

## PCPCC Support & Alignment Network for Patient, Caregiver & Community Engagement

### ***Person and Family Engagement: Getting Started for Patients and Family Members***

*This page answers some common questions that patients or their family members may have about why getting involved in your clinic's quality activities can make a difference, and how to get started. Visit the [PCPCC SAN website](#) for links to more information.*

#### **Why would a patient or family member want to get involved in health care?**

You are the expert on your health. You are the one who knows if the services you get are helping, and if you are being treated with dignity and respect. When your doctors and nurses involve patients and families in improving care in the clinic, and partner with patients to improve health, it is called patient-centered care. All around the US clinicians are working to improve patient-centered care. You can help your doctors and nurses to improve your care and your experiences at the clinic. Patients and families can help the clinic to better meet the needs of all patients and their families by sharing their ideas, experience, and opinions. Some clinics also invite patients or their family members to participate in activities such as support groups or mentoring other patients. Peer supporters are trained to help other patients manage their conditions or solve problems. Patient and family involvement helps the clinic to think about ways to improve health care and your experience visiting the office.

#### **What is patient-centered care?**

[The Centers for Medicare and Medicaid Services Person and Family Engagement Strategy defines person-centered care with this description:](#) “Patients and families are partners in defining, designing, participating in and assessing the care practices and systems that serve them to assure they are respectful of and responsive to individual patient preferences, needs and values. This collaborative engagement allows patient values to guide all clinical decisions and drives genuine transformation in attitudes, behavior and practice.” Patient-centered care is also sometimes referred to as person centered care or person and family centered care (with ‘family’ including any group of people who support the person in care). We use both terms in PCPCC material.

Core concepts of patient and family centered care include:

- People are treated with **respect and dignity**.
- Health care providers **communicate and share complete and unbiased information** with patients and families in ways that are affirming and useful.
- Patients and families are encouraged and supported in **participating in care and decision-making** at the level they choose.
- **Collaboration** among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.

## Ways that patients and families can be involved

There are many different ways or “jobs” that benefit by the insights of people like you. All of them provide you with a chance to work with us to improve care for everyone. [Click on this link to see some ways that other patients have gotten involved in improving care.](#) Some of the ways patients and their families get involved include:

- Joining a Patient and Family Advisory Council
- Participate in a quality team at the clinic
- Help the clinic by reviewing educational material to be sure people like you can understand it
- Be a part of a ‘focus group’ to talk about your experiences on a certain topic
- Be part of a team that meets with new staff to share your experience as a patient
- Participating as a peer support worker
- Working with a community based organization to provide information and support to other people similar to you.

## What does a patient and family partner do?

Once you are on board as an advisor, the clinical practice will look for your input to help them improve the effectiveness of care you and other patients receive. They will likely also be working on improving your experiences with care throughout the organization (including the time you spend with doctors, nurses, front desk staff and in any other part). Here is a link to [some tips for being an effective patient or family member advisor](#) and some things that are helpful:

- Actively participate both in and out of meetings to achieve the purpose stated by the specific job assigned.
- Be prepared for meetings, ask questions, contribute ideas and provide input during the meeting
- Share personal experiences, stories, observations and opinions as a patient or family member. Share both positive and negative experiences in a constructive way.
- 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 family 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.
- Work effectively with other Improvement Partners as well as the organization’s staff, leaders and clinicians.
- Help the organization set quality goals that address the patient and family experience.
- Maintain confidentiality of information about patients and the organization you are working with.

## How can I prepare to be a patient or family member advisor?

Most people will need some training and information to participate effectively as an advisor. Patient and family advisors should have a chance to discuss their questions or thoughts about the work with a staff member (often called a “staff liaison”) who has time dedicated to coordinating activities with advisors. Some patient and family roles, such as peer support need specific training.

The clinic or practice organization should offer an orientation for patient and family advisors that includes information on the following:

- Who will be your staff liaison, and information about meetings, phone calls or other advisory roles you will have
- The mission, goals, and priorities of the practice
- What the organization is trying to achieve through patient- and family-centered care.
- What the organization is doing to improve patient experience, quality, and safety.
- What the organization is asking of you – such as specific skills and knowledge - to be an effective team member
- Their ways of keeping private information private, and the importance of privacy and confidentiality
- Communicating collaboratively and ways to express your perspective so others will listen
- How to ask tough questions and what an advisor should do when you don't agree
- If needed, specialized training for the role you will be carrying out (advisor, peer support, quality team member)

### **Staying Involved and asking questions of other advisors: the PFAC Network**

Many people will find it helpful to share their experiences and ask questions from others who are in similar positions. The [Patient and Family Advisory Council Network \(PFACNetwork\)](#) is an online forum hosted by the Institute for Patient and Family Centered Care to help people working on patient and family engagement to stay in touch. It is a place for those who share a passion for engaging patients and family members in communication, shared decision-making, and collaboration in all areas of health care. Anyone is invited to join the PFACNetwork for free. It is a place to ask questions and share information with a supportive and helpful group. The PFACNetwork is a wonderful resource to ask questions, engage in discussion, brainstorm ideas and build relationships while working together to promote high quality and safe health care experiences. The PFACNetwork is for patients and family members as well as health care staff, clinicians, educators, and administrative leaders as well as community organizers.

[Contact PCPCC SAN](#)