

CF Learning Network Key Driver Diagram

Primary Drivers: "WHAT"

SMART Aim

Design a system that will improve outcomes for people with CF and their families in the following ways:

- Standardize HRQOL measures
- Improve quality of life from x to y
- Improve life expectancy/longevity from x to y

By December 31, 2021

Global Aim

All people involved with CF care have access to the information, resources, and treatments they need to enable individuals with CF to live full productive lives.

Care Delivery & Improvement

Best treatment, developed with family

Reliable, personalized, evidence-based timely care

Measures:

- Reduce the incidence of FIES by 50%.
- Increase routine data capture, reporting and use of HRQOL in clinical care from baseline to 85% of PwCF.
- Develop a portfolio of interventions designed to improve HRQOL and implement at least 2 of these at 90% reliability in 80% of programs

Advance CFLN Process Maturity

Organize people and organizations to share and collaborate together

Measure:

Mature 95% of relevant (NMM) processes to <3.75 as rated by NLT

Accelerate Development & Implementation of Innovation

Design and develop system for accelerating innovations

Measure:

Establish process for facilitating the development of innovations into care

Increase Impact

Scaling and spreading practices from CFLN to broader Care Center Network

Measure:

Increase % of PwCF in the US impacted by CFLN from 20% to 50%

Secondary Drivers: "Detailed WHAT"

Reliable application of [chronic care model](#) elements with care:

- Designed to be effective and efficient
- Consistent with scientific evidence & patient preferences
- Organized with patient & population level data
- That empowers patients to manage their health
- That fits patient's cultural background

Continuous collaborative learning and QI

Co-produced care, delivered in an equal & reciprocal relationship between providers, PwCF & their families

- Minimal administrative burden
- Effective use of clinical resources (material and human)

Ongoing strategic planning to inform the domains and components to mature

- Easy access to peer-to-peer support and information
- Transparent, real-time, measurement, data sharing
- Better, faster, cheaper, more relevant research

- Culture and community that encourages generosity in sharing information
- Shared commitment to improving outcomes
- Shared governance and oversight of community and common resources
- Clear expectations for active involvement by all
- Enhanced leadership and coproduction knowledge and skills

QI Portfolio: "HOW"

1. FIES

- Decrease the incidence of FEV1 Indicated Exacerbations (FIEEX) from 1.2 per patient to 0.6 per patient by December 31, 2021

2. HRQOL

- Increase Patient/Family Reports of Health-Related Quality of Life (HRQOL) from X to Y, by December 31, 2021

3. 180 Day Challenge: PROs

- By May 1, 2019, CF Programs participating in the PRO learning challenge will:
 - Collect* and acknowledge** health related quality of life for at least 80% of patient visits
 - Use HR-QOL to inform clinical care for at least 80% of visits with scores < 3

4. 180 Day Challenge: PSDC

- Increase partnership with our patient/families as "comfortable" using the 5 Principles of Partnering tip sheet from 0% to 80% by May 2019

5. Timely Data

- Automate data collection and decision support

6. Clinical Pre-Visit Planning

- Measure in progress