Patients and Families As Advisors in Pediatric Clinical Research

**Aims**

- Increase annual number of pediatric faculty with any FE in current research from 3 to 12
- Increase annual number of active pediatric studies with FE from 4 to 12
- Increase Research Studios at monthly Family Advisory Council meetings from 25% to 70%

*By Feb 2019*

**Global Aim**

To improve the quality and patient centeredness of pediatric clinical research through meaningful integration of families and patients in research design, execution and presentation

**Key Drivers**

- Sustainable system for matching and supporting researchers and family advisors
- Routine inclusion of Research Studios at monthly Family Advisory Council meeting Studios
- Family Advisory Council capacity and experience with research
- Researcher demand and capacity for FE
- Institutional engagement, integration and support

**Interventions**

- Develop structures for varying levels of FE in research: network/comment > studio > embedded
- Benchmark and review existing PFE/Research programs for core elements
- Design & implement curriculum and tools for preparing researchers and families for research
- Train and support family research advisors
- Measure Impact and Track interactions (qual and quant)
- Develop and sustain FE – Researcher screening system
  - Build Steering Committee for FER allocation
- Design & implement researcher engagement plan
  - Orientation & awareness building
  - Pilot invited FE Studios with potential researchers
  - Technical assistance for study design and grant proposals
- Identify funding sources
- Develop standard templates for researchers
- Partner with CTSI RRU Patient Research Council to test, collaborate family engagement in research

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