ADVANCING THE PRACTICE OF PATIENT- AND FAMILY-CENTERED CARE IN PRIMARY CARE AND OTHER AMBULATORY SETTINGS

How to Get Started…

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Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care professionals. These partnerships at the clinical, program, and policy levels are essential to assuring the quality and safety of health care.

Since 1992, the **Institute for Patient- and Family-Centered Care (IPFCC)** has provided national and international leadership to advance the understanding and practice of patient- and family-centered care. IPFCC promotes change in organizational culture and enhances the quality and safety of health care through its on-site and off-site training and technical assistance; webinars, seminars, and international conferences; development of print and digital guidance resources; information dissemination; research; and policy initiatives.

IPFCC serves as a resource to primary care and other ambulatory care, hospital, and health system administrative and clinical leaders, program planners, direct service providers, patient experience officers, educators of health care professionals, researchers, facility design professionals, and patient and family leaders.

For further information about patient- and family-centered care in primary care and other ambulatory settings, visit www.ipfcc.org/advance/topics/primary-care.html.

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What is patient- and family-centered care? Why does it matter? How does it fit with our primary care or ambulatory practice's overall mission? And finally, what can our clinic do to advance the practice of patient- and family-centered care? Where do we start?

Today, leaders, clinicians, staff, patients, and families nationwide are asking these questions. The purpose of this document is to provide some answers.

Part I provides a rationale for a patient- and family-centered approach to care, defines its core concepts, and highlights the views of key leaders and leadership organizations about the importance of patient and family partnerships to ambulatory transformation and the development of the medical home.

Part II outlines steps a primary care clinic or ambulatory practice can take to begin to create partnerships with patients and families, and offers practical suggestions for getting started.

Part III, "The Role of Leaders," outlines the various roles and related action steps for leaders to build the infrastructure to support and sustain effective partnerships with patients and families.

Part IV, "Where Do We Stand?," describes a self-assessment process for a practice to determine the degree to which patient- and family-centered approaches are embedded in an ambulatory practice's current organizational culture.

Part V "Recruiting, Selecting, Preparing, and Supporting Patient and Family Advisors," offers practical guidance for beginning the process of partnering with patient and family advisors in change and improvement.

Part VI, "Selecting an Approach: Patient and Family Advisory Council or Integration of Advisors into Existing Teams," provides a tool for deciding which mechanism is best for involving patients and families as advisors in your practice transformation.

Part VII lists selected print and audiovisual resources.

Part VIII, "Appendices," includes three practical tools for beginning the development of effective partnerships with patients and families in ambulatory care.

Appendix A—Partnering With Patients and Families: An Ambulatory Practice Self-Assessment

Appendix B—Partnering With Patients and Families in Primary Care Improvement and Redesign: A Worksheet to Support Progress

Appendix C—Sample Application for Patient and Family Advisors in Ambulatory Care

Appendix D—Suggestions for Interview Questions in Selecting Patient and Family Advisors

PART I: WHAT IS PATIENT- AND FAMILY-CENTERED CARE?

Rationale

In their efforts to improve health care quality and safety, health care leaders today increasingly realize the importance of including a perspective too long missing from the health care equation: the perspective of patients and families. The experience of care, as perceived by the patient and family, is a key factor in health care quality and safety.

Bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of health care, and thereby improving its quality and safety is what patient- and family-centered care is all about. Studies and experience increasingly show that when health care administrators, providers, and patients and families work in partnership, the quality and safety of health care rise, costs decrease, and provider and patient satisfaction increase.

Definition

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care professionals. These partnerships at the clinical, program, and policy levels are essential to assuring the quality and safety of health care.

Core Concepts

Dignity and Respect. Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.

Information Sharing. Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

Participation. Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

Collaboration. Patients, families, health care practitioners, and health care leaders collaborate in policy and program development, implementation, and evaluation; in facility design; in professional education; and in research, as well as in the delivery of care.

Partnerships with Patients and Families – Perspectives of Leaders

"...in a growing number of instances where truly stunning levels of improvement have been achieved, organizations have asked patients and families to be directly involved in the process. And those organizations' leaders often cite this change—putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history."

—Reinersten, et al., *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care*, 2008

"We envisage patients as essential and respected partners in their own care and in the design and execution of all aspects of healthcare. In this new world of healthcare:

Organizations publicly and consistently affirm the centrality of patient- and family-centered care. They seek out patients, listen to them, hear their stories, are open and honest with them, and take action with them."

—Leape, et al., *Quality and Safety in Health Care*, 2009

The IOM report, *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*, offers ten key recommendations; the fourth states:

"In a learning health care system, patient needs and perspectives are factored into the design of health care processes, the creation and use of technologies, and the training of clinicians."

—Institute of Medicine, *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*, 2012

The Role of Patients and Families in Patient-Centered Medical Home Implementation

The Joint Principles for the Medical Home, signed by key primary care organizations in 2007, embraced the concept of partnership at all levels of care

- "…A care planning process driven by a compassionate, robust partnership between physicians, patients, and the patient's family…
- Patients actively participate in decision-making…
- Care is coordinated. . .in a culturally and linguistically appropriate way.
- Information technology is utilized appropriately to support…enhanced communication.
- Patients and families participate in quality improvement at the practice level."

—AAFP, AAP, ACP, & AOA, *Joint Principles of the Patient Centered Medical Home*, February 2007

Many physician organizations and practices are in some phase of implementing a Patient-Centered Medical Home (PCMH). The PCPCC report, *Benefits of Implementing the Primary Care Patient-Centered Medical Home: Review of Cost & Quality Results,* states:

"…the PCMH improves health outcomes, enhances the patient experience of care and reduces expensive, unnecessary hospital and ED care."

—Nielsen, et al., *Benefits of Implementing the Primary Care Patient-Centered Medical Home: Review of Cost & Quality Results*, 2012

Positive outcomes can be substantially accelerated through patient- and family-centered practices. This is especially true when patients and families are involved in quality improvement and redesign efforts.

Based on almost seven years of experience with PCMH collaboratives, McCallister and colleagues reported that:

"…family-centered care with parents as improvement partners" was one of the most significant drivers for transformation."

—McAllister, et al., *Annals of Family Medicine*, 2013

In a large-scale implementation of PCMH concepts in the VA, among the steps identified as critical to establishing successful medical homes was:

"engaging patients and other key stakeholders in redesigning care processes…"

—Klein, *The Veterans Health Administration: Implementing Patient-Centered Medical Homes in the Nation's Largest Integrated Delivery System*, 2011

In a study of 112 primary care practices, Han and colleagues suggested that while only 33% involve patients in quality improvement, those that do, experience significant benefits. They reported:

"These practices stated that robust patient involvement in every aspect of the practice, including designing effective patient engagement strategies, positively affected the way in which patients and families interacted with physicians and staff, supporting stronger relationships and enabling patients to feel more empowered to become active partners in their care."

—Han, et al., *Health Affairs*, 2013

In their commentary about factors that are critical to creating medical homes, Homer and Baron noted:

"In our experience, the unique perspective that family members bring refocuses transformation efforts away from provider concerns and toward bringing value for families and patients."

—Homer & Baron, *Journal of General Internal Medicine*, 2010

PART II: MOVING FORWARD WITH PATIENT- AND FAMILY-CENTERED CARE: ONE STEP AT A TIME

Establishing patient- and family-centered care requires a long-term commitment. It entails transforming the organizational culture. This approach to care is a journey, not a destination—one that requires continual exploration and evaluation of new ways to collaborate with patients and families. An organizational culture that embraces the concepts of respect and dignity for all, effective sharing of information, patient and family participation in care and decision-making, and authentic partnerships with patients and families in direct care and at the practice level is beneficial to all—clinicians, staff, patients, and families.

The following steps can help set a primary care or ambulatory practice on its journey in developing effective partnerships with patients and families and advancing the practice of patient- and family-centered care.

1. Appoint a practice leader as an Executive Sponsor.
2. Designate a Staff Liaison to coordinate and support work with patient and family advisors.
3. Identify at least two patient or family advisors to serve on the clinical transformation team.
4. Implement a process for key leaders and the clinical transformation team to learn about patient- and family-centered care and partnerships with patients and families in primary care and other ambulatory care.
5. Assess the extent to which patient- and family-centered core concepts and strategies are currently implemented within your primary care or other ambulatory practice. (More information about this assessment process can be found in Part IV.)
6. Identify initial roles for patient and family advisors.
7. Determine the qualities and skills that advisors serving in the above roles should have.
8. Develop a patient and family advisor recruitment and selection plan, informational materials for recruitment, and an application form.
9. Provide an orientation program for patient and family advisors and prepare them for serving on improvement and practice transformation initiatives.
10. Provide education and support for administrative leaders, clinicians, and staff for collaborating with patient and family advisors.
11. Plan and facilitate initial working meetings with patient and family advisors.
12. On the basis of the assessment, set priorities and develop an action plan for developing authentic partnerships with patients and families and advancing the practice of patient- and family-centered care.
13. Track changes and new initiatives. Document results.

14. Evaluate processes, measure the impact of collaborative endeavors, continue to advance the practice of patient- and family-centered care, and celebrate and recognize success.

A detailed worksheet to support the progress in advancing the practice of patient- and family-centered care and developing partnerships with patient and family advisors can be found in **Appendix B**.

PART III: THE ROLE OF LEADERS IN BUILDING THE INFRASTRUCTURE TO SUPPORT AND SUSTAIN EFFECTIVE PARTNERSHIPS

Health care organizations that have been successful in partnering with patients and families to advance patient- and family-centered care have leaders who understand that their commitment and their support is essential. This section lists roles and action steps that leaders can use to guide their efforts.

Essential Roles	Key Action Steps
Leaders make an explicit commitment to patient- and family-centered care and serve as role models for engaging in partnerships with the individuals and families they serve across the continuum of care.	▸ Build leadership commitment to partnerships. ▸ Serve as role models – walk the talk. ▸ Serve as the executive champion/s for patient- and family-centered care and for partnerships with patients and families.
Leaders provide resources and support for partnerships with the individuals they serve.	▸ Establish the infrastructure to support partnerships. ▸ Assess the current status of patient- and family-centered care. ▸ Remove institutional and attitudinal barriers to patient- and family-centered care. ▸ Create opportunities for administrators, clinicians, staff, patients, and families to learn how to partner.
Leaders encourage partnerships as a pathway to improve health care quality and safety.	▸ Partner with advisors to develop strategies and tools to prepare patients and families to become active in ensuring the quality and safety of care. ▸ Involve patient and family advisors in strengthening the capacity of an organization to ensure quality and safety.

Essential Roles	Key Action Steps
Leaders oversee and encourage partnerships with patients and families in strategic initiatives.	▸ Partner with patients and families to change and improve care practices. ▸ Partner with patients and families to enhance planning for changes to the built environment. ▸ Partner with patients and families to expand the use and usefulness of information technology. ▸ Partner with patients and families to improve the education of health care professionals.
Leaders put systems in place to measure the outcomes of collaborative processes.	▸ Measure the effect of patient- and family-centered care on key outcomes. ▸ Document the efforts and impact of patient and family advisors. ▸ Share outcomes with leaders, clinicians, staff, patients, families, and community members.
Leaders recognize that profound organizational change takes time.	▸ Affirm the commitment to patient- and family-centered care. ▸ Celebrate the successes.

Adapted from Johnson, B. H., & Abraham, M. A. (2012). P*artnering with Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-Term Care Communities*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

PART IV: WHERE DO WE STAND? A SELF-ASSESSMENT TOOL FOR CLINIC ADMINISTRATORS, PROVIDERS, STAFF, AND PATIENT AND FAMILY LEADERS

An effective action plan for moving forward with patient- and family-centered care and developing effective partnerships with patients and families is based on a thoughtful assessment of the degree to which a primary care or ambulatory practice has already incorporated key principles of this approach to care, and of the areas in which progress remains to be made.

Appendix A includes questions that can serve as a springboard for such an assessment. It asks the organization to think about key areas that impact patient- and family-centered care practices including leadership, patient and family advisory programs, patient and family participation in care and decision-making, their access to information, education, and support as well as the education of clinicians, staff, and trainees of the practice. Ideally, the clinical transformation team, with its patient and family advisors, completes the assessment and uses the assessment findings to develop an action plan. This process can occur in organizations before you have established an advisory program as a way to learn about the ways advisors could be involved in the practice.

PART V: RECRUITING, SELECTING, PREPARING, AND SUPPORTING PATIENT AND FAMILY ADVISORS

In many health care settings including primary care and ambulatory practices, leaders are increasing their efforts to partner with patients and families in policy and program development, patient safety, quality improvement, patient experience, health care redesign, professional education, facility design planning, and research and evaluation. They are asking patients and families to serve on patient and family advisory councils and on clinical transformation teams and other committees. Effective recruitment and appropriate selection, preparation, and support of patient and family advisors are key to effective partnerships.

Characteristics of Successful Patient and Family Advisors

A patient or family advisor is an individual or family member who has experienced care in the ambulatory setting. In identifying patient and family advisors, look for individuals who have demonstrated an interest in partnering with providers in their care or the care of their family member. Consider those who have offered constructive ideas for change and who have a special ability to help staff and clinicians better understand the patient or family perspective.

Seek individuals who have the following skills, qualities, and interests:

- The ability to share personal experiences in ways that others can learn from them.
- The ability to see the ”big” picture.
- Interested in more than one agenda issue.
- Demonstrated commitment to partnership and collaboration.
- The ability to listen and hear other points of view.
- The ability to connect with people.
- Interest in improving health care.
- A sense of humor.
- Representative of the patients, families, and members served by the ambulatory practice.

Recruiting Patient and Family Advisors

Before beginning a formal recruitment process, identify some initial, tangible ways to involve patients and family advisors. Roles and tasks you might consider: serving as members of a clinical transformation team, a patient and family advisory council, or on a quality improvement committee; serving as members of teams to improve safety or work flow; assisting in the development of a patient portal, educational materials or programs; planning for renovation or construction of new facilities; or planning and conducting a research or

evaluation endeavor. Some patient and family advisors may be interested in all of these areas; some may have particular skills and interests that will be valuable to these collaborative endeavors in addition to the expertise, perspectives, and experience they bring as patients and family members.

Appendix C includes a sample application form that can be used or adapted for specific primary care or other ambulatory practices.

To find patient and family advisors with qualities and skills described on page 8:

- Ask clinicians and other staff for suggestions. Attend a staff or provider meeting and describe or share a list of the qualities and skills of effective advisors. Ask that attendees provide recommendations for potential patient and family advisors.
- Review letters or emails from patients or families that have provided constructive feedback to the practice.
- Include information about patient and family advisors in informational materials on the clinic's website, and in patient experience and satisfaction surveys.
- Place notices in clinic/practice publications or in relevant publications or communication vehicles used by the health system.
- Post information on Twitter and Facebook.
- Reach out to patient representatives, ombudsmen, community outreach workers, and current patient and family advisors.
- Contact community groups such as the YMCA, Rotary, Kiwanis, fire stations, and religious organizations as another way to find individuals who might be interested in serving as advisors.
- Connect with peer support groups.
- Post signs/brochures on bulletin boards in reception areas, corridors, and lobbies about the opportunity to be an advisor.
- Ask patients/families during a clinic visit when appropriate.

Seek individuals from the populations of patients and families your clinic/practice serves. Recruitment of individuals from diverse ethnic and cultural backgrounds can be most effective if you partner with trusted community organizations serving those populations (e.g., faith communities, social service and public agencies).

Selecting Patient and Family Advisors

Matching patients and families to meaningful advisory opportunities is critical to building an effective partnership for improvement. Once a patient or family member expresses interest in being an advisor through completion of an application, having a dialogue about mutual

interests can help both you and the potential advisor in determining if this is a good fit. Some organizations have a brief meeting with interested applicants, either individually or in a group setting. Others choose to do a phone screening to gather information from the potential advisor. In either case, time is provided for applicants to ask questions about the organization as well as for the organization to learn more about the skills, interests, and experiences the applicant brings to the role. Below are a few questions that can help begin the conversation:

- Tell me why you are interested in becoming an advisor? What would you like to accomplish in this role?
- What would you like to ask me about the advisory roles in our practice?
- Can you describe a recent health care experience you or a family member has had? What worked well and what could have been improved to make it a better experience?
- Can you share an experience working in a group to solve a problem?

More interview questions can be found in **Appendix D**.

Informing Potential Patient and Family Advisors About Their Roles

Before individuals can make decisions about whether they wish to participate on an advisory council, clinical transformation team, patient safety committee, a quality improvement team, or in other health care redesign initiatives, they should be informed of the responsibilities and privileges associated with the role. A fact sheet, containing the following information, can be prepared and offered to individuals who are being asked to participate:

- Mission, goals, and priorities of the ambulatory practice.
- Description, priorities, and goals of the council, team, committee, or project.
- Expectations for patient and family advisor participation.
- Meeting times, frequency, and duration.
- Expectations for communication among team members between meetings.
- Time commitment beyond meeting times.
- Reimbursement or compensation offered.
- Benefits of participation (i.e., what are the expected outcomes of their involvement).
- Training and support to be provided.

Reimbursement/Compensation

In order to ensure diversity in your advisor pool, consideration about barriers to participation and costs should be addressed upfront. At a minimum, the organization should offer reimbursement to patients and families to offset expenses incurred in association with their work with the clinic/practice (e.g., parking, transportation, child care). In some cases, an advisor may choose to decline this support. Some organizations also offer stipends or honoraria for participation in meetings. These payments typically range from $12 - $25 per meeting. Consider the needs of the patient or family advisor and ask about their preferences. If they have no means to cash a check, stipends will have to be offered in an alternative way (e.g., store voucher, gift card, cash).

Preparing and Supporting Patient and Family Advisors

In order for patients and families to participate effectively as advisors, appropriate orientation, training, preparation, and support should be provided. Patient and family advisors should have a chance to discuss their questions or thoughts about the work with a staff member (often called a "staff liaison") who has time dedicated to coordinating activities with advisors.

The orientation for patient and family advisors should include information on the following if it has not been provided during your recruitment process?

- The mission, goals, and priorities of the primary care or ambulatory practice
- Patient- and family-centered care.
- Overview of patient experience, quality, and safety.
- Specific skills and knowledge needed to be an effective team member (e.g., quality improvement methodology for those serving on a quality improvement team).
- HIPAA and the importance of privacy and confidentiality.
- Communicating collaboratively:
    - Expressing your perspective so others will listen
    - How to ask tough questions
    - What to do when you don't agree
    - Listening to, and learning from, the perspectives of others.
    - Thinking beyond your own experience.

If the organization has a volunteer program, its orientation and training may be very useful for patient and family advisors. Other training issues to consider include:

- Speaking the organization's language, "Jargon 101." While it is best to reduce the amount of jargon used in collaborative endeavors, sometimes it is impossible to completely eliminate jargon. If there are terms that will be used frequently in meetings, make sure that patient and family advisors understand them. Encourage them to ask for an explanation of anything they don't understand.
- Who's who in the organization or on the project team and how to contact team members.
- How to prepare for a meeting: what to wear, what to do ahead of time, and what to bring.
- How meetings are conducted: format, agenda, minutes, roles (e.g., secretary, timekeeper).
- Training for any technologies that will be used (e.g., conference calls, web-based tools).

SPECIAL TIP: It is extremely helpful for new patient and family advisors to have a "coach" or mentor who can provide informal ongoing support to them. A member of the council, clinical transformation team, or committee who has experience working on collaborative initiatives (either a staff person or an experienced patient/family advisor) can be assigned to this role. This person can ensure that patient and family advisors are prepared for each meeting. During meetings, this person can actively encourage participation of the advisor. They can debrief after each meeting to determine what additional information or resources patient and family advisors need. Most importantly, they can support patient and family advisors in participating fully on the team by providing feedback and encouragement.

PART VI: SELECTING A PARTNERSHIP APPROACH: PATIENT AND FAMILY ADVISORY COUNCIL OR INTEGRATION OF ADVISORS INTO EXISTING TEAMS

It is important to thoughtfully consider the different approaches to implementing a patient and family advisory program. Two common ways to build partnerships for quality and safety with patients and families in primary care and other ambulatory settings is to start a Patient and Family Advisory Council or invite patients and families to join the clinical transformation team and other specific improvement committees. A mature patient- and family-centered clinic/practice often uses both. However by reviewing your needs and understanding the pros and cons of each approach can help you decide where to start. It can be used for self-reflection and as a way to spark discussion among staff and clinicians before beginning to work with patients and families.

Below is a summary of each approach and a list of the pros and cons for your consideration. There is no right or wrong approach. Choose the approach that fits best for your organization's needs and capacity. The goal is to create mutually beneficial partnerships that provide

a way to integrate the patient and family voice into decisions made about your practice's programs and services.

Approach	Pros	Cons
Patient and Family Advisory Council (PFAC): A group representing the voices of your patient population who partner with key staff and leaders. The majority of members on a PFAC are patients and family members.	Allows a broad representation of the populations served	Generally is a longer term commitment of 1-2 years for volunteer advisors
	Provides a mechanism to gain input on clinic-wide issues on a monthly basis	Recruitment and screening process can occur over a longer period of time
	Establishes a formal group that reports to leadership and is sponsored by an executive	Orientation to the organization is comprehensive and takes more time
	Creates a strong message to staff and others that partnerships with patients and families is valued by the organization	There is a greater cost and time factor (meals and staff time)
	Generally, council meets in the evenings to allow both employed and non-working participants an opportunity to be engaged with those delivering care	Sometimes is limited to higher level conversations and not on-the-ground work
	Creates community-wide ambassadors for your clinic	Some advisors may not work well in a group situation
	Gives administration an opportunity to understand what patients and families think about their clinic	Limited to those who can attend at a particular time, doesn't allow as much flexibility
	Is a mechanism where input from patients and families can impact many projects	The council may not be able to address all issues brought to them in a timely way
	Builds a cadre of people who can reach out to their communities to gather more opinions and ideas	May not give advisors enough of a direct, hands-on experience working through a specific change

<table>
<tr><th>Approach</th><th>Pros</th><th>Cons</th></tr>
<tr><td rowspan="7">Advisors Integrated into Quality Improvement and Other Committees

Some examples:

- Invite patients with a chronic condition to participate in a clinic team working on improving educational materials or programs to that population of patients.

- Invite new patients new to participate in a “walk-about” to take pictures and discuss ways the clinic is welcoming and places where the messages could be more positive or where way-finding is confusing.

- Ask patients and family members to identify one change that would improve the clinic or their care experience? Collect responses and form a clinic team with advisors to follow-up on suggestions</td><td>Recruitment is targeted to a specific topic/area</td><td>Advisors don’t have opportunity to participate/influence other aspects of the clinic operation</td></tr>
<tr><td>Generally these efforts are time specific and don’t require a long-term commitment</td><td>Schedule for existing committee meetings may not work for advisors; so may need to change the time of the group to get advisor input</td></tr>
<tr><td>Advisors can choose which topics they are most passionate about to work in partnership with clinic staff</td><td>Takes time to bring advisors up-to-date on work already done</td></tr>
<tr><td>Helps match people with their specific strengths and expertise</td><td>Takes time to educate advisors on process/scope of project or any limitations to what can be changed</td></tr>
<tr><td>Advisors can work more closely with staff on the ground</td><td>One advisor cannot be the voice of all patients, so it is important to ensure at least two advisors are assigned to a committee</td></tr>
<tr><td>Orientation is limited to the improvement topic and can be provided with the orientation for other members of the improvement team.</td><td>Takes time to prepare staff who work on the committee because if the role of advisors is not clearly understood by the staff, advisors may not be effectively integrated in meaningful ways as a committee member</td></tr>
<tr><td>Advisors are recruited based on their specific experience and/or chronic condition, so they are immediately recognized for their “expertise”</td><td></td></tr>
</table>

Believe Patient and Family Participation is Essential

Regardless of the structure for patient and family partnerships, the single most important guideline for involving patients and families in advisory roles is to believe that their participation is essential to the design and delivery of optimum care and services. Without sustained patient and family participation in all aspects of policy and program development and evaluation, the the clinic/practice will fail to respond to the real needs and concerns of those it is intended to serve. Effective patient/family/provider partnerships will help to redesign health care and improve safety and quality. It will lead to better outcomes and enhance efficiency and cost-effectiveness. Providers will also discover a more gratifying, creative, and inspiring way to practice.

Involving patients and families as partners and advisors will:

- Bring important perspectives about the experience of care.
- Teach how systems really work.
- Inspire and energize staff.
- Keep staff grounded in reality.
- Provide timely feedback and ideas.
- Lessen the burden on staff to fix the problems… staff don't have to have all the answers.
- Bring connections with the community.
- Offer an opportunity for patients and families to "give back."

This material in Part V and VI has been adapted from two resources: *Developing and Sustaining a Patient and Family Advisory Council and Essential Allies—Patient, Family, and Resident Advisors: A Guide for Staff Liaisons* published by the Institute for Patient- and Family-Centered Care.

PART VII: SELECTED RESOURCES

Available from the Institute for Patient- and Family-Centered Care

Abraham, M., Ahmann, E., & Dokken, D. (2013). *Words of advice: A guide for patient, family, and resident advisors*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

Conway, J., Johnson, B. H., Edgman-Levitan, S., Schlucter, J., Ford, D., Sodomka, P., & Simmons, L. (2006). *Partnering with patients and families to design a patient- and family-centered health care system: A roadmap for the future*. Bethesda, MD: Institute for Family-Centered Care. Retrieved from www.ipfcc.org/pdf/Roadmap.pdf

Crocker, L., & Johnson, B. (2014). *Privileged presence: Personal stories of connections in health care* (2nd ed.). Boulder, CO: Bull Publishing Company.

Crocker, L., Webster, P. D., & Johnson, B. H. (2012). *Developing patient- and family-centered vision, mission, and philosophy of care statements*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

Institute for Patient- and Family-Centered Care. (2012). *Partnerships with patients, residents, and families: Leading the journey* [video]. Bethesda, MD: Institute for Patient- and Family-Centered Care.

Johnson, B. H., & Abraham, M. R. (2012). *Partnering with patients, residents, and families—A resource for leaders of hospitals, ambulatory care settings, and long-term care communities*. Bethesda, MD: Institute for Patient- and Family-Centered Care.

Johnson, B., Abraham, M., Conway, J., Simmons, L., Edgman-Levitan, S., Sodomka, P., Schlucter, J., & Ford, D. (2008). *Partnering with patients and families to design a patient- and family-centered health care system: Recommendations and promising practices*. Bethesda, MD: Institute for Family-Centered Care. Retrieved from http://www.ipfcc.org/tools/downloads.html

Minniti, M., & Abraham, M. (2013). *Essential allies—Patient, family, and resident advisors: A guide for staff liaisons*. Bethesda, MD. Institute for Patient- and Family-Centered Care.

Visit IPFCC's website for additional written and audiovisual resources at www.ipfcc.org.

Additional Resources

American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, & American Osteopathic Association. (2007, February). J*oint principles of the patient centered medical home*. Retrieved from http://www.pcpcc.net/content/joint-principles-patient-centered-medical-home

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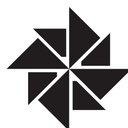

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APPENDIX A: PARTNERING WITH PATIENTS AND FAMILIES: AN AMBULATORY PRACTICE SELF-ASSESSMENT

This assessment can be completed by the clinic transformation team or other group which includes administrative and clinical leaders, managers, frontline staff, and patient and family advisors. The group can then discuss responses and develop an action plan.

	YES	NO	PRIORITY FOR CHANGE LOW		HIGH
Leadership Commitment					
Does your practice/clinic have patient- and family-centered vision, mission, and philosophy of care statements that promote partnerships with patients and families?	☐	☐	1	2	3
Does your practice/clinic communicate its patient- and family-centered vision, mission, and philosophy of care clearly to:					
‣ Clinic/practice staff and clinicians?	☐	☐	1	2	3
‣ Patients and families?	☐	☐	1	2	3
‣ Others in the community?	☐	☐	1	2	3
Do practice/clinic leaders:					
‣ Create the expectation for partnering with patient and family advisors in clinic/practice improvement and ambulatory redesign?	☐	☐	1	2	3
‣ Invest time, financial, and personnel resources in patient- and family-centered initiatives?	☐	☐	1	2	3
‣ Through their words and actions, hold the following accountable for collaborating with patients and families:					
○ Staff?	☐	☐	1	2	3
○ Clinicians?	☐	☐	1	2	3

	YES	NO	PRIORITY FOR CHANGE LOW		HIGH
			1	2	3
Does your practice/clinic budget time, financial and personnel resources in patient- and family-centered initiatives [e.g. review patient education materials, improve facilities, quality improvement teams, etc?]	☐	☐	1	2	3
Does your practice/clinic have a Patient and Family Advisory Council?	☐	☐	1	2	3
Do patients and families serve on committees and work groups involved in:					
▸ Patient/family education?	☐	☐	1	2	3
▸ Care of chronic conditions (e.g., self-management support)?	☐	☐	1	2	3
▸ Planning the use of group visits?	☐	☐	1	2	3
▸ Transition planning?	☐	☐	1	2	3
▸ Peer-led education and support?	☐	☐	1	2	3
▸ Medical Home implementation/ambulatory care redesign?	☐	☐	1	2	3
▸ Quality improvement?	☐	☐	1	2	3
▸ Patient safety?	☐	☐	1	2	3
▸ Use of information technology?	☐	☐	1	2	3
▸ Oversight of culturally and linguistically appropriate services?	☐	☐	1	2	3
▸ Connections with community services and programs?	☐	☐	1	2	3
▸ Staff orientation and education?	☐	☐	1	2	3
▸ Policy and procedure development?	☐	☐	1	2	3
▸ Facility design?	☐	☐	1	2	3
▸ Evaluation and research initiatives?	☐	☐	1	2	3
▸ Other? ______________________					

Signage and Facility Design

The signage and design of clinic/practice facilities:	YES	NO	LOW		HIGH
▸ Creates positive and welcoming impressions throughout the facility for patients and families?	☐	☐	1	2	3
▸ Displays messages that communicate to patients and families that they are essential members of the health care team?	☐	☐	1	2	3

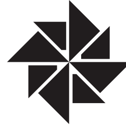
	YES	NO	PRIORITY FOR CHANGE		
			LOW		HIGH
Patient and Family Participation in Care and Decision-making					
Do staff or clinicians encourage patients to define their family or other care partners who will be involved in care and decision-making?	☐	☐	1	2	3
Are patients and their families, according to patient preference, encouraged and supported to participate in their care planning and decision-making?	☐	☐	1	2	3
Do staff and clinicians view patients and families, according to patient preference, as essential members of the health care team?	☐	☐	1	2	3
Are the cultural and spiritual practices of patients and families respected and incorporated into care planning and decision-making?	☐	☐	1	2	3
Do providers encourage and support patients and their families, according to patient preference, to set goals and create action plans for self-management of chronic conditions?	☐	☐	1	2	3
Are staff practices consistent with the view that patients and families are allies for patient health, safety, and well-being?	☐	☐	1	2	3
Patient and Family Access to Information, Education, and Support					
Are systems in place to ensure that patients and their families have access to complete, unbiased, and useful information.	☐	☐	1	2	3
Are there a range of informational and educational programs and materials provided:					
‣ In primary languages of the community served?	☐	☐	1	2	3
‣ At appropriate literacy levels?	☐	☐	1	2	3
‣ That include examples and images that reflect the diversity of patients and families served by the practice/clinic?	☐	☐	1	2	3
‣ In a variety of formats (e.g., written, video, web-based)?	☐	☐	1	2	3

	YES	NO	PRIORITY FOR CHANGE LOW		HIGH
Do patients have easy access to their medical records [paper or electronic]?	☐	☐	1	2	3
▸ Do patients have access to their clinical notes?	☐	☐	1	2	3
Are peer-led educational programs available and accessible to patients and families?	☐	☐	1	2	3

Education of Staff, Clinicians, Students, and Trainees

Do clinic/practice orientation and education programs prepare the following people for collaboration with patients and families in care and decision-making:

	YES	NO	PRIORITY FOR CHANGE LOW		HIGH
▸ Staff?	☐	☐	1	2	3
▸ Clinicians?	☐	☐	1	2	3
▸ Students and Trainees?	☐	☐	1	2	3
Are patients and families involved as presenters in orientation and educational programs?	☐	☐	1	2	3



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APPENDIX B: PARTNERING WITH PATIENTS AND FAMILIES IN PRIMARY CARE IMPROVEMENT AND REDESIGN: A WORKSHEET TO SUPPORT PROGRESS

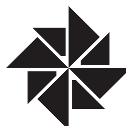
Action Steps	Progress	Date
1. Appoint a Practice Leader as an Executive Sponsor for advancing the practice of patient- and family-centered care and developing meaningful, sustained partnerships with patients and families.		
2. Designate a Staff Liaison to coordinate and support work with patient and family advisors for the Medical Home and other initiatives to redesign primary care and other ambulatory care.		
3. Identify at least two patient and family advisors to serve on the clinical transformation team.		
4. Implement a process for key leaders and the clinical transformation team to learn about patient- and family-centered care and partnerships with patients and families in primary care and other ambulatory care. Participate in webinars, attend seminars and conferences, create a journal club to review and discuss articles, and visit websites such as: www.ipfcc.org, www.pcpcc.org, and www.healthcarecommunities.org.		
5. Assess the extent to which patient- and family-centered core concepts and strategies are currently implemented within your primary care or other ambulatory practice. (A brief initial self-assessment tool appears in Appendix A.)		

Action Steps	Progress	Date
6. Identify initial roles for patient and family advisors who will assist in developing the Medical Home and redesigning primary care and other ambulatory care. The following are possibilities: a. Serve on an advisory council of patients and families who receive care at the ambulatory practice with selected staff and clinical leaders. b. Serve as members of the clinical transformation team. c. Serve as members of task forces and work groups related to facility design, waiting room activities, registration procedures, clinic flow, documentation systems, ePHRs, patient safety, and other quality improvement endeavors. d. Participate on site visit teams to other programs. e. Participate in brainstorming sessions before developing educational materials and throughout the development process. f. Assist in adapting patient information materials to meet the literacy and language needs of patients served by the practice. g. Serve on teams to plan, conduct, and evaluate ambulatory group visits. h. Lead or co-lead educational and support programs. i. Serve in volunteer or staff positions such as clinic greeter, peer mentor/coach, or peer liaison. j. Participate in identifying and building relationships with community programs and resources. k. Join staff when they meet with funders and community groups. l. Present at staff orientation and in-service programs. m. Offer professionals-in-training or staff the opportunity to spend a day with them to observe how patients and families manage their care in their daily life. n. Conduct follow-up phone calls with other patients and/or families after clinic visits to gather their perspectives on how they experience care. o. Facilitate or co-facilitate quarterly or semi-annual coffee hours for other patients, families, staff, and clinicians to explore ideas for improving care. p. Participate in creating or revising a patient/family satisfaction survey and developing strategies to respond to concerns and problems reported.		

Action Steps	Progress	Date
q. Facilitate or co-facilitate focus groups of other patients and families as specific issues arise. r. Participate in planning, conducting, and disseminating research and evaluation.		
7. Determine the qualities and skills of advisors who will serve in the roles described above. The following are possibilities: a. The ability to share personal experiences in ways that others can learn from them. b. The ability to see the "big" picture. c. Interested in more than one agenda issue. d. Demonstrated commitment to partnership and collaboration. e. The ability to listen and hear other points of view. f. The ability to connect with people. g. Interest in improving health care. h. A sense of humor. i. Representative of the patients, families, and members served by the ambulatory practice.		
8. Develop a patient and family advisor recruitment and selection plan, informational materials for recruitment, and an application form. a. Develop an application form (use or adapt the form in Appendix C and other recruitment materials. b. Develop informational materials for recruiting patient and family advisors. ○ Mission, goals, and priorities of the ambulatory practice. ○ Description, priorities, and goals of council, committee, or project. ○ Expectations for patient and family advisor participation. ○ Meeting times, frequency, and duration. ○ Expectations for communication between meetings. ○ Time commitment beyond meeting times. ○ Reimbursement or compensation offered. ○ Benefits of participation (i.e., what are the expected outcomes of their involvement). ○ Training and support to be provided.		

Action Steps	Progress	Date
c. Consider the following approaches for recruitment: ○ Asking staff and clinicians for suggestions. ○ Post signs/brochures on bulletin boards in reception areas, corridors, and lobbies about the opportunity to be an advisor. ○ Ask patients/families during a clinic visit when appropriate. ○ Place notices in the clinic's or health system's publications, websites, information kiosks, and TV systems. ○ Contact support groups and community organizations such as Rotary, Kiwanis, fire stations, and religious organizations. ○ Ask current patient and family advisors for the clinic, affiliated hospital, or health system. ○ Call or send a mailing to patients and families served by the practice. ○ Post information on Twitter and Facebook. d. Plan the selection process, especially who will interview patient and family advisors and the criteria for selection.		
9. Provide an orientation program for patient and family advisors and prepare them for serving on improvement and practice transformation initiatives. a. The mission, goals, and priorities of the primary care or ambulatory practice. b. Patient- and family-centered care. c. Overview of patient experience, quality, and safety issues and strategies. d. Specific skills and knowledge needed to be an effective team member (e.g., quality improvement methodology for those serving on a quality improvement team). e. HIPAA and the importance of privacy and confidentiality.		

Action Steps	Progress	Date
f. Communicating collaboratively: ○ Expressing your perspective so others will listen. ○ How to ask tough questions. ○ What to do when you don't agree. ○ Listening to, and learning from, the perspectives of others. ○ Thinking beyond your own experience. g. Who's who in the organization or on the project team and how to contact team members. h. How to prepare for a meeting: what to wear, what to do ahead of time, and what to bring. i. How meetings are conducted: format, agenda, minutes, roles (e.g., secretary, timekeeper). j. Training for any technologies that will be used (e.g., conference calls, web-based tools).		
10. Provide education and support for administrative leaders, clinicians, and staff for collaborating with patient and family advisors. Address such issues as: a. How to encourage collaborative discussions. b. The importance of listening. c. Effective approaches to meeting facilitation. d. Acting on advisors observations and recommendations when appropriate and providing information when not implemented. e. Being open to questions and challenges. f. Responding/explaining without being defensive.		
11. Plan and facilitate initial working meetings with patient and family advisors.		
12. On the basis of the assessment, set priorities and develop an action plan for developing authentic partnerships with patients and families and advancing the practice of patient- and family-centered care.		
13. Track changes and new initiatives. Document results.		
14. Evaluate processes, measure the outcomes and impact of collaborative endeavors, continue to advance patient- and family-centered practice, and celebrate and recognize success.		



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APPENDIX C: PATIENT AND FAMILY ADVISORS IN AMBULATORY CARE: SAMPLE APPLICATION FORM

(Please Print)

Name: ______________________________

Address: ______________________________

City: ______________ State: ______ Zip Code: __________

Home Phone: (_____) ______________________

Cell Phone: (_____) ______________________

Work Phone: : (_____) ______________________

Email Address: ______________________________

What is the best way to contact you? (Circle One) Home Cell Work Email

Will you allow your contact information to be shared with other advisory council/ committee members? ☐ Yes ☐ No

Language(s) You Speak ______________________________

. . . .

(Please check the following boxes as appropriate)

☐ I am a patient ☐ I am a family member of a patient

Location(s) where you/your family receive primary or ambulatory care: ______________

____

☐ I am a patient with a chronic health condition (e.g., diabetes, heart failure, asthma, depression, arthritis).

☐ I help a family member or friend in managing a chronic health condition.

Why would you like to serve as an advisor?

Issues of special interest to you:

Please specify times when you are able to attend meetings:

☐ Daytime: ____________ ☐ Evening: ___________ ☐ Weekend: ______________

Do you know of other individuals and families who have experienced care at __________ who might be interested in serving as advisors?

____

____

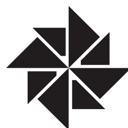
____

Please call them for us or list name(s) and phone number(s) below:

____

____

Please return form to:



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APPENDIX D: SUGGESTIONS FOR INTERVIEW QUESTIONS IN SELECTING PATIENT AND FAMILY ADVISORS

- Please briefly tell us about you and your family.
- What types of health care services have you used?
- What positive experiences with health care have you had? (This would be an experience where you and your family felt respected or supported, where you had the information you needed and wanted, or where you and your family could participate in your health care decisions in ways that you wanted?)
- Have you had an experience that was not so helpful?
  - How it could have been changed or improved?
- If you had a magic wand, and could change/improve health care for you and your family and others in the community, what changes would you want to make?
- Have you served on a committee at work, or in the community as a volunteer? Please share some of your experiences there.
- Please share with us strengths you have that would be useful in working with a group?
- Do you find it easy to share your opinion with a group of others? What if you have a different opinion than most of the group? What do you do in that situation?
- Would you be interested in presenting your story about your health care experiences to others to highlight what was helpful and what could be improved?
- Discuss various opportunities for patient/family advisor participation and elicit the potential advisor's interests and preferences:
  - Sharing your opinion and respond to survey questions over the telephone.
  - Providing feedback on a specific issue in a group format.

- Serving as an e-advisor.
- Serving as a member of the clinical transformation team.
- Serving as a member of a committee (e.g., working with staff to make specific improvements).
- Sharing stories of your health care experiences with staff, clinicians, or trainees or other patients and families (e.g., for staff orientation, education for trainees, patient educational session).
- Being a member of a patient and family advisory council (monthly evening meetings)
- Discuss issues related to timing and location of meetings, language and transportation assistance, mobility accommodations, dietary requirements.

Adapted from *Essential Allies: Patient, Resident, and Family Advisors: A Guide for Staff Liaisons*. Many organizations contributed questions and were acknowledged in Essential Allies.