



# ACTION GUIDE FOR ACCELERATING IMPROVEMENT IN CYSTIC FIBROSIS CARE



We believe that the life expectancy of people with CF can be extended through the consistent implementation of evidence-based clinical care and practice improvement



Clinical  
Microsystems

A PATH TO HEALTHCARE EXCELLENCE

The place where  
patients, families and  
care teams meet



## TABLE OF CONTENTS

|                             |    |                                      |    |
|-----------------------------|----|--------------------------------------|----|
| Introduction .....          | 4  | Diagnose .....                       | 25 |
| A Path Forward.....         | 5  | Treat Your CF Center .....           | 26 |
| Form Your Lead Team .....   | 7  | Plan-Do-Study-Act.....               | 28 |
| Assess Your CF Center ..... | 9  | Standardize-Do-Study-Act.....        | 29 |
| Purpose .....               | 9  | Follow-Up.....                       | 30 |
| Patients.....               | 9  | Case Study and Storyboard .....      | 31 |
| Professionals.....          | 13 | Between CF Contributing Units .....  | 34 |
| Process.....                | 18 | Patient and Family Involvement ..... | 35 |
| Patterns .....              | 21 | Patient and Family Case Study .....  | 39 |
| Metrics That Matter.....    | 23 | Glossary .....                       | 40 |

All forms and examples are available electronically at [www.PortCF.org](http://www.PortCF.org) and [www.clinicalmicrosystem.org](http://www.clinicalmicrosystem.org)

Special acknowledgement to the Cystic Fibrosis Foundation and the many organizations and colleagues who have made critical substantive contributions to the development of these materials.

**NOTE:** We have developed this workbook with tools to give ideas to those interested in improving healthcare. "Dartmouth-Hitchcock Medical Center and the developers of this workbook are pleased to grant use of these materials without charge, providing that recognition is given for their development, and that the uses are limited to an individual's own use and not for re-sale."

# Accelerating the Rate of Improvement in CF Care



## STRATEGIC PLAN

The strategic plan outlined here is based on extensive input from CF center directors, adult program directors, nurse coordinators, adults with CF, parents of children with CF and an advisory group comprised of representatives of these same stakeholder groups as well as our colleagues in quality improvement at Dartmouth-Hitchcock Medical Center.

**Developing and sustaining leadership for change:** To empower change at CF care centers, leaders in all disciplines must be recruited and educated on state-of-the-art quality improvement methodologies, including benchmarking, evidence-based medicine, systems thinking and collaborative learning. This Action Guide is one way the CF Foundation is working to develop and sustain quality improvement at all care centers. We continue to invest in developing leaders and to provide mechanisms for the continued support and growth of these leaders.

**Sharing quality improvement tools and approaches with all CF care centers:** Key resources such as this Action Guide and other quality improvement tools developed at individual care centers are available to all. These resources are available in the Resource section of Port CF in the sub-folder “Quality Initiative.”

**Incorporating people with CF and their families into the improvement work:** To truly deliver patient- and family-centered care, the perspective of people with CF and their families must be incorporated into the work. This action guide provides some practical tools for accomplishing this work. A strong partnership among patients, families and care providers is critical if we are to achieve optimal outcomes for CF. This partnership will also facilitate the customization of care to the needs and preferences of the individual. Furthermore, it will lead to the incorporation of self-management strategies and promotion of adherence to the daily medical regimen.

**Identifying and enabling “best practices”:** An important component of this strategy is the identification of care centers with “best practices” as suggested by medical outcomes in the Patient Registry. We need to fully understand the practices and care processes at these centers in order to establish the benchmark for excellence and enable “best practices” nationally. We recognize that “best practices” are actually “potentially better practices” that require adaptation and testing at each local care setting. An important corollary of this strategy is the incorporation of what is learned into the Clinical Practice Guidelines and Consensus Statements. The CF Foundation is committed to data transparency. This will facilitate the process of centers learning from one another and strengthen the partnership between care providers and people with CF and their families.

**Providing decision support for care teams:** To improve outcomes, CF care teams (with patients and families at the core) need information at the point of care delivery, including current care guideline recommendations, patient alerts, clinic reminders and graphical displays of change in key outcomes over time. Summarized feedback reports of center-level practice patterns and outcomes are important to assess the results of improvement activities. The Web-enabled registry allows deployment of templates for the assessment and treatment of common conditions and access to timely reports. Practice guidelines will be updated based on expert interpretation of systematic, evidenced-based reviews of the scientific literature and practical lessons learned through ongoing improvement work. Recommendations derived from this work will guide the data collection and reports that are incorporated into Port CF.

Striving for exemplary care and achieving the goal of extended life expectancy and improved quality of life for people with CF will take a concerted commitment and a multi-faceted approach. The CF Foundation is committed to accelerating the rate of improvement in CF care. This Action Guide is one of the resources to enable the success of this initiative.

**T**he mission of the Cystic Fibrosis Foundation is to assure the development of the means to cure and control cystic fibrosis (CF) and to improve the quality of life for those with the disease. The history of CF care has been one of continuous improvement. Advances in the formulation of pancreatic enzymes, the change to high-fat diets, the development of new pulmonary treatments, the description and treatment of CF-related diabetes and many other changes in clinical care have resulted in improvements in life expectancy and quality of life for people with CF. Despite these successes, much work remains to be done. Our ongoing investments in research, drug discovery and drug development will pave the way for future progress. We also remain committed to the **vision of exemplary care at all of our care centers in order to further extend the quality and length of life for people affected by this disease.**

The CF Foundation’s Patient Registry reveals variation in rates of pulmonary function decline and the percentages of malnourished patients among our accredited care centers. Some variability is to be expected given the fact that care centers, like people with CF, are unique. Nonetheless, this variability in clinical outcomes represents an opportunity to identify “best practices” and develop strategies to facilitate their implementation at all care centers. A crucial aspect of this effort is the underlying philosophy that our data are for learning and not judgment.

The strategies that we describe below have been heavily influenced by the Institute of Medicine report, “Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century” (National Academy Press, 2001). This report asserts that health care has both safety and quality problems because it relies on outdated systems of work. Health care has been slow to adopt information technology. **Benchmarking\*** to identify better methods of providing care remains rare. Standardization of clinical care **processes** often meets resistance. Health care organizations have invested too little in the development of highly effective front-line teams. The “Chasm” report posits a set of principles to guide the **redesign** of care processes and proposes approaches to create an environment that fosters and rewards improvement. The best clinical care is described as safe, effective, patient-centered, timely, efficient and equitable.

We are leaders in health care delivery for a chronic disease. The CF Foundation’s Clinical Practice Guidelines and Consensus Statements provide a framework for the care of CF patients. The Patient Registry complements these documents by providing insight on actual practice **patterns** and medical outcomes. With continual refinement and better integration into clinical workflow, the guidelines and consensus statements can become more powerful tools for CF care centers in improving care.

The CF community also has a tradition of partnership among people with CF, their families and multidisciplinary health care providers. People with CF and their families have tremendous practical knowledge about the disease. They also have the unique perspective of being the consumers of the services provided in our care centers. Strengthening this partnership, thus the CF care team, will facilitate and accelerate improvement.

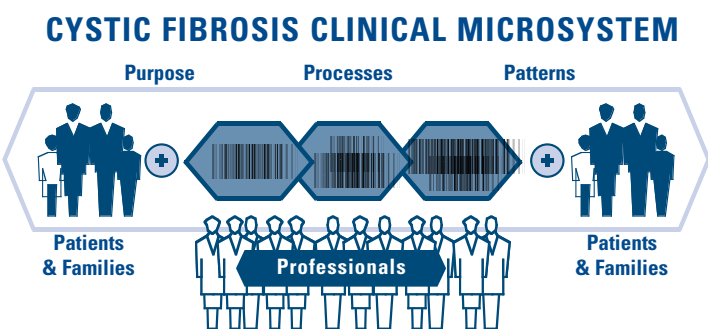
\* Words that appear in **bold and italic** are defined in the glossary, page 40.

# Cystic Fibrosis Clinical Microsystems

Strategies for improving “The place where patients, families and care teams meet.”

## ASSESSING, DIAGNOSING AND TREATING YOUR CF CENTER AN OVERVIEW

People with cystic fibrosis (CF) have many interdisciplinary health **profession-als** coming together with them and their family to provide care and services. We call this place where patients, families and care teams come together the



Your CF **clinical microsystem** consists of individual **contributing units** as shown in the diagram. Collectively, these contributing units come together to provide care for your CF patients. Your CF clinical microsystem has essential functions that must be carefully assessed and improved to result in the best possible outcomes. Each person’s quality of care depends on what happens within each contributing unit and the “hand-offs” between contributing units. Microsystems also include patients, families, staff, processes, technology and recurring patterns of information, behavior and results. The microsystem is where

- Care is made
- Quality, safety, reliability, efficiency and innovation are made
- Staff morale and patient satisfaction are made.

Clinical microsystems are the frontline units that provide day-to-day health care. It is the “sharp” end of health care and can most easily be thought of as the “places where patients, families and health care professionals meet.”

Technically, clinical microsystems can be seen as the smallest replicable units in the health care system and are defined as:

“A **small group** of people who work together on a regular basis to provide care to discrete **subpopulations of patients**. It has clinical and business **aims**, linked **processes** and a shared information environment and it produces performance **outcomes**.”

Clinical microsystems (the places where care is delivered within home care, a CF center or an inpatient unit) are the building blocks that form the CF microsystem.

For quality of care to be improved and to be sustained, work must continually be done within and across the respective microsystems. Therefore, all health care professionals—this is inclusive of everyone working within the microsystem—have two jobs. Job 1 is to provide high-quality, safe, patient- and family-centered care. Job 2 is to continually work with patients and families to improve care.

To effectively accomplish these two jobs, improvement efforts must be blended into the everyday activities of everyone. Absent this, dedicated effort to continually improve how both work is done and care is provided, optimal quality will not be achieved and the unit, as a microsystem, will not perform at its highest level.

This workbook provides the tools and methods that will help staff, patients and families, achieve the improvement goals in the CF clinical microsystem. The tools in this workbook present a tested approach to provide effective collaboration of people with CF and their families, health care teams and senior leaders, in conjunction with an effective use of technology and performance data within the clinical microsystem.

**IMPORTANT REMINDER: These tools are intended to provide an organizing structure that can be adapted to local settings.**

## A Path Forward

This workbook guides you and those who work with you to a higher level of performance. Just as you can assess, diagnose and treat patients, you can assess, diagnose and treat your clinical microsystem, in this case, the CF center.

The steps in the workbook help you evaluate how your CF center functions and how it can be improved. The workbook’s tools and forms are based upon the experiences and research of individuals and clinical teams including CF centers around the United States and the world. Although this is not the only way in which improvement can be achieved, it is a way that has been demonstrated to be effective in achieving higher quality care, enhanced workforce morale, satisfaction and partnerships with people with CF and their families.

To help you in the process, additional coaching is available through the enclosed DVD. A specific segment on the DVD helps explain in more detail how to use the workbook and how to perform the specific steps in assessing, diagnosing and treating your CF microsystem.

Colleagues around the USA have implemented this methodology. Seek them out to gain support and advice through the CF Foundation’s Port CF Web site resource section at [www.PortCF.org](http://www.PortCF.org)

All workbook forms and additional information, forms, tools and examples are available at the Port CF Web site [www.PortCF.org](http://www.PortCF.org) and the Dartmouth Clinical Microsystem Web site: [www.clinicalmicrosystem.org](http://www.clinicalmicrosystem.org).

For a clinical microsystem to achieve optimal performance, the steps for enabling improvement are ones that are never ending. Once one cycle of improvement is completed, another cycle can begin and then many more cycles will follow. Opportunities for improvement are never ending as patient care and the workforce experience can always be improved.

### STEPS IN THE PATH

The following steps walk you through the process of evaluating and improving your CF center. After reviewing the steps, you should read the case study on pg. 31 to get a better sense of how a microsystem was able to improve.

#### ■ STEP 1: ORGANIZE A “LEAD TEAM”

Successful sustainable change requires the commitment and active engagement of all members of your CF clinical microsystem with identified senior leader sponsors. To keep your CF improvement on track and focused, a “Lead Team” of representatives of all roles from the CF microsystem should be formed. The person with CF travels across several clinical units; therefore, representatives from all contributing units in the CF microsystem are included in the Lead Team. For example, your CF Lead Team should include people with

CF and family members, CF physicians, nurse coordinators, dietitians, physical/respiratory therapists, social workers and clerical staff, as well as MDs, RNs, social workers, clerical staff, administrative staff and support staff from the inpatient adult or pediatric unit and key contacts from the specialties such as gastroenterology, endocrinology, radiology and psychology.

**Team Tips:** The following tips can be found at [www.PortCF.org](http://www.PortCF.org) along with helpful tools and forms.

- Use effective meeting skills and timed **agendas** to ensure productive meetings.
- Hold **“huddles”** before your CF clinic starts to review recent activities, plan for the day and subsequent days in a proactive manner (see pg. 27).
- Hold weekly Lead Team meetings to maintain focus, make plans and oversee improvement work.
- Hold monthly “town hall” meetings to engage and inform patients and families as well as all members of the center and inpatient unit.
- Explore creative ways for the Lead Team to communicate and keep all staff engaged in the improvement work. Develop strategies for communicating with patient and family advisors. Use e-mail, newsletters, listservs, paper, visual displays, communication boards and conversation.
- Actively engage people with CF and families with the Lead Team. See pg. 35-39 and PortCF [www.PortCF.org](http://www.PortCF.org) to learn more about engaging people with CF and families.

## ■ STEP 2: DO THE ASSESSMENT

- Review the workbook contents and create a timeline for the assessment process using the worksheet on pg. 8. Designate individuals who will have principal responsibility for each major section. The whole workbook can be completed at the pace that suits your setting. Some microsystems have the capacity and resources to move quickly through the workbook in a short period of time. Many microsystems need to pace themselves through the workbook and complete the worksheets and assessment over a longer timeline. Some microsystems may need to start an important improvement immediately while starting the assessment process. In this case, the ongoing assessment will give you valuable context and will help you make better improvements.
- Complete an assessment of your CF center and inpatient unit based on **Purpose**, Patients, Professionals, Process, Patterns (the 5Ps); and review the Registry data at [www.PortCF.org](http://www.PortCF.org) and **Metrics That Matter**, on pg. 23. The worksheets in this workbook will guide you. The aim is to create the big picture of your CF center or inpatient unit system to see beyond one person at a time. Assessing the “5Ps,” using registry data from [www.PortCF.org](http://www.PortCF.org) and then reflecting on their connections and interdependence usually reveals new improvement and redesign opportunities.
- This assessment process is best achieved when completed by the improvement lead team. Building common knowledge and insight into the microsystem by all members of the CF center or inpatient unit will create a sense of equal value and ability to contribute to improvement activities.

Remember, however you choose to progress through the workbook, it should be done within the context of your improvement lead team.

## ■ STEP 3: MAKE A DIAGNOSIS

The Lead Team must analyze the 5Ps assessments, Registry data from [www.PortCF.org](http://www.PortCF.org) and Metrics That Matter worksheets and identify a “theme” for improvement. A theme may be selected using the CF Foundation’s Seven Worthy Goals and the Institute of Medicine’s Six Aims (see right panel). Opportunities for improvement may come from within your own microsystem, your organization’s strategic goals or may come from outside your microsystem. Focus on improving only one theme at a time and working with all the “players” in your system to make a big improvement in the area selected.

## ■ STEP 4: TREAT YOUR MICROSYSTEM

Based on your selected theme, create a **specific aim** statement and identify measures that will keep everyone focused and productive. Use proven quality improvement techniques such as **PDSA (plan-do-study-act)** pg. 28 and **SDSA (standardize-do-study-act)** pg. 29 to test changes and then ensure the improvements are adopted into the workflow.

## ■ STEP 5: FOLLOW-UP

Improvement in health care is a continuous journey. Monitor the new patterns of results and move to new themes. Embed new habits into daily work with the use of “huddles” to review and remind staff, weekly lead team meetings, monthly “town hall” meetings, **data walls** and **storyboards**. These reminders keep everyone focused on improvements and sustaining results.

### The Cystic Fibrosis Foundation’s Seven Worthy Goals

The Seven Worthy Goals that fuel our improvement efforts are:

- 1) Patients and families are full partners with the CF care team in managing this chronic disease. Information and communication will be given in an open and trusting environment so that every patient/family will be able to be involved in care at the level they desire. Care will be respectful of individual patient preferences, needs and values.
- 2) Children and adolescents will have normal growth and nutrition. Adult nutrition will be maintained as near normal as possible.
- 3) All patients will receive appropriate therapies for maintaining lung function and reducing acute episodes of infection. Pulmonary exacerbations will be detected early and treated aggressively to return patients to previous levels of lung function.
- 4) Clinicians and patients will be well-informed partners in reducing acquisition of respiratory pathogens, particularly *P. aeruginosa* and *B. cepacia*.
- 5) Patients will be screened and managed aggressively for complications of CF, particularly CF-related diabetes.
- 6) Severely affected patients who are facing decisions about transplantation and end-of-life care will be well supported by their CF team.
- 7) Patients will have access to appropriate therapies, treatments and supports regardless of race, age, education or ability to pay.

### Institute of Medicine’s Six Aims

In 2001, the Institute of Medicine (IOM) described a “quality chasm” that exists within today’s health care system. The IOM called for fundamental reform of health care for all Americans. In its report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, the IOM articulated six quality aims for improving care, stating that care should be:

1. **Safe** – avoiding injuries to patients from care that is intended to help them.
2. **Effective** – providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit.
3. **Patient-centered** – providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.
4. **Timely** – reducing waits and sometimes harmful delays for both those who receive and those who give care.
5. **Efficient** – avoiding waste, in particular waste of equipment, supplies, ideas and energy.
6. **Equitable** – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographical location and socioeconomic status.

# STEP 1

## FORM YOUR LEAD TEAM

Which Senior Leaders will “sponsor” CF improvement?

|                        | Adult Program | Pediatric Program |
|------------------------|---------------|-------------------|
| Hospital Administrator |               |                   |
| Division Chief         |               |                   |
| Department Chair       |               |                   |
| Site Contact:          |               |                   |

Who will be on the Lead Team for improvement and attend regular meetings?

|                               | Adult CF Clinic | Pediatric CF Clinic |
|-------------------------------|-----------------|---------------------|
| MD                            |                 |                     |
| Clinic Coordinator            |                 |                     |
| Social Worker                 |                 |                     |
| RN                            |                 |                     |
| Dietitian                     |                 |                     |
| Nursing/Medical Assistant     |                 |                     |
| Secretary                     |                 |                     |
| RT/PT                         |                 |                     |
| CNS                           |                 |                     |
| NP                            |                 |                     |
| Patient/Family (1-2 Advisors) |                 |                     |
| Other                         |                 |                     |

Who are the “as needed” members that will be included?

Identify key contacts for each supporting unit such as gastroenterology, endocrinology, dietary, pharmacy and radiology. These members will be included based on the process being considered.

---



---



---



---

**Regular Meeting Time**

**Date**

**Location**

List communication strategies to share information with all staff of the involved units and patients and families. Identify who will oversee the various communications, for example, newsletters, bulletin boards, e-mails, and all staff meetings.

---



---



---



---

- With your improvement lead team, review this workbook. **Use this form to determine which measures you can obtain from your organization and therefore don't need to use the worksheets.** Be sure the data is current and not months old.
- Determine which worksheets will be used. Plan who, when, and how the worksheets will be completed
- Decide who oversees the completion of each worksheet or alternative data source
- Create your timeline

## CF MICROSYSTEM ASSESSMENT OF DATA SOURCES AND DATA COLLECTION

| Page/Type of Data  | Data Source/Data Collection Action | Date/Owner |
|--|------------------------------------|------------|
| <b>Know Your Patients (see pages 9-12)</b>                               |                                    |            |
| Estimated Age Distribution of Patients                                   |                                    |            |
| Health Outcomes  |                                    |            |
| Top 10 Diagnoses/Procedures  |                                    |            |
| Top 5 Services Used  |                                    |            |
| ER Visit Rate  |                                    |            |
| Patient Satisfaction Scores - Access                                     |                                    |            |
| Patient Population Census - Overall                                      |                                    |            |
| Through the Eyes of the Patient  |                                    |            |
| <b>Know Your Professionals (see pages 13-17)</b>                         |                                    |            |
| Current Staff  |                                    |            |
| Travelers  |                                    |            |
| On-Call Staff  |                                    |            |
| Float Pool   |                                    |            |
| Per Diems  |                                    |            |
| Supporting Departments   |                                    |            |
| Staff Satisfaction   |                                    |            |
| Personal Skills Assessment   |                                    |            |
| Activity Survey  |                                    |            |
| <b>Know Your Processes (see pages 18-20)</b>                             |                                    |            |
| Create <b>Flow Charts</b> of Routine Processes                           |                                    |            |
| Patient <b>Cycle Time Tool</b>   |                                    |            |
| <b>Core and Supporting Processes</b>                                     |                                    |            |
| The "Hand-Offs"  |                                    |            |
| <b>Know Your Patterns (see pages 21-22)</b>                              |                                    |            |
| Unplanned Activity Tracking  |                                    |            |
| Most Significant Patterns  |                                    |            |
| Successful Change  |                                    |            |
| Most Proud of  |                                    |            |
| Financial Status   |                                    |            |
| Telephone Tracking Log   |                                    |            |
| <b>Know Your Outcomes/ Measures/Metrics that Matter (see page 23-24)</b> |                                    |            |
| 1. FEV <sub>1</sub> , Children ages 6–17 years                           |                                    |            |
| 2. FEV <sub>1</sub> , Adults 18 years and older                          |                                    |            |
| 3. Median BMI Percentile, Patients 2–20 years                            |                                    |            |
| 4. Median BMI, patients 21 years and older                               |                                    |            |
| 5. Screening for CFRD  |                                    |            |
| 6. Annual Goals for Care (4 visits, 2 PFTs, 4 sputum cultures)           |                                    |            |

# STEP 2

## ASSESS YOUR CF CENTER

### Purpose

Why does your CF center exist?

Raise this question to EVERYONE, including patients and families in your CF center to create the best statement of purpose that everyone can relate to. This engages everyone in meaningful conversation that isn't achieved by just taking out a mission statement. Use your purpose to guide decision making and to focus all improvements.

---

---

---

---

---

---

---

---

### Patients

#### KNOW YOUR PATIENTS

Take a close look at your center; create a "high level" picture of the PATIENT POPULATION that you serve. Who are they? What resources do they use? How do the patients view the care they receive?

Use the Profile to know your patients. Determine if there is information you need to collect or if you can obtain this data from existing sources. Remember, the goal is to collect and review data and information about patients and families that might lead to new designs in processes and services.

#### CF CENTER PROFILE

| Estimated Age Distribution/Gender of Patients |  | % |
|---|--|---|
| Birth-5 years                                 |  |   |
| 6-12 years                                    |  |   |
| 13-18 years                                   |  |   |
| 19-24 years                                   |  |   |
| >24 years                                     |  |   |
| % Females                                     |  |   |

| List Your Top 10 Diagnoses/Procedures |
|---------------------------------------|
| 1.                                    |
| 2.                                    |
| 3.                                    |
| 4.                                    |
| 5.                                    |
| 6.                                    |
| 7.                                    |
| 8.                                    |
| 9.                                    |
| 10.                                   |

| Access/Patient Satisfaction Scores | % Excellent |
|------------------------------------|-------------|
| Experience via phone               |             |
| Length of time to get appointment  |             |
| Saw who I wanted to see            |             |
| Personal manner                    |             |
| Time spent with person you saw     |             |

| Health Outcomes  |
|------------------|
| FEV <sub>1</sub> |
| BMI %            |
| BMI              |
| CFRD Screen      |

| Patient Population Census: Do these numbers change by season? (Y/N) | # | Y/N |
|---|---|-----|
| # Pts seen in a day   |   |     |
| # Pts seen in past week   |   |     |
| # New Pts in past month   |   |     |
| # Encounter per provider per year                                   |   |     |

| Out of Clinic Visits       |  |
|----------------------------|--|
| Emergency Room Visit Rate  |  |
| Direct Hospital Admissions |  |

| List Your Top 5 Other Services Used |                               |
|-------------------------------------|-------------------------------|
| Services                            | What other services are used? |
|                                     |                               |
|                                     |                               |
|                                     |                               |
|                                     |                               |
|                                     |                               |



## Patients

- Patients and families have valuable insight into the quality and process of care we provide. Two surveys are included here: Patient Access Survey and the Clinic Patient Viewpoint Survey that measures overall satisfaction. You can choose to measure patient feedback specific to “access to care”—how patients and families experience getting an appointment—using the Patient Access Survey. Real time feedback can pave the way for rapid responses and quick **tests of change**. This **“Point of Service”** Survey can be completed at the time of service to give real time measurement of satisfaction.
- You can also choose to measure the overall visit experience using the Clinic Patient Viewpoint Survey (pg.11).
- Conduct the patient/family satisfaction surveys for 2 weeks if you currently DO NOT have a survey method. If you have a method, be sure the data are up to date and reflect the current state of your CF center.



### PATIENT ACCESS SURVEY

Think about this center visit.

Date \_\_\_\_\_

1. How would you rate your satisfaction or the patient's satisfaction with getting through to the office by phone?

- Excellent       Very Good       Good       Fair       Poor

2. How would you rate your satisfaction or the patient's satisfaction with the length of time to get today's appointment?

- Excellent       Very Good       Good       Fair       Poor

3. Did you or the patient see the preferred clinician or staff member today?

- Yes       No       Didn't matter who I saw today

4. How would you rate your satisfaction or the patient's satisfaction with the personal manner of the person seen today (courtesy, respect, sensitivity, friendliness)?

- Excellent       Very Good       Good       Fair       Poor

5. How would you rate your satisfaction or the patient's satisfaction with the time spent with the person seen today?

- Excellent       Very Good       Good       Fair       Poor

6. What would make this CF center better for you or the patient?

---



---



---

## CLINIC PATIENT VIEWPOINT SURVEY\*

## Today's Office Visit

Date \_\_\_\_\_

Here are some questions about the visit you or the patient just made to this CF center. We would like to know how you would rate each of the following.

|   | Excellent                | Very Good                | Good                     | Fair                     | Poor                     |
|---|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Length of time to wait to get an appointment   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Convenience of the location of the CF center   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Getting through to the office by phone   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Length of time waiting at the office   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Time spent with the person in the clinic   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Explanation of what was done at the clinic   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. The technical skills (thoroughness, carefulness, competence) of the person seen        | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. The personal manner (courtesy, respect, sensitivity, friendliness) of the person seen  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. The clinician's sensitivity to special needs or concerns                               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. The satisfaction with getting the help and information that you or the patient needed | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. The quality of the visit overall  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## General Questions

Here are some general questions about your satisfaction or the patient's satisfaction with the CF center.

12. If you or the patient could go anywhere to get health care, would you choose this CF center or would you prefer to go someplace else?  
 Would choose this clinic     Might prefer someplace else     Not sure
13. "I am delighted with everything about this CF center because my expectations for service and quality of care are exceeded."  
 Agree     Disagree     Not sure
14. In the past 12 months, how many times have you or the patient gone to the emergency room for care?  
 None     One time     Two times     Three or more times
15. In the past 12 months, was it always easy to get a referral to a specialist when one was needed?  
 Yes     No     Does not apply to me
16. In the past 12 months, how often did you or the patient have to see someone else when you wanted to see a personal doctor or nurse?  
 Never     Sometimes     Frequently
17. Are you or the patient able to get to appointments when you choose?  
 Never     Sometimes     Always
18. Is there anything our CF center can do to improve the care and services?  
 No, everything is satisfactory  
 Yes, some things can be improved: (please specify)  
\_\_\_\_\_  
\_\_\_\_\_  
 Yes, lots of things can be improved: (please specify)  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

19. Did you or the patient have any good or bad surprises while receiving care?  
 Good     Bad     No Surprises

Please describe:  
\_\_\_\_\_  
\_\_\_\_\_

## About You or the Patient

20. In general, how would you rate your overall health or the health of the patient?  
 Excellent     Very Good     Good     Fair     Poor
21. What is your age or the age of the patient?  
 Under 18 years     18 – 25 years     26 – 35 years     over 35 years
22. What is your gender or the gender of the patient?     Male     Female

**OPTIONAL** As we continue to strive to improve CF care, would you be interested in serving as an advisor to the care center?

- Yes     No     Maybe

Name \_\_\_\_\_

Phone/e-mail \_\_\_\_\_

See the Hospital CAHPS survey ([www.cms.hhs.gov](http://www.cms.hhs.gov)) for other questions that ask the patient's perspective on care.

\*This survey is from the Medical Outcomes Study (MOS) Visit-Specific Questionnaire (VSQ), 1993 Patient Utilization, Dartmouth Medical School.

© 2001, Trustees of Dartmouth College, Godfrey, Nelson, Batalden, Institute for Healthcare Improvement

© 2006, Adapted from the original version, Cystic Fibrosis Foundation, Version 1

- Gain insight into how your patients and families experience care in your CF center. One simple way to understand the patient and family experience is to experience the care. Members of your staff can assume the role of a person with CF in your CF microsystem. Try to make this experience as real as possible, this form can be used to document the experience.
- You can also capture the person’s experience through direct observation of care, taking pictures or making an audio- or videotape.
- This exercise can be adapted to any setting, including the inpatient care unit.

## THROUGH THE EYES OF YOUR PATIENTS AND FAMILIES

### Tips for making the experience most productive

1. Determine with your staff where the starting and ending points should be, taking into consideration the usual journey of CF patients across several contributing units.
2. Two members of the staff should role-play with each playing a role: patient and partner/family member.
3. Set aside a reasonable amount of time to experience the patient journey. Consider doing multiple experiences along the patient journey at different times to piece together the whole journey. Remember CF care occurs 24/7/365. Observe on different shifts and days. Experience outpatient and inpatient experiences.
4. Make it real. Include time with registration, lab tests, new patient appointment, follow-up, minor procedures, prescriptions, and referrals. Sit where the patient sits. Wear what the patient wears. Experience the diagnostic and treatment process. Make a realistic paper trail including chart and lab reports.
5. During the experience note both positive and negative experiences, as well as any surprises. What was frustrating? What was gratifying? What was confusing? Was there variation between shifts? Again, an audio- or videotape can be helpful.
6. Debrief your staff on what you did and what you learned.

Date: \_\_\_\_\_ Role Play/Walk Through Begins When: \_\_\_\_\_ Ends When: \_\_\_\_\_

Staff Members: \_\_\_\_\_

| Positives | Negatives | Surprises | Frustrating/Confusing | Gratifying |
|-----------|-----------|-----------|-----------------------|------------|
|           |           |           |                       |            |

# Professionals

## KNOW YOUR PROFESSIONALS

Use the following template to create a comprehensive summary picture of your CF center. Who does what and when? Is the right person doing the right activity? List all roles, total FTEs and overtime by role. Are the roles

being optimized? Are all roles that contribute to the patient experience listed? What days and hours is the CF center open?

| Current Staff            | FTE | CF Care Center Days and Times |    |    |    |    |    |
|--------------------------|-----|-------------------------------|----|----|----|----|----|
| Enter names below totals |     | Mo                            | Tu | We | Th | Fr | Sa |
| MDs Total                |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
| NP/PAs Total             |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
| RNs Total                |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
| LPN/NA/MAs Total         |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
| PT/RTs Total             |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
| RD/Nutritionist Total    |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
| Social Worker Total      |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
| Secretaries Total        |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
| Others:                  |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |
|                          |     |                               |    |    |    |    |    |

Do you use on-call staff?  Yes  No

Do you use a float pool?  Yes  No

### SUPPORTING MICROSYSTEMS

such as pulmonary, dietary, gastroenterology, pharmacy

### STAFF SATISFACTION SCORES

How stressful is this clinic?  
(% Very Stressful) \_\_\_\_\_

Would you recommend it as a great  
place to work? (% Strongly Agree) \_\_\_\_\_

---



---



---



---



---

- Creating a joyful work environment starts with a basic understanding of staff perceptions of the clinic. All staff members should complete this survey. You will find a tally sheet at [www.PortCF.org](http://www.PortCF.org) to summarize your results.
- Ask all CF center staff to complete the staff survey. Often you can distribute this survey to any professional who spends time in your clinic. Set a deadline of one week and designate a place for the survey to be dropped off. You may have an organization-wide survey in place that you can use to replace this survey, but be sure it is CURRENT data, not months old, and that you are able to capture the data from all professionals specific to your CF center.

## STAFF SATISFACTION SURVEY

1. I am treated with respect every day by everyone that works in this clinic.

- Strongly Agree     Agree     Disagree     Strongly Disagree

2. I am given everything I need—tools, equipment, and encouragement—to make my work meaningful to my life.

- Strongly Agree     Agree     Disagree     Strongly Disagree

3. When I do good work, someone in this clinic notices that I did it.

- Strongly Agree     Agree     Disagree     Strongly Disagree

4. How stressful would you say it is to work in this clinic?

- Very stressful     Somewhat Stressful     A Little Stressful     Not Stressful

5. How easy is it to ask anyone a question about the care we provide?

- Very Easy     Easy     Difficult     Very Difficult

6. How would you rate other people's morale and their attitudes about working here?

- Excellent     Very Good     Good     Fair     Poor

7. This clinic is a better place to work than it was 12 months ago.

- Strongly Agree     Agree     Disagree     Strongly Disagree

8. I would recommend this clinic as a great place to work.

- Strongly Agree     Agree     Disagree     Strongly Disagree

9. What would make this clinic better for patients and their families?

---



---



---



---



---

10. What would make this clinic better for those who work here?

---



---



---



---

- Development of each member in the CF center is a key to success for staff and the microsystem. The Personal Skills Assessment tool helps determine the education and training needs of staff. All staff members complete this survey and then discuss an **action plan** to talk with leadership and other staff. A plan is developed to help members achieve goals so they can become the best they can be.
- This tool provides guidance for individual development plans along with assessing the “group” needs to plan larger learning and training sessions.

| CF CENTER–PERSONAL SKILLS ASSESSMENT   |                          |                          |                          |                          |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| Name _____   |                          | Clinic _____             |                          |                          |
| Role _____   |                          |                          | Date _____               |                          |
| <b>Clinical Competencies:</b><br>Please create your list of clinical competencies and evaluate.  | <b>Want to Learn</b>     | <b>Never Use</b>         | <b>Occasionally</b>      | <b>Frequently</b>        |
|  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Clinical Information Systems (CIS):</b><br>What features and functions do you use?  | <b>Want to Learn</b>     | <b>Never Use</b>         | <b>Occasionally</b>      | <b>Frequently</b>        |
| Provider/On-Call Schedule  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Patient Demographics   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Lab Results  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pathology  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Patient and Family Goals and Action Plan   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Review Reports/Notes   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Documentation  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Direct Entry   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Note Templates   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Medication Lists   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Insurance Status   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Durable Power of Attorney  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Radiology  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| OR Schedules   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>NOTE:</b> CIS refers to hospital, or clinic-based information systems used for such functions as checking in patients, electronic medical records and accessing lab and x-ray information. Customize your list of CIS features to determine skills needed by various staff members to optimize their roles. |                          |                          |                          |                          |
| <b>Technical Skills:</b><br>Please rate the following on how often you use them.   | <b>Want to Learn</b>     | <b>Never Use</b>         | <b>Occasionally</b>      | <b>Frequently</b>        |
| CIS  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| E-mail   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| PDA (e.g. Palm Pilot)  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Digital Dictation Link   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Word Processing (e.g. Word)  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Spreadsheet (e.g. Excel)   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Presentation (e.g. Power Point)  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## CF CENTER–PERSONAL SKILLS ASSESSMENT, CONTINUED

Name \_\_\_\_\_ Clinic \_\_\_\_\_

| <b>Technical Skills cont'd:</b><br>Please rate the following on how often you use them.  | <b>Want to Learn</b>     | <b>Never Use</b>         | <b>Occasionally</b>      | <b>Frequently</b>        |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| Database (e.g. Access or File Maker Pro)   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Patient Database/Statistics  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Internet/Intranet  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Printer Access   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Fax  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Copier   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Telephone System   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Voice Mail   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pagers   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Tube System  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Acudose/Pyxis  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Meeting &amp; Interpersonal Skills:</b><br>What skills do you currently use?          | <b>Want to Learn</b>     | <b>Never Use</b>         | <b>Occasionally</b>      | <b>Frequently</b>        |
| Effective Meeting Skills (brainstorm/multi-vote)   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Timed Agendas  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Role Assignments During Meetings   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Delegation   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Problem Solving  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Open and Effective Communication   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Feedback – Provide and Receive   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Managing Conflict/Negotiation  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Emotional/Spiritual Support  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Improvement Skills and Knowledge:</b><br>What improvement tools do you currently use? | <b>Want to Learn</b>     | <b>Never Use</b>         | <b>Occasionally</b>      | <b>Frequently</b>        |
| Flowcharts/Process Mapping   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Trend Charts</b>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <b>Control Charts</b>  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Plan-Do-Study-Act (PDSA) Improvement Model   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Standardize-Do-Study-Act (SDSA) Improvement Model  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Aim Statements   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Fishbones  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Measurement and Monitoring   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Surveys-Patient and Staff  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| STAR Relationship Mapping  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Patient- and Family-Centered Care  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
|  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

- What do you spend YOUR time doing? What is your best estimation of how much time you spend doing it? The goal is to have the right person doing the right thing at the right time. The group can discuss which activities are or are not appropriate for the individual's level of education, training and licensure.
- You can start with one group of professionals such as MDs, NPs, RNs or clerical staff, assessing their activities using the Activity Survey. This estimate of who does what is intended to reveal, at a high level,

where there might be mismatches between education, training, licensure and actual activities. It is good to eventually have all roles and functions complete this survey for review and consideration. Be sure to create the same categories for each functional role. Some groups may hesitate to make time estimates; if this happens, just ask them to list their activities for the first review.

- Electronic versions, blank sheets and examples can be found at [www.PortCF.org](http://www.PortCF.org)

### ACTIVITY SURVEY SHEET

| Position: MD  | % of Time |
|---|-----------|
| Activity: See Patients in Clinic<br>Specific Items Involved:<br>• Review chart history<br>• Assess/diagnose patient<br>• Determine treatment plan | 30%       |
| Activity: Minor Procedures  | 9%        |
| Activity: OR Procedures   | 10%       |
| Activity: See Patients in Hospital  | 2%        |
| Activity: Write Prescriptions   | 5%        |
| Activity: Dictate/Document Patient Encounter<br>Specific Items Involved:<br>• Dictate encounter<br>• Review transcriptions and sign off           | 20%       |
| Activity: Complete Forms<br>Specific Items Involved:<br>• Referrals<br>• Workers comp   | 5%        |
| Activity: Follow-up Phone Calls/Emails<br>Specific Items Involved   | 5%        |
| Activity: Manage Charts   | 5%        |
| Activity: Evaluate Test Results<br>Specific Items Involved:<br>• Review results and determine next actions  | 5%        |
| Activity: See Patients in Nursing Home  | 2%        |
| Activity: Miscellaneous<br>Specific Items Involved:<br>• CME; attend seminars; attend meetings  | 2%        |
| Total   | 100%      |

| Position: RN   | % of Time |
|--|-----------|
| Activity: Triage Patient Issues/Concerns<br>• Phone<br>• Face to face  | 15%       |
| Activity: Patient/Family Education<br>Specific Items Involved:   | 3%        |
| Activity: Direct Patient Care<br>• See patients in clinic<br>• Assist Provider with patients<br>• Injections                     | 30%       |
| Activity: Follow-up Phone Calls/Emails<br>Specific Items Involved:   | 22%       |
| Activity: Review and Notify Patients of Lab Results<br>Specific Items Involved:<br>• Normal with follow-up<br>• Drug adjustments | 5%        |
| Activity: Complete Forms<br>Specific Items Involved:<br>• Referrals<br>• Workers comp  | 18%       |
| Activity: Call in Prescriptions<br>Specific Items Involved:  | 5%        |
| Activity: Miscellaneous<br>Specific Items Involved:<br>• CME; attend seminars; attend meetings                                   | 2%        |
| Total  | 100%      |

### ACTIVITY OCCURRENCE EXAMPLE

*What's the next step? Insert the activities from the Activity Survey here.*

Activities are combined by role from the data collected above. This creates a master list of activities by role. Fill-in THE NUMBER OF TIMES PER SESSION (AM and PM) THAT YOU PERFORM THE ACTIVITY. Make a mark by the activity each time it happens, per session. Use one sheet for each day of the week. Once the frequency of activities is collected, the clinic should review the volumes and variations by session, day of week, and month of year. This evaluation increases knowledge of predictable variation and supports improved matching of resources based on demand.

| Role: RN                      | Date: July 1      | Day of Week: Monday |            |
|-------------------------------|-------------------|---------------------|------------|
| Visit Activities              | AM                | PM                  | Total      |
| Triage Patient Concerns       | ### II            | ### II              | 14         |
| Family/Patient Education      | ### III           | III                 | 11         |
| Direct Patient Care           | ### ### ### ### I | ### ### ### ### I   | 42         |
| <b>Non-Visit Activities</b>   |                   |                     |            |
| Follow-up Phone Calls/E-mails | ### ###           | ### ### ### I       | 26         |
| Complete Forms                | ### ### I         | ### III             | 19         |
| Call in Prescriptions         | ### I             | ### ###             | 16         |
| Miscellaneous                 | ###               | ### ###             | 15         |
| <b>Total</b>                  | <b>68</b>         | <b>75</b>           | <b>143</b> |



# Process

## KNOW YOUR PROCESSES

How do things get done in the microsystem? Who does what? What are the step-by-step processes? How long does the care process take? Where are the delays?

### Do you use any of the following?

Check all that apply

- Phone follow-up
- Phone care management
- Port CF reports
- Protocols/guidelines
- E-mail
- Web site
- RN clinics
- Conference calls with patients

| Appointment Types | Duration | Cycle Time | # of Exam Rooms | Comments |
|-------------------|----------|------------|-----------------|----------|
|                   |          |            |                 |          |
|                   |          |            |                 |          |
|                   |          |            |                 |          |
|                   |          |            |                 |          |
|                   |          |            |                 |          |
|                   |          |            |                 |          |
|                   |          |            |                 |          |
|                   |          |            |                 |          |
|                   |          |            |                 |          |

## IDENTIFY SUPPORTING MICROSYSTEMS

For example, pulmonary, dietary, gastroenterology, pharmacy

---



---



---

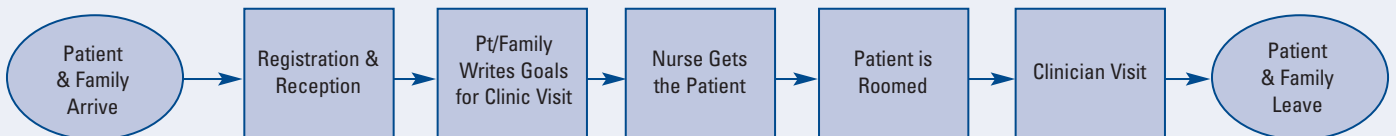
## CREATE FLOWCHARTS OF ROUTINE PROCESSES

- Deming has said, "If you can't draw a picture of your process you can't improve anything." He is referring to the improvement tool of **process mapping**. With your improvement lead team, create a high-level flowchart of the appointment process or the entire treatment experience. Start with just ONE flowchart. Eventually you will wish to create flowcharts for many different processes in your clinic and processes with other microsystems. Keep the symbols simple!
- Review the flowchart to identify unnecessary **rework**, delays and opportunities to streamline and improve.
- See [www.PortCF.org](http://www.PortCF.org) for inpatient-specific flowcharts.

### Suggested Processes to Flowchart

- Overall appointment process
- Overall treatment process

### EXAMPLE OF A HIGH-LEVEL FLOWCHART APPOINTMENT PROCESS



#### Symbol Key

- Process beginning or end
- Activity step
- Decision points
- Waits and delays
- Process flow direction
- Connector (e.g. off page)

### CYCLE TIME TOOL

One key measure of clinical microsystem efficiency is the patient cycle time. It is important to understand that cycle time is a result of systems, processes and individual style. This is defined as the time from when a patient enters the clinic until they leave. The Patient Cycle Time Tool can be administered

in several ways: a) Patients and families can carry the clipboard through their visit and note the times, b) Staff can write the times as the patient travels through the clinic or c) Patients can be “shadowed” by a person to document the times. There is space to write comments along the way.

**INSTRUCTIONS:** Please fill in the time for each step of the clinic visit.

Scheduled appointment time \_\_\_\_\_ Date \_\_\_\_\_

| TIME |   |
|------|---|
|      | 1. Time you arrived at the clinic.  |
|      | 2. Time you checked in.   |
|      | 3. Time you were shown to the exam room.                                      |
|      | 4. Time the nurse finished measurements (e.g. weight, height, lung function). |
|      | 5. Time you were ready to see first CF team member.                           |
|      | 6. Note below the times the clinicians entered and left the room.             |

|                  | Nurse | Social Worker | Dietitian | PT/RT | Physician | Other |
|------------------|-------|---------------|-----------|-------|-----------|-------|
| <b>Time In:</b>  |       |               |           |       |           |       |
| <b>Time Out:</b> |       |               |           |       |           |       |

|  |   |
|--|---|
|  | 7. Time you were ready to leave clinic. |
|--|---|

**COMMENTS:**

---



---



---



---



---



---



---

- Review, adapt and distribute the Core and Supporting Processes Assessment form to ALL CF center staff. Be sure the list is accurate for your center and then ask staff to evaluate the CURRENT state of these processes. Rate each process by putting a tally mark under the heading that most closely matches your understanding of the process. Also mark if the process is a source of patient complaints. Tally the results to give the lead team an idea as to where to begin to focus improvement from the staff perspective.
- Some clinics create and hang a wall-sized version of the Core and Supporting Process Assessment chart and ask all staff to select choices with using different colored dots for each role. This creates a visual display showing all the ratings and priorities for all staff to see.
- Steps for Improvement:** Explore improvements for each process based on the outcomes of this assessment tool. Each of the processes below should be flowcharted in its current state. Based on the flowcharts of the current state of your processes and determinations of your **Change Ideas** (see pg. 26), you will use the PDSA (plan-do-study-act) cycle worksheet (pg. 28) to run tests of change and to measure your change ideas.

### CF CENTER CORE AND SUPPORTING PROCESSES ASSESSMENT

| Processes                                 | Works Well | Small Problem | Real Problem | Totally Broken | Cannot Rate | We're Working on It | Source of Pt/Family Complaint |
|---|------------|---------------|--------------|----------------|-------------|---------------------|-------------------------------|
| Answering phones                          |            |               |              |                |             |                     |                               |
| Contact patients due for an appointment   |            |               |              |                |             |                     |                               |
| Messaging                                 |            |               |              |                |             |                     |                               |
| Scheduling procedures                     |            |               |              |                |             |                     |                               |
| Retrieving needed diagnostic test results |            |               |              |                |             |                     |                               |
| Prescription renewals                     |            |               |              |                |             |                     |                               |
| Making referrals                          |            |               |              |                |             |                     |                               |
| Pre-authorization for services            |            |               |              |                |             |                     |                               |
| Billing/Coding                            |            |               |              |                |             |                     |                               |
| Phone advice                              |            |               |              |                |             |                     |                               |
| Orientation of patients to your clinic    |            |               |              |                |             |                     |                               |
| New patient work-ups                      |            |               |              |                |             |                     |                               |
| Goal setting & plan for patients/families |            |               |              |                |             |                     |                               |
| Prevention assessment/activities          |            |               |              |                |             |                     |                               |
| Chronic disease management                |            |               |              |                |             |                     |                               |
| Growth and nutrition                      |            |               |              |                |             |                     |                               |
| Pulmonary maintenance                     |            |               |              |                |             |                     |                               |
| Pulmonary exacerbations                   |            |               |              |                |             |                     |                               |
| Screening for CF-related diabetes         |            |               |              |                |             |                     |                               |

# Patterns

## KNOW YOUR PATTERNS

What patterns are present but not acknowledged in your microsystem? What is the leadership and social pattern? How often does the microsystem meet to discuss patient care? Are people with CF and families involved? What are your results and outcomes?

- Does every member of the clinic meet regularly as a team?
- How often does your CF microsystem meet to discuss CF care?
- How do leaders across your CF microsystem relate to one another?
- Do the members of the clinic regularly review and discuss safety and reliability issues?

- Are people with CF and families involved? (Use [www.familycenteredcare.org](http://www.familycenteredcare.org) or [www.PortCF.org](http://www.PortCF.org) or [www.cff.org](http://www.cff.org))
- What is the most significant pattern of variation?
- What have you successfully changed?
- What are you most proud of?
- What is your financial picture?
- What are your CF results and outcomes?
- How do leaders relate to staff?

- Patterns are present in our daily work and we may or may not be aware of them. Patterns can offer hints and clues to our work that inform us of possible improvement ideas. The Unplanned Activity Tracking Card is a tool you can ask staff to carry to track patterns of interruptions, waits and delays in the process of providing smooth and uninterrupted patient care. Start with any group in the staff. Give each staff member a card to carry during a clinic day or shift, to mark each time an interruption occurs when direct patient care is delayed or interrupted. The tracking cards

should then be tallied by each person and within each group to review possible process and system redesign opportunities. Noticing patterns of unplanned activities can alert staff to possible improvements.

- This collection tool can be adapted for any role in the CF clinic to discover interruptions in work flow. Circles in the example indicate processes to further evaluate for possible improvements.

### UNPLANNED ACTIVITY TRACKING CARD

| UNPLANNED ACTIVITY TRACKING  |              |
|--|--------------|
| Name: _____  |              |
| Date: _____  | Time: _____  |
| <b>Place a tally mark for each occurrence of an unplanned activity</b> |              |
|  | <b>Total</b> |
| Interruptions  |              |
| • Phone  |              |
| • Secretary  |              |
| • RN   |              |
| • Provider   |              |
| Hospital Admissions  |              |
| Patient Phone Calls  |              |
| Pages  |              |
| Missing Equipment  |              |
| Missing Supplies   |              |
| Missing Chart: Same-Day Patient  |              |
| Missing Chart: Patient   |              |
| Missing Test Results   |              |
| Emergent Cases   |              |

### EXAMPLE

| UNPLANNED ACTIVITY TRACKING  |              |
|--|--------------|
| Name: _____  |              |
| Date: _____  | Time: _____  |
| <b>Place a tally mark for each occurrence of an unplanned activity</b> |              |
|  | <b>Total</b> |
| Interruptions  |              |
| • Phone IIII IIII IIII   | 15           |
| • Secretary  |              |
| • RN IIII IIII   | (10)         |
| • Provider   |              |
| Hospital Admissions IIII IIII II                                       | (12)         |
| Patient Phone Calls  |              |
| Pages IIII IIII IIII IIII  | 20           |
| Missing Equipment  |              |
| Missing Supplies IIII  | 5            |
| Missing Chart: Same-Day Patient  |              |
| Missing Chart: Patient IIII IIII                                       | (10)         |
| Missing Test Results   |              |
| Emergent Cases   |              |

- Patterns can be found through tracking the volumes and types of telephone calls. Review the categories on the telephone tracking list to ensure they reflect the general categories of calls your clinic receives. Ask clerical staff to track the telephone calls over the course of a week to find the patterns of each type of call and the volume peaks and valleys. New processes, such as using a Web site to reorder prescriptions or make appointments, may eliminate some calls. Be alert for new design possibilities.
- Put a tally mark each time one of the phone calls is for one of the listed categories. Total the calls for each day and then total the calls in each category for the week. Note the changes in volume by the day of the week and am/pm.

**CLINIC TELEPHONE TRACKING LOG**

| Week of<br><br>[ ]       | Day of Week |    | Day of Week |    | Week Total |
|--------------------------|-------------|----|-------------|----|------------|
|                          | AM          | PM | AM          | PM |            |
| Appointment for Today    |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Appointment for Tomorrow |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Appointment for Future   |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Test Results             |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Nurse Care               |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Prescription Refill      |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Referral Information     |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Need Information         |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Message for Provider     |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Talk with Provider       |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Phone Advice             |             |    |             |    |            |
| Total                    |             |    |             |    |            |
| Day Total                |             |    |             |    |            |

## Metrics That Matter

- Measures are essential for microsystems to make and sustain improvements and to attain high performance. Review your registry data to identify gaps in current care. All clinical microsystems are awash with data but relatively few have rich information environments that feature daily, weekly and monthly use of Metrics That Matter (MTM). The key to doing this is to get started in a practical, doable way; and to build out your Metrics That Matter and their vital use over time.
- Some guidelines for your consideration are listed below. Remember these are just guidelines and your microsystem should do what makes sense in the way of collecting, displaying and using measures or Metrics That Matter.

### CYSTIC FIBROSIS METRICS THAT MATTER

1. **What?** Every microsystem has vital performance characteristics, things that must happen for successful operations. Metrics That Matter should reflect your microsystem's vital performance characteristics.
2. **Why?** The reason to identify, measure and track MTM is to ensure that you are not "flying blind." Safe, high-quality and efficient performance will give you specific, balanced and timely metrics that show:
  - a. When improvements are needed
  - b. If improvements are successful
  - c. If improvements are sustained over time
  - d. The amount of variation in results over time
3. **How?** Here are steps you can make to take advantage of MTMs.

#### ■ LEAD TEAM

Work with your **Lead Team** to establish the **need** for metrics and their **routine** use. Quality begins with the intention to achieve measured excellence.

#### ■ BALANCED METRICS

Build a **balanced set of metrics** to provide insight into what's working and what's not working. Some categories to consider are: process flow, clinical, safety, patient and family perceptions, staff perceptions, operations, and finance/costs. Avoid starting with too many measures.

**Every metric should have an operational definition, data owner, target value and action plan.**

#### ■ DATA OWNER

Start small and identify a **data wall** owner(s) who is guided by the lead team.

Identify a **data owner(s)** for each metric. The **owner** will be responsible for getting this measure and reporting it to the lead team. Seek sources of data from organization-wide systems.

If the needed data are not available, use manual methods to measure. Strive to build data collection in the flow of daily work.



#### ■ DATA WALL DISPLAYS

A data wall is a designated space to display your Metrics That Matter over time. Build a data wall and use it daily, weekly, monthly, and annually. Gather data for each metric and **display** it on the "data wall" reporting

- Current Value
- Target Value
- Action Plan to improve or sustain level

Display metrics as soon as possible—daily, weekly and monthly metrics are most useful—using visual displays such as **time trend charts** and bar charts.

#### ■ REVIEW AND USE

**Review** your set of metrics on a regular basis—daily, weekly, monthly, quarterly and annually.

**Use** metrics to make needed improvements whenever possible.

Make metrics fun, useful and a lively part of your microsystem development process. Discuss Metrics That Matter frequently and take action on them as needed.

Strongly consider using the metrics reported in the CF Foundation's center-specific registry reports, JCAHO\* metrics whenever they are relevant to your microsystem, vital metrics based on your own experience and strategic initiatives and other "gold standard" sets such as measures from NQF.\*

\*JCAHO, Joint Commission on Accreditation of Healthcare Organizations; NQF, National Quality Foundation

## The Cystic Fibrosis Foundation's Seven Worthy Goals

The Seven Worthy Goals that fuel our improvement efforts are:

- 1) Patients and families are full partners with the CF care team in managing this chronic disease. Information and communication will be given in an open and trusting environment so that every patient/family will be able to be involved in care at the level they desire. Care will be respectful of individual patient preferences, needs and values.
- 2) Children and adolescents will have normal growth and nutrition. Adult nutrition will be maintained as near normal as possible.
- 3) All patients will receive appropriate therapies for maintaining lung function and reducing acute episodes of infection. Pulmonary exacerbations will be detected early and treated aggressively to return patients to previous levels of lung function.
- 4) Clinicians and patients will be well-informed partners in reducing acquisition of respiratory pathogens, particularly *P. aeruginosa* and *B. cepacia*.
- 5) Patients will be screened and managed aggressively for complications of CF, particularly CF-related diabetes.

- 6) Severely affected patients who are facing decisions about transplantation and end-of-life care will be well-supported by their CF team.
- 7) Patients will have access to appropriate therapies, treatments and supports, regardless of race, age, education or ability to pay.

## Institute of Medicine's Six Aims

In 2001, the Institute of Medicine (IOM) described a "quality chasm" that exists within today's health care system. The IOM called for fundamental reform of health care for all Americans. In its report *Crossing the Quality Chasm: A New Health System for the 21st Century* the IOM articulated six quality aims for improving care, stating that care should be:

1. **Safe** – avoiding injuries to patients from care that is intended to help them.
2. **Effective** – providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit.
3. **Patient-centered** – providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.
4. **Timely** – reducing waits and sometimes harmful delays for both those who receive and those who give care.
5. **Efficient** – avoiding waste, in particular waste of equipment, supplies, ideas and energy.
6. **Equitable** – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographical location and socioeconomic status.

## CF CENTER METRICS THAT MATTER

- Review the currently determined "best metrics" that CF clinics should be monitoring.
- List current performance on these metrics and what targets are.

| Name of Measure                                       | Goal                        | Current & Target Values | Definition & Data Owner | Action Plan & Process Owner |
|---|-----------------------------|-------------------------|-------------------------|-----------------------------|
| <b>CF Patient Registry Outcome Measures</b>           |                             |                         |                         |                             |
| FEV <sub>1</sub> , Children ages 6 -17 years          |                             |                         |                         |                             |
| FEV <sub>1</sub> , Adults ages 18 years and older     |                             |                         |                         |                             |
| Median BMI Percentile, People 2 – 20 years            | 50 <sup>th</sup> percentile |                         |                         |                             |
| Median BMI, People 21 years and older                 |                             |                         |                         |                             |
| • Female  | 22 BMI                      |                         |                         |                             |
| • Male  | 23 BMI                      |                         |                         |                             |
| <b>Visit Guidelines</b>                               |                             |                         |                         |                             |
| • Clinic Visits                                       | at least quarterly          |                         |                         |                             |
| • Pulmonary function tests                            | at least every six months   |                         |                         |                             |
| • Respiratory cultures                                | at least quarterly          |                         |                         |                             |
| CFRD screening, People 14 yrs & older                 | yearly                      |                         |                         |                             |
| <b>Patient &amp; Family Perceptions</b>               |                             |                         |                         |                             |
| Collaborative Goal Setting with Patients and Families |                             |                         |                         |                             |
| Patient/Family Action Plan                            |                             |                         |                         |                             |
| <b>Access</b>   |                             |                         |                         |                             |
|   |                             |                         |                         |                             |
| <b>Staff Morale</b>                                   |                             |                         |                         |                             |
|   |                             |                         |                         |                             |
| <b>Safety</b>   |                             |                         |                         |                             |
|   |                             |                         |                         |                             |
| <b>Finance</b>  |                             |                         |                         |                             |
|   |                             |                         |                         |                             |

# STEP 3

## DIAGNOSE

With the improvement lead team review the 5Ps assessment and Metrics That Matter, and with consideration of your organizational strategic plan, select a first “theme,” (e.g., registry outcome data, growth and nutrition, lung function, reduction of respiratory pathogens and CF-related diabetes screening) for improvement.

The purpose of assessing is to make an informed and correct overall diagnosis of your microsystem.

- First, identify and celebrate the strengths of your system.
- Second, identify and consider opportunities to improve your system.
  - The opportunities to improve may come from your own microsystem—based on assessment, staff suggestions and/or patient and family needs, perceptions, priorities and concerns.
  - The opportunities to improve may come from outside your microsystem—based on a strategic project or external performance/quality measures, e.g. JCAHO.

- Not only look at the detail of each of the assessment tools, but also synthesize all of the assessments and Metrics That Matter to “get the big picture” of the microsystem. Identify linkages within the data and information. Consider:
  - Waste and delays in the process steps. Look for processes that might be redesigned to result in better functions for roles and better outcomes for patients.
  - Patterns of variation in the microsystem. Be mindful of smoothing the variations or matching resources with the variation in demand.
  - Patterns of outcomes you wish to improve.
- It is usually smart to pick or focus on one important theme to improve at a time and to work with all the “players” in your system to make a big improvement in the area selected.
- Suggestions on how to make your diagnosis and select a theme follow next.

### DIAGNOSE YOUR CF CENTER

Write your Theme for Improvement

---



---



---

#### “GLOBAL” AIM STATEMENT FOR THEME

Create an aim statement that will help keep your focus clear and your work productive.

We aim to improve \_\_\_\_\_  
(Name the process)

In \_\_\_\_\_  
(Clinical location in which process is embedded)

The process begins with \_\_\_\_\_  
(Name where the process begins)

The process ends with \_\_\_\_\_  
(Name the ending point of the process)

By working on the process, we expect \_\_\_\_\_  
(List benefits)

---

It is important to work on this now because \_\_\_\_\_  
(List imperatives)

---



---



---



# STEP 4

## TREAT YOUR CF CENTER

Draft a clear specific aim statement and way to measure the aim using improvement models—PDSA (Plan-Do-Study-Act, pg. 28) and SDSA (Standardize-Do-Study-Act, pg. 29).

- Now that you've made your diagnosis and selected a theme worthy of improving, you are ready to begin using powerful change ideas, improvement tools and the scientific method to change your microsystem.
- This begins with making a specific aim and using Plan-Do-Study-Act (PDSA), which is known as the "model for improvement." The improvement model raises three important questions to answer before starting to make changes.
  1. What are we trying to accomplish?
  2. How will we know that a change is an improvement?
  3. What changes can we make that will result in an improvement?
- After you have run your tests of change and have reached your measured aim, the challenge is to maintain the gains that you have made. This can be done using Standardize-Do-Study-Act (SDSA), which is the other half of making improvement that has "staying power."
- You will be smart to avoid totally reinventing the wheel by taking into consideration best known practices, Change Ideas that other clinical teams and patients and families have found to really work. A list of some of the best "Change Ideas" that might be adapted and tested in your clinic follows the aim statement worksheet.
- The Change Ideas will continue to develop as more field testing is done and more colleagues design improvements. These ideas are derived from the collaborative innovation work of the CF Foundation. For more information visit [www.PortCF.org](http://www.PortCF.org) or [ihi.org](http://ihi.org) (Institute for Healthcare Improvement).

### SPECIFIC AIM STATEMENT

Create a specific aim statement that will help keep your focus clear and your work productive.

**Use numerical goals, specific dates, and specific measures.**

#### SPECIFIC AIM

---



---



---



---



---

#### MEASURES

---



---



---



---



---

### CF CENTER CHANGE IDEAS TO CONSIDER

1. Pre-clinic huddle to prepare for the day's patients
2. Follow-up phone calls with patients and families
3. Develop and consistently apply algorithms for care
  - a. Nutrition (BMI and BMI %)
    - i. Identification system with matched follow up based on need
    - ii. Hand-out copies of growth curves and nutritional recommendations at every visit
  - b. Pulmonary-Routine and exacerbation care
4. Patient and family care conferences to develop short-term and long-range plans of care
5. Utilize registry data and give summary reports to patients and families at each visit
6. Utilize visit worksheets that include visit expectations and goals for care and identification of risk factors for adherence to plans of care
7. Build an action plan with patient and family for care that is mutually agreed upon and meets the patient's and family's goal(s)

Consider the *Change Concepts* on page 295 of *The Improvement Guide* by Langley, Nolan, Nolan, Norman and Provost (1996). The main change categories are listed below.

- A. Eliminate Waste
- B. Improve Workflow
- C. Optimize Inventory
- D. Change the Work Environment
- E. Enhance the Producer/Customer Relationship
- F. Manage Time
- G. Manage Variation
- H. Design Systems to Avoid Mistakes
- I. Focus on the Product or Service

Langley G, Nolan K, Nolan T, Norman T, Provost L. *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*. 1<sup>st</sup> ed. The Jossey-Bass Business & Management Series. San Francisco, CA: Jossey-Bass Publishers; 1996: xxix, 370.

\*Visit [www.PortCF.org](http://www.PortCF.org) and [www.clinicalmicrosystem.org](http://www.clinicalmicrosystem.org) for actual documents, forms and latest ideas

# Huddle Sheet

- What can we proactively anticipate and plan for in our work day/week? At the beginning of the CF clinic hold a review of today's patients' past visits, review of plans for today and preview of upcoming days. Frequency of clinic review is dependent on the situation, but a mid-day review can be helpful.
- This worksheet can be modified to add more detail to the content and purpose of the huddles.

## Huddle Sheet

**Clinic:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**Aim:** Enable the clinic to proactively anticipate and plan actions based on patient need and available resources, and contingency planning.

### FOLLOW-UPS

**"HEADS UP" FOR TODAY:** (include special patient needs, sick calls, staff flexibility, contingency plans)

**Meetings:**

### REVIEW OF NEXT CLINIC DAY AND PROACTIVE PLANNING

**Meetings:**

# Plan-Do-Study-Act (PDSA)

Complete the Plan-Do-Study-Act worksheet to execute the Change Idea in a disciplined, measured manner, to reach the specific aim. See [www.PortCF.org](http://www.PortCF.org) and [www.clinicalmicrosystem.org](http://www.clinicalmicrosystem.org) for examples.

**PLAN** ➤ How shall we PLAN the *pilot test*? Who? What is the task? When? With what tools? What baseline data will be collected, over what period of time, to determine if the AIM is being achieved?

| Tasks to be completed to run test of change | Who | When | Tools Needed | Measures |
|---|-----|------|--------------|----------|
|   |     |      |              |          |
|   |     |      |              |          |
|   |     |      |              |          |
|   |     |      |              |          |
|   |     |      |              |          |
|   |     |      |              |          |
|   |     |      |              |          |
|   |     |      |              |          |

**DO** ➤ What are we learning as we DO the pilot? What happened when we ran the test? Any problems encountered? Any surprises?

**STUDY** ➤ As we STUDY what happened, what have we learned? What do the measures show?

**ACT** ➤ As we ACT to *hold the gains* or abandon our pilot efforts, what needs to be done? Will we modify the change? Make a PLAN for the next cycle of change.

The lead team should continue to meet weekly to review progress in the design of the PDSA and then during the execution of the test of change in a pilot format to observe and learn about the Change Idea implementation. Remember to always test Change Ideas in small pilots to learn what adaptations and adjustments need to be made before implementing on a larger scale. Data collection and review during the testing is important to answer the question: How will we know if the Change Idea is an improvement?

Once the PDSA cycle is completed and the lead team reviews the data and qualitative findings, the plan should be revised or expanded to run another cycle of testing until the aim is achieved.

When the Change Idea has been tested and adapted to the context of the clinical microsystem and the data demonstrate that the Change Idea makes an improvement, the lead team should design the Standardize-Do-Study-Act

(SDSA, pg. 29) process to ensure the process is performed as designed. During this process it is important to continually learn and improve by monitoring the steps and data to identify new opportunities for further improvement. You will move from PDSA to SDSA and back to PDSA in your continuous improvement environment. New methods, tools, technology or best practice will often signal the need to return to PDSA to achieve the next level of high performance. You want to be able to go from PDSA to SDSA and back to PDSA as needed. The scientific method is a two-way street that uses both **experimentation** (i.e., PDSA) as well as **standardization** (i.e., SDSA).

# Standardize-Do-Study-Act (SDSA)

## STANDARDIZE CURRENT BEST PROCESS AND HOLD THE GAINS

**STANDARDIZE** the process (specify which roles do what activities in what sequence with what information flow). A good way to track and standardize process is through the creation of a **Playbook**. The Playbook is the collection of **process maps** to provide care and services that all staff are aware of and accountable for. The Playbook can be used to orient new staff and patient/family advisors, document current processes and contribute to performance appraisals.

**DO** the work to integrate the standard process into daily work routines to ensure reliability and repeatability.

**STUDY** at regular intervals. Consider if the process is being adhered to and what adjustments are being made. Review the process when new innovations, technology or roles are being considered. Review what the measures of the process are showing.

**ACT** based on the above, maintain or tweak the standard process and continue doing this until the next wave of improvements/innovations takes place with a new series of PDSA cycles.

### STANDARDIZE



How shall we **STANDARDIZE** the process and embed it into daily practice? Who? What's the task? When? With what tools? What needs to be "unlearned" to allow this new habit? What data will inform us if this is being standardized daily?

| Tasks to be completed to "embed" standardization and monitor process | Who | When | Tools Needed | Measures |
|--|-----|------|--------------|----------|
|  |     |      |              |          |
|  |     |      |              |          |
|  |     |      |              |          |
|  |     |      |              |          |
|  |     |      |              |          |
|  |     |      |              |          |
|  |     |      |              |          |
|  |     |      |              |          |
|  |     |      |              |          |

\*Playbook-Create standard process maps to be inserted in your Playbook.

### DO



What are we learning as we **DO** the standardization? Any problems encountered? Any surprises? Any new insights to lead to another PDSA cycle?

### STUDY



As we **STUDY** the standardization, what have we learned? What do the measures show? Are there identified needs for change or new information or "tested" best practice to adapt?

### ACT



As we **ACT** to hold the gains or modify the standardization efforts, what needs to be done? Will we modify the standardization? What is the Change Idea? Who will oversee the new PDSA? Design a new PDSA cycle. Make a **PLAN** for the next cycle of change. Go to PDSA worksheet (pg.28).

# STEP 5

## FOLLOW-UP

### IMPROVEMENT IN HEALTH CARE IS A CONTINUOUS JOURNEY

The new patterns need to be monitored to ensure the improvements are sustained. Embedding new habits into daily work with the use of “huddles” to review and remind staff, as well as weekly lead team meetings keeps everyone focused on improvements and results that can lead to sustained and continuous improvements.

Data walls, storyboards and monthly all-staff and patient/family advisor meetings are methods to embed new habits and thinking for improvement.

The lead team should repeat the process for newly recognized themes and improvements that are identified in the assessment and outcomes/performance metrics.



| What   | When | Who | Where |
|--|------|-----|-------|
| Clinic Huddles   |      |     |       |
| Weekly Meetings–<br>Lead Team                                      |      |     |       |
| Monthly Meetings<br>• All Staff<br>• Patient & Family Advisors     |      |     |       |
| Quarterly Reports of<br>Outcomes and Progress<br>to Senior Leaders |      |     |       |
| Annual Retreat for<br>Review and Reflection                        |      |     |       |
| Data Wall  |      |     |       |
| Storyboards  |      |     |       |

# Case Study: CF Care Center

MEDICAL CENTER/MEDICAL CENTER HOSPITAL, ANYWHERE, U.S.A.

## CONTEXT

The CF center cares for approximately 150 patients. Our pediatric clinic is located in the pulmonary outpatient department of the Medical Center and our adult program is across the street at the pulmonary department of Medical Center Hospital. We operate as two teams. The pediatric team consists of 3 pulmonologists, 2 nurses, a dietitian, a social worker, and a respiratory therapist. The adult team consists of 2 pulmonologists, 2 nurses, a dietitian, a social worker, and a respiratory therapist. Pediatric outpatient clinic is held once a week as a full day clinic. The adult clinic is a full day clinic twice a month. Patients with specific issues such as CF-related diabetes, GI issues, etc. see specialists through separate appointments in the appropriate departments. Each team convenes a pre- and post-clinic meeting to address patient issues. The pediatric and adult CF teams meet once a month.

## THEME, PURPOSE, AND AIMS

The center embarked on the journey of continuous improvement and joined the CF Foundation's Learning and Leadership Collaborative. We sent a **lead team** of six staff to the collaborative with members from the pediatric and adult CF teams. As a center we agreed that our **purpose** is to "help each person with CF fulfill his or her maximal potential by providing exemplary care."

The lead team reviewed our CF registry data. They were struck by our nutrition data and thought the center could do better. Our initial **theme** became nutrition care. To pursue this theme we started by improving the nutrition health of patients, focusing on kids ages 2 to 20 years as our **global aim**.

## "GLOBAL" AIM STATEMENT FOR THEME

Create an aim statement that will help keep your focus clear and your work productive.

**We aim to improve** the nutrition health of CF patients between 2 and 20 years of age  
(Name the process)

**In** our CF Center

(Clinical location in which process is embedded)

**The process begins with** identification of patients 2 to 20 years of age currently being seen in our CF Center  
(Name where the process begins)

**The process ends with** implementation of new process for nutrition care

(Name the ending point of the process)

**By working on the process, we expect** improved median BMI percentile, appropriate dosing of enzymes, frequent return visits, and increased use of supplements and feeding for malnourished  
(List benefits)

**It is important to work on this now because** the median BMI percentile for our center is below the national average (35th percentile), our patients have low BMI percentiles and with improved BMI percentiles, the health of our patients will be improved.  
(List Impetus)

Our **specific aim** in the short term was to capture current BMI percentile, enzyme dose, and number of visits on all of our patients age 2-20 years by July 2005.

## SPECIFIC AIM STATEMENT

Create a specific aim statement that will help keep your focus clear and your work productive.

**Use numerical goals, specific dates, and specific measures.**

**SPECIFIC AIM** We aim to capture current BMI percentile, enzyme dose, and number of clinic visits.

### MEASURES

On all of our patients ages 2-20

years of age by July 2005.

With our aims in place, we felt it was important to adopt a **communication plan** to get everyone involved. Upon the lead team's return from the collaborative meeting, we had an all staff CF care team meeting, including clerical staff, key inpatient staff and specialists. The lead team assumed a different **role** in the meeting to review what was taught in the collaborative, share the center's data and the global and specific aims. We also met with

**senior leaders**, e.g. department chairs, section chiefs, vice-presidents, to share our work and aim. Another key set of stakeholders we engaged early in the efforts were our **patients and families**. We agreed to go transparent and share our center specific patient registry data. We asked for their help to improve nutrition outcomes. Our goal was to engage them as active partners in the quality improvement work of the center.

## ASSESSMENT-CURRENT STATE

In trying to understand how we currently deliver care and how we currently deliver nutrition care we realized we needed to collect data on our **patients, professionals, processes, and patterns**. We started to understand our patient population in four ways. We reviewed our CF registry data and categorized **patients** by the percent of males and females and the age distribution of our patients, e.g. birth-2 years, 2-5 years, 6-12 years, etc. We asked patients to complete a **patient satisfaction survey** and distributed the **patient cycle time tools** to assess how long patients were in clinic and how long each clinician saw them. We also initiated a **patient and family advisory group** to help us and invited interested patients and families to our center meetings.

As we were getting a sense of our practice through the **eyes of the patients**, we also started to collect data about our **professionals**. We tallied data on the number of FTEs in our clinics, provided an anonymous **staff satisfaction survey**, and asked clinicians to complete a **skills assessment**. This information was invaluable and helped us have a few crucial conversations as a team.

At the heart of our assessment was our look at the evidence-based nutrition and screening recommendations from the CF Foundation and working toward changing our **process** and **patterns** based on the recommendations. We created a **fishbone diagram** to identify causes of the effect of poor nutrition in our center.

We drew a **flowchart** of our current appointment and visit process. Looking at the data from the patient cycle time tool and the staff **skills assessment**, we developed an algorithm to decide which clinicians would verify the patient's nutrition status and enzyme dose, who and how the frequency of visits by the patients would be tracked and how many members of the care team would provide nutrition education.

## TESTS OF CHANGE

We conducted the following tests of change or cycles of Plan-Do-Study-Act (PDSA).

### PDSA Cycle I

- Introduce a new algorithm for nutrition screening to decrease variance

### PDSA Cycle II

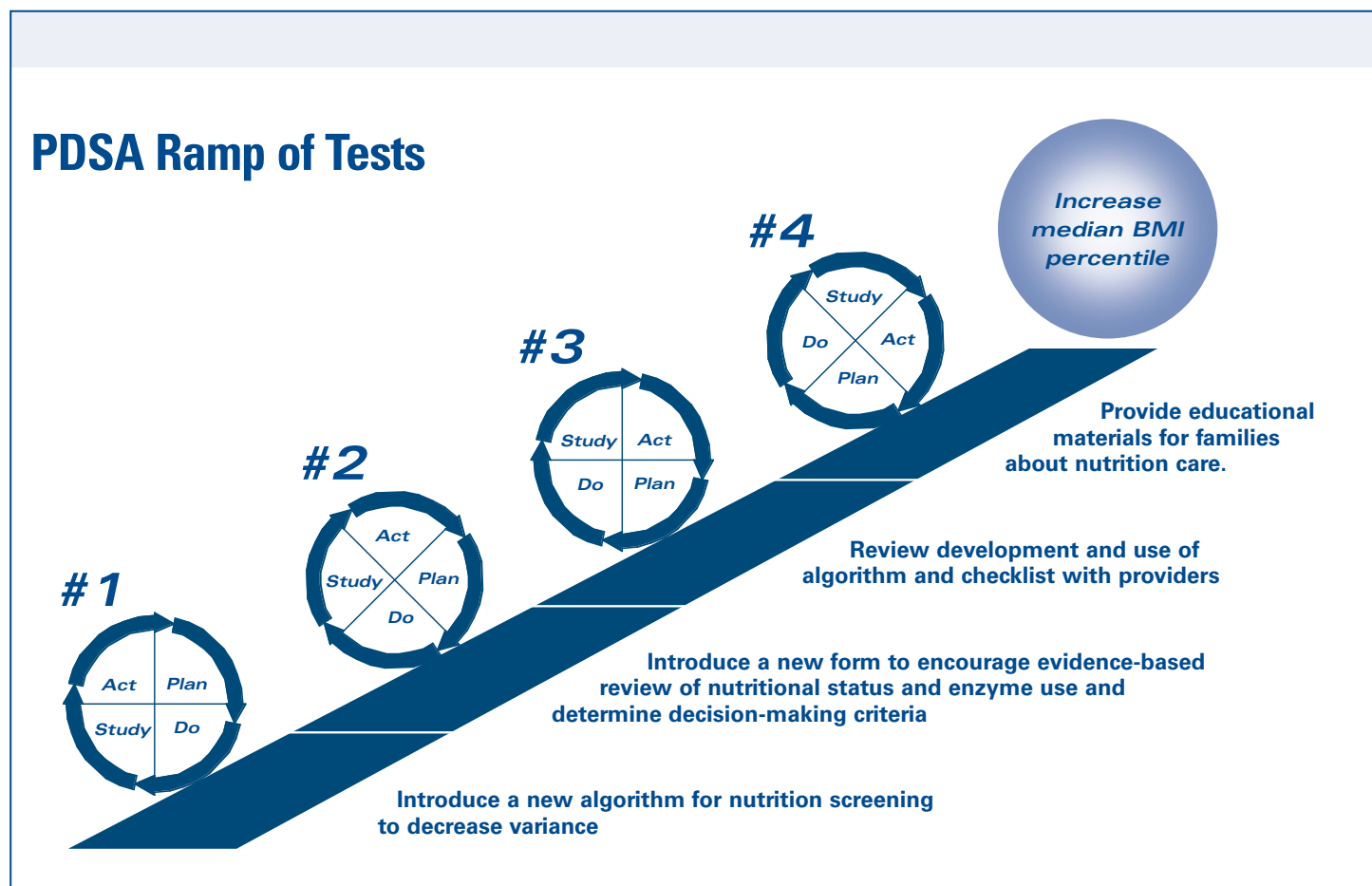
- Introduce a new form to encourage evidence-based review of nutritional status and enzyme use and determine decision-making criteria

### PDSA Cycle III

- Review development and use of algorithm and checklist with providers

### PDSA Cycle IV

- Provide educational materials for families about nutrition care.



## MEASUREMENT

As our process changed we instituted a system to measure the impact of the changes. We agreed to **measure** the following metrics, analyze our practice **patterns**, and post the results on our data wall for all staff to review.

- Number of patients currently below the 50<sup>th</sup> BMI percentile
- Number of patients not taking appropriate dose of enzymes
- The percent of patients per clinic with charted BMI percentiles
- The percent of patients using nutritional supplements, oral and/or tubes
- Changes in BMI percentile and Quality of Life score

## STANDARDIZATION AND FOLLOW-UP

Concluding our tests of change and standardizing our process (**SDSA – Standardize-Do-Study-Act**) of screening nutritional status of patients, we created a **playbook** of our work. This book is a compilation of our current nutrition care process outlining who does what, when, and recommended measures and monitors to ensure the process is consistent and standardized. This playbook is utilized to orient new staff, conduct performance appraisals and reinforce actions to standardize the process. Now that we have successfully changed the process related to the delivery of nutritional care to appropriate patients, we are going to use the same process and focus on ways we can improve the pulmonary care delivered at CF Care Center, Medical Center Hospital.

CF Center, Medical Center Hospital  
 ...where people are great, we just make them better

Aim: Improve the nutrition health of CF patients, especially those between 2 and 20 years old.

Specific Aim: Capture current BMI percentile, enzyme dose, and number of visits on all of our patients 2-20 years old by July 2005

TEAM

- John Buck, M.D. Karen Douglas, M.D.
- Mike Strong, M.D. Jennifer Smith, R.N.
- Ginny Dresser, R.N. Connie Cho, R.D.
- Melissa Martin, R.N. Joanne Parker, M.S.W.

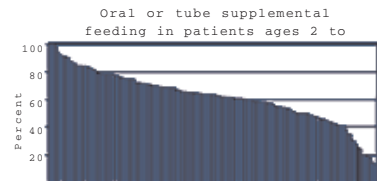
TIMELINE

- |   |  |
|---|--|
| June '04  | new algorithm to whole center                                      |
| • Reviewed Center Report from the CF Foundation Registry data   | • Survey perception of health and care providers                   |
| • Established our aims to address nutrition care at our center. |  |
| July '04  | November '04   |
| • Established regular team meetings                             | • Use algorithm  |
| • Developed new algorithm for nutrition interventions           | • Develop nutrition checklist assessing factors in decision-making |
| • Senior Leadership Meeting                                     | • Survey patient perceptions of barriers to health care            |
| October '04   | December '04   |
| • Review, revise, and present                                   | • Start utilizing nutrition checklist                              |
|   | • Begin daily posting of nutrition screening run charts and data   |
|   | January '05  |
|   | • Review algorithm and nutrition checklist with care providers     |

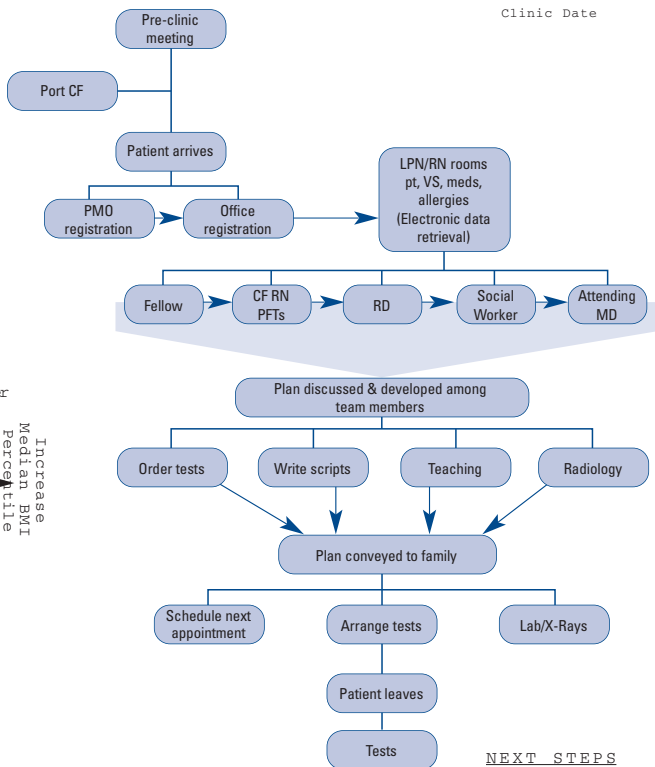
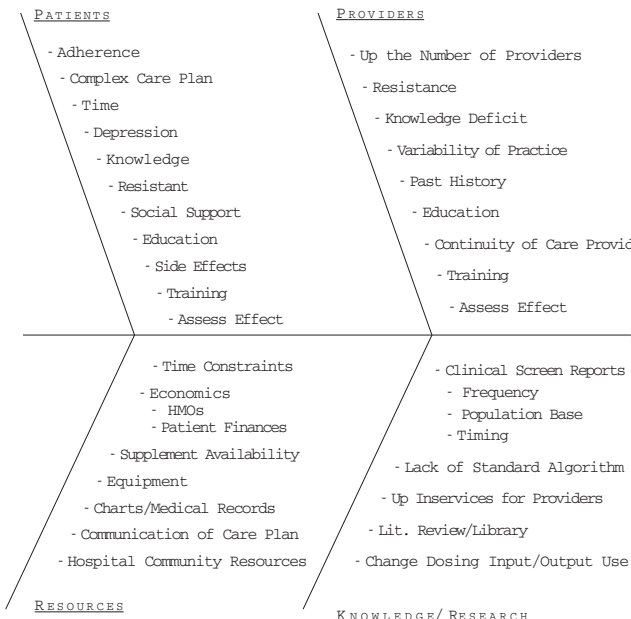
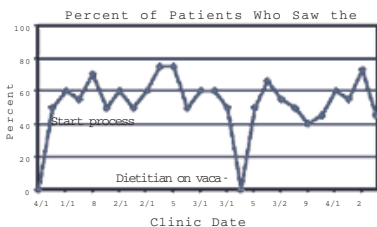
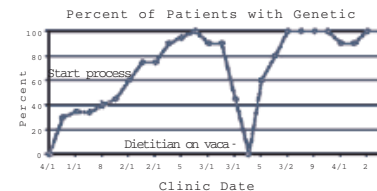
IMPROVEMENTS/CHANGES

- PDSA Cycle I**  
Introduce a new algorithm for nutrition screening to decrease variance
- PDSA Cycle II**  
Introduce new form to encourage evidence-based review of nutritional status and enzyme use and determine decision making criteria
- PDSA Cycle III**  
Review development and use of algorithm and checklist with providers
- PDSA Cycle IV**  
Provide educational materials for families about nutrition care

- MEASURES
- Number of patients currently below the 50th BMI percentile
  - Number of patients not taking appropriate dose of enzymes
  - Percent of patients per clinic with charted BMI percentiles
  - Percent of patients using nutritional supplements, oral and/or tubes
  - Change in BMI percentile and Quality of Life scores

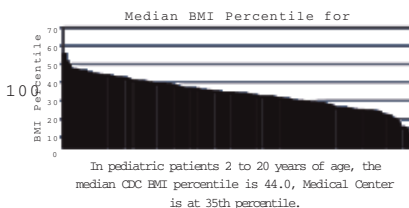


In pediatric patients 2 to 20 years of age with a BMI < 50th percentile, 61.9 percent receive either oral or tube supplemental feeding,



DIAGNOSTICS

- Number of patients to screen (CF Registry) 113
- Number of staff trained (MDs/RNs/NPs/PAs/RDs) 15
- Number of patients seen since algorithm implemented 93
- Number of patients eligible to screen since algorithm 93
- Number of patients eligible to screen since checklist 53
- Number of patients seen screened since checklist 22



NEXT STEPS

- Analyze changes to outcomes (BMI percentile, well-being)
- Re-evaluate and modify nutrition algorithm
- Follow evidence-based medicine for other preventive interventions
- Family night presentation
- Meet with hospital administration



## Between CF Contributing Units in CF Microsystem: The “Hand-Offs”

Assess the “within” contributing units of your CF microsystem and the “between” CF contributing units or “hand-offs.”

Contributing units come together to provide care and services to patients with CF. The intentional planning and knowledge of each unit contributes to the overall quality and outcomes of your CF microsystem.

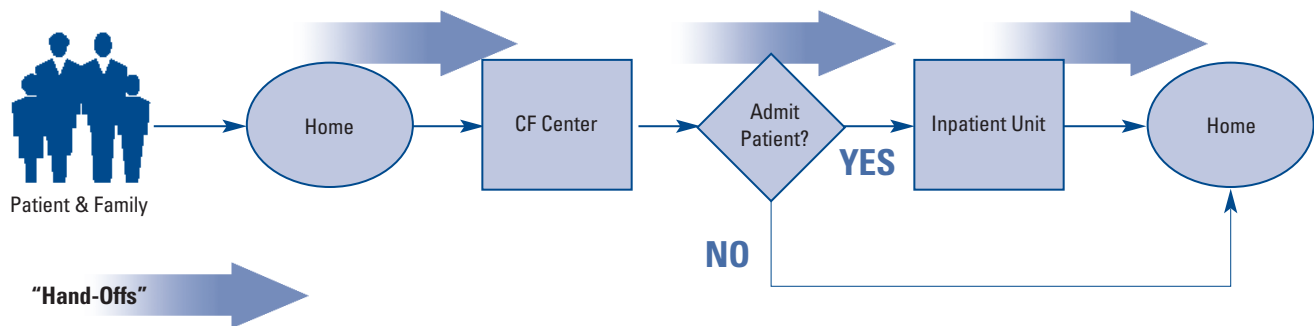
### “HAND-OFFS” BETWEEN CONTRIBUTING UNITS

An essential element is detailed insight of the “hand-offs” of patients, information, data and materials between the contributing units. The “hand-offs” between units is one place where errors, omissions, waste, rework and

gaps in care can occur. The patient becomes very vulnerable and “at risk” during these hand-offs. Your CF microsystem must commit to designing the process of the “hand-offs” between units to be highly reliable, defect-free, and as predetermined as possible. “Hand-offs” also occur between the CF center and supporting departments such as dietary. Be thoughtful about that transition time and how to ensure the “hand-off” includes the best information and data to support patient care.

### EVALUATE YOUR “HAND-OFFS”

Identify the “hand-offs” between contributing units that occur within your CF microsystem. (See diagram)



#### Evaluate if the “hand-offs” between units and “at risk” periods are

- Predetermined and highly specified?

For example, when your CF patient is transferred from the CF center to the inpatient unit, how are information, medication orders and plan of care, including patient and family preferences, communicated?

#### Convene the contributing units to focus on “hand-offs”

- What are patient and family perceptions on hand-offs? What’s helpful? What isn’t helpful? What would they improve?
- How do we currently “hand-off” patients, information, data and materials?
- Have we ever discussed what the receiving unit requires in a standard way?
- Have we ever determined what WE need to receive in a standard way from units who “hand-off” to us? Have we communicated this?
- Is there one direct way to send patients, information, data and materials?
- Is the “hand-off” process predefined, highly specific, simple and direct, without loops and rework?

- Are there regular opportunities to provide feedback about the “hand-off” process from the sender and receiver?
- Do we meet on a regular basis to review our entire CF microsystem?

Based on the exploratory discussion, design how to improve the “hand-offs” toward the goal of being defect-free, highly reliable, predictable and simple.

### Consider the 4 Rules for Design when developing improvement strategies

#### “Hand-Offs” 4 Rules for Design <sup>Δ</sup>

1. All work must be highly specified as to content, sequence, timing, location and expected outcome.
2. Every customer-*supplier* connection must be highly specified and direct, and there must be an unambiguous yes-or-no way to send requests and receive responses.
3. The pathway for every product and service must be predefined, highly specified, simple and direct, with no loops or forking.
4. Any improvement must be made in accordance with the scientific method, under the guidance of a teacher, at the lowest possible level, aiming toward the ideals.

<sup>Δ</sup> [www.prhi.org](http://www.prhi.org).

Visit [www.ihl.org](http://www.ihl.org) and [www.clinicalmicrosystem.org](http://www.clinicalmicrosystem.org) for the latest ideas

# Framework For Patient and Family Involvement in a CF Care Center\*

The following represents a framework for ways to think about including patients and families in CF care center work. Overall, the table is divided into different levels of patient and family involvement. The suggestions build on each other, i.e., the ways in which patients, families and/or staff might prepare within one level assumes the preparation included at all previous levels as well as that particular level. Examples of specific patient or family responsibilities are listed at each level. These lists are not comprehensive, but examples of what patients or family members' responsibilities might be.



| Patients'/Families' Roles <sup>1A</sup>  | Patient/Family Responsibilities  | Staff/Healthcare Providers' Responsibilities Preparation/Compensation   |
|--|--|---|
| <p><b>Patients or Families as Participants</b></p> <ul style="list-style-type: none"> <li>Respond to surveys and questionnaires</li> <li>Members of focus group</li> </ul> | <ul style="list-style-type: none"> <li>Family perceptions of care and quality are elicited and used in shaping improvement initiatives.</li> <li>Data/information from families is used in measuring improvement.</li> <li>Responsibilities end when their input is received unless they are asked to provide feedback on the interpretation of the data.</li> <li>Review and give feedback related to materials developed specifically for patients or families, e.g., educational materials.</li> <li>Provide suggestions for improvement in writing as appropriate.</li> <li>Respond to surveys/questions openly and honestly.</li> </ul> | <p><b>PREPARATION:</b></p> <ul style="list-style-type: none"> <li>All efforts should be made to ensure that patients' and families' real experience is accurately measured and interpreted.</li> <li>Attention is focused more on the instruments, methods and analysis than on significant patient or family participation, training or preparation of them as participants (beyond what is necessary for them to make an informed choice to participate and to complete the activity).</li> <li>In keeping with a patient- and family-centered approach, efforts to ensure that all (or an adequate sample that reflects the diversity of populations served) are included.</li> </ul> <p><b>COMPENSATION:</b></p> <ul style="list-style-type: none"> <li>Acknowledgement of appreciation for their participation is necessary.</li> <li>Supplying patients/families with a summary of the data and information about how the data is/will be used to improve area of focus (e.g., quality care, education, etc.). This can occur in a patient/family meeting, education day, written summary, etc., and may be additional compensation.</li> </ul> |

\*For more information on patient and family involvement and creating an advisory council, visit [www.PortCF.org](http://www.PortCF.org) or the Institute for Family Centered Care Web site at [www.familycenteredcare.org](http://www.familycenteredcare.org)

<sup>Δ</sup> Notes are on page 37

| Patients'/Families' Roles <sup>1</sup>   | Patient/Family Responsibilities   | Staff/Healthcare Providers' Responsibilities Preparation/Compensation   |
|--|---|---|
| <p><b>Patients or Families as Advisory Board Members<sup>2</sup></b></p> <ul style="list-style-type: none"> <li>• Members of committee</li> <li>• Members of task force</li> <li>• Patients or families serve on advisory boards for the quality improvement team</li> </ul> | <ul style="list-style-type: none"> <li>• Responsibilities will depend on level of involvement of the advisory board.</li> <li>• If the advisory board is used to review policies, programs and evaluation methods after staff has written them, there are few opportunities for teamwork.</li> <li>• If the advisory board assists in the planning, implementation and evaluation of improvement projects, education materials, etc., then its responsibilities will be much greater and they will be viewed as more of a partner than advisor/reviewer.</li> </ul> | <p><b>PREPARATION:</b></p> <ul style="list-style-type: none"> <li>• The most effective patient/family advisory boards have established means for recruitment, selection, membership requirements and setting bylaws, as well as ongoing strategic planning that identifies goals, activities, and evaluation. Support for these boards can be space for meetings, or administrative support (e.g., mailings, secretarial support, printing costs, etc.).</li> <li>• Staff members are identified to serve as liaisons to the advisory boards (and their time is covered by the unit/hospital) in order to build communication, coordination, and partnership.</li> </ul> <p><b>COMPENSATION:</b></p> <ul style="list-style-type: none"> <li>• Care centers can show their commitment by providing the advisory board regular opportunities for the board to report to senior leadership and/or to participate within a shared governance model.</li> <li>• The more involved the patients and families are in the planning, implementation and evaluation, the more there is a building of a partnership rather than just giving the “rubber-stamp” approval of an activity.</li> <li>• Other preparation issues to consider include childcare, meetings that include meals, parking and other transportation costs, and stipends for participation.</li> </ul> |

| Patients'/Families' Roles <sup>1</sup>  | Patient/Family Responsibilities  | Staff/Healthcare Providers' Responsibilities Preparation/Compensation  |
|---|--|--|
| <p><b>Patients or Families as Active Advisors/Consultants<sup>3</sup></b></p> <ul style="list-style-type: none"> <li>• Active task force/committee members</li> <li>• Faculty for staff education</li> <li>• Participants at collaborative meetings/conferences</li> <li>• Mentors for others in work (patients, families or staff)</li> <li>• Trainers for other patients and families involved</li> <li>• Orientation of staff</li> <li>• Work closely with the quality improvement team</li> </ul> | <ul style="list-style-type: none"> <li>• At this level, patients/families have a continuous and more active involvement with the care center, e.g., improvement lead team, educational materials.</li> <li>• Service time is usually clearly limited, e.g., 2-3 years or whatever is agreed upon by the care center, patient and/or family member.</li> <li>• They would be active participants as members of the teams who are planning, implementing and evaluating either individual projects and/or the work of the collaborative team as a whole.</li> <li>• Help in the quality improvement effort, all components of the Plan-Do-Study-Act (PDSA) cycle.</li> </ul> | <p><b>PREPARATION:</b></p> <ul style="list-style-type: none"> <li>• In order for patients and families to participate at this level, training, preparation and support would be comparable to what the staff receives. They require training specifically in the area of responsibility, e.g., quality improvement model and processes. Consider joint training sessions with patients, families and staff.</li> <li>• Expectations for involvement would be defined and regularly reviewed. In addition, this level would also require that teams receive training in working collaboratively with patients and families.<sup>4</sup></li> <li>• Experienced staff, patients and/or families can serve as experienced trainers and mentors for others.</li> </ul> <p><b>COMPENSATION:</b></p> <ul style="list-style-type: none"> <li>• Determine how staff, patients and families will be compensated and provided the means to participate at meetings. Consider reimbursement for time and travel. Don't forget to plan for other issues such as childcare, transportation costs, parking and meals.</li> <li>• Commitment by the care center and value of the patient/family input is demonstrated through the continuing funding of patient and/or family participation.</li> </ul> |

| Patients'/Families' Roles <sup>1</sup>   | Patient/Family Responsibilities  | Staff/Healthcare Providers' Responsibilities Preparation/Compensation   |
|--|--|---|
| <p><b>Patients or Families as Co-Leaders</b></p> <ul style="list-style-type: none"> <li>• <b>Facilitator</b></li> <li>• Content expert</li> <li>• Evaluator<sup>5</sup></li> <li>• Author</li> <li>• Hospital/clinic employee</li> </ul> | <ul style="list-style-type: none"> <li>• A high level of involvement patient and/or family.</li> <li>• Adequate skills and knowledge are required.</li> <li>• Previous work/education in focused content (e.g., QI, healthcare) is very valuable.</li> <li>• Consider community leadership experiences when choosing members to bring a different perspective and an awareness of other community needs.</li> <li>• Experiences serving in any of the previously outlined roles may provide the necessary knowledge without professional or educational experience.</li> </ul> | <p><b>PREPARATION:</b></p> <ul style="list-style-type: none"> <li>• This level requires all of the preparation included in all previous levels of involvement as well as additional preparation related to how to effectively collaborate with clinic/hospital leaders/administration.</li> <li>• Supervision and evaluation of those involved should be formalized.</li> <li>• Consider employing patients and/or families as clinic/hospital staff because of the requirements, commitment and role expectations of the co-leaders.</li> <li>• Intensive training and support for patients, families and staff who participate at this level should be developed. Consider participation in retreats, on-site coaching, even off-site training and evaluation.</li> </ul> <p><b>COMPENSATION:</b></p> <ul style="list-style-type: none"> <li>• Determine how staff, patients and families will be compensated and provided the means to participate at meetings. Consider reimbursement for time and travel. Don't forget to plan for other issues such as childcare, transportation costs, parking and meals.</li> </ul> |

These patient and family role ideas are based on work from the Vermont-Oxford Network. Mutual trust and respect must be built no matter what level people are serving in or whether they are staff, a patient or family member. This takes time. As patients and families are offered more opportunities to participate, the time spent in building an understanding of individual areas of expertise and common goals will help strengthen a team's capacity to col-

laborate and further partnership in improving CF care. This will require integration of teambuilding activities while building the partnership between patients, families and care centers. The CF Foundation believes that increasing patient/family involvement in the work at the care center supports our mission to find a cure and improve the quality of life for people with CF.

#### Notes:

<sup>1</sup> The framework for the roles was adapted from an article on participatory action research by Turnbull, Friesen, Ramirez, 1998 (see references).

<sup>2</sup> For a comprehensive resource on family advisory boards, refer to Webster, Johnson, 2000 (see references).

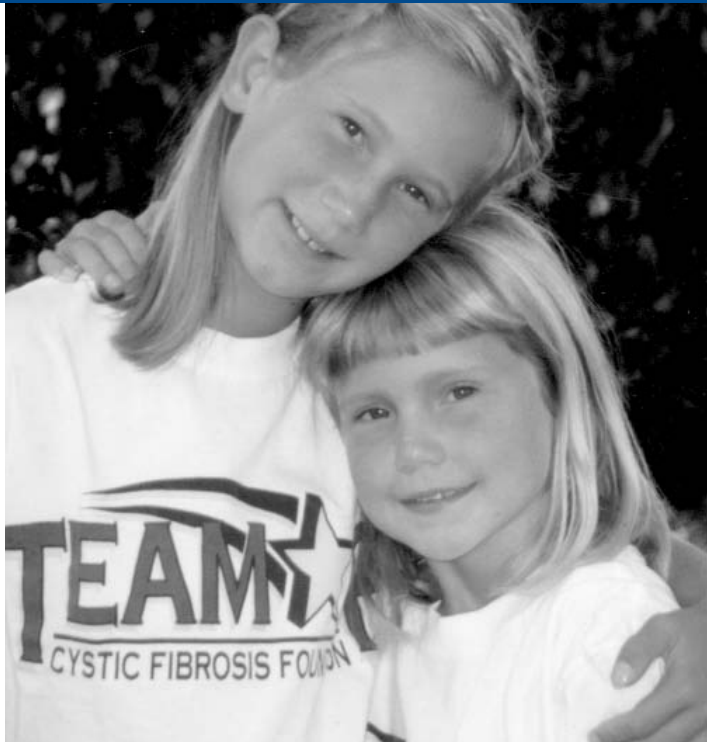
<sup>3</sup> Refer to Dillon, 2003 (see references) for guidance on parent participation on quality improvement teams.

<sup>4</sup> Refer to Jeppson, Thomas, 1995, 1997 and Turnbull, et al., (see references).

<sup>5</sup> For an annotated bibliography of families serving on evaluation teams refer to Jivanjee, et al., 2004 (see references).

## SELECTED REFERENCES

- American Hospital Association, Institute for Family-Centered Care. *Strategies for Leadership: Patient and Family-Centered Care*. Chicago, IL: American Hospital Association; 2004.
- Batalden PB, Nelson EC, Edwards WH, Godfrey MM, Mohr JJ: *Microsystems in Health Care: Part 9. Developing Small Clinical Units to Attain Peak Performance*. Jt C J Qual Saf. 2003;29(11):575-585.
- Blaylock B, Ahmann E, Johnson BH. *Creating Patient and Family Faculty Programs*. Bethesda, MD: Institute for Family-Centered Care; 2002.
- Boote J, Telford R, Cooper C. *Consumer involvement in health research: A review and research agenda*. Health Policy. 2002;61:213-236.
- Connor JM, Nelson EC. *Neonatal intensive care: Satisfaction measured from a parent's perspective*. Pediatrics. 1999;103(1):336-349.
- Dillon AD. *Parents Partners: Creative Forces on Medical Home Improvement Teams*. Greenfield, NH: Center for Medical Home Improvement; 2003.
- Giachello AL, Arrom JO, Davis M, et al. *Reducing diabetes health disparities through community-based participatory action research: The Chicago Southeast Diabetes Community Action Coalition*. Public Health Rep. 2003;118:309-323.
- Hanson JL, Randall VF. *Evaluating and improving the practice of family-centered care*. Pediatr Nurs. 1999;25(4):445-449.
- Jeppson ES, Thomas J. *Families as Advisors: A Training Guide for Collaboration*. Bethesda, MD: Institute for Family-Centered Care; 1997.
- Jeppson ES, Thomas J. *Essential Allies: Families as Advisors*. Bethesda, MD: Institute for Family-Centered Care; 1995.
- Jivanjee P, Schutte K, Robinson A. *Families as Evaluators: Annotated Bibliography of Resources in Print*. Portland, OR: Portland State University Research and Training Center on Family Support and Children's Mental Health; 2004.
- Turnbull AP, Friesen BJ, Ramirez C. *Participatory action research as a model for conducting family research*. JASH. 1998;23(3):178-188.
- Vander Stoep A, Williams M, Jones R, Green L, Trupin E. *Families as full research partners: What's in it for us?* J Behav Health Serv Res. 1999;26(3):329-344.
- Webster PD, Johnson BH. *Developing and Sustaining a Patient and Family Advisory Council*. Bethesda, MD: Institute for Family-Centered Care; 2000.
- White G, Suchowierska M, Campbell M. *Developing and systematically implementing participatory action research*. Arch Phys Med Rehabil. 2004;85(2):S3-S12.



## Patient & Family Involvement Beyond Clinic\*

There are countless ways that patients and families can participate in care. They can serve as advisors, help with orientation of staff, education, quality improvement and in making connections with others. Some are formal and ongoing, others are time-limited and informal. At other times, it may be important to seek patients' and families' input on one specific issue. All are necessary to ensure that health care is truly responsive to the needs, priorities, goals and values of people with CF and their families. Below is a list of some of the ways that patients and families can be involved in their CF care center. You can find more ideas and tools at [www.PortCF.org](http://www.PortCF.org) and [www.cff.org](http://www.cff.org).

### EDUCATION

- Have patients and families involved in planning, developing and/or revising educational materials.
- Involve patients and families in the development of center's Web site
- Ask patients and families to assist in translating patient information materials, e.g., into another language or making information understandable to others.
- Have families and patients involved in planning, developing and presenting at center's Family Education Day.

### QUALITY IMPROVEMENT

- Include patient and family in benchmarking visits to other programs. Get their idea of what can be improved at your care center.
- Develop, with patients and families, a consumer satisfaction survey and involve them in developing the responses to issues and problems identified; i.e., start with the satisfaction survey in "Assess Your CF Center" (pg. 9).
- Keep suggestion forms in waiting rooms, so patients and families can record their ideas. Allow opportunity for suggestions to be submitted anonymously either in the clinic or by mail if desired.

### ORIENTATION

- Invite patients or families to present at staff orientation and inservice programs. Topics such as:
  - Care needs of the patient/family
  - Infection control
  - Discuss snacks and nutritional needs inpatient and outpatient
- Ask patients or families to host a dinner for a professional-in-training.
  - New residents, fellows, medical students
  - New nurses, therapists, social workers—both inpatient and outpatient
- Have patient or families orient new families to care center—e.g., moved to the center or transitioned from pediatric to adult or newly diagnosed.

### MAKING CONNECTIONS

- Develop a newsletter about care center happenings – written and produced by patients/families.
- Hold a monthly/regular family/staff coffee hour.
- Create peer mentor or family liaison positions, e.g., for newly diagnosed, first hospitalization.
- Create regular opportunities (e.g., monthly meetings, coffee hours) for patients and families to talk with department heads or the senior management team.
- Ask patients and families to join the health care providers when they meet with local, state or federal government representatives, funders or other community groups.
- Conduct follow-up phone calls with patients and families after hospital discharge or, as consented, have a patient or family member call the person who was discharged (or their family) as a mentor post-hospitalization.
- Set up "exit interviews" with administrators when patients and families are leaving the hospital or transferring to another clinic.
- Organize support groups or e-mail pen-pals for patients

### ADVISORY COUNCIL

- Create an advisory council with patients and families to provide input and direction to clinic work, e.g., QI activities, educational materials, support network.
- Have a patient/family task force that reviews suggestions or is a contact for others for suggestions/issues/comments. This task force works closely with the professional care providers to make change happen.
- Appoint patients and families to task forces and work groups related to clinic flow, quality improvement, infection control processes, renovations when occurring, admitting procedures, discharge planning, patient safety, pain management and other continuous quality improvement endeavors.
- Convene focus groups of patients and families as specific issues arise. Have the task group members serve for a specific amount of time.

\*Adapted from Jeppson, E. & Thomas, J. (1994). *Essential Allies: Families as Advisors*. Institute for Family-Centered Care; 1994, Bethesda, MD. Revised 2005.

Additional resources available through the CF Foundation ([www.cff.org](http://www.cff.org)) or the Institute for Family-Centered Care ([www.familycenteredcare.org](http://www.familycenteredcare.org)):

Webster, P. D., & Johnson, B. H. (2000). *Developing and Sustaining a Patient and Family Advisory Council*;  
Blaylock, B. L., Ahmann, E., & Johnson, B. H. (2002). *Creating Patient and Family Faculty Programs*.

## CASE STUDY

# Improving Patient and Family Involvement in the CF Care Center at Arkansas Children's Hospital Through Development of a Family Advisory Board



Mary Jo Chambers, MSW, LCSW [ChambersMJ@archchildrens.org](mailto:ChambersMJ@archchildrens.org); Lauren Willis, RRT-NPS [willislaurenm@uams.edu](mailto:willislaurenm@uams.edu); Fran Vaught, RNP; Holly Hink, APN; Pam Laramie, RN, Dennis Schellhase, MD, *Arkansas Children's Hospital and University of Arkansas for Medical Sciences College of Medicine Department of Pediatrics, Little Rock, Arkansas, USA*

### INTRODUCTION

The CF care center at Arkansas Children's Hospital established a multidisciplinary CF Leadership Team in July 2005 to improve CF care in the areas of patient care, education, research, QI initiatives, patient and family support and advocacy. Family perceptions of care and quality are an important aspect of this objective. Our current level of family involvement has been intermittent receiving input only as requested through various surveys, questionnaires, and parent attendance at annual Parent Resource events. The ideas of transparency of CF center data and partnership with families were presented during the annual Parent Resource day held in Sept. 2005. The CF team set a goal to establish a Family Advisory Board (FAB) to assist with design and implementation of pilot projects, educational material, family support services and active participation within the CF center as a whole.

### METHOD/STRATEGY

The CF team identified 70 dependable family members, representing half of our center's total patient population. The selected group was mailed a letter of invitation, a job description outlining responsibilities of a FAB member, and an application. Candidate applications were reviewed by members of the CF team. Twelve members and four alternates were selected as the first FAB ensuring broad representation of a variety of patient ages, geographical locations from within the state, and CF center physicians. The four alternates are spouses of FAB members.

The currently identified major goals of our CF center's FAB are:

- To offer ideas and suggestions regarding policy and practice affecting family-centered care.
- To review recommendations and concerns as referred by other parents, staff, physicians and/or administration.
- To serve in an educational role, as needed or requested, regarding patient/family perception of care and services.
- To assist in the planning and implementation of new services/processes as requested by CF center staff.

### CONCLUSION

Our CF center is committed to family-centered care and wants to ensure the needs of our patients and their families are considered and met. The purpose of our FAB is currently to serve as an advisory resource committee to the CF care center providing constructive input and assistance as the CF center seeks to continually improve. The initial meeting was held March 25, 2006 to introduce the selected members to each other, complete a hospital orientation, and to establish the policy for the FAB. The next step will be incorporating the FAB in our CF center's QI activities and developing a working relationship between the FAB and the current CF team.

# GLOSSARY

**Action plan:** Detailed “next steps” and “to do” with clearly identified and accountable people and time line

**Agenda:** Plan for meeting with roles, timed segments and clear objectives

**Aim (Global):** Goal of improvement with clear boundaries, reasons to improve and projected results

**Aim (Specific):** Detailed measurable goal with specific dates and specific measures

**Balanced set of metrics:** Set of measures that include data from a variety of perspectives.

**Benchmarking:** Search for best practices that consistently produce best-in-the-world results. A systematic process of continuously measuring an organization’s critical business processes and results against leaders anywhere in the world to gain information that will help the organization take action to improve its performance. Steps include planning the study, collecting information, analyzing results and implementing improvements.

**Change Concepts:** Family of change ideas

**Change ideas:** Specific action ideas to list in a process that result in a change

**Clinical microsystem:** The place where patients, families and care teams meet. A small group of people who work together on a regular basis to provide care to discrete subpopulations of patients. Frontline clinical units including patients, families, professionals, data and information with common purpose with shared business and clinical aims. It produces performance outcomes.

**Contributing units:** Multiple clinical units a patient travels through for an episode of care

**Control chart:** Graphic format for displaying information that show data points in the order in which they occurred with statistically calculated upper and lower natural process limits

**Core and supporting processes:** Core processes are the routine activities that are essential to functioning within a system of care. Supporting processes intermittently provide care and services to support the process of care

**Cycle time tool:** Study to measure time intervals during a visit to identify waits, delays and waste

**Data owner:** Accountable person to oversee specific data collection and display

**Data wall:** Designated space to display measures and improvement progress over time. Utilized daily and weekly to review current values and target values to assess progress toward aims. Based on the structure or anatomy of a clinical microsystem, Purpose, Patients, Professional, Processes and Patterns.

**Facilitator:** Person with training, skill and expertise in both clinical improvement and group process

**Flow chart:** Graphic representation of a process using symbols and arrows

**Hold the gains:** System improvement over time and assurance that new habits are embedded in daily practice

**Huddle:** Short meeting, no longer than 10 minutes, of a clinical team to review clinical care, anticipate needs and review any improvement progress

**Metrics that matter:** Key measures specific to diagnostic group or system of care. Can include organizational goals, professional standards and national benchmarks, e.g. CF outcome measures of BMI, FEV<sub>1</sub>

**Owner:** Person with the responsibility and authority to lead the improvement of a process. Also, the person with responsibility for a given process

**Pilot test:** Small scale test of a proposed solution

**Patterns:** Repeating predictable cycles and behaviors which can be observed and articulated, e.g. meeting frequency, social activities, financial performance

**PDSA (Plan-Do-Study-Act cycle):** Schema for continuous quality improvement originally developed by Walter Andrew Shewhart and made popular by W. Edwards Deming, who ascribed inherent variation in processes to chance and intermittent variation to assignable causes. The PDSA cycle is a four-part method for discovering and correcting assignable causes to improve the quality of processes

**Playbook:** Collection of process maps to standardize care and processes that all staff are aware of and accountable for

**Point of service:** Exact real time of interacting with patients to deliver care or services

**Process maps:** Chronological graphical displays of steps in a process. Different types of process maps include flowcharts, deployment charts and value stream mapping

**Processes:** Any activity that is a series of steps with a beginning and end resulting in products or outcomes

**Professionals:** Members of the frontline team including administrative staff, lead MDs, nurses, therapists, social workers, dietitians, etc.

**Purpose:** Common aim and reason to come together to strive and be accountable for achieving

**Redesign:** Methodical process of opening insight into current states, exploring best knowledge practices, systems and creating a new process

**Rework:** Work to redo or correct what was not done right the first time

**SDSA (Standardize-Do-Study-Act):** Steps taken when one or more PDSA cycles have been successfully done to determine that original aim is reached. Purpose is to hold the gains that were made using PDSA cycles and standardize process in daily work

**Storyboards:** Visual display used to document and communicate a team’s improvement journey. Includes aims, PDSAs, team members, measured outcomes and next steps

**Supplier:** Person, business or other entity (such as another department, individual or unit) responsible for an input to a process

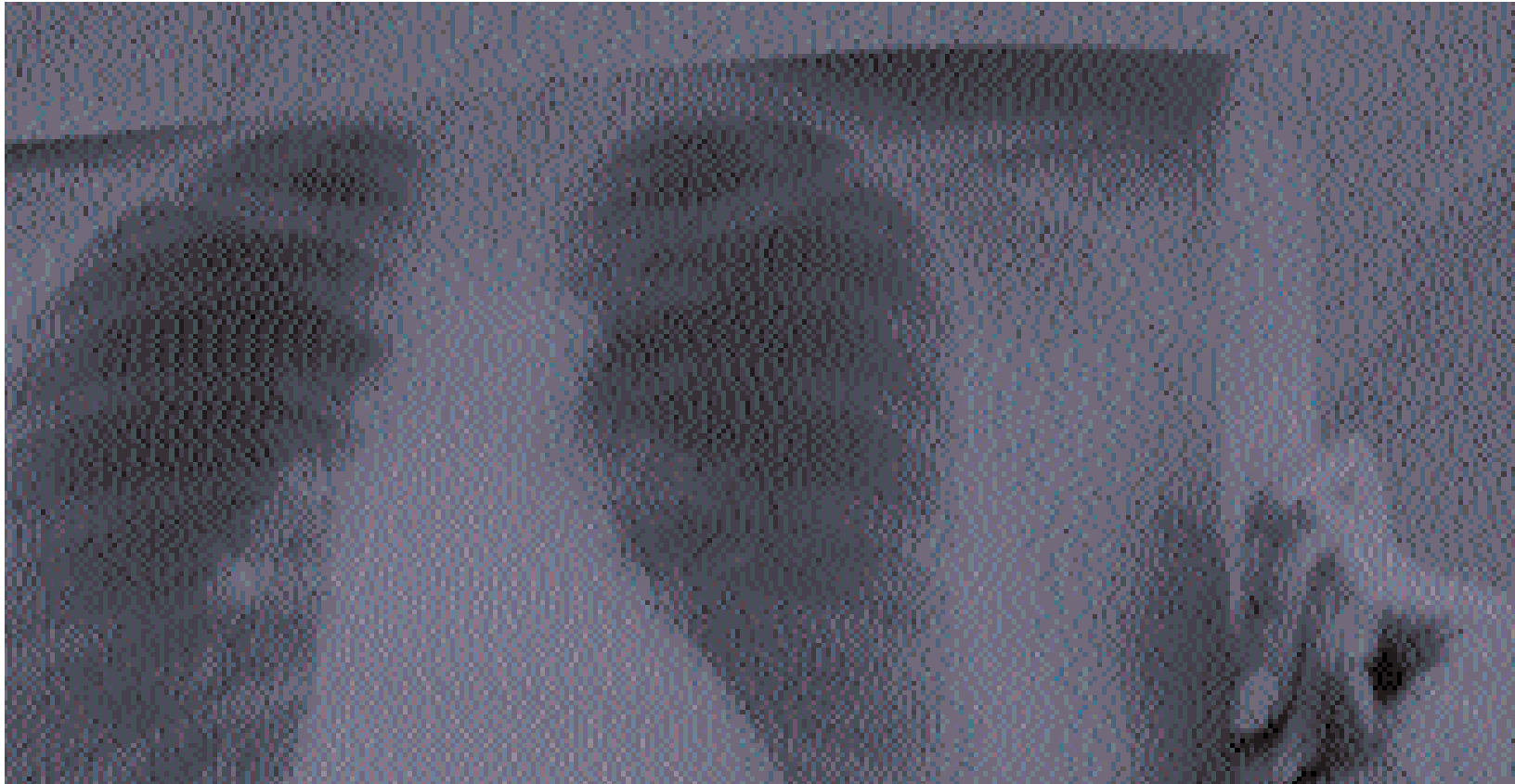
**Tests of change:** See PDSA

**Time trend charts:** Chronological data over time, also known as a run chart

# NOTES



# NOTES



[www.cff.org](http://www.cff.org)



[www.clinicalmicrosystem.org](http://www.clinicalmicrosystem.org)

