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.

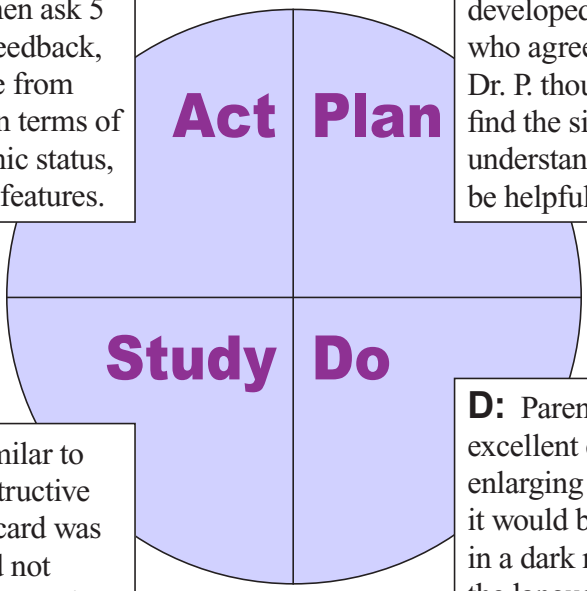
Depending on their comfort level, these roles can expand over time. It may be particularly helpful to assign a small concrete task early on, to build confidence and rapport. For example, you could ask for input on a short document or a sign, or ideas to make waiting more pleasant.

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.