Long-term, this may involve strategies like:

- Assigning ownership.
- Formally including changes in orientation and training.
- Setting up standard processes and policies.
- Measuring, observing, and auditing.
- Changing job descriptions.

Source: UnityPoint Health. Institute for Healthcare Improvement: Model for Improvement, 2009.

Summary of Key Points

- Low health literacy is associated with poor health outcomes and increased costs.
- Nearly 90% of adults in the U.S. do not have the health literacy skills needed to navigate the U.S. health care system.
- Seniors and ethnic and racial minorities are at increased risk of low health literacy.
- Improving health literacy requires system changes and establishment of health literate organizations that address health literacy and patient understanding as a priority.
- The *National Action Plan to Improve Health Literacy* calls for a multi-sector approach and suggests evidence-based and best practice strategies for achieving a health literate society.
- The Model for Improvement is a useful tool for small tests of health literacy changes and interventions to promote quality care.
- A health literate organization recognizes that health literacy arises from individuals' capacities and the health literacy-related demands and complexities of the health care system.

---

1 Ratzan SC, Parker RM. Introduction. In: *National Library of Medicine Current Bibliographies in Medicine: Health Literacy*. NLM Pub. No. CBM 2000-1. Selden CR, Zorn M, Ratzan SC, Parker RM, eds. Bethesda, MD: National Institutes of Health, U.S. Department of Health and Human Services. 2000.

2 Rudd R. Communicating health: Priorities and strategies for progress. Objective 11-2. Improvement of health literacy. Washington, DC: U.S. Department of Health and Human Services. 2003. Available at: http://odphp.osophs.dhhs.gov/projects/healthcomm/objective2.htm. Accessed: March 18, 2013.

3 Baker DW. The Meaning and the Measure of Health Literacy. Journal of General Internal Medicine 21(8):878-883. 2006. Available at: http://onlinelibrary.wiley.com/doi/10.1111/j.1525-1497.2006.00540.x/abstract. Accessed: March 18, 2013.

4 Coleman C, Kurtz-Rossi S, McKinney J, Pleasant A, Rootman I, Shohet L. The Calgary Charter on Health Literacy: Rationale and Core Principles for the Development of Health Literacy Curricula. The Centre for Literacy of Quebec, CA. October 2008. Available at: http://www.centreforliteracy.qc.ca/sites/default/files/CFL_Calgary_Charter_2011.pdf. Accessed: November 17, 2013.

5 Institute of Medicine Committee on Health Literacy. *Health Literacy: A Prescription to End Confusion*. Nielsen-Bohlman L, Panzer AM, Kindig DA, eds. Washington, DC: The National Academies Press; 2004. Available at: http:www.nap.edu/catalog/10883.html. Accessed: November 3, 2012.

6 Berkman N, Sheridan S, Donahue K, et al. *Health Literacy Interventions and Outcomes: An Updated Systematic Review. Evidence Report/Technology Assessment No. 199. Executive Summary*. Prepared by RTI International–University of North Carolina Evidence-based Practice Center under contract No. 290-2007-10056-I. AHRQ Publication Number 11-E006. Rockville, MD. Agency for Healthcare Research and Quality. March 2011. Available at: http://www.ahrq.gov/clinic/tp/lituptp.htm. Accessed: June 29, 2012.

7 Vernon J, Trujillo A, Rosenbaum S, et al. *Low health literacy: implications for national health policy*. 2007. Available at: http://sphhs.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10_4_07.pdf. Accessed: March 31, 2014.

8 Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy.* National Center for Education Statistics. U.S. Department of Education. 2006. NCES Publication No. 2006-483. Available at: http://nces.ed.gov/naal/health.asp. Accessed: June 29, 2012.

9 Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Smedley BD, Stith AY, Nelson AR, eds. Washington, DC: The National Academies Press; 2003. Available at: http://www.nap.edu/openbookphp?isbn=030908265X. Accessed: November 5, 2012.

10 American Medical Association and American Medical Association Foundation. Health Literacy and Patient Safety: Help Patients Understand: Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment. Chicago, IL: 2007. Available at: http://www.ama-assn.org/ama1/pub/upload/mm/367/hl_monograph.pdf. Accessed: November 5, 2012.

11 *Proceedings of 2005 White House Conference on Aging, Mini-Conference on Health Literacy and Health Disparities*. American Medical Association; 2005.

12 Koh HK, Berwick DM, Clancy CM, et al. New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'. *Health Affairs*. 2012;31(2). Available at: http://content.healthaffairs.org/content/early/2012/01/18/hlthaff.2011.1169.abstract. Accessed: November 5, 2012.

13 Koh H, Brach C, Harris LM, Parchman ML. A proposed 'health literate care model' would constitute a systems approach to improving patients' engagement in care. *Health Affairs*. 2013;32(2). Available at: http://content.healthaffairs.org/content/32/2/357.full.pdf+html. Accessed: November 17, 2013.

14 Patient Protection and Affordable Care Act (PPACA). 111th United States Congress, Public law 111-148. Available at: http://www.gpo.gov/fdsys/pkg/BILLS-111hr3590enr/pdf/BILLS-111hr3590enr.pdf. Accessed: September 23, 2013.

15 U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality. Consumer Assessment of Healthcare Providers and Services (CAHPS). 2012. Available at: https://cahps.ahrq.gov. Accessed: September 30, 2013.

16 U.S. Department of Health and Human Services. Partnership for Patients. Available at: http://partnershipforpatients.cms.gov/about-the-partnership/aboutthepartnershipforpatients.html. Accessed: September 23, 2013.

17 Joint Commission. *What Did the Doctor Say? Improving Health Literacy to Protect Patient Safety*. 2007. Available at: http://www.jointcommission.org/assets/1/18/improving_health_literacy.pdf. Accessed: November 5, 2012.

[18] National Quality Forum. *Safe Practices for Better Healthcare – 2010 Update: A Consensus Report.* 2010. Washington, DC: National Quality Forum. Available at: http://www.qualityforum.org/Publications/2010/04/Safe_Practices_for_Better_Healthcare_–_2010_Update.aspx. Accessed: July 1, 2010.

[19] Rudd RE. Improving Americans' health literacy. *N Engl J Med*. 2010;363:2283–2285.

[20] Parker R, Ratzan SC. Health literacy: a second decade of distinction for Americans. J Health Communication. 2010;15 Suppl 2:20-33. Available at: http://www.ncbi.nlm.nih.gov/pubmed/20845190. Accessed: November 5, 2012.

[21] Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington DC: National Academy of Sciences; 2012. Available at: http://iom.edu/~/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH_Ten_HLit_Attributes.pdf. Accessed: October 16, 2012.

[22] Rudd RE. Health literacy skills of U.S. adults. Journal of Health Behaviors. 31(S1):S8-18. 2007. Available at: http://www.ncbi.nlm.nih.gov/pubmed/17931141. Accessed: March 14, 2013.

[23] Parker RM. 2009. *What? So what? Now what?* Paper presented at Measures of Health Literacy Workshop, Washington, DC.

[24] U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). *National Action Plan to Improve Health Literacy*. Washington, DC. Available at: http://www.health.gov/communication/hlactionplan/pdf/Health_Literacy_Action_Plan.pdf. Accessed: November 5, 2012.

[25] UnityPoint Health - Home. Available at: http://www.unitypoint.org. Accessed: January 17, 2014.

[26] UnityPoint Health - Health Literacy. Available at: http://www.unitypoint.org/health-literacy.aspx. Accessed: November 5, 2013.

[27] U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality. Innovations Exchange. Program makes staff more sensitive to health literacy and promotes access to understandable health information. Available at: http://www.innovations.ahrq.gov/content.aspx?id=1855. Accessed: September 23, 2013.

[28] Institute for Healthcare Improvement: Model for Improvement. Available at: http://www.ihi.org/IHI/Topics/Improvement/ImprovementMethods/HowToImprove/. Accessed: November 5, 2012.

This page intentionally left blank.

3 | Engaging Leadership

> "Health literacy has become common language in our organization. We think about it every time we post a sign, write a memo to staff, update our web-site, print materials, etc." (CEO, Grundy County Memorial Hospital)

Being a health literate organization means those in clinical areas *and* those in the board room recognize the need for clear communication.[1] Organizations with the most successful health literacy programs have champions within the ranks of senior leadership. An organization's leadership sets the tone and expectations when it comes to service delivery and customer service. Having this kind of organizational support creates an opportunity to move health literacy practices forward and an opportunity to generate momentum to maintain health literacy efforts as a priority for the long term.

You will want to give your organization's senior leaders what they need to enable you to carry out your health literacy work. The ideas and tools in this chapter are designed to help you:

- Teach leaders about health literacy and its importance.
- Give leaders tools to integrate health literacy throughout your organization.
- Collaborate with your leaders to achieve success.

In a Health Literate Health Care Organization Senior Leaders are Champions of Clear Communication

This chapter directly addresses Attribute 1 and will help you provide senior leadership with resources and support to make health literacy integral to your organization's mission, structure, and operations.

Source: Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington, DC: National Academy of Sciences, 2012.

Leaders' roles vary by the kind and size of an organization. They may have formal or informal titles: chief executive officer, chief medical officer, chief nurse executive, chief quality officer, department director, head of a clinic or practice, executive director, office manager, lead nurse, or head of the clinic. No matter their title, senior leaders generally are the highest-ranking and most respected people in your organization. They have both

the authority and responsibility to move the organization toward improvement. Senior leaders are responsible for:

- Quality of care and outcomes.
- Ethical and legal concerns.
- Meeting regulatory and accreditation requirements.
- Patient and worker safety.
- Patient, family, and worker satisfaction.
- Worker development and accountability.
- Lowering costs and raising efficiency.
- Staying in business.

Health literacy can affect every one of these responsibilities. So addressing health literacy is important for your leaders' success.

Leadership Establishes an Organization's Culture

"Leadership establishes an organization's culture through its language, expectations, behavior it models, and design of services and processes."

Source: Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington, DC: National Academy of Sciences, 2012.

Why Involve Senior Leaders?

Involving your organization's senior leaders in health literacy is one of the most important things you can do.[2] Why? Because leaders can:

- Take the status quo off the table.
- Remove barriers.
- Get your projects seen by others.
- Make sure you have the time and money you need.
- Help build will and support in your organization to make your job easier.

You must give your leaders the tools they need to channel attention to key leverage points for advancing health literacy efforts.

The Currency of Leadership is Attention

"It has been said that the currency of leadership is *attention*. If that is true, then leaders who wish to transform their organizations should channel their attention to the key leverage points for the quality transformation, and use their chosen leverage points well."

Source: Reinertsen J, Pugh M, Nolan T. *Executive Review of Improvement Projects: A Primer for CEOs and other Senior Leaders,* 2005.

Leverage Points For Leaders to Improve Health Literacy

Show your leaders how health literacy intersects with their roles and responsibilities in advancing your organization's mission and improving outcomes. For example:

- Linking health literacy initiatives to the organization's goals, such as those related to improving quality, safety, and patient-centered care; measuring progress; and developing an executable strategy to achieve these goals.
- Setting, overseeing, and broadcasting goals to improve staff skills in clear health communication at the system level.
- Focusing attention on improving health communication throughout the organization through personal leadership, supporting systems, and openness about progress.
- Choosing and supporting the right team of health literacy, patient education, communication, and quality leaders, *and* patients and families.
- Building the business case for health literacy as a quality and safety issue, and involving senior financial leadership to make the business case.
- Getting doctors engaged, and showing that their leadership is important in health literacy, clear communication, and advancing health knowledge and skills among patients and their families.
- Building capacity throughout the whole organization to improve communication with patients and families.[2]

What You Want Senior Leaders To Do

Here's what you want your senior leaders to do:

- Identify health literacy and clear health communication as vital to the organization's mission.
- Use their bully pulpit to underscore health literacy's relationship to quality and patient safety.
- Carry the importance of health literacy to board members, other leaders, and all staff and departments.
- Give time and resources to support improvement efforts.
- Model plain language communication in their own speech and writing.

What Does Success Look Like?

Here is how it might look when senior leaders focus attention on key leverage points to improve health literacy. Think about what success might look like in your setting:

- The Chief Executive Officer integrates health literacy into the organization's strategic goals and objectives.
- The Executive Director models plain language in everyday speaking with and writing for staff and the community.
- The Chief Medical Officer advocates for including and integrating health literacy initiatives into patient safety and performance improvement work.
- The Board of Directors expects periodic health literacy reports, especially as they relate to quality and safety.
- Managers expect to be held accountable for setting and reaching department goals that relate to building health literacy and communication skills.
- Clear verbal communication and plain language writing skills are included in job descriptions and performance reviews.
- Performance improvement leaders include clear communication and patient health literacy skill development in chronic disease management and self-management projects.
- Patient safety officers include clear health communication principles and teach-back to check for understanding in medication safety initiatives.

- Leaders of diversity efforts and language services use clear health communication principles and skills in their work.
- Risk managers know and convey the importance of effective communication and ensuring patient understanding in consent processes.
- Physician leaders and teaching staff model plain language and teach-back.
- Leaders responsible for patient satisfaction set high goals (*very* satisfied) for communication-related measures on patient surveys.
- Senior executives, doctors, and nurse leaders know local literacy data and risk factors for low health literacy.
- Gathering patients', families', and adult learners' input is part of the organization's culture.

How Can You Get Leaders Involved?

What can you do to make these scenarios real? First, you need to teach about and show your leaders why it is important to address health literacy—and how. Then, you must give them the tools they need to channel attention. This section shows ways to use tools and resources in a three-pronged approach:

- Teach leaders about the important role that health literacy plays in care quality and safety.
- Help leaders champion health literacy improvement and model clear communication in the organization and out in the community.
- Help leaders stay connected with your health literacy work.

Use Tools and Resources

Tools and resources for educating your senior leaders can be quick or in-depth. Both should be part of your toolkit. At each chance, use what fits the available time and communication style of your leaders. Use these resources to make sure your leader understands:

- What the term *health literacy* means, the prevalence of low health literacy, and its association with poor health outcomes and increased costs.
- How the health literacy skills of the U.S. public compare with the health literacy demands of the health care system.

- How the gap between patients' health literacy skills and the health literacy demands of the organization impact quality, safety, and costs.[3,4]

You will need evidence and data to convey this information. But you also want to shed light on your local picture and put a face on it. Make it personal by using data and stories from your setting, and involving your own workers and patients. Show that clear health communication challenges exist everywhere.

Health Literacy Tools for Leaders

Literacy and Health Literacy Data

Resource	Description
National Assessment of Adult Literacy State & County Estimates of Low Literacy (2003) http://nces.ed.gov/naal/estimates/StateEstimates.aspx	Data base for searching state and county literacy rates
The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy http://nces.ed.gov/naal/health_results.asp	Report summarizes national health literacy findings

Health Literacy Reports

Resource	Description
AHRQ (2011). *Health Literacy Interventions and Outcomes: An Updated Systematic Review* http://www.ahrq.gov/clinic/tp/lituptp.htm	Systematic review of health literacy research on possible interventions and their effectiveness
IOM (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century* http://www.nap.edu/openbook.php?record_id=10027	In-depth report on healthcare quality
IOM (2004). *Health Literacy: A Prescription to End Confusion* http:www.nap.edu/catalog/10883.html	Comprehensive report describes the consequences of low health literacy and proposes solutions
IOM (2003). *Priority Areas for National Action: Transforming Health Care Quality* http://www.nap.edu/openbook.php?record_id=10593&page=1z	Describes health literacy as a cross-cutting priority for transforming health care and improving health care quality
U.S. Department of Health and Human Services, (2010). *National Action Plan to Improve Health Literacy* http://www.health.gov/communication/hlactionplan/	Provides a plan for addressing health literacy from multiple perspectives and sectors including health care, education, business, etc.

Making the Quality and Business Case

Resource	Description
AMA Foundation and AMA (2007). *Health Literacy and Patient Safety: Help Patients Understand: Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment* http://www.ama-assn.org/resources/doc/ama-foundation/healthlitclinicians.pdf	Explores how ineffective communication and low health literacy can affect patient safety, and approaches for improvement
Brach C, Keller D, Hernandez LM, et al. (2012). *Ten Attributes of Health Literate Health Care Organizations* http://www.iom.edu/~/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH_HLit_Attributes.pdf	Provides a comprehensive organization-wide approach to addressing the challenges of low health literacy
Joint Commission (2007). *What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety* http://www.jointcommission.org/What_Did_the_Doctor_Say/	Identifies low health literacy and limited English proficiency as impacting healthcare quality and patient safety
The Joint Commission (2010). *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals* http://www.jointcommission.org/assets/1/6/ARoadmapforHospitalsfinalversion727.pdf	Provides guidance, tools, and relevant Joint Commission requirements for how to integrate communication, cultural competence, and patient-centered care into hospitals
Kimble J (2012). *Writing for Dollars, Writing to Please* http://www.cap-press.com/books/isbn/9781611631913/Writing-for-Dollars-Writing-to-Please	Describes how using plain language can save money and provide clarity and simplicity to complex documents
Koh HK, Berwick DM, Clancy CM, et al. (2012). *New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'* http://content.healthaffairs.org/content/early/2012/01/18/hlthaff.2011.1169.abstract	Provides an overview of how current federal policy initiatives address health literacy
Minnesota Health Literacy Partnership (2007). *Making a Business Case for Health Literacy* http://healthliteracymn.org/downloads/Business-Case-white-paper.pdf	Planning tool that provides templates for making the business case for addressing low health literacy
Vernon J, Trujillo A, Rosenbaum S, et al. (2007). *Low health literacy: implications for national health policy* http://sphhs.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10_4_07.pdf	Report that outlines the economic impact of low health literacy

Toolkits and Other Media

Resource	Description
AMA Foundation and AMA (2007). *Health Literacy Kit* http://www.ama-assn.org/ama/pub/about-ama/ama-foundation/our-programs/public-health/health-literacy-program/health-literacy-kit.page?	Includes instructional video with facts, strategies, patient testimonials, and manual for clinicians
America's Health Insurance Plans (2010). *Health Literacy: A Toolkit for Communicators* www.ahip.org/content/default.aspx?docid=30683	Provides steps for initiating or advancing a health literacy program
Centers for Disease Control and Prevention (2012). *Health Literacy: Accurate, Accessible and Actionable Health Information for All* http://www.cdc.gov/healthliteracy/	Offers health literacy information for public health, includes resources, current practices, research, and evaluation; highlights the work of others implementing health literacy strategies
DeWalt DA, Callahan LF, Hawk VH, et al. (2012). *Health Literacy Universal Precautions Toolkit* http://www.ahrq.gov/qual/literacy/healthliteracytoolkit.pdf.	Includes tools to help healthcare practices take a systems approach to improving health literacy
Jacobson KL, Gazmararian JA, Kripalani S, et al. (2007). *Is Our Pharmacy Meeting Patients' Needs? A Pharmacy Health Literacy Assessment Tool User's Guide* http://www.ahrq.gov/legacy/qual/pharmlit/	Includes tools to help pharmacy staff evaluate how well they are serving patients with limited health literacy
Rudd R, Anderson J (2006). *The Health Literacy Environment of Hospitals and Health Centers. Partners for Action: Making Your Healthcare Facility Literacy-Friendly* http://www.ncsall.net/fileadmin/resources/teach/environ.pdf	Provides tools and describes approaches to evaluating health literacy barriers to accessing and navigating healthcare facilities

Keep It Short

Bear in mind that leaders are pressed for time. Use excerpts or brief materials to make key points, knowing you have more information if needed. Try to find an incident from your health care setting where poor communication or lack of understanding could have or did end in harm to a patient. This harm may have been short- or long-term, physical, emotional, or mental. Invite your leaders to reflect on their own or their family's care, or to think of a time when it was hard for them to understand health information.

Have a Plan Ready

Be ready with an answer if your leader responds, "So, how do we fix our system to meet the health information needs of the people we serve?" Focus your answer on creating lasting improvements in how your organization communicates with and shows respect for patients and families. This cannot be done by just *educating* providers. It means changing provider *behavior*. In the end, you want your organization to:

- Provide a welcoming care environment that communicates clearly, invites questions, and involves patients in organizational planning.
- Ensure a prepared workforce that uses plain language principles and teach-back to effectively communicate key information that patients and families need to know to care for themselves.
- Use reader-friendly principles in all print and web materials.

To do this, your organization's health literacy team will have to:

- Set an organizational aim.
- Take advantage of existing and new opportunities to educate and train staff.
- Use small tests of change and coaching to start putting health communication skills into practice and build long-term support.
- Work toward measurable goals.

It may work best to break this into parts. Look at the ten attributes of a health literate health care organization and choose one or two areas you want to start with. Begin with one unit, department, condition, or initiative, possibly one already underway. This is important so you can work out the bugs, build support, and embed changes over time, before spreading organization-wide. Build the skills of managers so they can coach staff as they adopt new communication habits. This approach has the added benefit of gaining new champions to help you.

Give the Leader a Role

"What do you want me to do?" may be the next question a senior leader asks. Here is where you want to take advantage of the influence of leaders, who can:

- Assure resources: "Please give me some protected time to work on health literacy."

- Assemble a team: "Can you choose two or three people you think would be great to add to our health literacy team?"
- Channel attention: "Could you make health communication and health literacy a standing agenda item for board, quality committee, and department meetings?"
- Position health literacy as a key organizational objective: "Ask the leaders of our chronic disease management, medication safety, and strategic planning committees to integrate health communication into their goals and objectives."
- Model clear health communication principles and patient involvement: "Use plain language principles in your letters and memos." "Join us for a navigation exercise to see how well patients and families can find their way in our hospital."

Set a Timeline... But Not in Stone

Setting timelines is a basic element of your work with your senior leaders (and yourself). It will help you make clear what you need to get the job done by a certain date. Be realistic and flexible. But put it in writing and review progress with your senior leader.

Establish Aims and Measures

Explain how the attributes of a health literate health care organization[5] and the overarching aims for improvement for health care[6] relate to your aims and measures. Show measures from the following three categories to give an accurate picture of the impact within your system:

- Outcome Measures (voice of the patient): How is the system performing? What are the results?
- Process Measures (voice of the working of the system): Are the parts/steps in the system performing as planned?
- Balancing Measures (looking at different parts of the system): Are changes improving one part of the system but causing new problems in another?

Integrating Health Literacy With Health Care Performance Measurement[7] is a useful starting point for linking health literacy to quality measures and integrating health literacy performance measurement into all aspects of the patient experience.

Crossing the Quality Chasm
Six Overarching Aims for Improving Health Care

Safe: Avoid injuries to patients from the care that is intended to help.

Effective: Avoid overuse of ineffective care and underuse of effective care.

Patient-Centered: Honor the individual and respect choice.

Timely: Reduce waiting for both patients and those who give care.

Efficient: Reduce waste.

Equitable: Close racial and ethnic gaps in health status.

Source: Institute of Medicine Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC: The National Academies Press, 2001.

Get On the Schedule and Check In Often

It is critical to meet together regularly and report on your progress, barriers, lessons learned, and resources needed. Senior leaders can't help if they don't know what problems you are facing. They can't recognize progress if they don't know how things are going. During regular updates and reports, your leader can help:

- Solve problems.
- Remove barriers.
- Raise visibility.
- Promote spread throughout the organization.

Make good use of leaders' time. Make your meetings meaningful. Use the tools described in this chapter to help when you talk with senior leaders.

Summary of Key Points

- Give leaders the tools and resources they need to channel attention to health literacy and clear health communication efforts.
- Have a plan that includes a specific role for your senior leader.
- Use tools that fit your senior leader's available time and working style.
- Involve your leader in setting an organizational aim and measurable goals.
- Look for ways to integrate health literacy and clear communication into ongoing quality and safety efforts.
- Use small tests of change to start putting health literacy-related interventions into practice and build support.
- Check in with your senior leader regularly.

---

1 Reinertsen J, Pugh M, Nolan T. *Executive Review of Improvement Projects: A Primer for CEOs and other Senior Leaders*. 2005. Available at: http://www.ihi.org/knowledge/Pages/Tools/ExecutiveReviewofProjectsIHI.aspx. Accessed: November 7, 2012.

2 Reinertsen JL, Bisognano M, Pugh MD. *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care (Second Edition)*. IHI Innovation Series white paper. Cambridge, MA: Institute for Healthcare Improvement; 2008. Available at: http://www.ihi.org/knowledge/Pages/IHIWhitePapers/SevenLeadershipLeveragePointsWhitePaper.aspx. Accessed: November 15, 2012.

3 Vernon J, Trujillo A, Rosenbaum S, et al. *Low health literacy: implications for national health policy*. 2007. Available at: http://sphhs.gwu.edu/departments/healthpolicy/CHPR/downloads/LowHealthLiteracyReport10_4_07.pdf. Accessed: March 31, 2014.

4 Koh HK, Berwick DM, Clancy CM, et al. New federal policy initiatives to boost health literacy can help the nation move beyond the cycle of costly 'crisis care'. *Health Affairs*. 2012;31(2). Available at: http://content.healthaffairs.org/content/early/2012/01/18/hlthaff.2011.1169.abstract. Accessed: November 5, 2012.

5 Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington DC: National Academy of Sciences; 2012. Available at: http://iom.edu/~/media/Files/Perspective-Files/2012/Discussion-Papers/BPH_Ten_HLit_Attributes.pdf. Accessed: October 16, 2012.

6 Institute of Medicine Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: The National Academies Press; 2001. Available at: http://www.nap.edu/openbook.php?record_id=10027. Accessed: October 16, 2012.

7 DeWalt DA, McNeill J. *Integrating Health Literacy with Health Care Performance Measurement*. Discussion Paper, Institute of Medicine, Washington, DC. 2013. Available at: http://www.iom.edu/Activities/PublicHealth/%7E/media/Files/Perspectives-Files/2013/Discussion-Papers/BPH-IntegratingHealthLiteracy.pdf. Accessed: September 24, 2013.

4 | Preparing the Workforce

> "As I observed…healthcare provider-patient interactions, it became clear to me that patient education is a habit – the strategy a healthcare provider uses to educate patients is the same strategy they use over and over again. Habits are not changed by education; they are changed by coaching to a new behavior." (Improvement Learning Network Manager, UnityPoint Health)

To be a health literate organization, everyone on the health care team needs to be aware of and trained in clear health communication skills. The importance of effective communication with patients and families cannot be understated since it is central to carrying out the mission of most health care organizations. Fostering skill-building and long-term adoption of clear communication practices is vital.

Knowing is not the same as doing. That is, education and training do not automatically translate into behavior change. Still, both are needed to become a health literate health care organization. Providers and staff must see the connection between what they have learned and what happens in their care setting and put that into action. The ideas and tools in this chapter are designed to help you:

- Make the case for all health care providers and staff to understand health literacy and use clear health communication.
- Identify and use patient and provider experiences as teaching tools, and recruit health literacy champions.
- Build capacity for clear effective health communication among all members of the health care team.

A Health Literate Health Care Organization Prepares Its Workforce

This chapter directly addresses Attribute 3 and will help you prepare all members of the health care team to be health literate, and to monitor progress.

Source: Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington, DC: National Academy of Sciences, 2012.

Clear Communication Is Everyone's Job

Health education and communication are not just one person's or one profession's responsibility. They are the responsibility of all members of the health care team. Everyone must understand:

- What low health literacy is.
- That anyone can experience low health literacy.
- Its adverse impact on health behaviors, outcomes, and costs.
- How low health literacy plays out in their own setting.
- That low health literacy may underlie labels like *non-compliant*.
- That health literacy is both an individual and systems problem.

Note that patients and families may ask questions of staff who do not give direct clinical care. These staff may seem more approachable and talk with patients and families informally. They include workers in administration, registration, housekeeping, transportation, food services, maintenance, and others. So *all* staff need to be able to do the following for *any* patient:

- Give clear answers.
- Assess their own ability to answer and recognize when to go to someone else.
- Convey important questions to the right person for an answer.
- Recognize signs that the questioner needs more help.
- Pass what they observe along the continuum of care.
- Go the extra mile to help out.

It's also important for all staff to recognize that when a patient or family member is confused or does not understand, it may reflect an opportunity to make a systems change that could help all patients.

Health Literacy Training Has Many Benefits

Training to improve health communication can help your organization meet continuing education needs; comply with guidelines, recommendations, requirements, and

regulations; and improve care and outcomes. The transforming health care system also includes financial incentives where better communication can have a positive impact.

Examples include:

- Reducing unplanned readmissions.
- Improving care transitions.
- Enhancing patient experiences.
- Establishing medical homes.
- Chronic disease management.

Also, newly-trained health care professionals enter the workforce knowing more about patient education and communication. Health care organizations can and should build on that foundation.

Your Own Workers May Need Help, Too

Increasing awareness about low literacy and low health literacy can help your organization in unexpected ways. Some of your own workers may struggle with reading. This may interfere with their ability to perform their job well and live their lives fully. They may need to read manuals, directions on hazardous products and equipment, and steps to follow in an emergency like a tornado or fire.

Your workers use health services and benefits, too. Improved understanding of how to care for themselves and their families may help them use these resources better. It may even lead to better job performance. The same may hold true for workers, patients, and families whose first language is not English.

Remember, only 12% of people in the U.S. have proficient health literacy skills.[1] Add to this the fact that almost half of U.S. adults struggle with reading. Chances are that some of these are your patients, and some are your staff and co-workers.

What Does Success Look Like?

What a successful health literacy and clear health communication skills training program for all health care providers and staff looks like:

- An action plan for training with goals and aims is in place.
- Health literacy and the need for clear health communication are part of orientation at all levels: organization, department, unit, and volunteer.
- As part of credentialing, doctors view the American Medical Association (AMA) and AMA Foundation video, *Help Your Patients Understand*.
- Policies are in place to ensure all health care providers and staff are trained and retrained in clear health communication.
- Providers and staff earn continuing education credit for education and training in health literacy, health communication, and patient teaching.
- Competencies are set for key health literacy skills, like using plain language and checking understanding using the teach-back method.
- Storytelling and personal observation and reflection are part of all health literacy and health communication talks, training, and workshops.
- Lay representatives are given a way to provide their important perspective in health literacy and health communication talks, training, and workshops.
- All health literacy and health communication talks, training, and workshops lead to action steps.
- Engaging learning modes (e.g., video, case studies) and outside experts are used for training about health literacy and health communication skills.
- Direct observation and coaching are used to help staff move from long-standing patient education habits toward new health communication habits.

What success looks like when training leads to all health care providers and staff understanding the importance of health literacy and applying clear health communication skills:

- All health care providers and staff use plain language and confirm patient and family understanding of key information.
- Plain language principles are used in all communication including marketing, public relations, billing, and volunteer services.
- Employee handbooks are written using plain language principles. Supervisors are trained on how to talk workers through the handbooks.
- Plain language principles are used in developing computer-based and other learning modalities so they are user-friendly for intended learners.

- All staff and doctors can readily describe how clear communication and effective patient teaching relate to quality, safety, and patient-centered care.
- Standard order sets and electronic health records call for use of teach-back or other means of checking for and ensuring understanding during patient education.
- Managers and supervisors are equipped to coach and empower staff to always use plain language, teach-back, and other health literacy skills.
- Job descriptions and performance reviews include responsibilities related to clear health communication.
- All departments and units set goals for improving health communication, and managers are responsible and accountable.
- A formal process is in place to share communication-related stories and lessons learned from patient, family, and provider points of view.
- Incidents involving poor communication are considered markers for possible harm; the organization reviews and addresses such communication-related adverse events.[2]
- Leaders publicly praise staff and teams leading health literacy improvement.

The Power of Personal Stories

Raising awareness about health literacy should combine teaching and training with health care providers' own experiences. Providers need to move from abstract knowledge to personal insight, and recognize signs of limited health literacy within their own setting. Overlaying data with stories of patient experiences can be a powerful way to achieve this. This is especially true when stories come from the health care team's own setting. It can be easy for health care providers to dismiss data as not reflecting their own patients. Finding just one or two stories demonstrating a patient's lack of understanding can move the health care team toward action. Providers' experiences as patients or family members can underscore the fact that *anyone* can have low health literacy at times. This holds true even for highly educated health professionals, and shows the importance of better health communication for all patients.[3] When these *a-ha* moments happen, they become tipping points for change. Providers begin to:

- Communicate differently with patients.
- Be more willing to try new approaches.
- Open up to partnering with patients.
- Evolve into being health literacy champions.

What if no one speaks up when you ask them to share a story or personal experience?

This seldom happens if you wait long enough. But in case it does, tell your own stories or use the ones you'll find in this guidebook. These stories should show the harm—real or potential—that can come from poor health communication. Prepare two or three questions to ask after they hear each story. Better yet, ask someone in your audience to read the story aloud and ask the first question. Don't be afraid of silence. Someone will step forward to fill it. Your job is to make it comfortable for them to start talking.

Raising Awareness and Changing Behavior

Keep in mind that principles of changing behavior show that increasing a person's conviction that making a change is important, and their confidence in being able to make a change, make it more likely they will be successful. You can give providers tools to assess their conviction and confidence in using health literacy-related techniques (like teach-back). Their conviction and confidence levels can guide you in focusing training and coaching. If learners are not convinced of the adverse impact of low health literacy and its widespread nature they are less likely to adopt a new way of communicating with patients and families. So you want to be sure they understand the importance of limited health literacy. On the other hand, if they are not confident in how to use a technique like plain language, you want to build their comfort and skill in this area.

Here are three approaches to raising awareness and changing behavior among all members of the health care team:

- Traditional methods
- Marketing strategies
- Coaching to a new habit

Traditional Methods

Traditional ways of conveying knowledge to health providers and staff may be most useful when you are introducing health literacy the first time. They need to come away with an understanding of health literacy, how common low health literacy is, its

relationship to poor health outcomes, and what can be done to improve it and move your organization toward becoming more health literate. Here are tips for how to plan your approach and some tools to help you move forward.

Identify Your Audience. Think about who you want to influence—senior organizational leaders, doctors, department managers, front-line staff, informal leaders—and seek them out.

Find Ways to Reach Them. Look for opportunities to connect with your audience whenever you can. Take advantage of formal and informal ways to talk with them. You may have a one-time opportunity to speak to 100 doctors at a staff meeting, or a 5-minute conversation with one nurse.

Take advantage of these pre-existing educational activities and opportunities and build on what's already in place.

Continuing Education

- Grand rounds
- Conferences
- Lunch and learns
- Educational special events

Employee Training

- Orientation
- Credentialing
- Skills fairs
- Recertification
- Competency assessment
- Computer-based learning
- Performance reviews

Meetings

- Department meetings
- Quality meetings
- Board meetings
- Committee and project meetings (e.g., patient safety, diabetes)
- Planning meetings

Decide on and Prepare Your Message. Think ahead about the most important information you want to convey. There are lots of ideas in this guidebook to help you identify important topics and supporting information to help you feel prepared to deliver your message.

Get to know national data and key health literacy information. Then collect stories about communication-related troubles of patients who struggle with reading *and* patients with strong literacy skills who didn't understand.

Choose what information and which stories will mean the most to your audience. If you can, invite a patient to share his or her story. Make sure this person feels all right sharing his or her experience in a group setting with health care professionals. Many people find this daunting, not just those who struggle with reading.

My Father's Story: Diagnosed with Lung Cancer

"One week ago my father was diagnosed with lung cancer. Today we met with the oncologist to discuss the treatment plan. During our visit we were told the cancer previously thought to be non-small cell was small cell. The nurse said she would give us some information on this new diagnosis. She handed us a computer printout titled *Pathobiology and staging of small cell carcinoma of the lung*. It is 11 pages of single-spaced text written at a level that even I, as a health professional, have *no idea* how to interpret. I was so appalled at the fact that this was it—this was all the education he was going to get—I spoke up. I asked the nurse how she thought a patient would ever understand this information. How can a patient, specifically my 63-year-old father who is an intelligent man, make out anything from this document? The nurse simply answered that this was the patient-friendly version they use all the time…"

Nurse Director, 2007

Questions

- What are some things the nurse could do to help this patient and his daughter?
- What do you do when the only patient education materials you have are hard to read and understand?

Have Tools Ready. It's good to give your audience something to look at or use later. This can illustrate a point, reinforce your message, and give you a reason to check back later.

Health Literacy Tools for Teaching and Training

Resource	Description
AMA Foundation and AMA (2007). *Health Literacy Kit* http://www.ama-assn.org/ama/pub/about-ama/ama-foundation/our-programs/public-health/health-literacy-program/health-literacy-kit.page?	Includes a 22-minute instructional video with facts, strategies, patient testimonials, and manual for clinicians
American Academy of Pediatrics (2007). *Putting Health Literacy Into Practice: A Pediatric Approach* http://www2.aap.org/commpeds/presentations/2007/health-literacy.html	Presentation slides, recordings, and video clips that illustrate the challenges of limited health literacy from a parent's perspective
American College of Physicians Foundation. *Health Literacy Video* http://www.acponline.org/multimedia/?bclid=782539368001&bctid=790962260001	6-minute video features physicians interacting with patients challenged by low health literacy
Centers for Disease Control and Prevention. *Health Literacy Training for Public Health Professionals* http://www2a.cdc.gov/TCEOnline/registration/detailpage.asp?res_id=2074	Free web-based training offers continuing education credit targeted for public health professionals
DeWalt DA, Callahan LF, Hawk VH, et al. (2012). *Health Literacy Universal Precautions Toolkit* http://www.ahrq.gov/qual/literacy/healthliteracytoolkit.pdf	Describes and links to an assortment of health literacy teaching tools.
Health Literacy Studies (2004). *In Plain Language* http://www.hsph.harvard.edu/healthliteracy/overview/#Video	15-minute video developed to raise awareness about low health literacy for medical and public health professionals
Health Resources and Services Administration. *Effective Healthcare Communication 100 and 101* http://www.hrsa.gov/healthliteracy/	Free online training on low health literacy, limited English proficiency, and working with interpreters
Iowa Geriatric Education Center (2013). *Geriasims, Health Literacy* http://www.healthcare.uiowa.edu/igec/resources-educators-professionals/geriasims/acadMenu.asp	Free online health literacy training for clinicians working with older adults; includes an interactive virtual patient simulation, decision tasks, and mentor guidance
Ohio State University AHEC. *Health Literacy Distance Education Modules* http://healthliteracy.osu.edu/modules	Eight online modules providing instruction on health literacy
UnityPoint Health (2013). *Always Use Teach-back! Toolkit* http://www.teachbacktraining.org/	Online toolkit includes introduction to teach-back, interactive learning module, and tools
World Education (2004). *Health Literacy: A New Field with New Opportunities* http://www.healthliteracy.worlded.org/docs/tutorial/SWF/flashcheck/main.htm	Online tutorial for heath and literacy educators includes stories and successful strategies

Deliver Your Message.

- Briefly present national data and evidence about low health literacy. Put it in the context of a system that is hard to use for almost 90% of the people it is supposed to help.
- Follow with local literacy data. You can get estimates from the 1993 National Adult Literacy Survey data using the tool at http://nces.ed.gov/naal/estimates/.
- Explain the stigma and shame of low literacy. Build empathy using a backward reading exercise, and invite them to share how it made them feel.
- Share one or more stories about poor communication from your own health care setting. Then invite your audience to share their own stories.
- If you have patients willing to do so, ask them to share their experiences.
- If you do not have a partnership with patients or adult learners, you can use short videos as a good way to share patients' points of view.
- Emphasize that even people with strong literacy skills can struggle to understand in some circumstances.

Backward Reading Exercise

This training exercise simulates what readers with low literacy experience with the printed page. Ask participants to read the paragraph out loud and together. Hint: The words are written backward. For example, the word "wercsnu" is read "unscrew." As you discuss the questions, point out that the feelings of frustration they may have felt are similar to how patients with limited literacy may feel.

Wercsnu eht dehcton gnirkcol no eht dnah-tfel edis fo eht mottob tekcarb eno nrut. Gnisu eht nip hcnerw fo eht mottob tekcarb sloot, nethgit eht dnah-tfel gniraeb puc. Nethgit eht gnirkcol ylmrif, gnikam erus eht gniraeb puc seod ton nrut htiw ti.

Questions

- How did you feel trying to read the passage?
- What did you remember from reading the passage?

Source: Van der Plas, R. *Simple Bicycle Repair*. Cycle Publishing/Van der Plas Publications. San Francisco, CA, 2004.

Help Your Audience Connect the Dots. Your audience will care most about things that hold meaning for them. To carry your message home, answer "What's In It For Me?" Help your audience see the relationship between health literacy and what *they* are focusing on. Talk about how health literacy affects their specific clinical area, like diabetes, heart failure, or patient safety, or how it can help them by increasing patient adherence, improving the informed consent process, decreasing cancelled procedures, or preventing interruptions. Get them to ask what is the health literacy impact on everything.

Mr. G.'s Story: Too Many Pills

Mr. G. is a 45-year-old Hispanic immigrant. He has a health screening for a new job. He is told his blood pressure is very high… He goes to the local public hospital and gets a prescription for a beta-blocker and diuretic… The providers choose 2 drugs known to work well and be simple for adherence because they each are supposed to be taken once a day. Mr. G. comes to the emergency room one week later with dizziness. His blood pressure is very low. He says he has been taking the medicine just like it says on the bottle. Several doctors discuss the case, but can't figure out what happened. Finally, a doctor who speaks Spanish asks Mr. G. how many pills he took each day. "Twenty-two," Mr. G. replies. The doctor explains to his colleagues that "once" means "11" in Spanish.

Questions

- What could providers have done during Mr. G.'s first visit to be sure he understood how to take his medicine?
- If the Spanish-speaking doctor had not been there, how else could providers have uncovered the problem?

Source: Institute of Medicine Committee on Health Literacy. *Health Literacy: A Prescription to End Confusion*. The National Academies Press. Washington, DC, 2004.

My Son's Story: Anti-Convulsant Drug Overdose

"My son had a brain concussion. He was going in and out of convulsions. I called the doctor. I was giving him, I think, 3 teaspoons 3 times a day and the doctor told me to give him one more teaspoon. Well, I was confused. So, I was giving him 4 teaspoons, 3 times a day. The poor little thing was walking into doors and into walls. And here was a chair, and he'd sit down over there. I couldn't figure out what was wrong with him, so I brought him in to see the doctor. He wasn't having any more convulsions. So the doctor asked me how much medicine I gave him. I told him, and he said, 'No, no. Just one more extra teaspoon.' Well, I didn't understand and I should have asked questions. But I didn't. It's a wonder I didn't harm him worse than I did; but he's fine now."

New Reader

View video of My Son's Story:
http://vimeo.com/48471644

Questions

- What do you think about the conversations that took place between the doctor and the mother? What do you think about her feelings about what happened?
- What can be done to check that patients understand instructions given over the telephone?

Show Them What They Can Do. Describe how using health literacy tools and techniques with all patients and families can help them obtain and understand the information they need to take care of themselves. Emphasize how important it is to create a shame-free care environment that makes it comfortable for patients and family members to ask questions and fosters dialogue; and use plain language for verbal and written communication, and teach-back to assess whether key information was understood. Highlight the special importance of using these techniques, tools, and strategies during critical times, like a new diagnosis, change in treatment, or hospital discharge or other care transition. Show how these help people feel less embarrassed about asking questions, and identify areas of misunderstanding.

Call to Action. Close by asking your audience to commit to *doing* something specific. Here are some questions you can ask to get them started:

- What can you do by Tuesday to improve one aspect of health communication or patient education in your setting?
- Do you think you could try using this plain language hand-out during discharge education for one patient?
- Would you be willing to try teach-back with your last patient tomorrow?
- Could you ask a patient or family member for feedback to help you improve your check-in process?
- …and can I call or email you next week to find out how it went?

Engaging Doctors

Doctors are a key audience for addressing health literacy. They are leaders of the health care team and influence what other people think, say, and do. But, there are tremendous demands on their time, and you are asking them to change their behavior, which is hard to do. Remember, change happens best when perceived benefit outweighs perceived discomfort. Make sure you address: "What's in it for me — how will this help me provide better care for my patients?"

Marketing Strategies

Seeking out busy health providers–especially doctors–may mean taking a non-traditional approach. So try these lessons learned from the marketing industry on how to develop a successful sales pitch to promote use of health literacy-based interventions and tools. (Frank Burns, personal communication, 2012)

Pre-call Planning

- Set a specific goal or goals.
- Think ahead to objections the provider may make.
- Prepare and practice.

The Pitch

Opening. Get the provider's attention and guide the conversation toward what you want to talk about. State the problem and offer your solution.

Explain benefits. Give the *benefits* of your solution:

- Use short, convincing sentences. Don't talk fast; talk briefly.
- Limit yourself to 3 key points. That's all most people can absorb at one time.
- Use visual aids like a hand-out or brochure to open a conversation, illustrate a point, handle an objection, or as a reminder of your conversation.

Ask questions. What does the listener think, feel, or need? Try to find out what his or her objections are. Then wait for their answers and listen. Silence can be powerful.

- How do you feel when patients don't keep their follow-up appointments?
- Where do you see using teach-back as being most helpful?
- Is there something you don't like about using plain language hand-outs?
- How do you see yourself using this reader-friendly diabetes guide?

Handle objections.

- Don't be defensive or take objections personally.
- Objections mean they are interested enough to listen and think about what you said.
- Believe body language and tone of voice over words.
- Restate the objection to ensure you understand each other. Clarify your own points if needed.
- Address the provider's issues.
- Provide guidelines or research to support your point.

Handling Possible Objections	
Objection	**Response**
There isn't enough time.	Ask for a few minutes to show them how: – Plain language and teach-back may save time in the long run by making sure patients understand. – Providers find that once they get the hang of it, they use teach-back throughout the visit and it doesn't take longer. – Plain language and teach-back may also improve quality of care and patient satisfaction.
That isn't my job.	Acknowledge that they are busy, with many demands placed on their time. – Underscore how making sure patients and families understand is the responsibility of all members of the health care team. – Suggest approaches that invite other members of the health care team to help with plain language explanations and teach-back. – Offer to help train the health care team in these techniques.
This isn't a problem in my practice.	Emphasize that health literacy can be a problem for any patient. – Note it can be hard to recognize when someone doesn't understand—you can't tell by looking. – Even highly educated people can experience low health literacy, especially if they are sick, worried, sleep-deprived, or in a lot of pain. – Invite them to consider a time when they did not understand what they were being told by an engineer, attorney, or physician in another specialty. – Research show that people often do not admit that they don't understand (Parikh 1996). Show the provider the reference.
No one can really do anything about it anyway.	Highlight that while addressing health literacy is a challenge, the rewards are great. – Plain language and asking people to review what you said in their own words can go a long way in helping them understand, remember, and use the information you gave them to care for themselves. – Research shows using teach-back among patients with diabetes is associated with improved outcomes (Schillinger 2003). Show the provider the reference.

Source: Parikh NS, Parker RM, Nurss JR, et al. Shame and Health Literacy: The Unspoken Connection. Patient *Educ Couns*. 1996. Schillinger D, Piette J, Grumbach K, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. *Arch Intern Med*. 2003.

Closing. Always close with a call to action. Try to gain a specific commitment. For example, you might say:

- Would you be willing to use this plain language hand-out tomorrow when you talk with a parent about fever and safe use of over-the-counter medicines?
- Would you be willing to talk to your colleagues about the problem of low health literacy and how poor communication affects patients?
- ... and can I follow up with you on this in ____ days/weeks?

Post-call Notes

- Did you meet your goals for this conversation?
- What is your plan for following up?
- Be sure to follow up on objections.
- Continue to build your case with other supporting concepts or documents. If you tell them you will give them more information or resources, note when you will deliver what you promised. Be specific.

Follow Up

When you follow up, check on the action plan you discussed—what was done and how it went. If things went well, encourage another step. If things didn't go well, help figure out how to make it go better, and encourage the health care provider to try again.

- Don't expect too much at first. It can take eight calls to create buy-in.
- Remember WIFM. (What's In it For Me?)
- Show how your health literacy solution is a win-win.
- Use the power of brand recognition; reinforce key words and techniques, like *plain language* and *teach-back*.
- Watch body language to see how they are reacting to what you say.
- Paint a picture. Give real-life examples that reflect the provider's setting.
- Confidence and enthusiasm make a lot of sales. The way you convey your message can create success.
- Remember, *you* are the health literacy expert!

Early Adopters and Physician Champions

One way to speed improvement and adoption of evidence-based or best practices is to work with early adopters (those willing to try new ideas early on). Often we spend a lot of energy trying to convince those most resistant to change or most invested in traditional patterns. Trying to make change happen this way can be frustrating.

Instead, focus your energy on early adopters—those open to new ideas and willing to try them.

- Give them the data and stories.
- Elicit their experiences or observations that show the importance of understanding.
- Invite them to try a new health communication skill with just one patient. From one patient, they can build to a few more patients on a few more days with a few more conditions. Eventually, the skill is built into their practice patterns.
- Then invite and encourage them to share their experience with colleagues, thus evolving into champions.

Your goal should be to identify and engage early adopters—those willing to try using improved communication techniques, who may become champions and help advance your work.

Coaching to a New Habit

Giving staff knowledge of health literacy interventions is important. But, to change from long-standing patient communication and education habits to routinely using plain language principles and checking for understanding by using teach-back takes coaching. Coaching can help staff be successful by enhancing their skills in moving away from long-standing habits and integrating new ones. Here are tips to help you coach staff to new health communication habits.[4,5,6]

Build motivation.

- Encourage use of the new habit by focusing on patient-centered/ideal care.

Honor the current work through acceptance.

- Establish relationships by observing those seeking to build the new habit (teach-back).

Understand that change is hard and uncomfortable.

- Use active and reflective listening.
- Use open-ended *what* and *how* questions to determine individual barriers:
  - What worries you about using teach-back?
  - How did using teach-back with your patient make you feel?
  - Tell me more about…

Resistance to change is natural.

- Resistance comes from fear of change.
- Confront the problem, not the person.
- Resistance is a signal to change the response and approach.

Promote new skill development.

- Promote each individual's belief in their ability to change.
- Focus on previous successes.
- Focus on skill development.
  - Set goals: I will use teach-back with each patient.
  - Develop a change plan: Habit change happens with conscious planning.
  - Mentally rehearse:
    - What is the most important thing I want to be sure the patient understands?
    - How would I ask this question?
  - Embed cues to use teach-back in established habits:
    - After each interaction, I will ask open-ended questions to elicit understanding.

Build confidence to integrate the new habit into work patterns.

- Rate your confidence in using teach-back on a scale of 1 to 5…
- What might help you increase your confidence from a 3 to a 4?

Coaching Tips Handout

http://teachbacktraining.org/assets/files/PDFS/Teach%20Back%20-%20Coaching.pdf

Source: Abrams MA, Rita S, Nielsen GA. *Always Use Teach-back! Toolkit*, 2012. http://www.teachbacktraining.org/.

Build reliability.

- Even when people have goals, they often need reminders and support to be successful.
  - Create standard work: content, sequence, timing, and outcome.
  - Build in job aides and reminders.
  - Take advantage of pre-existing work and habits.
  - Make the desired action the default rather than the exception.
  - Create redundancy to reduce risk or enhance safety.
  - Group related tasks.

Manage relapses.

- Make a plan for follow-up coaching to reinforce the new habit.
- Share questions and problems. Develop program improvements.
- Recognize, reward, and celebrate!

Always Use Teach-back!

Conviction and Confidence Scale

Fill this out before you start using teach-back, and 1 and 3 months later.

Name: _____

Check one: ◯ Before - Date: _____

◯ 1 month - Date: _____

◯ 3 months - Date: _____

1. On a scale from 1 to 10, how **convinced** are you that it is important to use teach-back (ask patients to explain key information back in their own words)?

Not at all important Very Important

1	2	3	4	5	6	7	8	9	10

2. On a scale from 1 to 10, how **confident** are you in your ability to use teach-back (ask patients to explain key information back in their own words)?

Not at all confident Very Confident

1	2	3	4	5	6	7	8	9	10

3. How often do you ask patients to explain back, in their own words, what they need to know or do to take care of themselves?

◯ I have been doing this for 6 months or more.

◯ I have been doing this for less than 6 months.

◯ I do not do it now, but plan to do this in the next month.

◯ I do not do it now, but plan to do this in the next 2 to 6 months.

◯ I do not do it now and do not plan to do this.

1

UnityPoint Health · Picker Institute · Des Moines University · Health Literacy Iowa

Conviction and Confidence Scale continued

4. Check all the elements of effective teach-back you have used **more than half the time in the past work week.**

- ◯ Use a caring tone of voice and attitude.
- ◯ Display comfortable body language, make eye contact, and sit down.
- ◯ Use plain language.
- ◯ Ask the patient to explain, in their own words, what they were told.
- ◯ Use non-shaming, open-ended questions.
- ◯ Avoid asking questions that can be answered with a yes or no.
- ◯ Take responsibility for making sure you were clear.
- ◯ Explain and check again if the patient is unable to teach back.
- ◯ Use reader-friendly print materials to support learning.
- ◯ Document use of and patient's response to teach-back.
- ◯ Include family members/caregivers if they were present.

Notes: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

2

UnityPoint Health · Des Moines University

For a downloadable copy:
http://teachbacktraining.org/assets/files/PDFS/Teach%20Back%20-%20Conviction%20and%20Confidence%20Scale.pdf

Always Use Teach-back!

Teach-back Observation Tool

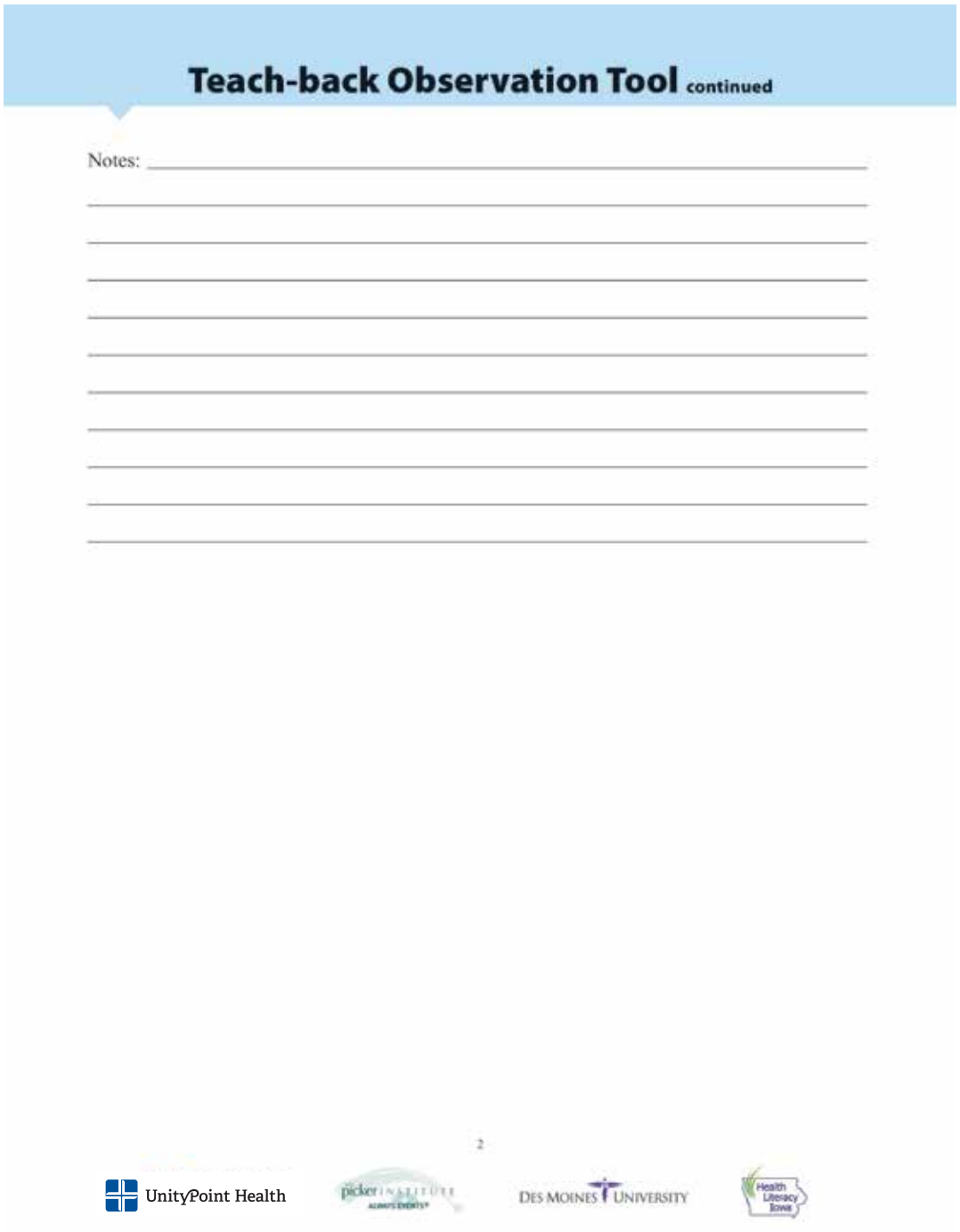
Care Team Member: _____ Date: _____

Observer: _____ Time: _____

Did the care team member…	Yes	No	N/A	Comments
Use a caring tone of voice and attitude?				
Display comfortable body language, make eye contact, and sit down?				
Use plain language?				
Ask the patient to explain in their own words what they were told to do about: • Signs and symptoms they should call the doctor for? • Key medicines? • Critical self-care activities? • Follow-up appointments?				
Use non-shaming, open-ended questions?				
Avoid asking questions that can be answered with a yes or no?				
Take responsibility for making sure they were clear?				
Explain and check again if the patient is unable to use teach-back?				
Use reader-friendly print materials to support learning?				
Document use of and patient's response to teach-back?				
Include family members/caregivers if they were present?				

1

UnityPoint Health picker INSTITUTE DES MOINES UNIVERSITY Health Literacy Iowa



Teach-back Observation Tool continued

Notes: _____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

2

UnityPoint Health

picker INSTITUTE

DES MOINES UNIVERSITY

Health Literacy Iowa

For a downloadable copy:
http://teachbacktraining.org/assets/files/PDFS/Teach%20Back%20-%20Observation%20Tool.pdf

Move From Awareness to Action

All the education and training in the world can't bring about sustained behavior change. Get people started by challenging everyone in your health literacy training to find *one* small change they can make in *one* aspect of their work by next Tuesday to improve health communication. This shifts their thinking toward action. It also decreases the perceived risk of making a change, and builds confidence to try it again.

Repeated small tests by one person, followed with more testing by others, spreads experience and acceptance of new ways of communicating with patients. This process can also lead to creative problem-solving as people work to figure out what might have been done differently to make the test go better, and it helps you work out the bugs, build support, and figure out how to make improvements last and spread.

Work with staff to set short- and long-term goals to drive and assess progress toward improving health communication. A long-term vision gives guidance and motivation. Starting with one or two key areas provides focus and allows people to see progress, for example, using teach-back for patients who have diabetes, making paperwork simpler, or offering help with forms.

Then use small tests of change to help adapt interventions and tools quickly and easily for their settings. This works better than trying to introduce blanket policies all at once because improving health communication practices calls for:

- A cultural shift and continuous improvement.
- Making sure improvements last by hard-wiring changes into normal operating procedures and systems.
- Spreading change throughout the system.

Combining small tests with short- and long-term measures and goals moves people toward action, with timelines and measures to gauge success. This underscores the importance of working together and across disciplines, and with patients and families. And it builds confidence among team members that they can succeed.[7]

Make It Stick

For permanent change, embed improvements in standard operating procedures, and use systems to support and sustain those improvements.

Set Up Policies and Procedures

Use operating guidelines like these to make sure your improvements last.

- Add clear communication responsibilities to all job descriptions and performance reviews.
- Address health literacy during orientation and be sure staff understand they will be responsible for effective communication.
- Build in policies that ensure new staff and those changing jobs or roles are trained in health literacy activities they are responsible for in their new situation.
- Hospitals and clinic systems may include clear health communication education as part of physician credentialing. For example, require doctors to watch the AMA and AMA Foundation video *Help Your Patients Understand*.

Take Advantage of Systems

- Create or use computer-based or on-line learning modules to meet continuing education, certification, and credentialing requirements. Assign these and make sure they are completed.
- Also be sure that everyone gets periodic review and reinforcement. Use opportunities like recertification and skills fairs. Use observation and feedback to keep skills and techniques from eroding. This provides opportunity for improvement and a chance to celebrate progress and success.

- Don't miss chances to build plain language skills and teach-back into all care guidance and processes. For example:
  - A standard of care for pneumonia calls for use of plain language and teach-back during patient education about the condition.
  - A home health nursing competency for a dressing change includes plain language teaching and teach-back.
- Use incentive and bonus strategies. Some clinics include health literacy as an area in which managers can apply for a quality improvement bonus.

Keep It In Front of Everyone

Here are ways to keep health literacy as a guiding principle for your organization:

- Include health literacy-related topics as a standing agenda item for quality and board meetings.
- Include health communication in your organizational performance scorecards. This can help direct more attention and resources for sustaining improvements in patient communication.
- Develop ways to identify, examine, and address communication-related adverse events.
- Include lay reader review as a standard part of developing written materials.
- Faculty for health professions students should teach, model, and evaluate use of clear communication skills (especially teach-back) for their learners.
- Include teach-back in evaluations for all health care professional training rotations.
- Recognize those who show leadership and demonstrate successes in health literacy and health communication. Highlight their work.
- Use opportunities like Health Literacy Month (October) to feature projects and successes. Invite the community to join you by addressing health literacy in events like health fairs and talks to community groups.

Involve Patients

Create ways to involve patients in your work. It may be simplest to set up or draw upon a Patient and Family Advisory Council. These councils work with members of the hospital staff to provide valuable feedback and personal insight on the patient care experience.

If your setting is already involving patients, find how to involve them on health literacy teams and invite their feedback in more ways. These could include navigation interviews, written materials reviews, and presentations to health care providers and other staff.

Base your efforts in patient-centered care principles. Patient- and family-centered care is an innovative approach to planning, delivery, and evaluation of health care that is based on mutually beneficial partnerships among health care providers, patients, and families. The core concepts of patient- and family-centered care are dignity and respect, information sharing, participation, and collaboration.[8]

Summary of Key Points

- Anyone can experience low health literacy.
- Health care providers and staff need to understand the role of health literacy in general, and in their setting in particular.
- It's easy to think that communication is not a problem in your setting. But the statistics say otherwise.
- Learning good communication and education skills is ongoing. It needs to be reinforced, repeated, recognized, and rewarded.
- Awareness, education, training, and personal connection are needed to change behavior. But they won't bring about behavior change on their own. You need to prompt members of the health care team to action.
- Use small tests and cultivate coaching skills to support lasting changes in providers' use of health literacy interventions.
- To make changes long-term, build clear health communication into policies, procedures, job descriptions, daily routines, and organizational priorities.

1 Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy*. U.S. Department of Education. National Center for Education Statistics, 2006. NCES Publication No. 2006-483. Available at: http://nces.ed.gov/naal/health.asp. Accessed: November 5, 2012.

2 American Medical Association Foundation and American Medical Association. *Health Literacy and Patient Safety: Help Patients Understand: Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment*. Chicago, IL: 2007. Available at: http://www.ama-assn.org/resources/doc/ama-foundation/healthlitclinicians.pdf. Accessed: November 5, 2012.

3 DeWalt DA, Callahan LF, Hawk VH, et al. *Health Literacy Universal Precautions Toolkit*. AHRQ Publication No. 10-0046-EF. Rockville, MD. Agency for Healthcare Research and Quality. April 2010. Available at: http://www.ahrq.gov/qual/literacy/healthliteracytoolkit.pdf. Accessed: October 18, 2012.

4 Abrams MA, Rita S, Nielsen GA. 2012. *Always Use Teach-back! Toolkit*. http://www.teachbacktraining.org/. Accessed: March 31, 2014.

5 Lally P, Wardle D, Gardner B. Experiences of habit formation: a qualitative study. *Psychol Health Med*. August 2011; Aug;16(4):484-9. Available at: http://www.ncbi.nlm.nih.gov/pubmed/21749245. Accessed: February 6, 2013.

6 Miller NH. Motivational interviewing as a prelude to coaching in healthcare settings. *Journal of Cardiovascular Nursing* 2010; 25:247- 251. Available at: http://motivationalinterviewing.org/content/motivational-interviewing-prelude-coaching-healthcare-settings. Accessed: March 13, 2013.

7 Berwick D. *Taking Care to New Heights: Patient-Centered Care*. Paper presented at: Kaiser Permanente, National Quality Conference. July 2006; Denver, CO.

8 Institute for Patient-and Family-Centered Care. Available at: www.ipfcc.org. Accessed: December 28, 2012.

5 | The Care Environment

> "I knew I was supposed to ask questions, but I didn't know what to ask."
> (Patient, Allen Hospital)

Each entry into a health care encounter sets the stage for subsequent interactions, perceptions, and outcomes. Whether a website, telephone call, clinic, dental office, emergency department, outpatient testing facility, rehabilitation center, inpatient unit, or health department, the ease and comfort with which people are able to find and use information to meet their needs can go a long way in creating a health literate culture within an organization.

It can also help decrease the shame and stigma that accompany low literacy.[1] But while especially true for patients with limited reading and math skills, confusion and embarrassment can affect *anyone* in the health care setting. And sometimes, the more educated people are, the more embarrassed they may feel asking for help.

The ideas and tools in this chapter are designed to help you:

- Understand what a shame-free care environment is and why it is needed.
- Make your health care setting more welcoming, safe, and patient-friendly by fostering dialogue and questions.
- Make it easier for patients to find, understand, and use your information and services to manage their health.

A Health Literate Health Care Organization Offers a Shame-free Care Environment

This chapter directly addresses Attributes 5 and 7, and will help you "provide easy access to health information and services and navigation assistance" to "meet the needs of populations with a range of health literacy skills while avoiding stigmatization."

Source: Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington, DC: National Academy of Sciences, 2012.

Why Do We Need to Change?

People Hide Their Reading Problems

Patients with limited literacy skills may feel like "less of a person" or that "something is wrong with me." This can make them anxious, fearful, angry, or suspicious.[2] Many patients with limited skills hide their reading problem because they have had bad experiences in school or, maybe, in the health care setting.

Nearly 20% of people with limited literacy skills have never told *anyone*.[2] That's one in five. So patients may not reveal their reading troubles, not even in a long-term trusting doctor-patient relationship. Even if they are asked about it in a caring way, they may not share their problems with reading, understanding, and learning.

Many patients who struggle with reading *never* ask for help.

The Ways Patients Cope

People who struggle with reading learn to cope in the health care setting. To avoid appearing uneducated or stupid, they may act in ways that adversely affect their health and health care. For example, they may:

- Wait to come into the health setting until they absolutely have to, when their illness has worsened.
- Act difficult by walking out of the waiting room before being seen, making excuses, becoming angry or demanding, or clowning around.
- Answer questions or talk about things in ways that sidestep the health provider's intent, so the provider misses the patient's real concern.
- Be quiet and passive, not bringing up a concern if it wasn't asked about directly.
- Or not ask any questions at all, to end the visit more quickly.[3]

These actions lead providers to assume the patient understands. Or, depending on the behavior, the provider may mistakenly label the patient as difficult, non-compliant, or even ideal when no questions were asked, keeping a visit short.

Screening for Low Literacy May Not Help

"A doctor's office is no place for a reading test." (New Readers of Iowa, 2004)

Several literacy screening tools are available, and have been used mainly for research. Should we test patients for reading skill in the clinical setting? Some think it might aid in finding those who need extra help. Providers could then refer patients to adult literacy programs and other services to enhance understanding. But we know there is the possibility of shame and embarrassment when people are tested. Adult learners say they have spent their entire lives being tested. They do not want to be tested when they seek help from a doctor or hospital when they are sick or in pain. Some say they won't come back if they are tested in the health care setting. Moreover, highly- and semi-skilled readers don't like taking tests either. They may find taking a reading test in a health care setting uncomfortable, alienating, or irritating.

Also, think about what you will or can do differently if you know a patient has trouble reading. Does your clinic have a library of easy-to-read handouts along with the usual materials? Will your providers teach and check for understanding differently than with other patients? If not, then it may not make sense to routinely screen patients' reading levels. In addition, testing alone won't improve patients' understanding. You may alienate them by testing them, and alienated patients may not return until their health problems are much worse.

At this time, there is not enough evidence to recommend routine screening for low literacy or low health literacy in the clinical setting. It hasn't been shown to be effective, and there is the potential for harm in the form of shame and alienation. So it is reasonable to conclude that the possible harm outweighs the possible benefit.[4]

At this time, health literacy testing in clinical settings is not recommended.

Tools used to measure health literacy are, however, used in research settings where people being tested know about it in advance and give their informed consent. You will surely hear about tools for measuring literacy and health literacy, so it's good to know about them.

A single question: "How confident are you filling out medical forms by yourself?" This question may be useful for detecting patients with inadequate health literacy, although it has only been evaluated in selected settings. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2324160/?tool=pubmed

The Newest Vital Sign: This is a 3-minute test in English and Spanish where the person is given an ice cream nutrition label and asked six questions about it. It assesses document and number literacy. http://www.pfizerhealthliteracy.com/physicians-providers/newestvitalsign.aspx

REALM: The Rapid Estimate of Adult Literacy in Medicine is a list of 66 medical terms in English and Spanish that the person is asked to read aloud in 2-3 minutes. It checks word recognition and reading but not understanding of numbers. http://www.hsph.harvard.edu/healthliteracy/files/2012/09/doakappendicies.pdf

TOFHLA: The Test of Functional Health Literacy in Adults is available in long (10-22 minutes) and short (5-12 minutes) form in English and Spanish. The person answers multiple choice fill-in-the-blank questions on a page of medical instructions to check reading and understanding of numbers. Long version available at: http://www.ncbi.nlm.nih.gov/pubmed/8576769. Short version available at: http://www.nmmra.org/resources/Physician/152_1485.pdf

Taking a Universal Approach

Reading problems aren't the only reason patients have trouble understanding or remembering all the information they get during a health care encounter. Here are some other reasons:

- The health system is more and more complex.
- There is a growing need for self-care due to the aging population and increasing chronic illness.
- Providers rely on printed materials to teach patients about their condition. Yet, they often lack simple written handouts to give along with their spoken instructions.
- Pain or illness, worry, medication, lack of sleep, preoccupation, and other concerns can all make it hard to understand and retain health information.

Interventions for people with low literacy can also help those with higher literacy skills.[5] Even good readers prefer information that is concise and easy-to-read.[6,7] This is

why we need to use a universal approach to address health literacy—to improve health communication for *everyone*.

Even good readers prefer information that is concise and easy-to-read.

There are several basic principles for using a universal approach to address health literacy:

- *Everyone* benefits from clear information.
- Many patients are at risk of misunderstanding, but it's hard to identify them.
- Screening literacy levels does *not* ensure patient understanding.[8]
- Interventions for people with low literacy also help people with higher literacy.[5]

Acting on these principles leads to a safer health care environment, one where patients:

- Understand health events.
- Make informed health decisions.
- Know what they need to do.
- Do not experience a sense of shame or embarrassment at any time.

By creating a safer, shame-free care environment we address our duty to recognize, anticipate, and act on potential patient harm or risk and mitigate or avoid risk through system change.[8]

What Does Success Look Like?

Here is what it could look like when a health care organization creates a shame-free environment that fosters dialogue and offers navigation assistance.

- All patients are greeted with eye contact and a smile.
- All patients are offered help with paperwork in a friendly way.
- Patients and families know that questions are welcome and expected.

- Patients get easy-to-understand directions when they move from one department or location to another, or are referred to a specialist.
- Information on paper and websites is easy to read, understand, and use.
- Websites include audio, video, and interactive learning tools.
- Signs and wayfinding tools are easy to understand and use.
- Facilities and materials, including websites, are easy to access, navigate, and understand for people with disabilities.
- Facilities and materials, including websites, are easy to access, navigate, and understand for people who do not have English as their main language.
- Patients, families, volunteers, or other non-clinicians participate in planning and evaluating interventions to improve the care environment.
- Patients, families, volunteers, or other non-clinicians routinely provide input about print and web materials intended for patients and families.
- Patient surveys show very high scores for questions about satisfaction with communication.
- Written training and education policies ensure all workers recognize signs that suggest patients do not understand, and know what to do to help.
- All staff use patient safety methods like SBAR (Situation-Background-Assessment-Recommendation) to pass along concerns about patient understanding.
- Trained interpreter services are readily available for patients who do not speak English as their primary language.

Making Your Environment Shame-Free

A shame-free care environment is welcoming. Everyone is greeted with a smile, help is offered proactively and sensitively, questions are encouraged, and signs, directions, and electronic information are easy to read and follow. This kind of setting allows patients to feel comfortable:

- Saying they don't understand.
- Asking questions.
- Talking openly about their health and concerns.

Encourage People to Ask Questions

Ask Me 3 http://www.npsf.org/for-healthcare-professionals/programs/ask-me-3/, a program of the National Patient Safety Foundation, promotes the use of three questions to help encourage patient-provider communication.

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

Estimate the Prevalence of Low Literacy

To help raise awareness and stimulate action to address health literacy, you may find it helpful to estimate the prevalence of low literacy in your patient population. The Prevalence Calculator applies a simple formula to estimate the number of patients in your practice who have demographic risk factors associated with low literacy. You can't use the prevalence calculator to tell whether an individual patient has limited literacy skills, but it can give you an idea of what percentage of *your* patients might have trouble understanding health information. This helps motivate staff to improve the care environment, as well as start using ways to communicate more clearly.

To find a rough percent of your patients who may have limited literacy skills, try using the Prevalence Calculator:

http://www.pfizerhealthliteracy.com/physicians-providers/PrevalenceCalculator.aspx

Take a Look Around Your Care Setting

It might be best to bring some fresh eyes to your care setting. Invite a friend, colleague, volunteer, or willing patient to walk through in a navigational interview.[9] To do this, you ask the volunteer to find or go to a specific place in your setting. You have them talk aloud about what they are seeing and experiencing. You ask them to tell you what is guiding them as they find their way.

This type of exercise can tell you a great deal. It can give a starting point for your work to improve your care environment. It can alert staff to problems with signs, directions, and instructions. It may bring to light communication problems that usually go unspoken, like a sign that's hard to read because of color, size, or wording.

You can also assess your printed materials, telephone systems, how providers and staff talk to patients, and common procedures. Tools like a *Checklist for Patient-Friendly Office Procedures*[3] and getting patients' and families' input can help you.[5,10] Findings from such assessments can serve as a baseline to follow your progress in addressing problems and testing interventions.

You can also raise awareness and brainstorm responses with your staff by asking them to think about times when they or a family member:

- Were not greeted when they came to a clinic registration desk.
- Were put on hold or got bewildered in an automated telephone answering system.
- Lost their way trying to find the right department.
- Wanted to ask a question but felt like they couldn't because a doctor or nurse was too busy.

Then get started making improvements. Creating a patient-friendly care environment doesn't take a lot of money. Take a look at the hospitality industry. Hotel and restaurant workers are trained to greet people with a smile and eye contact, and to say hello and ask if they can help. These are easy things to do. Smiles and eye contact are free, and they can change the entire atmosphere.

Tools for Assessing the Health Care Setting

- Health Literacy Universal Precautions Toolkit
  http://www.ahrq.gov/legacy/qual/literacy/healthliteracytoolkit.pdf
- The Health Literacy Environment of Hospitals and Health Centers. Partners for Action: Making Your Healthcare Facility Literacy-Friendly
  http://www.ncsall.net/fileadmin/resources/teach/environ.pdf
- Is Our Pharmacy Meeting Patients' Needs? A Pharmacy Health Literacy Assessment Tool User's Guide
  http://www.ahrq.gov/legacy/qual/pharmlit/

Create a Welcoming Setting

AIDET[11] (Acknowledge, Introduce, Duration, Explanation, Thank you) is a tool intended to reduce anxiety, inform people of what is about to happen, make them feel comfortable and cared for, answer basic questions, provide patients opportunities to ask questions, and confirm understanding before tests and treatments. Here is an example of how using AIDET as a health literacy tool helps create a welcoming and shame-free care environment.

Using AIDET in A Health Literate Care Environment

A – Acknowledge. Welcome the patient or client by name. This helps patients feel confident that you know and care about them, and understand why they are here.

I – Introduce. "My name is Nicole. I am here to draw some blood. I've had 7 years of experience so this should be quick and easy." Introduce yourself by position or role in terms people understand. This creates confidence you are the right person for the job. And they know who to follow up with, if needed.

D – Duration. Tell the patient how long this will take. For example, "Registration takes about 5 minutes and then I will take you to X-ray." Patients want to know how long they will be here or how long it will be until they get answers. When you respect a person's time they become less anxious and can concentrate on what you are saying.

E – Explanation. In plain language, explain the need-to-know information about what is going to happen. For example, "I will put warm gel on your shoulder and move the ultrasound wand over the sore area in small circles. It should not hurt at all. And it will help lessen your pain and swelling. What questions do you have before we start?" Using plain language allows the person to understand what is about to happen, how it will feel, and what it is for. It allows for questions before things progress. This is a time to use teach-back if needed.

T – Thank you. Thank the patient for allowing you to care for them. Include an open-ended question regarding follow-up or other issues. Use teach-back one last time, if needed. It is common for people to think of a question at the end, especially if they are anxious or distressed about anything. People have choices. Let them know you appreciate their confidence and trust.

Make Sure Signs are Understandable

Make clear signs and maps available whenever patients need to find their way. This is especially important when making referrals for tests or procedures or to a specialist in a different care setting.

When you have wayfinding tools, point them out so patients can use them. Consider using wayfinding symbols that have been shown to be helpful in health care settings.[12]

Follow the Green Arrows

A patient came out of a clinic exam room and couldn't find checkout. A nurse noticed and showed him the way, saying this happens a lot, in a friendly way. While this did make the man feel better about being lost, why wait for him to be confused? The clinic had green arrows in the carpet to help patients find their way out. Try pointing those out up-front. This can prevent the patient from feeling confused and embarrassed, and the nurse from being interrupted.

Give Patients Help with Paperwork

Staff should offer help with paperwork to *everyone*. Make it clear that it's no trouble by saying something like: "These forms are complicated. A lot of people need a little help filling them out. I'm happy to help you. We do it all the time."

Point to the parts of forms you are talking about and give simple explanations. For example: "This is a form that tells about the laws that keep your health information private." Be sure to:

- Always point to exactly where people should sign a form.
- Ask for the same information only once.
- Give patients the chance to fill out paperwork before they come to see you.

Watch for Clues that a Patient May Need Help

All staff should be able to spot clues that a patient may struggle with reading. These may include taking too much time filling out forms, incomplete or inaccurate answers, or asking if it's okay to take paper work home to complete. These tell providers and other staff to:

- Take extra measures to ensure understanding.
- Consider asking about reading comfort.
- Pass along the patient's need for extra help to other providers.

Make sure staff know how to convey concerns about lack of understanding or low literacy to other members of the health care team. Also, investigate the adult literacy, adult basic education, and English-as-a-second language (ESL) programs in your area, so you can make referrals when appropriate.

Clues that May Indicate Limited Literacy

Behaviors

- Forms that are incomplete or inaccurately completed
- Frequently missed appointments
- Non-adherence to medication regimens
- Lack of follow-through with lab tests or referrals
- Reports taking medicine but has no change in condition
- Becoming angry and walking out of the waiting room
- Clowning around and using humor
- Being quiet and passive
- Having difficulty explaining health concerns
- Detouring—letting doctor miss the concerns
- Having no questions

Responses to receiving written information

- "I forgot my glasses. I'll read this when I get home."
- "I forgot my glasses. Can you read this to me?"
- "Let me bring this home so I can discuss it with my children."

Responses to questions about medication regimens

- Unable to name medications
- Unable to explain what medications are for
- Unable to explain timing of medication administration

Adapted from: Weiss BD. *Health Literacy and Patient Safety: Help Patients Understand: Manual for Clinicians*. Second Edition. American Medical Association Foundation and American Medical Association. Chicago, IL, 2007.

Literacy, Language, and Culture

The United States population is becoming more and more diverse. This diversity includes great variety in culture and language, and in people's oral and written language skills. Many U.S. adults understand, speak, read, and write English very well. Others may understand, speak, read, and write well in several languages. Still others may understand and speak both English and another language very well, but read and write only in a language other than English. And there are those who cannot read or write in their own language.

Note these trends:

- By 2060, half the people in the U.S. will belong to a racial or ethnic minority.[13]
- Between 1980 and 2010, the number of Americans who spoke a language other than English at home grew from 23.1 million to 59.5 million (a 158% increase).[14]
- Nearly 21% of U.S. residents speak a language other than English at home.[14]
- About 25.3 million people in the U.S. report their English-speaking ability as something below "very well."[14]

Health literacy skill levels tend to be lower among people who are elderly, have less education, are poor, belong to minority groups, are recent immigrants, or have limited English.[15] Language barriers add to communication problems for patients and stand in the way of good health care.[16] When cultural differences and language barriers combine, the results can be misunderstanding, non-adherence, harm, or poor outcomes.

Culture and language barriers can lead to poor health outcomes and even harm.

What Is Cultural and Linguistic Competence?

Several federal and state laws require health care organizations to provide care that takes into account the cultural and linguistic differences of patients and families. An organization is said to be culturally and linguistically competent when it can deliver this kind of care. In 2000, the Office of Minority Health issued Standards for Culturally and Liguistically Appropriate Services (CLAS). The recently enhanced CLAS Standards (2013) explicitly address health literacy and expand the scope to include physical, mental, social, and spiritual health, and health care of individuals and groups.[17]

Providing Culturally Competent Care

To provide culturally and linguistically appropriate services, an organization must have the policies, resources, and commitment to meeting the needs of a diverse patient population. For example:

- Having trained bilingual/bicultural staff and interpreters available.
- Training service providers so they can communicate effectively in ways that can be easily understood by different audiences.
- Providing equal access to services for all groups.
- Being respectful of traditional healing systems and beliefs, and integrating them where possible.
- Creating an environment in which patients feel comfortable talking about their beliefs and practices and how they relate to treatment.
- Providing print materials in the languages of the community.
- Weaving knowledge of a patient's culture and community into policy and practice.
- Involving the community in evaluating the quality of services.

Source: U.S. Department of Health and Human Service. Office of Minority Health. *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice*, 2013.

The Institute of Medicine (IOM) report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare,*[18] concluded that "low health literacy may contribute to health disparities." The IOM attributes health disparities to a variety of other factors as well. These include: differences among patients' help-seeking and attitudes toward treatment; cultural and linguistic barriers; mistrust of the health care system; and discrimination on the part of health care providers, including biases, stereotyping, and hesitancy.

All these factors point to the need to improve the health literacy of both patients and providers. This can help reduce health disparities and promote health equity.

Make Your Environment Accessible

Meeting the needs of people with disabilities is part of providing optimal care. Your care environment should be accessible for people with limited vision, hearing, motor, or other impairments, including limited literacy. This also includes making your information accessible. Structure and simplicity are the foundation for making documents and websites accessible. While digital information is still primarily text-based, the Internet provides unique opportunities to make information accessible through audio, visual, and interactive content. And, accessible design provides flexibility that benefits *all* users.

To Learn More about Accessible Web-based Materials

- WebAim.org – information and resources about web accessibility including a web accessibility tool
- 4Syllables.com.au – training, resources, and services for writing accessible web content
- W3c.org/wai – web accessibility initiative developing and sharing protocols and guidelines to help make websites work

What To Do When You See a Problem

Any member of the health care team who sees signs that patients may be struggling with reading or understanding should pass their concerns along. A standardized patient safety communication tool—SBAR (Situation, Background, Assessment, Recommendation)[19]—can be useful for front office and other non-clinical staff to pass communication concerns to clinicians who can look into it further and take steps to ensure understanding and offer help.

SBAR Example - Front Office Staff to Medical Assistant

Situation: Mrs. Reston seems to have something bothering her.

Background: She is here for a diabetes check and when I gave her the paperwork to update her forms, she kept the clipboard a lot longer than most people, and when she gave it back to me, it was only half-filled out.

Assessment: I think she may have trouble reading or at least not be able to see the forms very well.

Recommendation: Can you make sure everyone goes over her health problems and medicines very clearly, and makes sure she really understands when to come back? Maybe someone should ask if she wants to bring somebody with her to her appointments.

Talk with patients about their reading when the time is right. Understanding is vital to health care, and literacy is key to understanding. But it's also important to raise the subject of reading comfort in a non-threatening way. Explore reading comfort in the context of a trusting patient-provider relationship. Physicians can use the social history to explore this and open the door to talk about literacy issues. Ask patients questions like these:

- How comfortable are you with your reading?
- How confident are you filling out medical forms by yourself?[20]
- Have you ever had trouble reading the materials you get from your health care provider?
- Would you be interested in a program to help you read better?[21]

The DIRECT Approach

If you choose to ask patients about their reading comfort, this approach can be used to find out if patients have problems with reading and then refer them for help.

D – Ask about **difficulty reading**: "Have you ever had a problem with reading?"

I – Ask if they have an **interest in improving**: "Would you be interested in a program to help you improve your reading?"

R – Have **referral information** for adults and family literacy programs ready to give to patients identified with reading difficulty.

E – Ask **everyone** about their literacy skills. Let patients know it is your policy to ask everyone.

C – Emphasize that low literacy is a **common problem** and they are not alone: "Half of Americans have some difficulty with reading!"

T – **Take down barriers** to joining literacy classes (e.g., help with the initial phone call, make follow-up contact to see if they find the right class, etc.).

Source: Abrams MA, Dreyer BP. Plain Language Pediatrics: *Health Literacy Strategies and Communication Resources for Common Pediatric Topics*, 2009.

Know Your Community's Adult Education Resources

Search ProLiteracy Worldwide http://proliteracy.org/our-solutions/referral/national-literacy-directory to find out about adult literacy programs in your area. They give information about what adult literacy education is available, contact information, hours, and directions. When you make a referral to an adult literacy program, do it in the context of the patient-provider relationship. And do it with sensitivity.

Preventing Low Literacy through *Reach Out and Read*

Programs like *Reach Out and Read* http://www.reachoutandread.org can be used to incorporate literacy promotion into doctors' practices and explore reading comfort among parents or other caregivers. *Reach Out and Read* prepares young children to succeed in school by partnering with doctors to prescribe books and encourage families to read together. This research-based intervention helps parents learn how to support their children's literacy development, have more books in their home, and read to their children more. At every well-child visit from 6 months through 5 years, providers:

- Advise parents about reading aloud to their children.
- Give a new book tailored to the child's age and development.
- Offer literacy-rich waiting areas.

The Joint Commission report, *"What Did the Doctor Say?:" Improving Health Literacy to Protect Patient Safety,* describes *Reach Out and Read* as a precedent for addressing literacy in health care and a way to start talking with parents about literacy. It can be used to help prevent low literacy and low health literacy among both children and their adult caregivers. In addition to preparing children to enter kindergarten ready to read, learn, and succeed, providers can use *Reach Out and Read* to explore parents' reading comfort and respond appropriately (e.g., improved communication, referral to adult reading programs).

Source: Joint Commission. *"What Did the Doctor Say?:" Improving Health Literacy to Protect Patient Safety*, 2007.

Use Data from Surveys to Help You Improve

Use *Consumer Assessment of Healthcare Providers and Systems* (CAHPS),[22] *Hospital Consumer Assessment of Healthcare Providers and Systems* (HCAHPS),[23] the *CAHPS Item Set for Addressing Health Literacy Supplement,*[24] or patient satisfaction data to track patients' care experiences. Look at data on communication with nurses and doctors, new medications, and discharge processes, and set goals for improving these scores. Since hospital reimbursement is influenced by HCAHPS scores, this is an ideal way to link staff health communication skills and patient involvement with other efforts to improve quality of care and promote the business case. Target low-performing items with interventions to raise those scores, and follow them frequently.

Sample HCAHPS Domains and Items Related to Health Literacy

Communication with Doctors

- How often did doctors treat you with courtesy and respect?
- How often did doctors listen carefully to you?
- How often did doctors explain things in a way you could understand?

Communication with Nurses

- How often did nurses treat you with courtesy and respect?
- How often did nurses listen carefully to you?
- How often did nurses explain things in a way you could understand?

Communication about Medicines

- Before giving you any new medicine, how often did hospital staff tell you what the medicine was for?
- Before giving you any new medicine, how often did hospital staff describe possible side effects in a way you could understand?

Discharge Information

- Did doctors, nurses, or other hospital staff talk with you about whether you would have the help you needed when you left the hospital?
- Did you get information in writing about what symptoms or health problems to look out for after you left the hospital?

Source: U.S. Department of Health and Human Services Centers for Medicare and Medicaid Services. *Patients' Perspectives of Care Survey*, 2013.

Use the results from health literacy survey tools to give your organization baseline and period feedback on health literacy related to the care enviornment.[5,9,10]

Sample Health Literacy Survey Items Related to the Care Environment

- Does your staff offer everyone help regardless of appearance (e.g., filling out forms, giving directions)?
- Does your office have an automated phone system with an option to speak with a person?
- Are signs written in English and in the primary languages of the populations being served?
- Do your patient handouts show awareness of and respect for diversity, and use culturally-appropriate words and examples?
- Does your pharmacy use simple visual graphics or illustrations in patient education brochures that the patient takes home?
- Do you have a call-in telephone line for patients to ask questions?

Summary of Key Points

- Even patients with high literacy skills can have trouble understanding. Approach patient communication with universal communication principles.
- Shame and stigma are major barriers to improving health literacy. There is a risk of driving patients away by routinely testing their reading skills.
- Patients who have trouble understanding health care information often hide the problem. So it's important to always use clear communication principles and check for understanding.
- A shame-free care environment allows patients to feel comfortable saying they don't understand, asking questions, and talking about their health.
- For many minority groups, language or cultural barriers can contribute to communication problems.
- Be sure your organization, materials, and websites are accessible to people with disabilities.
- Learn to recognize signs of reading trouble and treat it like other awkward but important health topics.

- Health care organizations can learn from businesses like hotels and restaurants that work hard to make people feel welcome.
- Learn about resources in your community that offer help with literacy, as well as English for non-native speakers.
- Use tools to help people find their way around your care setting, feel comfortable asking questions, and get the information they need.

---

1 Institute of Medicine Committee on Health Literacy. *Health Literacy: A Prescription to End Confusion*. Nielsen-Bohlman L, Panzer AM, Kindig DA, eds. Washington, DC: The National Academies Press; 2004. Available at: http://www.nap.edu/catalog.php?record_id=10883. Accessed: June 30, 2012.

2 Parikh NS, Parker RM, Nurss JR, et al. Shame and health literacy: the unspoken connection. *Patient Education and Counseling*. 1996;27:33-39. Available at: http://www.pec-journal.com/article/0738-3991(95)00787-3/abstract. Accessed: February 25, 2013.

3 Weiss BD. *Health Literacy and Patient Safety: Help Patients Understand: Manual for Clinicians*. Second Edition. American Medical Association Foundation and American Medical Association. Chicago, IL: 2007. Available at: http://www.ama-assn.org/ama1/pub/upload/mm/367/healthlitclinicians.pdf. Accessed: June 29, 2012.

4 Paasche-Orlow MK, Wolf MS. Evidence does not support clinical screening of literacy. *J Gen Intern Med.* 2008;23(1):100-102. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2173929/pdf/11606_2007_Article_447.pdf. Accessed: February 25, 2013.

5 DeWalt DA, Callahan LF, Hawk VH, et al. *Health Literacy Universal Precautions Toolkit*. AHRQ Publication No. 10-0046-EF. Rockville, MD. Agency for Healthcare Research and Quality. April 2010. Available at: http://www.ahrq.gov/legacy/qual/literacy/healthliteracytoolkit.pdf. Accessed: June 29, 2012.

6 Davis TC, Bocchini J A, Fredrickson D, et al. Parent comprehension of polio vaccine information pamphlets. *Pediatrics*. 1996;97(6), 804-810. Available at: http://pediatrics.aappublications.org/content/97/6/804.abstract. Accessed: February 25, 2013.

7 Kleimann S, Enlow B. *Is plain language appropriate for well-educated and politically important people?* Results of research with Congressional correspondence. *Clarity*. 2003;50:4-11.

8 American Medical Association Foundation and American Medical Association. *Health Literacy and Patient Safety Help Patients Understand. Removing Barriers to Better, Safer Care. Reducing the Risk by Designing a Safer, Shame- Free Health Care Environment*. 2007. Available at: http://www.ama-assn.org/ama1/pub/upload/mm/367/hl_monograph.pdf. Accessed: February 7, 2013.

9 Rudd R, Anderson J. *The Health Literacy Environment of Hospitals and Health Centers. Partners for Action: Making Your Healthcare Facility Literacy-Friendly*. National Center for the Study of Adult Learning and Literacy. Health and Adult Literacy and Learning Initiative, Harvard School of Public Health. 2006. Available at: http://www.ncsall.net/fileadmin/resources/teach/environ.pdf. Accessed: January 1, 2013.

10 Jacobson KL, Gazmararian JA, Kripalani S, et al. *Is Our Pharmacy Meeting Patients' Needs? A Pharmacy Health Literacy Assessment Tool User's Guide*. (Prepared under contract No. 290-00-0011 T07.) AHRQ Publication No. 07-0051. Rockville, MD: Agency for Healthcare Research and Quality. 2007. Available at: http://www.ahrq.gov/legacy/qual/pharmlit/. Accessed: August 14, 2013.

11 AIDET (Acknowledge, Introduce, Duration, Explanation, Thank you). Available at: http://www.somc.org/employee/assets/employment/AIDET-Guide.pdf. Accessed: August 14 2013.

12 Hablamos Juntos. Language Policy and Practice in Health Care. Signs that Work. Available at: http://www.hablamosjuntos.org/signage/default.index.asp. Accessed: February 25, 2013.

13 Population Division, U.S. Census Bureau. Figure 13. *Projections of the Population by Race, and Hispanic Origin for the United States: 2012 to 2060*. Release date: December 12, 2012. Available at: http://www.census.gov/population/projections/data/national/2012.html. Accessed: February 7, 2013.

14 U.S. Census Bureau. C. Ryan. Language Use in the United States: 2011 American Community Survey Reports. August 2013. Available at: http://www.census.gov/prod/2013pubs/acs-22.pdf. Accessed: September 24, 2013.

15 Kutner M, Greenberg E, Jin Y, Paulsen C. *The Health Literacy of America's Adults: Results from the 2003 National Assessment of Adult Literacy*. National Center for Education Statistics. U.S. Department of Education. 2006. NCES Publication No. 2006-483. Available at: http://nces.ed.gov/naal/health.asp. Accessed: June 29, 2012.

16 Flores, G. Language Barriers to Health Care in the United States. *New England Journal of Medicine*. 2006; 355:229-231. Available at: http://content.nejm.org/cgi/content/full/355/3/229. Accessed: February 25, 2013.

17 U.S. Department of Health and Human Services. Office of Minority Health. *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice*. Washington, DC: 2013. Available at: http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=15. Accessed: November 25, 2013.

18 Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Smedley BC, Stith AY, Nelson, AR, eds. The National Academies Press. Washington, DC: 2003. Available at: http://www.nap.edu/openbook.php?isbn=030908265X. Accessed: February 25, 2013.

19 Institute for Healthcare Improvement. *SBAR Technique for Communication: A Situational Briefing Model*. Available at: http://www.ihi.org/IHI/Topics/PatientSafety/SafetyGeneral/Tools/SBARTechniqueforCommunicationASituationalBriefingModel.htm. Accessed: February 25, 2013.

20 Chew LD, Griffin JM, Partin MR, et al. Validation of Screening Questions for Limited Health Literacy in a Large VA Outpatient Population. *J Gen Intern Med* 2008; 23(5):561-6. Available at: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2324160/?tool=pubmed. Accessed: February 25, 2013.

21 Abrams MA, Dreyer BP. Plain Language Pediatrics: *Health Literacy Strategies and Communication Resources for Common Pediatric Topics*. 2009. Available at: https://www.nfaap.org/netForum/eweb/DynamicPage.aspx?webcode=aapbks_productdetail&key=7c5e160d-fa79-468f-8503-20a524bc5ae9. Accessed: February 4, 2013.

22 U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality. *Consumer Assessment of Healthcare Providers and Services (CAHPS)*. Available at: https://cahps.ahrq.gov. Accessed: November 17, 2013.

23 U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality. *Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)*. Available at: https://cahps.ahrq.gov/surveys-guidance/hospital/index.html. Accessed: November 17, 2013.

24 U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality. *CAHPS Item Set for Addressing Health Literacy*. Available at: https://cahps.ahrq.gov/surveys-guidance/item-sets/literacy/index.html. Accessed: November 17, 2013.

This page intentionally left blank.

6 | Involving Populations Served

> "It is neither just, nor fair, to expect a patient to make appropriate health decisions and safely manage his or her care without first understanding the information needed to do so. (American Medical Association [AMA] and AMA Foundation, *Health Literacy and Patient Safety: Help Patients Understand: Reducing the Risk by Designing a Safer, Shame-Free Health Care Environment*, 2007)

Involving patients, families, and adult learners is an important way to "meet the needs of populations with a range of health literacy skills."[1] Not only can it help make your materials and communication styles clearer, it will improve and enrich your work and your organization. It may seem challenging at first, but learning to do this well, and making it part of your standard way of operating, will become integral to providing patient-centered care.

The ideas and tools in this chapter are designed to help you:

- Understand the importance of patient and family involvement and benefit from the feedback you get.
- Recognize the significant contribution that adult learners can make.
- Find ways to involve patients, family members, and adult learners in your health literacy work.

In a Health Literate Health Care Organization Populations Served Inform How Health Information and Services are Provided

This chapter directly addresses Attributes 4 and 5, and will help you achieve a health literate organization that includes populations served in program design, implementation, and evaluation to best meet the needs of people with a wide range of skills.

Source: Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations.* Washington, DC: National Academy of Sciences, 2012.

Why Involve Populations Your Organization Serves?

Patients and their families are the experts in what they need to know to care for their own health. They can tell you what they do and don't understand. They also can tell you what helps or hinders them in understanding and remembering health information.

Patient Involvement Is Basic to Patient-Centered Care

Involving patients and families is basic to patient-centered care, one of the six elements of quality health care,[2] and an integral component of the medical home.[3]

The core concepts of patient- and family-centered care are:

- **Dignity and Respect.** Health care providers listen to and honor patient and family ideas and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are included in the planning of care.
- **Sharing Information.** Health care providers communicate and share information that is complete, accurate, and timely so patients and families can effectively participate in care and decision-making.
- **Participation.** Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- **Collaboration.** Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in facilities design; in professional education; and the delivery of care.[4]

Health Literacy Is Central to Patient Involvement

Health literacy is central to carrying out the components of patient-centered care, and more health organizations are realizing this. Patients and families can play formal roles on Patient and Family Advisory Councils. They also can be partners in specific health literacy efforts within a care setting. These partnerships can include several types of activities, including:

- Informal review of written materials and your organization's website.
- Navigational interviews.[5]

- Serving on health literacy teams and committees.
- Acting as faculty and spokespersons about health literacy.

Adult Learners Offer Important Insights

> "Doctors who can read and write well assume other people are at the same level." (New Reader of Iowa, 2004)

One aspect of patient involvement is partnering with adult learners—those who struggle with reading and are learning to read as adults. Including adult learners' voices puts a face on data. For staff, it transforms working on health literacy "from a project to a passion" (Vonda Wall, personal communication, 2005). It shows providers that people they see, interact with, and care for every day in *their* practice may have hidden literacy problems. Furthermore, the embarrassment, coping strategies, and consequences of low literacy and low health literacy become real when expressed by those seeking care. This kind of testimonial can engage leadership, promote staff buy-in, lead to provider *a-ha* moments, and generate solutions to communication problems.

Who are Adult Learners?

In this guidebook, we use the term *adult learner* for someone who is taking action to improve his or her literacy, math, or English language skills. Some work with literacy tutors. Others enroll in adult basic education (ABE) or English-as-a-second-language (ESL) courses. Adult learners bring an important perspective, so be sure to involve them in your health literacy discussions.

New Readers

A term often used in the literacy community is *new readers*. This refers specifically to adults who are learning to read. In the early 1990s, two national adult literacy organizations sponsored a gathering in Washington, DC. Adult literacy and ESL student representatives from every state gathered to learn about government, visit their legislators, and request continued funding for adult education. It was the first gathering of its kind. The group found it an ideal forum in which to tell literacy providers and others how they felt. They created a formal statement asking literacy practitioners to refer to them as *new readers* instead of illiterates, which they said was a negative term.

What Does Success Look Like?

Here is what it could look like when patients, families, and adult learners are fully involved in health literacy improvement efforts:

- Health literacy is a key part of Patient and Family Advisory Council work.
- Patients, families, and adult learners serve on quality improvement teams.
- The voices of patients, families, and adult learners are represented on other key health care teams, such as patient safety and chronic disease management.
- When members of the organization discuss health communication issues, they include stories and recommendations from the community they serve.
- Patients, families, and adult learners participate in educational presentations related to health literacy by presenting and sharing their stories.
- The organization conducts periodic navigational audits with adult learner or patient and family participation to improve navigation and wayfinding.
- Patients, families, and adult learners are called on as resources in development and revision of written materials for patients.
- All staff know how to appropriately address or pass along concerns about patients' reading comfort.
- Staff know how to make referrals to adult literacy and English-as-a-second-language (ESL) programs in their area.

- There is two-way, mutually beneficial communication between adult literacy programs in the community and the health care organization.
- Patients', families', and adult learners' stories and experiences serve as a bellwether for recognizing and addressing the importance of employee literacy in the workplace.
- Consumer Assessment of Healthcare Providers and Systems (CAHPS),[6] Hospital CAHPS (HCAHPS),[7] and patient satisfaction data are monitored regularly and serve as guides to improve health communication.

How Do You Involve Patients and Families?

Begin by seeking patient communication-related stories in your care setting. Once attuned to health literacy issues, most health care providers can identify examples from their own experience. Look for stories where communication problems resulted or could have resulted in a quality-of-care or patient safety problem. Identifying and sharing such stories raises awareness and builds will to take action. It also starts the process of finding patients and families who may be willing to take a more formal role in this work.

Find Patients and Family Members Willing to Help

Institute for Patient- and Family-Centered Care (IPFCC) guidelines can be useful as you seek members for your team.[8] The IPFCC recommends asking staff and doctors to identify patients or families they believe would function well on a team such as a Patient and Family Advisory Council. It also recommends reviewing surveys and other sources of feedback to identify patients who have constructive input. In addition, your staff may have talked with a patient who shared a personal story and expressed willingness to take that to the next level.

A Patient and Family Advisory Council

The Patient and Family Advisory Council works with members of the hospital staff to provide valuable feedback and personal insight on the patient care experience. Members of a Patient and Family Advisory Council can:

- Provide input, feedback, and approval on projects and initiatives presented by staff at regular meetings.
- Participate as full members on institutional committees and projects, consistently infusing the patient/family perspective into discussions and decision-making.
- Participate with staff on executive search and interview committees.
- Help create and edit patient and family education and communication materials, both written and visual.
- Help design and plan patient care areas and new programs.
- Generate new program ideas to benefit patients, family members, and caregivers/staff.

Ask Patients and Family Members What They Think

An easy way to begin is by asking a patient or family member for feedback on written materials you are creating or revising. Say that you are working to make these easy to read, and ask for their impressions and suggestions. Tell them what you are working on and your purpose, for example:

- Making forms easier for patients to fill out.
- Making patient handouts simpler.
- Making the consent process better.
- Getting better at following guidelines for patient care.

Ask a few specific questions to get the patient or family member started. This also helps show you really want their input. Try several of these questions:

- Is this easy to read?
- What parts are hard to understand?
- How would you make this better?
- What words are hard to understand?
- What is a better way to say this?

In addition to giving you useful feedback on your print materials, this helps staff:

- Get comfortable seeking patient and family input.
- Recognize the value of the input.
- See how easy it can be to get the input.

Invite Patients and Family Members to Join Your Team

Now you're ready for the next step. Let's say you have identified a few patients and family members to approach. These could be referrals from doctors or from your other contacts and efforts. Tell them you are working on improving care for patients by improving communication. Invite them to help you do that by expressing their unique point of view as a patient or family member. Tell them you have a team working on this that meets regularly. Ask if they would be willing to come to the meetings to get to know the team, and to help figure out ways to work together to improve communication.

Creating a Volunteer Health Literacy Work Group

At Storm Lake's Buena Vista Regional Medical Center (BVRMC), a 5-member team—the Volunteer Health Literacy Work Group—meets with the head of the BVRMC Health Literacy Team every month for two hours to review patient education materials and teaching brochures.

To establish this committee, the Volunteer Coordinator suggested candidates who might be interested in participating in a workgroup. She selected them from current volunteers who help elsewhere in the hospital. An initial meeting was used to introduce the potential team members to health literacy using UnityPoint Health training and education presentations. The group then discussed the goals of this committee, when they would meet, and desired outcomes. From the initial volunteers, five chose to participate. They began meeting in June 2012.

The committee looks at materials that are currently in use or are being revised or developed by hospital staff and could benefit from review by end-users. The group utilizes plain language guidelines and the UnityPoint Health Checklist for Reader-Friendly Print Materials to make recommendations. They provide feedback to the Health Literacy Leader who jots down their suggestions and sends this back to the materials developer. After being reworked by the developer, materials are returned to the group for another look. It is important and motivating for them to see the results of their efforts in the final product.

This approach has been very successful. Patient and staff feedback of revised materials has been positive. In addition, BVRMC believes this process of end-user review of written materials is, at least in part, playing a direct role in improving patient satisfaction scores related to patient understanding.

Don't Forget About Adult Learners

Remember that about half of U.S. adults function in the below basic or basic levels for literacy. They are not likely to volunteer their opinions on written materials. So as you collect feedback, keep in mind that you are probably hearing from more literate members of your patient group. You may want to make a special effort to get feedback from less-skilled readers at some point.

The Challenge in Finding and Involving Adult Learners

Involving patients with low literacy skills or those who have learned English-as-a-second language is one of the best ways to learn how to meet their needs. Including them as team members helps make the team even more attuned to literacy and navigation issues. But it can be hard to find and recruit these patients for two reasons:

- Low literacy carries with it a great deal of shame and stigma.[9]
- Patients need English language skills to take part in team activities.

If you haven't been able to recruit team members with this background from your patient pool, try searching out adult learners in your community.

The best place to find adult learners is in adult basic education programs. These programs may be linked to your local community college or public school system. Or there may be a community-based organization that serves adult learners. In some areas, social service groups and non-profits offer education in their programs. You can usually find local programs through these websites: http://www.proliteracy.org/our-solutions/referral/national-literacy-directory or http://proliteracy.org/find-a-program.

Offer Adult Literacy Programs Something in Return

It's important to understand a few basics about these programs and their learners before you make contact. Funding for adult education is limited. The programs are often understaffed and use volunteers as the primary tutoring and teaching workforce. They have few resources and many demands. Working with local health care organizations is usually not part of their mission. This may be true even if they see the connection and want to partner with you. It's best to find creative ways of helping them as they help you.

Working With Adult Literacy Programs

Communication between adult literacy programs and health organizations fosters collaborative health literacy work, such as:

- Health care providers making presentations or offering question-and-answer sessions on health-related topics.
- Health care representatives volunteering in adult literacy programs as tutors or board members.
- Adult learners taking part in the organization's health literacy improvement efforts.

Adult Learners May Need Mentoring

Learners in adult education programs face many challenges, but they have conquered the first one—coming forward, admitting they need help, and enrolling in a program. Overcoming the shame of being a poor reader can be a huge stumbling block. And because of their literacy or language barriers, some adult learners may have low-paying jobs, work two jobs, struggle to make ends meet, and have transportation problems.

Just getting to classes and doing homework are big achievements. Adult learners' lives may leave little time for gaining experience as speakers or committee members. They may be intimidated at the thought of being on a team with educated, highly literate people. Given these facts, you can't simply call an adult literacy program, tell them what you're looking for, and expect several adult learners to attend your next meeting.

A few local or state literacy organizations across the country have leadership training programs for learners who want to help the program by:

- Speaking in the community to raise awareness and recruit new learners.
- Serving on the board or committees.
- Serving as staff in the program.

It's important to know if the program in your area has done any formal leadership training. If not, you may need to work with the program to find and prepare learners for the roles you wish them to fill. If you're lucky, the coordinator may know of two or three adult learners he or she thinks may be willing to take part, and offer to check with those

people. Generally, you should expect to spend time orienting, training, and supporting the adult learners you recruit. Remember that standard meeting items like agendas, flip charts, and minutes often require high-level literacy and language skills. Remember, too, that e-mail or written notes may be less helpful. Be sure to contact adult learners by phone to confirm dates, times, and locations.

Valuing Patients, Families, and Adult Learners

The following suggestions will help ensure that laypeople feel welcome and are active members of health care teams:

- Always include at least two patients, family members, and/or adult learners on the team, so they feel comfortable.
- Assign someone to meet, greet, and mentor them in initial meetings, regardless of whether or not they are adult learners.
- Provide clear directions for getting to the building and the meeting room. Meet and orient them. Provide parking vouchers.
- Consider some form of compensation for attendance. Reimburse their mileage and pay a stipend. You can also work with your volunteer department so they can go through the usual process for helping in your organization. This lets them accrue volunteer hours for their time.
- Respect their time and constraints.

In meetings and presentations, involve patients, family members, and adult learners up-front. Don't be afraid to turn to them for input and comments during the meeting, being careful not to put them on the spot. This can be helpful when you reach a stumbling block about wording or how to resolve a communication or navigation challenge. They have a fresh, external, non-clinical perspective that health care providers can't provide regardless of good intentions. By making sure they are involved in discussions, you can help prevent and offset objections like "This isn't possible." or "It won't work." or "There isn't enough time to do this."

Case Study: UnityPoint Health and New Readers of Iowa

Here's an example of adult learners and health care providers coming together to improve health literacy.

A very important partnership developed between the New Readers of Iowa and UnityPoint Health, Health Literacy Teams. Outcomes of note include the 15th (2004), 16th (2005), and 17th (2007) Annual Iowa New Readers Conferences. All were devoted to health literacy. These conferences supported the health literacy efforts of the more than 100 adult learners and health professionals present. Events included the following:

- A panel of health care professionals made up of a doctor, nurse, pharmacist, respiratory therapist, medical technologist, and radiology technologist gave tips to New Readers members about how to talk with health care providers. They also responded to members' questions and concerns.
- Small groups of adult learners critiqued UnityPoint Health written materials and gave valuable feedback about wording and layout.
- Adult learners developed several health literacy statements in guided workshops.
- State, national, and international leaders in health literacy presented on different areas of literacy and health care. Speakers came from the American Medical Association, Harvard School of Public Health, and the United Kingdom.
- Pharmacists conducted one-on-one medication reviews with adult learners.
- Adult learners took part in a panel discussion about their experiences using the *Ask Me 3* questions.
- Health screenings were provided for New Readers members.
- New Readers members participated in a hospital navigational interview to help improve wayfinding.

Case Study: UnityPoint Health and New Readers of Iowa (cont.)

These conferences got national attention. They were groundbreaking platforms where health professionals and adult learners came together on equal footing to address health literacy. This partnership resulted in several members of the New Readers playing roles at the regional and national levels:

- Adult learners participated in workgroups and on committees of other health professional organizations, including the American Medical Association and American Academy of Pediatrics.
- New Readers members presented and co-presented with health care professionals to discuss and provide training about health literacy and patient safety.

The partnership is ongoing. New Readers of Iowa members continue to participate in materials reviews and health literacy training for audiences in multiple disciplines. Four more joint meetings were held that brought New Readers and health providers together. UnityPoint Health also supported the New Readers in getting a leadership development grant to build leadership capacity among adult learners. New Readers members learned about mentoring other adult learners through educating, empowering, communicating, and advocating. They also built their skills in raising awareness of and educating health providers about health literacy. They learned how to use various individual and group venues for this purpose, such as patient encounters, professional health conferences and meetings, and media coverage. A New Reader of Iowa member served as co-chair for the UnityPoint Health Patient Safety Implementation Team which led patient safety improvement work across the system.

Adapted from: Osborne H. Health and literacy working together: a health literacy conference for new readers & health professionals. Health Literacy Consulting, 2004.

Adult Learners Reviewing Written Materials

Here is how one adult learner helps improve written materials at Finley Hospital in Dubuque, Iowa. He reads through print materials the Health Literacy Team wants to simplify, marks out all words he doesn't understand or can't read, and then returns it to them to review with much of the content missing. This technique provides insight on how challenging it is to read information when you don't understand significant parts of the content, and gives guidance for changing words that are hard to read or understand because they are too complex, or are technical terms or jargon. The Health Literacy Team then makes revisions to the document to lower its reading level and improve readability.

Let People Choose How They Will Help

Bear in mind that patients, family members, and adult learners may take on specific roles or choose those they can do on an as-needed basis. They may prefer to review written materials when needed. They may choose to take part in periodic health literacy walkthroughs of your care setting. This is where you ask a layperson to find a location or go through a process in your setting without help. It raises staff and provider awareness and helps identify areas for improvement. Depending on their comfort level, patients and family members, and adult learners may be willing to share their stories—in person or in videos.

You can offer a menu of ways that patients, families, and adult learners can help, such as:

- Sharing their stories and perspectives about health care concerns.
- Brainstorming with the team to identify areas to work on.
- Giving feedback on ideas and care experiences.
- Reviewing written materials.
- Taking part in navigational interviews and other wayfinding improvement activities.
- Sharing in presentations to represent and convey patients' perspectives.

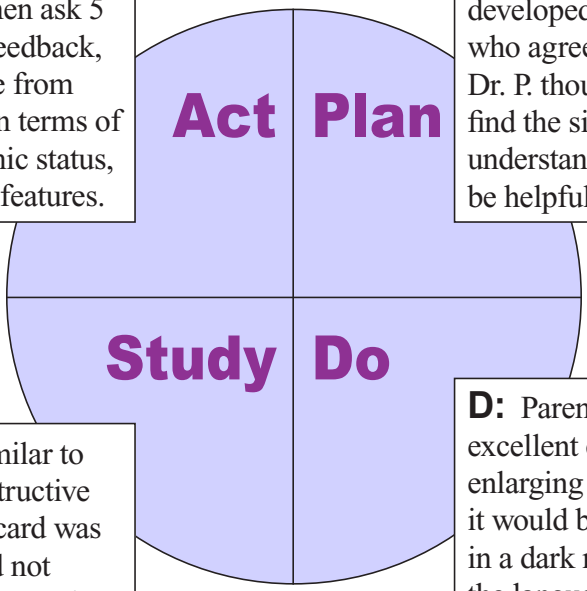
Depending on their comfort level, these roles can expand over time. It may be particularly helpful to assign a small concrete task early on, to build confidence and rapport. For example, you could ask for input on a short document or a sign, or ideas to make waiting more pleasant.

Next Steps

As you and your organization become more familiar and comfortable with patient, family, and adult learner involvement, spread it to other areas. Explore opportunities to include lay people on other teams where clear communication is critical, like working to reduce unplanned readmissions by improving care for patients with heart failure. As your colleagues see the benefits of this approach, they will likely seek out and request patient involvement proactively. Use patient experience and survey data to guide your progress. Use small tests of change to get everyone on staff involved.

Example PDSA Cycle: Involving Populations Served

P: To improve care for children hospitalized for migraine headaches, Dr. P. developed a sign listing the kinds of things visitors should not do around these children. A draft was developed and shown to a parent who agreed to give feedback. Dr. P. thought the parent would find the sign easy to read and understand, and think it would be helpful.



D: Parent said color was excellent choice. Recommended enlarging font size of title so it would be more eye-catching in a dark room. Parent thought the language was "very clear" and that the clip art accurately reflected the precautions. Thought that having the list displayed would be useful to the parents. For example, they can refer to the sign if visitors are too loud. Recommended a cell phone restriction such as patient not to be on a cell phone and set phone to vibrate.

S: The results were similar to predicted. A set of constructive criticisms about the placard was received. The parent did not appear uncomfortable answering questions concerning the placard.

A: Dr. P. will use the feedback to revise the placard. Then ask 5 more parents for their feedback, being sure to ask people from different backgrounds in terms of education, socioeconomic status, and other demographic features.

Summary of Key Points

- To get a patient's point of view, talk to a patient. To benefit from patient feedback, involve patients in your health literacy work.
- Patients and family members can play various roles on your team.
- To get started finding members for your team, ask colleagues to share stories of problems they have had in communicating with patients. Ask if they have patients who might be willing to share their stories and opinions.
- Many patients and family members willing to review documents, practices, and procedures have high literacy. That is, they represent the more educated members of your patient community. Their input is valuable because it's patient-focused and non-technical.
- You will also want to gain insights into the patient/family care experience of people with weaker literacy or English language skills. For this, you may need to seek out adult learners in the community.
- To recruit adult learners to your team, contact local adult basic education programs or literacy groups. Adult learner volunteers will need varying amounts of mentoring to fulfill advisory roles. Those who have already gone through leadership training in their literacy or ESL programs can be especially helpful.
- All your team members need to be respected and valued. This is especially true for laypeople, who may feel like outsiders or non-experts.
- Track your success through HCAHPS or patient satisfaction data.

1 Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington DC: National Academy of Sciences; 2012. Available at: http://iom.edu/~/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH_Ten_HLit_Attributes.pdf. Accessed: October 16, 2012.

2 Institute of Medicine Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21stCentury*. Washington, DC: The National Academies Press; 2001. Available at: http://www.nap.edu/openbook.php?record_id=10027. Accessed: January 1, 2013.

3 Cassidy A. Patient-Centered Medical Homes. *Health Affairs*, September 14, 2010. Available at: http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_25.pdf. Accessed: January 21, 2013.

4 Institute for Patient- and Family-Centered Care. Available at: http://www.ipfcc.org/pdf/CoreConcepts.pdf. Accessed: January 17, 2013.

5 Rudd R, Anderson J. *The Health Literacy Environment of Hospitals and Health Centers. Partners for Action: Making Your Healthcare Facility Literacy-Friendly*. National Center for the Study of Adult Learning and Literacy. Health and Adult Literacy and Learning Initiative, Harvard School of Public Health. 2006. Available at: http://www.ncsall.net/fileadmin/resources/teach/environ.pdf. Accessed: January 1, 2013.

6 U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality. *Consumer Assessment of Healthcare Providers and Services (CAHPS)*. Available at: https://cahps.ahrq.gov. Accessed: November 17, 2013.

7 U.S. Department of Health and Human Services. Agency for Healthcare Research and Quality. *Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS)*. Available at: https://cahps.ahrq.gov/surveys-guidance/hospital/index.html. Accessed: November 17, 2013.

8 Institute for Patient-and Family-Centered Care (IPFCC). Available at: http://www.ipfcc.org/pdf/PartneringwithPatientsandFamilies.pdf. Accessed: March 13, 2013.

9 Institute of Medicine Committee on Health Literacy. *Health Literacy: A Prescription to End Confusion*. Nielsen-Bohlman L, Panzer AM, Kindig DA, eds. Washington, DC: The National Academies Press; 2004. Available at: http:www.nap.edu/catalog/10883.html. Accessed: January 1, 2013.

7 | Verbal Communication

> "Healthcare providers have a duty to provide information in simple, clear, and plain language and to check that patients have understood the information before ending the conversation." (White House Conference on Aging, Mini-Conference on Health Literacy and Health Disparities, 2005)

Using clear communication in interpersonal verbal communication is key to ensuring patients and families have actionable information they need to manage their health. Using health literacy strategies and confirming understanding throughout the care continuum are among the most important attributes of a health literate organization. Care transitions—whether within or between health care settings, or on return to home—are especially important times that carry additional risk. Ensuring understanding in these situations has the potential to bring added safety and improve quality of care.

The ideas and tools in this chapter are designed to help you:

- Explain and demonstrate how to use health literacy tools like teach-back.
- Show how *all* staff can help with communication.
- Get providers started building new communication habits into their routine.
- Set up systems that make checking for understanding standard practice.

A Health Literate Health Care Organization Confirms Understanding

This chapter directly addresses Attributes 6 and 9 which call for using "health literacy strategies in interpersonal communications and confirm[ing] understanding at all points of contact" especially in "high-risk situations, including care transitions and communications about medicines."

Source: Brach C, Keller D, Hernandez LM, et al. Ten Attributes of Health Literate Health Care Organizations. Washington, DC: National Academy of Sciences, 2012.

Why Is Clear Communication So Important?

There is good research linking low health literacy to poor health outcomes. Communication impacts patient safety, adherence, and health equity. Even patients who have good general literacy skills can be confused by medical terms and jargon. More and more attention is being focused on how well providers and health care delivery systems communicate with patients and their families so they know what to do to care for themselves. Directly or indirectly both public and private organizations are incorporating health literacy into education, funding streams, research agendas, and quality initiatives.

Organizations Incorporating Health Literacy into Education, Funding, Research, and Quality Initiatives

- Agency for Healthcare Research and Quality
- American Medical Association
- Centers for Disease Control and Prevention
- Center for Medicare and Medicaid Services
- Health Resources and Services Administration
- Joint Commission
- National Institutes of Health
- National Quality Forum

Communication is at the Heart of Patient Care

Communication is at the heart of patient care. "Patients have the right to understand health care information that is necessary for them to safely care for themselves, and the right to choose among available alternatives."[1] *In Reducing the Risk by Designing a Safer, Shame-free Health Care Environment*,[2] the AMA and AMA Foundation underscore that:

- Patient understanding is the first patient right.
- A lack of understanding limits the patient's ability to exercise all other rights.
- This isn't a right that doctors confer, but one they help their patients to exercise freely.
- It isn't just or fair to expect a patient to make good health decisions without being able to understand the information needed to do so.

This moves us from talking *to* patients toward talking *with* them, keeping in mind that *everyone* appreciates clear communication.

We Need to Make Complex Health Information Clear

Health providers work hard to master complex technical language and concepts. These terms are used to convey accurate information between members of the health care team. But it's also important to convey clear information to patients and families. Patients' care is directed by health care providers a relatively small amount of time; they and their families are the ones who must carry out health care regimens. Those with chronic illnesses may interact with the health care system for a half hour every few months. The rest of the time, they're at home, alone or with family. To stay as healthy as possible, they need to know what to do to care for themselves and how to do it. To make sure of this, the health care team needs to practice and master clear communication techniques:

- Translating technical health care terms and jargon into every day, living room language.
- Using smaller, common words and analogies from the lives of patients rather than medical culture.
- Prioritizing and limiting the amount of information conveyed.
- Checking for understanding, and re-teaching, as needed, through teach-back.
- Supplementing teaching with reader-friendly printed material.

All members of the health care team can expand on, supplement, or reinforce important health information.

The most important hand-off is to the patient.

What Does Success Look Like?

Here's what it might look like in a setting where all members of the health care team use plain language and work to ensure patient understanding:

- All staff are educated and trained in using plain language.
- Plain language is used for all patient- and family-related communication.
- Leaders use and model plain language in their speech and writing.
- All members of the health care team use teach-back every time it is indicated to support patients and families throughout the care continuum, especially during transitions and when discussing medications.
- Order sets call for use of teach-back during patient education.
- Documentation systems include prompts for and places to record use of and patient response to teach-back.
- Teach-back is built into patient care competencies.
- Health professions students learn to use teach-back through instruction, modeling, practice, and evaluation.
- Teaching faculty model effective use of teach-back.
- Patients are invited to include a family member or friend during health care visits to help them ask questions and remember information.
- Tools like *Ask Me 3* are used to help patients and families ask questions and make sure they understand key health information.
- All doctors and staff know when and how to access and work with trained medical interpreters.

- Policies are in place so any member of the health care team can *stop the line* if they sense a patient or family member doesn't understand or is confused by what they're told.
- Clinical and non-clinical members of the health care team use SBAR[3] to pass along the need for clearer communication with a patient or family member.
- Patient strengths and limitations in teach-back are included as part of the hand over to providers in community settings.

How Do You Move Toward Clear Communication?

Start by showing how people are vulnerable when they come to the health care setting. They may be ill, worried, distracted, or in pain. They may be suffering from medication effects or lack of sleep. Or perhaps they just can't follow and remember the technical information and jargon used in health care.

Underscore that the health care team is responsible for making sure patients and families have what they need to care for themselves or their family member. Show what can happen when patients or family members don't understand.

What Can Happen When Patients Do Not Understand

At a care conference during the third week of rehabilitation in a skilled care facility, the occupational therapist reported that a 76-year old man was no longer making good progress and appeared to not want to participate in self-care or activities. The highly-motivated patient replied that he thought he was working hard, and had just asked to delay some therapy sessions because he wanted to be ready to go to his follow-up doctor's appointment and wasn't sure there would be enough time. During the ensuing discussion, it became clear that his understanding of therapy was confined to the specific sessions. Within 24 hours of this being clarified, he had taken on several self-care tasks with assistance, walked to and from meals, and attended a group function in the activity room. By not checking for and ensuring understanding, the staff misinterpreted this patient's motivation, abilities, and functional potential. This could have led to premature discharge, curtailment of his rehabilitation, inability to return to his home where he had previously lived independently, and significant financial repercussions.

Model and Use Plain Language

Plain language means using clear language that conveys exactly what the audience needs to know "without unnecessary words or expression." Key elements include use of everyday words, active voice, logical organization, and easy-to-read design features. "It is not 'unprofessional writing' or a method of 'dumbing down' or 'talking down' to the reader."[4]

Plain language helps everyone, not just those with limited literacy skills. Few patients understand health care terms any more than a surgeon might understand the language of an engineer or lawyer. Using plain language can help bridge the communication gap between patients and health care providers by presenting information in ways that make it easier for everyone to understand.[5]

The following plain language principles can help improve understanding when used in interpersonal and written communication with patients and families.[2]

- Focus on need-to-know rather than nice-to-know information. Nice-to-know may get in the way of need-to-know information.
- Use examples and analogies to explain uncommon words. For example, saying "your heart is like a pump, moving the blood all through your body" helps the patient create a mental image.
- Limit the amount of information you give at one time. Research shows patients remember less than half of what clinicians explain to them.[6,7] Focus on the three to five most important things you want the patient to remember.
- Use non-medical language and avoid jargon. Speaking with patients in non-medical, conversational language—living room language—facilitates understanding and creates opportunities for dialogue.
- Chunk your information and review important points. Chunk and Check refers to clearly explaining one concept and confirming understanding before moving on to the next one.
- Encourage questions and interaction. Use a positive tone. Let patients and caregivers know who they can contact later for answers to their questions.

Plain Language

Writers of plain English let their audience concentrate on the message instead of being distracted by complicated language. They make sure that their audience understands the message easily.

Source: Plain Language Action Information Network (PLAIN). What is Plain Language? Definition of plain language defined by Professor Robert Eagleson. Australia, 1996.

Teach Staff to Use Teach-Back

Teach-back is a way to make sure you—the health care provider—explained information clearly; it is not a test or quiz of patients. It involves asking a patient (or family member) to explain—in their own words—what they need to know or do, in a caring way. It is a way to check for understanding and, if needed, re-explain and check again. And it is a research-based health literacy intervention that promotes adherence, quality, and patient safety.[8]

Using teach-back creates the opportunity for dialogue in which the provider gives information, and then asks the patient to respond and confirm understanding before adding any new information.

Here are some examples of how to ask patients to demonstrate understanding, using their own words:

- "I want to be sure I explained everything clearly. Can you please explain it back to me so I can be sure I did?"
- "What will you tell your child care provider about how to give the medicine to your baby?"
- "We've talked a lot about how you can increase your physical activity. Please go over what we talked about. How will you make it work at home?"
- "Can you tell me in your own words how often and when you will use these inhalers? And show me how you will you use them."
- "These instructions for preparing for your procedure can be confusing. Can you go over what you're going to do to get ready for your surgery?"
- "It can be really hard to find the x-ray department from our office. I don't want you to get lost, so can you tell me what landmarks you will watch for?"

- "We want to be sure you understand what your insurance will and will not cover. Can you go over it for me using your own words? This will help me know if I explained it well."

If the patient does not teach back correctly: rephrase and re-explain the information; ask the patient to teach back the information again, using their own words, until comfortable they really understand it; and consider using handouts, pictures, models, demonstration, and other teaching strategies if they still do not understand.

Sometimes a patient will not be able to teach back, despite more than one attempt to explain the information. If that happens, consider these ideas:

- Be sure they are using their eyeglasses, hearing aids, or other assistive devices, if needed.
- Ask if they would like to include a family member or friend.
- Ask another person on the health care team to help with teaching and explaining.
- Schedule another visit or call.
- Check for language, literacy, or cultural barriers. Get additional help or support, as needed.
- Pass along the need for extra help to other staff and providers.

Teach-back should be used for all important patient education, specific to the condition. Hospital-to-home transitions and communication about medications are especially high-risk. Discharges are busy, associated with multiple exchanges of information and materials, and can be anxiety-provoking since patients and families are being asked to assume or resume care after one or more significant health events that led to hospitalization. Confusion, declines in health status, and changes to medication and care regimens can result in misunderstanding that leads to non-adherence and errors.

Observations of a Family Physician Who Introduced Teach-back into His Practice

"There were surprising misconceptions of patients' understanding of instructions [before using teach-back]. Nonverbal cues do not seem reliable. In [the] absence of teach-back, the only indicator of misunderstanding may be [a] medication mistake or patient error, which could be harmful."

Use interactive learning modules and videos like those in the *Always Use Teach-back!* Toolkit[9] www.teachbacktraining.org to teach and show how teach-back is used correctly.

Teach-back in Action

Here is a good example of teach-back in action. Watch how the doctor shows empathy and effectively uses a hand-out. To watch the video click on the picture or go to http://www.screencast.com/t/VFrb3ysN5.

Overcoming Concerns about Time

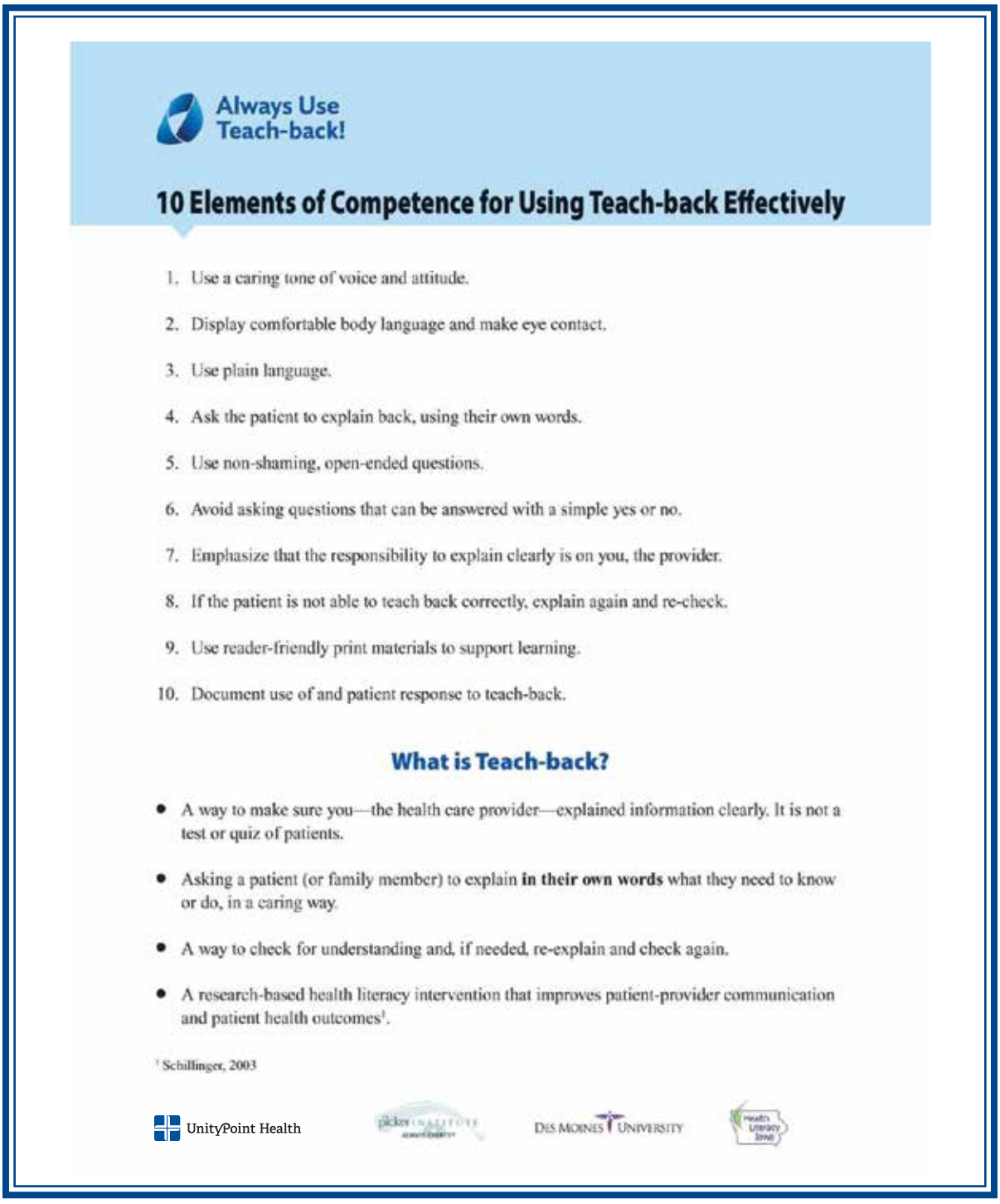
Providers often worry about how much time teach-back will take. Studies show that using teach-back does not significantly increase the length of a visit. On average it takes 1.8 minutes more (Schillinger 2003). But, doctors can *lose* time looking for missing information; trying to figure out why a patient is not responding to therapy even though the patient answers yes when asked if they are taking their medicines according to the prescription labels; and responding to interruptions to answer questions and give clarifications for staff on behalf of patients who didn't understand. The same is true for nurses who handle telephone calls and other patient questions.

Teach-back is an *investment* in improving care. Doctors have reported that once they got the hang of it, teach-back didn't lengthen the visit because they didn't add it on at the end. Instead, they changed the way the visit flowed, with little teach-backs throughout.

As understanding increases, there may be fewer call backs and cancellations, better adherence, and smoother transitions in care. Then providers can focus more on ensuring the information they convey to patients is understood and gives them what they need to care for themselves later.

Source: Schillinger D, Piette J, Grumbach K, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. *Arch Intern Med.* 2003;163(1):83-90.

When working with staff, use the *10 Elements of Effective Use of Teach-back*[9] to guide training and assess skills.



Always Use Teach-back!

10 Elements of Competence for Using Teach-back Effectively

1. Use a caring tone of voice and attitude.
2. Display comfortable body language and make eye contact.
3. Use plain language.
4. Ask the patient to explain back, using their own words.
5. Use non-shaming, open-ended questions.
6. Avoid asking questions that can be answered with a simple yes or no.
7. Emphasize that the responsibility to explain clearly is on you, the provider.
8. If the patient is not able to teach back correctly, explain again and re-check.
9. Use reader-friendly print materials to support learning.
10. Document use of and patient response to teach-back.

What is Teach-back?

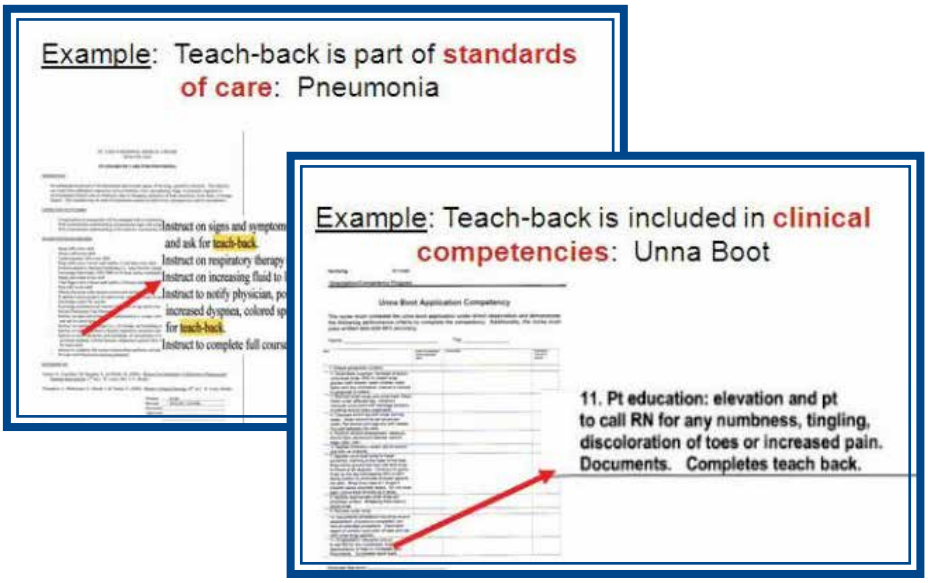
- A way to make sure you—the health care provider—explained information clearly. It is not a test or quiz of patients.
- Asking a patient (or family member) to explain **in their own words** what they need to know or do, in a caring way.
- A way to check for understanding and, if needed, re-explain and check again.
- A research-based health literacy intervention that improves patient-provider communication and patient health outcomes[1].

[1] Schillinger, 2003

UnityPoint Health · Des Moines University

For a downloadable copy:
http://teachbacktraining.org/assets/files/PDFS/Teach%20Back%20-%2010%20Elements%20of%20Competence.pdf

Include teach-back in skills fairs, and patient care and education competencies.



Finally, providers should document use of and the patient's or family member's response to teach-back after each encounter.

Teach Staff to Encourage Patients to Ask Questions

In addition to encouraging patients and families to ask questions, *Ask Me 3* can guide providers in identifying key messages and using plain language to ensure patients know the answers to these questions—the need-to-know information—before concluding the health care encounter. Here is an example:

Patient: Ramon, 4-year-old boy with cavities	
***Ask Me 3* Questions**	**What the parent should understand at the end of the visit**
What is my child's main problem?	• Ramon has cavities, or holes in his teeth.
What do I need to do?	• I should stop his bottle. • I should brush his teeth two times every day. • I should stop giving him sugary drinks, including juice. • I should get him a dentist appointment as soon as possible.
Why is it important for me to do this?	• If Ramon's cavities get worse, he will have pain and might even need a big operation to fix them. They might even hurt his health later in his life.

Changing the Way I Talk with Parents

One pediatric resident noted, "Using *Ask Me 3* changed the way I talk with parents." It helped her highlight what parents *needed to know* to care for their child. She said, "The three questions helped me make sure I gave them the answers to these important questions in a way they could understand."

Tools to Encourage Patients to Ask Questions

Information Rx http://www.informationrx.org/ helps guide patients to MedlinePlus http://www.nlm.nih.gov/medlineplus/, a reliable online consumer health information resource. Providers can use Information Rx to write a prescription for information that can be used to find information on MedlinePlus, in English, Spanish, or other languages. People can do this themselves, or take it to a librarian for help. MedLinePlus has accurate, up-to-date information, and features that make it easier to use, like various reading levels, multiple languages, and interactive tools.

Questions Are the Answer http://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/ an Agency for Healthcare Research and Quality campaign, has videos and tools to help patients and families prepare for health visits and procedures. It gives people ideas for questions to ask before, during, and after appointments and procedures. *Questions Are the Answer* tells patients they have an important role to play to ensure they get the best quality healthcare.

Ask Me 3 http://www.npsf.org/for-healthcare-professionals/programs/ask-me-3/ is a program of the National Patient Safety Foundation. It was developed by communication and health literacy experts as a tool to improve communication between providers and patients. It encourages the asking and answering of three questions to focus patient-provider communication.

Reducing Parent Anxiety: Health Information and the Internet

"My grandson was diagnosed with strep throat which then got worse. His doctor referred him to a specialist who described his diagnosis in language that left his parents in total terror by the time they left the office. They called me and I decided to do a little research on my own.

A friend had been using a medical website she was very comfortable with and shared it with me – MedlinePlus.gov. I went into this site very skeptical. I found the medical term was very easy to pull up and the language level was easy to understand. This site explained the symptoms, diagnosis, and treatment, answering many of my questions and concerns.

I would recommend this website to anyone who has questions on health-related topics and concerns. I shared it and my findings with my daughter and she was very impressed with the simplicity and information you could get your hands on right away. The best diagnosis to this story is that my grandson is a very healthy 5-year old again."

Patient Caregiver, Buena Vista Regional Medical Center

Teach Staff to Use SBAR

SBAR (Situation-Background-Assessment-Recommendation) is a standard, objective format that streamlines communication and ensures no crucial information is left out.[3] Staff members, clinical and nonclinical, can also use SBAR to *stop the line* if they think a patient or family member has not understood what they were told by someone on the health care team.

This is especially important in settings where it might otherwise be awkward to raise such a concern. For example, if a staff member sees a problem arising from how a nurse gave information to a patient or family member, SBAR gives that person a way to ask the nurse to clarify when there are concerns about understanding. This could take the form of additional discharge education, talking with the family member, delaying a procedure until a patient shows their questions have been answered, or using teach-back to confirm understanding before a test or procedure.

SBAR can be used to pull in the entire care team. For example, a housekeeper may hear a family member say they didn't understand anything the doctor told them. With SBAR as a standard communication tool for all staff, the housekeeper could tell a nurse that based on what she heard, it sounds like the patient and family have questions. The nurse can then follow up appropriately.

SBAR Example - Housekeeper to Nurse

Situation: I think Mrs. Juarez's family has a lot of questions.

Background: She's the patient in Room 3237 who just got back from surgery.

Assessment: I heard her family talking after Dr. Kunan left. They sounded very confused and they thought they were getting mixed messages.

Recommendation: Can you make sure someone goes in to answer all their questions? Her daughter is the main person everybody talks to but she's not always there, so I think an interpreter should come too.

SBAR Example - Dietitian to Nurse

Situation: I'm concerned that Mr. Jones isn't ready for discharge.

Background: He's a 65-year old man with COPD and is supposed to go home with oxygen for the first time.

Assessment: When I went in to see him, he seemed very upset. I think he may be worried about how his home oxygen is going to work. Or there may be something else upsetting him.

Recommendation: I recommend you talk with him about his concerns and go over what will happen with his oxygen when he gets home.

SBAR Example - Resident to Resident

Situation: Mr. Sutter's scan isn't back yet and his wife wants to be with him when he gets the results. She can only be here in the evening so you'll need to talk with her about the results.

Background: The scan will determine what we do next and he might need surgery. They just moved and are trying to find a place to live, start their jobs, and get their kids in school. They are pretty stressed.

Assessment: I'm worried they aren't going to be able to take everything in and will be overwhelmed.

Recommendation: Be sure to use teach-back to make sure they really understand—not only about the results but possible next steps. And let them know Dr. Powell and I will be here tomorrow to go over everything again.

Teach Staff to Work with Interpreters

All providers should know how to access and work with a competent medical interpreter. Asking a family member or using staff who speak the language but are not skilled to interpret medical information can result in omissions, additions, opinions, and errors. Asking a child to interpret for a parent is especially problematic due to confidentiality issues and the stress it puts on roles and responsibilities within a family. TeamSTEPPS® Enhancing Safety for Patients with Limited English Proficiency Module http://www.ahrq.gov/legacy/teamsteppstools/lep/ is a good resource for staff to help them work as a team with interpreters to improve safety.

The enhanced *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care* (CLAS Standards) give guidance for responding to diversity in health and health care.[10] The Principal Standard explicitly recognizes the issue of health literacy and calls on health professionals to be "responsive to diverse cultural health beliefs and practices, preferred languages, health literacy and other communication needs." The standards are designed to provide a common understanding and structure for advancing health equity, improving quality, and eliminating health disparities by specifically addressing three areas:

- Governance, Leadership, and Workforce
- Communication and Language Access
- Engagement, Continuous Improvement, and Accountability

Language access services are generally provided through translation of written materials and direct interpreting of verbal language. In health care, interpreting is consecutive. The provider speaks, then pauses for the interpreter to interpret. The patient speaks and again there is a pause so the interpreter can interpret. When working with an interpreter there are some key elements the provider should know:

- The provider faces and speaks directly to the patient.
- The patient should face the provider and interact directly with the provider.
- The interpreter uses first person speech and interprets everything that is said. Transparency is critical.

Sometimes the interpreter may intervene to clarify or to explain a cultural practice. If so, the interpreter is playing a cultural broker role. It is important that everyone knows what role the interpreter is playing, whether it be direct message converter, message clarifier, or cultural broker.

Be sure your interpreters know how teach-back works. Also be sure your providers are trained in how to work effectively with an interpreter. The Health Resources and Services Administration (HRSA) on-line course, *Effective Communication Tools for Healthcare Professionals: Addressing Health Literacy, Cultural Competency, and Limited English Proficiency*, http://www.hrsa.gov/publichealth/healthliteracy/uhcregistrationinstructions.pdf is an excellent resource that combines health literacy and cultural competency training to improve health communication.

Effective Communication Tools for Healthcare Professionals: Addressing Health Literacy, Cultural Competency, and Limited English Proficiency

- Module 1: Introduction to Health Communication
- Module 2: Health Literacy
- Module 3: Cultural Competency
- Module 4: Limited English Proficiency
- Module 5: Capstone Activity

http://www.hrsa.gov/publichealth/healthliteracy/

Communicate Across Settings

Clear communication techniques should be used in the hospital, primary care, and home health settings where patient education, especially for self-care after going home, is vital. Patients may have gotten a new diagnosis, undergone a major procedure, or had big changes in their health management regimen. When they leave the hospital, they must care for themselves or be cared for by family members. This means bringing new medications, routines, and behaviors into their lives. And all this has to be done while recovering from whatever led to their hospital stay.

Begin Discharge Education at Admission

Education should begin at admission, not wait until the day of discharge. Starting right away makes it possible to cover multiple topics, reinforce critical information, and identify issues that are unclear. Confusing areas may need different teaching techniques or approaches. Teach-back should be used especially to go over: self-care regimens; what signs or symptoms to look for; when to call the doctor; and when, where, and how to follow up.

Confusion after Discharge

- "When I was in the hospital all I was focused on was getting home. And then I got home and realized I didn't know what I needed to do."
- "I wasn't clear on what medicines I needed to stop taking."
- "There are some symptoms that I've been having, but I wasn't sure if I should just wait for my appointment in three weeks."

The research-based Re-Engineered Discharge (RED) Toolkit http://www.ahrq.gov/professionals/systems/hospital/toolkit/ is a good resource for improving the discharge process. It includes actions the hospital can take during and after the hospital stay to ensure a smooth and effective transition at discharge.

Use Follow-up Calls

Follow-up phone calls are useful since questions often arise after patients return home. The volume and complexity of information at discharge can be overwhelming, so timely follow-up call(s) to review key information and ensure understanding can help prevent adverse outcomes. Be sure to use plain language and teach-back during these calls to be sure patients really do understand.

Comparison of Follow-up Calls Using Yes/No versus Teach-back Questions

Yes/No Questions	Teach-back Questions
Do you have your follow-up doctor appointment scheduled?	Please tell me when your next appointment with your doctor is.
Do you understand your medications and how you are to take them?	Sometimes medicines can be confusing. Let's talk about some of the key medications you are taking. Please tell me what you know about your medications. Tell me about when you take them.
Do you have any pain?	How are you handling your pain?
Do you have any further questions or concerns or need for further health information?	What questions do you have about everything you need to do to take care of yourself over the next week or two? What questions do you have about what we went over today?

Revealing Other Issues

"Using teach-back during follow-up phone calls reveals other issues that impact patient care and have not come up in the past when we were asking the yes/no questions. For example, we have discovered several patients with issues related to buying groceries and having access to healthy food. With the open-ended format the approach is more conversational, which allows the patient to share more information and not be held to a quick yes/no answer. This has resulted in other issues being identified that need to be addressed. I think this is a positive outcome of changing the approach to the questions and has allowed us to take a holistic approach to the patient."

Director of Population Management
UnityPoint Health

Use Teach-back at Home Health Visits

Use home health referrals, even if only for a few visits. The stress of being in the hospital can make learning difficult. Also, questions may not arise until patients and families are back home and actually dealing with self-management in their usual setting. Using teach-back at home health visits can:

- Identify and clarify areas of uncertainty or confusion.
- Answer questions.
- Review and reinforce key information.
- Assess for ongoing risk.
- Reveal information that should be relayed to doctors by either the home health team or patients themselves.

Teach-back in Action

Watch how the home health nurse re-explains, uses handouts, and re-asks for teach-back. To watch the video click on the picture or go to http://www.screencast.com/t/KcmJFvmQK.

Build Teach-back into Your Documentation Systems

Build teach-back into electronic medical records and patient care documentation systems. Include prompts for using teach-back in electronic health record systems and paper-based order sets, and document its use and patients' responses to teach-back. Electronic systems can be used to periodically track the percentage of patients with whom teach-back was used and their ability to teach back. Use these measures to drive improvement over time.

As providers get better at using teach-back, patients should be able to teach back with fewer tries.

Changing Behavior and Making It Last

To change from long-standing patient education habits to reliably using plain language and teach-back to confirm understanding via the patient's own words takes time. Use small tests of change and coaching to help providers change how they communicate with patients and sustain those improvements over time.

Small Tests of Change

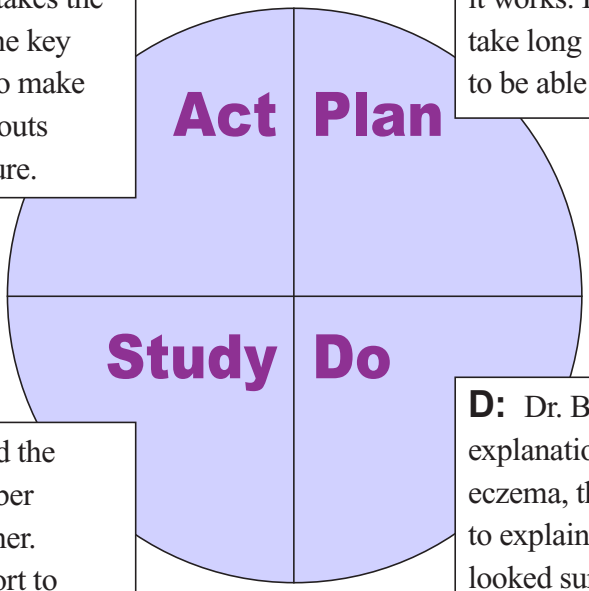
Small tests of change can help doctors and other health care team members adopt plain language and build teach-back into their routines gradually.

A doctor can begin with the last patient of the day. This removes the burden of getting behind schedule. If this small test goes well, the doctor can expand to three to five patients, or all patients with a certain condition. He or she can gradually share successes with colleagues, and work the change into his or her practice patterns. If the small test does not go well, the doctor can study the test, figure out why it didn't go well, modify the plan, and try it again. This way, they can build their experience and confidence, work out the bugs, and then expand use of teach-back into routine practice patterns.

Example PDSA Cycle: Using Plain Language and Teach-back

A: Tomorrow Dr. B. will work to use plain language, emphasize the main points, and ask for a teach-back with 2 patients. He will track time and how many times it takes the patients to teach back the key information. He plans to make his most common handouts easier to read in the future.

P: Dr. B. tries hard to explain things clearly, completely, and in a friendly way to patients. He's heard about teach-back and is willing to try it once, to see how it works. He doesn't think it will take long and expects the patient to be able to explain back easily.



D: Dr. B. provided his usual explanation for managing eczema, then asked the patient to explain back. The patient looked surprised and confused, attempted to explain back, then stopped. Dr. B. then went over the main points more slowly, making an effort to use non-technical terms.

S: Dr. B. was surprised the patient couldn't remember everything he had told her. He felt it took more effort to slow down and use non-technical words. But also felt it was worth it, to be sure the patient really knew what to do.

Coaching

Coaching is a next step beyond giving staff knowledge on teach-back and its effectiveness; it's providing ongoing motivation, encouragement, understanding, and reinforcement. The on-line *Always Use Teach-back!* Toolkit[9] http://teachbacktraining.org has an interactive case-based training module enabling learners to identify and use key aspects of plain language and teach-back throughout the care continuum, by following a patient's experience during hospital discharge through the home health and primary care settings; coaching tips and tools to help managers and supervisors empower staff to use teach-back whenever it is indicated; and readings, resources, and videos to learn more.

Always Use Teach-back! Toolkit

Helping health care providers learn to use teach-back—every time it is indicated—to support patients and families throughout the care continuum, especially during transitions in care

- Interactive Teach-back Learning Module
- Coaching to Always Use Teach-back tips and tools
- Readings, resources, and videos

http://teachbacktraining.org/

Help Patients Learn to Teach Back

Since not all providers will use teach-back, introduce teach-back at talks and classes for the community. Help patients and families practice how to ask for teach-back by using phrases like these:

- "Let me be sure I understand. This is what I heard you say..."
- "I want to go over this because it's complicated..."
- "Can you write that down for me...?"

Explain this in the context of their role as partners in their care:

- They are checking to be sure they understand the information they need.
- They are making sure they get the highest quality care.

The following videos show how a patient or family member can elicit teach-back.

Watch how this mother asks for a re-explanation for her son and the provider responds with a teach-back approach. To watch the video, click on the picture or go to http://www.screencast.com/t/ohX4RNYW2xpW.

Watch how this teen asks his doctor to re-explain issues related to social media safety and health. To watch the video, click on the picture or go to http://www.screencast.com/t/tolv4kzfDXFz.

Summary of Key Points

- Communication is at the heart of patient care. Without understanding, patients can't become partners in their care.
- Providers have a responsibility to make sure patients and families have the needed information and can use it.
- *All* members of the health care team should use plain language and reinforce and supplement important health information, either themselves or by getting another person to help.
- Without teach-back, you may only learn that a patient didn't understand when an adverse event has occurred.
- Teach-back should always be used to support patients and families throughout the care continuum, especially during transitions between health care settings and discussion of medications.
- Small tests of change and coaching can help providers build methods like teach-back into their routines. Cues to providers, staff, and patients, like *Ask Me 3*, can help promote use of plain language and identify key actionable messages.
- Using plain language and teach-back take extra time at the beginning. But they can soon become second-nature.
- Investing time to communicate clearly up-front may lead to time saved in problem-solving later.
- All providers should know how to access and work effectively with a competent medical interpreter.

1 Proceedings of 2005 White House Conference on Aging, Mini-Conference on Health Literacy and Health Disparities. American Medical Association; 2005.

2 American Medical Association Foundation and American Medical Association. *Health literacy and patient safety: help patients understand. Reducing the risk by designing a safer, shame-free health care environment*. 2007. Available at: http://www.ama-assn.org/ama1/pub/upload/mm/367/hl_monograph.pdf. Accessed: February 26, 2013.

3 Institute for Healthcare Improvement. *SBAR Technique for Communication: A Situational Briefing Model*. Available at: http://www.ihi.org/IHI/Topics/PatientSafety/SafetyGeneral/Tools/SBARTechniqueforCommunicationASituationalBriefingModel.htm. Accessed: February 8, 2013.

4 NIH Plain Language Initiative. *What is Plain Language?* Available at: http://www.nih.gov/clearcommunication/plainlanguage.htm. Accessed: August 14, 2013.

5 Plain Language Action Information Network (PLAIN). What is Plain Language? Definition of plain language defined by Professor Robert Eagleson, Australia. Available at: http://www.plainlanguage.gov/whatisPL/definitions/eagleson.cfm. Accessed: June 29, 2012.

6 Ley P. Communicating with Patients: Improving Communication, Satisfaction, and Compliance. Croom Helm; 1988. Available at: http://psycnet.apa.org/psycinfo/1989-97003-000. Accessed: June 29, 2012.

7 Rost K, Roter D. Predictors of recall of medication regimens and recommendations for lifestyle change in elderly patients. *Gerontologist*. 1987;27:510–515. Available at: http://gerontologist.oxfordjournals.org/content/27/4/510.abstract. Accessed: June 29, 2012.

8 Schillinger D, Piette J, Grumbach K, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. *Arch Intern Med*. 2003;163(1):83-90. Available at: http://archinte.ama-assn.org/cgi/content/full/163/1/83. Accessed: June 29, 2012.

9 Abrams MA, Rita S, Nielsen GA. 2012. *Always Use Teach-back!* Toolkit. http://www.teachbacktraining.org/. October 12, 2012. Accessed: March 31, 2014.

10 U.S. Department of Health and Human Services. Office of Minority Health. *National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice*. Washington, DC: 2013. Available at: https://www.thinkculturalhealth.hhs.gov/pdfs/EnhancedCLASStandardsBlueprint.pdf. Accessed: March 31, 2014.

8 | Reader-Friendly Materials

> "I had a cold... Everybody told me to go to the doctor, but I put it off, and I put it off... And I still had this cough... And I knew it was getting into my lungs because I've had bronchial pneumonia before. My husband said, 'You're going to the doctor.' And I said, '[Then] *you're* going to go and fill out the papers.' Because that's why I don't go to the doctor, [and why I kept putting it off]. So he took me there and he filled out the papers... And I *did* have bronchial pneumonia, and they wanted to put me in the hospital."

View video of New Reader telling her story:
http://www.aap.org/commpeds/resources/video/Barriers2.wmv

In a health literate organization, everyone who interacts with patients and families using print or web-based material understands the importance of clear information in these formats. They understand how readable, easy-to-use print and web information supports quality of care, patient safety, and health equity. They strive to find, revise, or create materials that are relevant, effective, and usable to the widest range of patients possible, in other words, reader-friendly.

Ideally, your organization will have all the print materials and web-based information needed to serve patients, employees, and other stakeholders effectively. It will also have weeded out or replaced unneeded, confusing, or ineffective materials.

The ideas and tools in this chapter are designed to help you:

- Evaluate the materials you already have.
- Select new materials that match the literacy needs of your patients.
- Develop your own materials using plain language writing and design principles.

A Health Literate Health Care Organization Has Materials that Are Easy to Understand and Use

This chapter directly addresses Attribute 8 and will help you "design and distribute print, audiovisual, and social media content that is easy to understand and act on."

Source: Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations.* Washington, DC: National Academy of Sciences, 2012.

Why do Materials Need to be Reader-friendly?

Much of your patients' contact with the health care system, and with health information, is through the written word, whether on paper or the Internet. Patients use written information when they are:

- Finding a doctor's office or lab.
- Reading health education handouts.
- Searching for accurate health information on the web.
- Reading prescription and over-the-counter drug labels.
- Filling out health history forms.
- Reading and understanding consent forms.
- Following hospital discharge instructions.
- Filing insurance forms and paying medical bills.

No matter how well you explain an illness or treatment, and answer questions, patients may not remember what you say after they leave the exam room or hospital. Or they may not remember it accurately enough. For this reason health care providers should supplement verbal communication with effective print materials.

Websites you refer patients to or emails you write need to be user- and reader-friendly as well. These forms of written communication are taking a larger role in everyday life. While the Internet is a great tool for communicating and teaching, it is only as effective as its form and content. And remember that patients with limited education or incomes still may not have easy access to the Internet.

Effective Materials Support Adherence

Here are some reasons patients need good print or web-based information to manage their health:

- Patients often need more time to process what they have heard in their doctor's office.
- Good handouts can guide, reinforce, and supplement providers' explanations.
- Patients are only with their health care providers a fraction of the time they are dealing with their health conditions. Most self-management of health conditions is carried out by patients and families at home, work, or school.
- Caregivers rely on printed information to help them support loved ones.

Good Materials Help Ensure Safety and Quality

Clear, usable, and accurate information is essential. What can happen without it?

- Patients may skip over questions they don't understand. Some patients have described marking no to every condition on a health history form so they are not asked about questions they don't understand. Important responses may be missing, like an allergy to a medicine, leaving doctors without information needed to diagnose and manage health problems. Then, treatments or medications may not address the real problem. Or they could cause harm.
- When patients don't understand instructions, they can't follow them. If patients and families don't understand how to manage a chronic condition, take medicines, or care for themselves before and after surgery, it could lead to poor outcomes or repeated hospital stays.
- Patients may not know their rights or how to use the system. When patients don't know their rights within the health care system or how to use their insurance benefits, they may be less likely to use the system appropriately. They may over- or under-use care.
- Remember, informed consent is a process, not just a form. Patients may be asked to read and sign consent forms without really being informed. Many consent forms are written at college level, making them extremely difficult for most patients to read. If patients don't fully understand their choices, the risks and benefits, or possible health outcomes related to their surgery or procedure, they may have results they didn't expect, and providers may be at risk of liability.

Good Materials Can Help Lessen Health Disparities

Clear, easy-to-understand and easy-to-use print and web information can help overcome communication barriers that contribute to health disparities.

Cultural differences can get in the way of communication. For example, if a medicine is prescribed for a patient who believes his illness is caused by an evil spirit, effective information can help him understand the importance of taking the medicine alongside his belief. The way that information is delivered is key to its acceptability.

When language is a barrier, high quality translations are needed. Effective print and web materials in the patient's native language and reflecting the patient's culture become very important. People with disabilities may also experience health disparities that can be addressed by clear, easy-to-read information. For example:

- People with a visual impairment or learning disability may need to have an enlarged document with easy-to-navigate headings. On the web, they may use screen-reading software that works best with clearly-formatted documents.
- American Sign Language, which is a distinct language not based on English, is likely to be the first language of people who are deaf. They may have limited English proficiency and may need documents written in simple English without idioms.
- People with physical disabilities may use assistive devices that work best with clear, easy-to-navigate web-based information.

What Does Success Look Like?

Here is what a health literate organization with easy-to-understand and easy-to-use print and web information may have in place:

Your Materials

- Print and web materials are appealing to look at and easy for their intended audiences to read, understand, and act on.
- Print materials are written at 8th grade reading level or below.
- Materials highlight the most important, need-to-know and need-to-do information for the reader.

- Readers can tell who and what materials are for at first glance.
- All print and web materials adhere to reader-friendly guidelines, from consent forms to navigation on your website to signs in your facilities.
- Print and web materials are not assumed to replace verbal communication, and don't conflict with what providers and staff say.
- Written materials are available in the primary languages spoken by your community. Translators use plain language or, when possible, materials are created directly in the language so translation is not necessary.

Your Health Care Providers and Staff

- Health care providers understand the importance of using reader-friendly print and web materials and choose the most reader-friendly materials available.
- Staff are trained to make sure they get the right materials into the right hands at the right time.
- A core group of people is trained and have experience in *developing* new materials that are effective with the specific audiences that need them.
- Health care providers and staff who are not fully trained to develop new materials have learned some strategies for *revising* existing materials to better meet the needs of patients and families, and the public.
- Health care providers learn and use strategies to mark up print materials as they go over them with patients. This helps patients with all levels of literacy find, understand, remember, and use the information later on their own.
- Health care providers check for patient and family understanding of print materials using teach-back.

Your Organization

- Your organization has adopted policies that call for use of reader-friendly print and web-based information. The policies include guidelines that describe what *reader-friendly* is and how to assess its characteristics.
- Your patients, staff, and community have easy access to relevant effective materials on many common topics.

- Your organization's leaders devote resources to health literacy, for example they support funding for revising existing and developing new materials, translation services, training for providers and staff, electronic systems that are simple to maintain and widely available when needed, and time and staff to update web information on a regular basis.
- Navigation interviews are used to identify opportunities to improve signage.
- Adult learners and Patient and Family Advisory Committee members provide insights on developing print materials.
- Paperwork and forms to be completed are minimized. Paperwork is sent or downloadable ahead of time so people can fill it out at home. Help is offered to everyone in a friendly, pro-active, non-shaming way.
- Letters and correspondence from your organization, like lab and x-ray results or billing notices, are written using plain language principles.
- Print and web-based information is accessible for those with disabilities.

How Do You Make Materials More Reader-friendly?

What can you do to improve the print materials and web-based information your organization provides? How can you get access to good materials? How do you know if the materials you are using are effective? There are a number of ways to ensure your organization's materials match the literacy needs of your patients.

Find Reader-friendly Materials

You can find a variety of reader-friendly health information from federal agencies, consumer sites, health publishers, and others. More materials are being developed all the time. It's important to know what's out there. And it's important to choose print materials, computer-based training programs, and websites that will work with your audiences.

However, it can be challenging to find reader-friendly materials. They are spread here and there, rather than listed all in one place. For example, you can find some great easy-to-read materials for seniors on the National Institute on Aging website www.nia.nih.gov, but they may not be identified that way in their descriptions.

Another challenge is finding materials labeled reader-friendly that really *are*! Many vendors label their materials easy-to-read without testing them with the intended audience or measuring them against known guidelines. So make sure you review materials before ordering them.

Similarly, health publishers may offer reader-friendly print materials but they may not be listed separately in a catalog or website, so you may need to review each description to find them.

Evaluate the Materials You Find

There are many aspects of materials and websites that help make them readable and appropriate for your audience. The checklist approach helps you assess aspects beyond simply vocabulary and sentence structure, like organization, graphic design, and cultural appropriateness. The Suitability Assessment of Materials (SAM)[1], AHRQ Patient Education Materials Assessment Tool (PEMAT), and the CDC Clear Communication Index use the checklist approach. The SAM was one of the first examples and can be adapted to meet the specific needs of your audience. The Clear Communication Index http://www.cdc.gov/healthcommunication/ClearCommunicationIndex/ is an evidence-based tool used by the Centers for Disease Control and Prevention to assess public health messages. The PEMAT http://www.ahrq.gov/pemat is an instrument to evaluate the understandability and actionability of patient education materials.

Readability Checklist Example

Content is Well-planned

- ☐ Does the content have only 3 to 5 main points?
- ☐ Does the content tell patients only what they need to know to do the desired action?
- ☐ Are the key points in the order readers expect to find and use them?
- ☐ Is the content appropriate for the audience's age and culture?

Content is Conversational

- ☐ Does the content use mostly one- and two-syllable words?
- ☐ Are sentences short and clear?
- ☐ Does the content avoid confusing jargon?
- ☐ Are acronyms used sparingly and spelled out on the first use so they make sense to the patient?
- ☐ Is the content written in the active voice?
- ☐ Is the content written at or below a 6th to 8th grade level?

Fonts and Styles are Consistent

- ☐ Is the body of the text written in at least 12-point serif font?
- ☐ Does the content have no more than 3 different font styles?
- ☐ Is the format consistent throughout?
- ☐ Is the text in upper and lower case instead of ALL CAPITALS?

Layout is Easy to Read

- ☐ Is the format clean and simple?
- ☐ Does the text cover no more than 50% of the space?
- ☐ Does the content have headings and subheadings?
- ☐ Does the content use bulleted lists?
- ☐ Are illustrations easy to recognize? Do they relate to the text? Do they make sense to the patient? Are they age- and culturally-appropriate?
- ☐ Is the document accessible to people with disabilities of all kinds?

Evaluation Tools for Websites

Resources for evaluating the usability of websites can be found at http://www.usability.gov/guidelines/. These guidelines cover a wide range of characteristics. However, they do not include information on ease of use for people who are not strong readers. Studies show readers with low literacy skills read and use websites quite differently than readers with high literacy skills. To learn about the differences and how to tell if your sites are likely to help or impede people with lower literacy skills, go to http://www.useit.com/alertbox/20050314.html.[2]

Resources for evaluating accessibility of websites for people with disabilities can be found at http://www.w3.org/WAI/. This site provides international standards from the Web Accessibility Initiative which include recommendations for addressing the needs of a wide array of web users.

Finally, find out *how* information is being used. For example, there may be easy-to-understand video modules available on-line but there may not be enough computers for all patients. Staff may print out a written version of the information for patients, not realizing the written version may not be easy to understand. Just listening to the audio or being handed a printed version of the tutorial does not mean patients will understand, learn, remember, and act on new concepts.

Get User Feedback

Asking potential users is the only sure way to know what is effective. This can be done with focus groups or on a smaller scale with individual interviews. It can also be helpful to interview family members or other caregivers who may need to use your print materials or websites. Having people tell you where they struggle or succeed as they go through the text shows you where you can improve.

Create New or Revise Existing Materials

Your goal should be that everyone in your organization who uses print and web materials understands the importance of reader-friendly information. And they should know the basic characteristics of reader-friendly print and web information. For example, a pediatric nurse may not have been trained to create a handout for parents from scratch, but should at least know how to revise existing materials by making a few changes that will fix the biggest barriers for readers. Over time and with practice and coaching, you can develop a core group of go-to plain language materials experts.

Hands-on Workshops

The best way to learn the process (from conceptualizing your message to designing to field testing) is an in-person, hands-on workshop conducted by a qualified experienced trainer. In a live, in-person training, you can see many examples of what works and what doesn't, and learn why. You learn the basics, practice what you learned, and get feedback from the trainer and fellow participants. Consider inviting an expert, such as a member of the Clear Language Group http://www.clearlanguagegroup.com, to lead a tailored on-site training for a group from your organization. In addition to helping build expertise and capacity within your organization, this will establish a critical mass of trained, excited people who will, in turn, build momentum and commitment.

Books and On-line Resources

Learning from health literacy and materials development books, articles, guides, toolkits, and on-line resources is a way to get started and an option if resources are limited. However, learning from a book or web-based guide is usually not enough guidance to learn to create reader-friendly materials or websites from scratch. If you want your organization to have a group of go-to experts, they should have in-depth training.

Health Literacy Tools for Developing Print Materials

Resource	Description
Agency for Healthcare Research and Quality (2014). *Patient Education Materials Assessment Tool* http://www.ahrq.gov/pemat/	A tool to assess the understandability and actionability of print and audiovisual patient education materials
Center for Medicare Education (2000). *Writing Easy-to-Read Materials* http://medicine.osu.edu/sitetool/sites/pdfs/ahecpublic/Writing_EasytoRead_Materials.pdf	Issue brief describes the basics for writing easy-to-read materials
Centers for Disease Control and Prevention (2013). *Clear Communication Index* http://www.cdc.gov/healthcommunication/ClearCommunicationIndex/	Evidence-based tool used for developing and assessing public health messages.
Centers for Medicare and Medicaid Services (2010). *Toolkit for Making Written Material Clear and Effective* https://www.cms.gov/WrittenMaterialsToolkit/Downloads/ToolkitPart03.pdf	Comprehensive guidebook that includes practical tools to improve printed material
Doak C, Doak L, Root J (2006). *Teaching Patients with Low Literacy Skills* http://www.hsph.harvard.edu/healthliteracy/resources/teaching-patients-with-low-literacy-skills/	Provides many plain language strategies and includes the suitability assessment of materials (SAM), a checklist approach to assessing the readability of materials
Maximus (2005). *The Health Literacy Style Manual* http://www.coveringkidsandfamilies.org/resources/docs/stylemanual.pdf	Provides guidance for developing easy-to-read materials
National Institutes of Health (2003). *Clear and Simple: Developing Effective Print Materials for Low-Literate Readers* http://www.cancer.gov/cancertopics/cancerlibrary/clear-and-simple/page5	Guide includes a brief checklist along with step-by-step information on creating materials

Health Literacy Tools for Creating Websites

Resource	Description
Department of Health and Human Services (2010). *Health Literacy Online: A guide to writing and designing easy-to-use health Web sites* http://www.health.gov/healthliteracyonline/index.htm	Comprehensive online guide geared toward web designers, web content specialists, and health communication professionals
Eichner J, Dullabh P (2007). *Accessible Health Information Technology (Health IT) for Populations With Limited Literacy: A Guide for Developers and Purchasers of Health IT* http://healthit.ahrq.gov/sites/default/files/docs/page/literacy_guide.html	Evidence-based guide for website developers includes general recommendations for improving accessibility of all health IT and specific recommendations that address the needs of users with limited literacy
Krug S (2005). *Don't Make Me Think: A Common Sense Approach to Web Usability* http://www.sensible.com/dmmt.html	Proposes a simple approach to usability testing appropriate for anyone involved in development of a website
Nielsen J (2005). *Lower-Literacy Users: Writing for a Broad Consumer Audience* http://www.useit.com/alertbox/20050314.html	Describes the barriers users with low literacy experience when searching websites for information
Usability.gov http://www.usability.gov/guidelines/	Includes usability guidelines established by the federal government
Web Accessibility Initiative http://www.w3.org/WAI/users/Overview.html	Includes strategies, guidelines, and resources to help make the web accessible to people with disabilities

Principles for Creating and Revising Materials

Once you learn basic principles about reader-friendliness, it's time to begin creating or revising some written materials. You may never feel like you know enough, but this is an area where the more you work on it—and the more you seek feedback from end-users—the better you get. You will no doubt go through multiple drafts as you work through a document, and you will likely see things you missed and continue to make changes over time. You can use the following approach to get started.

Plan Your Materials

First, consider the needs and expectations of all your audiences—the people who will read and use your materials. This will include the obvious audiences of patients and their families but other stakeholders, as well.

Involve Stakeholders

Start by making sure you know who the stakeholders are. Medical and legal professionals, administrators, policy specialists, and others in your organization may want or need to approve the materials. Perhaps the materials were funded by an agency or foundation whose staff or members have a stake in how they turn out. Think about these people early in the process, inform them about your work, and get their involvement and support. Help them understand that reader-friendly and plain language communication are appreciated by people of *all* reading abilities. Using these principles is *not* dumbing things down.[3]

Learn about Patients, their Families, and the Community

Learn about your patients, their families, and the communities your organization serves. Research their demographics: race, ethnicity, age, educational level, languages they speak, whether they are new to your area or the U.S., socioeconomic status, gender identities, cultural groups with which they identify, their health beliefs, and their preferences and expectations about how health care is delivered. How do you learn all this?

- Research government databases about your community.
- Build relationships with representatives of the communities.

- Ask patients and their families to help you understand their perspectives, and involve them in creating materials. They can tell you:
  - The topics they are interested in and need information about.
  - Whether your key messages are appropriate and compelling.
  - How they perceive your proposed illustrations or photographs and graphic elements such as color and design.
  - How cultural beliefs and norms need to be addressed.

Create Your Key Messages

Limit your document to 3-5 key points or messages most readers will want to know at the time they are reading the text. Include only what readers must know to carry out the recommended action—the need-to-know versus nice-to-know. Because we tend to include much more than patients need or want to know, a good guideline is "If in doubt, leave it out." Avoid including information that answers questions the audience would not likely ask.

Think from the perspective of your users. Make sure your 3 to 5 key points are in the order readers will expect to find and use them. Let's say you're developing a brochure for parents on what to feed their babies and toddlers. You might think of the foods in categories and be tempted to list them that way. But how will parents look for the information? By the age of their child. If you list the information by age groups, parents can quickly find and read just the information that matters to them. If you list it by food groups, they will have to read each section looking for the content that applies to their child's age.

The User's Perspective

Following surgery for a fractured hip and 12-week stay in a rehabilitation center complicated by readmissions due to bleeding, an 88-year old woman was ready for discharge. She would be returning to her home where she previously lived alone. Her out-of-town daughter would be staying with her for 4 days.

Rehabilitation staff made repeated efforts to help the woman demonstrate that she was able to resume managing her many medications, several of which had been changed during her stay. They wrote a list of her medicines and asked her to describe how she would take them. But she was unable to explain her medication regimen, and recommendations were made for various medication management services.

When she and her daughter got home, her daughter rewrote the medication list in the way she knew her mother thought about her medications—according to the times of the day. Her mother was then able to take over her own medication management and continue her successful recovery.

Write in Plain Language

When switching from spoken to written English there is a tendency to be more formal. (In other languages the difference can be quite marked.) Words and sentences usually become longer and, in general, tend to be more official or academic. Avoid that, and write as though you are talking to your mom or grandfather.

- **Use shorter, more conversational words.** Use one- or two-syllable words. For example, instead of "demonstrate" use "show." Or instead of, "If you're unable to perform your exercises because of pain, please tell your therapist," write, "If it hurts to do your exercises, please call us."
- **Avoid medical and scientific jargon.** For example, telling someone with no medical background that they will be *intubated* during surgery is probably not very helpful. Try saying there will be a tube put into their airway to help them breathe while they are asleep. Describing a treatment as *palliative* vs. *curative* is also unlikely to be helpful. Many people will not know either term. Instead, you might say, "I'm afraid your cancer cannot be cured. The hospice treatment will make you more comfortable in your last weeks."
- **Explain new words and concepts in context.** Give concrete examples. For example, when warning about post-operative problems, instead of "excessive bleeding" try "blood that soaks your bandage all the way through."
- **Avoid acronyms or make sure you explain them first.** For example, you might use BMI instead of body mass index all the time. Remember that your patients need to be specifically taught: 1) What BMI stands for, and 2) what body mass index means, why it matters, and what theirs should be.

Use Shorter, Clear Sentences

Don't let the urge to be formal make your sentences longer than necessary. The average sentence length should be 10-15 words. That means some sentences can be up to 20 words long if most are shorter. If all the sentences are less than 15 words, the writing may sound awkward and unnatural, which can impair understanding. Also, make sure the sentences are simple, clear, and straightforward. Here is an example. (Note: BBTD stands for baby bottle tooth decay.)

Original	Revised
When you consider the potential cost of treating the problems associated with BBTD, it is best to prevent this condition from developing in the first place. (26 words)	It can cost a lot to treat Baby Bottle Tooth Decay. (11 words) So start taking care of your baby's teeth before the first tooth comes in. (14 words)

Use Active Instead of Passive Voice

Active sentences put the person or thing doing the action before the action word. Passive voice often uses the sentence structure, "X was done by Y." Here are some examples:

Passive Voice	Active Voice
Members have been confused by some of the new regulations.	Some of the new regulations have confused members.
Patient satisfaction was evaluated by the hospital in 2010.	The hospital evaluated patient satisfaction in 2010.
Blood sugar levels can be evaluated often with these strips.	You can check your blood sugar often with these strips.

Write Directly to Your Readers in a Friendly Tone

Personalize your message by writing *to* your readers rather than *about* them. You might use "you" or just address your readers with an "understood you" as in "Check your blood sugar after each meal." It works well to use "you" for the reader/consumer and "we" for the organization. If the document comes from your organization, it's obvious who "we" stands for. Being friendly and inviting is important, too. Sometimes it's even more important if you're using the direct approach. Focus on people rather than things.

Original	Revised
This medicine may cause drowsiness.	This medicine may make you sleepy.
Vaccines are important for protecting children's health.	Protect your child's health. Get the right vaccine on time.
The client must arrive for the first appointment 20 minutes early.	Please come 20 minutes early for your first visit.

What About Readability Formulas?

Readability formulas can help you measure how hard the text is to read, but they don't tell the whole story. They use a mathematical formula to estimate the reading grade level at which a material is written. But just because someone finished 12th grade does not mean they read at 12th grade level. And what is taught in a certain grade now is much different from what was taught in the 1940s when readability formulas were developed. Therefore, it is best to think of these tests as measures of difficulty on a continuum.

In general, the formulas count the average number of syllables in a word and average number of words in a sentence. Those are the two most significant factors in reading difficulty so readability formulas do give very important information.

But, there are many other aspects of printed materials that formulas cannot measure and that influence understandability, appeal, relevance, and more.[4]

- Organization and density of information
- Familiarity of vocabulary or concepts
- Influence of format, design, or visuals
- Cultural sensitivity or relevance
- Credibility or believability
- Readers' readiness to learn

Often-used formulas in health care are the SMOG and Fry.[1] You can learn to use them both by hand or you can go to websites that calculate the scores for you. If you prefer not to analyze reading level by hand, you can either go on-line to a website or use software on your computer. Be careful when using readability functions in word processing software. This might be handy but there have been reports of problems with their reliability and accuracy.

Health Literacy Tools for Analyzing Text

By Hand	Electronically
The Fry formula http://www.readabilityformulas.com/fry-graph-readability-formula.php	**The Fry formula** http://www.csudh.edu/fisher/readability.htm
The SMOG formula http://www.hunter.cuny.edu/irb/education-training/smog-readability-formula	**The SMOG (and other formulas)** http://www.online-utility.org/english/readability_test_and_improve.jsp

Your organization might also consider purchasing software which analyzes reading level. A good choice is *Readability Formulas*™ http://www.micropowerandlight.com/rd.html. Some readability software also provides suggestions to make the text more readable. *Health Literacy Advisor*™ http://www.healthliteracyinnovations.com/home analyzes reading level with several different formulas and also provides plain language substitutions for words and phrases. It also has a Spanish version. *Stylewriter*™ http://www.stylewriter-usa.com/index.html analyzes reading level and suggests a variety of plain language edits which can be very useful and save time.

Understanding Results

Whether you test your content using readability software, the web, or manually, you will get a score that indicates a grade level. Most formulas are only accurate to within one or two grade levels. Suppose your score is 6.7. Round the number to the nearest whole number, but know it would be unrealistic to say for sure the content tests at 7th grade level. It is actually more accurate to say the content is probably written at 6th to 7th grade reading level, or to be safe, 6th to 8th.

If the score is higher than your target level, go through the guidelines above and apply them more stringently. Cut out jargon. Shorten sentences that are longer than 20 or 25 words. Hunt down the 3- or 4-syllable words you can change to shorter, more commonly-spoken words. Go back through the document and reassess the necessity and relevance of every word. Look at all aspects of the text.

In summary, readability formulas are just one of many tools for creating and assuring reading ease. They should not be the final step in determining whether or not your content is easy-to-read *and* understand.

Graphic Design, Layout, and Visuals

Good design is just as important to readability as content, words, and formatting.[5,6] Few patients want to spend time wading through unnecessary information. They want it fast and efficiently. Good design can help. If you don't have resources to work with a professional graphic designer, use these guidelines.

Fonts Influence Readability

There has been a debate among document designers, graphic designers, and readability specialists for decades about use of two different families of fonts, also called typefaces: serif and sans serif. A serif font has little curls at the end of each letter. These little curls are called serifs. Serifs are thought to help move your eyes from one letter to the next, which is a good thing when you don't read well or you want to read information quickly. Serif fonts work well for written materials. Sans serif fonts have straight letters. Sans means without, so sans serif fonts are missing the little curves on the letters. The letters end abruptly, which in theory, slows your eyes as they move from letter to letter, at least in printed materials.[7]

The Difference Between Serif and Sans Serif Letters (fonts or typefaces)

Times New Roman is one of the standard, most used serif fonts. Serif fonts are almost always best for the main text and also work for headings. Sans serif typefaces are fine used as headings but generally not for the main text. *Arial*, also popular, is a sans serif font, and it works nicely for headings.

For images on computer screens (e.g., websites or e-mail) sans serif fonts may be best. Some experts say sans serif fonts "hold together" better on screens because they can be digitized more easily.

White Space Gives Readers a Visual Break

When you're creating easy-to-read materials, give readers a visual break by surrounding content with white or open space. How much is enough? In general, 50% of the page. White space generally means an open area free of text. It can be colored as well as white and can include non-text elements such as illustrations, photos, or easy diagrams. You can create white space with:

- At least one-inch margins on the top, bottom, and sides in letters and flyers—anything on 8½" by 11" paper.
- Headings and subheadings that introduce information.
- Short paragraphs with space between them.
- At least half an inch between columns of text.
- Bulleted text with one quarter inch between the bullet and its text.

Use dark type on a white or light background for good contrast between the text and background. Light or white text on a dark background is called reverse type and should be avoided in print materials. It can be hard to read in print. Interestingly, though, it seems to work fine for websites or text projected on a screen.

Emphasize What You Want Patients to Remember

Use one or two of these methods to highlight the most important messages.

- Write short paragraphs with one or two key points, or put information in a text box, also known as a call-out box.
- Bold a term or phrase but don't overdo it.
- Italicize a few key words. However, be aware that too many words in italics can be hard to read and slow readers down.
- When there are multiple items, use numbers if there are steps that should be done in order. Use bullets for lists. Limit length to 5-7 items.

Good Headings Grab Attention and Provide Content

Headings and subheadings are great for directing your readers' eyes to specific information. They can instruct, inform, catch and guide the reader's eye, and drive your message home.

Carefully written text can also help your headings and subheadings do double duty. Instead of simply introducing a topic, headers can provide content as well. For example, "What Is Depression?" introduces the topic clearly but doesn't give new content. A more powerful heading like "Depression is More than Just the Blues" introduces the topic and gives new content. Using headings to deliver content as well as announce a new topic can be especially effective for reluctant readers who may read only headings.

Pictures Encourage Understanding

Illustrations and photos can be great teaching tools—if they make sense. Illustrations, photos, clip art, graphs, and other visual elements should complement and explain information. Look at the visual elements and ask:

- Do they help explain your point?
- Are they a clue to the content?
- Do they add understanding for the reader?
- Do they make sense all by themselves?

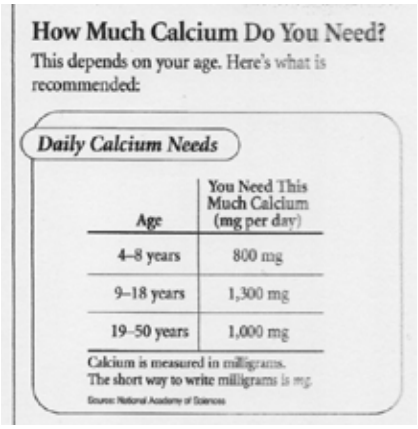
If you answer yes, then use them. If they are just pretty pictures, leave them out. Illustrations and photos should resonate with your intended audience. Remember that if your material is intended for a specific culture, your photos should be of people from that culture. Consider how color images, illustrations, and graphic features will look if printed in black and white. Also consider whether their meaning will be clear if the person using it cannot read the accompanying text.

Tables, Graphs, Charts, and Figures

Tables, graphs, charts, and figures can be a great way to visually explain information if done simply, but they can also confuse readers. Before using any of these formats, test them with your intended audiences to be sure they are understandable.

A table should require no more than a simple strategy like finding the correct column, going to the correct row, and then going to the next column to find the information.

A simple table might be two columns with a few rows like this example. Notice the helpful brief introduction and the simple label that tell readers exactly what they will find in the table.



How Much Calcium Do You Need?

This depends on your age. Here's what is recommended:

Daily Calcium Needs

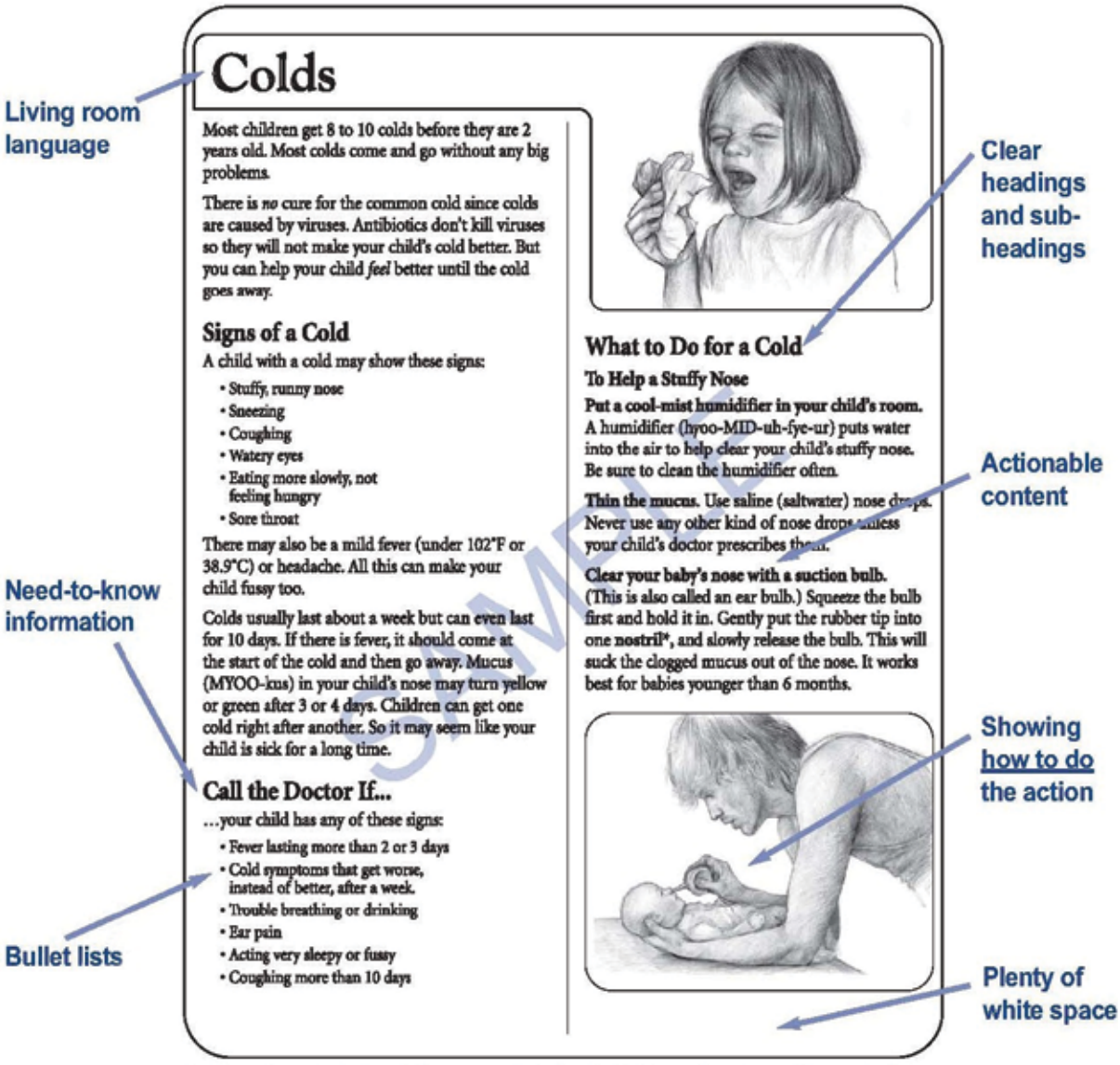
Age	You Need This Much Calcium (mg per day)
4–8 years	800 mg
9–18 years	1,300 mg
19–50 years	1,000 mg

Calcium is measured in milligrams. The short way to write milligrams is mg.

Source: National Academy of Sciences

Graphs and charts can be particularly difficult. Many people were not exposed to them in school and have little experience reading them. Pictograms, as shown below, are an option.

The following example shows plain language design principles in action.



Reprinted with permission from *Plain Language Pediatrics: Health Literacy Strategies and Communication Resources for Common Pediatric Topics*, copyright 2009 by the American Academy of Pediatrics.

Culturally- and Linguistically-Appropriate Materials

Different people learn in different ways, and culture may influence this. Some prefer learning the facts. Others prefer learning through stories. Still others prefer non-print like video and audio. You don't want to assume that how you learn best is how others learn best or that what you've written will have meaning to others. To ensure your materials are understandable and make sense to people from cultures other than your own, you must ask.

A Brochure about Home Poison Prevention

A brochure about home poison safety had been translated from English into Spanish. In field-testing the Spanish version, interviewers discovered that talking about *home* safety didn't resonate with Spanish-speakers. They said it was about keeping their *family* safe, not their *home*. The new version focused on making sure the family is safe in the home. This is a subtle shift but, without it, the audience would have found the brochure puzzling and irrelevant.

Collaborate with Your Target Audience

Collaborate with your target audience in developing materials and take what they tell you to heart. Otherwise your materials are unlikely to be used.

- Show a few community members the material to determine if it is culturally appropriate. You don't want to offend your audience or present information that is simply not relevant. You want to use an approach and examples that fit with their views and the best way to know this is to ask.

- Use words, concepts, and idioms from the population's everyday language. Ask members of the community what is meaningful to them. They'll help you decide what to say and how to say it.

- Make sure you use photos and illustrations that will resonate with your audience(s). Think hard about what your illustrations represent and run them past members of the community. You want your audience to personally identify with the photos, illustrations, and other images in your piece.

Tips for Ensuring Quality Translations

- Make sure the English material is written in plain language. Revise and format your handout so it is easy to read and understand before translation.
- Ideally, the translator will be a member of the intended community and will have worked with patients who have low literacy skills.
- Conduct a quality assurance translation check to ensure an accurate translation and that the translated version is written at the easiest reading level possible. Best practice is to have two independent translators, from different cultural backgrounds, translate the document and reconcile any differences. Then have a third translator conduct the final review.
- Go back to your intended audience to test the translated document and get their feedback. Ask them questions about the content and illustrations/photos. Be sure to ask questions that will result in useful feedback. Revise the document based on the community feedback.

Field Test Materials

Ultimately, you cannot know if your intended audience is going to read, understand, and act on the information in your materials unless you ask them. If you don't, you run the risk of spending time and money to create materials patients will not use.

Field testing asks your intended audience for their opinions. And in most cases, they are more than happy to tell you what they think. Take their feedback to heart. Listen carefully to what they say and don't say.

Writing field testing questions is tricky. Don't ask yes or no questions because all you will get are yes and no answers, which doesn't tell you much. Instead, you need to develop questions that will get at readability, acceptability, accessibility, appeal, comprehension of words or concepts, self-efficacy (do they believe they can do the suggested action), usefulness (does the action make sense for them), and persuasion (were they persuaded by the message). Here are sample questions (followed by the area that they are intended to learn about).

Sample Questions for Field Testing

- Would you say this booklet is easy to read and understand or hard to read and understand? Please tell me why you say that. (acceptability, accessibility, self-efficacy)
- What would you say are 2 or 3 of the main points the hospital wants to get across in this booklet? (comprehension)
- Who do you think this booklet is written for? (acceptability, appeal)
- Would you give this booklet to a family member or friend? If yes, why? If no, why not? (acceptability, appeal)
- Please flip through the booklet and look at all the photos. Do the people in them look like people you know? Are there any you would change? (acceptability, appeal)
- Now let's open up to the first two pages. What do you think about the way these pages look? For example, what do you think about the size of the letters and how many words are on the pages? The colors, like green ink on the headings? (appeal, readability, accessibility)

Health Literacy Tools for Field Testing Materials

Resource	Description
Krueger R, Casey M (2008). *Focus Groups: A Practical Guide for Applied Research* http://www.amazon.co.uk/Focus-Groups-Richard-Krueger/dp/1412969476	Guidebook on setting up and conducting focus groups
Centers for Medicare and Medicaid Services. *Toolkit for Making Written Material Clear and Effective* (Part 6) https://www.cms.gov/Outreach-and-Education/Outreach/WrittenMaterialsToolkit/Toolkit-Part-6-Feedback-Sessions.html	Free, in-depth, online resource for getting feedback from patients

Using Handouts with Patients

Now that you've read this far, you should have a much better idea of what makes a good patient handout and what doesn't. From now on, you'll probably look at all patient materials with a more discerning and wise eye. If you need to find or create better alternatives, you can make those you do have work in the meantime. Here are a few tips for getting the most out of handouts you already have:

- Highlight the key points. Circle or mark the most relevant and important information for the patient. For example, say, "I'm circling this information on what to do if you have pain and swelling after we pull your wisdom teeth." Use a star, or underline or highlight other information. Tell the patient what you're doing, for example, "Another thing to watch for is a fever. If your temperature goes over 101°F, call us. I'm putting a star by this to help you remember."
- Use handouts as a springboard for discussion. Don't be surprised if patients say they have no questions when glancing at the materials. Most need time to digest the information. If you have to leave the room for five or ten minutes, that can be enough time for the patient to read through a handout and decide if there's something they don't understand. When you return, remember they may not tell you they don't understand unless you ask, especially if they do not read well.
- Write notes on the handout. Print clearly rather than using cursive.
- Offer to read the materials with the patient. This can help patients remember what you told them, especially if you rephrase what you're reading, using simple language.
- Realize the limitations of handouts. They don't work for people who can't read well enough to get meaning from print (about 1 in 5 adults). Also, if they're not visually appealing, patients are less likely to read them.

Policies about Print and Web Materials

It's good to have a policy at your organization that sets expectations for use of reader-friendly principles for print and web-based materials. This can provide opportunities for leadership support, guidance for managers and department heads to create time and resources for improving written materials, and recognition that your organization considers this an important priority to providing safe, high-quality, patient-centered care.

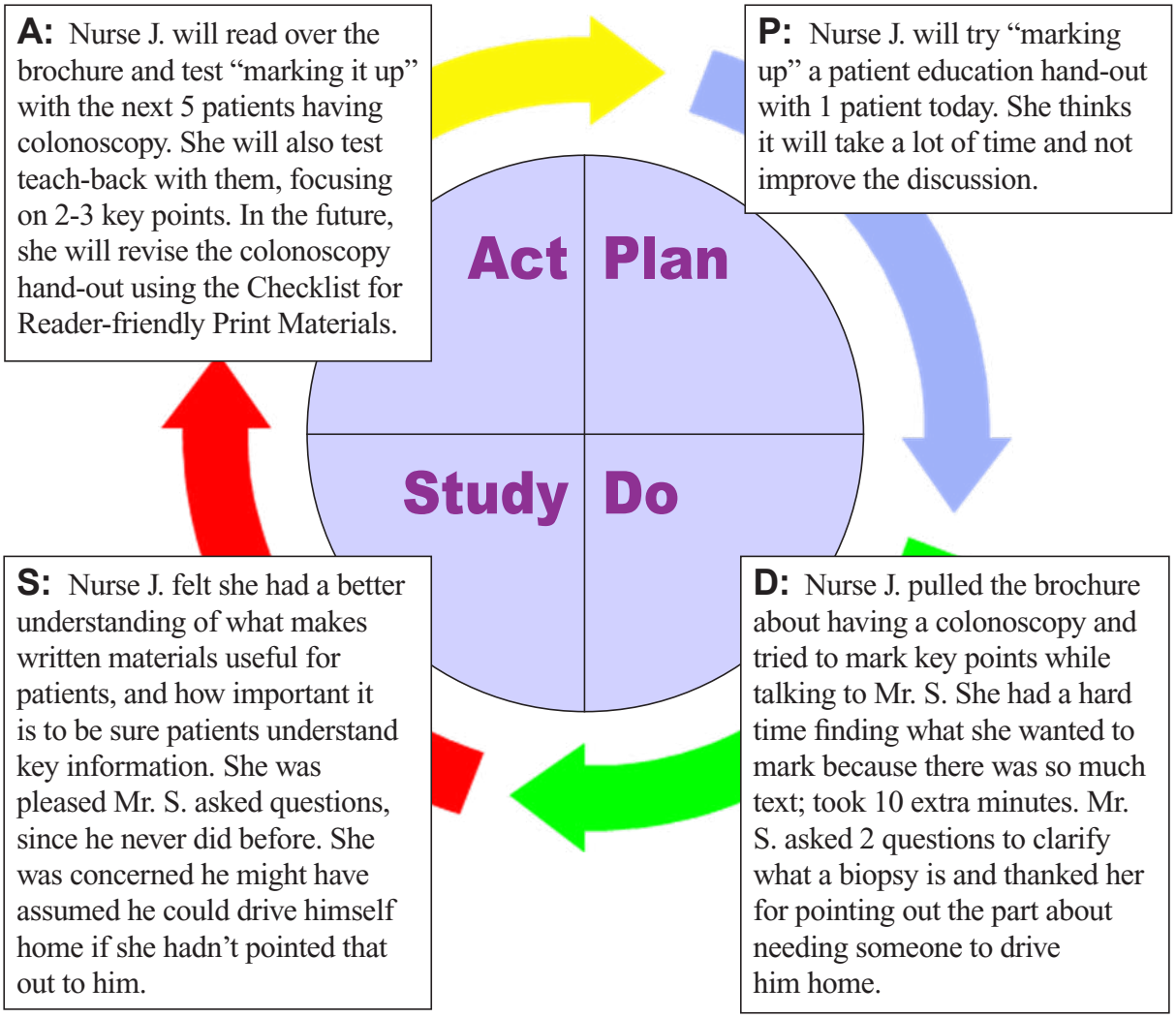
Consider the following Excerpt from the UnityPoint Health Patient and Family Printed Education Materials Policy.

Excerpts from the UnityPoint Health Patient and Family Printed Education Materials Policy

The purpose of this policy is to endeavor to ensure that patient and family education and information print materials are developed, revised, and/or selected using health literacy guidelines about content, graphic design and layout, and reading level.

- "Content: The content expert (primary writer) examines the material for accuracy, completeness, and relevance, ensuring it reflects current nationally- and UnityPoint Health-accepted guidelines and practices. Content should also be developed taking into account health literacy writing principles."
- "Graphic Design and Layout: Technical design principles, including font style and size, headings, subheadings, white space, appropriate visuals, and other characteristics that enhance the readability of the materials, should be used."
- "Reading Level: The Patient Education or Health Literacy Coordinator will evaluate the reading level of education materials using approved readability formulas or software. For the general public, 6th to 8th grade level is best."

Example PDSA Cycle: Using Reader-friendly Health Education Materials



A: Nurse J. will read over the brochure and test "marking it up" with the next 5 patients having colonoscopy. She will also test teach-back with them, focusing on 2-3 key points. In the future, she will revise the colonoscopy hand-out using the Checklist for Reader-friendly Print Materials.

P: Nurse J. will try "marking up" a patient education hand-out with 1 patient today. She thinks it will take a lot of time and not improve the discussion.

S: Nurse J. felt she had a better understanding of what makes written materials useful for patients, and how important it is to be sure patients understand key information. She was pleased Mr. S. asked questions, since he never did before. She was concerned he might have assumed he could drive himself home if she hadn't pointed that out to him.

D: Nurse J. pulled the brochure about having a colonoscopy and tried to mark key points while talking to Mr. S. She had a hard time finding what she wanted to mark because there was so much text; took 10 extra minutes. Mr. S. asked 2 questions to clarify what a biopsy is and thanked her for pointing out the part about needing someone to drive him home.

Summary of Key Points

- Much communication between patients and health care systems is through the written word. Effective print materials are a key element of good health communication.
- Reader-friendly print and web materials promote safe high-quality care, and adherence.
- Patients may not remember much of what is said, so they need clear information in print to take with them and refer to later.
- Your organization can provide effective, reader-friendly information by: finding existing materials and websites outside the organization; revising materials already used in the organization; or creating new materials.
- Staff responsible for choosing, revising, or creating print or web-based information should undergo training on plain language and clear design principles.
- Checking the reading grade level at which a material is written is not sufficient to assess readability, understandability, and usability.
- Design, layout, and visuals are key ways to enhance reader-friendliness.
- Culturally-sensitive, accessible materials can help address health disparities, including disparities experienced by people with disabilities.
- Both print and web-based information should be accessible to people with a variety of disabilities. Be sure to consider the needs of all people as you evaluate, develop, and deliver health information.
- Ideally, materials in languages other than English should be produced directly in the language and culture of the audience. If translation is needed, use qualified translators and be sure to field test the translation with members of the target audience.
- Field testing your materials is the only way to know if your materials are effective. Even a few interviews will give you great information about how well your materials are working. Don't skip this step.

1 Doak CC, Doak LG, Root JH. *Teaching Patients with Low Literacy Skills. Second Edition*. Philadelphia, PA: J.B. Lippincott Company; 2007. Available at: http://www.hsph.harvard.edu/healthliteracy/resources/teaching-patients-with-low-literacy-skills/. Accessed: June 29, 2012.

2 Nielsen J. *Lower-Literacy Users: Writing for a Broad Consumer Audience*. Neilson Norman Group. Jacob Nielsen's Alertbox. March 14, 2005. Available at: http://www.useit.com/alertbox/20050314.html. Accessed: March 17, 2013.

3 Stableford S, Mettger M. Plain language: A strategic response to the health literacy challenge. *Journal of Public Health Policy* 2007; 28:71-93.

4 Pichert J, Elam P. Readability formulas may mislead you. *Patient Educ Couns* 1985;7:181-191. Available at: http://www.sciencedirect.com/science/article/pii/0738399185900084. Accessed: February 7, 2013.

5 Williams R. *The Non-Designer's Design Book, 2nd ed*. Berkeley, CA: Peachpit Press; 2004. Available at: http://dl.acm.org/citation.cfm?id=1207648. Accessed: February 7, 2013.

6 Lohr L. *Creating Graphics for Learning and Performance: Lessons in Visual Literacy*. New Jersey: Merrill Prentice Hall; 2003. Available at: http://www.worldcat.org/title/creating-graphics-for-learning-and-performance-lessons-in-visual-literacy/oclc/636001191. Accessed: February 7, 2013.

7 Wheildon C. *Type & Layout: How Typography and Design Can Get your Message Across—or Get in the Way*. Berkeley, CA: Strathmoor Press; 1995.

9 | Case Study

> "Health care organizations that embody these [ten] attributes [of health literate health care organizations] create an environment that enables people to access and benefit optimally from the range of health care services." (*Ten Attributes of Health Literate Health Care Organizations*, 2012)

An overview of the reader-friendly consent initiative is included here as a case example to demonstrate how multiple attributes of a health literate health care organization can be addressed to improve health literacy and health care quality.[1] This case study is an example of how one organization used a health literacy initiative to become more health literate.

The ideas and information in this chapter are designed to help you:

- Describe how one health literacy initiative can help an organization become more health literate.
- Visualize success and apply the ten attributes of a health literate health care organization to improve the health literacy of your organization.

A Health Literate Health Care Organization Values True Informed Decision-Making

This chapter addresses virtually all the attributes of a health literate health care organization and demonstrates how health literacy is critical to patient understanding and delivery of high quality health care.

Source: Brach C, Keller D, Hernandez LM, et al. *Ten Attributes of Health Literate Health Care Organizations*. Washington, DC: National Academy of Sciences, 2012.

To support their overarching health literacy goals of improving interpersonal and written communication and creating a patient-centered care environment, UnityPoint Health decided to focus on enhancing its process for obtaining and documenting informed consent for surgery from patients. As part of this effort, each affiliate hospital's health literacy team was invited to identify and implement goals to create a patient-centered care environment and improve patients' understanding and the informed consent process through targeted efforts toward improving interpersonal and written communication.

Specifically, the overarching goals of the consent project were to: educate staff about health literacy concepts; develop an understanding that consent is a process not a form; develop a reader-friendly consent form; improve patient understanding through use of plain language; incorporate teach-back to evaluate patient understanding; and facilitate a general culture of peri-operative consent communication. The process and formal evaluation have been described elsewhere.[2,3,4,5]

Developing a New Approach

The informed consent process for surgery and invasive procedures sometimes fails to fully engage the patient in informed decision-making for various reasons, including time constraints for providers and consent forms that can be difficult to understand (especially for patients with low health literacy). As a result, patients may undergo surgery without fully understanding the procedure, its potential risks and benefits, and possible alternative treatments.

Planning and development of a health literate approach to informed consent should incorporate several attributes of a health literate health care organization. In the case of UnityPoint Health, the health literate informed consent initiative included the following steps:

- Obtain support of health system leaders. Health literacy representatives met with system leaders and representatives of the Law Department to present the idea of designing a reader-friendly consent form to be used across the system, with the decision to adopt the reader-friendly consent form and process voluntary for each affiliate hospital.
- Obtain plain language expert training. Affiliate health literacy teams attended a UnityPoint Health-sponsored training workshop on developing reader-friendly print materials. This was pivotal to teams' understanding and skill-building for development of reader-friendly print materials, including the new consent form.
- Revise the current consent form. Affiliate health literacy team representatives revised the initial consent form in collaboration with adult learners, affiliate risk managers, health care providers, and the UnityPoint Health Law Department.
- Obtain feedback and revise the form. Input from the New Readers of Iowa was critical. The team revised the consent form through an iterative process that involved multiple reviews to clarify terms and improve reader-friendliness. The final consent form was translated into Spanish.

- Pilot-test in one setting. The final draft of the consent form was piloted through a small test-of-change process with documented steps to facilitate implementation at other system hospitals.
- Expand system-wide and to other procedures. After pilot-testing and additional drafts, the first hospital adopted the new consent form for all surgical procedures. Additional UnityPoint Health affiliates subsequently adopted the new consent form/process following the implementation steps.

The entire initiative involved a foundation of education and understanding focusing on health literacy principles, the concept of informed consent versus a consent form, and utilization of the new consent and teach-back process to ensure patient understanding. The reader-friendly surgery/procedure consent form has subsequently been used to develop additional consent forms with similar reader-friendly print material principles, including consents for non-physician and radiology procedures, and blood transfusion.

While health literacy teams devoted significant effort to up-front development, staff education, and implementation, the program has not required additional financial resources other than a small grant for the formal research evaluation. Existing staff incorporate it into their daily routines. An active health literacy team to test and implement health literacy interventions and spread understanding of health literacy principles was instrumental to system-wide success.

The Health Literate Consent Process

Following an initial discussion with the surgeon, the patient is guided through an interactive process using a simple, reader-friendly, health literacy-based consent form designed to increase the likelihood that the patient reads and understands the consent form, understands his or her procedure, and feels comfortable asking questions prior to giving consent. The purpose of this enhanced process is to promote patient understanding through use of plain language principles and teach-back. Key elements include:

- Surgeon-patient discussion: The project encouraged the surgeon to use plain language verbal communication principles (e.g., speaking clearly and slowly; avoiding use of acronyms and complex medical language when possible) to discuss with the patient the need for the surgery, the nature of the procedure, the risks and benefits associated with it, and alternative treatments. This discussion

may occur in the surgeon's office or at the patient's bedside (if surgery is scheduled during hospitalization). The surgeon documents the discussion in the patient's medical record.

- Reader-friendly, health literacy-based consent form: The surgeon or nurse uses the reader-friendly, health literacy-based consent form to reinforce and confirm the patient's understanding of the surgical procedure. The new form replaced the standard consent form that was written at college reading level. Features of the new form include:
  - Reader-friendly wording and format: Written at 7th to 8th grade reading level, the consent form includes simple words, short sentences and paragraphs, and minimal use of medical terminology. It is designed to be reader-friendly with large (12 to 14 point) serif font, clear headings, liberal use of bullets and numbering, ample white space, key use of bold text, and 1.5-line spacing.
  - Space for patient description of procedure: The consent form includes the traditional section for description of the procedure in medical terms, as well as a section for writing the patient's description of the procedure in his or her own words. This additional element incorporates use of teach-back, a research-based strategy for assessing patient understanding.
  - Key elements of informed consent: The consent form outlines six elements of informed consent in bulleted form. By signing the form, the patient gives permission for the procedure and confirms the following: "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 results."

- Plain language description of additional components of surgery: The consent form outlines, in plain language, additional components of a surgical procedure, including use of anesthesia, unexpected conditions encountered during surgery, removal of tissue or body parts, creation of pictures or video if needed for a medical reason, presence of observers (such as medical students), and the potential need for blood products.
- Reminder to ask questions: To further encourage communication the form includes a prompt to the patient to be sure all of his or her questions have been asked and answered before signing it.
- Obtaining consent: After reviewing the form with the patient and making sure they have no more questions, the surgeon or nurse obtains the patient's signature on the consent form. If the nurse deems the patient's understanding to be inadequate or the patient has questions, the nurse will alert the surgeon of the need for additional discussion with the patient prior to obtaining the patient's signature on the consent form.

Findings and Feedback

The new form and consent process have increased the proportion of patients observed to be reading the form and who were able to describe their surgery in their own words, and enhanced patients' comfort level with asking questions.[2,3,5] Anecdotal reports also suggest that patients, families, and nurses are satisfied with the enhanced process and form.

- More patients able to describe surgery: Approximately 71% of patients undergoing total hip/knee replacement (elective procedures) or gall bladder surgery (a more time-sensitive emergent procedure) who used the new consent form and process strongly agreed with the following statement, "I was asked to tell the nurse what surgery I was having done, using my own words," significantly higher than the 59% of patients using the original form and consent process. This finding suggests that health literacy principles can be used to refine the consent process to promote patient understanding through use of plain language and teach-back.
- Greater comfort asking questions: Patients with whom the new form and consent process were used were also more likely to strongly agree with the statement, "I felt comfortable asking questions about my surgery," consistent with facilitating a culture of communication.

- Satisfaction with form and process change: Anecdotal feedback suggests that patients/families as well as nurses are satisfied with the process change and the new reader-friendly consent form. Nurses reported more patients reading the new consent form compared to the original form.

Lessons Learned

- **Articulate health literacy as system goal.** Would-be adopters can obtain support for the program from administrators and providers by emphasizing the industry's increasing focus on health literacy and patients' right to understand health care information, including presenting informed consent in a way that is simple, clear, and in plain language.
- **Emphasize that the form alone does not ensure informed consent.** The consent form is a tool to document that the informed consent discussion took place and help drive use of plain language and teach-back in the consent process continuum.
- **Get feedback from consumers.** Input from patients/consumers (particularly those with low literacy) can be very valuable to improving the readability and user-friendliness of print materials, and thus to ensuring they contribute to patient understanding and the ability to make informed choices about health care options.
- **Emphasize the value of teach-back.** Listening to patients describe what they have heard in their own words allows providers to be sure they understand relevant health information, and provide additional teaching and re-check for understanding if necessary.
- **Monitor and report on program impact.** Tracking and reporting key metrics related to the program's impact (such as the proportion of patients reading the consent form and able to describe their surgical procedure) can help gain and sustain the support of administrators and providers. Over time, as providers use the new form and process and patients react positively to them, the revised health literacy-based reader-friendly consent form and process can become part of standard operating procedures.

Relationship between Elements of a Health Literacy-based Consent Process and the Attributes of a Health Literate Health Care Organization

Attributes of Health Literate Health Care Organizations	Elements of Health Literacy-based Consent Process
1. Has leadership that makes health literacy integral to its mission, structure, and operations.	Health literacy representatives met with system leaders and representatives of the Law Department to present the idea of designing a reader-friendly consent form to be used across the system.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.	Obtained support from administrators and providers by emphasizing the industry's increasing focus on health literacy and patients' right to understand health care information, including presenting informed consent in a way that is simple, clear, and in plain language.
3. Prepares the workforce to be health literate and monitors progress.	Affiliate health literacy teams attended a UnityPoint Health-sponsored training workshop on developing reader-friendly print materials that was pivotal to teams' understanding and skill-building for development of reader-friendly print materials, including the new consent form.
4. Includes populations served in the design, implementation, and evaluation of health information and services.	Input from the New Readers of Iowa, a group of individuals who learn to read later in life, was critical. Health literacy teams revised the consent form with multiple versions, each reviewed by the New Readers of Iowa and/or UnityPoint Health health literacy teams, to clarify terms and improve reader-friendliness.
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.	Consent form includes traditional section for description of the procedure in medical terms and section for writing the patient's description of the procedure in his or her own words, incorporating teach-back. Purpose of this process was to promote patient understanding through use of plain language principles and teach-back.
7. Provides easy access to health information and services and navigation assistance.	To further encourage communication the new form includes a prompt to the patient to be sure all of his or her questions have been asked and answered before signing it.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.	Written at 7th-8th grade reading level, including simple words, short sentences and paragraphs, and minimal use of medical terminology. Reader-friendly features include: large (12 to 14 point) serif font, clear headings, liberal use of bullets and numbering, ample white space, key use of bold text, and 1.5-line spacing.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.	The enhanced process addresses the risks associated with the informed consent process by engaging patients in this important decision so they fully understand the procedure, its potential risks and benefits, and possible alternative treatments.

1 Brach C, Keller D, Hernandez LM, et al. Ten attributes of health literate health care organizations. Washington DC: National Academy of Sciences; 2012. Available at: http://iom.edu/~/media/Files/Perspectives-Files/2012/Discussion-Papers/BPH_Ten_HLit_Attributes.pdf. Accessed: July 31, 2013.

2 Miller MJ, Abrams MA, Earles B, Phillips K, McCleary EM. Improving patient-provider communication for patients having surgery: patient perceptions of a revised health literacy-based consent process. *Journal of Patient Safety*. 2011 March;7(1):30-38. Available at: http://www.ncbi.nlm.nih.gov/pubmed/21921865. Accessed: July 31, 2013

3 Agency for Healthcare Research and Quality. Innovations Exchange. Simple, patient-friendly informed consent process increases proportion of patients reading form and able to describe surgical procedure. Available at: http://www.innovations.ahrq.gov/content.aspx?id=3270. Accessed: March 19, 2013.

4 Abrams MA, Earles B. Developing an informed consent process with patient understanding in mind. NC Med Journal 2007;68:352-355.

5 Lorenzen B, Melby CE, Earles B. Using principles of health literacy to enhance the informed consent process. AORN Journal 2008;88:23-29. Available at: http://www.ncbi.nlm.nih.gov/pubmed/18603032. Accessed: July 31, 2013