



Five Questions for Patient Family Advisory Councils (PFACs) to Ask Researchers at Their Organization

Below is a collection of five questions designed to engage patient-family advisory councils (PFACs) and researchers in meaningful conversations about patient and family involvement in the research.

Specifically, these questions are designed to:

- Help both groups see the potential of partnerships between patients, families, and researchers.
- Sensitize researchers to patient and family experiences.
- Sensitize patients to research regulations and processes.
- Develop deeper levels of perspective taking among and between both groups.
- Co-develop research questions that reflect the needs and interests of all groups.
- Brainstorm ways that patient and family partners can serve as meaningful members of the research team in every phase of the research life cycle.

What is Meaningful Engagement in Research?:

According to the Patient-Centered Outcomes Research Institute, "engagement in research," is defined as, "meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to sharing the results or findings with the public (learn more at www.pcori.org).

MEANINGFUL ENGAGEMENT IN EACH PHASE OF RESEARCH





Five Questions for PFACs to Ask Researchers at Their Organization:

1. Tell us more about the areas of research that you are most interested in or currently have projects. How do you use ideas, interests, and concerns from patients and family members to shape the research questions you ask and/or the projects you decide to study?
 - If you are not currently doing this, what are some of the potential benefits you see of including patient and family member voices when choosing research topics in the future?
2. Meaningful engagement of patient and family partners in the research process includes asking them to help with the design and conduct of the study (ie.- what you are going to do and how you are going to do it). This can include many tasks and roles, such as- patients and family members recruiting participants for the study, developing questionnaires or surveys, conducting interviews and focus groups, to name a few. How are patients and family partners included in the design and conduct of research for projects at our organization?
3. One could say that the greatest value of research is in sharing the results and information learned from the project with those who need it most. That can include many groups, such as, patients, family members, medical professionals, other researchers, insurance payers, safety experts, state and federal policy makers, etc. First, how are patients and family members involved in getting the word out about your research study findings? Second, how do you ensure that patients and family members have access to your research findings? In other words, beyond publishing information in professional journals, how does the average consumer get information about what you learned?
4. The evaluation phase of the research life cycle is the point at which people describe and assess the value of the research. This can include things like: describing the value of the research project to patients and families in terms of their ability to use the information learned to make healthcare decisions or improve their quality of life living with a condition. As a researcher, when you evaluate your current and past research projects through the eyes of patients and families, what are you most proud of in terms of the impact of your research in their lives?
5. Can you take a few minutes to explain some of the constraints or barriers that researchers may encounter when trying to partner with patients and families in research? What are some ways to overcome them? What ideas do you have about ways that we can partner on projects in the future? What is the best way for our groups to stay in touch after our meeting today?