



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 together in QI and research.

Before QI and 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.	Find out if e-sharing will work for Patient and Family Advisor. Email families background and team contact info.
Meet or speak with your liaison to ask questions before the first meeting.	Identify a liaison to support Patient and Family Advisors and answer questions.
Learn about basic QI and/or research concepts and terms such as: IRB, consent, and PDSA cycles.	Provide information relevant to research and define common terms.
Get familiar with the research goals and team.	Share information about the study, meeting schedule, timeframe and goals.
During QI and Research Meetings	
Imagine how you would feel if you were the research subject or subject's family-share your feedback. Recognize the unique perspective you bring.	Welcome Patient and Family Advisors to the team. Emphasize the value of their perspective with all team members.
Ask questions. Every question helps the team learn.	Welcome and address patient and family questions. Be patient. Being on a team may be new to patients and families.
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 by presenting to the Patient and Family Advisory Council.
After QI and Research Meetings	
Know the value of your contributions and how they make a difference.	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 patients and 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.