HASSENFELD CHILDREN'S HOSPITAL AT NYU LANGONE

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:

Preparing for Family & Research Partnership:	
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 facilitator to ask questions before the first meeting.	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 in advance to provide time for review.
Understand that the team will not be able to incorporate every suggestion.	**Welcome each contribution from families even if unable to incorporate into the study.**
During Research Meetings:	
Focus on specific questions asked.	Limit slides and request specific input rather than broad reaction. The larger the group of Family Advisors, the more specific ask.
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. Be patient. Having families on a research team may be new to researchers.	Welcome Patient and Family Advisors to the team. Emphasize the value of their perspective with all team members. Be patient. Being on a research 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. The ratio of research to family time should be 1:3.
Offer feedback and concerns about research, including: hypothesis, subject recruitment, how the study could be done, and how to share the results of the study with families or other stakeholders.	Be flexible. You may need to change initial study goals and designs based on family input.

Created in partnership with families and expertise from our Sala Institute for Child and Family Centered Care

After Study is Completed:	
Know the value of your contributions.	Recognize the contributions of Patient and Family Advisors in publications and presentations.
Be prepared for results that may differ from what you or the team expected.	Return to family advisors to share findings. 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.