Patient and Family Leadership in the CFLN Key Driver Diagram (KDD)

Global Aim

Improve Learning Network processes and outcomes by growing diverse leaders and increasing Learning Network quality improvement capacity and capabilities

SMART Aim

We want to increase % of centers with at least one PFP rating a 5 or above on LOE from 69% to 85% ("rolling data")

By January 15, 2019

Key Drivers

- Patients and parents who are engaged and successfully onboarded
- Network models, supports & encourages patient/family leadership (% of Centers with at least 1 PFP responding with 7 on LOE Score)
- Patients and parent are comfortable with their QI skills (% Centers who have at least 1 PFP rating 4+ on at least 3 QI Skills on the QI Skills Self-Assessment)
- Clear and transparent opportunities for growth
- Connected PFP Community that communicates (% Programs w/ PFPs who attend no. PEP calls)
- Network that incorporates PFP Voice in all work (% of CFLN workgroups that are including a PFP)
- Psychological Safety for PFPs among their relationship with QI Teams & the Network (% valued member/satisfied of the QI team and % valued member of Network)

Interventions (LOR#1)

- Create a list or table that can most effectively identify patient and family partners whose interests, experiences and passions match this work
- Develop and distribute Patient and Family Partner Onboarding Materials, record the onboarding time per PFP
- Develop database to keep track of families who are onboarded and contact those interested in leadership
- Hold well-attended monthly PFP Calls for PFPs to share learnings with each other: model and practice leadership
- Develop a system of peer-led QI support and coaching for patient and family led QI projects
- Create multiple accessible and flexible QI training opportunities
- Develop a document template and process to communicate to PFPs the vast opportunities available for patient and family leadership
- Develop a tool for measuring leadership
- Identify support mechanisms for Patient and Family members who have financial and health barriers to serving in leadership positions
- Identifying willing CF Programs to add a PFP Partnering with Community Voice to identify interested Patients
- Reach out to PFP if they express they are not satisfied with the working relationship with their team or don’t feel valued

Population

Patient and Family Members within the CF Learning Network

Legend

- Potential intervention
- Active intervention
- Adopted/Abandoned intervention

Note: LOR# = Level of Reliability Number, e.g., LOR 1