

**CF Foundation-Cincinnati Children's Hospital Medical Center-
The Dartmouth Institute
CF Care Model Design Project**

Care Center Questionnaire

The following document is intended to help us develop an understanding of the current Cystic Fibrosis Foundation Care Center Network (Network). This questionnaire contains items that will allow us to catalog the features and functionality provided the Network.

For each of the questions, please highlight the appropriate response(s) based on your assessment or perspective of the **current state** of the Network. If the existing system does not address the topic in question, please select the No response; if you feel that multiple responses apply, feel free to select multiple responses. If you are unsure of a response or if none of the options apply, simply write the appropriate response in the Notes/Comments section of the question. As you are responding to the questions within the document, please feel free to add any additional clarification into the Note/Comments section.

1.) Clinical care delivery: Please describe the extent to which delivery of clinical care is consistent across the Network

1. Clinical care at each center is variable with minimal to no similarities between the centers
2. Clinical care is somewhat similar between centers, with only high level outcomes being consistent
3. Clinical care is similar between centers with only minimal variation of low-mid level outcomes
4. Clinical care is seamless across centers, with consistently applied standards such that visits between centers are indistinguishable.
5. No response.

Notes / Comments:

2.) Peer-reviewed accreditation: Please describe the extent that the peer-reviewed accreditation reduces variation in care across the Network.

1. Peer-review accreditation adds little to no value to the functioning of a CF care center
2. Peer-review accreditation helps centers understand the minimum requirements established by the CF Foundation; Assists all centers secure required personnel, physical space, and resource support from local hospital/institutions to provide CF care, however there is variation across centers as to how these standards or requirements are carried out.
3. CF Foundation peer-review accreditation process ensures all centers secure required personnel, physical space, and resource support from local hospital/institutions to provide CF care; the required annual reports and site visits ensure all centers are meeting CF Foundation standards of CF care and helps to maintain consistency in essential CF care roles: physicians, nursing, social work, dietitian, respiratory therapists.
4. CF Foundation peer-review accreditation process ensures all centers secure required personnel, physical space, and resource support from local hospital/institutions to provide CF care; the required annual reports and site visits ensure all centers are meeting CF Foundation standards of CF care and mitigated variation in essential CF care roles: physicians, nursing, social work,

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dietitian, respiratory therapists and has led to attracting and retaining experience CF health care professionals.

5. The CF Foundation peer-review accreditation process should be replicated across all chronic care models as a system for ensuring access to high quality and replicable care experiences across a structured network that satisfies patient and healthcare professionals.
6. No response

Notes/Comments:

3.) Patient and Family Involvement: Please indicate the extent to which patient and families are involved/engage in the Network.

1. Patients and family involvement is important however there is no mechanism to make it a consistent component of care center operations.
2. Patients and family involvement is limited to care center advisory boards and occasional focus groups or requests for surveys, it is not network focused; Consequently a high degree of variation exists.
3. Patients and family involvement is limited to care centers, but plays a vital role to care center operations; centers consistently involve patients and families: routinely meet with advisors, share center-specific reports and ask for feedback and input on improvement priorities.
4. Care centers are actively involving patients and families and many are connecting across the network either on their own (center to center or patient/family to patient/family advisory group) or by way of organized national opportunities: CF Foundation sponsored email listserv, sessions at the North American CF conference.
5. Patient and family involvement is a cultural norm and expectation in all aspects of CF care. Patient and family involvement is just as important as input from CF healthcare professionals in the operation of a CF care center; there is no aspect or decision regarding care center operations that patient and family input would not be considered.
6. No response.

Notes/Comments:

4.) Discipline Specific Mentoring Programs, and Professional Development Programs (Program for Adult Care Excellence (PACE), DIGEST (GI Specialty Training), Learning and Leadership (LLC) Leadership Development Program or Quality Coach Program): Please select the extent to which training is available and systematically offered across the Network.

1. Professional development or training opportunities are limited.
2. Professional development or training opportunities are limited, however, the material is shared and accessible to other health care professionals.

**CF Foundation-Cincinnati Children's Hospital Medical Center-
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3. Professional development or training opportunities while limited are made available in a timely manner to maximize chances for participation from across a range of care centers (size, geographic diversity, etc.)
4. The diversity of professional opportunities offered to support health care professionals keeps professionals connected with their peers, update-to-date in the latest CF-specific care issues, and creates a community of practice.
5. The diversity of professional opportunities offered to support health care professionals keeps professionals connected with their peers, update-to-date in the latest CF-specific care issues, creates a community of practice, and continues to attract and retain the best health care providers.
6. No response.

Notes/Comments:

5.) Clinical Care Guidelines Development and Implementation: Please select the extent that evidence-based or consensus clinical care guidelines move from development to implementation across the Network.

1. Clinical care guidelines are issued, however, there is little expectation of systematic implementation by care centers.
2. Clinical care guidelines are issued, opportunity for feedback is provided to care centers, however there is little expectation of systematic implementation by care centers.
3. Clinical care guidelines are issued, opportunity for feedback is provided to care centers, care centers are expected to implement the guidelines and center-specific reports will measure guideline adherence.
4. Clinical care guidelines are issued, opportunity for feedback is provided to care centers, care centers are expected to implement the guidelines, center-specific reports will measure guideline adherence and implementation resources and tools are readily accessible to care centers.
5. Clinical care guidelines quickly become the standard of care with measured results and it is evident how to systematic implement care recommendations into practice at a care center.
6. No response.

Notes/Comments:

6.) Integration of Clinical Care and Clinical Research: Please select the extent that clinical care and clinical research are coordinated across the Network.

1. Clinical care and clinical research are two separate enterprises at most centers and there is no overlap in their execution.

**CF Foundation-Cincinnati Children's Hospital Medical Center-
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2. Clinical care and clinical research sometimes coordinate efforts to maximize efficiencies, however there are challenges to execution with scheduling, personnel demands and patients willingness to see multiple providers for clinical and research visits.
3. Clinical care and clinical research coordinate efforts to maximize efficiencies, challenges with scheduling, personnel demands and patients willingness to see multiple providers for clinical and research visits is aptly dealt with at centers.
4. Clinical care and clinical research are seamless at care centers: scheduling, personnel demands and patients willingness are not issues that impede center operations.
5. Clinical care and clinical research are seamless at care centers: everything is coordinated across the center and maximized to achieve best care and provide research opportunities for patients and families.
6. No response.

7.) Care Center Network. Please include any other relevant information on the Care Center Network that is has not been covered by the previous questions.

Notes/Comments: