# Cystic Fibrosis Research News

**Title:**
Cystic Fibrosis Foundation Position Paper: Redefining The Cystic Fibrosis Care Team

**Lay Title:**
Guidance for Changing the CF Care Team

**Authors:**
Rebekah F. Brown[1]*, Charlotte T. Close[2]*, Molly G. Mailes[3], Luis J. Gonzalez[4], Danielle M. Goetz[5], Stephanie S. Filigno[6], Rebecca Preslar[7], Quynh T. Tran[8], Sarah E. Hempstead[8], Paula Lomas[8], A. Whitney Brown[8,9], Patrick A. Flume[10] on behalf of the CFF Care Model Committee

**Affiliations:**
1. Department of Pediatrics, Division of Allergy, Immunology and Pulmonary Medicine, Vanderbilt University Medical Center, Nashville, TN, USA
2. Division of Clinical Genetics, Department of Pediatrics, Columbia University Irving Medical Center, New York, NY, USA
3. Division of Pulmonology and Sleep Medicine, Mayo Clinic, Jacksonville, Florida, USA
4. Departments of Outpatient Pharmacy and Internal Medicine, University of New Mexico Hospitals, Albuquerque, NM, USA
5. Division of Pediatric Pulmonology & Sleep Medicine, Department of Pediatrics, University at Buffalo School of Medicine, Buffalo, NY, USA
6. Divisions of Behavioral Medicine and Clinical Psychology and Pulmonary Medicine, Cincinnati Children's Hospital Medical Center, Cincinnati, OH, USA Department of Pediatrics, University of Cincinnati College of Medicine, Cincinnati, OH, USA
7. Community Advisor to the Cystic Fibrosis Foundation, Bethesda, MD, USA
8. Cystic Fibrosis Foundation, Bethesda, MD, USA
9. Advanced Lung Disease and Transplant Program, Inova Fairfax Hospital, Falls Church, VA
10. Departments of Medicine and Pediatrics, Medical University of South Carolina, Charleston, SC, USA
*Denotes Joint First Authorship
The Care Model Position Paper Committee members included:

- Stacy Bichl, Nurse Practitioner
- Linda Bowman, Individual with CF
- A. Whitney Brown, MD
- Charlotte Close, MS, Certified Genetic Counselor±
- Jennifer Kyle, Individual with CF

# Cystic Fibrosis Research News


- Stephanie Filigno, Psychologist
- Rebekah Flowers Brown, MD
- Patrick Flume, MD
- Danielle Goetz, MD
- Luis Gonzalez, PharmD
- Sarah Hempstead, Methodology Facilitator
- Ryan Juel, Dietitian
- Adaobi Kanu MD
- Paula Lomas, Nurse
- Randee Luben, Social Worker
- Molly Mailes, Nurse, Program Coordinator
- Christian Merlo, MD
- Judith H. Neff, Nurse Practitioner/ Pediatric Coordinator
- Amy Nelson, Respiratory Therapist
- Rebecca Preslar, Parent of Two Individuals with CF
- Noah Singer, Parent of an Individual with CF
- Olivia Surry, Individual with CF
- Quynh Tran, Communications and Patient Activation Facilitator


## What was your research question?

Given the changes that people with CF are experiencing with their health now and possibly well into the future, should the roles and responsibilities that make up the structure of the CF care team and how that team uses technology to provide care, also change and if so, how?

## Why is this important?

Knowing how CF programs can change the structure of their teams is important because the medical care these teams provide have led to steady improvements in the health of people with CF (pwCF). This care acknowledges that pwCF know their bodies while their CF care teams know how to treat their disease. The rapid changes in how pwCF are experiencing their health compels the review of how CF care teams are structured to treat CF, so that the care they provide continues to support individuals with CF now and as they face new challenges over longer life spans.

## What did you do?

To address this question, a committee of interdisciplinary CF care team members, adults with CF, and parents of children with CF was formed to review the CF team structure, and determine what, if any, changes should be considered. Through the lens of clinical expertise and lived experiences, the committee reviewed research, services provided by CF programs, and results from a national survey capturing perspectives on CF care. Where research was unavailable, the committee identified areas of agreement. Feedback provided by CF care teams and the community through public comment informed revisions to the draft guidance prior to publication.

### What did you find?

We found that the structure of the interdisciplinary CF team (core) remains effective for providing CF specific care, but with some changes. The core team should include three additional members: a mental health coordinator to support mental health as part of comprehensive health, a pharmacist to address the complexity of CF medications, and access to a genetic counsellor for genetic-based treatment and family planning considerations. As pwCF experience improved health, ensuring prevention and care of non-CF concerns is important, highlighting the need for CF teams to partner with primary care providers and subspecialists for shared patients with CF.

### See Diagram

# Cystic Fibrosis Research News

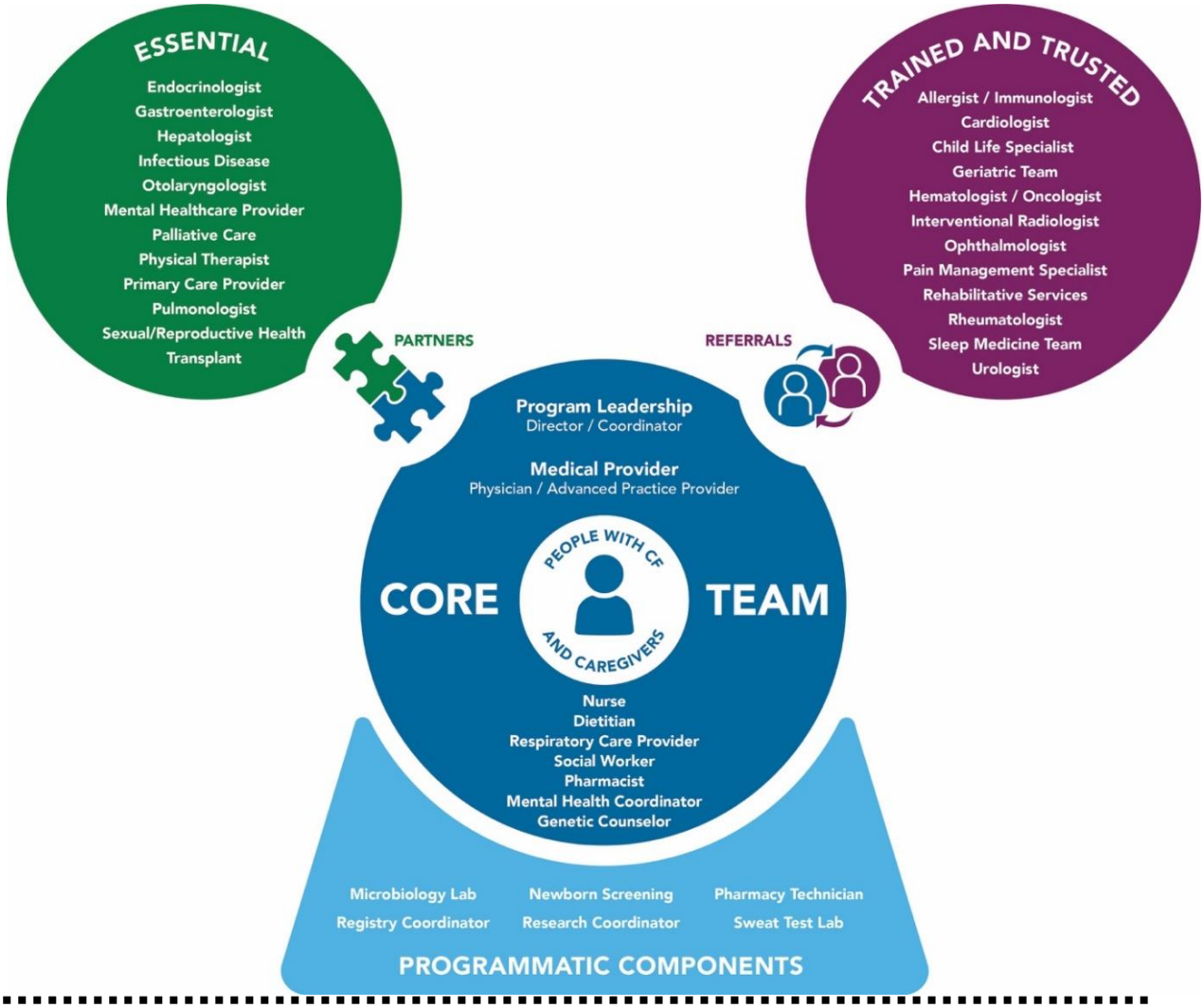


Diagram legend: Illustration of the interaction between CF care team members involved in CF care.



cfresearchnews@gmail.com

# Cystic Fibrosis Research News

### What does this mean and reasons for caution?

This guidance considers changes to the structure of CF care teams to meet the health needs of people with CF throughout their lifespans. Expectations should be managed as programs make changes with varying timelines and areas of focus depending on the needs unique to their patients. This is why partnering with patients and families to determine what and how to change the structure of their CF care teams is important. Additionally, changes to support communication between the CF team, primary care providers, and subspecialists will be critical to meet the needs of shared patients as they age.

### What's next?

CF teams can now reference this guidance to secure institutional support and resources to prioritize changes to their team structure and adapt the care they provide to patients now and throughout their life spans. Monitoring health and further research will help inform continuous improvements in the quality of care provided.

### Original Manuscript citation in PubMed

https://pubmed.ncbi.nlm.nih.gov/39327194/