I²S² Project Title: Operationalizing Patient and Family Engagement and Leadership within the CF Learning Network

Team Leader: Breck Gamel

Team:
J.F., Adult with cystic fibrosis
L.D., Parent of a child with cystic fibrosis
S.N., CFLN Operational Staff
M.S., CFLN Project Investigator
K.S., CF Community Expert

Date: 6/31/19

BY NC SA

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

Project Leader(s): Breck Gamel

Revision Date: ***5/31/2019 (v5)***

Global Aim

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

SMART Aim

We will increase the number of movements towards leadership among CLFN Patient and Family Partners within the Participating, Contributing and Leading levels from 0 to 2.5 movements bi-weekly by April 30, 2019.

Population

Patient and Family Members within the CF Learning Network

Key Drivers

- Patients and parents who are successfully onboarded
- Patients and parents who are interested and engaged
- Network that encourages strong relationships and supports patient/family leadership in QI
- Patients and parent are knowledgeable in QI
- Effective assessment and evaluative tools
- Clear and transparent opportunities for growth
- System that supports financial and health independence

Interventions (LOR#1)

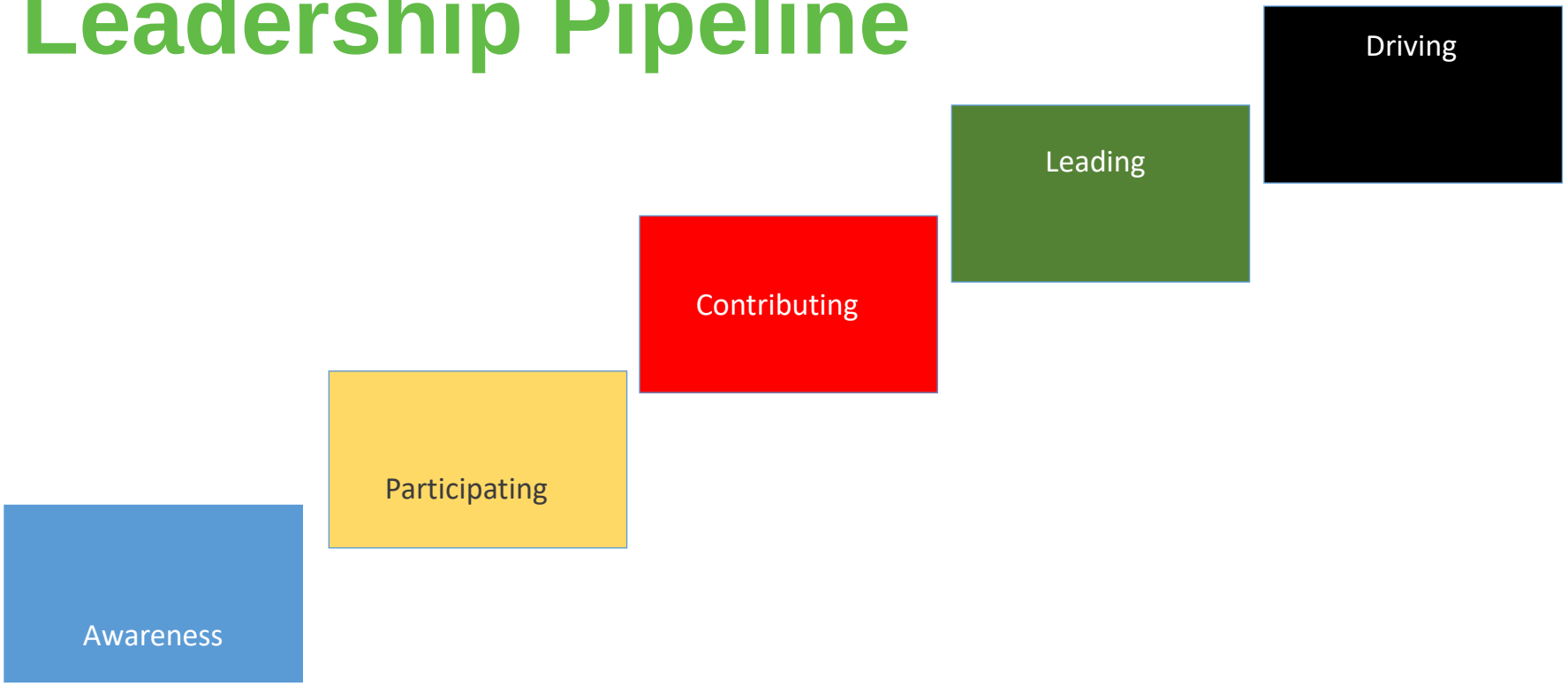
- Create a list or tool to that can most effectively identify patient and family partners whose interests, experiences and passions match this work. (Testing)
- Develop and distribute Patient and Family Partner Onboarding Materials (Adopted)
- Develop database to keep track of families who are onboarded (Adopted; Working on Sustainability)
- Hold well-attended monthly PFP Calls for PFPs to share learnings with each other (Adopted)
- Develop a system of peer-led QI support and coaching for patient and family led QI projects (Testing)
- Create an accessible and flexible QI training that includes an assessment (Testing)
- Develop a tool for measuring Network-Level Leadership (Adopted)
- Document and communicate 1:1 and in the Network the vast opportunities available for patient and family leadership (Adopted; Working on Sustainability)
- Identify support mechanisms for Patient and Family members who have financial and health barriers to serving in leadership positions. (Testing)

Legend

- Potential intervention
- Active intervention
- Adopted/Abandoned intervention

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

Developing Leaders in the CFLN: Network CoProduction Leadership Pipeline

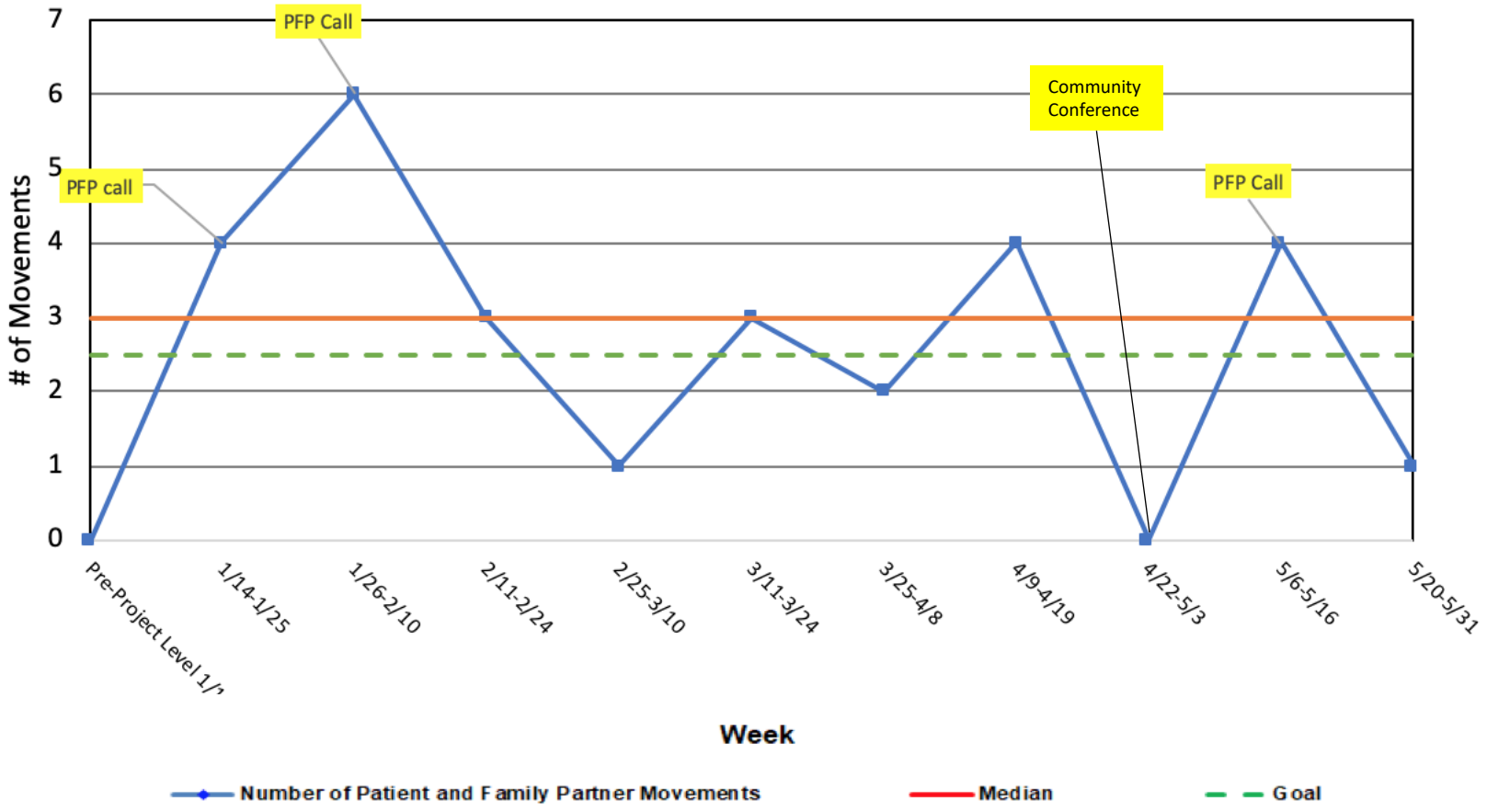


I²S²

Cincinnati Children's
changing the outcome together

Measures

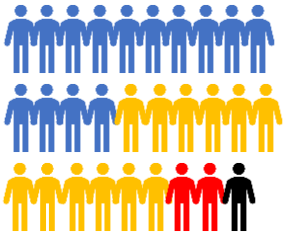
Number of Patient and Family Partner Movements
to the Participating, Contributing and Leading levels



Measures

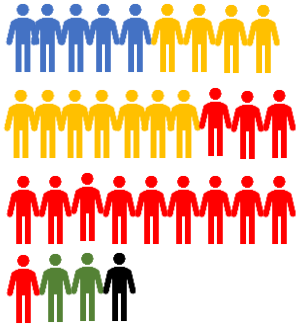
Levels:
- Awareness
- Participating
- Contributing
- Leading
- Driving

BASELINE
as of 1/1/2019



From 12 Participating &
2 Contributing

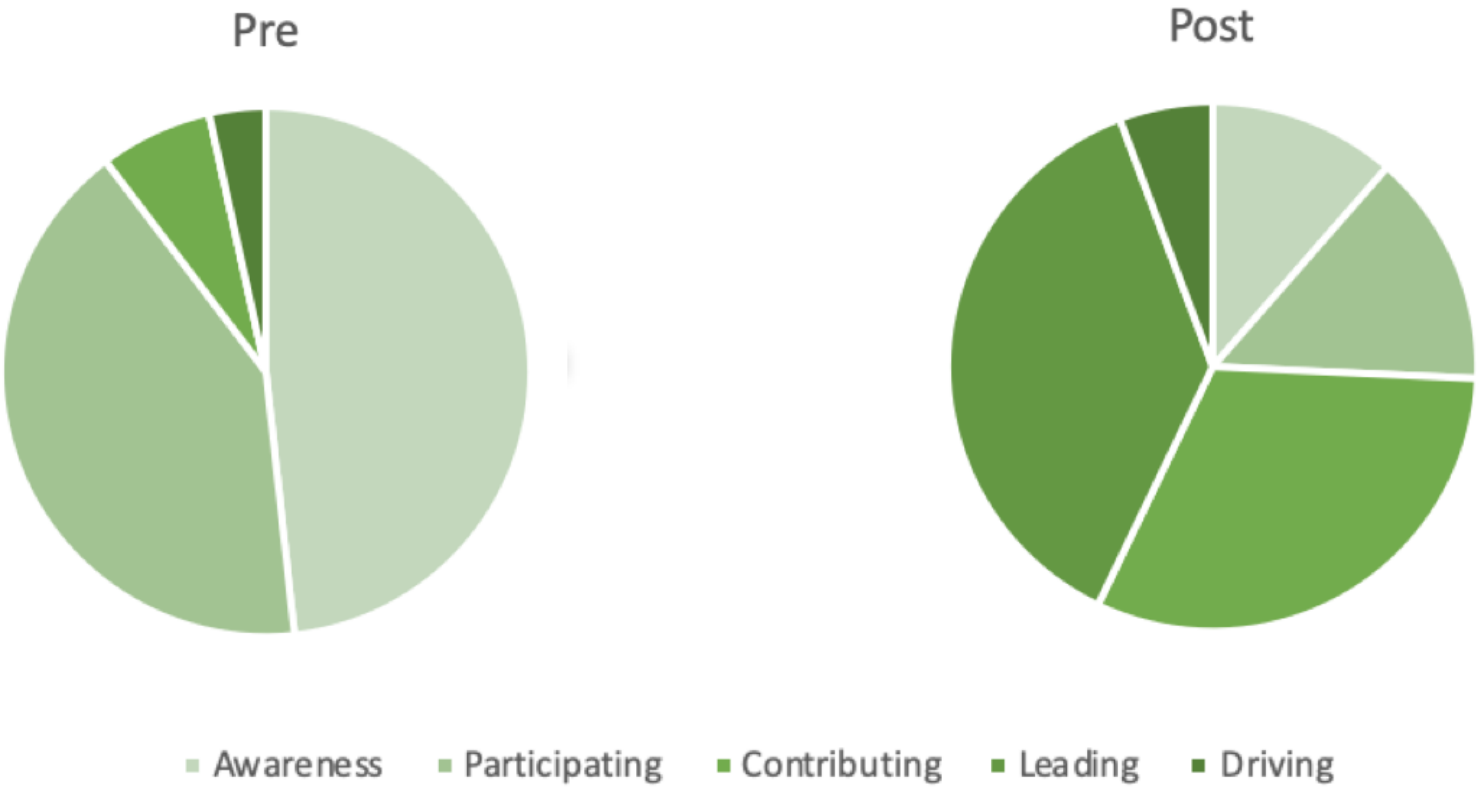
AFTER INTERVENTIONS
as of 5/31/2019



To 11 Participating &
13 Contributing!

In 20 weeks, we increased the total number of Patient and Family Partners who are participating, contributing and leading in Network Co-Production from 14 to 26.

Measures



In a little over 4 months, the percentage of Patient and Family Partners actively participating, contributing and leading through Network co-production went from 50% to 84%!

Completed PDSAs

- Developed and distributed Onboarding Materials
- Created a database to keep track of families who are onboarded
- Held well-attended PFP Calls and gave opportunities for PFP members to contribute
- Developed a tool for measuring Network Level Leadership
- Documented and communicated 1:1 and in the Network the vast opportunities available for leadership

Leadership Pipeline Rubric

Stages	Attributes	Awareness	Participating	Contributing	Leading	Driving
Archetypes	Engagement	Little to no engagement	Some engagement	Moderage engagement	High engagement	Ownership
	Reliability	Not reliable	Some reliability	Reliable	High reliability	Excellent reliability
	Influence	Unknown influencer	May be an influencer	Potential influencer	Influencer in the Network	Influencer in the Network
	QI experience	Little or no QI experience	Little or no QI experience	Some QI experience	Moderate QI experience	Extensive QI experience
	Expertise	Unknown expertise	Possible expertise	Potential expertise	Recognized expertise	Recognized expertise
	Coaching Needs	Little to interest in being coached	Open to being coached	Interested in being coached	High desire to be coached	Finds own coaches
	Support Needs	Involvement not sustainted with support	Involvement is sustainted with support	Leadership is sustainted with support	Leadership is sustainted with some support	Engagement is self-sustained

Stages	Attributes	Awareness	Participating	Contributing	Leading	Driving
What it looks like:	Network Survey	No or rare involvement in monthly PFP survey (0-2 surveys per year)	Irregularly fills out surveys (3-6 surveys per year)	Regularly fills out surveys (7-12 per year)	Regularly fills out surveys (7-12 per year); directs survey questions	Regularly fills out surveys (7-12 per year); directs survey questions
	Network PFP Calls	Little to no attendance on Patient and Family Partner Calls (present on 0-20% or 0-2 PFP calls per year)	Irregular attendance on Patient and Family Partner Calls (present on 30-70% or 3-7 PFP calls per year)	Regularly attends Patient and Family Partner Calls (present on 75-100% or 8+ PFP calls per year)	Regularly attends Patient and Family Partner Calls (present on 75-100% or 8+ PFP calls per year); Leads Patient and Family Partner Calls	Leads and helps set direction of Patient and Family Partner Calls
	Network Participation and QI work	Receives emails from Network; Little to some engagement in the Network	Actively participates in Network QI (i.e. attends Network Webinars, PFP Calls)	Taking ownership in a project; Makes valuable contributions Network QI (i.e. Participates in ad hoc CFLN projects)	Leading an QI effort in the Network; teaching others (i.e. Participates on the NLT)	Ownership of QI effort in the Network; Coaching others in leading Network QI projects; Regularly communicating/teaching Network QI work through Network Webinars, Community Conferences, NACFC Posters and through published work
	Center Participation and QI work	Some engagement with the local QI Program	Actively participating in QI work at their Care Center	Taking ownership in a project; Makes valuable contributions to the QI team at their Care Center	Leading an QI effort at the Care Center; teaching others	Leading an QI effort at the Care Center; teaching others
	Community Conference	Has never attended a Community Conference (virtually or in person)	Has attended one or more Community Conferences (virtually or in person)	Regularly attends one or more CC (virtually or in person)	Regularly attends one or more CC (virtually or in person) per year; Contributes at the CC (i.e. participates in planning, submit proposals, gives an Ignite Talk, co-leads a session)	Regularly leads at one or more CC (virtually or in person) per year

Sustainability of QI Project: Developing Standard Operating Procedures (SOPs)

Patient and Family Partner Standard Operating Procedure

Task	PFP Newsletter
Role	PFP Newsletter Reporter
Revision Date	6.2.19
Description	Every two weeks, the Network releases as newsletter called, "The Forward Thinker." The Patient and Family Partner Working Group is invited to submit a blurb to the newsletter in every addition of the Newsletter. It is the responsibility of the PFP Newsletter Reporter to submit this information to the correct person in the Network by the deadline in order for the information to be captured in the Newsletter.
Process Steps	Step 1: PFP Newsletter Reporter captures notes from the Afternoon and Evening Patient and Family Partner Calls. On the call, the Newsletter Reporter asks the group: "What do you feel is important for us to report to the Network about what's going on in the Patient and Family Partner community? What did we talk about on the Call today do you think is important to share with others?" Step 2: Sarah and/or the Newsletter Reporter captures responses to this question and places the information in full sentences totally no more than 150 characters. Step 3: The Newsletter Reporter emails Julia at c3nCF@cchmc.org these sentences by the deadline of the newsletter.

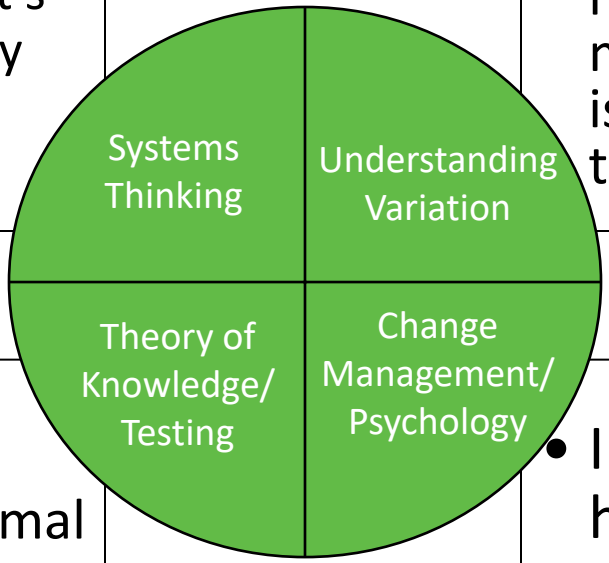
Overall Learnings

QI Learning (Ex. Learned benefits of failing on a small scale)	**Leadership Learning** (Ex. Importance of communicating with stakeholders)	**Project Process Learning** (Ex. Importance of documenting throughout the project)
QI Learning 1 QI really helps you quickly see the weak spots in your system. While I was busy increasing leaders, I realized I can't fail to focus on improving newest PFPs as well.	Leadership Learning 1 I learned how much like a garden this work is like – takes time and effort. Need more people/time to be put on it.	Project Process Learning 1 I need to set aside time to do it daily or weekly. "I have to change the system to change the system."
QI Learning 2 I learned the value of Standard Operating Procedures (SOPs).	Leadership Learning 2 It's hard work to communicate to others in a meaningful way. How to use team best?	Project Process Learning 2 Project still hinges on one person's efforts.
QI Learning 3 I learned it's really important to make sure slides are self explanatory as much as possible.	Leadership Learning 3 We are still in a very vulnerable place where people need people to grow. It's not automatic, growing on it's own, yet.	Project Process Learning 3 Process needs a lot of support from bigger system to keep growing.

Overall Challenges

- System that is so heavily reliant on a person is burdensome and moves slowly. It's critical to move away from this as soon as possible.

- Variation seems to be directly connected to how hard I work. It means my system isn't sustainable at this point.



- It's hard to run formal PDSAs while doing so much innovation

- I underestimated how vital I am to the process continuing.

Next Steps
(e.g. testing, analysis, leadership, system thinking)

- Improving Sustainability
  - I am trying to train more PFPs to do QI Work. (KDD: Create accessible and flexible QI Training; Develop a system of peer-led QI support and coaching for patient and family led QI projects
  - I am creating as many Standard Operating Procedures (SOPs). (KDD: Identify support mechanisms for Patient and Family members who have financial and health barriers to serving in leadership positions.)