Family Engagement in Research

Introduction and Templates for Research Teams
Mechanisms for FE in Research at HCH

FAC for Research/ Studio:
• routine meetings
• any design phase, not time-sensitive

Embedded Family Research Advisor
• Included as part of the research team
• Provide feedback for phases of research

Researcher with idea/study

Ad-Hoc Advisory Group of FA
• Grant applications
• Strategies for studies in progress
# Roles and Responsibilities

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<tr>
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<th>Embedded FA</th>
<th>Ad-Hoc (2-3 FAs)</th>
<th>Family Advisory Council</th>
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<tr>
<td>Family Advisor</td>
<td>• Collaborate with researcher routinely</td>
<td>• Participate in research review session with facilitator</td>
<td>Participate in group discussion</td>
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<td>• Review relevant background material</td>
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<td></td>
<td>• Routine report back to Facilitator</td>
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<tr>
<td>Researcher</td>
<td>• Meet with facilitator to learn best practices of FA engagement</td>
<td>• Meet with facilitator to learn best practices of FA engagement</td>
<td>Report back to FAC every 6 months</td>
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<td></td>
<td>• Routine updates on FE and overall study</td>
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<td>Facilitator</td>
<td>• Mentor Family Advisor</td>
<td>• Mentor Family Advisors</td>
<td>Schedule FAC follow-up visit and assist with template;</td>
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<td></td>
<td>• Attend first meeting with researcher and FA</td>
<td>• Attend first meeting with researcher and FA</td>
<td>Gather interim data</td>
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<td></td>
<td>• Orient researcher about best practices of FA engagement</td>
<td>• Ensure FE roles are clear</td>
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<td>• Routine check in with Researcher</td>
<td>• Orient researcher about best practices of FA engagement</td>
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Initial Process for Researcher Desiring Family Engagement

**Researcher will…**

Complete family and youth engagement intake form* (see slide 10 for details on research section of intake form)

Complete template and review with FE Team

Share with FA

**Family Engagement Research Team will…**

Match resources to need:
A. FAC Studio
B. Embedded Advisor
C. Ad Hoc Advisory Group

A,B,C: Provide template

B&C: Identify/Recruit FA

B&C: Facilitate First Meeting
Template for Family Partner Presentation
Research Topic

Name, Department
Date
1. Background: *Use lay language to describe the problem trying to solve and example of a clinical situation that inspired, if relevant*

2. Hypothesis and study aims *Broadly!*

3. Proposed or current design: *Disregard if this is preliminary stages but helpful to have some idea (prospective/chart review/etc)*

4. Goal for family engagement: *State why you are coming to FAC or engaging an FA for this project; examples - last time, did study and unable to recruit; want to see if study is feasible with current design; etc*
Opportunities for Family Advisor Engagement in Pediatric Research

**Preparatory**
- Agenda/idea
- Funding

**Planning/Design**
- Determine outcomes
- Plan procedures/data collection
- Plan recruitment/retention

**Execution**
- Recruitment/retention modifications
- Direct recruitment
- Actual data collection (surveys)
- Analysis/Interpretation

**Translation/Dissemination**
- Dissemination Mechanisms
- Implementation
- Evaluation
Questions for Family Advisors

3 clear, concise and specific questions to solicit feedback from the group