Patient and Family Advisory Council Guide for Ambulatory Practices

MARYLAND HEALTH CARE COMMISSION

March 2019

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Introduction

Overview of the Patient and Family Advisory Council (PFAC) Guide for Ambulatory Practices

The Patient and Family Advisory Council Guide for Ambulatory Practices (Guide) provides Maryland ambulatory practices (practices) with information and resources to help create, integrate, and expand a Patient and Family Advisory Council (PFAC). PFACs are a key component for practice transformation[1] and an ongoing mechanism to support meaningful partnerships among patient and family advisors (PFAs)[2], staff, clinicians[3], and organizational leaders.

PFACs and Why They Are Important

A PFAC is a mechanism for bringing the perspectives of patients and families directly into the planning, delivery, and evaluation of care with the goal of improving care through policy and program changes. PFACs are comprised of PFAs, practice staff, and clinicians. By working together, they strive to create systems that deliver patient and family-centered care (PFCC). PFCC is built upon the core concepts of dignity and respect, affirmative and useful information sharing, support for participation in direct care, and collaboration in policy and program design.[4]

Designing a system that embodies all these concepts requires meaningful partnerships between those who deliver care and those who receive it. Establishing a PFAC sets the stage for this collaboration. When PFAs' viewpoints are integrated to create a transformed delivery system, the practice is more prepared to respond to patient needs, priorities, and values. This usually results in higher quality and better coordinated care.

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[1] Reinertsen, J. L., Bisagnano, M., & Pugh, M.D. Institute for Healthcare Improvement (IHI). IHI Innovation Series. *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care, 2nd Edition.* 2008. Available at: ihi.org/resources/Pages/IHIWhitePapers/SevenLeadershipLeveragePointsWhitePaper.aspx.

[2] Patient and family advisors (PFAs) consist of patients and families of a practice who volunteer to advise the practice on how to improve the health care services the practice provides.

[3] As used throughout the Guide, the term "clinicians" is inclusive of physicians, nurse practitioners, and physician assistants.

[4] Institute for Patient-and Family-Centered Care (IPFCC). *PFCC Best Practices, Core Concepts of Patient- and Family-Centered Care*. Available at: ipfcc.org/about/pfcc.html.

How do PFACs Benefit Maryland Practices?

Establishing a PFAC will enable practices to fulfill a critical care delivery program requirement of many current alternative payment models. Some examples of programs/certifications that include a patient and family engagement requirement are the National Committee for Quality Assurance Patient-Centered Medical Home, the Transforming Clinical Practice Initiative (TCPI) Practice Transformation Networks, and the Maryland Primary Care Program (MDPCP). Patient and family engaged care produces multiple benefits including improving quality, increasing patient self-efficacy, reducing staff and clinician burnout, and decreasing costs. PFAs help focus practice changes to optimize patient and family engagement.

How to Use the Guide

The Guide includes information to help practices establish PFACs, engage participants in meaningful activities to improve care, and expand the PFAC's impact. The Guide is organized into three sections; sustainability is discussed in each section. Practices can review sections most relevant to their needs and capacity to generate ideas and purposeful action.

- **Section One: Creating a PFAC (Beginner).** This section is for practices that have not implemented a PFAC or those that are looking to re-establish their PFACs. It contains basic information on PFAC structure and processes that prepare a practice and its patients and families for partnership. It also ensures the PFAC is positioned to advance practice transformation.
- **Section Two: Strategic PFAC Integration (Intermediate).** This section is targeted to practices with some PFAC experience. It provides practices with strategies for effectively utilizing a PFAC and integrating PFA perspectives into key strategic and transformational efforts.
- **Section Three: Expanding the PFAC's Impact (Advanced).** This section is designed for practices with advanced PFACs.[5] It includes strategies for involving PFACs in chronic care and other direct care improvement efforts.

Within each section, the Guide addresses key topics, providing concrete and actionable steps accompanied by tips, links to additional tools, and frequently asked questions (FAQs). At the end of the Guide, additional forms (Appendix A) and resources (Appendix B) are available to users.

[5] Advanced PFACs have typically been in existence for several years and usually address in-depth quality and safety issues not typically seen in newer PFACs.

About the Guide

A number of practices provided guidance during the development of the Guide. The Guide is targeted to meet the needs of Maryland practices that plan to convene or have convened a PFAC. Practices are encouraged to use the Guide to inform PFAC decision-making. This Guide is not intended to address all PFAC implementation challenges.

Section One: Creating a PFAC (Beginner)

Assessing a Practice's Readiness for Partnership with Patients and Families

WHAT:	A practice should assess its capacity for and commitment to implementing a PFAC.
WHY:	Ensuring readiness will help practices develop sustainable partnerships with patients and families that lead to longer-lasting benefits, such as higher quality and better coordinated care.

HOW:	• Start by identifying initial strengths, needs, and challenges of the practice (before recruiting PFAs and building expectations among the patients in the practice).
	• Explore the questions below in meetings with practice leadership and staff:
	  ○ Are key practice leaders, staff, and clinicians supportive of patient and family partnerships? Are they willing to listen to and make changes based on PFA input?
	  ○ What opportunities exist to partner with PFAs? What strategic initiatives and quality improvement projects are planned or currently underway that might benefit from PFA involvement?
	  ○ Is the practice willing and able to establish and maintain a process to identify, select, and support PFAs? Who will be responsible and accountable for this process?

Frequently Asked Questions

What are some of the organizational benefits for practices establishing a PFAC?

Practices that use PFACs have found organizational benefits including improvements in staff and patient satisfaction ratings, practice image, and market share.[6]

What if the practice readiness assessment identifies concerns?

Most practice readiness assessments for partnering with patients and families will bring to light some concerns. Engaging staff and clinicians and obtaining their perspectives about the partnership with PFAs assists a practice in proactively addressing any apprehension and developing a well thought out approach for establishing a PFAC.

What do practices typically find is the anticipated level of cost and technology investment to implement a PFAC?

Practices typically find PFACs to be a low cost and low technology investment because no new equipment is needed.[7] The main PFAC investment is staff time.

Tips

- A practice can benefit from dedicating certain PFAC planning members to staff PFAC meetings or serve as members of the PFAC itself.[8]
- Like quality improvement efforts themselves, assessing practice readiness for PFAC is not a linear process. As practices engage patients and families, they should expect to reconsider and revisit some of the practice readiness assessment steps.[9]
- To learn how other practices developed and used PFACs and to identify best practices, practice staff should interview PFAC coordinators from other practices that have implemented PFACs.[10]

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[6] American Medical Association (AMA). STEPS Forward. *Forming a Patient and Family Advisory Council*. Available at: stepsforward.org/modules/pfac.

[7] *Ibid*.

[8] *Ibid.*

[9] Davis S., Gaines, M. E., Pandhi, N. University of Wisconsin (UW) Health. Primary Care Academics Transforming Healthcare. UW Health Innovation Program. *Patient Engagement in Redesigning Care Toolkit, Version 2.0. Center for Patient Partnerships*. 2017. Available at: hipxchange.org/PatientEngagement.

[10] Niehaus, K., Epstein, C., Temple, L., Sepkowitz, K. New England Journal of Medicine Catalyst. *Capturing The Patient Voice, A Patient and Family Advisory Council for Quality: Making Its Voice Heard at Memorial Sloan Kettering Cancer Center. December 2016*. Available at: catalyst.nejm.org/pfac-quality-memorial-sloan-kettering/.

Provider Perspective

"The advances [PFACs] have driven have made us better than we could have been on our own. We believe this is the future of patient-centered care." - *Maureen Fagan, Brigham and Women's Hospital, Executive Director for the Center for Patients and Families*[11]

Selecting a PFAC Coordinator for Patient and Family Partnerships

WHAT:	It is important to select a PFAC Coordinator to serve as the liaison between the PFAC and the practice. This individual supports the integration of PFAs in practice transformation.
WHY:	Creating and sustaining a PFAC requires time and focus. A PFAC Coordinator can manage the operational details needed to implement and support the PFAC.
HOW:	• The practice should outline the PFAC Coordinator's responsibilities, which typically include: overseeing recruitment, selection, and training of PFAs; managing PFAC activities; serving initially as the PFAC chair or co-chair; working with clinicians and staff to identify opportunities for involvement; and tracking and communicating PFAC accomplishments to practice staff and patients. • PFAC Coordinators need access to practice leaders and dedicated time with practice leaders to complete key tasks. Practice staff and clinicians need to be aware of the PFAC Coordinator's role and responsibilities.

Frequently Asked Questions

Who may serve as a PFAC Coordinator?

Any patient-facing staff, such as care managers, nursing staff, patient navigators, and practice managers may serve as a PFAC Coordinator.

Is the PFAC Coordinator a full-time role?

Typically, a PFAC Coordinator is a part-time role and may be combined with another job/responsibility.

[11]Epic. Using Patient and Family Advisory Councils to Drive Patient Satisfaction. *Patient Knows Best.* November 2016. Available at: epic.com/epic/post/using-patient-family-advisory-councils-drive-patient-satisfaction.

What qualities should I consider in selecting a PFAC Coordinator?

A practice should select a PFAC Coordinator with an understanding of the role of the PFAC and a strong passion for patient and family-centered care.[12]

Tips

- Practices should select PFAC Coordinators familiar with the principles of PFCC.[13] The core concepts of PFCC are: dignity and respect, information sharing, participation, and collaboration.
- The practice should assign the PFAC Coordinator a significant role when establishing the PFAC. Over time, the PFAC Coordinator should share more responsibility with PFAs, including preparing meeting agendas and notes, co-chairing the PFAC, and suggesting and selecting projects.
- A PFAC Coordinator should have strong facilitation and collaboration skills, the ability to build a rapport easily with diverse individuals, and experience in implementing new processes.

Provider Perspective

"A PFAC, as a vehicle for collaboration promoting the patient voice, can be much more than a checked box for CPC+. A successful Patient and Family Advisory Council can serve as a collaborative source of expertise for improving your practice." - *Keesha Goodnow, PFAC Coordinator*[14]

Preparing Clinicians and Staff for PFAC Collaboration

WHAT:	Educating clinicians and staff about the principles of patient and family collaboration.
WHY:	Practice leaders, clinicians, and other staff may not be familiar with PFAs and their role. Providing information on the purpose of partnering with patients and families may address concerns or misconceptions about PFACs, and help clinicians and staff understand how to work more effectively with PFAs.

[12] West, M., and Brown, L. *Patient and Family Advisory Council, Getting Started Tool Kit*. Available at: cdn.ymaws.com/www.theberylinstitute.org/resource/resmgr/webinar_pdf/pfac_toolkit_shared_version.pdf.

[13] See n. 4, *Supra*. (IPFCC).

[14] Goodnow, K. Physicians Practice. *7 Lessons in Launching a Patient and Family Advisory Council.* December 2017. Available at: physicianspractice.com/patients/7-lessons-launching-patient-family-advisory-council.

HOW:	Understanding the key elements of PFCC is an important first step in working with PFAs. Select a PFAC coordinator who can champion the idea of working with PFAs and obtain buy-in from other staff.

Frequently Asked Questions

What if some staff question whether patients know enough about health care to add value?

The practice should reassure staff and provide examples on how diversifying a group adds new perspectives to challenges, awareness of a wider array of resources, and a rich catalog of experience in reforming systems.[15]

What if some staff are resistant to working with PFAs?

Some resistance, particularly in the beginning, is natural. Traditionally, clinicians have not been trained to partner with patients and families to improve care processes. Providing a combination of reassurance about the benefits of patient collaboration and information about the patient engagement process will help alleviate concerns and resistance.

How can a practice build support among clinicians and staff for PFAC collaboration?

A practice can build support among clinicians and staff by discussing the benefits and value of working with PFAs. The practice should encourage staff and clinicians to share their concerns about partnering with PFAs and then proactively address the issues.[16]

Tips

- Practices should invite staff and clinicians to attend PFAC meetings and invite PFAs to attend staff meetings to talk about their experiences.
- Practices should be patient; despite initial skepticism, team members' attitudes about patient engagement improves over time.[17]
- Sharing examples from other practices will help clinicians and staff understand the benefits of working with PFAs.

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[15] See n. 9, *Supra*. (Davis)

[16] See n. 12, *Supra*. (West).

[17] Davis S., Berkson S., Gaines M.E., Prajapati P., Schwab W., Pandhi N., Edgman-Levitan S. Journal General Internal Medicine. *Implementation Science Workshop: Engaging Patients in Team-Based Practice Redesign-Critical Reflections on Program Design*. 2016; 31(6):688-95.

Provider Perspective

"What we think they want or what we think will be helpful is not always what they want." *Meggan Grant-Nierman, DO, physician advisor, First Street's PFAC.*[18]

Defining the PFAC's Purpose, Structure, and Membership

WHAT:	Develop PFAC guidelines that outline its purpose, establish its structure, and define membership.
WHY:	The guidelines provide a foundation to keep everyone working toward shared goals. They also create a framework to guide decisions about membership, procedures, and expectations.
HOW:	• Create a PFAC charter that outlines: ○ Purpose and goals (i.e., PFAC mission statement).[19] ○ Structure and size of the PFAC: Specify to whom the PFAC reports and its relationship to practice leadership. Provide guidelines about size and the percentage of PFAs that comprise the PFAC;[20] best practices suggest that at least half of PFAC members should be PFAs.[21] ○ Membership eligibility, qualifications, and terms: While no special skills are needed to serve as a PFA, individuals should have recent experience with the practice. PFAs typically serve up to two years, although membership may continue longer if mutually desired.[22] ○ PFAC meeting schedule: Indicate when the PFAC will meet and for how long. Most PFAC meetings are monthly, and last for up to two hours.[23]

[18] See n. 6, *Supra*. (AMA).

[19] Aligning Forces for Quality (AFQ). Robert Wood Johnson Foundation. *Engaging Patients in Improving Ambulatory Care*. March 2013. Available at: rwjf.org/en/library/research/2013/03/engaging-patients-in-improving-ambulatory-care.html.

[20] Centers for Medicare and Medicaid Services (CMS) and the National Partnership for Women & Families. *Key Steps for Creating Patient and Family Advisory Councils in CPC Practices*. 2013. Available at: innovation.cms.gov/Files/x/cpci-patientfamengresource.pdf.

[21] See n. 4, *Supra*. (IPFCC).

[22] See n. 19, *Supra*. (AFQ).

[23] See n. 12, *Supra*. (West).

	○ Responsibilities and duties of PFAC members: Outline expectations for respectful partnership, training and orientation, attendance at meetings, and anticipated work or activities outside of meetings (e.g., participation in committees or transformation teams).[24] Many PFACs ask clinicians, staff, and PFAs to commit to attending at least 80 percent of the meetings.[25] ○ Confidentiality procedures: Discuss expectations related to privacy and confidentiality, including any documents that PFAC members are required to review and sign.[26] ○ Budget and reimbursement for expenses: Practices should provide PFAs with information about the PFAC budget and covered expenses, including food for meetings, stipends (if possible) and reimbursement for travel-related expenses or childcare. Other budget items may include supplies and communication-related expenses.[27]

Frequently Asked Questions

Who should draft the PFAC charter?

The PFAC Coordinator and staff should develop the draft PFAC charter. The practice should review and adjust the charter as the PFAC evolves, with input from PFAs.

How many people should be on the PFAC?

PFAC size may vary depending on the practice. Ideally, small practices (one to two clinicians) should include around six PFAs; while larger practices should include up to 18 PFAs. While smaller-sized PFACs will be easier to facilitate, it is important to include sufficient numbers of PFAs to ensure strong representation of patient and family perspectives at every meeting.

How should the practice manage PFAC turnover?

A practice should consider bringing new PFAC members onboard every three to six months rather than all at once. This will create a balance of both new and experienced members and avoid having a large number of PFAs turn over simultaneously.

[24] *Ibid*.

[25] *Ibid*.

[26] See n. 6, *Supra*. (AMA).

[27] See n. 12, *Supra*. (West).

Tips

- A practice should invite individuals from the medical neighborhood[28], such as representatives from specialists and hospitals to whom a practice makes referrals, to be members of the PFAC.
- The practice should draft the PFAC mission, vision, and goal statements, and at the initial meeting be prepared to discuss these statements, seek feedback, and be open to changes.[29]
- The practice should outline roles and responsibilities at the first few PFAC meetings. These meetings are critical for setting the tone and establishing an appropriate meeting structure.

Provider Perspective

"I like the collaborative feel of it. It may be useful to start each meeting stating the mission or goal of the group. It can sometimes get too focused on individual experiences." - *Survey response from Sibley Memorial Hospital staff* [30]

Recruiting Patient and Family Advisors

WHAT:	Identifying and recruiting PFAs who are well suited for the role is a foundational step in developing successful PFACs and partnerships.
WHY:	The practice should devote time and attention to ongoing recruitment efforts to identify patients and family members who are a good match with a practice's needs, interested in improving the quality and experience of care for all patients, and assist in generating ideas in productive and collaborative ways.
HOW:	• Develop recruitment materials and publicize information about the PFAC: Create a one-page flyer or brochure for patients and families that describes the PFAC, characteristics of effective PFAs,[31] the work involved, the time commitment, and other logistics. Flyers may be posted at the front desk, in

[28] The medical neighborhood is defined by the Patient Centered Primary Care Collaborative (PCPCC) as a clinical-community partnership that includes the medical and social supports necessary to enhance health, with the PCMH serving as the patient's primary hub and coordinator of health care delivery. Available at: pcpcc.org/content/medical-neighborhood.

[29] See n. 20, *Supra*. (CMS)

[30] Hopkins Medicine. *Patient and Family Advisory Council (PFAC) Annual Report 2013*. Available at: hopkinsmedicine.org/sibley-memorial-hospital/_documents/about-the-hospital/pfac_annual_report_2013.pdf.

[31] PCPCC. *How You Can Be An Effective Patient & Family Advisor: Guide to Partnering with Your Clinic*. June 2017. Available at: pcpcc.org/resource/how-be-effective-patient-family-advisor..

	waiting room areas, and in exam rooms. A practice may also distribute information about the PFAC at patient support groups[32] and in the community. Engage community groups as ongoing PFA recruitment partners, and meet with them to provide information and answer questions. • Clinicians and staff should share information about the PFAC with potential PFAs via conversations and recruitment flyers and brochures. Practices should engage potential PFAs in a conversation focused on learning about their interests and experiences to inform on needs for the practice to address and ensure a diverse representation on the PFAC. • Follow up with individuals who have provided constructive comments. Reviewing patient and family comments, compliments, and complaints may help identify individuals who have constructive input to offer. A practice may also consider contacting patients that have provided helpful input via patient satisfaction surveys, if applicable.

Frequently Asked Questions

What do patients and families see as the benefits of serving as PFAs?

Many patients and families view PFAC participation as an opportunity to contribute to the practice and represent the needs of patients like themselves in the community.

What are the most important characteristics to consider in recruiting PFAs?

It is helpful for a practice to identify people who work effectively in groups, listen to and consider diverse perspectives, and who have time to serve as PFAs. The practice should think about representation of the patient population—for example, age, health conditions, geographic location, and other demographics—to ensure inclusion of diverse perspectives.[33]

Does a practice need to have marketing expertise for recruitment?

Practices do not need to have marketing expertise for PFA recruitment. When practices first start to recruit PFAs, knowledge of patients and families is the best recruitment strategy. For ongoing efforts, some practices use other methods (e.g., social media, practice website or patient portal) to recruit PFAs.

[32] Merriam Webster defines support groups as a group of people with common experiences and concerns who provide emotional and moral support for one another. Available at: merriam-webster.com/dictionary/support%20group.

[33] See n. 6, *Supra*. (AMA).

Tips

- When recruiting PFAs, look for patients and family members that are actively involved in their care or the care of a family member.[34]
- A practice should view recruitment as an ongoing process, not a one-time event. Continued attention to the infusion of new PFAs helps ensure long-term success and sustainability of the PFAC.[35]
- Five ways to identify potential PFAs are (1) referrals from clinicians; (2) review of patients receiving care coordination services; (3) outreach to trusted community groups (e.g., faith communities, social service organizations); (4) asking patients attending practice sponsored education or health forums; and (5) referrals from existing PFAs.[36]
- A practice having difficulty recruiting PFAs should take time to identify and address potential barriers to participation. Addressing concerns such as having trouble understanding the duties of a PFA or whether the practice truly will make changes based on PFA input will help in promoting PFA participation.[37]

Provider Perspective

"After almost seven years of experience, one of the most significant drivers for PCMH transformation: family-centered care with parents as improvement partners." *Reported by a provider in a study published in The Annals Family Medicine*[38]

Selecting PFAs

WHAT:	Selecting PFAs who are both suited for and committed to the role.

[34] AMA and Johns Hopkins University. Improving Health Outcomes: Blood Pressure (Iho: Bp). *Patient and Family Advisor Recruitment Guide and Onboarding Toolkit, Version 1.0*. 2015. Available at: ama-assn.org/sites/default/files/media-browser/public/about-ama/iho-bp-patient-and-family-advisor-recruitment-guide_0.pdf.

[35] Agency for Healthcare Research and Quality (AHRQ). *Patient and Family Advisor Orientation: Helpful Resources for Hospitals*. Publication No. 17-0005-EF, December 2016. Available at: innovations.ahrq.gov/learning-communities/patient-and-family-centered-care/resourceguidepatient-and-family-advisor-orientation-helpful-resources-hospitals.

[36] See n. 20, *Supra*. (National Partnership for Women & Families).

[37] *Ibid.*

[38] McAllister, J. W Cooley W. C., Cleave, J. V, Boudreau, A. A., and Kuhlthau, K. Annals Family Medicine. *Medical Home Transformation in Pediatric Primary Care—What Drives Change?* May/June 2013 11:S90-S98; doi:10.1370/afm.1528.

WHY:	PFAs who are committed to the role are a critical step in developing successful PFACs.
HOW:	• Selecting PFAs involves three key steps: ○ Develop a simple application form for potential PFAs to gather contact information, demographics, skills, interests, and time availability. ○ Schedule in-person or telephone interviews. The PFAC Coordinator should conduct interviews, either alone or with another member of the practice. During the interview, ask about the patient or family member's health care experiences, skills, and why they are interested in joining the PFAC. Share with them information about the role of the PFAC including meeting logistics and expense reimbursement. ○ Follow up with an invitation letter or email reiterating PFA expectations, roles, and time commitment. Include information about the orientation session and next scheduled PFAC meeting.

Frequently Asked Questions

Should the practice only select PFAs who have had positive care delivery experiences with their practice?

Positive experience with the practice is not a requirement for PFAs. PFAs should be able to share and apply their own experiences in constructive ways. The PFAC will be more effective if PFAs represent the diversity of the patient population – including individuals who have had positive and negative experiences of care.

What if a potential PFA expresses concern about their capability to serve as a PFA?

The practice should ask questions to understand the source of the potential PFA's concern and address that concern. Provide reassurance that no specific clinical knowledge is needed. PFAs' greatest expertise is their lived experience.

Are patient and families receptive to being asked to serve on advisory councils?

The AMA STEPS Forward™ PFAC module states that people are receptive and welcome the opportunity to help their care team and have their voices heard.[39] In messaging, present PFAC membership as an opportunity for meaningful volunteer work.[40]

[39] See n. 6, *Supra.* (AMA).

[40] *Ibid.*

Tips

- Make the interview process as comfortable and flexible as possible. Initial interviews should last about 30 minutes.[41] Some potential PFAs may not have extensive experience with interviews.
- A practice should invite more PFAs than they think they will need. Expect approximately 10 to 25 percent of individuals contacted to respond. The invitation itself spreads good will.[42]
- Small practices may be challenged with finding time to conduct recruitment, screening, and selection of PFAC members. For these practices, an invitation to discuss possible participation in a PFAC may occur through flyers and posters.

Provider Perspective

"Through their unique perspectives, [patients] give input on issues that impact care, ensuring that the next patient or family member's journey is easier." - *Meghan West and Laurie Brown, BJC Healthcare*[43]

Orienting and Training PFAs

WHAT:	Providing orientation and training for PFAs is critical in developing a successful PFAC and partnerships.
WHY:	Orientation helps PFAs understand the responsibilities and expectations of the role and how they may partner with the practice in meaningful ways.

HOW:	• Determine the format for a PFA PFAC orientation. Orientation may be conducted as a one-on-one meeting with the PFAC Coordinator and the PFA, a group meeting with multiple PFAs, or by providing information for PFAs to review on their own.
	• Compile relevant orientation material. Key orientation topics include:
	  ○ Brief overview of PFCC and the importance of partnership with patients and families;
	  ○ Overall purpose and structure of the PFAC, roles and responsibilities, a list of PFAC members, and expectations for serving as a PFA;

[41] See n. 34, Supra. (Hopkins).

[42] See n. 9, *Supra*. (Davis).

[43] See n. 12, *Supra*. (West).

	○ Overview of the practice, its goals for transformation, and how the PFAC will help address those goals; ○ Information about the impact on the practice of any current or past quality improvement programs (e.g., TCPI, MDPCP), and any care delivery partners (e.g., local hospitals or community health organizations); ○ Logistic meeting information, such as time and location, meeting duration, and who to contact with questions; and ○ Information regarding privacy and confidentiality, compensation, and expense reimbursement. • Education and training should be ongoing. After the initial orientation, PFAs benefit from ongoing education to help them understand evolving issues in health care and quality improvement.

Frequently Asked Questions

Should practices develop a formal orientation handbook or manual?

Practices should develop orientation material for PFAs. For the first few PFAC meetings, a practice should develop and provide written materials to support orientation. As the PFAC evolves, integrate these materials into a resource guide.

Should a practice only select PFAs with a clinical background?

A clinical background is not required to serve as a PFA. Practices should provide PFAs with a glossary of clinical terms that may be used in discussions. Prior to PFAC meetings, consider what information (clinical and otherwise) is needed to facilitate meaningful PFA participation.

How should practices address the learning and orientation needs of PFAs from different backgrounds?

A mixed media approach which includes adding aural and visual elements to instructional materials works best since the type of resources that a patient or support person responds to varies from person to person.[44]

[44] MedlinePlus. *Choosing Effective Patient Education Materials*. November 2017. Available at: medlineplus.gov/ency/patientinstructions/000455.htm.

What if staff are worried about compliance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA)[45] or Maryland privacy laws, such as the Maryland Medical Record Confidentiality Act[46] when working with PFAs?

PFAs should be given the same privacy and confidentiality training as practice staff. Reassure staff and clinicians that anything discussed in PFAC meetings must remain confidential and provide them with information about HIPAA and PFCC.

Tips

- Practices should consider asking existing PFAs to serve as mentors for new members.[47]
- Consider asking the PFAC to develop a PFA orientation resource guide.[48]
- Practices should avoid the use of jargon and acronyms in PFAC orientation and training materials, and during PFAC meetings.[49]

Patient Perspective

"No one cares more about the quality of health care than patients and families. What this convening has shown is that patients are ready, willing, and able to be partners with health care professionals to achieve better quality both in our personal care and in the improvement of health care in general. Some patients will insist on engagement, others only need to be asked."[50]
- *David Andrews, Patient Advisor, Georgia Regents Medical Center*

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[45] The Health Insurance Portability and Accountability Act of 1996 (HIPAA), Public Law 104-191, included Administrative Simplification provisions that required the U.S. Department of Health & Human Services (HHS) to adopt national standards for electronic health care transactions and code sets, unique health identifiers, and security. A summary of these regulations may be found at: hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html.

[46] The Maryland Confidentiality of Medical Records Act (MCMRA) includes any oral, written or other transmission in any form which is entered into the record of and relates to the health care of the patient and which identifies or can readily be associated with the patient. A comparison chart developed to explore similarities and differences between MCMRA and HIPAA may be found at: mhcc.maryland.gov/mhcc/pages/hit/hit_hipaa/documents/HIPAA_St_vs_Fed_Compare_HIPAA_Privacy_Statute_Reg_20120808.pdf.

[47] See n. 12, *Supra*. (West).

[48] CMS. *Workshop for the New York State Partnership for Patients (NYSPFP)*. July 2016. Available at: nyspfp.org/MeetingMaterials/285/NYSPFP_PFAC_Patel_7_28_2016.pdf. (CMS2)

[49] See n. 9, *Supra.* (Davis).

[50] Carman, K. L., Dardess, P., Maurer, M. E., Workman, T., Ganachari, D., Pathak-Sen, E. *A Roadmap for Patient and Family Engagement in Healthcare Practice and Research*. September 2014. Available at: https://www.air.org/project/roadmap-guides-patient-and-family-engagement-healthcare/.

Sustaining the Partnership

WHAT:	A practice developing a PFAC should also plan for its sustainability.
WHY:	Many improvement initiatives, including PFACs, start off with momentum but experience a decline over time.[51]
HOW:	• Helping PFAs develop additional skills, (e.g., communication, co-facilitation of the PFAC and improvement initiatives) will enable the PFAC to work more effectively as a group and support long term sustainability.[52] • Be ready to integrate new members when interested individuals come forward.[53]

Frequently Asked Questions

Why is it important to describe all PFAC goals to new PFAs?

The risk is that initially PFAs will not have enough knowledge of the practice's objectives to fully contribute to the work. Patient feedback provided without structure and insufficient knowledge among PFAs can cause the PFAC to be ineffective.[54]

How much information should be provided to PFAs?

The practice should establish and maintain effective communications with PFAs. It can be discouraging for PFAs to discuss an issue or policy and not see evidence that their input was valued or led to any changes.[55]

How can proper PFA orientation impact sustainability?

Failing to provide proper orientation undermines the overall effectiveness of the PFAC. It can lead PFAs to becoming frustrated or lose interest. Staff may also be skeptical of the PFA's motives or lose patience with them not knowing basic information about practice functions.[56]

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[51] Colorado Hospital Association. *Patient and Family Advisory Councils; A Hospital Toolkit to Engage Patients*. 2015. Available at: dfwhcfoundation.org/wp-content/uploads/2018/05/PFAC-Toolkit-April-201533220.pdf.

[52] *Ibid.*

[53] *Ibid.*

[54] Hoy, L. Relias Media. *Patient and Family Councils Make a Difference*. September 2018. Available at: https://www.reliasmedia.com/articles/143150-patient-and-family-councils-make-a-difference.

[55] *Ibid.*

[56] *Ibid.*

Tips

- Provide PFAC meeting/activity summaries to PFAs and practice staff to demonstrate how PFA feedback is being incorporated into the practice.
- Hold meetings at a mutually agreed upon time and date to encourage regular attendance by PFAs and practice staff.[57]
- Follow up with PFAs via phone, e-mail and text to show their input is valued.[58] PFAs are more likely to stay engaged if the practices recognize the value of the PFA input.

Patient Perspective

"Being a part of the newly designed Patient Family Advisory Council allows me to really feel like I am making a difference in the way the patient is seen through the eyes of the caregivers. I have the ability now to be involved in greater depth and to an extent I had never really experienced before. I truly feel like I am part of the history of this hospital, making a difference in the care, and future care, of many people in our community." - *Emma Course, Patient Family Advisor*[59]

Section Two: Strategic PFAC Integration (Intermediate)

Facilitating Meetings to Ensure Meaningful Participation

WHAT:	Meetings need to be carefully planned and facilitated to ensure that a PFAC functions effectively as a group.
WHY:	PFAC members and practice staff want to feel productive.[60] Meetings should be structured to support collaboration.
HOW:	Follow best practices for effective meetings[61], including:

[57] *Ibid.*

[58] *Ibid.*

[59] Long Beach Memorial Miller Children's Hospital. *Long Beach Memorial Medical Center & Miller Children's Hospital Patient and Family Engagement Success Story*. August 2013. Available at: healthinsight.org/Internal/hen/PFE_Long_Beach_Story_FINAL.pdf.

[60] See n. 9, *Supra*. (Davis).

[61] Knox L., Powell J., Suchman A. *Primary Care Practice Facilitation Curriculum (Module 22)*.

	• Distribute agendas in advance along with relevant background and meeting materials; • Start and end on time; and • Conclude with a summary of major issues discussed, responsibilities, and action items/next steps.

Frequently Asked Questions

What happens when the behavior of certain members is disruptive to the meeting process, e.g., monopolizing the conversation, interrupting others, or focusing too much on their own personal experiences?

In these situations, the PFAC Coordinator or chair should intervene during the meeting to shift the conversation in a more productive direction. After the meeting, the PFAC Coordinator or chair should meet privately with the individual member and provide constructive feedback about their behavior on the group process.[62]

Who should facilitate discussion so that everyone is heard?

The PFAC coordinator or chair should facilitate the discussion to encourage participation from all members.[63] The effectiveness of the PFAC is in part driven by the diversity of ideas from the PFAs.

How should I include time on the agenda for updates on PFAC work?

PFAC members want to understand how their input impacts change. Periodically, include time on meeting agendas to discuss how the PFAC is functioning and to celebrate accomplishments and milestones.[64] Practices should establish a process for PFAs to contribute to PFAC agenda items.

Tips

- Many PFACs begin meetings with a patient story to ground discussions in real life experiences of care and to encourage PFAs to share their unique expertise.[65]

AHRQ Publication No. 15-0060-EF, Rockville, MD: Agency for Healthcare Research and Quality, September 2015. Available at: pcmh.ahrq.gov/sites/default/files/attachments/pcpf-module-22-meetings.pdf.

[62] See n. 4, *Supra.* (IPFCC).

[63] See n. 12, *Supra.* (West).

[64] See n. 6, *Supra*. (AMA).

[65] See n. 34, *Supra*. (Hopkins).

- Leave time for patient discussion, questions, and interaction. If a practice has a significant amount of information to share with PFAC members, consider doing this in advance of the meeting to preserve time for patient interaction and discussion.[66]

- A practice should track PFA attendance to encourage and optimize the range and diversity of PFA feedback at meetings.

Provider Perspective

"I think PFAC is the most interesting and thought provoking committee I attend- I leave each meeting stimulated to how I can do things better as a physician and how we can do things better as a cancer center." [67] - *Physician on PFAC*

Evaluating a PFAC's Effectiveness

WHAT:	PFACs that truly influence an organization's leadership, strategies, and operations regularly evaluate their own effectiveness.[68]
WHY:	Establishing a system for measuring, tracking, and communicating the PFAC's work helps assess its impact and demonstrates the benefits of partnering with PFAs.[69]

HOW:	• Develop a system for measuring and tracking PFA activities and outcomes of projects where PFAs are involved.[70] Capture summary information about the PFAC including:
	  ○ The number of PFAs recruited and trained;
	  ○ Clinicians and staff who have been involved in collaborative work;
	  ○ Distinct projects where PFAs have participated;
	  ○ Outcomes of PFAC projects; and
	  ○ Total hours logged by PFAs.[71]
	• Use the measurements collected above to conduct a performance assessment.

[66] See n. 20, *Supra*. (National Partnership for Women & Families).
[67] See n. 12, *Supra.* (West).
[68] See n. 4, *Supra.* (IPFCC).
[69] *Ibid.*
[70] *Ibid.*
[71] See n. 4, *Supra*. (IPFCC).

	• On a periodic basis, collect information from PFAC members about their participation experience related to the questions below. Share the responses with practice leadership and PFAC members, as well as medical neighborhood partners.[72]
	  ○ Do you find the work interesting and valuable?
	  ○ Do you feel that your ideas are heard?
	  ○ To what extent are you seeing the results of your work?

Frequently Asked Questions

How often should we conduct performance assessments?

Many PFACs prepare an annual report that provides summary information about the PFAC, including a list of the PFAC's activities and accomplishments.[73]

What are some measures I can use to determine impact and success of a PFAC?

PFAC Coordinators should consider practice-level measures, such as those related to patient surveys, experience or quality of care. Comparing practice scores on these measures over time can help assess the impact of the PFAC

How can I track the PFAC's performance over time?

Use summary data collected by the PFAC coordinator that tracks PFA activities and outcomes of PFAC projects to create dashboards with benchmarks for quality improvement efforts.[74]

Tips

- One way to document the effectiveness of PFAC activities is to catalog before and after photos of projects (e.g., changes to the EHR patient portal).[75]
- Include PFAC dashboards in staff/practice newsletters to describe the progress of the PFAC quality improvement (QI) work and the benefits of the PFAC.
- Report on any PFAC work that helped fill specific gaps identified in the practice's initial person and family engagement (PFE) self-assessment to practice and PFA team members.[76]

[72] See n. 9, *Supra*. (Davis).
[73] See n. 34, *Supra*. (Hopkins).
[74] See n. 50, *Supra*. (Carman).
[75] See n. 12, *Supra*. (West).
[76] See n. 6, *Supra*. (AMA).

Provider Perspective

"If just one person's cancer journey is benefited, it will be a priceless contribution. I hope the Patient and Family Advisory Council simply diminish some of the fear and lack of control that is so intense when a cancer diagnosis stuns one's world."[77]- *RN, Oncology*

Selecting Patient-Identified Quality Improvement Projects

WHAT:	Partner with the PFAC in QI work and integrate PFAs into existing projects and committees to ensure that transformation work addresses practice needs and patient and family priorities.
WHY:	With a growing emphasis on increasing value from the perspective of patients and families, practices must address care delivery issues that are important to recipients of care. PFACs can help identify gaps in care and provide a mechanism to prioritize improvement opportunities and possible changes based on what is important to patients and families.[78]

HOW:	• The PFAC should identify themes, concerns, and improvement opportunities:
	  ○ Ask each PFAC member to identify and prioritize improvement opportunities by identifying the most important areas to address, and select the two areas with the most votes for additional discussion and action.
	  ○ Brainstorm ideas for changes or improvement projects that might address those areas, including additional data that is needed to inform further discussion, and select projects for more exploration or implementation based on the discussion.
	• Encourage practice leaders to attend PFAC meetings to better understand why patients and family members have chosen those priorities. If practice leadership is not present for the prioritization process, the PFAC coordinator or a PFA should present the PFAC recommendations to them.[79]

[77] See n. 12, *Supra*. (West).

[78] Johnson, K. E., Mroz, T. M., Abraham, M., Figueroa G., M., Minniti, M., Nickel, W., Reid, R., Sweeney, J., Frosch, D. L., Ness, D. L., Hsu, C. Advances in Therapy. *Promoting Patient and Family Partnerships in Ambulatory Care Improvement: A Narrative Review and Focus Group Findings*. 2016, 33(8), 1417-39. Available at: ncbi.nlm.nih.gov/pmc/articles/PMC4969329/.

[79] See n. 20, *Supra*. (National Partnership for Women & Families).

Frequently Asked Questions

At what point should the practice solicit input from the PFAC on a QI project?

Solicit input from PFAs on QI projects as soon as possible. Learning upfront what has or has not worked well from the patient and family perspective will inform and contribute to the development of solutions.[80] It is important for the PFAC to be involved throughout the entire cycle of QI projects, from project conception to debrief.

Should I share information about the practice's QI priorities with the PFAC?

When PFAs understand practice goals, they are better able to meaningfully contribute to practice QI projects.[81] PFAs can provide input on what is important from the patient and family perspective. PFAs can also gather ideas and concerns from their network of family and friends.

How should a practice determine which QI projects can benefit from PFAC participation?

Determining QI projects that benefit from PFAC participation is an iterative process.[82] Involve members in project development early on to optimize the use of member skills, time, and effort. The PFAC should be generating and suggesting ideas for QI projects as well as providing feedback on practice identified QI projects.

Tips

- PFAs will not remain engaged in the PFAC if they feel they are only involved with the practice to fulfill a requirement and are not making a difference. It is important for the practice to continually demonstrate that patients' and family caregivers' voices are being heard and taken seriously.[83]
- Advisors should always know the outcome of their advice, even if their suggestions cannot always be implemented.[84]
- Have a standing PFAC agenda item for sharing information about upcoming new QI projects and updates about ongoing improvement teams.

[80] See n. 79, *Supra.* (Johnson).

[81] See n. 4, *Supra*. (IPFCC).

[82] See n. 10, *Supra*. (Niehaus).

[83] See n. 20, *Supra*. (National Partnership for Women & Families).

[84] *Ibid*.

Provider Perspective

"The autonomous governance and recruitment practices of the Patient and Family Advisory Council for Quality (PFACQ) have been instrumental in imbuing the group with a sense of empowerment and trust, which has, in turn, fostered innovative thinking."[85] - *Memorial Sloan Kettering Cancer Center*

Sustaining the Partnership

WHAT:	Practices should continually monitor PFACs for loss of momentum.
WHY:	After the development phase, practices need to focus equally on sustaining PFACs. [86]
HOW:	• Invest in current members. PFAs are committing time to the practice because they want to make a positive difference and learn from the experience.[87] • Educate new practice staff about the PFAC and its role.[88]

Frequently Asked Questions

How does a practice address the challenge of staff and PFAs who do not attend meetings regularly?

The PFAC Coordinator should seek out these members to ask about barriers to participation, (e.g., time of the meetings or conflicting priorities). Once barriers are identified, solutions can be explored (e.g., virtual participation options for a PFA who has difficulty attending in-person meetings).

What can a practice do if the PFAC members are not representative of the patient population?

Periodically assess the composition of the PFAC and define specific patient populations that may be under-represented.[89] Work with clinicians and community groups to reach out to these populations, and explore ways that the practice might engage potential PFAs.

What happens when practice leaders do not stay actively involved in the PFAC?

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[85] See n. 10, *Supra*. (Niehaus).

[86] Colorado Hospital Association. *Patient and Family Advisory Councils; A Hospital Toolkit to Engage Patients*. 2015. Available at: dfwhcfoundation.org/wp-content/uploads/2018/05/PFAC-Toolkit-April-201533220.pdf.

[87] See n. 12, *Supra*. (West).

[88] See n. 6, *Supra*. (AMA).

[89] See n. 20, *Supra*. (National Partnership for Women & Families).

Leaders are critically important to creating PFACs, sustaining their momentum, and linking PFACs to broader practice priorities. Ideally, practices will have at least one senior leader who serves as a member of the PFAC.

Tips

- Providing PFAs with additional training, coaching, or mentoring as needed will help sustain the PFAC long term.[90]
- Examining the match between advisor skills and practice needs will improve the satisfaction of the PFAs and encourage PFAC engagement.[91]
- The practice should debrief PFAC members on QI projects regularly.
- The practice should continue to develop and communicate the business case for the PFAC to practice leadership so they remain engaged and supportive.[92]
- The practice should address any problems related to the PFAC quickly.[93]

Provider Perspective

"In the past, the healthcare industry has made certain assumptions about what patients and families want. It was important to us to have their voices in the room when we are making decisions so we know what quality of care actually means to them." - *Rusty Holman, M.D., LifePoint's Chief Medical Officer.* [94]

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[90] See n. 48, *Supra*. (CMS2).

[91] *Ibid.*

[92] See n. 6, Supra. (AMA).

[93] *Ibid.*

[94] Castellucci, M. Modern Healthcare, Patient-led Advisory Councils Tackling Bigger Matters, October 2017. Available at: www.modernhealthcare.com/article/20171028/NEWS/171029924.

Section Three: Expanding the PFAC's Influence and Impact (Advanced)

PFACs as Facilitators of Strategic Community Partnerships

WHAT:	Many practices are reaching out to other health care organizations in the community to coordinate improvement work and share information.
WHY:	Patients and their families are the constants across care transitions. They can be effective partners in identifying care delivery gaps that create unsafe or confusing experiences.
HOW:	• Set aside at least two PFAC meetings annually for this specific topic, and invite representatives from other community organizations, such as local hospitals or health care systems. During the meetings, ask PFAs to share stories of care where better communication, collaboration, and coordination could have made care more effective. • Invite a third party (e.g., United Way, Chamber of Commerce) to convene a community forum that would include participation of PFAC members from multiple organizations.

Frequently Asked Questions

How do practices fit into the larger strategic community effort to optimize the value of health care?

Practices that collaborate with other community organizations to optimize patient-centered care play an important role in facilitating strategic community partnerships by preventing hospitalizations and avoiding unnecessary readmission for chronic conditions.[95]

How can collaboration among clinical partners set the stage for enhanced ambulatory care?

There are many ways collaboration among clinical partners set the stage for enhanced ambulatory care. One example is a primary care practice may assist patients in setting up

[95] Vega, K., Healthcare Financial Management Solutions. Leadership Plus. *How to Optimize Ambulatory Care*. September 2017. Available at: hfma.org/Leadership/Archives/2017/September/How_to_Optimize_Ambulatory_Care/.

their specialist appointment. Practices have found that the combination of the primary care endorsement of the specialist and the scheduled appointment has improved patient adherence and reduced the specialty provider's no-show rates.[96] PFACs can provide practices with guidance on the specialist referral process and follow-up.

What sort of collaboration between providers and health plans can enhance ambulatory care?

Ambulatory care practices can enhance care delivery by utilizing additional resources provided in collaboration with health plans such as dietitians, social workers, and behavioral health providers. This can be particularly effective when embedded into the practice. Additional resources can assist in proactively identifying potential issues before they potentially result in an acute care visit or a negative health outcome. Although it is a higher-cost model in the ambulatory setting, it is a lower-cost model overall when successfully preventing unnecessary hospitalizations, overutilization, and duplication of services.[97] PFACs can provide guidance as to what additional resources provided in collaboration with health plans are viewed as most beneficial to patients and families.

Tips

- Conduct a kickoff meeting for community partners to introduce themselves and build relationships with the goal of creating an action plan for collaborative efforts.[98]
- Health care improvement goals may be set for the whole community or a specific population within the community.[99]
- Partners in collaboration with the PFAC should establish metrics for assessing partnership effectiveness.[100]

Provider Perspective

"It means so much to be a member of a group of patients, caregivers, and coworkers who are sounding boards, champions, devil's advocates, and coaches — all working together to push the envelope of what it means to provide exceptional care to our patients." - *Memorial Sloan Kettering Cancer Center*[101]

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[96] *Ibid.*

[97] *Ibid.*

[98] American Hospital Association. Health Research & Educational Trust. *A Playbook for Fostering Hospital-Community Partnerships to Build a Culture of Health*. July 2017. Available at: aha.org/system/files/hpoe/Reports-HPOE/2017/A-playbook-for-fostering-hospitalcommunity-partnerships.pdf.

[99] *Ibid.*

[100] *Ibid*.

[101] See n. 10, *Supra*. (Niehaus).

Implementing Shared Medical Appointments

WHAT:	Shared medical appointments (SMAs), sometimes called group visits[102], offer an innovative, interactive approach to health care that brings patients with common needs together. During a typical SMA, 10 to 15 patients are seen together in a setting that encourages asking questions, and sharing concerns and experiences.
WHY:	A PFAC can provide realistic and useful suggestions to facilitate adoption of an SMA model that is sensitive to patient needs. While an individual appointment typically lasts 15 to 30 minutes, a shared appointment is 90 minutes long, allowing participants to spend more time with the health care team, while also interacting with and learning from their peers.
HOW:	• Share information with the PFAC about the benefits of SMAs and how they work, including other practices' experiences. • Ask the PFAC to develop a SMA frequently asked questions flyers that take into consideration different cultural and age-specific populations within the practice to encourage patients to participate in SMAs.

Frequently Asked Questions

How can PFAC members help practices feel comfortable with the use of SMAs?

The practice should engage PFAC members to support clinicians and staff during SMA skill development learning sessions, such as role playing.

How can PFAs improve the implementation and use of SMAs?

As practices develop or improve SMA processes, PFAs can be collaborators, helping to incorporate the patient and family perspective into all aspects of development and implementation.

How can the practice overcome staff concerns about SMAs?

The practice can overcome concerns by talking to the team and addressing the concerns, such as patient privacy.

[102] Jaber, R., Braksamher A., Trilliing, Journal Family Practice Management. *Group Visits for Chronic Illness Care: Models, Benefits, and Challenges.* (2006) 13(1), 37-40. Available at: https://www.aafp.org/fpm/2006/0100/p37.html

Tips

- Practices should solicit ideas from the PFAC regarding how to communicate the practice's SMA model with patients and families.
- The practice should ask the PFAC to role play physician-patient interaction in simulated SMAs. SMAs allow patients to see how the physician interacts with other patients, which allows them to get to know the physician and better determine their level of trust.[103]
- The practice should ask the PFACs for guidance on how to optimize the group dynamics of an SMA. SMAs lead patients and providers to develop more equitable relationships.[104]

Patient Perspective

"Do you know…what [SMA] helps me to see is what the physician, his devotion of trying to solve a health problem and trying to correct it. That actually reestablishes my faith in the medical system because you can see that they're really devoted to trying to figure out really what is ailing you" - *Patient #13*[105]

Implementing a Shared Decision Making Process and Tools

WHAT:	Shared decision making (SDM) is a process where clinicians and patients work together to make decisions based on clinical evidence that balances risks and expected outcomes with patient preferences and values.[106]
WHY:	Use of SDM in practices can improve quality of patient care, health outcomes, and patient and provider satisfaction.[107]
HOW:	• Ask the PFAC to review potential decision tools that are under consideration by the practice and provide feedback, or prioritize the tools they believe would be most useful for patients and families. • Work with the PFAC to develop the process for introducing SDM processes and tools to the practice and the patients and families.

[103] *Ibid.*

[104] *Ibid.*

[105] *Ibid.*

[106] Mayo Clinic. *Shared Decision Making National Resource Center*. Available at: shareddecisions.mayoclinic.org/.

[107] Agency for Healthcare Research and Quality. The CAHPS Ambulatory Care Improvement Guide. *Practical Strategies for Improving Patient Experience Strategy 6I: Shared Decision-making,* July 2017. Available at: ahrq.gov/sites/default/files/wysiwyg/cahps/quality-improvement/improvement-guide/6-strategies-for-improving/communication/cahps-strategy-section-6-i.pdf.

	• Ask PFAC members to identify key questions to ask in a patient survey, review the results and provide feedback to the practice. A practice may also ask the PFAC to interview patients about their experience.

Frequently Asked Questions

How can PFAC members help practices feel comfortable with the use of SDM?

Similar to SMA, the practice should engage PFAC members to support clinicians and staff during SDM skill development learning sessions, such as SDM role playing.[108]

How can PFAs improve the implementation and use of SDM?

Resembling PFAC contributions to SMA, as practices develop or improve SDM processes, PFAs can be collaborators, helping to incorporate the patient and family perspective into all aspects of development and implementation.

How can the practice overcome staff concerns about SDM?

The practice can overcome concerns by talking to the team and addressing the concerns, such as malpractice claims.

Tips

- Practices implementing shared decision-making can ask PFAs to follow-up with patients to determine whether they understood that they had options, how much the risks and benefits of each option was discussed, and whether their preferences were discussed to identify where the process of shared decision-making may be lacking and how it can be improved. [109]

- PFAC members can help promote SDM with patients. Patients who are fully engaged and participate in decisions about their care are more likely to adhere to care plans.[110]

- The practice should share stories of situations when patients felt encouraged to participate in SDM during PFAC meetings.

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[108] *Ibid*.

[109] *Ibid.*

[110] Montori, V., Gafni, A., Charles, C. Health Expectations. *A Shared Treatment Decision - Making Approach between Patients with Chronic Conditions and their Clinicians: the Case of Diabetes*. January 2006. Available at: onlinelibrary.wiley.com/doi/full/10.1111/j.1369-7625.2006.00359.x.

Stakeholder Perspective

"Patients used to feel like more is better… but sometimes less is more. Changing that mindset is a major victory." - *Daniel Wolfson, Executive Vice President of the ABIM Foundation*[111]

Implementing or Strengthening Patient Self-Management Support

WHAT:	Patient Self-Management Support (PSMS) represents a promising strategy for practices to treat patients with chronic conditions. Many patients do not understand what their doctors have told them and do not participate in decisions about their care, which leaves them ill prepared to make daily decisions and take actions that lead to good management. Others are not yet even aware that taking an active role in managing their condition can have a big impact on how they feel and what they are able to do.[112] PSMS allows patients to take a more active role in the management of their chronic conditions.
WHY:	PSMS can assist practices by providing a process to promote great patient and family engagement in managing illness.[113]
HOW:	• If the practice has not implemented a PSMS program, as a first step the practice and PFAC should learn the basics of helping a patient better self-manage their health care.[114] • Provide the PFAC with information on how the practice currently supports PSMS. Dedicate a PFAC meeting or series of meetings to this topic and share information pertaining to the effectiveness of the current PSMS program. • Ask the PFAC to propose ideas for improving the current PSMS techniques or offering alternative PSMS techniques.

Frequently Asked Questions

How can the PFAC help train the care team to implement PSMS?

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[111] Choosing Wisely. *Top Headlines of 2017*. January 2018. Available at: choosingwisely.org/resources/updates-from-the-field/top-headlines-of-2017/.

[112] IHI. *Partnering in Self-Management Support: A Toolkit for Clinicians.* Available at: ihi.org/resources/Pages/Tools/SelfManagementToolkitforClinicians.aspx.

[113] *Ibid.*

[114] South West Local Health Integration Network. *Self-Management Toolkit: A Resource for Health Care Providers.* Available at: swselfmanagement.ca/smToolkit/index.aspx.

PFAC members can work with the care team to develop skills needed to implement PSMS, such as motivational interviewing, reflective listening, and coaching.[115]

How can the PFAC guide PSMS data collection and reporting?

The PFAC should provide input on how the impact of PSMS will be measured, who will report the outcomes and how frequently the measures will be tracked and reported.[116]

How should the practice decide what PSMS tools to offer?

The practice should ask the PFAC to provide guidance on PSMS tools such as decision making and goal setting as well as tailored education and skills training materials appropriate for different cultures and health literacy levels.

Tips

- Develop a rating scale for the PFAC to use in evaluating existing educational material that supports PSMS.
- Practices should engage PFACs to advise on the presentation of PSMS data and reporting options including provider satisfaction, patient satisfaction, progress on goal attainment, and/or quality measures.[117]
- Consider a phased-in approach to implementing PSMS programs. This technique will enable the PFAC to provide guidance during the process, and for the practice to evaluate the program and appropriately implement lessons learned in other PSMS programs prior to implementation. For example, start with a diabetes PSMS program before adding a blood pressure program.

Patient Perspective

"I would prefer to know that I am making the decision. I mean after all it is your body right?"
- *65 year old female breast cancer patient*[118]

Sustaining the Partnership

WHAT:	Advanced PFACs should continue to plan for its sustainability.

[115] HealthTeamWorks. *Self-Management Support Implementation*. 2018. Available at: healthteamworks.org/resource/self-management-support-implementation.

[116] Ibid.

[117] Ibid.

[118] Tamirisa, N, et al. Health Expectations. *Patient and Physician Views of Shared Decision Making in Cancer*. May 2017. Available at: ncbi.nlm.nih.gov/pmc/articles/PMC5689235/.

WHY:	The complexity of issues patient and family advisory councils address often depend on the maturity of the PFAC.
HOW:	• Revisit the PFAC mission statement and goals and be willing to make changes as the goals and priorities of the practice change.[119] • Tracking the work accomplished by PFAs and communicating this information showcases how the PFAC and PFAs are making a difference.[120]

Frequently Asked Questions

How will goals and priorities that the PFAC addresses change over time?

Practice PFACs go through a growth period, they start with addressing ways to get patient input on cosmetic concerns, such as the design of a waiting room. Usually with time and support from leadership, PFACs progress to address issues that involve safety and quality.[121]

What can be done if the PFAC is not making progress, or its members are losing enthusiasm for the work?

To remain actively engaged, PFAC members need to feel that they are contributing. Suggest a PFAC project that can be completed quickly with a high probability of success, (e.g., redesigning a patient brochure or examining signage in the waiting room).[122] Review the initial PFAC plan to make sure key elements of sustainability have been addressed, including leadership buy-in and preparation of staff and clinicians.[123]

How can PFACs maintain momentum when there is a change in practice leadership?

Provide new leadership with information about the PFAC—specifically, how the group started, the work completed, and the impact of the work. Invite new leadership to attend a PFAC meeting to better understand its work.

[119] See n. 20, *Supra*. (National Partnership for Women & Families).

[120] See n. 6, *Supra*. (AMA).

[121] See n. 95, *Supra*. (Castellucci).

[122] See n. 6, *Supra*. (AMA).

[123] See n. 6, *Supra*. (AMA).

Tips

- If a practice has five or more clinicians, consider inviting select PFAs to participate in staff training activities focused on communication, team building, and facilitation to help the PFAC work together more effectively.[124]
- Explore community resources for low cost or free professional development opportunities for PFAC members, (e.g., Toastmasters, community workshops).[125]
- Provide opportunities for PFAC members to get to know each other. Building collaborative relationships involves more than just working on tasks together. Consider starting meetings with an icebreaker that allows people to share information about themselves.[126]

Patient Perspective

"I like the fact that New England Baptist Hospital (NEBH) is constantly looking for new patients and family members to get fresh experiences to talk about and evaluate. NEBH really listens to the PFAC." - *Linda Percy, PFAC member*[127]

[124] *Ibid*.

[125] See n. 20, *Supra*. (National Partnership for Women & Families).

[126] See n. 9, *Supra*. (Davis).

[127] New England Baptist Hospital. *Patient Stories*. Available at: nebh.org/for-patients-care-partners/patient-stories/.

Acknowledgements

The guide is based on material developed by the Institute for Patient- and Family-Centered Care. The MHCC appreciates the voluntary contributions made by stakeholders to ensure that the *Maryland PFAC Guidance Document* (guide) is relevant and valuable to practices. Twenty five providers offered feedback to the draft guide. The MHCC acknowledges and thanks the following individuals for their dedication to this important work:

Isabel Abarza
Johns Hopkins Bayview

Michelle Babcock
Kaiser Permanente, Mid-Atlantic States

Sharon Cameron
Anne Arundel Medical Center

Steve Clayton
Harford Primary Care

Lisa DeCamp, M.D.
Children's Medical Practice

Susan Delean-Botkin
Familycare of Easton, LLC

Willarda Edwards, M.D.
Edwards and Stephens

Michael Ferraro
Johns Hopkins Community Physicians Charles County

Mary Fugate
Pediatric Healthcare Associates, Inc.

Sandy Hudson
Anne Arundel Medical Center

Brenda Johnson
University of Maryland St. Joseph's Medical Center

Vijay Kannan, M.D.
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Suzanne Kunhardt
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Bob Lanza
Peninsula Regional Medical Group

John Lease
Calvert Internal Medicine Group

Scott Lilly
Frederick Primary Care Associates

Patricia McGrady
Johns Hopkins Community Physicians

Leia Medlock M.D.
Shady Grove Women's Center

Tara Price
Stone Run Family Medicine

David Wang, M.D.
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Colleen Watson
Johns Hopkins Community Physicians, Heart Care, Chevy Chase

Joseph Weidner, M.D.
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Appendix A: Sample Printable Tools

1- PFA Application

2- PFAC Charter Template

3- PFAC Confidentiality Form

4- Agenda Minutes Template

Printable tools provided by the Institute for Patient- and Family-Centered Care, www.ipfcc.org.

YOUR ORGANIZATION NAME

Patient & Family Advisor Application

Would you be a partner with us to deliver patient- and family-centered care every time in every encounter? To reach this goal, we need your ideas, feedback and participation as together we improve the experience of care for our patients and families. We are seeking individuals for a variety of opportunities – both short term and ongoing.

Date: _____

Name: _____
Last First MI

Address: _____ City: _____State: _____ Zip: _____

Home Phone:_____ Work Phone: _____ Cell Phone:_____

Email: _____

What is the best way to contact you? (circle one) Home Work Cell Email

Please check all that apply below:

☐ I am a patient at a name of hospital/clinic or facility

→If yes, from which location(s) do you receive services?_____

☐ I am the family member of a patient from _____

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

☐ I am involved in the care of someone who has a chronic health condition

☐ I am a patient/family member receiving preventative and/or occasional illness care

SKILLS & INTERESTS: If you wish to provide more information, please use the space below to describe any special training, interests, hobbies or experiences you feel could be valuable to your work as a Patient/Family Advisor with us.

_____

_____

Please indicate the ways in which you would like to participate as a Patient/Family Advisor:

___ Phone Interview: Share your opinion and respond to survey questions over the telephone.

___ Focus Group: Provide feedback in a group format with other patients/family members.

___ Participate on Committees: Bring the patient/family voice/experience to committee meetings.

___ Story Sharing: Share your health care experiences with care providers and other patients.

___ Be a partner in making improvements to specific health care services.

__ Be a member of a Patient Family Advisory Council (monthly evening meetings)

___I don't know yet, I need more information.

Please put an 'X' in the Day(s) and Time(s) you are available to meet for an interview and/or informational session:

	Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**
Mornings					
Afternoons					
Evenings					

Your responses are important in planning your involvement with us. If you have questions concerning the program or this application, please call NAME OF COORDINATOR, E-MAIL AND PHONE NUMBER.

Please return your completed application using the return envelope enclosed.

Approved: Date
Sponsoring Group

CHARTER

Patient and Family Advisory Council, NAME OF ORGANIZATION

Title:	Patient and Family Advisory Council (PFAC)
Date Chartered:	First Date of Charter
Time Line:	First Meeting and Ending Timeframe if applicable
Sponsor(s):	
Purpose:	• **To assure alignment and integration of patient and family centered care within ORGANIZATION, the PFAC will serve as a formal mechanism for involving patients and families in policy and program decision making in our ORGANIZATION NAME. Examples of PFAC involvement includes but is not limited to:** • Acting as champions of the Ideal Patient Experience and ensure its implementation across NAME OF ORG. • Reviewing communication to patients and families to ensure it builds on patient and family strengths and engages them in a partnership in health care services. • As needed, recommending to the Name of Executive Body areas for improvement in service quality. • Collaborate with quality and safety projects as appropriate including participation in teams and/or recruitment of other patients/families to serve as advisors to time-limited project focused efforts
Council Co-Chairs:	Initially a clinical Executive and One Patient/Family member to serve as Co-Chairs in first year. A transition plan is for Two Patient/Family Member of the PFAC will serve as Co-Chairs, with staff support to ensure responsibility for: • Convening meetings • Setting and Prioritizing agendas • Facilitation of meetings • Ensuring meetings are conducted efficiently • Ensuring support for members in presenting issues and needs • Ensuring correct leaders and staff are present for agenda topics as necessary

	• Working effectively with all stakeholders in pursuit of the quality vision that supports patient and family centered care • Working closely with quality staff, organized safety and quality bodies between meetings as needed • Responsible for accountabilities of the Patient and Family Advisory Committee • Participating in an annual evaluation for effectiveness. • Participating in leadership training/coaching/mentoring as needed
Committee Membership	• Membership (12-18 members) representing the diversity of the population we serve: • (Add specific numbers listed based on diversity of sites, populations and services provided) • Chief Medical Officer • Executive Team Member • Quality Director • Administrative Assistant to support PFAC • Other: • Invited guests per area of expertise as dictated by monthly agenda items
Committee Members' Responsibilities	• Each member is responsible to actively participate both in and out of meetings to achieve the council's purpose as stated above. • Share personal experiences, stories, observations and opinions as a patient or family member. Additionally, reach out broadly and listen to other patients, families, staff and community members as opportunities arise, • Be committed to improving care for all patients and families members. • Respect the collaborative process and the forum to discuss issues, be willing to listen to and consider differing viewpoints, share ideas for improvement and encourage other council members to do the same, • Share both positive and negative experiences in a constructive way. • Work effectively with other Council members as well as the organization's patients and families in identifying, promoting and ensuring a focus on creating the ideal patient experience.

	• Act as change agents to support the achievement and maintenance of quality goals including the patient and family experience until they become the standard across the organization. • Review materials provided prior to the meeting, so that each person is prepared to actively ask questions, contribute ideas and provide input during the meeting • Monitor their area of expertise and bring status reports and concerns/needs to the full committee. • The goal for decision-making will be consensus. However, if consensus cannot be reached, decisions will be made by a majority vote of all members. All members support meeting decisions once a decision leaves the room. • Maintain confidentiality of meeting content. • The Quality Director and/or Patient and Family Liaison will provide orientation and development opportunities to advisors to support their effectiveness on the council.
Meeting Frequency:	• Full Committee will meet the each month from x –x . 10 regular face to face meetings a year (no December and July Meetings) • Between meetings there may be conference calls scheduled to complete ongoing work (up to three). • Each member is expected to attend all meetings or notify the *Administrative Assistant* if barriers/conflicts prevent attendance. • There may be need for Ad hoc meetings and small group work as determined by the membership • Other times as needed to effectively execute its charter, including an orientation for new members each fall • Approx. 3-4 hours per month (standing meeting plus preparation and e-mail time)
Term:	• Our hope is that members will serve a 2-year term; other arrangement can be made as circumstances change. • Each council member may serve up to 3- concurrent terms (6 years). Other opportunities, if interested, will be made available to the seasoned advisor. • Open positions will be filled each year and new members will commit to a 2-year term, if possible. A minimum of one year is expected.

Membership Selection Process	• ORGANIZATION shall seek interest of individuals or family members of individuals who receive our services. Nominations and recommendations from staff and clinicians will be solicited. Postings on the website and through volunteer services (or other mechanism) will be used throughout the year to find appropriate and interested candidates. ○ Interested applicants will be asked to fill out an application. Applicants will be invited to an informational session to meet current Patient Advisors and staff to learn more about the opportunities. The purpose of the informational session is to answer questions of the candidates and determine how well their interests match the needs and vacancies of the Council. ○ Individual interviews will be held by chair of the PFAC and the Quality Director. If both parties approve of the applicant, they will be invited to join PFAC. When a consensus cannot be reached, the applicants will be forwarded to the Chief Medical Officer or Executive Director, who will make the determination on those individuals.
Removal and/ or Resignation	A member may resign at any time by submitting a written letter to the Council Co-Chairs. A member may be removed for failure to abide to the charter and guidelines set forth in the charter and by the sponsors.
Effectiveness Goals:	TBD by the Patient and Family Advisory Council Committee will be evaluated on a regular basis - TBD
Review Charter:	Minimum: Once a year in September with the NAME OF SPONSORING ORGANIZATION

Your Logo Here

Patient and Family Advisor Confidentiality Contract

I willingly agree to be a patient and family advisor and to work on improvement teams and/or give information to the Name of Clinic or Hospital . My role is to:

- Talk about – and help others talk about – ideas so Name of Organization and other healthcare providers in our community can make healthcare better.
- Talk about what happened to me as a patient or a patient's family member in ways to make healthcare better.
- Say what I think about changes to make things better for the patients and families getting care at Name of Clinic.
- Work together with staff and physicians in planning or improving service or programs.
- Think beyond what happened to me to help others.

As a patient and family advisor, I will talk to others and will learn about this organization and others. This includes personal information about patients and their families and operational information about Name of Clinic programs, clinicians and staff. I promise and agree that:

1. I will protect the confidentiality, privacy, and security of all information that I learn as a patient and family advisor.

2. I will not talk, e-mail, or write down anything I learn about patients or Name of Clinic unless it is part of my role as an advisor. I will not talk in a public place inside or outside of Name of Clinic about anything I learn in a meeting.

3. Even though names and medical details are not talked about, there may be enough information to figure out who a person is. I will not try to figure out who particular persons or events may be based on what I learn at any Name of Clinic meeting.

4. I will not use anything I learn as a patient and family advisor for any reason except helping Name of Clinic.

5. I am, and others in the meeting are, free to share their stories. I know that we do not have to say anything that we do not want to say. I know that some people I talk to do not have to follow federal and state laws that protect health information, and they may tell others, even if they are not supposed to.

6. My information and my ideas, alone or with other information and ideas, may be used by Name of Clinic. I give Name of Clinic the right to use such information and ideas.

7. I will tell someone who works at Name of Clinic if I do not, or someone else does not, follow this contract.

I have read and understand this contract. I know this contract does not end. I will do what I promised to stay a patient and family advisor to Name of Clinic.

Name (PRINT)	Affiliation / Title
Signature	Date

Patient Advisory Council Meeting Minutes

Date Location

Name	Role	In Attendance
PAC Guests		**Attendance**

Topic	Discussion	Decision	Assignment
Housekeeping/ FYI			
Solicit Agenda Items			
Process Check			
Next Meeting			

Parking Lot Items:

Appendix B: Additional Resources

Section One:

PFAC Implementation:

Assessing a Practice's Readiness:

- Leadership Self Reflection Questions

  https://www.pcpcc.org/sites/default/files/resources/Patient-Centered Leadership Self Reflection Quiz_0.pdf

- AHRQ Readiness to Partner with Patient and Family Advisors

  https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Tool_14_HO_508.docx

- IPFCC Checklist for Attitudes About Patients and Families as Advisors

  http://www.ipfcc.org/resources/Checklist_for_Attitudes.pdf

- IPFCC Patient and Family Advisor Guide to Partnering with Your Clinic

  https://www.pcpcc.org/sites/default/files/resources/Patient and Family Advisor Guide.pdf

- PCPCC Patient and Family Partner Roles

  https://www.pcpcc.org/resource/patient-and-family-partners-roles

Sustaining the Partnership:

- AHRQ Handout on Working with Patient and Family Advisors on Short Term Projects

  https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Tool_13_ShortTerm_HO_508.docx

Section Two:

Facilitating Meetings to Ensure Meaningful Participation:

- San Francisco Health Network Patient Advisor and Staff Handbooks in English and Spanish

  https://www.sfhealthnetwork.org/pac-collaborative/resources/

Addressing Common Challenges:

- AHRQ Presentation: Working with Patient and Family Advisors

  https://www.ahrq.gov/sites/default/files/wysiwyg/professionals/systems/hospital/engagingfamilies/strategy1/Strat1_Tool_11_PPT_508.pptx

Section Three:

PFACs as Facilitators of Strategic Community Partnerships:

- American Hospital Association Playbook for Fostering Hospital-Community Partnerships to Build a Culture of Health

  https://www.aha.org/system/files/hpoe/Reports-HPOE/2017/A-playbook-for-fostering-hospitalcommunity-partnerships.pdf

- Oregon Health Authority Coordinated Care Organizations and Community Advisory Councils

  https://www.oregon.gov/oha/HSD/OHP/Pages/CCO-Community-Advisory-Councils.aspx

- Oregon Health Authority Video: Community Advisory Council Orientation created by Advisory Member

  https://www.youtube.com/watch?v=Hz0s4zHtveM

Implementation of Shared Medical Appointments:

- Massachusetts General Hospital Group Visit Guide

  https://www.massgeneral.org/stoecklecenter/assets/pdf/group_visit_guide.pdf

- American Academy of Family Practice Group Visits for Chronic Illness Care Benefits and Challenges:

  https://www.aafp.org/fpm/2006/0100/p37.html

Implementation of Shared Decision Making Process and Tools:

- Mayo Clinic Shared Decision Making Tools Resource Center

  http://shareddecisions.mayoclinic.org/

- Choosing Wisely Tools

  www.choosingwisely.org

  - For Clinicians

  http://www.choosingwisely.org/getting-started/

  - For Patients and Families

  http://www.choosingwisely.org/patient-resources/

  - AHRQ Training and Tools on Shared Decision Making

  https://www.ahrq.gov/professionals/education/curriculum-tools/shareddecisionmaking/index.html

Health Care Glossary

*Glossary terms are an excerpt of and adapted from CMS and the National Partnership for Women & Families, *Key Steps for Creating Patient and Family Advisory Councils in CPC Practices*, 2013. Permission for use was granted by Christine Broderick at the National Partnership for Women and Families. Available at: innovation.cms.gov/Files/x/cpci-patientfamengresource.pdf.

Ambulatory Care

- Is medical care that does not require an overnight stay in a hospital.
- This kind of care can be provided in the following places:
  - Doctors' offices,
  - Clinics,
  - Emergency departments,
  - Outpatient surgery centers, and
  - Hospitals (when care does not involve a patient staying overnight).

Benchmark (Benchmarking)

- Is a way for doctors to keep track of, and measure, how well they are doing at providing excellent care while keeping costs down.
- To do this, they gather information (data) over different periods of time. Then, they use this information to:
  - Measure how well they are doing from one period to the next.
  - Measure how well they are doing compared to other doctors.
  - Find out what treatments work best and use that information to provide even better care.

Best Practices

- Are practices which result in the best patient health and lower patient risk of death or complications.
- These are also the most up-to-date treatments for patients.

Centers for Medicare and Medicaid Services (CMS)

- Is the agency within the U.S. Department of Health and Human Services that administers:
  - Medicare,
  - Medicaid, and
  - The State Children's Health Insurance Program (SCHIP or CHIP).

Consumer/Patient/Beneficiary

- Refers to a person who is experiencing significant personal or family interaction with the health care system.
    - It can refer to a person receiving care (such as someone covered by Medicare).
    - It can also refer to a family caregiver.

Consumer Assessment of Healthcare Providers and Systems (CAHPS)

- Is a survey that asks consumers and patients to report on and evaluate their experiences with health care.
- It focuses on care in *non-hospital settings* (physician offices, nursing homes, etc.).
- It asks the same questions and is scored in the same way, wherever it is used.
- It asks questions about how care is given. For example, it asks questions about how well health care providers talk with their patients and how easily patients can get the health services they need.
- The CAHPS survey is done every year. The results are sometimes reported to the public.

Consumer Assessment of Healthcare Providers and Systems (H-CAHPS or CAHPS Hospital Survey)

- Is a survey that asks consumers and patients to report on and evaluate their experiences with health care.
- Unlike the CAHPS survey, this survey focuses on hospital care.
- It asks the same questions and is scored in the same way, wherever it is used.
- It asks questions about how care is given. For example, it asks questions about how well health care providers talk with their patients and how easily patients can get the health services they need.
- The H-CAHPS survey is done every year. The results are sometimes reported to the public.

Cost

- Refers to the amount of money paid to a health care provider for a health care service.

Delivery System

- Refers to the way medical care is organized and provided to patients.
- This includes the care, products, and services patients receive from doctors, hospitals, and other professionals.

Department of Health and Human Services (HHS or DHHS)

- Is a U.S. government agency responsible for protecting Americans' health, in many ways, and for providing essential human services, particularly for people who need the most help. This includes financial assistance for people with low incomes.

Electronic Health/Medical Record (EHR or EMR)

- Generally, it is a medical record kept on a computer, instead of in a paper chart.
- Specifically, it is medical software with the electronic history of a patient's medical care.
- Using electronic records has a number of advantages:
    - It makes the health care system more efficient.
    - It allows for better coordination of care. Each provider can now see what another provider has done, so they can work better together to care for each patient.
    - It also gives patients the chance to look at and control their own medical records.

Family Caregiver

- Is a family member or friend who cares for and supports a patient with a chronic health condition or an illness.

Health Literacy

- Is the degree to which individuals are able to get, process, and understand basic health information and services needed to make appropriate health decisions.
- Health literacy is not simply the ability to read.
- It requires a complex group of reading, listening, analytical, and decision-making skills, and the ability to apply these skills to health situations.
- For example, health literacy allows people to understand instructions on medicine bottles and doctors' forms as well as talk about health needs and concerns with a doctor or nurse.

Hospital Readmission

- Happens when a patient is readmitted to a hospital after being released.
- Readmissions rates, usually within a certain time period (7 to 60 days), are viewed as one way of telling how well patients are being cared for.
    - Low readmissions rates tend to mean that patients are getting better care and do not need to return to the hospital because of more health problems.

Outcome

- Refers to a patient's health—whether it improves, declines, or stays the same—after an encounter with the health care system.

Patient Centered Medical Home (PCMH)

- Is not an institution or a place.
- Instead, it is a way of delivering outpatient care that emphasizes:
  - Care that is easy to access, is comprehensive and well-coordinated; and
  - Active involvement of the patient and family in health care decisions.
- In a medical home, the primary-care doctor acts as a home base for patients.
  - That doctor is chosen by the patient and becomes the patient's personal physician.
  - The doctor (along with nurses, medical assistants, and others in the office who are part of the care team) oversees all aspects of patients' health and coordinates care with any specialists or other providers involved in the patient's care.
  - Patients do not need a referral from their primary care doctor to see other doctors.
  - This is because the primary care doctor serves more as a manager than a gatekeeper of each patient's care.

Patient and Family Advisory Councils (PFAC)

- Are a way to involve patients and families in policy and program decision-making in health care settings.
- These councils help design, implement, and evaluate changes in policies, programs, and practices that affect the care and services individuals and families receive.
- Councils generally include:
  - Patients and family members,
  - Community members,
  - Consumer advocates,
  - Doctors, nurses, and other health care providers, and administrative staff.
- PFACs may be referred to by many names such as
  - Patient-Provider Councils,
  - Patient Advisory Boards,
  - Consumer Advisory Boards, etc.

Primary Care

- Is basic or general health care that helps patients and families to maintain and improve their health.
- It includes a range of prevention and wellness services, and treatment for common illnesses.
- Primary care is traditionally provided by doctors trained in:

- Family practice,
- Pediatrics,
- Internal medicine, and
- Gynecology, occasionally.

Provider

- Refers to a professional who provides health services.
- This includes:
  - Primary care doctors and nurses,
  - Specialists (such as podiatrists or cardiologists), and
  - Other allied health professionals (such as physical therapists).
  - Hospitals and long-term care facilities are also providers.

Quality (of care)

- Is the right care, at the right time, for the right reason.
- Ideally, it is also at the right cost.

Quality/Performance Measures

- Are ways to evaluate the care provided by doctors and hospitals, based on accepted national guidelines.
- These measures evaluate:
  - Access to medical care,
  - The way care is given,
  - Patient results after treatment (outcomes),
  - Patient experiences with care, and
  - Use of medical services.

Self-Management

- Is the ability of individuals to take care of health problems or conditions on a day-to-day basis.
- It is a skill that allows individuals and their families to use existing health services.
- It also helps patients make choices about:
  - Health care providers,
  - Medicines, and
  - Diet, exercise, and other lifestyle choices that protect or damage health.

Shared Decision-Making (SDM)

- Is a process in which patients and their doctors make medical decisions together.
- This is done while taking into account:
  - Medical recommendations, and
  - The patient's preferences, life situation, needs, and values.

Stakeholder

- Refers to any person, group, or organization that can affect or be affected by the health care system.
- It includes:
  - Patients,
  - Providers,
  - Employers, and
  - Health plans.

Health Care Acronyms

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AHA	American Hospital Association
AMA	American Medical Association
AHRQ	Agency for Health Care Research and Quality
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CMS	Centers for Medicare and Medicaid Services
ED	Emergency Department (preferred to ER)
EHR	Electronic Health Record
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health Act
PCMH	Patient Centered Medical Home
PCP	Primary Care Physician/Provider
PFAC	Patient & Family Advisory Council
QI	Quality Improvement
SDM	Shared Decision Making

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