Family Engagement in QI and Research

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

**SMART Aim**

Increase the % of trained Patient and Family Advisors and QI and research partners from 2% to 25% by July, 2017.

**Global Aim**

To increase the capacity of researchers, and patient and family advisors around QI and research at Hassenfeld Children’s Hospital

**Key Drivers**

- Access to a diverse team of patient and family advisors that are onboarded and trained
- A standardized tool that prepares families and researchers to partner on QI and research projects
- A culture of family engagement in QI and research projects
- A curriculum established around family engagement in research
- Leadership support of family engagement in QI and research

**Interventions**

- Recruit a diverse team of Patient and Family Advisors.
- Create a patient and family advisor module that prepares patients and families to engage in QI and research.
- Build awareness by presenting at QI and research division meetings.
- Create a workshop to educate researchers about partnering with families on QI and research projects.
- Engage Clinical and Translational Science Institute (CTSI) as a resource.
- Pilot family engagement in QI and research.
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

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<thead>
<tr>
<th>Before QI and Research Meetings</th>
<th>What Does the Research Team Do?</th>
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<tbody>
<tr>
<td>Why do you want to be a Patient and Family Advisor?</td>
<td>Find out what the role would look like for Patient and Family Advisors. Email familiar background and team contact info.</td>
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<tr>
<td>Meet or speak with your personal advisor to ask questions before the initial meeting.</td>
<td>Identify a liaison to support Patient and Family Advisors and answer questions.</td>
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<td>Learn about basic QI and research concepts and terms such as IRB, consent, and RAND cycles.</td>
<td>Provide information relevant to research and define common terms.</td>
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<td>Get familiar with the research goals and team.</td>
<td>Share information about the study, meeting schedule, timeline, and goals.</td>
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<th>During QI and Research Meetings</th>
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<tr>
<td>Imagine how you would feel if you were the research subject or subject's family. Share your feedback. Recognize the unique perspective you bring.</td>
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<td>Ask questions. Every question helps the team learn.</td>
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<tr>
<td>Review images and text. Share feedback on usability, and engagement.</td>
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<tr>
<td>Offer feedback and concerns about research, including hypotheses, subject recruitment, design, and intervention.</td>
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<th>After QI and Research Meetings</th>
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<tr>
<td>Know the value of your contributions.</td>
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<td>Be prepared for results that may differ from what you or the team expected.</td>
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<td>Attend debriefing sessions and provide feedback on what went well and what could be improved.</td>
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Engagement at Every Phase of QI and Research

Patient and Family Advisors have important roles in each phase

- Study Design
- Recruitment
- Implementation
- Data Analysis
- Dissemination of Findings
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

Before

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?
- Nervous?

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.

After

Have you been experiencing...
- Worried about your child’s health?
- Frustrated?
- Overwhelmed or reassured?
- Worried?

Do you...
- Sleep too much or too little?
- Fend off the non-stop taunts?
- 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 $100

For more information, contact Jeaneen Cho
Jeaneen.Cho@nyumc.org
844.754.7048

NYU Langone Medical Center
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 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
Thank you