

Sala Institute for Child and Family-Centered Care

Center for
Child and Family
Resilience

Center for
Child and Family
Experience

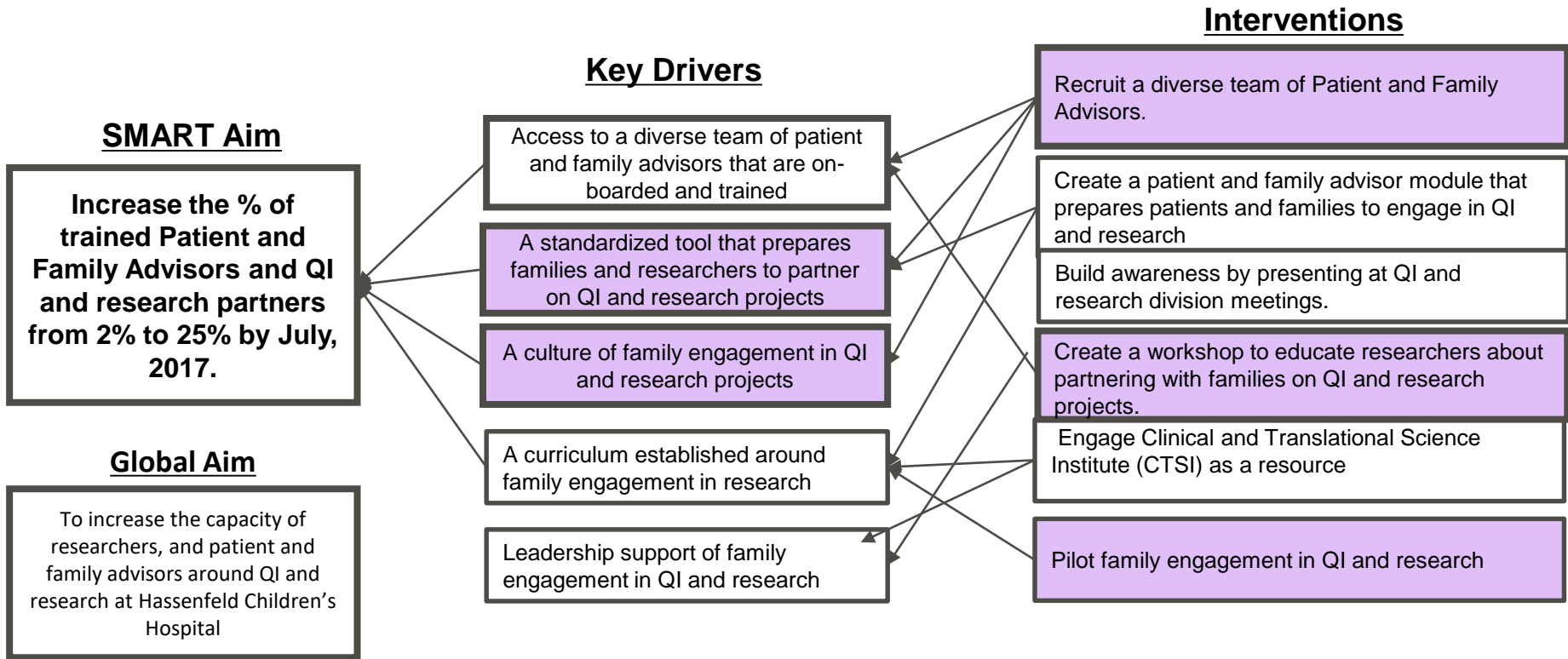
Center for
Patient Safety
and Quality

Center for
Education,
Learning, and
Innovation

HASSENFELD CHILDREN'S HOSPITAL OF NEW YORK



Patients and Families as Advisors in QI and Research: Building a Quality Improvement Model to Ensure Consistency



Mirror Image and Partnership Tool

This tool is designed to:

- **Offer transparency** regarding roles of the Patient and Family Advisors and researchers
- **Share learning and expectations** for Patient and Family Advisors and researchers
- **Prepare** Patient and Family Advisors and researchers before initial research meeting
- **Outline best practices** for Patient and Family Advisors and researchers *before, during* and *after* QI and research meetings



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.

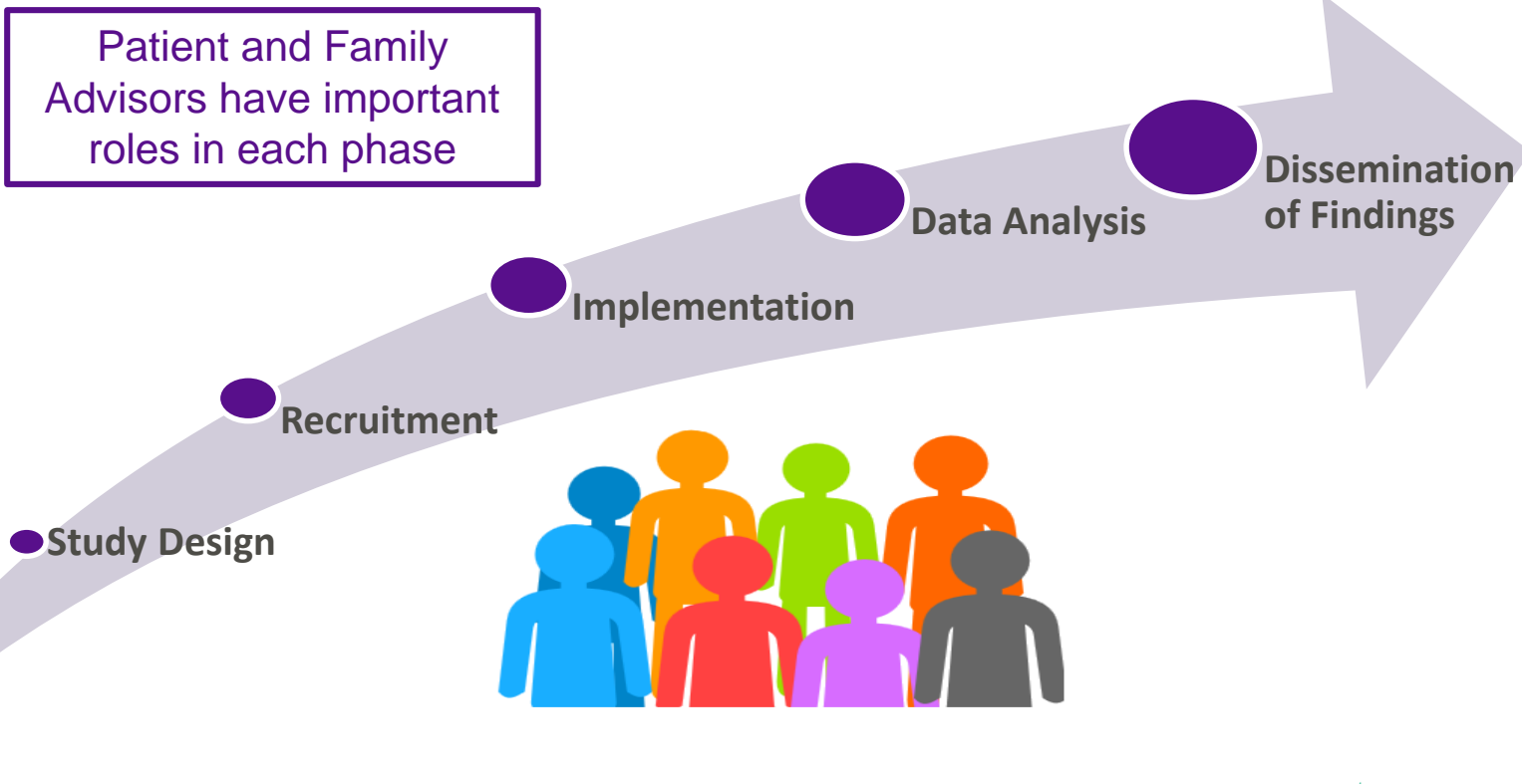
Before QI and Research Meetings	
As a Patient and Family Advisor, What Can You Do?	What Does the Research Team Do?
Write a 150-200 word story about your child's medical experience to share with the team.	Find out if e-sharing will work for Patient and Family Advisor. Email families background and team 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.	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.

March 7, 2017 | Page 1 of 1

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



Engagement at Every Phase of QI and Research



Design Phase of QI and Research

Patient and Family Advisors provide input on:

- Research hypotheses and questions
- Research goals
- Methodology



Recruitment Phase of QI and Research

Patient and Family Advisors provide input on:

- Recruitment materials (including health literacy, appeal, engagement)
- Recruitment strategies
- Subject qualifications
- Locations to find subjects
- Effective approaches to describing study to patients and families and inviting them to participate

Recruitment Flyers Influenced by Family Advisory Council

NYU Fink Children's Ambulatory Care Center
160 E 32nd Street, New York, NY 10016
212-263-5940

Have you been feeling...

- Anxious or full of worry?
- Sad or generally unhappy?
- Overwhelmed?
- Irritable or short tempered?
- Lonely or alone?
- Guilty? Worthless?
- Does your future feel hopeless?
- Like a failure?
- Numb?

Do you...

- Sleep too much or too little?
- Use alcohol or drugs to get through the day?
- Eat more or less than you used to eat?
- Have trouble concentrating or making decisions?

What about experiencing...

- An overwhelming sense of worry or fear?
- Obsessive thoughts that won't go away?
- Compulsive actions or restlessness?
- Panic attacks?

If you answered "yes" to any of these questions, or have experienced similar conditions that are disrupting your daily living, your pediatric gastroenterology team here at Fink wants to help. In association with the NYU Child Study Center, we invite you to participate in a research study designed to address the symptoms of depression and anxiety that you are experiencing.



- Improved readability
- Simpler language
- Visual engagement
- Relatability

Fink Children's Ambulatory Care Center

Have you been experiencing...
Worsening belly pain or diarrhea?

Have you been feeling...
Stressed out or anxious?
Sad or lonely?
Overwhelmed or misunderstood?
Moody?

Do you...
Sleep too much or too little?
Eat more or less than you used to?
Have trouble concentrating or making decisions?

If you answered "yes" to any of these questions, your pediatric gastroenterology team here at Fink wants to help.

You might be eligible for a research study at NYU Langone for teens and young adults ages 12 - 21 years with inflammatory bowel disease, such as Crohn's Disease or Ulcerative Colitis, and depression and/or anxiety.

Eligible Participants will receive:

- A no-cost evaluation to share your stresses or concerns
- Free counseling or help getting connected with a mental health provider
- You may be eligible to get up to \$50

For more information, contact Jeanne Cho
Jeanne.Cho@nyumc.org
646.754.7045

160 E 32nd Street • New York, NY 10016 • 212.263.5940



Implementation and Data Analysis Phases of QI and Research

Patient and Family Advisors provide input on:

- Intervention
- Intervention materials (including health literacy, appeal, engagement)
- Data interpretations and limitations

Patient and Family Advisors participate by:

- Offering patient and family perspective about key aspects of study
- Attending meetings
- Conducting audits
- Teaching clinicians (sharing family stories) as part of staff education
- Highlighting the importance of the study with staff and families
- Identifying new questions to explore

Dissemination of Results Phase of QI and Research

Patient and Family Advisors can participate in:

- Debriefing sessions (What went well? What could we improve on?)
- Review, writing, submission and co-authorship of abstracts and papers
- Internal and external presentations



Keys to Success – Patient and Family Advisors in QI and Research

- Prepare Patient and Family Advisors and researchers on how to collaborate in the most effective ways
- Emphasize the value and contributions of Patient and Family Advisors on QI and research teams – share examples!
- Identify a liaison to support Patient and Family Advisors and answer questions
- Teach Patient and Family Advisors basic QI and research concepts such as: IRB, consent and PDSA cycles
- Welcome Patient and Family Advisor input in all phases of QI and research including: Design, Recruitment, Implementation, Data Analysis, and Dissemination of Results
- Process, integrate and apply Patient and Family Advisor input
- After QI an research is complete, include Patient and Families in debrief and in publications and/or presentations about findings
- Celebrate your collaboration and the improved processes and results

