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The global leader in Person-Centered Care

Global Patient and Family Partnership Council Guide to PFAC/PFPC Best Practices

ABOUT THIS GUIDE

Patient and Family Partnership Councils/Committees (PFPCs), also known as Patient and Family Advisory Councils/Committees (PFACs), are represented through various names and titles across the globe. While PFAC and PFPC are often used interchangeably, for the purpose of this document the term PFPC will be used. PFPCs are platforms where patients, families, caregivers, and care partners [hereafter called ‘Patient(s)’] partner with staff of healthcare organizations (clinics, hospitals, and healthcare systems and networks) to define and co-design Person-Centered Care (PCC) that is provided to ‘Patients’.

By definition, an “Advisor” offers expertise and provides guidance, whereas, a “Partner” co-owns the initiative, and has rights and responsibilities. The Planetree Global PFPC (Global PFPC) believes there needs to be a continued transition of ‘Patients’ from advisors to partners. The objective is to co-own and co-design initiatives in partnership, amongst all stakeholders, moving beyond simply seeking the advice of ‘Patients’ to embedding their perspectives in decision making, implementation, and ongoing sustainability.

As healthcare organizations worldwide strive to enhance PCC, PFPCs provide a valuable vehicle for bringing the ‘Patient’ voice to the forefront of decision making, co-design and improvement efforts. While there is a significant amount of research and literature about organizing and establishing these groups, the Global PFPC has created this guide as a resource, developed by ‘Patients’ for all stakeholders. This document provides guidelines and best practices for healthcare organizations, staff and ‘Patients’ working together to advance and embed PCC. It is designed to inform healthcare leaders, clinicians, and partnership councils to build systems that respect and engage ‘Patient’ voices, improve communication, and establish trust. While the Guide provides an overview of PFPCs, it focuses primarily on the ‘How’, making it a pragmatic and usable document.

This guide is a living document that will be reviewed over time to capture prevailing trends and best practices. With the passage of time, healthcare systems change and so do the care needs of ‘Patients’. Hence, the role of PFPCs also needs to be kept current in the ever-evolving healthcare landscape.



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ROLE OF A PFPC

On a PFPC, 'Patients' and other stakeholders partner to improve the care experience across all clinical and non-clinical touchpoints and interactions. The experience of those delivering care is not the same as the experience of those receiving care, however, all are equally important and impactful to the consistent delivery of person-centered care. As part of the PFPC process, 'Patients' serve on hospital committees, working groups, task forces, etc. to ensure their point of view, perspective, and lived experience are not only heard, but valued and integrated into care delivery, which is co-designed to ensure high-quality PCC. Through lived experience, 'Patients' provide insights that enhance care, elevate quality and safety, and improve outcomes.

The role of a PFPC is to ensure that 'Patient' and community perspectives are integrated into all aspects of care. PFPCs provide expertise and meaningful input to help build a person-centered experience and culture that reflects the diverse community served.

In striving to be inclusive, PFPC members endeavor:

- To share unique lived experiences and insights
- To see beyond individual experiences to inform a broader perspective
- To communicate effectively in a group setting
- To listen, interact, respect, and work in partnership with others
- To effectively collaborate and co-design



GUIDING PRINCIPLES OF PFPCs

RESPECT AND DIGNITY



Person-Centered Care is grounded in respect and dignity for 'Patients' and other stakeholders. As such:

- Members are treated as equal partners
- Members actively listen and welcome all input
- Cultural, emotional, and personal values are honored
- Member expertise, knowledge, and beliefs are incorporated into the co-design and delivery of care

INFORMATION SHARING



Timely, complete, unbiased, accurate, and transparent information is shared in ways all members understand, which may include:

- Plain language - no acronyms or medical jargon
- Relevant, actionable data - patient experience scores, safety event reports, etc.
- Demonstration of the impact of 'Patient' and stakeholder feedback by "closing the loop" on all member contributions



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GUIDING PRINCIPLES OF PFPCs (continued)

PARTICIPATION



Impactful partnership reflects active member engagement, such as:

- Serving on organizational committees, sub-committees, boards, etc.
- Collaborating on task forces and working groups
- Initiating projects and areas for growth, learning, and improvement
- Highlighting priorities of 'Patients' and stakeholders to organizational leadership

CO-DESIGN



A purposeful relationship where all parties collaborate as equal partners, from inception for a shared outcome or goal. Examples include:

- Organizational policy and program development
- New initiatives
- Program implementation and evaluation
- Policy changes
- Quality Improvement and Patient Safety
- Patient Experience
- Facility design and healing environments

INCLUSION, DIVERSITY, EQUITY, AND ACCESSIBILITY



Membership reflects the diversity of the community served by:

- Representing underserved and/or under-represented populations
- Ensuring language access (interpreters, translated materials, etc.)
- Identifying and removing barriers to participation (childcare, transportation support, tech support, meals, meeting times, meeting locations, mode of meetings, etc)

SAFETY



Create a physically, emotionally, psychologically, and socially safe space which:

- Establishes clear group norms - no hierarchy, where all voices are heard and equally valued
- Normalizes the sharing of experiences
- Respects confidentiality of opinions
- Ensures feedback is free from fear of retaliation, bias, or judgment



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BEST PRACTICES

Below are foundational considerations for launching a PFPC and ensuring effective person-centered care:

MEMBERSHIP

A team of approximately nine to fifteen members consisting of:

- Patients' and community representatives of the population served informed by community health assessments and demographic information
- Executive leadership/staff - Decision makers and PCC experts are PFPC champions who actively ensure the PFPC works integratively with organizational operations
- Composition: 'Patients' at least 67%; Executive leadership and staff no more than 33%

RECRUITMENT AND ONBOARDING

A step-by-step process needs to be followed, which may include:

- Formal Application - specifies mandatory requirements, i.e., skill set, lived experience, professional experience, required immunizations, references, special accommodations/circumstances, etc.
- Formal interview
- Vetting - reference check, police/background check, etc.
- Commitment Letter, Non-Disclosure Agreement, Confidentiality Agreement, Conflict of Interest Declaration, Code of Conduct Agreement, etc.
- Orientation and onboarding
- Assignment of mentors/buddies
- Probationary period
- Term renewals and limits

GOVERNANCE

Every PFPC needs a well-defined Charter/Terms of Reference that covers key aspects of membership, such as:

- Purpose and Mission
- Policies and Procedures
- Roles and responsibilities of all members (voting/non-voting) - professional conduct, resignations, Leave of Absence, etc.
- Member expectations - attendance, RSVPs, pre-reading, pre-work, active engagement, participation in sub-committees, communication with PFPC leadership, representation of the organization, etc.
- Leadership – 'Patients' as Chair and/or Co-Chair/Vice-Chair
- Decision making authority
- Quorum
- Voting procedures
- Sphere of influence
- Compensation - pay/stipends help to retain, acknowledge, and value the work of PFPC members

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BEST PRACTICES (continued)

MEETINGS

Meetings play a crucial role in the success and sustainability of a PFPC, below are some key characteristics:

- Frequency
- Advanced scheduling - convenient for members
- Attendance record
- Flexibility in mode - virtual, in-person, hybrid
- Meeting location - onsite, offsite locations (community centers, libraries, etc.)
- Agenda
 - Co-designed by Chair/Co-Chair with Executive Liaison
 - Distributed to members in advance, along with all meeting materials
- Length of meeting and time-keeping
- Pre-meeting/post meeting debriefs and ad-hoc sessions, as required
- Record keeping of meetings, consent for recording of online meetings, circulation of meeting notes/minutes
- Guest speakers

MEASUREMENT OF IMPACT

Some of the most prevalent measures and metrics of the effectiveness of a PFPC include:

- Annual Member Experience Surveys
- Member engagement, participation, and contribution across an organization
- Impact of PFPC initiatives and decisions - Documentation summarizing PFPC work and accomplishments (ie Year in Review) shared organization-wide and beyond

SUSTAINABILITY

Organizational leadership and PFPC drive actions to promote Council sustainability.

Organizational leadership:

- Ensures adequate allocation of resources to support PFPC work
- Invests in the professional development of members - presentation, communication and leadership skills, training, education, etc.
- Promotes the work of PFPC and its impact through participation in conferences, forums, events, social media, presentations, podcasts, webinars, blogs, vlogs, etc.
- Devotes time to the planning and evaluation of PFPC efforts
- Reviews and publishes PFPC initiatives and activities
- Recognizes and celebrates PFPC successes, big and small

PFPC:

- Ensures the opinions of all members are heard and respected
- Maintains continued engagement and support of leadership
- Sets short-, medium- and long-term priorities and goals
- Focuses efforts on meaningful collaborative projects
- Recruits new members on a regular basis in line with a Representation Matrix
- Continually evaluates the progress towards goals
- Evolves and embraces new best practices



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BEST PRACTICES (continued)

PFPC ENGAGEMENT WITHIN AN ORGANIZATION

Members may engage with an organization in many different ways, such as:

- Co-design and support new and existing initiatives
- Content review - educational, social media, website, etc.
- Representation on Board of Directors, sub-committees, working groups, task forces, conferences, forums, etc.
- Policy revisions, organizational strategic planning, best practices, etc.
- Staff interviews

CONCLUSION

Excellence in patient engagement and person-centered care is no longer abstract; through PFPCs, it is visible, measurable, and tangible.

PFPCs are composed of dedicated patients, families, caregivers, care partners, and staff who humanize healthcare through partnership and collaboration. They help transform the healthcare experience from a service delivered to a partnership lived. PFPCs are an empowering tool for all healthcare organizations, irrespective of size. When done right, PFPCs can be transformational, helping to define the standard of 'Patient' engagement. Participating in PFPCs can be rewarding for all members. Acknowledging and integrating the lived experience and unique perspectives of 'Patients' transforms the overall experience for all stakeholders, resulting in more efficient, effective, and high-quality Person-Centered Care.

As PFACs evolve, it is vital from a strategic perspective, that PFACs transform to PFPCs. Planetree's Global PFPC itself has evolved from an advisory to a partnership - moving from an 'Inform & Ask' to an 'Embed & Partner' model, underscoring the impact and value of true partnership.

To learn more about establishing and/or sustaining a PFPC, please reach out to:
patient-family-partnership-council@planetree.org or info@planetree.org.



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GLOSSARY OF TERMS

Care Experience: The sum of a person's interactions, relationships, and experiences with a healthcare system throughout their care journey, including how they feel, what they encounter, and the impact of those experiences on themselves and their families/caregivers/care partners.

Care Partner: The individual, typically a family member or friend, the patient designates to provide for their care and support (emotional, legal, physical, medical, etc.).

Caregiver/Carer: Friend, family, healthcare staff, and others, involved in providing care to a patient and/or family. When referring to a caregiver, it is important to differentiate between a professional and a family caregiver.

Co-Design: Patients, families, caregivers, and care partners collaborate as equal partners with staff at the earliest stages of a project to share their lived experience and perspectives to ensure the initiative is shaped around real-world experience.

Family/Family Partner: Whomever the patient designates to be their "family"; can be biological relatives, friends, neighbors, etc.

Lived Experience: First-hand knowledge and understanding gained from personal involvement in a particular situation or circumstance, rather than through second-hand accounts or research. It emphasizes the unique perspective and insights individuals derive from their own direct personal encounters.

Members: This term refers to all members of a PFPC - patients, families, caregivers, care partners, staff, and leadership.

Patient(s): In this guide, patient(s) refers to patients, families, caregivers, and care partners.

Patient and Family Experience: The sum of all interactions shaped by an organization's culture, that impact patient and family perceptions across the continuum of care.

Patient and Family Partnership Council/Patient and Family Advisory Council (PFPC/PFAC): A team of patient and family caregivers with lived experience dedicated to advancing Person-Centered Care through collaboration and co-design with health systems and organizations.

Person-Centered Care (PCC): Compassionate, collaborative care that improves outcomes by focusing on what matters to everyone involved in healthcare experiences.

Representation Matrix: A table used to track and analyze the demographic composition of a PFPC, and an applicant pool to support the recruitment process. A matrix addresses diversity, equity, inclusion, and accessibility across a PFPC.

Stakeholder: Any individual, group, or organization that has an interest in or is affected by the outcome, success, or decision of a project, initiative, etc.

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DOCUMENT DETAILS

Title of Document	Planetree Global PFPC Guide To PFAC/PFPC Best Practices
Authors	Planetree Global PFPC Subcommittee: Jill Adolphe, Jon Hoch, Lisa Keitel, Ashish Sharma, Lynn Vosburgh
Release Date	Oct 12, 2026
Version	1
Next Review Date	2028

REFERENCES

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- AMA - Steps Forward, Forming a Patient and Family Advisory Council
- BJC - Patient and Family Advisory Council, Getting Started Toolkit, Meghan West and Laurie Brown Skunks Team
- Planetree – Miscellaneous resources
- Women’s and Children’s Health Network
Adelaide, Partnering with Consumers -
Consumer Engagement Strategy and
Framework 2026





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