

Engaging Patients and Families in Quality Improvement and Research

Patient and Family Advisors have a very important role on quality improvement and research teams. They bring a unique perspective that can influence planning, design and implementation. Below are ways families and researchers can partner in QI and research.

Before Research Meetings	
As a Patient and Family Advisor, What Can You Do?	What Does the Research Team Do?
Write a 150-200 word story about your child's medical experience to share with the team.	By email, give families background and contact info of team members. Determine if e-sharing will work for Patient and Family Advisor.
Meet or speak with your liaison to ask questions before the first meeting.	Identify a liaison to provide support and information to Patient and Family Advisors, including definitions of common acronyms.
Learn about basic research concepts and terms: IRB, informed consent, and PDSA cycles.	Provide information relevant to research and review common terms.
Get familiar with the research goals and team.	Share information about the research study, meeting schedule, timeframe and goals.
During Research Meetings	
Recognize the unique perspective you bring. Imagine how you would feel if you were a research subject or subject's family – share feedback and input.	Welcome Patient and Family Advisors to the team. Emphasize the value of their perspective with all team members. Be patient. Being on a team may be new to families.
Ask questions. Every question helps the team learn.	Welcome and address family questions.
Review images and text. Share feedback on readability and engagement.	Provide enough time for Patient and Family Advisors to review materials and for the team to make changes based on their input.
Offer feedback and concerns about research, including: hypothesis, subject recruitment, design and intervention.	Be flexible. You may need to change initial study goals and designs based on family input. Ensure diverse family input (Patient and Family Advisory Council).
After Research is Complete	
Know the value of your contributions.	Recognize the contributions of Patient and Family Advisors.
Be prepared for results that may differ from what you or the team expected.	As you analyze data and form conclusions, invite patient and family perspectives. Ask families to co-author a paper.
Attend debriefing session and provide feedback on what went well and what could be improved.	Host a debriefing session to discuss lessons learned.