IMPLEMENTATION GUIDE

PATIENT-CENTERED INTERACTIONS

Engaging Patients in Health and Healthcare

May 2013

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Introduction

Patient-centered interactions are the active expression of patient-centered care. Creating collaborative partnerships with patients helps them build skills, confidence, and trust, and engage actively in care decisions and health management. Yet delivering patient-centered care is challenging and patients in many settings do not receive optimal care. Between 30%-80% of patient expectations are not met in a routine primary care visit.[1] A Commonwealth Fund patient survey reported substantial gaps in doctor-patient communication, a key measure of patient-centered care.[2] Communication deficits can be addressed through use of proven strategies and decision aids to empower patients and enhance involvement in decision-making and self-management.

Involving patients in care requires the care team to know patients as "whole persons."[3] Practices need to gather feedback from patients to respond effectively to patient values, preferences, and needs, and to improve care experience. However, like the low prevalence of good communication, only 36% of primary care physicians and 20% of specialists collect and utilize patient surveys.[4] This lack of patient input creates a gap between the care patients need and want and the care patients receive. Strong patient-practice partnerships and an understanding of patients' care needs individually and as a population is a strong marker of a Patient-Centered Medical Home (PCMH).

Creating collaborative partnerships with patients helps them build skills, confidence, and trust, and engage actively in care decisions and health management.

Message to Readers

Practices beginning the PCMH transformation journey often have questions about where and how to begin. We recommend that practices start with a self-assessment to understand their current level of "medical homeness" and identify opportunities for improvement. The Safety Net Medical Home's self-assessment, the Patient-Centered Medical Home Assessment (PCMH-A), is an interactive, self-scoring instrument that can be downloaded, completed, saved, and shared.

Readers are also encouraged to download additional Safety Net Medical Home Initiative Patient-Centered Interactions materials:

- Patient-Centered Interactions Executive Summary provides a concise description of the Change Concept, its role in PCMH transformation, and key implementation activities and actions.
- Eliciting the Patient's Perspective Tool.
- The Patient-Centered Medical Home from the Patient's Perspective.
- Patient Visit Sheet.

This Guide addresses measurement of patient satisfaction and experience, and describes other mechanisms to gain and use patient and family feedback to meet needs and preferences. Along with Organized, Evidence-Based Care, this Guide offers information on the structure and flow of the patient visit and how the visit can be optimized to support positive patient health outcomes, lower cost, and enhance experience. This guide discusses:

- Building partnerships to help all patients and families understand the central role they play in their health and wellness.
- Using a variety of methods to elicit and understand patient experience of care.
- Actively engaging patients in their own healthcare and improving care delivery.

The Change Concepts for Practice Transformation: A Framework for PCMH

"Change concepts" are general ideas used to stimulate specific, actionable steps that lead to improvement. The Safety Net Medical Home Initiative established a framework for PCMH transformation to help guide practices through the transformation process. The framework includes eight change concepts in four groups:

- Laying the Foundation: Engaged Leadership and Quality Improvement Strategy.
- Building Relationships: Empanelment and Continuous and Team-Based Healing Relationships.
- Changing Care Delivery: Organized, Evidence-Based Care and Patient-Centered Interactions.
- Reducing Barriers to Care: Enhanced Access and Care Coordination.

The Change Concepts for Practice Transformation have been extensively tested by the 65 practices that participated in the Safety Net Medical Home Initiative and used by other collaboratives and practices nationwide. They were derived from reviews of the literature and also from discussions with leaders in primary care and quality improvement. They are supported by a comprehensive library of training materials that provide detailed descriptions and real examples of transformation strategies. These resources are free and publicly available. To learn more, see Change Concepts for Practice Transformation.

Key Changes for Patient-Centered Interactions

The eight change concepts represent the critical dimensions of PCMH transformation. Each concept includes multiple "key changes." These describe the general directions for the changes—the core elements a practice undertaking PCMH transformation must adopt. The key changes for Patient-Centered Interactions are:

- Respect patient and family values and expressed needs.
- Encourage patients to expand their role in decision-making, health-related behaviors, and self-management.
- Communicate with their patients in a culturally appropriate manner, in a language and at a level that the patient understands.
- Provide self-management support at every visit through goal setting and action planning.
- Obtain feedback from patients/family about their healthcare experience and use this information for quality improvement.

Groundwork for Building Partnerships

The groundwork for building partnerships between patients, providers, and care teams lies in respecting patient and family values and needs. The Institute for Patient- and Family-Centered Care defines four core concepts to guide the development of patient-centered interactions:[5]

- Dignity and Respect. Healthcare practitioners listen to and honor patient and family perspectives and choices. The provider and care team incorporate patient and family knowledge, values, beliefs, and cultural backgrounds into planning and delivery of care.
- Information Sharing. Healthcare practitioners communicate and share complete, unbiased information with patients and families in affirming and useful ways. Patients and families receive timely, complete, and accurate information to participate effectively in care and decision-making.
- Participation. The provider and care team encourage and support patients and families to participate in care and decision-making at the level they choose.
- Collaboration. Patients, families, healthcare practitioners, and healthcare leaders collaborate in policy and program development, implementation, and evaluation; facility design; professional education; and care delivery.

Involving patients and families in care improvement requires time and commitment, but pays off in noticeable changes toward a patient-centered culture. Safety net practices have long included patients on boards, but their role on advisory panels is quite different. As board members, patients contribute to decisions about legal, financial, and administrative functions of the practice. In advisory panels, patient members use their experiences of care at the facility to inform decisions about changes to care delivery. Patients may join with other members to develop programs such as patient orientations or take a role in professional education on patient-centered practice. For help involving diverse patients and family members more directly in the planning and delivery of care, refer to resources from the Institute for Patient- and Family-Centered Care.



Case Study: Engaging Patients as Partners in Care and Quality Improvement

Humboldt Del Norte Independent Practice Association, Eureka, CA and California Center for Rural Health Policy (CCRP), Arcata, CA (2012)

In 2006, Aligning Forces Humboldt (a healthcare quality initiative funded by the Robert Wood Johnson Foundation) began a community-wide program called Our Pathways to Health (the local branding for Stanford University's Chronic Disease Self-Management Program). A primary step in initiating work on Our Pathways to Health was recruiting community members with chronic health conditions to become workshop leaders. The program flourished and the cadre of active leaders soon became engaged in additional community improvement efforts. Humboldt launched Primary Care Renewal (PCR), an initiative to improve primary care, in 2008. In 2009, Pathways leaders acted as faculty at PCR meetings to discuss the patient perspective on living with a chronic health condition. When PCR 2.0 kicked-off with a focus on PCMH, recruitment of a "patient partner" team member was a requirement of participation, a foundational shift made possible by the presence of engaged and activated patients (the Pathways leaders) at previous PCR meetings. Aligning Forces Humboldt staff and consumer leadership developed training and tools to support the Patient Partners to be effective voices in improving healthcare delivery.

Patients and family members are engaged in two roles: serving as an advisor to the individual practice and providing collective feedback from the patient perspective on collaborative topics as a group. Betsy Stapleton, FNP, founding member of the Pathways Program, and Jessica Osborne-Stafsnes, Project Manager for Patient Engagement at Aligning Forces Humboldt, serve as guides and liaisons for the Patient Partners, briefing them on issues to discuss at PCR learning sessions. Stapleton and Osborne-Stafsnes compile the responses of Patient Partner group discussions into cohesive reports at PCR meetings.

"The Pathways leaders were wonderful sources of guidance for the project," says Stapleton, "They have had lots of interaction with the healthcare system and years of experience managing their own chronic conditions. They also are able to reflect on the experience of others in the workshops, so they can understand issues of broad relevance." Building on early lessons learned from work with Pathways Leaders, the Patient Partner model of engagement was developed. Participants are called "partners" because of their involvement and role in the quality improvement progress of their respective practices.

While the CDSMP program engages patients in their personal health, the Patient Partners program engages patients in voicing the patient perspective and understanding healthcare delivery. The PCR project engages two Patient Partners per clinical team. Patient partners receive on-going training and support and serve as ambassadors and advocates. The patient partners participate in clinical team meetings, collaborative meetings, and patient partner-only meetings.

Recruitment and integration of Patient Partners into the care teams and practice infrastructure require support from leadership. Physician and administrative leaders actively and visibly endorse patient engagement work. Rosemary DenOuden, Chief Operating Officer at Humboldt, says, "Practices often struggle with the 'fires' of the day, making it difficult to focus on larger constructs such as patient-centered care. The participation of Patient Partners on practice improvement teams keeps the importance of improving patient care at the forefront of discussion."

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The program trains patient partners in quality improvement methods and philosophy, an introduction to medical culture and "medical-ese," the PCMH, confidentiality issues and group dynamics. They provide on-going training, introducing curriculum, updates about the practice, brainstorming, and problem-solving sessions. Encouraging brainstorming sessions during these meetings became an important part of the Patient Partner culture. These sessions engage all members of the group, clarify areas of confusion, and serve as a first step toward topics for further discussion.

Patient Partners are required to attend one team or "practice improvement" meeting every month. Some offices have standing agenda items specifically for their Patient Partners. During these meetings, patients offer insight and work on projects specific to the practice. Projects have included reviewing practice brochures, working on more patient-friendly language, and testing patient portals.

PCR Collaborative meetings start with a standing agenda item to set the tone and prep the Patient Partner for presentation, and then use a varied presentation mode to illustrate patients' perspective. Patient Partners have offered skits or dramatizations of patient experiences to convey their message.

The biggest lessons learned have been:

- Initiate a Patient Partners program with a specific project or outcome in mind.
- Involve Patient Partners early in developing ideas for practice change
- Provide on-going training and support.
- Work with Patient Partners to come up with creative solutions to meet barriers such as transportation.
- Be prepared for learning curves.
- Thread the value of patient involvement throughout the entirety of the work.

In Humboldt, the medical home is the patient's home and ultimately the patient is in control of their care. Patient Partners can be catalysts for transformation when given support to bring their message to the table.



Measurement: Understanding Patient Need and Preference

Practices must clearly understand specific needs of patients to address their needs effectively in the healthcare visit. Understanding patient needs is especially important for safety net practices to serve diverse populations with dignity and respect. This section addresses three categories of patient measures: patient satisfaction, patient experience, and patient activation. The practice can use several methods to find out needed information: patient surveys, asking patients for input at the point of care, focus groups, and walkabouts.

Surveys

Understanding Patient Diversity

Community health centers and other safety net practices serve diverse populations. Collecting data on race, ethnicity, and primary patient language is an important step toward understanding patients. "Valid and reliable data are fundamental building blocks for identifying differences in care and developing targeted interventions to improve quality of care delivered to specific populations. The capacity to measure and monitor quality of care for various racial, ethnic, and linguistic populations rests on the ability both to measure quality of care in general and to conduct similar measurements across different racial, ethnic, and linguistic groups."[6] The Institute of Medicine (IOM) report Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare, issued in 2002, highlights both the evidence showing that racial, ethnic, and language-based disparities remain present in healthcare and the need for data to track these disparities and develop effective programs to reduce and eliminate them.[7] Data can also be a useful tool to:

- Evaluate population trends.
- Ensure nondiscrimination on basis of race and national origin.
- Provide meaningful access for persons with limited English proficiency.
- Ensure availability of sufficient language assistance services.
- Develop appropriate patient education materials.
- Track quality indicators and health outcomes for specific groups to inform improvements in quality of care.



For information on how to collect data, state and national requirements for these data, and issues of accreditation, see the AHA's Equity of Care: A Toolkit for Eliminating Health Care Disparities.

Patient Satisfaction

Many safety net providers, like Federally Qualified Health Centers (FQHCs), are required to regularly measure patient satisfaction. Patient satisfaction surveys are a good start for identifying areas for improvement, but have some limitations. Satisfaction questions assess the match between a patient's expectation of care and whether that expectation was met. Interpreting findings from patient satisfaction surveys is sometimes difficult because patient expectations for healthcare experience differ based on many factors such as age, race, income, and insurance status. If 90% of patients are fairly to totally satisfied with wait time, can a practice determine that the wait time is acceptable? What if an independent quality improvement (QI) team uncovers that the average wait time is several hours? Patients may have wait time expectations much lower or higher than the practice, making interpretation difficult.

Patient Experience

Patient experience measures move away from asking if patient expectation is met and instead ask about what actually happened during the patient visit. Some commonly used patient experience tools are described in Table 1: Examples of Patient Experience Survey Tools on the following pages. Incorporating actionable patient experience questions into practice QI work enables better understanding of patients' needs and preferences.

Thoughts on Collecting Patient Experience Data

- Set realistic expectations for amount of time and effort needed to see results.
- Use tested patient experience questionnaires and make sure to report changes occurring due to patient feedback to patients.

See Appendix B: Selecting and Using Survey Measures for more information about measurement issues.



Patient Activation

Aside from knowledge about healthy choices and skills to make those choices, patients need confidence. Confidence typically comes from experiencing success in health management. Having confidence in one's ability to manage health describes an "activated" patient. Judith Hibbard, health services researcher at Oregon Health Sciences University, developed the Patient Activation Measure (PAM) to measure this level of confidence, as well as knowledge and skills, in managing health behavior. The PAM quantifies activation through a series of questions that put a patient into one of four categories:

- Level 1: Belief that the patient role is important.
- Level 2: Having confidence and knowledge necessary to take action.
- Level 3: Taking action to maintain and improve one's health.
- Level 4: Maintenance or staying the course even under stress.

Hibbard found that 60% of patients feel passive about participating in health and healthcare.[8] Almost one quarter of those completing the PAM demonstrated a lack of ability to manage care, and over a third faced significant barriers in both knowledge and confidence in caring for themselves. Even the 40% who responded that they were able to participate actively in their own care were not confident about their ability to do so in stressful circumstances. Prioritize increasing patient confidence in self-management ability. Increased patient confidence benefits patient, provider and care team, and the practice as a whole.

Table 1: Examples of Patient Experience Survey Tools

Tool Name	Description	Developed by/ Use	Pros	Cons	Copyright/Fee
1. Consumer Assessment of Healthcare Providers and Systems (CAHPS)	Patient experiences with healthcare. Has PCMH, ambulatory care, child, adult, and clinician and group specific surveys.	The Agency for Healthcare Research and Quality (AHRQ). Used primarily by health plans, but increasingly by other groups as well.	PCMH-specific, publicly available, most commonly used patient experience measure. Research validates findings and some data are available about use in underserved populations. Comparative data available.	n/a	Publicly available for free: Click here.
2. Primary Care Assessment Tool (PCAT)	Patient perception of structures and process of primary care, defined as first contact care, person-focused care over time, comprehensive care, and coordinated care.	Barbara Starfield and colleagues from the Johns Hopkins Bloomberg School of Public Health.	Specifically focused on the core characteristics of primary care. Research shows this tool is valid and primary care characteristics may be linked to improved health. Adult, child, facility, and physician versions in both short and long forms are available.	The short version is 12 pages long. Questions are specific to primary care, and may not include all of the elements worth measuring for the PCMH Model of Care.	Publicly available for free: Click here.

Tool Name	Description	Developed by/ Use	Pros	Cons	Copyright/Fee
3. Patient Activation Measure	Knowledge, skills, and confidence of patients as self-managers of their health and healthcare.	Judy Hibbard and colleagues from the University of Oregon. Not condition-specific.	One of the few tools for assessing activation. Many versions available, including one that is only 11 questions.	Costs money to use. Narrow scope.	Must sign contract and pay licensing fee to use. Fees depend on the type of organization requesting its use and the purpose for which the results will be used. Click here.
4. Patient Assessment of Chronic Illness Care (PACIC)	Whether patient experience of clinical care is congruent with the Chronic Care Model.	Russ Glasgow and colleagues at the MacColl Center for Health Care Innovation.	Made up of 20 questions, the PACIC corresponds to the Assessment of Chronic Illness Care (ACIC) that clinics may be familiar with through the Breakthrough Series Collaboratives. Research validates tool. Available in Danish, Dutch, Japanese, Spanish, and large print versions.	Focused on patients with chronic illness, although some have adapted the questions to be more general in nature.	Publicly available for free: Click here.

Tool Name	Description	Developed by/ Use	Pros	Cons	Copyright/Fee
5. Primary Care Renewal Patient Experience of Care Survey	Patient's experience of care as part of a "primary care renewal" redesign, similar to the PCMH Model of Care.	CareOregon (a Medicaid managed care plan) for their multi-lingual FQHC partners.	Developed specifically for and used by safety net practices implementing the PCMH Model of Care. Also available in Spanish, Russian, Chinese, and Vietnamese. Open-ended questions may be helpful for QI.	Not rigorously tested for validity.	
6 Patient Experience Questionnaire (PEQ)	Patient experience.	Siri Steine, Arnstein Finset, and Even Laerum at the University of Stirling.	Short at 18 items, validated and reliable.	Not widely used.	Available as an index in a publication. Click here.
7. How's your health?	Patient care needs.	Dartmouth Medical School.	Easily available online.	Patients must complete online. Does not download into the EHR.	Publicly available for free unless providers wish to test and customize the tools. Click here.

Point-of-Care Data Collection

Applying patient survey information to specific issues or questions can be difficult. A clinic working toward greater visit efficiency may be wondering how to meet patient concerns in a more timely way and may be unsure whether to mail a visit prep form, have the reception staff offer the form when patients arrive, or have the medical assistant spend time asking about patients concerns when rooming patients. This type of redesign can affect quality of experience for patients and clinicians alike. The right answer can save time and increase productivity. Input from the patients and families can help practices uncover the best solution more quickly. Clinical teams that have become experts in asking patient input in care-delivery changes typically use three methods to get information they need:

- Point-of-care data gathered at the time of the visit.
- Patient and family focus groups.
- Patient and family walkthroughs or walkabouts.[9,10]

"Point-of-care" data are collected during or at the end of a visit, usually with a very brief written or verbal question. The visit is still fresh in the patient's mind and the question focuses on a specific area of interest or the general experience of the patient during the visit. Options for point of care data are:

- The medical assistant gives patients a form asking their preferences prior to the visit. Using a team member with whom the patient is familiar to introduce the form is helpful.
- A box in the waiting room for written responses for anonymity.
- A staff member asks, "On a scale of 1–10, how well did today's visit meet your needs?" or "What one thing could we have done to improve your experience?"

Focus Groups

Focus groups are used to answer many types of questions about healthcare delivery, from casual feedback to in-depth, multidimensional issues. Focus groups are advantageous when seeking information from a low literacy population and allow patients and families to engage in a discussion about care, rather than respond to written questions. Many practices formally convene focus groups to provide feedback on larger goals or when teams have a specific goal or question in mind.

Ann Lewis, CEO of CareSouth Carolina, says that her health system finds focus groups so useful that they have become adept at "pulling a focus group together whenever we need patient feedback."

For tips on recruiting for, planning, and executing focus groups, see the materials from the Institute for Patient- and Family-Centered Care. Posing one or more scenarios to help participants focus on the area of interest to the team is useful to set the stage quickly for responses and conversation. Holding focus groups frequently allows repeated input to advise the team on practice changes at various stages of design and implementation. Regular engagement of groups of patients to offer feedback on a particular area of interest to the team, or regular participation of patients and families on quality improvement teams, can lead to development of a fully-fledged advisory group with in-depth expertise in a particular area.

Thoughts on Collecting Point-of-Care Data

- Effective feedback comes from asking patients early and often. Do not wait until there is a draft version of patient materials before asking for input. Bring patients in at the design level as members of quality improvement teams.
- Family members are an important part of the healthcare team as well, and offer valuable perspectives. Include family members in care and advisory capacities.

Patient Walkabouts

One way to gather feedback from patients and families to make care more patient-centered is an exercise exploring care delivery through the patient's eyes. A "walkabout" is an activity used to obtain patient and family perspectives on any number of care delivery experiences, as well as the more general experience of the practice setting. Walkabouts can be as broad as the general experience of receiving care, or as focused as the experience of answering questions from the provider during a visit. Practices have used walkabouts to explore:

- Greeting of patients and families on arrival to the practice.
- The processes of care and exchange of information in the administrative (e.g., billing, appointments) and ancillary areas (e.g., lab, pharmacy).
- The processes of care and exchange of information during a visit and exam.
- Patient forms and educational materials (or other materials patients may receive or need to fill out as part of a visit).
- Characteristics of the physical environment (e.g., signage, artwork, color, lighting, visible equipment, and arrangement of furnishings).
- Public materials (e.g., posters, magazines, announcements).

The idea is to accompany and record perceptions of the care experience through the patient's eyes. Collect evidence by assigning one or more members to document the walkabout through:

- Digital photos, slides, or videotape.
- Notes from observation of simulated patient visit and exam.
- Patient response to forms, educational materials, messages on posters, and other announcements.

Patient-Centered Communication

Effective communication is the heart of patient-centered interactions, yet care teams frequently feel they lack the time and training to communicate effectively. Clinicians may be unaware of patient concerns and redirect patient comments at the beginning of a visit, and often give patients less than 30 seconds to tell their story.[11] During the visit, the provider and care team may not involve patients in decision-making about care or express empathy for patient concerns. Patients may not feel engaged in their own care and health, which results in patients remembering less than half of clinical recommendations.

Particularly in community health centers, patients have diverse social, cultural, and linguistic backgrounds. Communication challenges abound in healthcare due to cultural differences. Studies have repeatedly demonstrated differences in quality of care among racially diverse patients due to occupation, income, education, acculturation, English language proficiency, and national origin differences.[12] Numerous studies document that racial and ethnic minorities often receive lower quality care than non-minority whites. Studies also document differences in patient experience and perception. For example, Latino parents report more often than parents of other ethnicities that providers "never" or "only sometimes" understand their child's needs.[13] Data on race, ethnicity, and primary language are often unavailable or incomplete and thus meeting language need is difficult.[7] This section offers a framework to improve communication with all patients and specifically with patient populations from cultural backgrounds different from the provider and care team.

By eliciting and prioritizing patients' concerns at the start of the visit, healthcare providers begin a collaborative dialogue to engage patients in their care. This agenda setting and prioritizing process is described in Have you really addressed your patient's concerns?[14] Establishing rapport and expressing empathy, offering information in an accessible way, and using teach-back techniques to assess communication effectiveness are additional techniques covered in the section on self-management support.

Cultural Competency

Culture, a shared system of values, beliefs, and learned patterns of behavior, is shaped by multiple factors including neighborhood, education, income, gender, age, and sexual orientation.[15] To understand the role of a patient's culture in a medical encounter, the provider must first recognize that his/her own biomedical view of disease and illness may not coincide with the patient's view. Failure to uncover and address cultural differences in beliefs about illness cause and cure can lead to miscommunication and misunderstanding, with effects ranging from mild discomfort to lack of trust and inability to accomplish treatment regimens. *The Spirit Catches You and You Fall Down,* the story of conflict and misunderstanding between the Hmong and medical community regarding a Hmong girl's epilepsy, demonstrates the danger of non-patient centered interactions.[16] The Hmong community believes epilepsy to be primarily spiritual while the healthcare providers adhere to a medical model of disease. This difference in perception results in mutual distrust and poor health outcomes. One of the first tasks for a provider in a cross-cultural encounter is to elicit the patient's perspective. This step is necessary to negotiate a diagnosis and treatment regimen with the patient and, when appropriate, his or her family.

In a study on asthma, practice sites that emphasized and trained staff to be more culturally competent had patients who were more likely to take appropriate asthma medication, demonstrating the importance of recognizing cultural differences.[17]

See the corresponding tool: Eliciting the Patient's Perspective for an index of questions to elicit a patient's view of illness, social context, and expectations for care. The healthcare team should work toward a mutually acceptable agreement on diagnosis and treatment plan with the patient and family. The first step is presenting a diagnosis of the patient's condition involving the biomedical model and aligning the biomedical model with the patient's own views as much as possible.

- Describe the treatment plan in terms of priorities and options. Incorporate the patient's priorities into the treatment plan as much as possible to maximize adherence. If conflicts remain, focus on the highest priority aspects of the treatment plan that are acceptable to the patient.

Health Literacy

Regardless of racial and cultural background, more than a third of patients have limited health literacy, resulting in misunderstanding, poor management of chronic disease, poor ability to understand and adhere to medication regimens, increased hospitalizations, and poor health outcomes.[18]

Health literacy is a special subset of literacy and defined by the U.S. Department of Health and Human Services as "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[19] The first step in improving care for those with limited health literacy is clear oral communication. Health literacy can be measured using tools from AHRQ, currently available in English and Spanish in short (seven items) and long form (50 items).[20] AHRQ also provides instruction on how best to communicate with patients with varying degrees of health literacy.

The Agency for Healthcare Research and Quality (AHRQ) Health Literacy Universal Precautions Toolkit[18] notes that patients have difficulty understanding health information communicated orally during patient-clinician interaction. Patients understand and retain only about 50% of the information discussed by their physicians.[21,22] Lack of understanding has an enormous impact on patient safety and adherence. Those with limited health literacy are less likely to:

- Ask questions during the medical encounter.[23]
- Seek health information from print resources.[24]

Strategies for respectful and effective patient communication include:

- **Warm greeting:** Greet patients with a smile and a welcoming attitude.
- **Eye contact:** Make appropriate eye contact throughout the interaction.
- **Plain, non-medical language:** Use common words when speaking to patients. Take note of what words patients use to describe illness and use those same words in your conversation.
- **Slow down:** Speak clearly and at a moderate pace.
- **Limit content:** Prioritize items needing discussion and limit information to three to five key points.
- **Repeat key points:** Be specific and concrete in your conversation and repeat key points.
- **Graphics:** Draw pictures, use illustrations, or demonstrate with 3-D models.
- **Patient participation:** Encourage patients to ask questions, be involved in the conversation during visits and be proactive in their healthcare. For guidance on how to encourage patients to ask questions see the AHRQ Health Literacy Universal Precautions Toolkit.
- **Teach-back:** Confirm that patients understand what they need to know. Ask patients to "teach back" care instructions to the provider. The teach-back method, also known as "show-me" or "closing the loop," is a way to confirm that the provider and care team have explained to the patient what they need to know in a manner that the patient understands. Understanding is confirmed when the patient explains back instructions. For tools and resources on learning and using this method, see the AHRQ Health Literacy Universal Precautions Toolkit.

Additional resources in the Health Literacy Universal Precautions Toolkit include sections on providing clear written materials, telephone system considerations, and culture considerations.



Case Study: A Focus on Cultural Competency for Immigrant Populations

Squirrel Hill Health Center, Pittsburgh, PA (2012)

Squirrel Hill Health Center, located in Pittsburgh, Pennsylvania, is dedicated to providing high quality care to all clients. The Center was founded in 2006 with the mission of caring for older adults, refugees, immigrants, and anyone with cultural or financial barriers to care. The health center is the preferred provider for two refugee resettlement agencies located in Pittsburgh. "These patients and families come to us during the extremely difficult and trying time of starting anew in an unfamiliar place," says Meghan Powers, Program Coordinator for the health center.

Language issues are just part of the problem, as about one-third of the patients speak a primary language other than English and about 13% of the patient population are refugees. Spanish and Nepali make up the majority of non-English language use. Andrea Fox, Medical Director, says, "Recently, over the last 18 months or so, we have seen a large refugee population from Nepal. Many of the younger refugees speak English, but the older population, especially women, speak Nepali." The education level is also relatively low as many refugees do not read and most are unfamiliar with Westernized medicine. "Knowledge about preventive care, keeping appointments, getting refills for medication or knowing how and when to take medication is quite limited. Many of our patients are unaware that medication and treatment for a chronic disease needs to be continuous," says Fox. Communicating the importance of chronic disease management and medication adherence is especially important, as all new refugees to the United States are required to have a TB screening and many test positive for latent TB. Treatment consists of nine months of medication that is very time-consuming and frustrating for patients. Behavioral health issues also contribute to the disease burden of this refugee population as "many patients also have other conditions that may be chronic and patients can become overwhelmed."

To communicate with non-English speaking patients, the health center uses a mix of bilingual staff, in-person interpreters, and a telephone language line. "Unfortunately the language line service is fairly expensive and also causes our visits to last twice as long. Due to language needs, we can't always schedule people as quickly as we would like. However in the absence of an in person interpreter, the language line is preferable to using a family member who may be uncomfortable talking about personal medical issues," says Powers.

Furthermore, Powers and Fox report that Pittsburgh does not yet see itself as a culturally diverse place. Squirrel Hill has come to be seen as knowledgeable in culturally appropriate communication by area clinics and hospitals. Says Fox, "We often get calls from other clinics or hospitals asking to send our translators to them. We hear people say they do not know how to talk to these people. You have to keep in mind that any one group of people from a country is not all the same. They don't have all the same beliefs and you have to spend time figuring out what this person wants." However, the two also attribute the high rate of secondary migration, refugees who have previously settled in another U.S. location, to the communities and opportunities Pittsburgh provides.

Squirrel Hill has recently received a grant that will support a large part of work with refugee populations. "This grant will support our mobile unit that travels to areas of Pittsburgh with large refugee populations, allow our primary care providers to spend more time with patients who are refugees, and support training of 'cultural translators' who are refugees themselves wanting to educate and support our patient population. Working with a large refugee population is especially difficult as the population is continuously changing based on what groups are being resettled. We need a model of care that would work for any population," says Powers.

Powers and Fox say that their staff has learned together, and are continuously learning how to provide more culturally competent care. Fox attributes some of this success to the diversity of the staff and says, "We come from all over the world and speak multiple languages. Currently we have staff that speak Spanish, Russian, Hebrew, Arabic, Nepali, and American Sign Language. We learn about the culture of our patients through the eyes of all different cultures. All of us every day learn something new. It is a very stimulating place to work, very vibrant."

Self-Management Support

Effective communication is central to patient-centered care for all patients, all of the time; but specific communication skills and tools are crucial in helping people engage in the challenging work of maintaining healthy behaviors. Even the healthiest among us benefit from eating wholesome foods, being physically active, and regularly receiving recommended preventive healthcare services. Actively engaging in healthy activities and effective management is critical for those with chronic conditions. However, the Center for Advancing Health (CFAH) recently found that most people are not benefiting from healthy behaviors or available healthcare.[25] The average person is consistently engaged in healthy behaviors, including exercise and consuming a healthy diet, only about one-third of the time. Low health literacy, lack of education, poverty, advanced age, and cultural background increase the challenge of participating in healthy behaviors.

We all self-manage. It's how well we self-manage that makes the difference.[26]

Managing conditions like asthma, diabetes, and depression day-to-day requires skill and confidence. Chronic conditions deeply alter daily life and challenge patients to retain relationships and activities that make life meaningful. Managing medical treatments and navigating a disjointed healthcare system adds to the burden of a chronic condition. Success in managing chronic illness depends as much on what the patient does as on the actions of the healthcare team. Chronic Disease Self-Management Program creator Kate Lorig, RN, DrPH, professor at Stanford University School of Medicine, says, "We all self-manage. It's how well we self-manage that makes the difference."[26]

Implementing Self-Management Support

Patient-centered care goes beyond clinical services to interventions supporting health behavior change. Unfortunately, healthcare providers rarely receive training on collaborative and empowering interactions with patients that support self-management. Empowering interactions help providers, care teams, and patients collaboratively set a visit agenda. They also acknowledge patients' positive health behaviors and involve patients in decisions about care.

Training on patient-centered communication is an important first step to transform the clinical visit. Using tools such as the Patient Centered Observation Form training materials developed by Larry Mauksch, MEd at the University of Washington, Department of Family Medicine, can help providers receive effective feedback about the skills needed in a clinical encounter, reflect on their own practice and try new methods.

Care teams can also use techniques such as motivational interviewing to support patients to take better day-to-day care of themselves. Tools on motivational interviewing can be found here. For a video on how to conduct a brief motivational intervention, click here.

Core competencies for enhancing self-management support are:

- Asking patients' needs, expectations, and values.
- Sharing information clearly and checking for understanding.
- Collaboratively setting goals.
- Making action plans that help patients achieve their goals.
- Assessing barriers and problem solving.
- Ongoing follow-up.

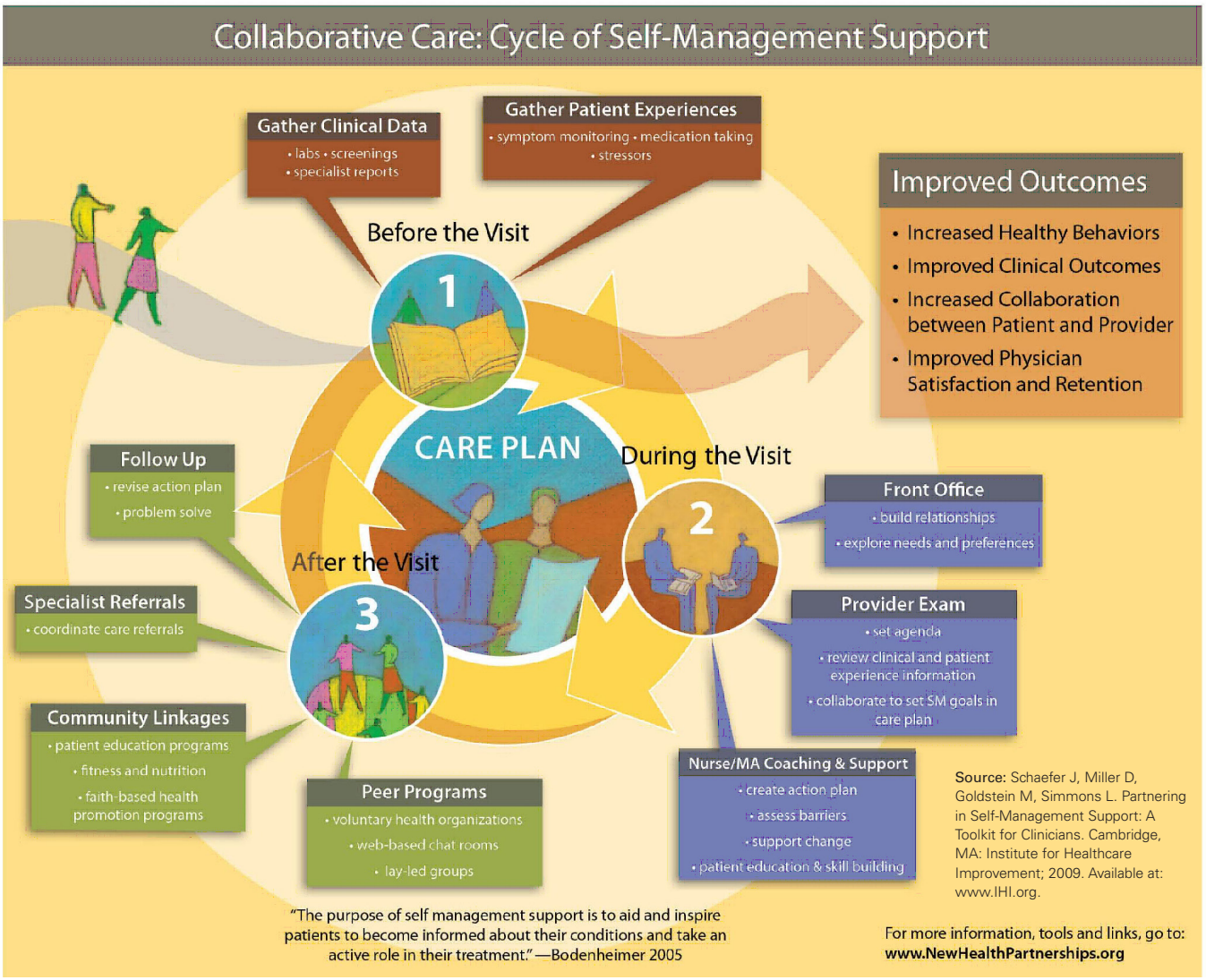
Implementing Self-Management Support in a Care Team

The pressures of a busy practice may make patient-centered interactions difficult. Key points to streamline workflow and make time for patient-centered interactions are:

- Utilize the entire team in self-management support tasks.
- Prepare by collecting clinical and patient experience information before the visit.
- Utilize effective, brief motivational interventions to support self-care.
- Connect patients with community resources that can actively help manage daily health.
- Document the care plan in an after visit summary and provide a copy for the patient.

The Cycle of Self-Management Support below shows how repeated brief motivational interventions targeted at patient-identified goals can improve health behaviors and outcomes and lead to better collaboration and satisfaction for patients, families, and the healthcare team. For a toolkit with links to many self-management tools, click here.

Figure 1: Collaborative Care: Cycle of Self-Management Support



Organizing the Patient-Centered Visit

Before the Visit

Preparing for a patient visit creates time and space within the visit to build and maintain relationships central to self-management. Health coaches, medical assistants, or front office staff can work from standing orders to ensure that tests are completed and the results are available to discuss in the visit and all necessary information is on hand ahead of the scheduled visit.

Conversations about goals and activities for healthy behaviors flow more easily if practices help patients prepare for visits. Patient experiences and concerns can be gathered in advance through mail or waiting room distribution of forms such as the Patient Activation Measure or "Ask Me Three."[27] These pre-visit forms help patients form questions to ask their providers and remind patients to bring needed information to the visit. "How's Your Health" is a web-based tool patients can access at home at their convenience and print out to bring or email to their providers.

Tips for visit preparation:

- Inform patients that the practice is working to improve care delivery and that the visit may be somewhat different. Patients feel more comfortable when they know what to expect. Asking patients to prepare in advance for their visits acknowledges the important role patients play.
- Use posters in the waiting room to tell the stories of patients on their way to successful self-management. Involving patient and family advisors in medical home implementation process is a good place to begin.
- Consider administering a depression-screening tool before the visit as standard care for patients with chronic conditions. One of the most commonly used depression screeners is the Patient Health Questionnaire-9 (PHQ-9), consisting of 9 questions about depression or the shorter two-question PHQ-2, used as the initial screening tool for major depression, both available here in multiple languages for no cost. Refer to the MacArthur Foundation Initiative on Depression and Primary Care Depression Tool Kit for further information.
- Ask patients to bring medication lists or the medications themselves, as well as questions and results of any monitoring they have done on symptoms or glucose testing if diabetic.

During the Visit

Change happens in small steps. Clinical teams can gradually help patients build skills and confidence in ability to manage their condition daily over a series of interactions. These same tools and skills are effective in preventive care to help healthy patients stay healthy. The 5A's of behavior change Assess, Advise, Agree, Assist, Arrange describe the steps during the visit to arrive at a personal action plan that can be used by the patient and family to effectively manage chronic conditions at home.



The 5 A's for Self-Management Support[28]

For a diagram and detailed instructions on how to integrate the 5 A's at the patient level, office environment, and community/policy level, click here.

1. Assess: Experiences, Beliefs, Knowledge, and Confidence

A visit preparation or assessment form completed by the patient before the visit can pave the way to building a shared agenda. Reviewing the form opens the conversation with patient concerns and experiences that have developed since the last visit. Patients have differing levels of readiness for changing health behaviors, and may be more ready to take action on a healthier diet than on quitting smoking. Focusing on a patient-identified health goal—something the patient wants to do—is more effective than mandating a certain change. Patient desire brings energy for change.

2. Advise: Sharing Information

As a clinician concerned about your patient's health, you will want to offer information and provide advice about treatment. Those concerns and recommendations may be better understood by patients and family members if you use techniques such as "Ask-Tell-Ask" from the Motivational Interviewing methods and "Closing the Loop" to guide the conversation. Asking permission to offer information, giving information specific to that topic, and then asking for understanding helps ensure that you have provided information in ways patients can use when they try to apply it at home. Offering tailored information based on a patient's own values or other clinical information makes information more accessible, and shared decision-making tools help present information in ways that facilitate collaborative decisions for some conditions. Patients who are good self-managers may keep data from self-monitoring of blood pressure, blood glucose, and oral anticoagulation agents. Conversations about self-management based on these records can help patients adapt regimens at home.

3. Agree: Collaborative Goal Setting

Studies of effective interventions to promote better self-care are mixed, but one clear finding is that providing information is necessary, but not sufficient. Collaborative goal setting is one way to connect clinical concerns and treatment planning of the clinician to patient priorities and preferences. Starting the visit conversation around goal setting and collaborating with the patient to arrive at agreed upon areas for treatment or change is useful. Patients may find it daunting to carry out complex treatment plans, especially in challenging circumstances. Encouraging patients to identify their own goals and supporting their choices whenever possible will help to ensure the successes upon which further change is possible. Clinicians might offer a menu of options to consider in defining goals.

Every practice has patients not ready for goal setting and action planning. If patients are not ready to take a more active role in their health, the best strategy is often to acknowledge the difficulty of managing a chronic condition and focus on what they have accomplished, even the fact that they have come in for the visit. This does not mean you are taking a passive role. You are expressing empathy and keeping the doors of communication open.

4. Assist: Action Planning

Often goals are helpful but cannot be achieved all at once. Providing patients assistance in thinking through how to achieve their goals can make a major contribution. Goals can be set for the next three to six months, but action plans are most helpful for periods of one to two weeks. Action plans determine small steps toward a goal and specify more precisely what, how, when, and where actions will take place and anticipate any barriers to attaining goals. Many of us don't have or use these skills, but care team members can learn to use them in a coaching and support role, and transfer the skills to patients over time. Action-planning forms provide a template for the health coach, medical assistant, or other team member to outline steps to follow in the process. Consider talking patients through the form as they plan. Make sure patients take the form, or a copy of it, as they leave the clinic as a reminder and guide. Document patients' goals and plans in the medical record so that the team can follow up on the plans in the future.

Steps to an effective action plan:

1. Base the plan on a patient-defined, collaboratively set goal: something the patient WANTS to do.
2. Make it behavior specific, e.g., "walking," not "increasing exercise."
3. Define specific steps: what, where, when, and how much or how often.
4. Anticipate barriers.
5. Assess the patient's confidence in completing the plan and adjust if low.

Goal setting and action planning can be done very effectively in group medical appointments, also known as group visits, or in group educational settings. Done in groups, action planning allows patients to hear about others' ideas and plans, see the process multiple times, and offer mutual support. Assessing confidence about completing the plan and anticipating barriers in the group setting are activities that generate active and helpful conversations among group members.

5. Arrange: Follow-Up and Links to Community Resources

The best time to plan for follow-up after a visit is during the visit. Setting up a follow-up call as part of the action plan is a wise choice, setting the expectation with the patient and finding a workable time.

Communication technique training, motivational interviewing, or other brief motivational skills help providers use open-ended questions to elicit patient experience, beliefs, and attitudes. "Ask-Tell-Ask" and "Closing the Loop" techniques improve information sharing so that clinical advice is directed at issues of central importance to patients and confirm that they understand and know how to use information to manage care when they get home.

Tips during the visit:

- Acknowledge and document what patients are already doing to manage their health. Help patients understand the benefits of active management and provide tools to do so.
- Provide guidelines for optimal care so patients and families know what to expect.
- Implement group medical appointments and group educational settings to provide an opportunity for patients and families to learn from and be inspired by the experience of others.
- Explicitly invite and involve family members and caregivers in the visit whenever possible. Family members and caregivers can be powerful agents for and sometimes barriers to change.
- Involve every primary care team member in helping patients take charge. Hearing empowering messages consistently from team members increases the dose of self-management interventions.
- Provide a care plan or after visit summary documenting collaborative decisions made during the visit to serve as a reminder of steps patients should take.

After the Visit

Follow-up on Action Plans. Even the best action plans can require course-correction. Medications may produce side effects or not produce the desired effect, requiring further support and explanation or alterations. Unexpected barriers to completing the plan may arise. For all of these reasons, regular contact with patients after a visit or change in treatment helps sustain positive change. Studies on depression, and diabetes, in particular, document the need to follow-up with patients to assist with action-plan success, particularly in adjustment of medication changes.

Many teams suggest a brief call to review and problem-solve issues arising for the patient in completing their action plan, as well as monitoring changes in treatment or medication regimen. The health coach, whether a medical assistant, nurse, social worker or community health worker, frequently makes follow-up calls. Coverage of the health coach time from other flow activities for one to three hours per week is often sufficient. Using a brief version of the 5 A's and open-ended questions, the coach can elicit problems and use problem solving techniques to help the patient adjust and revise their plan. Coaches offer support, normalizing what patients may consider failures, and acknowledge successes.

Make Effective Community Referrals. Community resources for self-management support provide convenient access and increase the likelihood of success since patients are learning about their condition with and from people like themselves. Programs like the YMCA Diabetes Program or **Self-Management Resource Center's Chronic Disease Self-Management Program are** offered in many communities. Holding culturally competent programs in community settings encourages participation and increases satisfaction, particularly among minority populations. Clinic/community partnerships offering programs can promote self-management more comprehensively and seamlessly than any one organization could do alone. Partnerships sponsoring activities such as year-round walking programs and farmers' markets also help individuals access these resources at the community level.

In addition to building referral resource guides for patients to identify help in the community, some healthcare systems are developing ongoing relationships with community agencies to fill gaps in services. Community-based *promotoras* and other community health workers do outreach and provide group self-management support. Partnerships with community agencies extend programs to meet the needs of specific populations.

Tips for effective community referrals:

- Feature only trusted sources in resource guides for patients and update regularly.
- Establish a person-to-person relationship with a representative from the community referral organization and "extend" the relationship to the patient in a warm handoff.
- Designate a community resource liaison within the practice to keep relationships healthy and active.
- Make in-service presentations to inform providers about quality community resources and what specific populations will benefit from the referral.

From the Patient's Perspective

For Mrs. Mendez, diagnosed with diabetes six years ago, a visit to her doctor was something she needed to do periodically to get prescriptions renewed. She liked Dr. Lowry, who was pleasant and always asked after her family, but for the last few appointments something in the office had changed. She felt Dr. Lowry was taking more of an interest in her. Several months ago, she received a call from Dr. Lowry's assistant, Phyllis, to schedule a diabetes appointment. Phyllis asked her to come in to get her lab tests done before the appointment and sent her a form asking about her concerns and questions. Thanks to the form, Mrs. Mendez remembered to bring up the arthritis pain she was worried about. It was so bad lately, she was afraid to take the regular walks she enjoyed.

When she saw Dr. Lowry, she reassured her that walking was good for her arthritis and helped keep her blood sugars under control, and that decreased exercise could help explain the higher blood glucose levels she was experiencing. Dr. Lowry asked Mrs. Mendez about taking pain medication before exercise and they discussed the benefits. At the end of their visit, she encouraged Mrs. Mendez to work with Phyllis to make a plan to include regular exercise in her routine, and explore resources in the community to support a more active life. Phyllis helped her complete an action plan form for her exercise goal. It included walking and an idea to explore the water aerobics classes in the community. At the end of the visit, Phyllis printed out an after visit summary that included information about pain medications Dr. Lowry discussed, Mrs. Mendez' exercise action plan, and contact information for the water aerobics class. Mrs. Mendez left the office thinking about inviting her neighbor to go with her next Tuesday.

Conclusion

Improved patient care is at the heart of the Patient-Centered Medical Home Model of Care. Collaboration between providers and care teams and patients and families is required to meet the care needs of all patients whether they have a chronic illness, an acute need, or are seeking regular prevention services. Measuring patient experience, interpreting the results, using effective communication techniques, and engaging patients in their healthcare through self-management support are all essential for building strong partnerships and empowering patients. Strive to engage patients in their healthcare and use proven tools to improve patient communications. Using available tools and techniques described in this Guide facilitates collaboration and builds lasting partnerships with patients and their families, leading to healthier, more satisfied patient populations.

Additional Resources

Involving Patients and Families in Their Care

Tools

Patient-Centered Care Improvement Guide
This guide from the Picker Institute and Planetree, Inc describes the strategies to implement patient-centered care.

Patient-Centered Care: What Does it Take?
This report from The Commonwealth Fund describes the goals, key attributes, contributing factors, and strategies for leveraging change to make a care patient-centered.

The Stoeckle Center of Massachusetts General Hospital
This website of the Stoeckle Center of Massachusetts General Hospital provides resources for patient experience of care by topic.

The Patient Engagement Framework
The Patient Engagement Framework is a model created to guide healthcare organizations in developing and strengthening their patient engagement strategies through the use of eHealth tools and resources.

Institute for Healthcare Improvement
The Institute for Healthcare Improvement offers many tools to facilitate patient-provider communication including, My Shared Care Plan, Patient- and Family-Centered Care Organizational Self-Assessment Tool, and Words of Advice: A Guidebook for Families Serving as Advisors.

Institute for Patient and Family-Centered Care
The Institute for Patient and Family-Centered Care offers a variety of tools for both inpatient and outpatient settings. Recommended tools include, Patients and Families as Advisors in Primary Care: Broadening Our Vision, Sharing Personal and Professional Stories, Staff Liaison to Patient and Family Advisory Councils and Other Collaborative Endeavors, and Wearing New Glasses: Seeing Self-Management from the Patient and Family Perspective.

Measurement

Tools

CAHPS
The Consumer Assessment of Healthcare Providers and Systems (CAHPS) program is a public-private initiative to develop standardized surveys of patients' experiences with ambulatory and facility-level care. Healthcare organizations, public and private purchasers, consumers, and researchers use CAHPS results to: Assess the patient-centeredness of care; compare and report on performance; and improve quality of care.

MAPI Research Institute
MAPI Research Institute is a non-profit international health outcomes organization established to support and promote research in the field of Health-Related Quality of Life (HRQoL). The Institute has particular expertise in cultural adaptation and linguistic validation of questionnaires, helpful instrument pages, a widely distributed newsletter, and useful links.

Articles

Maoulin R, Merten SL. Tools to evaluate the pediatric patient- and family-centered medical home. National Center for Medical Home Implementation. 2010. Available here.

Stewart AL, Napoles-Springer A. Health-related quality of life assessments in diverse population groups in the United States. *Med Care*. 2000;38(9):102-24.

Vrijhoef HJ, Berbee R, Wagner EH, Stuten LM. Quality of integrated chronic care measured by patient survey: identification, selection and application of most appropriate instruments. *Health Expect*. 2009; 12(4):417.

Communication and Self-Management Support

Tools

Helping Patients Manage Their Chronic Conditions
This tool is a primer on self-management support, providing basic skills, including examples of scripted phrases to help clinicians engage in behavior change conversations.

Partnering in Self-Management Support: AToolkit for Clinicians
A comprehensive guide from the Institute for Healthcare Improvement about communication techniques and implementation strategies for self-management support in primary care that includes links to tools and resources such as action plans and trainings.

Ultra-Brief Personal Action Planning (UB-PAP)
This outlines the steps of a brief motivational interaction to develop an action plan.

Primary Care Resources and Supports for Chronic Disease Self Management (PCRS)
The PCRS is a quality improvement tool for use by patient care teams in primary care to improve self-management support. Use this tool to assess and build capacity for self-management support and monitor progress toward improvement.

Videos

Video on Coaching Patients for Successful Self-Management
This video discusses how to develop an action plan to support healthy behavior change, and how to ensure patients are taking medications appropriately. Patients are coached on the skills they need to be active participants in their own care.

Articles

Denmark D. Patient-physician partnering to improve chronic disease care. *Fam Pract Manag*. 2004 May;11(5):55-56. Available here.

Cultural Competency

Tools

Reducing Racial and Ethnic Disparities: Quality Improvement in Medicaid Managed Care Toolkit

This toolkit details the experiences of a collaborative workgroup of Medicaid managed care organizations, Improving Healthcare Quality for Racially and Ethnically Diverse Populations. The workgroup was directed by CHCS and funded by the Robert Wood Johnson Foundation and The Commonwealth Fund. This online toolkit provides information on how to collect data accurately and use it effectively. It provides case studies, self-assessment tools, and staff training information.

Toward Culturally Competent Care: A Toolbox for Teaching Communication Strategies

This curriculum teaches the skills and knowledge to help health professionals provide culturally competent care. At the end of training, participants will be more effective in eliciting accurate clinical information and providing appropriate care to their patients, regardless of their cultural background. Providers also learn how to work with medical interpreters and acquire new approaches to addressing cultural differences.

A toolkit provides information on how to collect data accurately and use it effectively. It provides case studies, self-assessment tools and staff training information.

The Cross Cultural Healthcare Program

The Cross-Cultural Healthcare Program's primary goal is to improve the healthcare of communities that face linguistic and cultural barriers to receiving health services. The CCHCP develops training programs for healthcare providers and for medical interpreters, provides a central resource center, and works with underserved communities and institutions to change policies and procedures that create barriers to care.

EthnoMed

EthnoMed contains information about cultural beliefs, medical issues, and related topics pertinent to the healthcare of immigrants to Seattle or the US, many of whom are refugees fleeing war-torn parts of the world.

CDC Immigrant and Refugee Health

This site provides information about medical examinations, health guidelines, laws, and regulations.

National Center on Minority Health and Health Disparities, National Institutes of Health

The NCMHD promotes minority health and leads, coordinates, supports, and assesses the NIH effort to reduce and ultimately eliminate health disparities. NCMHD conducts and supports basic, clinical, social, and behavioral research; promotes research infrastructure and training; fosters emerging programs; disseminates information; and reaches out to minority and other health disparity communities.

National Center for Cultural Competence

Part of the Georgetown University Center for Child and Human Development University Center for Excellence in Developmental Disabilities, this site provides provider and practice assessment tools, a resource database, and further links in the field of Cultural Competence.

Literature

Betancourt JR, Green AR, Carillo JE, Park ER. Cultural competence and healthcare disparities: key perspectives and trends. *Health Affairs*. 2005;24(2):499-505.

Borra R. Working with the cultural formulation in therapy. *Eur Psychiat*. 2008;23(suppl 1):43-48.

Carillo JE, Green AR, Betancourt JR. Cross-cultural primary care: a patient-based approach. *Ann Intern Med*. 1999;130(10):829-834.

Kleinman A, Eisenberg L, Good B. Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research. *Focus*. 2006;4(1):140-149.

Kodjo C. Cultural competence in clinician communication. *Pediatr Rev*. 2009;30(2):57-63.

Powers BJ, Trinh JV, Bosworth HB. Can this patient read and understand written health information? *JAMA*. 2010;304(1):76-84

Saha S, Fernandez A. Language barriers in healthcare. *J Gen Intern Med*. 2007;22(suppl2):281-282.

Interpreter Services

Addressing Language Access Issues in Your Practice: A Toolkit for Physicians and Their Staff Members
This toolkit from the California Academy of Family Physicians and CAFP Foundation presents a systems approach to re-designing your office practice to provide high quality care to patients who speak limited English.

Providing Language Services in Small Healthcare Provider Settings: Examples from the Field
This paper from The Commonwealth Fund includes an 8-step plan to help providers develop a strategy to meet the needs of their patients with limited English proficiency and the community.

Appendix A:

Patient-Centered Interactions and Health Information Technology

Jeff Hummel, Peggy Evans, Trudy Bearden, and Michelle Glatt
Qualis Health

This addendum is supplemental to the primary Patient-Centered Interactions Implementation Guide.

Poorly implemented electronic health records (EHRs) can become a barrier to patient-centered interactions, particularly if providers focus attention predominantly on the computer, leaving patients to feel like extraneous onlookers. But when implemented wisely, EHRs support new levels of patient-centered interactions. This requires a commitment to increasing the amount of control patients are given over their healthcare. HIT can enhance shared decision-making by helping patients understand the information on which decisions are based, connecting patients to resources for self-management support, and communicating with the care team in a culturally appropriate environment. The goal must be to use HIT to honor the desire of each patient to receive "the care I need and want, exactly when and how I need and want it."[29] This addendum presents tips and strategies for using HIT to support and enhance patient-centered interactions.

Place patients at the center of clinical decisions. For preventive care and chronic disease management, many clinical decisions are grounded in evidence-based guidelines prescribing which interventions are needed and at what time. Many of treatments for chronic illness are also largely protocol driven. When primary care providers and the care team help patients understand these protocols and their supporting evidence, patients have an easier time participating productively in their care.

To establish a diagnosis, clinicians use a combination of decision pathways and community standards filtered through their experience, pattern recognition, and intuition to create a list of possible diagnoses. These possible diagnoses are then narrowed down based on tests and patient response to therapy. The key to patient-centered interactions is to make diagnostic or treatment options and supporting information as transparent as the patient would like. Part of the art of medicine is the ability to figure out in a given situation how much information a patient wants when the patient does not know which questions to ask. Inherent in patient-centeredness is the principle that patient choice trumps evidence-based medicine.

There are a number of specific ways that care teams can use HIT to encourage and support informed patient engagement in clinical care.

- Optimize how HIT hardware is set up in exam rooms to be as inclusive of patients and caregivers as possible. Seat provider and patient so both can easily look at one another and at the computer screen together. Visit documentation completed in the exam room during the visit takes less take time and is more accurate than chart notes completed later. Few providers have the keyboarding skills required to write a history while maintaining eye contact with a patient telling their story, but there are techniques for using a computer while focusing on the patient.
    - Begin the visit maintaining full eye contact for several minutes while establishing the agenda.
    - When documenting in the computer ask, "Do you mind if I make take notes now so I don't forget anything you're telling me?"
    - Explain frequently to the patient what you are doing rather than silently working at the user interface.
    - Turn the monitor so the patient can see notes and orders as they are created. The screen should be large enough for patients to easily see their record and the information about them as it is entered.

- Configure clinical decision support (CDS) to help patients understand what the information means. Graphs are better for displaying trends than tables or dashboards. Give information from the EHR to patients. Include information that the patient collects at home in the EHR.
  - Consider giving patients a "pre-visit summary" including preventive and chronic illness issues highlighting any differences between evidence-based recommendations and their status (e.g., blood pressure, weight and smoking status, eye exams). This information should also be clearly visible on the patient portal.
  - As much as technology allows, incorporate information from home monitoring devices or mobile applications into patient records and merge it with other EHR data in graphic displays, particularly for parameters responding to patient behavior and medication changes such as weight, blood pressure, or glycemic control.
- To the greatest extent possible, customize educational material to maximize its relevance to individual patients. Include visual displays in educational materials to help patients understand them. Materials should be easily accessible both at the point-of-care for the clinician to review with the patient and later to the patient through a portal.
- All patient information materials need to be reviewed by patients during their design to make sure that they will be of maximal utility to patients (e.g., clinical summaries, dashboards, graphs, and care plans that can be taken home and modified by the patient or the family if necessary).

To engage the whole care team in patient-centered communication, and to enhance continuity during follow-up with patients over time, patient goals and plans should live in the medical record. Providing an after visit summary, that includes collaborative decisions made during the visit along with action planning steps, helps patients and families remember and follow through on important care decisions and lifestyle changes.

Support communication between the care team and their patients. Use HIT to make communication easier. The most important technologies currently widely available for communication are EHR portals, asynchronous secure messaging (ASM) including texting from mobile devices, and the telephone. Use will depend largely on patient preference.

- Medical advice. Patients contact their care teams asking, "what do I do?" about a wide range of topics, many of which include a high level of anxiety. The care team must separate advice requests into those requiring a visit and those that do not.
  - Telephone. The goal for telephone advice calls is to answer the question the first time the patient calls. Staff, including providers, can be made available to answer advice calls at times they are most likely to occur. Technology can link the phones of advice nurses on different care teams so that if one is already on a call, a new incoming advice call can be routed to another who is free. Advice calls are an opportunity to update the patient medication lists and medication allergy lists.
  - Asynchronous secure messaging. Advice requests received via ASM are similar to telephone advice calls, but the medium of asynchronous communication denotes a lower expectation for an immediate answer. The care team should agree on a protocol for handling messages that route requests directly to the most appropriate care team member as quickly as possible. ASM is suited for simple questions and clarification of issues discussed at a recent visit. The amount of information carried in a typed message is significantly less than in a telephone conversation, and the potential for miscommunication is significant. Care team members should agree on criteria for switching to real-time telephone communication and/or an office visit whenever ASM communication is inadequate.

- Prescription renewals. HIT can make renewing prescriptions more efficient. Instruct patients to contact the pharmacy if the original prescription still has refills. Non-clinician care team members can use protocols and decision support to set up renewed ePrescriptions for chronic conditions (e.g., hypertension or diabetes). Care teams must decide how much of the work of reviewing the dose and number of refills should be done by non-provider team members before sending the order to a provider to sign. Route prescription renewals requiring more complicated clinical judgment directly to the original prescriber in the clinic if possible. The prescription renewal process requires a care team member to review the patient's chart, which is an opportunity to ensure that the patient's problem list includes the condition for which the medication was prescribed.
- Getting test results to patients. One of the best tactics for getting patients to activate their portal access is for the clinician to explain how much faster and easier releasing results using the portal is for both patient and care team. For patients who do not use a portal, letter templates allow test results, and accompanying explanation by the reviewing clinician, to be printed and mailed.

Use HIT tools to support culturally appropriate care. Cultural competence is about understanding and appreciating the different cultural contexts of patients and their families, including ethnicity, language, religion, socioeconomic status, education, and traditions. Care teams in a PCMH must be aware not only of the different levels of comfort with computers that patients in their panel may have, but also of ways HIT can support efforts to provide care that is culturally appropriate across a diverse population of patients.

- Documenting unique cultural needs of patients can be useful in empanelling patients and determining cultural needs of care teams based on their panel composition.
- Care teams should use a standardized place in the EHR to document patient-specific information including living situation, and when appropriate personal information such as grandchildren names. This can be referred to and updated if necessary at each visit.
- Patients requiring interpreters take additional time and resources. Use technology to schedule and document use of interpreters.

Appendix B:
Selecting and Using Survey Measures

Selecting a Survey

While there is no one best survey instrument there is a survey best suited to your particular practice setting, patient population, and/or evaluation need. Choice of survey should be based on:

- Relevance of domains to the patient population including access to care, timeliness of care, language barriers, access to interpreters, and perceived discrimination. You may want to select items and scales from various surveys to make your own survey if no one survey has all the domains of interest.
- Availability of benchmarking data or how patient scores compare to scores from other practices. Benchmarking data are frequently available for established surveys and surveys used by academic institutions. If this interests you, check with the survey developers, or a local health plan that has used the survey, to see if they may be willing to share benchmark data.
- Whether the survey has been used in a comparable population. Choosing a survey used in a patient population similar to your patient population is best and, ideally, validation research has also been done.
- Whether the survey has been translated into needed languages. Translating a survey is an expensive and time consuming process. If possible, use surveys that have translations in the language you need.

Measurement and Measurement Bias

Most survey instruments consist of single-item measures and one-dimensional multiple-item measures. Single-item measures are items such as "how would you rate your health," where the response options range from 0 (worst health possible) to 10 (best health possible). This score can be used alone or in combination with other items to evaluate health. Multiple-item measures combine scores from several items. For example, the CAHPS Health Plan measure for doctor communication consists of four items:

1. Doctor explained things clearly.
2. Doctor listened carefully.
3. Doctor respected your comments.
4. Doctor spent enough time.

Each item is administered with a 4-option response scale consisting of Never (1), Sometimes (2), Usually (3), and Always (4). To compute the summary score, each item score is linearly transformed to a 0–100 scale and item scores are averaged.

The most commonly reported psychometric properties of a measure are reliability and validity. The reliability of a measure is how consistently a scale measures a construct, while validity refers to whether a questionnaire measures the intended construct and not another. A reliable measure may be consistent without necessarily being valid; a measurement instrument like a broken ruler may always under-measure a quantity by the same amount each time, but the resulting quantity is incorrect.

A special concern when selecting a survey for diverse communities and multiple languages is the concept of equivalence. Without equivalence, measures may not operate similarly in different segments of the population, and results for different groups of respondents may not be comparable. Stewart et al. describe six levels of equivalence and basic methods for addressing each type of equivalence.[4] When selecting a survey, ask the survey equivalence in your groups of interest has been evaluated.

Mode of Administration

Every survey delivery mode has strengths and limitations. Selecting the right survey mode for your project depends on a number of factors including: characteristics of your sample (e.g., education, socioeconomic status), types of questions asked (closed-ended, open-ended), topics of questions (general topics, sensitive topics), desired response rates, costs, and time frame. The most common methods include:

- Personal (face-to-face) interview
- Self-administered in the clinic
- Phone
- Mail
- Internet
- Mixed modes (e.g., mail followed by phone; Internet followed by phone)

Internet-hosted surveys are the newest form of survey administration and therefore the least studied in minority populations. An important factor limiting the use of the Internet for survey administration in minority populations is the "Digital Divide," which refers to lower access to and use of the Internet by individuals of older age, lower socioeconomic status, minority race-ethnicity status, and non-English language preference.

Sampling Approaches

Sampling methodology should match survey purpose. Representative sampling is used when the practice wants to generalize findings to the group at large or wants to investigate how particular characteristics differ between two groups. Non-representative sampling should be used to answer exploratory questions, if the practice wants to know if a certain characteristic is occurring in the clinic population, or if time and money are limited. Sampling approaches that produce representative results are referred to as probability samples and consist of:

- Random samples: every member of a target population has an equal chance of being selected. Example: 100 patients selected at random from among all patients seen in the practice.
- Stratified random samples: a population is clustered into strata or subgroups, such as males and females or English and non-English speakers, that are relatively homogenous. The different strata are then randomly sampled. The number of people in each group should be large enough to be reasonably confident that the stratum represents the sub-population.

By contrast, non-probability samples provide information only about individuals included in the survey and are not generally representative of an entire patient population and consist of:

- Convenience sampling: used in exploratory research where the researcher is interested in getting an inexpensive approximation of the truth. As the name implies, the sample is selected because they are convenient. Examples: questionnaires of persons in the waiting room or from individuals leaving the hospital. There is no guarantee that the patients are representative of the whole sample.
    - Guidance from the field: In the case of waiting room samples, those not in the room may be avoiding care because of unknown problems and will not be included. Some clinics have found it helpful to call patients who miss an appointment and ask them if their absence was because of a problem with the care they received in the past, or a concern about their scheduled appointment (for example, not wanting to see a particular provider or inability to arrange for transportation). This information can help clinic staff better understand the reasons for missed appointments, and ensure that the concerns of patients not seen in the clinic are captured.
- Quota sampling: requires the researcher to first identify stratums of interest in the population. Then convenience sampling is used to select the required number of subjects from each stratum in a non-random manner.

- **Snowball sampling:** a special non-probability method used when locating respondents is difficult or cost prohibitive. Snowball sampling relies on referrals from initial subjects to generate additional subjects. While this technique can dramatically lower search costs, like convenience sampling, the respondents may not be representative.

Response Rates

A good response rate ensures that the results of your survey are representative of the patient population. Low response rates result in biased samples when non-response is related to the outcome of interest. For example, if the sickest patients are less likely to respond, then the view represented in the survey reposes are only those of well patients.

Tips for increasing response rates include:

- Use the most current contact information available. A major reason for low response rates is out-of-date or incorrect contact information. Find out when contact information was updated and only accept recent contact information.
  Set a standard to obtain current address and phone number for each patient.
- If appropriate, use incentives. Small ($5–$10), moderate ($10–$50), and large incentives ($50 or more) increase response rates for patient surveys.
- Build trust. In some communities, mistrust keeps individuals from participating in research projects, including surveys. Strategies to increase trust include collaborating with other community-based organizations, community leaders, and faith-based organizations and publicizing your study in local media.
- Use a mixed mode; mail and phone to gather data from people unlikely to respond to one method.
- Prepare in advance. If conducting a mail survey, send advance letters on clinic letterhead and mail surveys in multiple languages.

Survey Translation

Translation for the purposes of measurement is a complex and expensive task requiring skilled professional translators and the involvement of survey developers. Translations undertaken without the use of rigorous methods may produce misleading and invalid results. Whenever possible, use translations produced by the survey developer. Ask about how a translation was obtained and whether the translations have been evaluated.

Many surveys have been translated into common non-English languages used in the U.S. including Spanish and Chinese. If a translation you need is not available, working with a reputable vendor is best. A survey developer or foundation may be willing to share the costs. Resources for high quality translations include:

- RAND Survey Research Group: available here.
- Functional Assessment of Chronic Illness Therapy (FACIT): available here.
- University of Michigan, Survey Research Center: available here.

For a very good overview of translation methods see:
Eremencio S, Cella D, Arnold B. A comprehensive method for the translation and cross-cultural validation of health status questionnaires. *Eval Health Prof*. 2005; 28(2):212-232.

Guidance from the Field: Translation

While formal translations have the best evidence for valid and reliable results, they sometimes don't make sense to non-English speakers. When contracting a formal translation of your survey materials, be sure to field-test the survey on a small group of patients to ensure that the formal translation is understandable and appropriate before distributing it widely.

Literature

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Recommended citation: Safety Net Medical Home Initiative. Schaefer J, Van Borkulo N, Morales L, Coleman K, Brownlee B. Patient-Centered Interactions: Engaging Patients in Health and Healthcare. In: Phillips KE, Weir V, eds. *Safety Net Medical Home Initiative Implementation Guide Series.* 2nd ed. Seattle, WA: Qualis Health and The MacColl Center for Health Care Innovation at the Group Health Research Institute; 2013.

Acknowledgments: This document was created by the Safety Net Medical Home Initiative (SNMHI). The partner sites and Regional Coordinating Centers that participated in the SNMHI were members of a learning community working toward the shared goal of PCMH transformation. The *SNMHI Implementation Guide Series* was informed by their work and knowledge, and that of many organizations that partnered to support their efforts. We gratefully acknowledge the contributions of partner sites and Regional Coordinating Centers, and especially the following individuals and organizations that contributed to this specific guide.

Reviewers and content contributors to the second edition: Larry Mauksch (Department of Family Medicine, University of Washington School of Medicine); Elizabeth Powers, Keli Christman (Winding Waters Clinic, P.C.); Joanna Kreil, Joan Pernice (Massachusetts League of Community Health Centers); Sara Martinez (Scenic Bluffs Community Health Centers); Betsy Stapleton, Jessica Osborne-Stafsnes (Humboldt Del Norte Independent Practice Association); and Meghan Powers, Andrea Fox (Squirrel Hill Health Center).

Based on the following resources from the first edition of the *SNMHI Implementation Guide Series*:

- Schaefer J, Coleman K, Morales L, and Brownlee B. Patient-Centered Interactions Implementation Guide, Part 1: Measuring Patient Experience. 1st ed. Seattle, WA: The MacColl Center for Health Care Innovation at the Group Health Research Institute and Qualis Health, June 2010.
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Safety Net Medical Home Initiative

This is a product of the Safety Net Medical Home Initiative, which was supported by The Commonwealth Fund, a national, private foundation based in New York City that supports independent research on health care issues and makes grants to improve health care practice policy. The views presented here are those of the author and not necessarily those of The Commonwealth Fund, its directors, officers, or staff. The Initiative also received support from the Colorado Health Foundation, Jewish Healthcare Foundation, Northwest Health Foundation, The Boston Foundation, Blue Cross Blue Shield of Massachusetts Foundation, Partners Community Benefit Fund, Blue Cross of Idaho, and the Beth Israel Deaconess Medical Center. For more information about The Commonwealth Fund, refer to www.cmwf.org.

The objective of the Safety Net Medical Home Initiative was to develop and demonstrate a replicable and sustainable implementation model to transform primary care safety net practices into patient-centered medical homes with benchmark performance in quality, efficiency, and patient experience. The Initiative was administered by Qualis Health and conducted in partnership with the MacColl Center for Health Care Innovation at the Group Health Research Institute. Five regions were selected for participation (Colorado, Idaho, Massachusetts, Oregon and Pittsburgh), representing 65 safety net practices across the U.S.

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