

# Cystic Fibrosis Learning Network (CFLN)

## Charter for Patient & Family Partner Workgroup

### Background:

*Explain the justification or need for the workgroup.*

*For example: What problem does this workgroup aim to improve? Is there evidence that supports the need? What value does this workgroup add to the CF Learning Network?*

The Patient and Family Partner (PFP) Working Group is a cross-program, role-specific group whose purpose is to support and improve PFP coproduction with their CF Program. The PFP Working Group serves a **leadership development** function for PFP, including training, mentoring, and shared learning in order to advance co-production. Support is accomplished by learning from and educating others on the successes and challenges of Patient and Family Partners coproducing with their CF Programs. In addition, the PFP Working Group offers regular network support to PFPs with the goal to ensure that CF patients and families voice is highly valued by the Network. The PFP Working Group also identifies and develops PFP leaders to participate in leadership roles within the Network.

Strong care partnership is a Key Driver on the CFLN KDD and having Patient and Family Partners on improvement teams is important.

#### Key points:

Support of leadership development in PFP working group is important because (confidence to speak up in meetings with QI team, level the playing field, same language is used)

Higher level idea: Patient & family voice should be part of all future care models, ripple effect

Educating, teaching, improving QI skills

Sustainability

Need PFPs who feel like experts, confident, understand the system, feel safe

Financial recognition sheet

Renewal proposal

### Aim & Objectives:

*State specific aims and/or objectives for the workgroup.*

*For example: What is the SMART Aim? What results are expected? What benefits will be realized? Does a change package exist (or other related projects)?*

Fully supported & fully prepared to work with their clinic teams – also goes beyond their care team level

PFPs who are fully co-producing at both levels

We want people to work on what they want to work on and at the level they want to participate

Do we have 2 KDDs? Network level & Center level? Or two smart aims?

### Composition & Roles:

Title	Name	E-Mail	CFLN Program Association
SC Sponsor	Name 1		
Team Lead/Co-Lead	Name 2		

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<b>Team Lead/Co-Lead</b>	Name 3		
<b>Operational Support</b>	Name 4		

### Participation Expectations:

*Outline the various participation efforts and responsibilities below to establish standards for the workgroup roles. It is important to ensure all roles understand and are aligned with the expectations of what is required to participate in the workgroup.*

### Workgroup Co-Leader Responsibilities:

- Team Lead/Co-Lead (Name 3)
  - Set agenda of the PFP Call, including contacting speakers
  - Lead monthly PFP Call
  - Coach PFPs as needed (to lead calls and other)
  - Attend PFP Leadership Calls 2x month
  - Develop and present PFP work on Webinars, at Community Conference and elsewhere (i.e. NACFC)
- Team Lead/Co-Lead (Name 2)
  - Back up Team Lead/Co-Lead (Name 3) in leading the PFP calls
  - Develop monthly PFP survey questions
  - Help SC Sponsor work to build PFP leaders
  - Attend PFP Leadership Calls 2x month
  - Develop and present PFP work on Webinars, at Community Conference and elsewhere (i.e. NACFC)
- SC Sponsor (Name 1)
  - Stewardship Committee Sponsor
  - Coach PFPs as needed (to lead calls and other)
  - Work to build PFP leaders with Team Lead/Co-Lead
  - Lead and implement PFP QI initiatives / Develop the structure for learning about the PFP Working Group (aims, PDSAs, measures)
  - Send welcome e-mail to new PFPs with onboarding material
  - Develop and present PFP work on Webinars, at Community Conference and elsewhere (i.e. NACFC)
  - Field requests of the PFPs as needed
  - Attend PFP Leadership Calls 2x month

### Support Team Responsibilities: (Ops)

- Monthly Survey
  - Develop monthly PFP survey in SurveyMonkey
  - Export monthly data
  - update PFP data dashboard & Network Dashboard
- Monthly Calls
  - Manage calendar invitations
  - Develop slides
  - Send reminder to PFPs
  - Take notes during calls
  - Send notes after calls
- PFP Leadership Meetings

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- Manage calendar invitations
- Manage agenda
- Manage slides
- Take notes during calls
- Send notes after calls

### **Member Responsibilities:**

- Participate in monthly meetings
- Complete monthly survey
- Attend monthly Network Meeting
- Attend Community Conferences
- apply learnings in LN Teams and/or community

### **Communication:**

*Define expected communication types, delivery channels, facilitators, frequency, and audiences. If needed, detail escalation points (i.e. risks, mitigation) and progress status updates that will be provided and required throughout the workgroup duration.*

Communication Type	Delivery Channel	Facilitator	Timing/Frequency	Audience
PFP Calls	Zoom	Team Lead/Co-Lead	Monthly	All PFPs
Learning Network News (internal newsletter)	Constant Contact	All	Bi-weekly	CFLN
Forward Thinker (external newsletter)	Constant Contact	Varies	Quarterly	Non-CFLN
Leadership Huddle	Zoom	All	Bi-weekly	PFP Leadership
PFP Survey	SurveyMonkey	Operational Support	Monthly	All PFPs
E-mail	E-mail server	All	Always	All
Presentations				

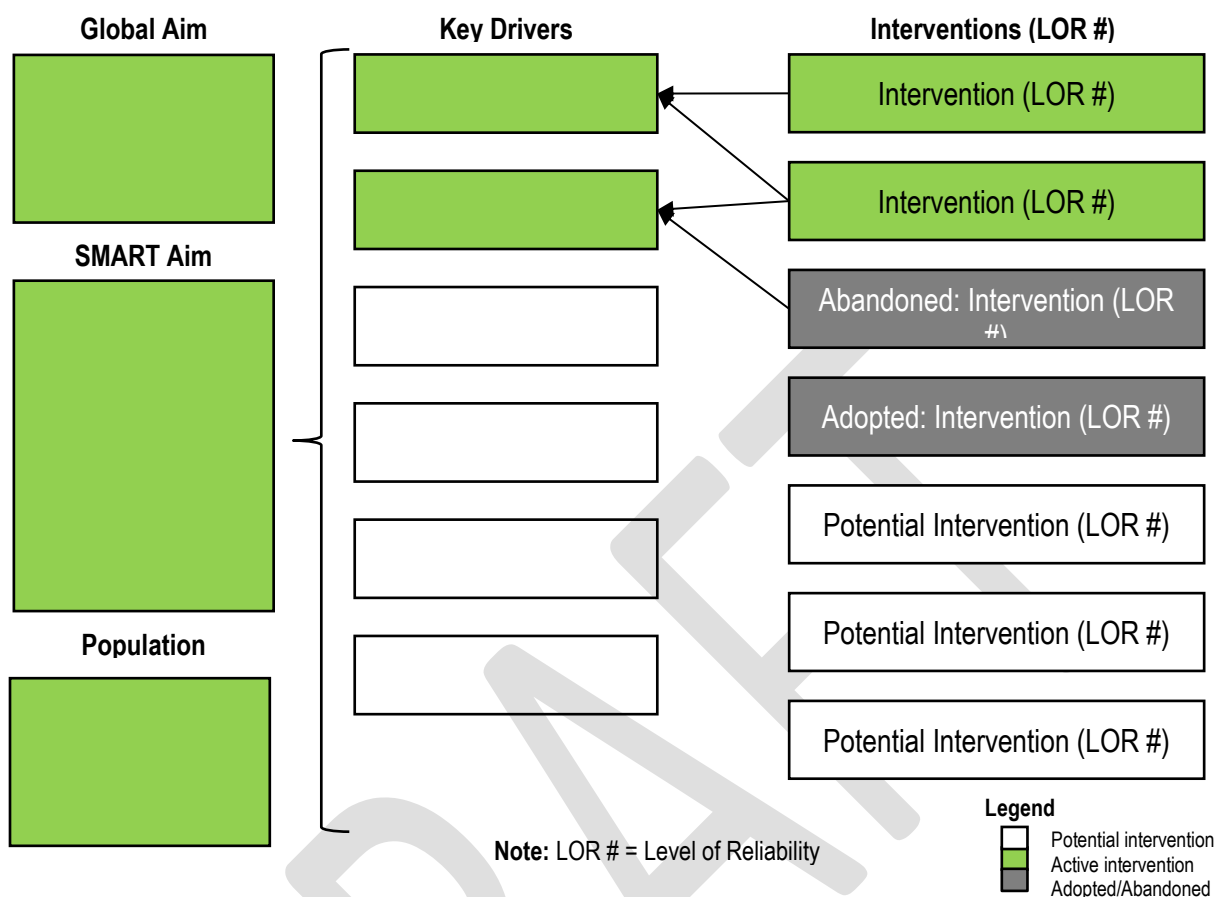
\*\*\* Optional Communication Plan Template \*\*\*

### **Key Driver Diagram:**

*Workgroups are encouraged to form a KDD however, it may not be applicable for all groups. In these instances, the workgroup should at least declare an aim statement or a statement of purpose. Which will provide structure and a shared understanding for the workgroup, why it is beneficial, and what is the scope.*

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### Measures & Data Collection:

*Describe the measure(s) that the workgroup would like to improve including what question(s) the measure(s) answer, desired direction of change, and the type of measure (e.g., process, outcome, or balancing). Include a summary or citation of evidence supporting this measure (if available). Describe the data and how it will be collected (i.e. daily), analyzed, and reported (i.e. method, frequency).*

Measure Name & Rationale	% PFP who report that they are leading a QI initiative	% PFP that report feeling they're a valued member of their care team in managing their/their child/partner's health	% PFP that report feeling they're a valued member of the CFLN
Operational Definition			
Desired Direction of Change			
Measure Type			
Inclusion/Exclusion			
Data Source			
Data Collection Method			
Data Collection Frequency			
Calculation			

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Data Reporting Method & Venues			
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\*\*\* Optional Template \*\*\*

### Key Milestones/Deliverables & Timeline:

Key milestones and workgroup deliverables will be used to manage and track the progress of workgroup activities. Each key milestone and deliverable will be documented within this workgroup charter. This charter will track past, current and future work within the workgroup in order to accurately assess the impact of any change(s) to the workgroup or to the milestones/deliverables within.

Workgroups may choose to list the timeline of key milestones/deliverables using a Gantt Chart.

1. Onboarding materials
2. Co-production change package
3. QI Onboarding videos