2ND EDITION
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 HEALTH CARE EXCELLENCE

The place where
patients, families, and
care teams meet

An instructional video to guide you through this

***2nd Edition Action Guide for Accelerating Improvement
in Cystic Fibrosis Care –***
can be found at
PortCF.outcome.com and clinicalmicrosystem.org.

This video provides a high-level roadmap of the improvement process
along with step-by-step instructions and details for this Action Guide.

All forms, examples, and electronic improvement learning modules
are available electronically at
PortCF.outcome.com and clinicalmicrosystem.org.

To access the electronic improvement learning modules,
click canvas.instructure.com/enroll/73YP3C.

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Aim: The aim of this 2nd Edition Action Guide for Accelerating Improvement in Cystic Fibrosis Care is to provide an overview including processes, tools, and materials of a field-tested improvement process based on The Dartmouth Institute Microsystem Academy improvement curriculum. This Action Guide can benefit individuals or CF improvement teams in starting and following a disciplined improvement process to achieve desired improvements in process and clinical outcomes.

* "Assess, Diagnose, and Treat" form the structure for improvement.

NOTE: We have developed this Action Guide with tools to give ideas to those interested in improving health care. The Dartmouth Institute Microsystem Academy and the developers of this Action Guide are pleased to grant use of these materials without charge, provided recognition is given for their development, and that use is limited to an individual's own use and not for resale.

ACCELERATING THE RATE OF IMPROVEMENT IN CF CARE

THE CYSTIC FIBROSIS FOUNDATION

"Adding Tomorrows and Living Today"

The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with the disease the opportunity to lead full, productive lives by funding research and drug development, promoting individualized treatment, and ensuring access to high-quality, specialized care.

Ten years (2002 to 2012) of accelerating the rate of improvement in CF care was showcased in the special *British Medical Journal* supplement that highlighted the significant improvements that have been made to improve care for people with CF (qualitysafety.bmj.com/content/23/Suppl_1.toc). Stevens and Marshall acknowledged multiple contributions to the increase of median predicted survival age from 31.3 years to 41.1 years. Contributions include the advent and use of the CF Patient Registry, benchmarking efforts to study and adapt best CF care practices, partnerships with people with CF and their families, and all care providers increasing their own improvement capabilities.

CYSTIC FIBROSIS PATIENT REGISTRY

The CF Foundation's *Patient Registry* illuminates the rates of variation of pulmonary function decline and the percentages of malnourished patients among our accredited care centers. Some variability is expected given the fact that care centers, like people with CF, are unique.

The identified variability in clinical outcomes represents an opportunity to engage in "**benchmarking**" of the best programs to consider how to adapt best program processes into one's own program. A crucial aspect of this transparency of data is the underlying philosophy that our data are for learning and promotion of best practices and not judgment.

The strategic plan to accelerate the rate of improvement in CF care is heavily influenced by the Seven Worthy Goals and the Institute of Medicine report, "Crossing the Quality Chasm: A New Health System for the 21st Century" (National Academy Press, 2001).

To help understand the multiple systems that contribute to improving care for people with CF, the "Transforming CF Through Partnerships" diagram (pg. 8) illustrates both opportunity and complexity in effecting change across all systems and with all people.

QUALITY IMPROVEMENT LEARNING AND LEADERSHIP COLLABORATIVE

The *Quality Improvement Learning and Leadership Collaboratives (QI LLCs)* have been able to cultivate improvement capabilities at the front line of CF care delivery, improve care for people with CF and their families, and improve the workplace for interdisciplinary staff in the programs. More than 90 percent of U.S. CF Centers have participated in an LLC. The LLCs have contributed to creating cultures of improvement at the front line where care for people with CF is provided and continuously improved. Specific actions include learning and developing new habits of a rhythm of improvement through regular meetings using effective meeting skills, increasing knowledge of each team member's contribution to the delivery of care, learning a standard improvement discipline, and intentionally including people with CF and their families in the improvement process.

Improvement measurement has been simplified to make it easy to know if change is an improvement demonstrated by measured results. The measured results support sharing and comparing process and clinical outcomes across the CF community to promote benchmarking and networking to advance improvement (pg. 40).

COMMUNICATION AND RELATIONSHIPS

Recognizing improvement is not only a technical activity but also a "lived experience" between people. New communication skills and enhancement of relationships throughout the program have improved the workplace and the care provided.

CREATE CONDITIONS FOR SUCCESSFUL IMPROVEMENT

Leaders help encourage successful improvement by creating the conditions that include providing protected time to learn and practice improvement and setting clear expectations of health care staff to provide and improve care. Leaders of CF programs offer and reinforce a clear vision and strategy of improvement goals and offer regular encouragement and reinforcement.

PARTNERSHIPS

Significant gains have been achieved through learning new strategies to partner with people with CF and their families. "Partnerships for Sustaining Daily Care" seeks to engage care teams, people with CF, and their families in a collaborative effort to develop treatment plans that align personal life goals with health goals (CFF.org/Care/Partnerships-for-Sustaining-Daily-Care). Partnerships include seeking new knowledge through the use of the Patient and Family Experience of Care survey (pg. 20), observing and shadowing episodes of CF care (pg. 21), and gaining deeper knowledge through people with CF and family member discussions (pg. 22).

All CF care is "coproduced" between people with CF, their families, and CF care providers. The degree and balance of contributions varies — sometimes the contributions are the "right balance" and other times the contributions are "imbalanced." Efforts to increase the contributions of people with CF and families while increasing the awareness of this new balance are underway in the CF improvement community. All LLC programs have and will continue to include people with CF and their families in dialogue and efforts to improve the "life plans" and delivery of care to meet their needs (pg. 8). Planning time to listen to and partner with people with CF, their families, and interdisciplinary care providers contributes to learning about how to best design and provide high-value care and services.

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 *Pseudomonas aeruginosa* and *Burkholderia 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 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

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CHRONIC CARE MODEL

Recognizing CF as a chronic disease, the *Chronic Care Model (CCM)* provides guidance to the improvement of care for people with CF and their families. The CCM is a widely adopted approach to improving ambulatory care and has guided clinical quality initiatives in the United States and around the world.
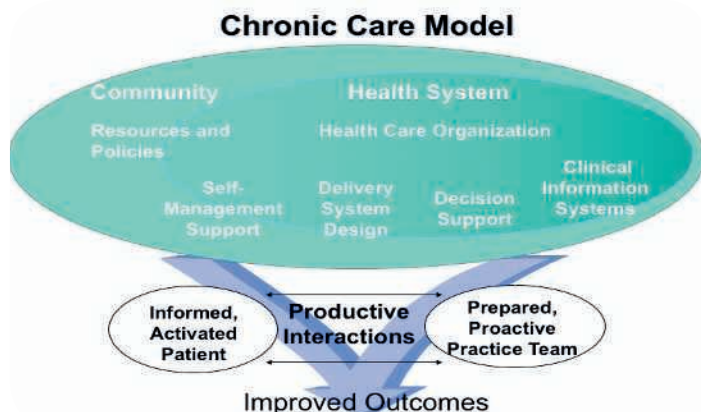
(Coleman K, Austin BT, Brach C, Wagner EH. Evidence on the chronic care model in the new millennium. *Health Affairs.* 2009;28(1):75-85. doi:10.1377/hlthaff.28.1.75)

Despite advances in the effectiveness of treatment, research shows that people with CF frequently do not get the care they want or need. The CCM is designed to help practices improve patient health outcomes by changing the routine delivery of care through six interrelated system changes meant to make patient-centered, evidence-based care easier to accomplish.

The aim of the CCM is to transform the daily care for patients with chronic illnesses from acute and reactive to proactive, planned, and population-based care. It is designed to accomplish these goals through a combination of effective team care and planned interactions, self-management support bolstered by more effective use of community resources, integrated decision support, patient registries, and other supportive information technology (IT). These elements are designed to work together to strengthen the provider-patient relationship and improve health outcomes.

STRATEGIC PLAN

CF leadership at all levels, people with CF and families, and an advisory group of CF colleagues and improvement experts from the Dartmouth Institute for Health Policy and Clinical Practice helped design the execution of the CF strategic plan for improving care for people with CF. The strategy is based on the Seven Worthy Goals and includes leadership, using the CF Patient Registry, decreasing variation in care delivery, and adapting consensus practice guidelines and best practices. People with CF and their families are critical members of improvement activities.

The CF Foundation continues to demonstrate its commitment to continuous improvement of CF care by providing quality improvement tools and processes to all CF care centers. Key resources such as this Action Guide, leadership development programs, and LLCs offer many sources to guide improvement at the front line of care. Programs such as the *CF Learning Network (CFLN)*, Port CF (PortCF.outcome.com), and electronic learning platforms provide reinforcement of improvement efforts to sustain and continue improvement gains.

LEADERSHIP

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.

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 perspectives of people with CF and their families must be incorporated into the work. This Action Guide provides some practical tools for accomplishing this work with a focus on partnership and co-creating care (pg. 8). A strong partnership among patients, families, and care providers is critical if we are to achieve optimal outcomes for CF.

Identifying and enabling "best practices": An important component of this strategy is the identification of care centers with *"best practices"* or *"Smart Change Ideas"* 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. 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.

Standardization: Best practices that are adapted to local contexts should be documented through *"playbooks"* or *Standard Operating Procedures (SOP)* to hold all staff accountable to the new best practice. Processes should be in place to review and ensure that the best practices are being carried out.

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 on the basis of expert interpretation of systematic, evidence-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.

Measurement: Transparent and real-time performance data need to be readily available for leaders and all members of CF programs to track performance and improvement teams to know if changes are, in fact, improvements. The use of the CF Registry PDSA cycles that include measurement and dashboards all contribute to visual reporting.

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 multifaceted 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.

HOLDING IMPROVEMENT GAINS

We cannot be complacent or lose focus on the gains made over a decade of improvement in CF care. Holding the gains and sustaining the improved process and clinical outcomes over time in an ever-changing health care environment continue to require constant attention and strategies.

Health care professionals change in CF centers and take their clinical expertise and improvement knowledge, skills, and experience with them. Ongoing efforts to "refresh" or "reinforce" improvement capabilities at the front line of care is resulting in new ideas and systems to support programs.

Nationally, the CF Foundation provides leadership, coordination, support, and encouragement through the CF Registry, professional mentor programs, listservs, and the *North American Cystic Fibrosis Conference (NACFC)* to encourage sharing and learning across the CF network.

The CF Foundation Clinical Practice Guidelines and Consensus Statements provide a framework for the care of people with CF. 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.

Electronic Improvement Modules

Electronic improvement modules have been developed to provide "as needed" access to improvement knowledge, tools, and processes to orient new CF Center staff, refresh current staff, and reinforce the CF improvement process. The electronic improvement modules that include a case study can be accessed at canvas.instructure.com/enroll/73YP3C.

All worksheets in this Action Guide can be found at PortCF.outcome.com and clinicalmicrosystem.org.

References

Batalden PB, Davidoff F. What is "quality improvement" and how can it transform healthcare? *Qual Saf Healthcare.* 2007;16(1):2-3.
Parand, A, et al. The role of hospital managers in quality and patient safety: a systematic review. *BMJ Open.* 2014;4:e005055. doi:10.1136/bmjopen-2014-005055

* Words that appear in **bold and italic** are defined in the glossary (pg. 66).

CYSTIC FIBROSIS CLINICAL MICROSYSTEMS AND MESOSYSTEM

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

ASSESSING, DIAGNOSING, AND TREATING YOUR PROGRAM'S CLINICAL MICROSYSTEM (PEDIATRIC OR ADULT) AND SUPPORTING MICROSYSTEMS (E.G., LABORATORY, GASTROENTEROLOGY)

AN OVERVIEW

People with CF have many interdisciplinary health professionals coming together with them and their families to create care and services. We call this place where people with CF, families, and care teams come together the *Cystic Fibrosis Clinical Mesosystem*.

CYSTIC FIBROSIS CLINICAL MESOSYSTEM
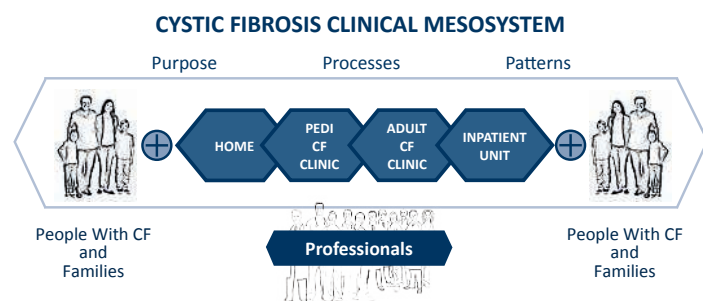
Your CF *clinical mesosystem* consists of individual *microsystems* as shown in the diagram. Collectively, these microsystems come together to provide care for people with CF. Your CF clinical microsystem has essential functions that must be assessed and improved to result in the best possible outcomes. Each person's quality of care depends on what happens within each microsystem and the "hand-offs" between microsystems. Microsystems 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 front-line units that provide day-to-day health care. The clinical microsystem 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 program, or an inpatient unit) are the building blocks that form the CF program system of care (mesosystem).

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

OVERVIEW OF MICROSYSTEMS APPROACH TO IMPROVE

A Path Forward

This Action Guide supports 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 mesosystem (program) and clinical microsystems (e.g., CF clinic).
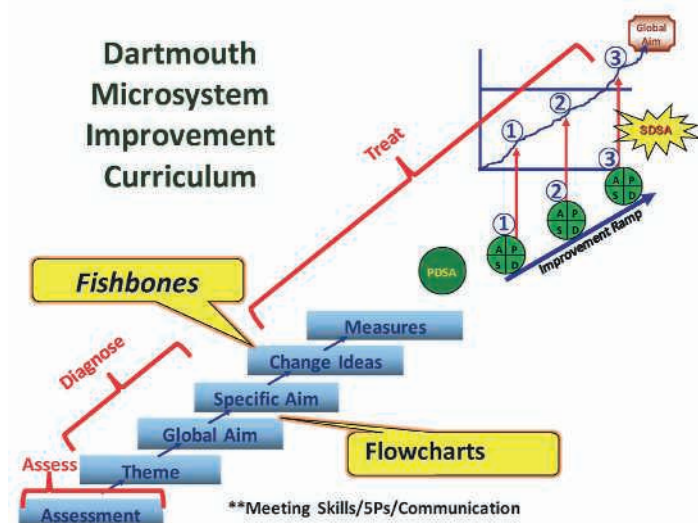
The steps in this Action Guide help you evaluate how your program functions and how it can be improved. This Action Guide's tools and forms are based upon the experiences and research of individuals and clinical teams including programs around the United States and the world. Although this is not the only way in which improvement can be achieved, it is a way that has been demonstrated to be effective in achieving higher quality and value care, enhanced workforce morale, satisfaction, and partnerships with people with CF and their families.

Colleagues around the U.S. have implemented this methodology. Seek them out to gain support and advice through the CF Foundation's Port CF website "Resource" section at PortCF.outcome.com.

All Action Guide forms and additional information, forms, tools, and examples are available at the Port CF website PortCF.outcome.com and the Dartmouth Institute Clinical Microsystem website 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 work—life experience can always be improved.

STEPS IN THE PATH

The following steps walk you through the process of evaluating and improving your program. After reviewing the steps, read the case study on pg. 9 to get a better sense of how a microsystem was able to make improvements.

▮ STEP 1: ORGANIZE A "LEAD IMPROVEMENT 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 Improvement Team"* of representatives of all roles from the microsystem should be formed. The patient travels across several clinical units; therefore, representatives from all contributing units in the microsystem are included in the Lead Improvement Team. For example, your Lead Improvement Team should include patients and family members, physicians, nurse coordinators, dietitians, physical/respiratory therapists, social workers, and clerical staff, as well as physicians, nurses, 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 PortCF.outcome.com along with other helpful tools and forms. (See sidebar, below).

⌘ Use effective meeting skills and timed *agendas* to ensure efficient and productive meetings.

⌘ Hold *"huddles"* before your CF clinic starts to review recent activities, and plan for the day and subsequent days in a proactive manner (pg. 45).

⌘ Hold weekly Lead Improvement Team meetings to maintain the *rhythm of improving* focus, make plans, and oversee improvement work.

⌘ Hold monthly "all-staff" 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 Improvement Team to communicate and keep all staff engaged in the improvement work. Develop strategies for communicating with patient and family advisors. Use email, newsletters, listservs, paper, visual displays, communication boards, and conversation.

⌘ Actively engage patients and families with the Lead Improvement Team. See pg. 59-62 and PortCF.outcome.com to learn more about engaging patients and families.

▮ STEP 2: DO THE ASSESSMENT

⌘ Review the contents of this Action Guide and create a timeline for the assessment process using the worksheet on pg. 16-17. Designate individuals who will have principal responsibility for each major section. This whole Action Guide can be completed at the pace that suits your setting. Some microsystems have the capacity and resources to move quickly through this Action Guide in a short period of time. Many microsystems need to pace themselves through this Action Guide 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 inform improvements.

⌘ Complete an assessment of your program/CF clinics and inpatient unit based on *Purpose, Patients, Professionals, Processes, Patterns (the 5Ps)*; and review the Registry data at PortCF.outcome.com and Metrics That Matter, on pg. 39-40. The worksheets in this Action Guide will guide you. The aim is to create the big picture of your program, CF clinics (pediatric or adult), or inpatient unit system to see beyond one person at a time. Assessing the "5Ps," using Registry data from PortCF.outcome.com, 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 Lead Improvement Team. Building common knowledge and insight into the microsystem by all members of the program, CF clinics, or inpatient unit will create a sense of equal value and ability to contribute to improvement activities.

Remember, however you choose to progress through this Action Guide, it should be done within the context of your Lead Improvement Team.

▮ STEP 3: MAKE A DIAGNOSIS

⌘ The Lead Improvement Team starts with analyzing the 5Ps assessment, Registry data from PortCF.outcome.com, and Metrics That Matter worksheets to identify a "theme" for improvement. A theme may be selected guided by the CF Foundation's Seven Worthy Goals and the Institute of Medicine's Six Aims (shown on pg. 4). Opportunities for improvement may come from within your own microsystem, your organization's strategic goals, or 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. 51-52) and *SDSA (standardize-do-study-act*; pg. 55) 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 Improvement Team meetings, monthly "all-staff" meetings, data walls, and storyboards. These reminders keep everyone focused on improvements and sustaining results (pg. 57).

Effective Meeting Skills

Using effective meeting skills provides a powerful tool to hold more productive, efficient, engaging, and fun meetings. *"A productive and effective meeting is one that is conducted in a disciplined manner, with active participation from all members resulting in clear action items, an evaluation of the meeting, an agenda for the next meeting and a sense among the members that their time was well spent."* (Quality By Design, pg. 245).

1. Clarify the aims of the meeting and what the team will get done during the meeting.
2. Review or assign the meeting roles: leader, recorder, timekeeper, and *facilitator*.
3. Review the agenda and determine how much time to spend on each item.
4. Work through the agenda items by discussing and reviewing data and information.
5. Review the meeting actions by reading through the record, making changes or additions, and deciding what to keep for the formal meeting record.
6. Plan the next actions and determine who will do what prior to the next meeting.
7. Evaluate the meeting; determine what went well and what could be improved in the future.

Additional information and resources including a meeting agenda template and meeting role explanations and cards are available at PortCF.outcome.com and clinicalmicrosystem.org.

Sample 1st Meeting Agenda

Organization Name: _____

– Agenda –

Department Name: _____
Day, Date: _____
Time of Meeting: _____
Meeting Location: _____

Aim of our microsystem:

Participants:

Time	Method	Item	Aim/Action
		1. Clarify Objectives	
		2. Review Roles: Leader: Recorder: Timekeeper: Facilitator:	Use meeting role cards to help function in the meeting roles
		3. Review Agenda and Times	Leader to move group through agenda. Time keeper track time for each agenda item. Recorder track action items
		4. Work Through Agenda Items	Track action steps for each item to be completed during action period (Use Action Plan)
		5. Review Meeting Record - Action Plan	Recorder reviews with group
		6. Plan Next Agenda	Leader helps group determine next agenda based on action plan and next steps in process
		7. Evaluate Meeting	Use 1-10 scale with 10 being the best meeting, comment on what went well and what could be improved for next meeting

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Meeting Roles and Process Cards

Leader

Prepares the agenda and helps move the team through the agenda by eliciting participation from all.

Facilitator

* Manage the group process and ensure balanced participation by all members of the group.
* Alert the group when the discussion is not focused on the agenda.

Recorder

Keeps the visual record for the team and tracks the "next steps/action" and parking lot lists.

Timekeeper

* Keeps the team on time through tracking time remaining for each agenda item and when necessary requesting the team to renegotiate time to complete discussions and actions.
* Announce halfway through the time.
* Give one-minute warning.
* Time is up.

7

PARTNERS IN CARE

Coproduction of Health Care Services

Drawing from the first of the Seven Worthy Goals, "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 respective of individual patient preferences, needs, and values."

The CF community strives to partner with people with CF and their families in all aspects of care delivery including continuous improvement.

The illustration below highlights the variety of ways that the CF community is partnering with people with CF, their families, and care teams to transform the delivery of CF care through community partnerships, research, and national policy.

Transforming CF Through Partnerships

Coproduction in CF care and services is a growing concept being adapted in front-line care delivery. Some of the tools and processes to support increasing knowledge and capability to partner with people with CF and their families are included in this Action Guide.

Coproduction of care has emerged as a helpful construct to ensure effective participation of people with CF, their families, and health care providers in the design and improvement of care. Care is already being "coproduced" between people with CF, families, and programs. The balance of contribution to the coproduction varies depending on individual perspectives, engagement, and expectations.

Coproduction of healthcare services (Batalden P, Margolis P, et al. *BMJ Qual Saf*. 2016;25(7):509-517. doi:10.1136/bmjqs-2015-004315) describes how "good outcomes are more likely to occur if the patient can and does seek and receive help in a timely way, if the clinician and patient communicate effectively, develop a shared understanding of the problem and a mutually acceptable evaluation and management plan."
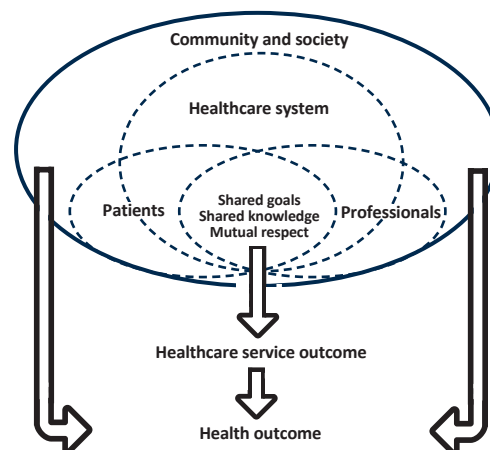
Source: Coproduction of healthcare services (Batalden P, Margolis P, et al. *BMJ Qual Saf*. 2016;25(7):509-517. doi:10.1136/bmjqs-2015-004315)

The coproduction diagram illustrates the *"systems within systems"* of care delivery starting at the inner circle of patient and professional interactions within a health care system that exists within the community and society. Critical to the patient and professional interaction is shared goals, shared knowledge, and mutual respect based on Jody Hoffer Gittell's relational coordination theory (rcrc.brandeis.edu).

⌘ Moving beyond patient satisfaction surveys to more robust Patient and Family Experience of Care Surveys (pg. 20) helps discover perspectives not considered before.

⌘ Observation and "shadowing" patients and families during the clinic visit or hospital episode of care can supplement traditional technical process knowledge of the care delivery (pg. 21).

⌘ Individual discussions with patients and family members can provide their perspectives of the care experience and uncover surprising aspects of the care experience to further inform improvement and *redesign* (pg. 22-23).

⌘ Creation of *"Patient experience maps"* can add to the collection of performance data to focus improvement on processes and steps that add value to the patient and family experience (pg. 24).

This territory will continue to evolve over the coming years. There is much to learn and consider as we strive to partner with people with CF and their families. (Review pg. 59-62 to learn about the Framework For Patient and Family Involvement in a CF Care Center.)

To help illustrate the path forward in accelerating improvement in CF care, this case study demonstrates the application of the Dartmouth Microsystem Improvement Curriculum.

The pages following the case study provide the worksheets and tools to help you develop your own improvement journey.

CASE STUDY: CF CARE PROGRAM
MEDICAL CENTER/MEDICAL CENTER HOSPITAL, ANYWHERE, U.S.A.

CONTEXT

Our program 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 three pulmonologists, two 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 or GI issues 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

Our center embarked on the journey of continuous improvement and joined the CF Foundation's Learning and Leadership Collaborative. We sent a Lead Improvement 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 patient fulfill his or her maximal potential by providing exemplary care."

The Lead Improvement 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 <u>nutrition health</u> of patients, focusing on patients 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
<div align="center">(Name the process)</div>

In our program
<div align="center">(Clinical location in which process is embedded)</div>

The process begins with identification of patients 2 to 20 years of age currently being seen in our program
<div align="center">(Name where the process begins)</div>

The process ends with implementation of new process for nutrition care
<div align="center">(Name where the process ends)</div>

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
<div align="center">(List benefits)</div>

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.
<div align="center">(List imperatives)</div>

Our specific aim in the short term was to capture current body mass index (BMI) percentile, enzyme dose, and number of visits on all of our patients aged 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 Improvement 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 Improvement Team assumed a different role in the meeting to review what was taught in the collaborative, and share the center's data and the global and specific aims. We also met with **senior leaders** (e.g., department chairs, section chiefs, and vice-presidents) to share our work and aim. Another key set of stakeholders we engaged early in the efforts was 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). 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.

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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 full-time equivalents (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 processes and patterns on the basis of 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 dosage, by whom 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 1

⌘ Introduce a new algorithm for nutrition screening to decrease variance.

PDSA Cycle 2

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

PDSA Cycle 3

⌘ Review development and use of algorithm and *checklist* with providers.

PDSA Cycle 4

⌘ Provide educational materials for families about nutrition care.

PDSA Ramp of Tests

#4

Increase median BMI percentile

Study / Do / Act / Plan

Provide educational materials for families about nutrition care.

#3

Study / Act / Do / Plan

Review development and use of algorithm and checklist with providers.

#2

Act / Study / Plan / Do

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

#1

Act / Plan / Study / Do

Introduce a new algorithm for nutrition screening to decrease variance.

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 results on our data wall for all staff to review.

⌘ Number of patients currently below the 50th BMI percentile

⌘ Number of patients not taking appropriate dosage of enzymes

⌘ The percentage of patients per clinic with charted BMI percentiles

⌘ The percentage of patients using nutritional supplements, oral and/or tubes

⌘ Changes in BMI percentiles 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.

EXAMPLE OF DESIGNING THE PDSA CYCLE STARTING WITH THE PLAN

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
Educate the staff on new algorithm for nutrition screening.	Lead RN Lead MD	Tuesday morning meeting	Measurement plan	Number of staff present at meeting / Total number of staff
Follow up with staff not able to attend meeting via email.	Lead RN	Tuesday afternoon	Measurement plan	Number of staff who received email / Number of staff not present at meeting
Create checklist of topics for dietitian to discuss with patient.	Lead Dietitian	Wednesday afternoon	Checklist (draft)	Completed checklist, reviewed by team
Share checklist to be reviewed by Lead Improvement Team.	Team	Thursday morning	Checklist (draft)	Agreement on checklist
Implement and audit new algorithm for nutrition screening.	Lead MD Dietitian	Tuesday afternoon	Tick and tally sheet for prior two weeks	Number of patients being assessed using the new algorithm for nutrition screening from dietitian/ Total number of patients aged 2-20 years seen in clinic each day

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?

Staff Attendance to Tuesday Meeting (N=10)

E-mail Follow-Up (N=3)

Patients Assessed With New Algorithm
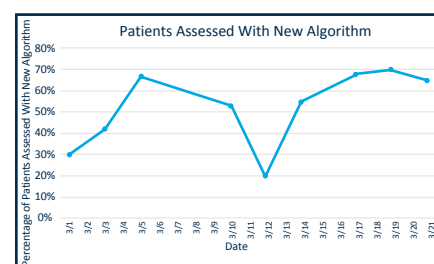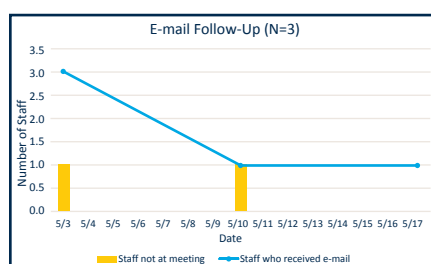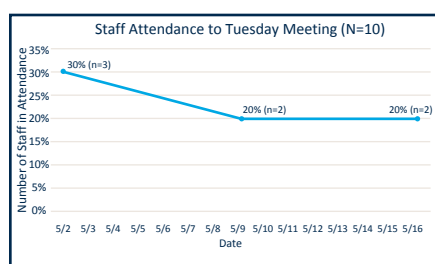
ACT > As we ACT to *hold the gains* or abandon our pilot efforts, what needs to be done? Will we modify the change? Make a PLAN for cycle of change #2.

STEP 1

FORM YOUR LEAD IMPROVEMENT TEAM

Which senior leaders will "sponsor" CF improvement?

	Pediatric Program	Adult Program
Hospital Administrator		
Division Chief		
Department Chair		
Site Contact		

⌘ **Check your type of program:** ☐ **Academic** ☐ **Private** ☐ **Pediatric** ☐ **Adult** ☐ **OneCF Center**

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

	Pediatric Program	Adult Program
MD		
Clinic Coordinator		
Social Worker		
Registered Nurse		
Dietitian		
Nursing/Medical Assistant		
Secretary		
Respiratory Therapist		
Physical Therapist		
Clinical Nurse Specialist		
Nurse Practitioner		
Patient/Family (1-2 Advisors)		
Other		

Who are the "as needed" members to be included?
Identify key contacts for each supporting unit such as gastroenterology, endocrinology, dietary, pharmacy, and radiology. These members will be included on the basis of 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, emails, and all-staff meetings.

_____

_____

PEOPLE WITH CF AND FAMILY TIP: Remember to invite people with CF and family members to be active on the Lead Improvement Team. Consider offering conference call lines, FaceTime, Skype, Zoom, and other communication methods to make it easy for all members of the improvement team to participate.

STEP 2

ASSESS YOUR PROGRAM: CREATE A HIGH-LEVEL PROFILE

Purpose

WHY DOES YOUR PROGRAM EXIST?

Raise this question with EVERYONE; include patients and families in your CF program to create the best statement of purpose everyone can relate to. This engages everyone in meaningful conversation that isn't achieved by just taking out a mission statement. What does this CF program mean to you? Use your purpose statement to guide decision making and improvement planning.

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 these 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.

PROGRAM PROFILE

Patient Demographics	Percent (%)
Birth - 5 years	
6 - 12 years	
13 - 17 years	
18 - 29 years	
>30 years	
% Females	

Health Outcomes	
FEV$_1$	
BMI %	
BMI	
CFRD Screen	

Mental Health Survey Scores	Total Patients Screened	Score Range
PHQ-9 Scores*		
GAD-7 Scores*		

*The PHQ-9 and GAD-7 detail can be found at phqscreeners.com.

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

List Your Top 5 Other Services Used	
Services	**What other services are used**

Out-of-Clinic Visits	
Emergency Department Visit Rate	
Direct Hospital Admissions	

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	

Patient and Family Experience of Care Scores	Composite Score

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

PEOPLE WITH CF AND FAMILY TIP: Engage people with CF and family members to help gather information and complete this form.

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Assessing the 5Ps of Your Program (Pediatric, Adult, or Specialty Clinics)

To begin to increase awareness of the systems and processes of care in the CF programs and to assess the unique features of any microsystem, use the 5P framework. The 5P framework can be thought of as a structured and organized method of discovering the anatomy of a program. Every complex system has a structure, process, patterns, and outcomes the members may or may not be aware of. This 5P flowchart maps the path forward to explore the 5Ps in an organized fashion.

Identification of data sources, including the CF Registry, Electronic Health Record Data Repository, and Manual Sampling helps to discover the inner workings of the CF clinic. If data cannot be identified from data sources, members of the microsystem can help collect data and information using the worksheets and processes within this Action Guide.

Assessing the 5Ps of Your CF Clinic

START HERE

Start assessing your CF clinic → Discuss your clinic's purpose → Complete Data Sources and Collection Worksheet → Review Data → Use data to inform understanding of your CF clinic

Complete Data Sources and Collection Worksheet → Define Measures → Are data already available?

Are data already available? — Yes → CF Registry, Electronic Health Record, Data Repository

Electronic Health Record → Consider including or identifying an IT representative to assist with data reporting

Are data already available? — No → Manual Sampling → Determine which tools/surveys to use → Create data collection plan (i.e., Ticks and Tallies) and collect data → Yes

Use data to inform understanding of your CF clinic → Begin to understand your patient population | Begin to assess the professionals in your CF clinic | Begin to review the current state processes in your CF clinic | Begin to review your CF clinic patterns

→ Are there additional data to be collected? — No → Review and modify the processes of your CF clinic with the data collected in the 5P assessment → Do additional data need to be collected to clearly depict your clinic? — No → Create and display a 5P assessment of your CF clinic

> Once the data are collected, take time with the Lead Improvement Team to review the data to see patterns, variation in practice, and connections between the Patients, Professionals, Processes, and Patterns to find improvement opportunities. Pages 64 and 65 list examples of discoveries and actions improvement teams have identified after completing the 5Ps assessment.

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Assessing Your Program/Clinic

⌘ With your Lead Improvement Team, review this form to determine which measures can be obtained from your organization and therefore the team won't need to use the sampling worksheets. Be sure the data are current and not months or years old.

⌘ Determine which worksheets will be used. Plan by whom, what data, where, and when the worksheets will be completed.

⌘ Decide who will oversee the completion of each worksheet or alternative data source.

⌘ Create your timeline to complete the data collection.

MICROSYSTEM ASSESSMENT OF DATA SOURCES AND DATA COLLECTION

Type of Data/Pages	Data Source/ Data Collection Action	Who	What Data	Where	When
Know Your Patients (see pg. 18-24)					
Estimated Age Distribution of Patients					
Health Outcomes					
Top 10 Diagnoses/Procedures					
Top 5 Services Used					
Emergency Department Visit Rate					
Patient Satisfaction Scores - Access					
Patient and Family Experience of Care (PFEC) Survey					
Patient Population Census - Overall					
Through the Eyes of the Patient					
Mental Health - PHQ-9 Survey					
Mental Health - GAD-7 Survey					
Know Your Professionals (see pg. 25-30)					
Current Staff					
Travelers					
On-Call Staff					
Float Pool					
Per Diems					
Supporting Departments					
Staff Satisfaction					
Personal Skills Assessment					
Activity Survey					
Know Your Processes (see pg. 31-36)					
Create Flow Charts of Routine Processes					
Patient Cycle Time Tool					
Core and Supporting Processes					
The "Hand-Offs"					
Know Your Patterns (see pg. 37-38)					
Unplanned Activity Tracking					
Most Significant Patterns					
Successful Change					
Most Proud of					
Financial Status					
Telephone Tracking Log					

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MICROSYSTEM ASSESSMENT OF DATA SOURCES AND DATA COLLECTION (continued)

Type of Data/Pages	Data Source/ Data Collection Action	Who	What Data	Where	When
Know Your Outcomes / Measures / Metrics That Matter (see pg. 39-40)					
1. FEV$_1$, Children Ages 6-12 Years					
2. FEV$_1$, Children Ages 13-17 Years					
3. FEV$_1$, Adults 18 Years and Older					
4. Median BMI Percentile, People With CF <24 Months					
5. Median BMI Percentile, People With CF 2-20 Years					
6. Median BMI, People With CF 21 Years and Older					
7. Median Weight-for-Length for People With CF <24 Months					
8. Median Weight for People With CF 2-19 Years					
9. Median Height for People With CF 2-19 Years					
10. Screening for CFRD (OGTTs)					
11. Annual Goals for Care (Four Visits, Two PFTs, Four Sputum Cultures)					

5P Wall Display

Source: Cooley Dickinson Health Care (used with permission)

PEOPLE WITH CF AND FAMILY TIP: People with CF and family members can discuss the CF program with staff and others using the new knowledge they have gained to have deeper insights into the CF program.

Patients

⌘ As described on pages 4, 5, and 8, people with CF and their families have valuable insight into the quality and process of care we provide. We can learn and begin to understand what patients and family member experience in their care.

⌘ Each program/CF clinic is unique and has varying amounts of resources and time to conduct surveys. Each program/CF clinic should review the surveys to determine which one(s) best match the current environment and provide the needed information the CF clinic is seeking. The surveys include:

• Satisfaction with access to the CF clinic by phone and through scheduling (pg. 18)

• Clinic viewpoint survey that assesses the overall program (pg. 19)

• Patient and Family Experience of Care survey aimed at reporting actual experience of care (pg. 20)

⌘ You can choose to measure patient feedback specific to "access to care"— including 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.

⌘ Conduct the patient/family satisfaction surveys for two 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 program.

ACCESS SURVEY

Think about this CF clinic visit.   Date _____

1. How would you rate your satisfaction or the patient's satisfaction with getting through to the CF clinic 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 clinic better for you or the patient?

_____

_____

_____

_____

_____

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PEOPLE WITH CF AND FAMILY TIP: People with CF and family members may be helpful in distributing and collecting some of these surveys. They are powerful allies in communicating the importance of completing the surveys to everyone to help guide improvements.

CLINIC PATIENT VIEWPOINT SURVEY*

Today's clinic visit.   Date _____

Here are some general questions about the visit you or the patient just made to this CF clinic. 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	☐	☐	☐	☐	☐
2. Convenience of the location of the CF clinic	☐	☐	☐	☐	☐
3. Getting through to the office by phone	☐	☐	☐	☐	☐
4. Length of time waiting at the office	☐	☐	☐	☐	☐
5. Time spent with the person in the clinic	☐	☐	☐	☐	☐
6. Explanation of what was done at the clinic	☐	☐	☐	☐	☐
7. The technical skills (thoroughness, carefulness, competence) of the person seen	☐	☐	☐	☐	☐
8. The personal manner (courtesy, respect, sensitivity, friendliness) of the person seen	☐	☐	☐	☐	☐
9. The clinician's sensitivity to special needs or concerns.	☐	☐	☐	☐	☐
10. The satisfaction with getting the help and information that you or the patient needed	☐	☐	☐	☐	☐
11. The quality of the visit overall	☐	☐	☐	☐	☐

General Questions

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

12. If you or the patient could go anywhere to get health care, would you choose this CF clinic or would you prefer to go someplace else?

☐ Would choose this CF clinic   ☐ Might prefer someplace else   ☐ Not sure

13. "I am delighted with everything about this CF clinic 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 department 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   ☐ Frequently

18. Is there anything our CF clinic 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 - 29 years   ☐ 30 years or older

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 _____

Email _____

See the Hospital CAHPS survey (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.

Moving From Satisfaction to Patient and Family Experience of Care

CF Patient and Family Experience of Care (PFEC) Survey

In 2012, the Cystic Fibrosis Foundation supported the development and validation of the **CF Patient and Family Experience of Care (PFEC) survey**. Learning about experience of care from the viewpoint of patients and families has been a growing trend in health care industry. Combining the PFEC survey findings with the CF Patient Registry measures, the experience of care measures could aid CF centers in planning improvement work – a worthy goal in which all people with CF receive quality care.

Between 2012 and 2014, the survey was deployed at programs having a **reaccreditation site visit** from the CF Foundation. In 2015, the survey was updated to reflect the new infection prevention and control guidelines and to change the data collection from a one-time event to a continuous data collection in which people with CF are asked twice a year to complete a survey (for those younger than 18 years of age, the parent or caregiver completes the survey).
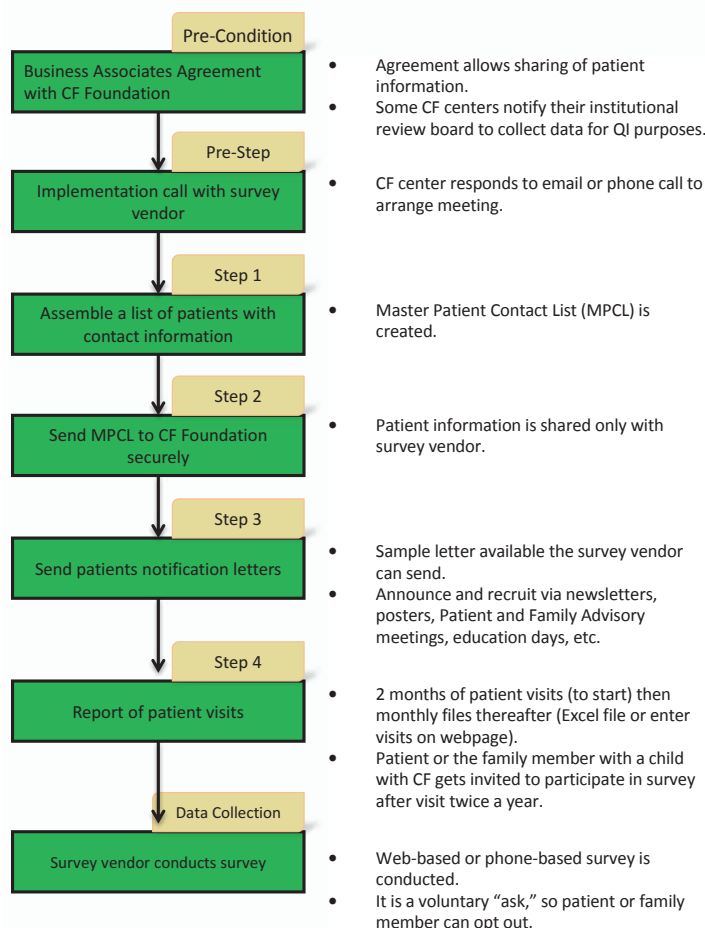
The PFEC survey contains questions about observations of care, **_not the level of satisfaction_**. A sample question from the observed experience of care specific to infection control follows: "Were you brought to the exam room as soon as you arrived for your appointment?" (Response choices are "Yes, definitely," "Yes, somewhat," and "No.") If the question were framed from a satisfaction perspective, the question could be worded as: "Were you satisfied with time you waited to see the first CF team member?" (Response choice ranges from "Very satisfied" to "Very unsatisfied.") Experience of care hinges on learning whether a need or clinical guideline was met or not and the satisfaction perspective learns about "happiness" in an aspect of care.

Reporting of the PFEC survey results occur in two ways. After 15 questionnaires have been received, the program can access their results via an electronic online reporting tool – Quality Desktop, which provides real-time access to their data anytime. The second reporting method is an emailed quarterly results report. Both reporting methods show results for the survey questions and a comparison of their result to other programs, and provides comments respondents shared in the open-ended questions' responses. From the survey result reports, a program can identify areas of care they excel in and areas of care that may need improvement.

A comparative data display of CF centers can show changes over time. The display compares one program to other programs to identify variation and possible benchmarking opportunities.

Please contact Karen Homa at homakaren@gmail.com for additional PFEC survey information.

Steps in Deploying the PFEC Survey

Pre-Condition
Business Associates Agreement with CF Foundation
- Agreement allows sharing of patient information.
- Some CF centers notify their institutional review board to collect data for QI purposes.

Pre-Step
Implementation call with survey vendor
- CF center responds to email or phone call to arrange meeting.

Step 1
Assemble a list of patients with contact information
- Master Patient Contact List (MPCL) is created.

Step 2
Send MPCL to CF Foundation securely
- Patient information is shared only with survey vendor.

Step 3
Send patients notification letters
- Sample letter available the survey vendor can send.
- Announce and recruit via newsletters, posters, Patient and Family Advisory meetings, education days, etc.

Step 4
Report of patient visits
- 2 months of patient visits (to start) then monthly files thereafter (Excel file or enter visits on webpage).
- Patient or the family member with a child with CF gets invited to participate in survey after visit twice a year.

Data Collection
Survey vendor conducts survey
- Web-based or phone-based survey is conducted.
- It is a voluntary "ask," so patient or family member can opt out.

Reference

Homa K, Sabadosa KA, Rogers WH, and Marshall BC. Development and validation of a cystic fibrosis patient and family member experience of care survey. *Qual Manag Health Care.* 2013;20(2):100-116.

The University of Iowa Hospitals and Clinics' Patient and Family Experience of Care Story

The University of Iowa Hospitals and Clinics (UIHC) has been collecting the CF Patient and Family Experience of Care survey (PFEC) since the national deployment began in 2015.

The PFEC survey includes an Infection Prevention and Control (IP&C) composite score consisting of four questions:

"Was a mask available?"
"Did the team wear gown and gloves?"
"Did the technicians wear gown and gloves?"
"Were you 6 feet from others with CF?"

Seventeen percent (58 respondents) selected "yes" to all four questions in the first six months of 2015.

UIHC formed an interdisciplinary improvement team of administrative staff, nurse educators, respiratory therapists, physicians specialized in infectious disease (ID) and pulmonary medicine (pediatric and adult), and a hospital infection preventionist who reviewed the IP&C guidelines to identify gaps in performance.

Improvement actions included:
⌘ Policies and protocols were modified to be in accordance with the CF IP&C guidelines.
⌘ New supplies and equipment were purchased to prevent the spread of pathogens between people with CF.
⌘ Educational sessions were held to update schedulers, front-desk clerks, medical assistants, nurses, respiratory therapists, physical therapists, and care providers who regularly come in contact with people with CF.

⌘ Families were provided information about the IP&C recommendations and policy changes through a letter from the CF center director, CF Foundation educational handouts, CF "passports," and infection control supplies for their personal use.

⌘ After education was completed, alerts were placed in the electronic medical record (EMR) of people with CF to clearly identify CF status upon arrival to the clinic or hospital, which resulted in early initiation of the ID prevention policies and protocol. The center officially activated the EMR alerts and new protocols on January 1, 2016.

Following these interventions, UIHC's IP&C composite score increased from 21 percent in 2015 (66 respondents) to 85 percent in March 2017 (65 respondents).

Variables	2015	2017
Composite score	21%	85%
Mask available	72%	98%
Team wore gown and gloves	27%	95%
Technicians wore gown and gloves	43%	87%
Six feet from others with CF	47%	58%

The UIHC story provides one example of how the PFEC survey findings can inform an interdisciplinary improvement team to develop a multifaceted approach with education and policy change to result in compliance improvements to meet the 2013 CF Foundation IP&C guidelines.

Special Acknowledgment: University of Iowa Hospitals and Clinics

PEOPLE WITH CF AND FAMILY TIP: Invite people with CF, family members, and staff to share stories of how the PFEC surveys impact the design and improvement of CF care.

Patients

One simple way to understand the patient and family experience of care is to *experience the care*. Members of your staff can assume the role of a patient in your 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, *"shadowing,"* and taking pictures or making an audiotape or videotape.

⌘ This activity can be adapted to any setting, including the inpatient care unit.

⌘ Consider resources to conduct this exercise, such as summer interns, students, or staff to name a few.

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 people with CF across several *contributing units*.

2. Two members of the staff could role-play with each playing a role: person with CF and partner/family member.

3. Set aside a reasonable amount of time to experience the person with CF's journey. Consider doing multiple experiences along the person with CF's 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. Consider difficult days and times of the week to shadow the person with CF's experience.

5. Make it real. Include time with registration, lab tests, new person with CF appointment, follow-up, minor procedures, prescriptions, and referrals. Sit where the person with CF sits. Wear what the person with CF wears. Experience the diagnostic and treatment process. Make a realistic paper trail including chart and lab reports.

6. 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 audiotape or videotape can be helpful.

7. Note the person with CF's and family's expressions and reactions along the care experience.

8. Debrief your staff on what you did and what you learned.

THROUGH THE EYES OF PATIENTS AND FAMILIES – "GO SHADOW" THEM!

Anthony M. Digiola, III, MD, and Eva Shapiro have developed a formal process to "Go Shadow" patients that we have adapted. The shadow experience is intended to inform *"co-design"* and "coproduction" of care (goshadow.org).

"You never really understand a person until you consider things from their point of view ... until you climb inside of their skin and walk around in it." ~Atticus Finch

People with CF and family shadowing is a process that can help all caregivers see any experience of care from the person's and family's points of view.

People with CF and family shadowing is the direct, real-time observation of people with CF as they move through each step of an episode of care. Through shadowing, you will see what care providers do and how people with CF and family members view these interactions. You may feel a renewed sense of empathy and help those interested in improvement and redesign of care move past "technical" improvement to actual lived experiences.

Shadowing should be done repeatedly over time — not just once. The care experience is dynamic and constantly changing.

"Go Shadow" – 6 Steps

1. Define the care experience to be shadowed.

2. Select someone to shadow people with CF and their families.

3. Gather information about the experience to observe.

4. Connect and coordinate with people with CF and their families.

5. Observe and record the experience through their eyes.

6. Share findings.

Date: _____   Shadowing Begins When: _____   Ends When: _____

Staff Members: _____

PEOPLE WITH CF AND FAMILY EXPERIENCES

Positives	Negatives	Surprises	Frustrating/Confusing	Expression/Reaction

PEOPLE WITH CF AND FAMILY TIP: Family members may wish to follow staff or follow other people with CF virtually to gain insights into the CF care process and provide valuable guidance for improvement.

Discussions
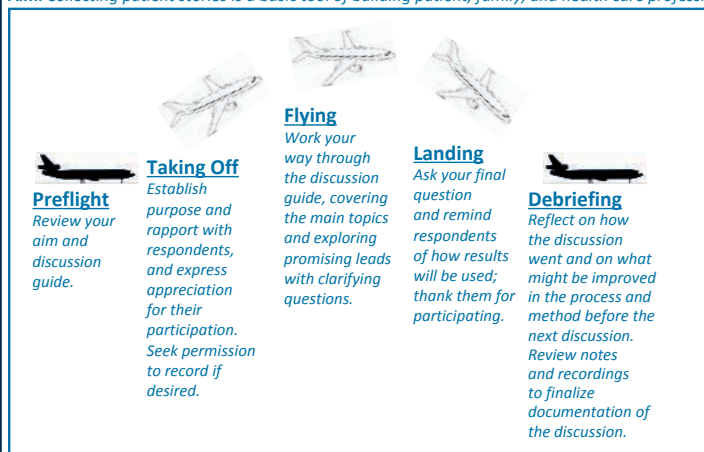
Discussion with people with CF and family members is another method to gain insights into their experiences of care. The collection of stories helps to build patient, family, and health care professionals' knowledge to inform improvement activities. The combination of observation and shadowing people with CF and families (pg. 21), the Patient Experience of Care survey (pg. 20), and the discussion process can provide deeper knowledge for more meaningful improvement and redesign of care.

One method to gain insights into the experience of care from the point of view of individuals with CF and family members is to talk and listen to them through a discussion. As a first step, create a discussion guide to ensure the discussion is efficient and consistent no matter who does the discussion. Identify who will hold the discussion with the person with CF or family member. A staff member, a student, a volunteer, or another family member could facilitate the discussion. Keep in mind people with CF and family members may be more comfortable discussing their care experiences with someone who is not a health care professional or a staff member of the CF center.

Because these discussions are guided conversations about the patient experience of care and intended for use to improve the quality of the experience and not for research (i.e., identifiable, recorded, aggregated or summarized, used for presentations or publications), approval or review by an institutional review board (IRB) is usually not required. If discussion data will be summarized and used beyond improvement of care delivery, seeking an exempt IRB review is recommended.

This is a helpful discussion guide to support gaining knowledge about the experience of care. This discussion guide was adapted from Chapter 2 of *Value by Design* (Nelson EC, Batalden PB, Godfrey MM, Lazar JS. *Value by Design*. San Francisco, CA: Jossey-Bass;2011).

Aim: *Collecting patient stories is a basic tool of building patient, family, and health care professionals' knowledge to result in improvements in health care. The discussion process is one method.*

Preflight
Review your aim and discussion guide.

Taking Off
Establish purpose and rapport with respondents, and express appreciation for their participation. Seek permission to record if desired.

Flying
Work your way through the discussion guide, covering the main topics and exploring promising leads with clarifying questions.

Landing
Ask your final question and remind respondents of how results will be used; thank them for participating.

Debriefing
Reflect on how the discussion went and on what might be improved in the process and method before the next discussion. Review notes and recordings to finalize documentation of the discussion.

Steps for Doing Discussions With People With CF and Their Family

1. Aim: Set the aim and frame the key question(s).
2. Who: Determine who will be included in the discussion and how they will be invited to participate.
3. Plan: Who will facilitate the discussion, in what setting, and with what tools and training? How will the results be recorded and analyzed?
4. Discussions: Conduct the discussion using a discussion guide.
5. Analysis: Analyze the content of the results to identify the response patterns that provide answers to your key questions.
6. Summarize: Reflect on your analysis and summarize the results. Consider doing this using major results that are linked to actual verbatim statements contained in the discussion notes.

Completed using a telephone, FaceTime, or Skype, or could be in person.

Tips
1. Use eye contact.
2. Use comfortable environment.
3. Consider audio/video taping
4. Follow clues: for instance, "high quality" — what would that look like? How would you describe quality?
5. Observe body language and facial expressions.

Notetaking Tips
1. Discuss notetaking.
2. Take notes regularly and promptly.
3. Try close-to-verbatim notetaking.
4. Don't let notetaking interfere with ability to listen and ask questions.
5. Ask permission to record.

Discussion # _____ : Facts

Today's Date: _____

Patient Name/Initials: _____

Family Member Name/Initials: _____

Microsystem Name: _____

Provider Name/Initials: _____

Permission Obtained: _____

Time Discussion Started: _____

Time Discussion Ended: _____

Aim of Discussion: _____

_____

_____

PEOPLE WITH CF AND FAMILY TIP: People with CF and family members can help develop the Discussion Guides. Take advantage of their expertise in the care process. Family members, volunteers, and students may also conduct discussions.

DISCUSSION GUIDE TEMPLATE

PREFLIGHT

• Hi my name is _____.
  I am part of the cystic fibrosis community and hoping to learn from you how we can improve care for people with CF and their families.

• We are talking with people with CF to learn about their experiences with CF care to get ideas and recommendations how we can improve care.

• Would you be willing to talk with me for 15-20 minutes to share your experiences and ideas? (If no, thank them for their time and leave.)

TAKING OFF

• Discussion Facts: Participation and Confidentiality

• Before we start, I'd like you to know your participation is completely voluntary. If you decide at any time you do not want to answer a particular question, we can skip it and move on. Also, if you decide that you would like to stop at any time, please let me know.

• Your answers will not impact your care in any way. I will share our discussion in GENERAL terms but not use any names or details that would identify you. This conversation is confidential.

• I will be taking notes as we talk.

  (Optional) I would like to record our discussion, if I have your permission, to ensure I accurately capture your thoughts and ideas.

• Do you have any questions? Are you willing to begin the discussion? (If no, thank you them for their time and leave.)

FLYING

• Do you remember when you or your child were first diagnosed with CF? How long ago was that and what was that like?

• What is it like living with CF? Tell us about the treatments. What is hard and easy? What helps make it easier? [**Probe:** How does CF affect home life, mental health, school, work, relationships, recreation/social life.]

  • What do you do yourself to help your CF?

  • When do you decide you need help from someone else? Who do you usually go to for help? [**Probe:** Executive director, CF clinic, family members, e.g., management exacerbation]

• Perceptions of care: To what extent do you feel like a real partner? [**Probe:** How do you prefer to partner? If you had a perfect partnership, what would it look like?]

• There are many different treatments and medicine to treat CF. Can you describe them for me? [**Probe:** Planning and Partnership]

  • Please describe your experiences with the treatments and medicines.

  • What, if anything, that makes it hard to do all this? [**Probe:** financial burden, difficulty using medical devices]

  • How do these medicines make you feel?

• We are interested in improving the way we care for people with CF. When you think about the care you get here, what is working well for you? What is not working or could be improved? What suggestions do you have? What would be helpful for you? **[Could use a flowchart to walk through]**

• Have you ever received care outside of this CF clinic? Where did you go and what was your experience like? [**Probe:** Was there something you were looking for here that we didn't provide? If so, what?]

LANDING

• Last question: write summative last question.
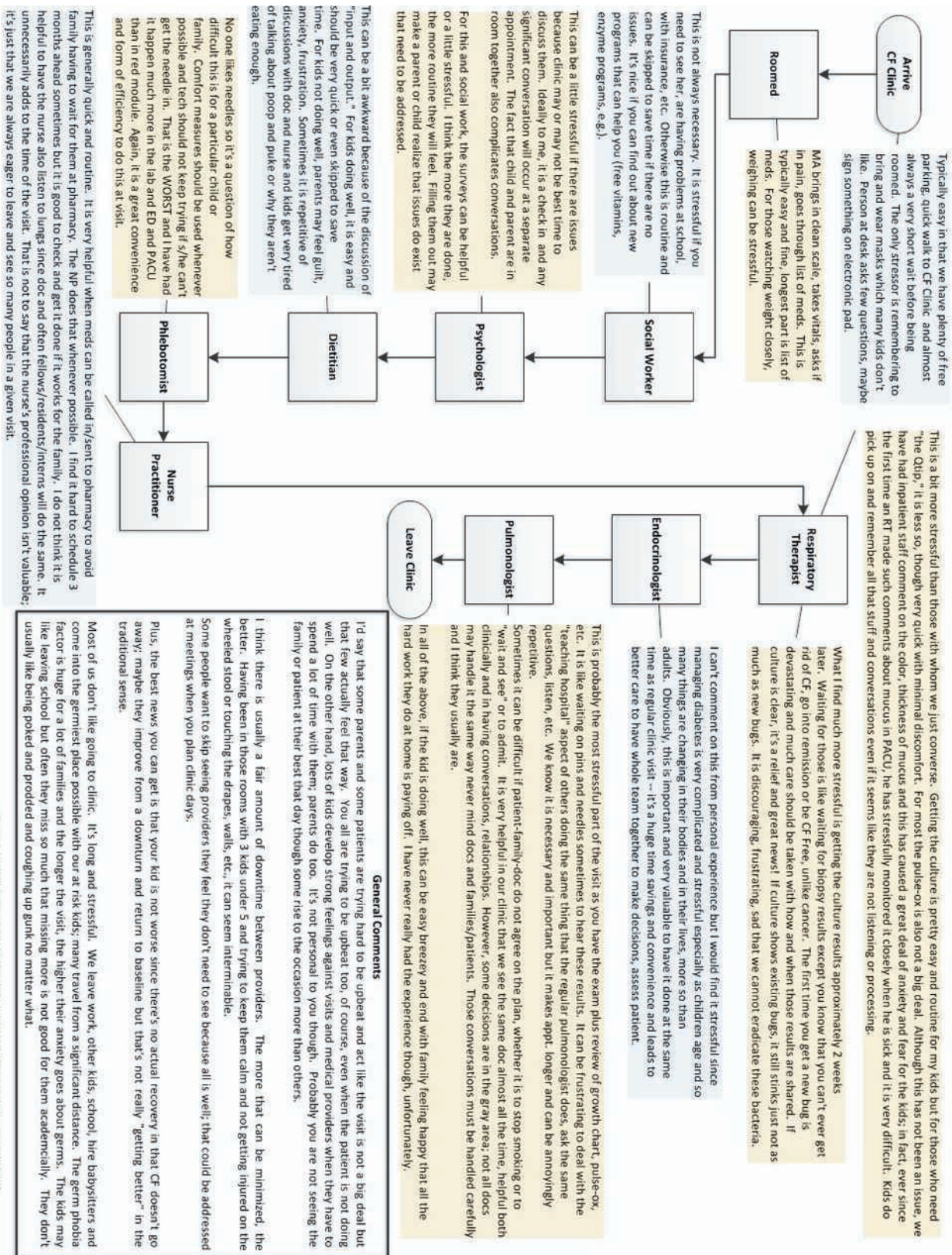 My last question is: _____

DEBRIEFING

• If taking notes: review notes and add to them to make as complete a record as possible.

• Consider what new is learned by the discussion.

• Consider refinements to discussion guide based on what is learned.

• Thank respondent and say goodbye.

People With CF and Family Experience of Care Map

Supplementing the "mechanical flow" of a CF visit with expressed perspectives from a discussion can help to identify value added steps in the process of care and where there are opportunities for improvement from a person with CF or family member perspective.

This is an example of a patient experience map showing how the "mechanical flow" is enhanced with the person with CF or family member discussion findings.

Arrive CF Clinic

Typically easy in that we have plenty of free parking, quick walk to CF Clinic and almost always a very short wait before being roomed. The only stressor is remembering to bring and wear masks which many kids don't like. Person at desk asks few questions, maybe sign something on electronic pad.

Roomed

MA brings in clean scale, takes vitals, asks if in pain, goes through list of meds. This is typically easy and fine, longest part is list of meds. For those watching weight closely, weighing can be stressful.

This is not always necessary. It is stressful if you need to see her, are having problems at school, with insurance, etc. Otherwise this is routine and can be skipped to save time if there are no issues. It's nice if you can find out about new programs that can help you (free vitamins, enzyme programs, e.g.)

Social Worker

This is a bit more stressful than those with whom we just converse. Getting the culture results is pretty easy and routine for my kids but for those who need "the Qtip," it is less so, though very quick with minimal discomfort. For most the pulse-ox is also not a big deal. Although this has not been an issue, we have had inpatient staff comment on the color, thickness of mucus and this has caused a great deal of anxiety and fear for the kids; in fact, ever since the first time an RT made such comments about mucus in PACU, he has stressfully monitored it closely when he is sick and it is very difficult. Kids do pick up on and remember all that stuff and conversations even if it seems like they are not listening or processing.

Psychologist

This can be a little stressful if there are issues because clinic may or may not be best time to discuss them. Ideally to me, it is a check in and any significant conversation will occur at a separate appointment. The fact that child and parent are in room together also complicates conversations.

Dietitian

For this and social work, the surveys can be helpful or a little stressful. I think the more they are done, the more routine they will feel. Filling them out may make a parent or child realize that issues do exist that need to be addressed.

Phlebotomist

This can be a bit awkward because of the discussion of "input and output." For kids doing well, it is easy and should be very quick or even skipped to save time. For kids not doing well, parents may feel guilt, anxiety, frustration. Sometimes it is repetitive of discussions with doc and nurse and kids get very tired of talking about poop and puke or why they aren't eating enough.

No one likes needles so it's a question of how difficult this is for a particular child or family. Comfort measures should be used whenever possible and tech should not keep trying if s/he can't get the needle in. That is the WORST and I have had it happen much more in the lab and ED and PACU than in red module. Again, it is a great convenience and form of efficiency to do this at visit.

Nurse Practitioner

This is generally quick and routine. It is very helpful when meds can be called in/sent to pharmacy to avoid family having to wait for them at pharmacy. The NP does that whenever possible. I find it hard to schedule 3 months ahead sometimes but it is good to check and get it done if it works for the family. I do not think it is helpful to have the nurse also listen to lungs since doc and often fellows/residents/interns will do the same. It unnecessarily adds to the time of the visit. That is not to say that the nurse's professional opinion isn't valuable; it's just that we are always eager to leave and see so many people in a given visit.

Respiratory Therapist

What I find much more stressful is getting the culture results approximately 2 weeks later. Waiting for those is like waiting for biopsy results except you know that you can't ever get rid of CF, go into remission or be CF Free, unlike cancer. The first time you get a new bug is devastating and much care should be taken with how and when those results are shared. If culture is clear, it's a relief and great news! If culture shows existing bugs, it still stinks just not as much as new bugs. It is discouraging, frustrating, sad that we cannot eradicate these bacteria.

Endocrinologist

I can't comment on this from personal experience but I would find it stressful since managing diabetes is very complicated and stressful especially as children age and so many things are changing in their bodies and in their lives, more so than adults. Obviously, this is important and very valuable to have it done at the same time as regular clinic visit — it's a huge time savings and convenience and leads to better care to have whole team together to make decisions, assess patient.

Pulmonologist

This is probably the most stressful part of the visit as you have the exam plus review of growth chart, pulse-ox, etc. It is like waiting on pins and needles sometimes to hear these results. It can be frustrating to deal with the "teaching hospital" aspect of others doing the same thing that the regular pulmonologist does, ask the same questions, listen, etc. We know it is necessary and important but it makes appt. longer and can be annoyingly repetitive.

Sometimes it can be difficult if patient-family-doc do not agree on the plan, whether it is to stop smoking or to "wait and see" or to admit. It is very helpful in our clinic that we see the same doc almost all the time, helpful both clinically and in having conversations, relationships. However, some decisions are in the gray area, not all docs may handle it the same way never mind docs and families/patients. Those conversations must be handled carefully and I think they usually are.

In all of the above, if the kid is doing well, this can be easy breezy and end with family feeling happy that all the hard work they do at home is paying off. I have never really had the experience though, unfortunately.

Leave Clinic

General Comments

I'd say that some parents and some patients are trying hard to be upbeat and act like the visit is not a big deal but that few actually feel that way. You all are trying to be upbeat too, of course, even when the patient is not doing well. On the other hand, lots of kids develop strong feelings against visits and medical providers when they have to spend a lot of time with them; parents do too. It's not personal to you though. Probably you are not seeing the family or patient at their best that day though some give rise to the occasion more than others.

I think there is usually a fair amount of downtime between providers. The more that can be minimized, the better. Having been in those rooms with 3 kids under 5 and trying to keep them calm and not getting injured on the wheeled stool or touching the drapes, walls, etc., it can seem interminable.

Some people want to skip seeing providers they feel they don't need to see because all is well; that could be addressed at meetings when you plan clinic days.

Plus, the best news you can get is that your kid is not worse since there's no actual recovery in that CF doesn't go away; maybe they improve from a downturn and return to baseline but that's not really "getting better" in the traditional sense.

Most of us don't like going to clinic. It's long and stressful. We leave work, other kids, school, hire babysitters and come into the germiest place possible with our at risk kids; many travel from a significant distance. The germ phobia factor is huge for a lot of families and the longer the visit, the higher their anxiety goes about germs. The kids may like leaving school but often they miss so much that missing more is not good for them academically. They don't usually like being poked and prodded and coughing up gunk no matter what.

Source: Alfred I. DuPont Children's Hospital Nemours (with permission)

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 are the professionals at the CF program?

Current Staff (Enter names below totals)	FTE	Program Days and Times					
		Mon	Tues	Wed	Thurs	Fri	Sat
MDs – Total							
NP/PAs – Total							
RNs – Total							
LPN/NA/MAs – Total							
Physical Therapists – Total							
Respiratory Therapists – Total							
RD/Nutritionists – Total							
Social Workers – Total							
Secretaries – Total							
Others – Total							

Do you use on-call staff? ☐ Yes ☐ No
Do you use a float pool? ☐ Yes ☐ No

STAFF SATISFACTION SCORES

How stressful is this program?
(% Very Stressful) _____

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

SUPPORTING MICROSYSTEMS

such as pulmonary, dietary, gastroenterology, and pharmacy.

_____

_____

_____

_____

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Professionals

⌘ Creating a joyful work environment starts with a basic understanding of staff perceptions of the clinic. 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 or years old, and that you are able to capture the data from all professionals specific to your CF center.

⌘ If you do not have a current organizational staff satisfaction survey, ask staff members to complete this survey. You will find a tally sheet at PortCF.outcome.com to summarize your results.

⌘ Often you can distribute this survey to any professional who spends time in your clinic. Set a deadline of 1-2 weeks and designate a place for the survey to be dropped off. An alternative is to use an electronic survey such as SurveyMonkey to invite staff to respond to the staff satisfaction questions.

⌘ It is important to emphasize that this survey is anonymous and is a voluntary activity.

STAFF SATISFACTION SURVEY

1. I am treated with respect every day by everyone that works in the program.

☐ 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 program notices that I did it.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

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

☐ 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 program is a better place to work than it was 12 months ago.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

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

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

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

_____

_____

_____

_____

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

_____

_____

_____

_____

Professionals

⌘ 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 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.

PROGRAM — PERSONAL SKILLS ASSESSMENT

Name _____   Clinic _____

Role _____   Date _____

Clinical Competencies: Please use your list of clinical competencies and evaluate which competencies you are learning	Want to Learn	Never Use	Occasionally	Frequently
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐

Clinical Information Systems (CIS*): What features and functions do you use?	Want to Learn	Never Use	Occasionally	Frequently
Provider/On-Call Schedule	☐	☐	☐	☐
Patient Demographics	☐	☐	☐	☐
Lab Results	☐	☐	☐	☐
Pathology	☐	☐	☐	☐
Patient and Family Goals and Action Plan	☐	☐	☐	☐
Review Reports/Notes	☐	☐	☐	☐
Documentation	☐	☐	☐	☐
Direct Entry	☐	☐	☐	☐
Note Templates	☐	☐	☐	☐
Medication Lists	☐	☐	☐	☐
Insurance Status	☐	☐	☐	☐
Durable Power of Attorney	☐	☐	☐	☐
Advance Directives	☐	☐	☐	☐
Radiology	☐	☐	☐	☐
OR Schedules	☐	☐	☐	☐

*NOTE: CIS refers to hospital, or clinic-based information systems used for such functions as checking patients in, 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.

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PROGRAM — PERSONAL SKILLS ASSESSMENT, CONTINUED

Name _____ **Clinic** _____

Technical Skills: Please rate the following on how often you use them.	Want to Learn	Never Use	Occasionally	Frequently
Clinical Information Systems (CIS)	☐	☐	☐	☐
Email	☐	☐	☐	☐
Digital Dictation Link	☐	☐	☐	☐
Word Processing (e.g., Word)	☐	☐	☐	☐
Spreadsheet (e.g., Excel)	☐	☐	☐	☐
Presentation (e.g., PowerPoint)	☐	☐	☐	☐
Database (e.g., Access or FileMaker Pro)	☐	☐	☐	☐
Patient Database/Statistics	☐	☐	☐	☐
Internet/Intranet	☐	☐	☐	☐
Registries	☐	☐	☐	☐
Printer Access	☐	☐	☐	☐
Fax	☐	☐	☐	☐
Copier	☐	☐	☐	☐
Voice Mail	☐	☐	☐	☐
Pagers	☐	☐	☐	☐
FaceTime, Skype, Zoom, and other video options	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐

Meeting and Interpersonal Skills: What skills do you currently use?	Want to Learn	Never Use	Occasionally	Frequently
Effective Meeting Skills	☐	☐	☐	☐
Timed Agenda	☐	☐	☐	☐
Role Assignment During Meetings	☐	☐	☐	☐
Brainstorm/Multi-voting	☐	☐	☐	☐
Decision Making	☐	☐	☐	☐
Delegation	☐	☐	☐	☐
Problem Solving	☐	☐	☐	☐
Open and Effective Communication	☐	☐	☐	☐
Feedback – Provide and Receive	☐	☐	☐	☐
Managing Conflict/Negotiation	☐	☐	☐	☐
Emotional/Spiritual Support	☐	☐	☐	☐

Improvement Skills and Knowledge: What improvement tools do you currently use?	Want to Learn	Never Use	Occasionally	Frequently
Surveys – Patient and Staff	☐	☐	☐	☐
Aim Statements	☐	☐	☐	☐
Flowcharts/Process Mapping	☐	☐	☐	☐
Fishbones	☐	☐	☐	☐
Measurement and Monitoring (Ticks and Tallies)	☐	☐	☐	☐
Plan-Do-Study-Act (PDSA) Improvement Model	☐	☐	☐	☐
Standardize-Do-Study-Act (SDSA) Improvement Model	☐	☐	☐	☐
Trend Charts (Run Charts)	☐	☐	☐	☐
Control Charts	☐	☐	☐	☐
Statistical Process Control (SPC)	☐	☐	☐	☐

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Professionals

⌘ 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 clinicalmicrosystem.org and PortCF.outcome.com.

ACTIVITY SURVEY SHEET EXAMPLES

Position: MD	% of Time
Activity: See patients in the program Specific items involved: • Review chart history • Assess/diagnose patient • 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 Specific items involved: • Dictate encounter/use scribe • Review transcriptions and sign off	20%
Activity: Complete forms Specific items involved: • Referrals • Prior authorizations	5%
Activity: Follow-up phone calls/emails Specific items involved:	5%
Activity: Manage charts	5%
Activity: Evaluate test results Specific items involved: • Review results and determine next actions	5%
Activity: See patients in outreach clinics	2%
Activity: Miscellaneous Specific items involved: • CME; attend seminars; attend meetings	2%
Total	100%

Position: RN	% of Time
Activity: Triage patient issues/concerns Specific items involved: • Phone • Face to face	15%
Activity: Patient/family education Specific items involved:	3%
Activity: Direct patient care Specific items involved: • See patients in the program • Assist provider with patients • Infusions	30%
Activity: Follow-up phone calls/emails Specific items involved:	22%
Activity: Review and notify patients of lab results Specific items involved: • Normal with follow-up • Drug adjustments	5%
Activity: Complete forms Specific items involved: • Referrals • Prior authorizations	18%
Activity: Call in prescriptions Specific items involved:	5%
Activity: Miscellaneous Specific items involved: • CME; attend seminars; attend meetings	2%
Total	100%

ACTIVITY OCCURRENCE SHEET AND 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 program 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 on the basis of demand. The blank activity occurrence sheet can be found on pg. 30.

Role:		Date:		Day of Week:	
Visit Activities	AM		PM		Total
Triage Patient Concerns					
Family/Patient Education					
Direct Patient Care					
Non-Visit Activities	AM		PM		
Follow-Up Phone Calls/Emails					
Complete Forms					
Call in Prescriptions					
Miscellaneous					
Total					

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Role: RN	Date: July 1	Day of Week: Monday	
Visit Activities	AM	PM	Total
Triage Patient Concerns	̶|̶|̶|̶|̶ ||	̶|̶|̶|̶|̶ ||	14
Family/Patient Education	̶|̶|̶|̶|̶				7
Direct Patient Care	̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶		̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶		42
Non-Visit Activities	AM	PM	
Follow-Up Phone Calls/Emails	̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶	̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶		26
Complete Forms	̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶		̶|̶|̶|̶|̶		17
Call in Prescriptions	̶|̶|̶|̶|̶		̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶	16
Miscellaneous	̶|̶|̶|̶|̶	̶|̶|̶|̶|̶ ̶|̶|̶|̶|̶	15
Total	**66**	**71**	**137**

Nursing Activities
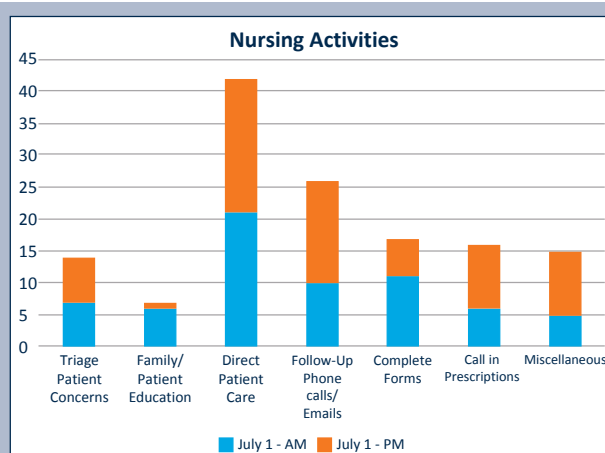
ACTIVITY SURVEY SHEET

The blank template below allows teams to customize the Activity Survey Sheet for the positions (e.g., MD, NP, RN, RD, RT, SW, and others) of members of your team and create activities that are relevant to that position. Using the template to customize the survey sheet provides the team with insight into each member's role and what they spend their time doing. This information will help when the team begins to plan for PDSA. The example above shows how data can be manually collected and displayed as a bar chart.

Position:	% of Time
Activity: Specific items involved: •	
Activity:	
Activity:	
Activity:	
Activity: Specific items involved: •	
Activity: Complete Forms Specific items involved: •	
Activity: Specific items involved: •	
Activity:	
Activity: Specific items involved: •	
Activity:	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity:	
Total	100%

Position:	% of Time
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity: Specific items involved: •	
Activity:	
Activity:	
Total	100%

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Processes

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
- ☐ Telemedicine
- ☐ Email
- ☐ Website
- ☐ RN clinics
- ☐ Conference calls with patients
- ☐ Smart phone apps

Appointment Types	Duration	Cycle Time (beginning to end of appointment)	Comments
Annual			
Quarterly			
Acute Visit			
Post-hospitalization			

IDENTIFY SUPPORTING MICROSYSTEMS
For example, pulmonary, dietary, gastroenterology, and pharmacy.

# of Exam Rooms	

_____

_____

_____

_____

_____

_____

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 Lead Improvement 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 PortCF.outcome.com for inpatient-specific flowcharts.

Suggested Processes to Flowchart

1. Overall appointment process
2. Overall CF care process
3. Specialty referral process
4. Inpatient process

Example of a High-Level Flowchart
Appointment Process

Person With CF and Family Arrive → Registration and Reception → Person w/CF and Family Write Goals for Clinic Visit → Nurse Gets the Person w/CF → Person w/CF Is Roomed → Multiple Clinician Visits → Person w/CF and Family Leave

Symbol Key

Process (beginning or end) — Process flow direction → Activity Step — Decision Point — Connector (e.g., off page) — Walls and Delays — Unknown
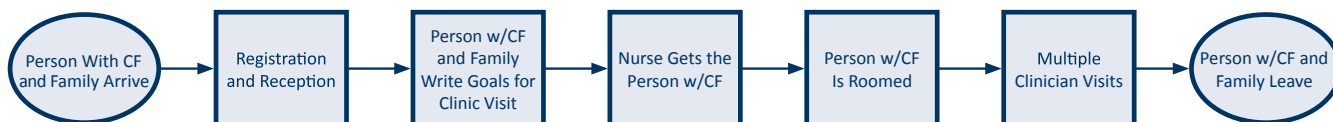
Pediatric CF Clinic Work Flow
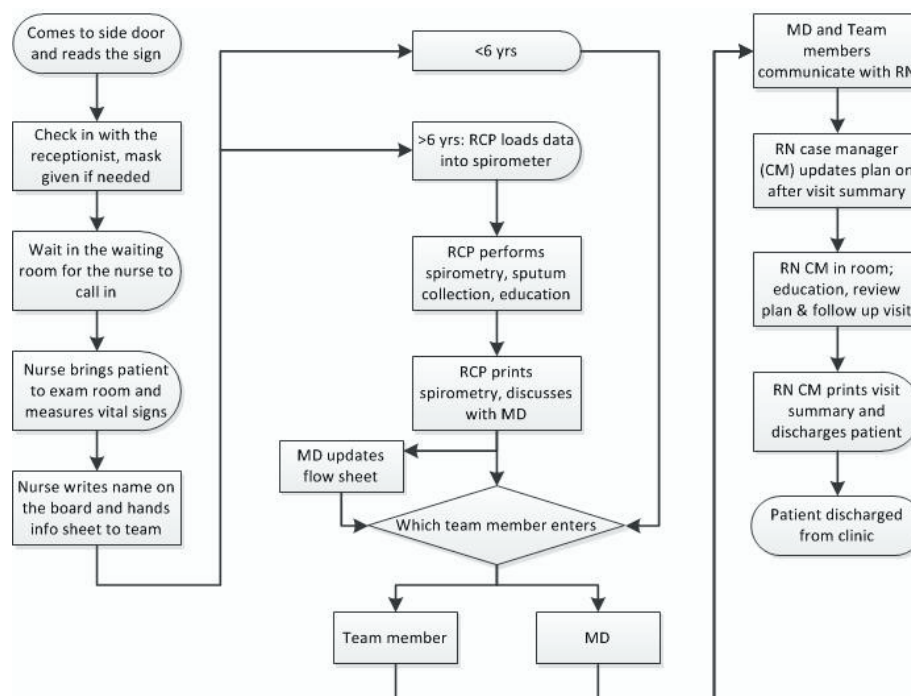
Source: Kaiser Permanente Southern California, Pediatric Program (used with permission)

Adult CF Clinic Work Flow
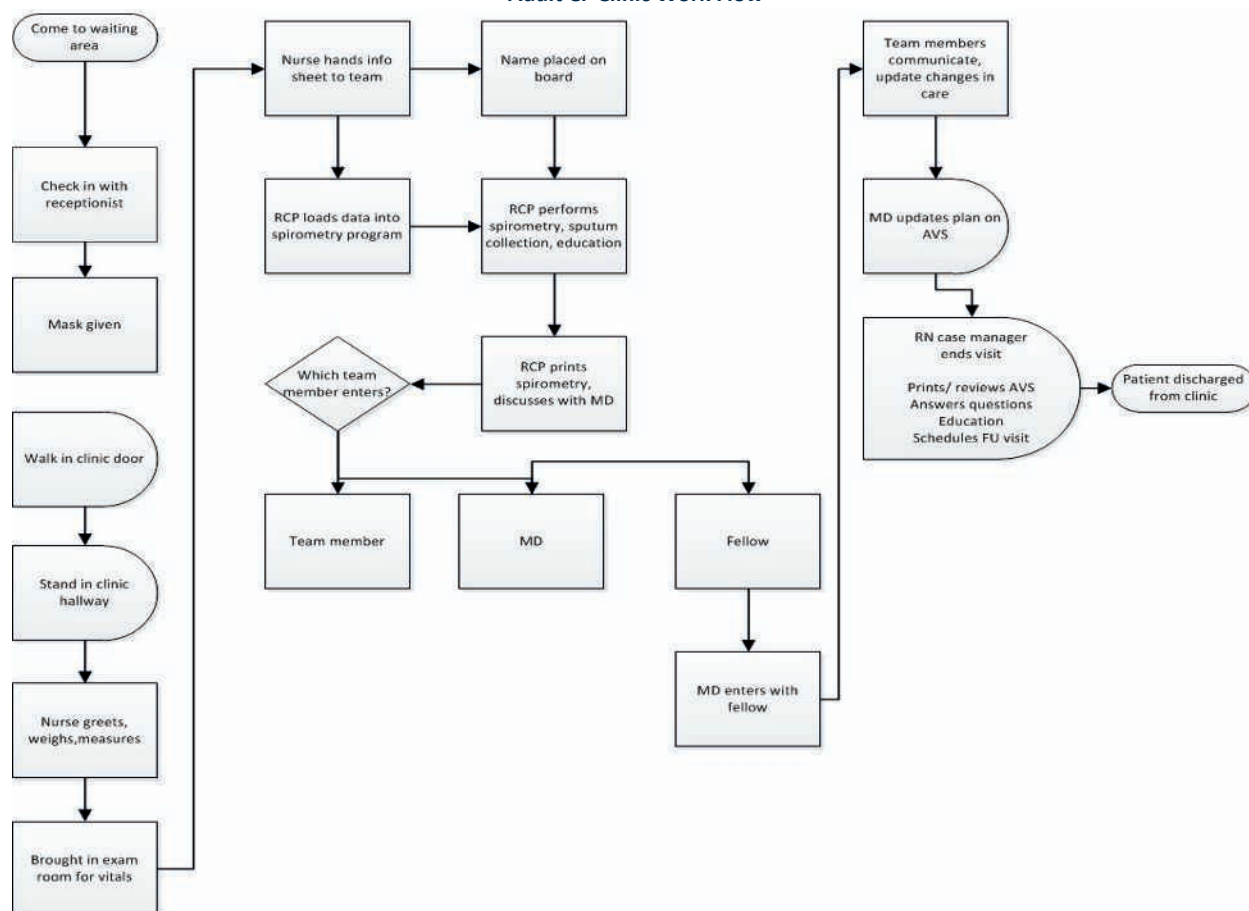
Source: Kaiser Permanente Southern California, Adult Program (used with permission)

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Processes

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.

Who completes this form? ⌘ **Person With CF** ⌘ **Family Member**

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 the first CF team member.
	6. Note below the times the clinicians entered and left the room.

	Nurse	Social Worker	Dietitian	Physical Therapist / Respiratory Therapist	Physician
Time In:					
Time Out:					
	Other	Other	Other	Other	Other
Time In:					
Time Out:					

TIME	
	7. Time you were ready to leave the clinic.

COMMENTS: _____

_____

_____

_____

_____

PEOPLE WITH CF AND FAMILY TIP: Invite people with CF and family members to help complete the Cycle Time Tool during their clinic visits. Some family members may be willing to follow multiple people with CF to track cycle times.

Processes

CYCLE TIME TOOL

Beginning to increase staff understanding of the processes of care and services in the practice is key to developing a common understanding and focus for improvement. Start with the high-level process of a patient entering your practice by using the Patient Cycle Time Tool. You can assign someone to track all visits for a week to get a sample, or the Cycle Time Tool can be initiated for all visits in a one-week period with many people contributing to the collection and completion of this worksheet.

Typically, other processes will be uncovered to measure and you can create time-tracking worksheets like this template to measure other cycle times.

PROGRAM PATIENT APPOINTMENT CYCLE TIME

Who completes this form? ⌘ **Staff**   ⌘ **Students**   ⌘ **Volunteers**

Day: _____   Date: _____

Scheduled Appointment Time _____   Provider(s) You Are Seeing Today _____

Time	
_____	1. Time person with CF checked in.
_____	2. Time person with CF sat in the waiting room.
_____	3. Time staff came to get person with CF.
_____	4. Time staff member left person with CF in exam room.
_____	5. Time first provider came into room. *Provider 1* _____
_____	6. Time first provider left the room.
_____	7. Time second provider came into room. *Provider 2* _____
_____	8. Time second provider left the room.
_____	9. Time third provider came into room. *Provider 3* _____
_____	10. Time third provider left the room.
_____	11. Time fourth provider came into room. *Provider 4* _____
_____	12. Time fourth provider left the room.
_____	13. Time person with CF left the exam room.
_____	14. Time person with CF arrived at check out.
_____	15. Time person with CF left the clinic.

Comments: _____

_____

_____

_____

_____

_____

_____

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Processes

CYCLE TIME TOOL

Below is a cycle time example provided by **Loyola University Medical Center** and used with their permission. The Loyola Lead Improvement team collected cycle time data from both a tool completed by people with CF and a tool completed by their staff, and then compared the cycle time data. The tools and data are provided below.

As a result of this cycle time tool and tracking, the Lead Improvement Team gained new insights into the experience of care that identified time in radiology and phlebotomy that added almost an hour to the total visit. They also identified variation in time spent in the clinic between Clinic #1 and Clinic #2 that led further inquiry to understand the differences. All data collection forms can be found at PortCF.outcome.com and clinicalmicrosystem.org.

CLINIC FLOW DATA COLLECTION

CF Multidisciplinary Clinic (STAFF VERSION)

	Time In	Time Out
Vitals		
Respiratory Therapist		
RN Clinic Coordinator		
Dietitian		
Social Worker		
Physician		
Other		
RN Checkout		

Schedule for LTX Clinic Appointment Day (PERSON WITH CF/FAMILY VERSION)

Date:_____ Time of Appointment:_____ Physician:_____

Location (circle one):   Maywood   Oakbrook

Time Arrived at Clinic:_____   Time Left Clinic:____

Comments:_____

_____

_____

_____

Timeline: Please document the time spent in each department and/or with each provider (include lab, radiology, nurse, doctor, respiratory, dietitian, social worker, everything!).

Time	ACTION/Provider	COMMENT
Example: 10:00-10:20	nurse	
10:25-10:35	dietitian	

CLINIC TIMELINE DATA – INITIAL AVERAGES

n = 5 patients   n = 18 patients
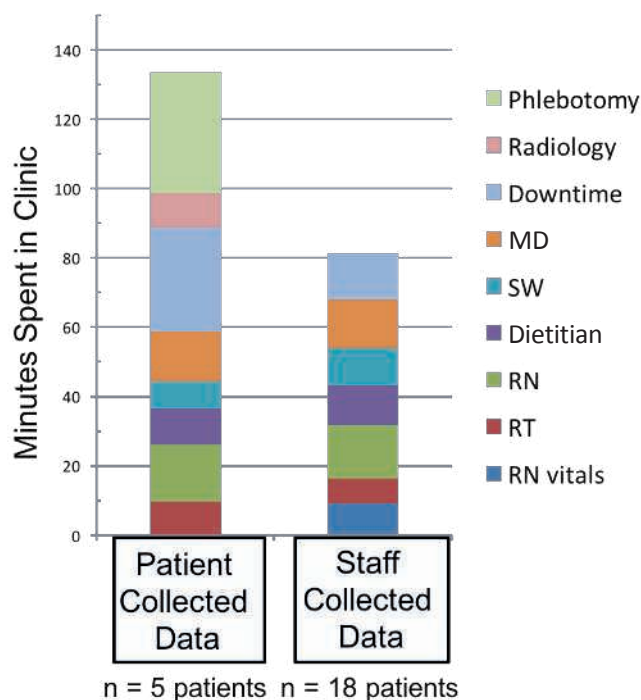
CLINIC TIMELINE DATA – FOUR MONTHS OF DATA
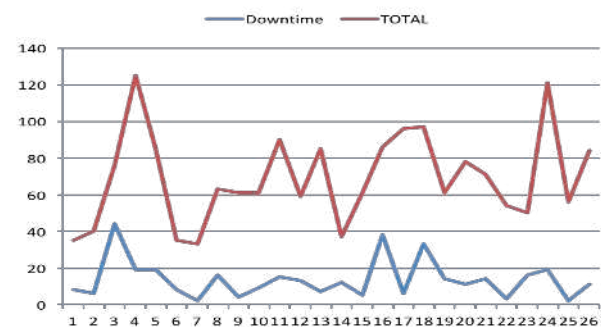
Time spent in clinic (min)	Clinic #1	Clinic #2
Arrival to room	11.1 min	15.8 min
Vitals	9.7 min	7.3 min
RT	11.8 min	10.0 min
RN	12.0 min	15.9 min
Dietitian	12.0 min	11.5 min
SW	9.3 min	9.6 min
M.D.	10.2 min	21.9 min
Downtime	13.6 min	22.3 min

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Processes

CORE AND SUPPORTING PROCESSES

Review, adapt, and distribute the *Core and Supporting Processes* Assessment form to ALL CF center staff. Be sure the list is accurate for your CF 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 Improvement Team an idea as to where to begin to focus on improvement from the staff perspective.

⌘ Some clinics create and display a wall-sized version of the Core and Supporting Process Assessment chart and ask all staff to select choices by using different colored dots for each role. This creates a *scatter plot display* of 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* (pg. 42-44), you will use the PDSA (plan-do-study-act) cycle worksheet (pg. 51-52) to run tests of change and to measure your change ideas.

PROGRAM CORE AND SUPPORTING PROCESSES ASSESSMENT

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

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Patterns

KNOW YOUR PATTERNS

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.

What patterns are present but not acknowledged in your microsystem? What are the leadership and social patterns? 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 microsystem meet to discuss CF care?

⌘ How do leaders across your microsystem relate to one another?

⌘ Do the members of the clinic regularly review and discuss quality, safety, and reliability issues?

⌘ Are people with CF and their families involved? (Use ipfcc.org, PortCF.outcome.com, or clinicalmicrosystem.org).

⌘ What is the most significant pattern of variation in your CF clinic? Do clinics vary by day of week or season? Do professionals vary their schedules? What other variations can one find?

⌘ What have you successfully changed?

⌘ What are you most proud of?

⌘ What is the financial trend for your program?

⌘ What are your CF results and outcomes?

⌘ How do leaders relate to staff?

⌘ 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 CF 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 program 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:
Place a tally mark for each occurrence of an unplanned activity	Total
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:
Place a tally mark for each occurrence of an unplanned activity	Total
Interruptions	
⌘ Phone	15
⌘ Secretary	
⌘ RN	(10)
⌘ Provider	
Hospital Admissions	(12)
Patient Phone Calls	
Pages	20
Missing Equipment	
Missing Supplies	5
Missing Chart: Same-Day Patient	
Missing Chart: Patient	(10)
Missing Test Results	
Emergent Cases	

Unplanned Activity Tracking
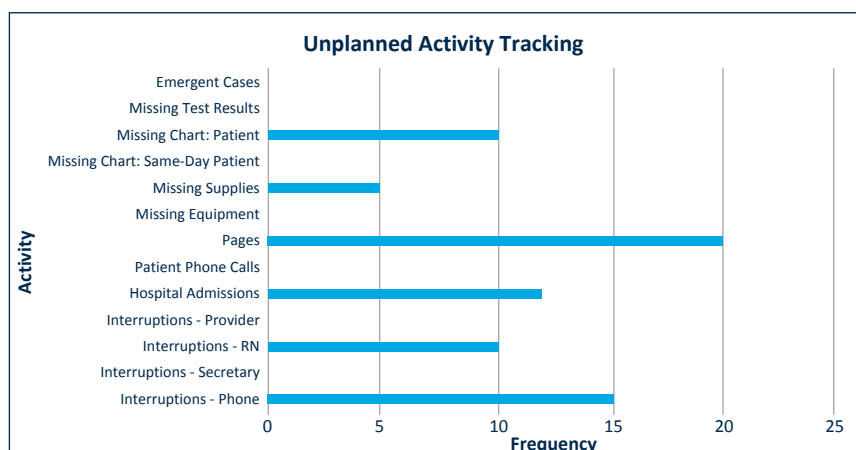
Patterns

⌘ 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 website 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.

PROGRAM TELEPHONE TRACKING LOG

Week of	Day of Week		Day of Week		Week Total
	AM	PM	AM	PM	
Appointment for Today					
Total					
Appointment for Tomorrow					
Total					
Appointment for Future					
Total					
Acute Appointment					
Total					
Quarterly Appointment					
Total					
Annual Appointment					
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

⌘ Metrics are essential for microsystems to make and sustain improvements to attain high performance. Review your CF program's Registry data to identify what you do well and where there are "gaps" in care and opportunities for improvement. 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 MTM 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 and MTM.

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 including Key Metrics for CF (see table).

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 Improvement Team

Work with your Lead Improvement 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. Pick a few measures to start with.

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

Conceptual Definition: tells what will be measured (e.g., patient waiting for CF clinic visit)

Operational Definition: tells how it will be measured (e.g., time elapsed from patient appointment time until time patient enters exam room in minutes)

■ 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

Key Metrics
Specific to Cystic Fibrosis

⌘ FEV_1, Children Ages 6-12 Years

⌘ FEV_1, Children Ages 13-17 Years

⌘ FEV_1, Adults 18 Years and Older

⌘ Median BMI Percentile, Patients <24 Months

⌘ Median BMI Percentile, Patients 2-20 Years

⌘ Median BMI, Patients 21 Years and Older

⌘ Median Weight-for-Length for Patients <24 Months

⌘ Median Weight for Patients 2-19 Years

⌘ Median Height for Patients 2-19 Years

⌘ Screening for CFRD (Oral Glucose Tolerance Test – OGTTs)

⌘ Patient Health Questionnaire (PHQ-9), Total Score

⌘ Generalized Anxiety Disorder Assessment (GAD-7), Total Score

⌘ Annual Goals for Care (Four Visits, Two PFTs, Four Sputum Cultures)

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.

■ DATA OWNER

Start small and identify a data wall owner(s) who is guided by the lead team to create a visual display of the MTM and other key metrics.

Identify a data owner(s) for each measure. The owner will be responsible for obtaining and reporting the measure to the lead team. Seek sources of data from organization-wide systems before manually counting.

If the needed data are not available, use manual methods to sample and provide a *"snapshot" of the data*. Strive to build data collection into the flow of daily work.

■ REVIEW AND USE

Review your data walls on a regular basis — daily, weekly, monthly, quarterly, and annually — to track the improvement process and determine if process and clinical outcomes are at the desired level of performance.

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

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Strongly consider using the metrics reported in the CF Foundation's center-specific Registry reports, the Patient and Family Experience of Care (PFEC) survey, and The Joint Commission (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 the National Quality Foundation.

THE DARTMOUTH MICROSYSTEM IMPROVEMENT RAMP WITH MEASUREMENT

Improvement activities and measurement are inextricably connected. To help you "see" this relationship, *The Dartmouth Microsystem Improvement Ramp* and the *Measurement Triangle* illustrate how improvement measurement can be woven into each step of the improvement ramp.

Careful consideration of the conceptual and operational definitions will ensure reliable measurement throughout the improvement process.

The development of data collection plans supports the PLAN of PDSA cycles. Together, these models create an improvement process that is grounded in *improvement sciences*.
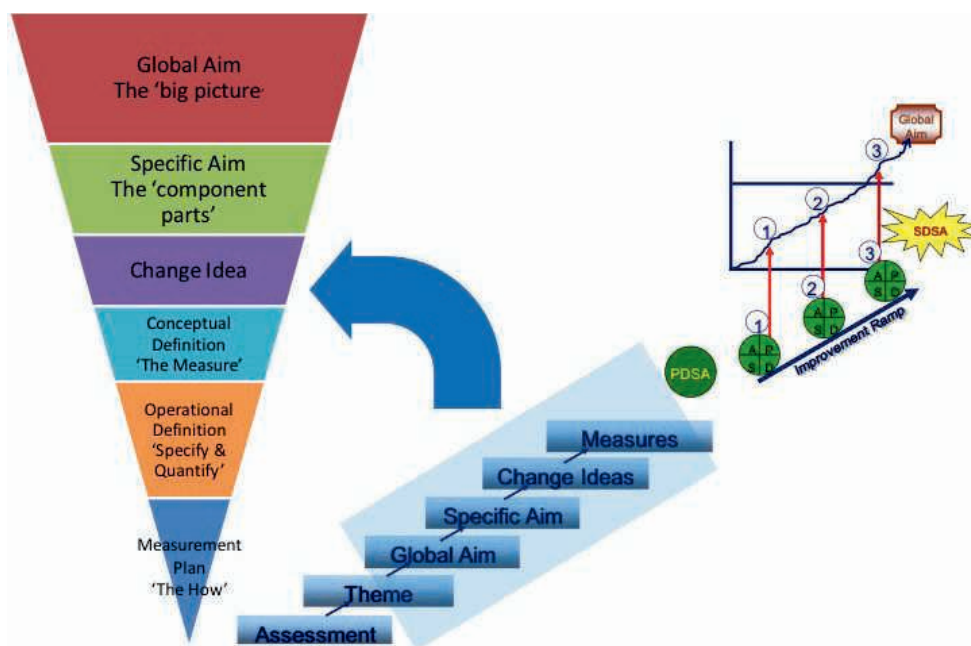
PROGRAM METRICS THAT MATTER

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

Name of Measure	Goal	Current and Target Values	Definition and Data Owner	Action Plan and Process Owner
CF Patient Registry Outcome Measures				
FEV_1, Children Ages 6-12 Years				
FEV_1, Children Ages 13-17 Years				
FEV_1, Adults 18 Years and Older				
Median BMI Percentile, Patients <24 Months				
Median BMI Percentile, Patients 2-20 Years	50th percentile			
Median BMI, Patients 21 Years and Older				
⌘ Female	22 BMI			
⌘ Male	23 BMI			
Median Weight-for-Length for Patients <24 Months				
Median Weight for Patients 2-19 Years				
Median Height for Patients 2-19 Years				
Visit Guidelines				
⌘ Clinic Visits	at least quarterly			
⌘ Pulmonary Function Tests	at least every six months			
⌘ Respiratory Cultures	at least quarterly			
Screening for CFRD (OGTTs)	yearly			
Annual Goals for Care (Four Visits, Two PFTs, Four Sputum Cultures)				
Patient and Family Perceptions				
Collaborative Goal Setting With Patients and Families				
Patient/Family Action Plan				
Access				
Staff Morale				
Safety				
Finance				

STEP 3

DIAGNOSE

With the Lead Improvement 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, or 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., The Joint Commission: jointcommission.org).

⌘ 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 PROGRAM

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_____
<div align="center">(Name the process)</div>

In_____
<div align="center">(Clinical location in which process is embedded)</div>

The process begins with _____
<div align="center">(Name where the process begins)</div>

The process ends with _____
<div align="center">(Name where the process ends)</div>

By working on the process, we expect _____
<div align="center">(List benefits)</div>

It is important to work on this now because _____
<div align="center">(List imperatives)</div>

_____

_____

_____

_____

*An example of this worksheet is found on pg. 9.

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STEP 4

TREAT YOUR PROGRAM

Draft a clear, specific aim statement and way to measure the aim using improvement models – PDSA (Plan-Do-Study-Act; pg. 51-52) and SDSA (Standardize-Do-Study-Act; pg. 55).

⌘ 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 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 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.

⌘ These ideas are derived from the collaborative innovation work of the CF Foundation. For more information, visit PortCF.outcome.com or ihi.org (*Institute for Healthcare Improvement*).

⌘ The Change Ideas will continue to develop as more field testing is done and more colleagues design improvements.

⌘ New ideas and innovation can be posted on PortCF.outcome.com.

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
_____
_____
_____
_____
_____

*An example of this worksheet is found on pg. 9.

PROGRAM CHANGE IDEAS TO CONSIDER

1. Have a pre-clinic huddle to prepare for the day's patients – pre-visit planning.

2. Conduct 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. Hold 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. Ensure timely Registry data entry.

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).

*Visit PortCF.outcome.com and clinicalmicrosystem.org for actual documents, forms, and the latest ideas.

CONSIDER THE *CHANGE CONCEPTS*

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/Patient, Family, and Health Care Professionals 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.* 1st ed. The Jossey-Bass Business & Management Series. San Francisco, CA: Jossey-Bass Publishers; 1996: xxix:295.

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Treat Your Program
Smart Change Ideas

PULMONARY SMART CHANGE IDEAS

1. Use REACT Program – Re-Education of Airway Clearance Techniques

2. Institute prevention program to include: flu shots, infection control measures, reducing smoking exposure.

3. Get the chronic medications "right."

4. Assess and impact adherence at every visit.

5. Standardize definition of pulmonary exacerbation (PE).

6. Maintain a checklist for other comorbid conditions.

7. Make a written action plan for every visit.

8. Standardize and optimize treatment of PE.

9. Follow every PE to resolution.

10. Enroll in exercise programs.

11. Assess every patient at every visit.

12. Involve the whole team and meet regularly.

13. Develop patient take-home materials.

14. Have pre-clinic huddle to prepare for the day's patients.

15. Have follow-up calls with patients and families.

16. Utilize visit worksheets that include visit expectations and goals for care as well as identify risk factors associated with adherence to care.

17. Build an action plan with patients and family for care that is mutually agreed upon and meets the patient's and family's goal(s).
   Credit: Robert Zanni and Paula Lomas

CFRD SMART CHANGE IDEAS

1. Diagnostic screening.

2. Education/self-management.

3. Impact nutritional status.

4. Use technology to treat CFRD.

5. Blood glucose control during tube feedings and hospitalizations.

6. Impact hemoglobin A1c (HgbA1c).

7. Screen for complications.

8. Improve CF center to endocrinology referral process.
   Credit: CFRD Collaborative

NUTRITION SMART CHANGE IDEAS

1. Re-educate and set goals with patient and family on increasing calories and vitamins/minerals and proactive nutrition.

2. Prevent malabsorption: Review and evaluate routine enzyme use in pancreatic-insufficient patients.

3. Increase registered dietitian (RD) patient contact time and frequency.

4. Provide standard screening/assessment of nutrition at every visit.

5. Assess and address feeding behaviors.

6. Form relationships with and increase referrals to gastroenterology, endocrinology, and psychology.

7. Treat adverse pulmonary, endocrine, and gastrointestinal symptoms.

8. Introduce the idea of a g-tube early in CF care.

9. Standardize nutritional interventions.

10. Provide more frequent monitoring of "at-risk" patients via clinic visits, phone calls, emails, and Skype.

11. Develop and consistently apply algorithms for care based on BMI and BMI percentage.

12. Assess every patient at every visit.

13. Define nutrition status at every visit as a goal is prevention, not rescue.

14. Involve the whole team in meetings to focus on nutrition assessment.

15. Develop patient take-home materials.

16. Consistently deliver message to families and team members regarding the importance of nutrition.

17. Pre-clinic huddle to prepare for the day's patients.

18. Have follow-up phone calls with patients and families.

19. Utilize visit worksheets that include visit expectations and goals for care as well as identify risk factors associated with adherence to care.

20. Build an action plan with patients and family for care that is mutually agreed upon and meets the patient's and family's goal(s).

Credit: Drucy Borowitz, Suzanne Michel, and Robert Zanni

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TREAT YOUR PROGRAM
Smart Change Ideas

COPRODUCTION CHANGE CONCEPTS/CHANGE IDEAS

1. Use pull systems.
2. Reduce choice of features.
3. Increase choice of features.
4. Give people more access to information.
5. Help people understand information.
6. Conduct training.
7. Implement cross-training.
8. Share risks and benefits.
9. Emphasize natural and logical consequences.
10. Develop alliances and cooperative relationships.
11. Listen to patients, families, and health care professionals.
12. Coach patients, families, and health care professionals to use products or service.
13. Focus on the outcome that matters to the patient, family, and health care professionals.
14. Understand contribution made by product or service to outcome that matters to the patient, family, and health care professionals.
15. Use a coordinator.
16. Reach agreement on expectations.
17. Standardize.
18. Customize.
19. Attend to emotion, aesthetic, and experience.
20. Don't waste the patient, family, and health care professionals' time.
21. Provide exactly what is wanted.
22. Provide exactly where it is wanted.
23. Provide exactly when it is wanted.
24. Ensure that goods and services work and that they work together.
25. Aggregate solutions to reduce patient, family, and health care professionals' time and hassle.
26. Recognize and invite individual patient and family agency and capacity.
27. Invite patients, families, and health care professionals to network and share solutions.
28. Remove barriers to use of product or service.
29. Understand and limit burdens created by product or service.
30. Optimize information technology to enable partnership.
31. Distinguish unique needs of different patients, families, and health care professionals.
32. Enable trust.
33. Share power.
34. Optimize time together.
35. Eliminate aspects of the product or service that do not add value.

Credit: Maren Batalden

SUSTAINING DAILY CARE CHANGE CONCEPTS/CHANGE IDEAS

Change Concept: Person before the patient
Change Ideas

1. During pre-clinic huddles when the patient list is being reviewed, include discussing something personal and nonmedical about the person and/or family to help understand the context of managing CF.
2. Identify member(s) of the care team with the best attributes to discuss an important health goal(s) with a patient/family.
3. Enter patient room with a smile and ask what is going on in their life. Share something about yourself to encourage personable connection.

Change Concept: Optimize interactions
Change Ideas

1. To set an agenda, ask your patients what their priorities are for your discussion.
2. Use active listening to explore their thoughts, feelings, and experiences about CF and their life.
3. Choose non-judgmental words and use open-ended inquiries to emphasize that you are there for your patients as a partner.
4. Choose words that acknowledge that everyone struggles to do everything at 100 percent. Setting realistic goals can help someone achieve what is best for them right now (shared humanity).
5. Use the "teach-back" method: Have them "teach" and reflect back what they understood you to say to make sure you are on the same page.
6. When discussing topics with your patients and colleagues, collect and share solutions and stories you've heard from others to help inspire patients to think differently.

Change Concept: Debrief before the handoff
Change Ideas

1. After seeing the patient, quickly debrief with the next team member before they see the patient to share important information in an effort to reduce redundancy and encourage new interactions.
2. Debrief after clinic on the list of patients and update your notes to inform the next visit.

Credit: Cindy George

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Treat Your CF Clinic
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

CF 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)

Patient Needs: | **Meetings:**

Clinic/Staff Needs:

REVIEW OF NEXT CLINIC DAY AND PROACTIVE PLANNING

                                                                | **Meetings:**

Driver Diagram

The ***driver diagram*** is a tool to organize and track multiple improvements to achieve the "Global Aim" of the "Theme" of improvement.

The driver diagram also shows the relationships among the theme, global aim, specific aims, measures, and PDSA cycles in a quick, visual way. Creating a ***"Gantt chart"*** to add pace to the improvement is often helpful.

The driver diagram can be used in two ways for improvement teams.

1. It can be used at the beginning of improvement to list and organize the evidence-based, best-known practices and other improvement PDSA cycles to conduct to reach the goals of improvement.

   The PDSA cycles can be conducted one-by-one (especially when you are learning improvement skills).

2. It can be used as a road map when multiple staff know the discipline of improvement and multiple PDSA cycles can be conducted simultaneously to move in a more timely fashion toward the desired aim.

Pulmonary Exacerbation Driver Diagram

Global Aim Statement (Include Registry Data)

We aim to improve the pulmonary manifestations of CF in the UTHSCSA CF Center.

The process begins with reviewing center data to better understand our current treatment practices and infection rate. **The process ends with** the development of standardized treatment algorithms for the first time and chronic *Pseudomonas aeruginosa* and MRSA infections, treatment of exacerbations, and optimization of chronic therapy use.

By working on the process, we expect to decrease chronic *Pseudomonas* and MRSA colonization rates, and exacerbation rates, and to sustain/improve pulmonary function.

It is important to work on this now because our current infection and exacerbation rates are higher and our use of inhaled antibiotics is lower than the top 10 centers.

Source: University of Texas Health Science Center at San Antonio, Pediatric Program (used with permission)

Registry Data:
FEV_1, exacerbation rate, MSRA and Pa colonization rates, rates of use of chronic medications

Specific Aim Statements

We will increase the use of a pulmonary exacerbation (PEx) scoring system from 0 to 100 percent by 12/31/15 for all patients seen in clinic or who contact the clinic due to illness.

We will decrease the rate of *Pseudomonas aeruginosa*-positive cultures in patients from 0-6 years to less than 10 percent by 12/2016.

We will decrease the rate of *Pseudomonas aeruginosa*-positive cultures in patients from 0-6 years to less than 10 percent by 12/2016.

We will reduce the rate of MRSA-positive cultures by 10 percent by 12/2016.

Measures (Operational Definitions)

% time RN/MA use the PEx scoring sheet

% time the PEx sheet completed appropriately

patients <6 years of age Pa+ monthly

patients <6 years of age Pa+ annually

% patients who undergo nebulizer cleaning technique evaluation/re-evaluation weekly by RT

% patients who were correctly cleaning nebulizers

patients with MRSA+ cultures monthly

% patients <18 years of age MRSA+ annually

% patients >18 years of age annually

PDSA Cycles

• Develop a consensus definition for PEx
• Development of a EMR template for sick calls
• Creation/distribution of PEX/contact magnets

• Infection control site visit
• Development of "Lung Bugs" pamphlet
• Develop culture database
• Formalize treatment algorithms

• Nebulizer cleaning assessment
• Re-education in conjunction with "Lung Bugs"

• Infection control site visit
• Development of "Lung Bugs" pamphlet
• Develop culture database
• Formalize treatment algorithms

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Pulmonary Knowledge Driver Diagram

Global Aim Statement (Include Registry Data)

We aim to improve our patients' knowledge of and adherence to prescribed pulmonary therapies at Children's Hospital Orange County.

The process begins with assessing baseline knowledge and adherence to prescribed pulmonary therapies via survey. **The process ends with** completion of a personally tailored education plan at the end of each cystic fibrosis patient visit.

By working on the process, we expect improved patient knowledge and self-care, improved patient lung function, improved patient and family satisfaction, and improved staff satisfaction.

It is important to work on this now because there is a global knowledge deficit with our patients and families, and this clinic is a source of staff dissatisfaction.

Registry Data:

Port CF – FEV$_1$, exacerbations/admits

Specific Aim Statements

Patient Knowledge
Improve patients' baseline knowledge as measured by a 50 percent improvement in their global CF RISE Score by 10/1/2016.

Mental Health
Improve our identification of and support for patients with depression and anxiety (by increased screening to 100 percent) by 10/1/2016.

Resources
Ensure patients are provided with individualized action plans that take into account available time, financial resources, and access to equipment and supplies by 10/1/2016.

Contact Time
We will improve contact time with providers per patient visit from 61 percent to >80 percent by 10/1/2016.

Measures (Operational Definitions)

Administer pulmonary knowledge CF RISE Assessment, remediate, and re-administer assessment at follow-up clinic visit.

Administer PHQ9 and GAD 7 screening tools to patients 12 years old and older and parents/caregivers of patients 0–17 years old per CF Foundation guidelines.

Divide number of patients that receive a CF action plan by the total number of CF patients to determine percentage of patients who receive a CF action plan. Administer patient and family survey to determine how well we are doing to provide resources and meet their needs.

Measure total time spent at CF clinic; time starts at check in and ends at discharge.

PDSA Cycles

- Tested REACT tool
- Trialed CF RISE
- RT ed with each clinic visit
- Measure effectiveness of RT ed
- Develop RT education tool

- Screen on annual
- Screen on first visit post-annual
- SW and Psych share discussions with parents and child
- Location for screening conversation
- Where in the visit to screen

- Prescribe or develop action plans
  – What action plans current exist
  – Trialed three possibilities all on paper
  – Currently doing PDSAs related to building an electronic version

- Arrivals
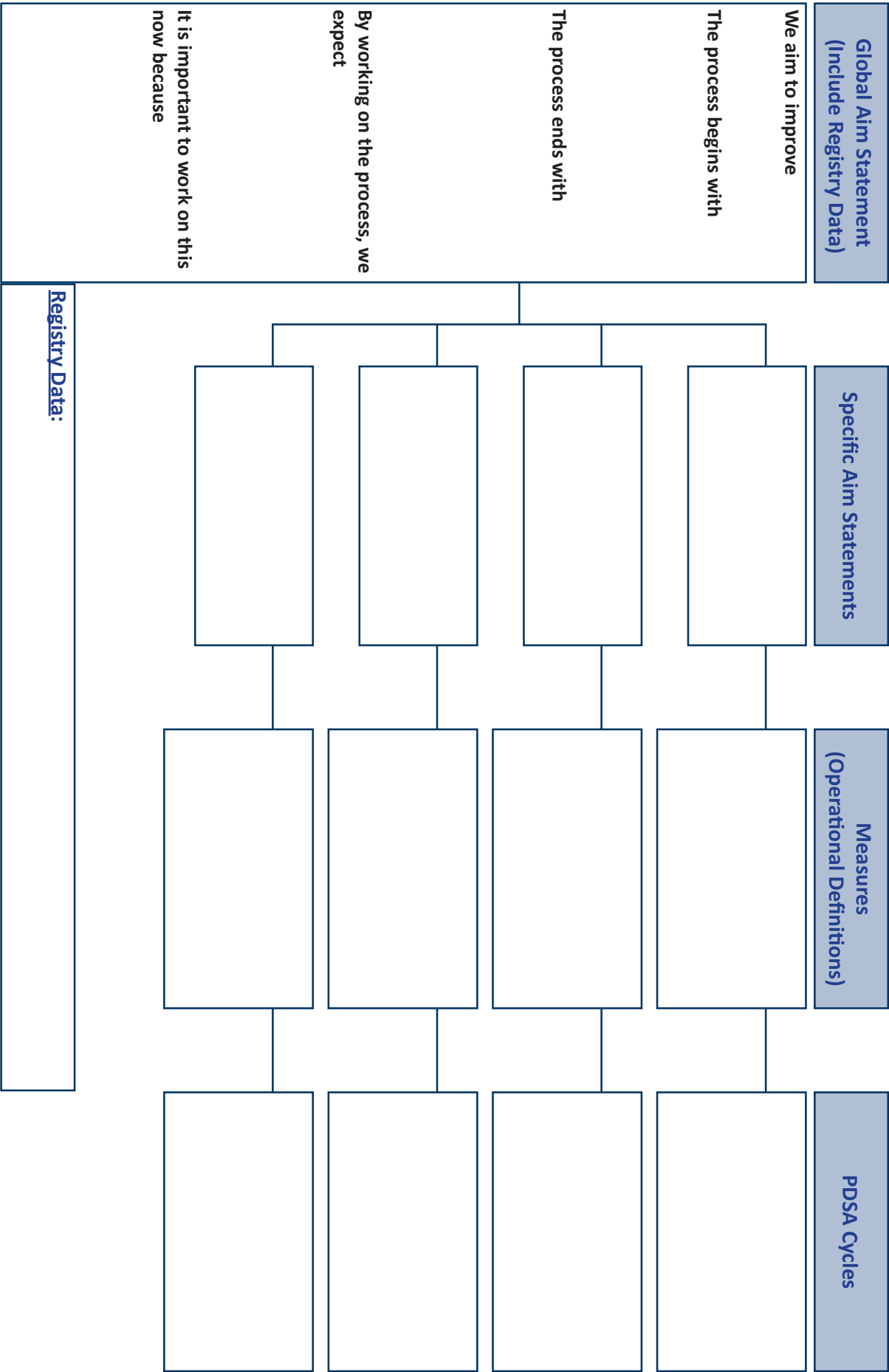- Sick patients outside of regular clinic
- Add psychology and RT ed to increase value add time

Source: Children's Hospital Orange County, Pediatric Program (used with permission)

Pulmonary Outcomes Driver Diagram

Global Aim Statement (Include Registry Data)	Specific Aim Statements	Measures (Operational Definitions)	PDSA Cycles
We aim to improve pulmonary outcomes for our patients in the University of Virginia Pediatric Cystic Fibrosis Center. **The process begins with** identifying modifiable factors that impact patient's lung health both in and outside of the clinic setting. **The process ends with** addressing and modifying the factors we have identified as barriers to improving lung health. **By working on the process, we expect** improved pulmonary outcomes for our patients. **It is important to work on this now because** the center report indicates a gap between our patient pulmonary outcomes and the top 10 centers. We have an opportunity and support for improvement through our LLC involvement.	Increase the percentage of patients following out-patient personal infection prevention and control (IP&C) practices (mask and handwashing for clinic entrance and exit) from baseline observation study of 75 percent wearing masks and 0 percent washing hands; to 100 percent adherence by all patients over the age of 2 by August 9, 2016.	• Observation data pre and and post: tick and tally	• Sticker on appointment reminder • Mail protocol with newsletter • Verbal reminder • In-clinic education with check-off sheet • Eventually add to EMR • New hygiene stations 1st and 3rd to supplement 6th floor station • Re-usable mask samples (Vog masks) • Front desk signage
	We will improve the quality of clinic hygiene by monitoring our cleaning practices according to IP&C protocols 100 percent of the time.	• Measure EVERY Tuesday clinic contact • ATP values <100 = pass for patient contact • ATP value <150 = pass for bathroom.	• Select swab location narrow to five locations • Change cleaning solution to Virex • Put weekly report on agenda and team troubleshooting • Change bathroom value threshold • Use dice app to randomize room selection • Bathroom magnet protocol
	Aim to improve and sustain FEV$_1$ in patients 6-12 years old (under construction).	• Education module scores (pre and post) • 6 min. walk test (pre and post) • CFQ-R scores (pre and post) • FEV$_1$ • Quittner Tool	• Under construction (planning phase) Projected start date November

Registry Data:

Median FEV$_1$ percentage of patients 6-17 years below national average since 2008.

Source: University of Virginia, Pediatric Program (used with permission)

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Global Aim Statement (Include Registry Data)

We aim to improve

The process begins with

The process ends with

By working on the process, we expect

It is important to work on this now because

Registry Data:

Specific Aim Statements

Measures (Operational Definitions)

PDSA Cycles

Gantt Charts and Action Plans (Rhythm and Pace)

These improvement tools are helpful to support busy Lead Improvement Teams stay on track in their improvement efforts. Field experience has showed us improvement teams who use *action plans* and Gantt charts are more organized and keep a *"rhythm and pace" of improvement*.

A Gantt chart is a useful organizing and management tool to plan and track overall improvement work. The Gantt chart provides a graphical illustration of the improvement activity schedule to be able to plan, coordinate, and track specific activities.

Inserting the driver diagram specific aim statements and PDSA cycles into the Gantt chart supports the team to plan immediate and long-term improvement actions. The Gantt chart can show estimated times of completion and resources needed, and can lay out the order of improvement to balance rhythm and pace of improvement. The Gantt chart often allays team member concerns with having too much to do when improvement is displayed using this tool.

Gantt charts also help to monitor progress and to quickly identify when improvement activities are behind schedule or not progressing to allow quick remedial action.

Gantt charts can be manually made or created through programs such as Microsystem Project or Excel.

Action Plans

An action plan is a list of tasks specific to the next steps that need to be completed to achieve current improvement aims. The action plan is a simple and helpful organizing tool often created at the end of an improvement meeting to ensure all action items are captured to be completed before the next meeting. Please note the detail of the action plan includes what the task is, by whom and how it will be completed, and by when.

Reference

Nelson EC, Batalden PB, and Godfrey MM. In: *Quality by Design*. Chapter 23, San Francisco, CA: Jossey-Bass; 2007.

Gantt Chart

Month #1 _____

Name of Activity, Theme, Aim, Test of Change	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31

Gantt Chart Example

Month #1 July 2014 _____

Name of Activity, Theme, Aim, Test of Change	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Implement preclinic huddle																															
Requisitions given to patients in clinic																															
Clerical staff input comments																															
Clinic flow coordinator trialled																															
Test a preclinic prep day by multi-disciplinary team																															
Arrival policy letters posted to patients																															
Letter posted in clinic, given to patients in clinic; reinforced verbally																															

Month #2 August 2014 _____

Name of Activity, Theme, Aim, Test of Change	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Implement preclinic huddle																															
Requisitions given to patients in clinic																															
Clerical staff input comments																															
Clinic flow coordinator trialled																															
Test a preclinic prep day by multi-disciplinary team																															
Arrival policy letters posted to patients																															
Letter posted in clinic, given to patients in clinic; reinforced verbally																															

Action Plan

What tasks will be done?	By whom?	By when?	How?	Comments

Plan-Do-Study-Act (PDSA)

The Lead Improvement 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 Improvement Team should design the Standardize-Do-Study-Act (SDSA, pg. 55) 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) and standardization (i.e., SDSA).

Reed and Card (2016) reflected on the use of the PDSA cycle and cautioned users not to use PDSA as a "stand-alone" method – it must be included in a suite of QI methods to ensure deeper understanding of the context and the problem. This action guide provides the suite of QI methods and encourages the rigorous use of reflective practice throughout the improvement process.

Reference

Reed JE, Card AJ. The problem with Plan-Do-Study-Act cycles. *BMJ Qual Saf.* 2016;25(3):147-152. doi:10.1136/bmjqs-2015-005076

Complete the Plan-Do-Study-Act worksheet to execute the Change Idea in a disciplined, measured manner, to reach the specific aim. See PortCF.outcome.com and clinicalmicrosystem.org for examples.

*An example of this worksheet is found on pg. 11.

Model for Improvement

What are we trying to accomplish? (Aim)

How will we know that a change is an improvement? (Measures)

What changes can we make that will result in an improvement? (Changes)

The PDSA Cycle

Act
- What changes are to be made?
- Next cycle?

Plan
- Objective
- Questions and predictions (why)
- Plan to carry out the cycle (who, what, where, when)

Study
- Complete the analysis of the data
- Compare data to predictions
- Summarize what was learned

Do
- Carry out the plan
- Document problems and unexpected observations
- Begin analysis of the data

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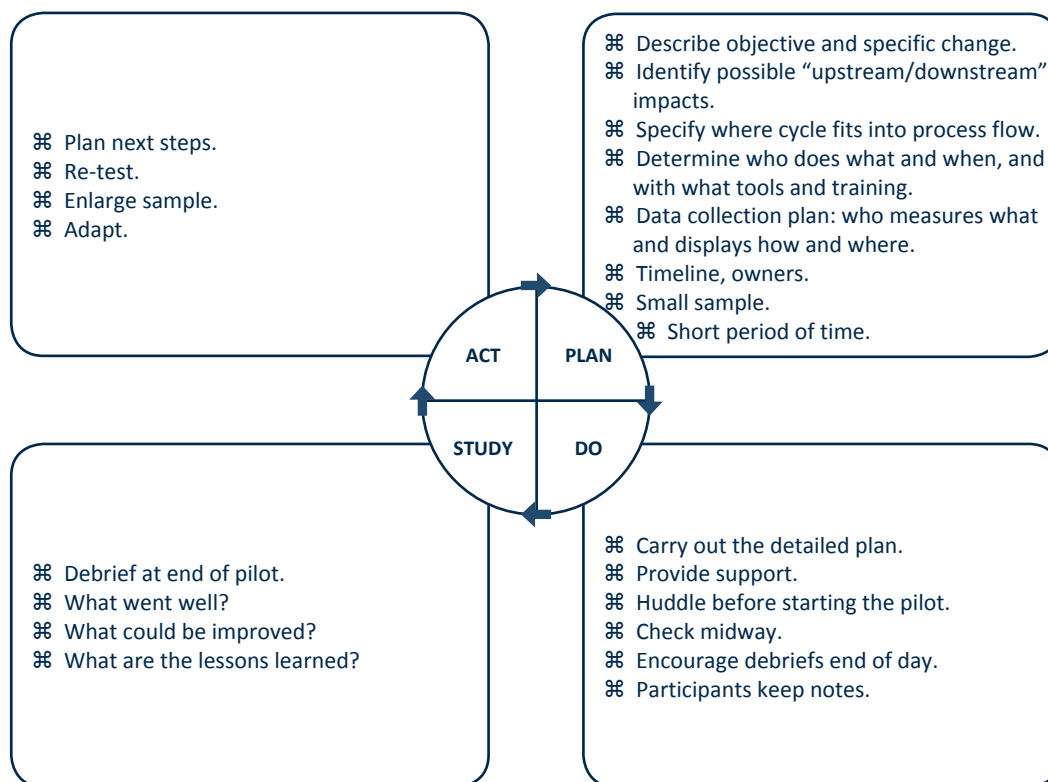
ACT ➤ As we **ACT** to hold the gains or abandon our pilot efforts, what needs to be done? Will we modify the change? Make a PLAN for the next cycle of change.
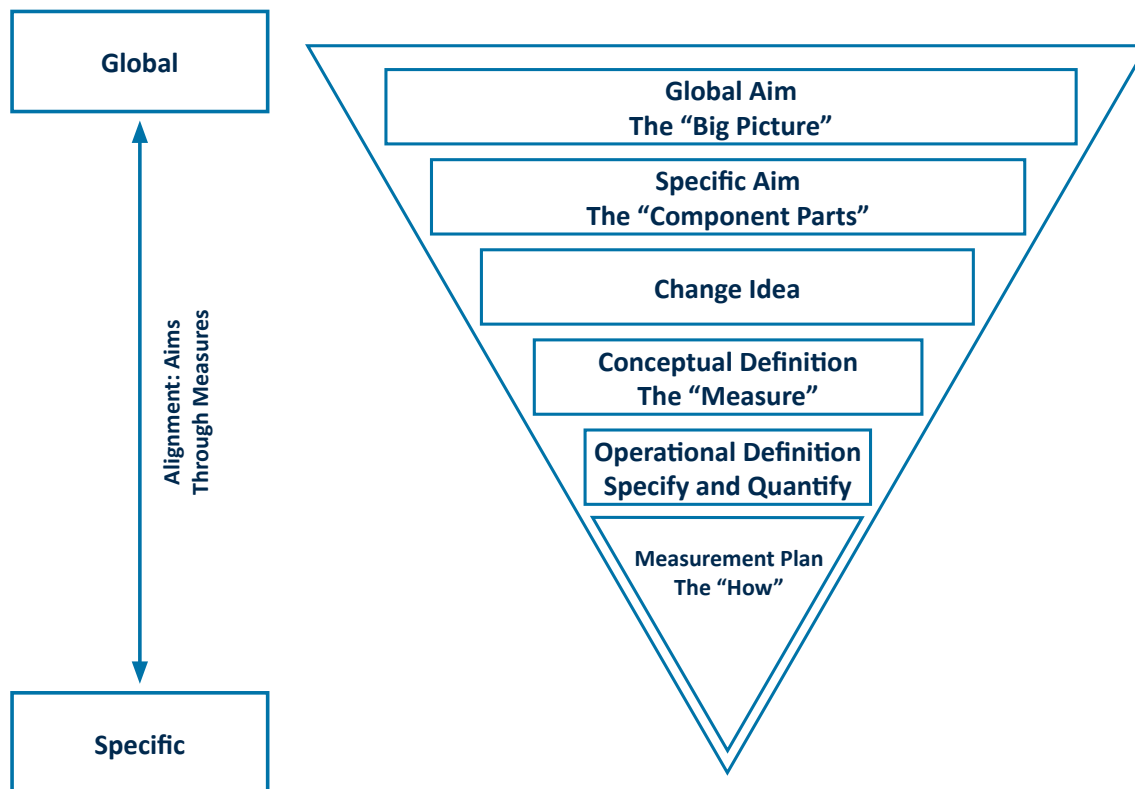
Example of Designing the PDSA Cycle Starting With the Plan

Tasks to be completed to run test of change	Who	When	Tools Needed	Measures
Educate the staff on new algorithm for nutrition screening.	Lead RN Lead MD	Tuesday morning meeting	Measurement plan	Number of staff present at meeting / Total number of staff
Follow up with staff not able to attend meeting via email.	Lead RN	Tuesday afternoon	Measurement plan	Number of staff who received email / Number of staff not present at meeting
Create checklist of topics for dietitian to discuss with patient.	Lead Dietitian	Wednesday afternoon	Checklist (draft)	Completed checklist, reviewed by team
Checklist to be shared and reviewed by Lead Improvement Team.	Team	Thursday morning	Checklist (draft)	Agreement on checklist
Implement and audit new algorithm for nutrition screening.	Lead MD Dietitian	Tuesday afternoon	Tick and tally sheet for prior two weeks	Number of patients being assessed using the new algorithm for nutrition screening from dietitian/ Total number of patients aged 2-20 years seen in clinic each day

ACT
- ⌘ Plan next steps.
- ⌘ Re-test.
- ⌘ Enlarge sample.
- ⌘ Adapt.

PLAN
- ⌘ Describe objective and specific change.
- ⌘ Identify possible "upstream/downstream" impacts.
- ⌘ Specify where cycle fits into process flow.
- ⌘ Determine who does what and when, and with what tools and training.
- ⌘ Data collection plan: who measures what and displays how and where.
- ⌘ Timeline, owners.
- ⌘ Small sample.
- ⌘ Short period of time.

STUDY
- ⌘ Debrief at end of pilot.
- ⌘ What went well?
- ⌘ What could be improved?
- ⌘ What are the lessons learned?

DO
- ⌘ Carry out the detailed plan.
- ⌘ Provide support.
- ⌘ Huddle before starting the pilot.
- ⌘ Check midway.
- ⌘ Encourage debriefs end of day.
- ⌘ Participants keep notes.

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MEASUREMENT FUNDAMENTALS: Operational and Conceptual Definitions Worksheet

Instructions: Complete the following worksheet to derive measurement definitions from your global and specific aims following these five steps:

Global

Alignment: Aims Through Measures

Specific

Global Aim
The "Big Picture"

Specific Aim
The "Component Parts"

Change Idea

Conceptual Definition
The "Measure"

Operational Definition
Specify and Quantify

Measurement Plan
The "How"

STEP 1: Global Aim (Insert your global aim statement here.)

We aim to improve:
In:
The process begins with:
The process ends with:
By working on this process, we expect:
It is important to work on this now because:

STEP 4: Conceptual Definition (Describe **ONE measure** that you could use to assess the effectiveness of change idea you listed in Step 3.)

STEP 2: Specific Aim (List **ONE specific aim** derived from your global aim in Step 1.)

We aim to (by how much):

By (when):

STEP 5: Operational Definition (Define very precisely what you conceptually described above in Step 4.)

STEP 3: Change Ideas (List **ONE change idea** that will appropriately address the specific aim listed in Step 2.)

STEP 6: Measurement Plan (Define **HOW** you will collect the data described above in Step 5.)

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MEASUREMENT FUNDAMENTALS: Data Collection Plan Worksheet

Instructions: Draft a data collection plan for the measure that you conceptually and operationally defined.

      1. List the Operational Definition of your selected measure here (refer to your Definitions worksheet, pg. 53).

      2. Complete the table below to create a basic data collection plan for your measure.

WHO? Who will collect and manage the data and how will they be trained? What is the data source (i.e., patients, providers, data registry owners, electronic medical record)?	
WHAT? What data will be collected (i.e., survey, observation, discussions or other techniques).	
WHERE? Where will the data be collected (i.e., inpatient clinic, specialty clinic, or other setting).	
WHEN? When will the data be collected (i.e., pilot test dates, pre-intervention, and post-intervention data collection, frequency of data collection).	
HOW? How will the data be collected, how will you ensure consistency and accuracy of measurement, how will you deal with missing data, and is your plan feasible to implement in the current system at this time?	

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 innovation, 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. 51).

DATA WALL (DASHBOARD)

Performance Dashboards

Health care delivery systems frequently operate without measured performance systems that monitor performance and population health outcomes in real time. *Performance dashboards* can provide programs key information in real time to do the work of providing care and continuously improve the delivery of care and services. Using performance dashboards, microsystem and mesosystem level performance measurement can be employed effectively and efficiently to create rich and actionable information environments that can facilitate continuous improvement.

A basic dashboard template can be used to structure measures of population, outcome (clinical and experience of care) and process measures that can be extracted from the initial 5P assessment.

A data wall can be created in the CF clinic to display the dashboard along with PDSA cycle measured results to keep staff and people informed on how the program is performing.

Reference

Using measurement to improve health care value. In: Nelson EC, Batalden PB, Godfrey MM, Lazar JS. *Value by Design*. San Francisco, CA: Jossey-Bass; 2011: 129-160.

PERFORMANCE DASHBOARD TEMPLATE

POPULATION MEASURE #1	POPULATION MEASURE #2
CLINICAL OUTCOME MEASURE	EXPERIENCE OUTCOME MEASURE
PROCESS MEASURE #1	PROCESS MEASURE #2

An example of a populated dashboard using the template

(Source: University Texas Southwestern ll Children's Medical Center Dallas and Plano, Pediatric Program OneCF Center and B.J. Oliver, PhD)

POPULATION MEASURE #1 — Dallas OneCF Center Population by Age Category

POPULATION MEASURE #2 — Percentage of Patients Transferring by Season

CLINICAL OUTCOME MEASURE — Registry Outcome Data

EXPERIENCE OUTCOME MEASURE — Satisfaction Survey Scores: XmR chart (Mock Data)

PROCESS MEASURE #1 — Patients with Transfer Problems by Season

PROCESS MEASURE #2 — Percentage of Eligible Patients Transitioned within 90 Days by Quarter (p Chart)

STEP 5

SUSTAINING IMPROVEMENT

"Holding the Gains of Improvement"

For decades, health care organizations have invested valuable time and resources to improve systems of care and outcomes. The challenge continues to be how to sustain the improvement gains made and not reverting back to old performance levels.

Sustaining improvement in the CF clinic requires committed leadership who reinforce, promote, and role model improvement in daily care. The leadership team usually consists of a physician, a nurse, and/or administrative role.

The CF clinics that sustain the culture of improvement maintain the rhythm of improvement through weekly improvement meetings including people with CF and their families, monthly all-staff meetings, and annual retreats to review and plan improvement strategies. Strong linkages to the overall organization and CF Foundation national improvement strategy and resources, meetings, and events contribute to sustaining improvement.

Using a standard discipline of improvement science including the use of playbooks, and measurement tracking and monitoring systems, such as dashboards (pg. 56), provide transparent visual feedback on performance and contribute to ongoing encouragement and feedback to continue improvement.

There are processes to standardize improvements such as "Standardize-Do-Study-Act" and "playbooks" or standard operating procedures (SOPs) to ensure best practices stay in place. There is a process to review standard processes and hold all staff accountable for using them in the delivery of care.

All staff at the front line have improvement capabilities and continuously learn and share insights in the daily work of providing care and services. Human resource policies support and expect staff engagement in improvement.

New CF Foundation programs such as the Cystic Fibrosis Learning Network (CFLN) can provide a stimulating and encouraging virtual environment to share and learn about the continuous improvement journey for improving care for people with CF.

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Nelson EC, Batalden PB, Godfrey MM. *Quality by Design.* San Francisco, CA: Jossey-Bass; 2007.

K. Sustaining Improvement. IHI White Paper. Cambridge, MA: Institute for Healthcare Improvement; 2016. (Available at ihi.org)

FOLLOW-UP

IMPROVEMENT IN HEALTH CARE IS A CONTINUOUS JOURNEY

The new processes and habits 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 Improvement 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 Improvement 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 – Lead Improvement Team			
Monthly Meetings ⌘ All Staff ⌘ Patient and Family Advisors			
Quarterly Reports of Outcomes and Progress to Senior Leaders			
Annual Retreat for Review and Reflection			
Data Wall			
Storyboards			
Annual NACFC Meeting			

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Transition and Transfer of Young Adults to Adult Care

Advances in CF treatment, standardization of care processes and systems, and ongoing research have resulted in people with CF moving into adulthood able to lead meaningful and productive lives. The *transition and transfer process* from pediatric to adult care has been under evaluation and improvement in the CF community.

The transition from pediatric to adult care presents many challenges for care providers and health care systems to ensure continuity of care. The lack of generally accepted guidelines and process to support transition to adult care has resulted in delays in care, lost follow-up in care, decreased clinical outcomes such as loss of pulmonary function and decrease in body mass index (BMI), hospitalizations, and emotional and financial stress for the young adult and their families. In 2015, there were three areas of focus identified to create "a safer and lower cost transition to adult care:

⌘ building and supporting *self-management* during the critical transition;

⌘ engaging receiving care; and

⌘ providing checklist-driven services during the transition."

Additional needs identified to help support the transition of pediatric to adult care include improved communication, improved care coordination, empowering the pediatric patient while engaging the patient and family, and addressing insurance changes.

Additionally, not all health care professionals are prepared to care for young adults with CF. The adult CF provider systems are usually separate from the pediatric clinics and may not have the expertise to provide care and services.

Recognition of this current state led to the CF Foundation leadership supporting a *"OneCF" Learning and Leadership Collaborative (LLC)* to create a program merging pediatric and adult resources and processes to provide a transition "bridge" from pediatric to adult care.

OneCFAim: Assess and develop a CF care center that provides seamless care from the time of diagnosis through advanced care. This includes a focus on integrated care, smooth transitions (pediatric to adult), warm handoffs and transfers, and improvement of mesosystem care such as referral to specialists (e.g., endocrinology, gastroenterology, ears-nose-throat, and psychology) and inpatient care.

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Okumra, MJ, Ong T, Dawson D, et al. Improving transition from pediatric to adult cystic fibrosis care: program implementation and evaluation. *BMJ Qual Saf.* 2014;23i64-i72.

Vaks Y, Bensen R, Steidtmann D, et al. Better health, less spending: Redesigning the transition from pediatric to adult health care for youth with chronic illness. *Healthc (Amst).* 2015;4(1):57-68. doi: 10.1016/j.hjdsi.2015.09.001i
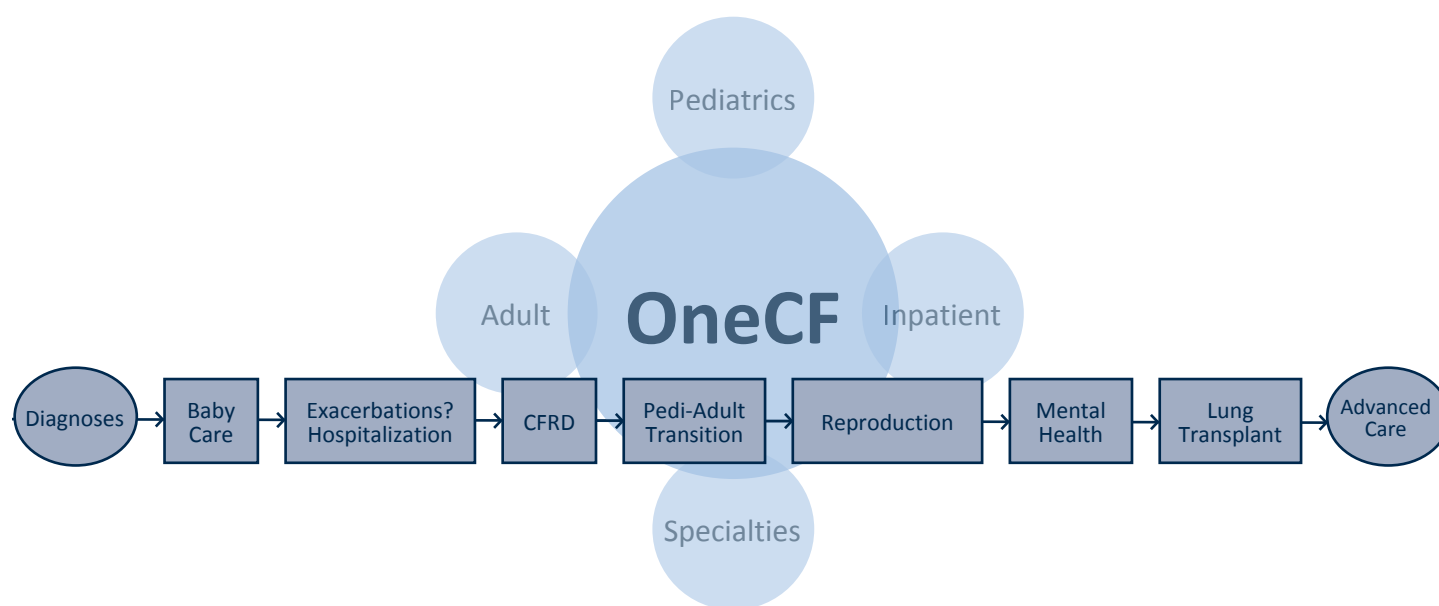
To support improvement of transition of care from pediatric to adult care, several resources are available.

1. CF R.I.S.E. (Responsibility. Independence. Self-Care. Education) program developed by Gilead in partnership with the CF community starting in 2011. The mission of the program is to foster patient ownership of CF care through an educational program focused on the achievement of independence. A CF Transition Advisory Council consisting of practitioners across the CF community was formed to develop transition tools including assessment of knowledge and skills, resources, form letters, and tracking forms. Materials are available in a paper and electronic format (cfrise.com).

2. Got Transition Center for Health Care Transition improvement is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health. Their aim is to improve transition from pediatric to adult care through the use of new and innovative strategies for health professionals and youth and families. Got Transition identifies three top transition-of-care needs: improving care coordination, improving communication, and identifying appropriate providers. The Six Core Elements of Health Care Transition provide further guidance (gottransition.org).
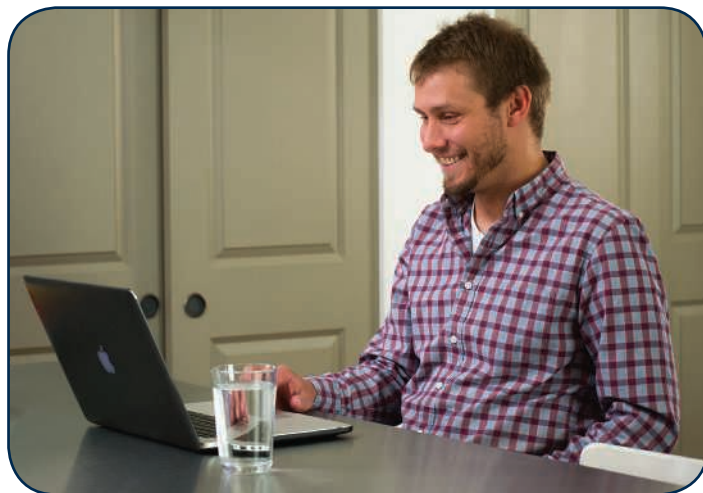
The Six Core Elements of Health Care Transition

i. Transition Policy

ii. Transition Youth Registry

iii. Transition Preparation

iv. Planning

v. Transfer of Care

vi. Transfer Completion

*gottransition.org.

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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 – in other words, 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 are examples of what patients' or family members' responsibilities might be.

Patient/Family Roles[1, Δ]	Patient/Family Responsibilities	Staff/Health Care Provider Responsibilities Preparation/Compensation
Patients or Families as Participants ⌘ Respond to surveys and questionnaires ⌘ Members of focus group	⌘ Family perceptions of care and quality are elicited and used in shaping improvement initiatives. ⌘ Data/information from families is used in measuring improvement. ⌘ Responsibilities end when their input is received unless they are asked to provide feedback on the interpretation of the data. ⌘ Review and give feedback related to materials developed specifically for patients or families (e.g., educational materials). ⌘ Provide suggestions for improvement in writing as appropriate. ⌘ Respond to surveys/questions openly and honestly.	**PREPARATION:** ⌘ All efforts should be made to ensure that patients' and families' real experience is accurately measured and interpreted. ⌘ 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). ⌘ 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. **COMPENSATION:** ⌘ Acknowledgment of appreciation for their participation is necessary. ⌘ Supplying patients/families with a summary of the data and information about how the data are/will be used to improve area of focus (e.g., quality care, education). This can occur in a patient/family meeting, education day, written summary, etc., and may be additional compensation.

* For more information on patient and family involvement and creating an advisory council, visit PortCF.outcome.com or the Institute for Patient- and Family-Centered Care website at ipfcc.org.

Δ Footnotes are on pg. 61.

Patient/Family Roles[1]	Patient/Family Responsibilities	Staff/Health Care Provider Responsibilities Preparation/Compensation
Patients or Families as Advisory Board Members[2] ⌘ Members of committee ⌘ Members of task force ⌘ Patients or families serve on advisory boards for the quality improvement team	⌘ Responsibilities will depend on level of involvement of the advisory board. • If the advisory board is used to review policies, programs, and evaluation methods after staff has written them, there are few opportunities for teamwork. • 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.	**PREPARATION:** ⌘ 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). ⌘ 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. **COMPENSATION:** ⌘ 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. ⌘ 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. ⌘ Other preparation issues to consider include childcare, meetings that include meals, parking and other transportation costs, and stipends for participation.

Patient/Family Roles[1]	Patient/Family Responsibilities	Staff/Health Care Provider Responsibilities Preparation/Compensation
Patients or Families as Active Advisors/Consultants[3] ⌘ Active task force/committee members ⌘ Faculty for staff education ⌘ Participants at collaborative meetings/conferences ⌘ Mentors for others in work (patients, families, or staff) ⌘ Trainers for other patients or families involved ⌘ Orientation of staff ⌘ Work closely with the quality improvement team	⌘ At this level, patients/families have a continuous and more active involvement with the care center (e.g., Lead Improvement Team, educational materials). ⌘ 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). ⌘ They would be active participants as members of the teams who are planning, implementing, and evaluating either individual projects or the work of the collaborative team as a whole. ⌘ Help in the quality improvement effort, all components of the ***Plan-Do-Study-Act (PDSA)*** cycle.	**PREPARATION:** ⌘ 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. ⌘ 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.[4] ⌘ Experienced staff, patients, and/or families can serve as experienced trainers and mentors for others. **COMPENSATION:** ⌘ 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. ⌘ Commitment by the care center and value of the patient/family input is demonstrated through the continuing funding of patient and/or family participation.

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Patient/Family Roles[1]	Patient/Family Responsibilities	Staff/Health Care Provider Responsibilities Preparation/Compensation
Patients or Families as Co-Leaders ⌘ *Facilitator* ⌘ Content expert ⌘ Evaluator[5] ⌘ Author ⌘ Hospital/program employee	⌘ A high level of involvement by patient and/or family. ⌘ Adequate skills and knowledge are required. ⌘ Previous work/education in focused content (e.g., QI, health care) is very valuable. ⌘ Consider community leadership experiences when choosing members to bring a different perspective and an awareness of other community needs. ⌘ Experiences serving in any of the previously outlined roles may provide the necessary knowledge without professional or educational experience.	**PREPARATION:** ⌘ 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 program/hospital leaders/administration. ⌘ Supervision and evaluation of those involved should be formalized. ⌘ Consider employing patients and/or families as clinic/hospital staff because of the requirements, commitment, and role expectations of the co-leaders. ⌘ 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. **COMPENSATION:** ⌘ 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.

These patient and family role ideas are based on work from the Vermont-Oxford Network and Institute for Patient- and Family-Centered Care (IPFCC). 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 goals will help strengthen a team's capacity to collaborate and further partnership in improving CF care. This will require integration of team building 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:
[1] The framework for the roles was adapted from an article on participatory action research by Turnbull, Friesen, Ramirez, 1998 (see references).
[2] For a comprehensive resource on family advisory boards, refer to Webster, Johnson, 2000 (see references).
[3] Refer to Dillon, 2003 (see references) for guidance on parent participation on quality improvement teams.
[4] Refer to Jeppson, Thomas, 1995, 1997 and Turnbull et al. (see references).
[5] For an annotated bibliography of families serving on evaluation teams refer to Jivanjee et al., 2004 (see references).
[6] Further information about the Vermont-Oxford Network can be found at public.vtoxford.org.
[7] Further information about the Institute for Patient- and Family-Centered Care can be found at ipfcc.org.

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Patient and Family Involvement Beyond Clinic*

There are countless ways that patients and families can partner in improving 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 PortCF.outcome.com and 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 website.

⌘ Ask patients and families to assist in translating patient information materials (e.g., into another language or making information understandable for 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 ideas of what can be improved at your care center.

⌘ Develop a consumer satisfaction survey with patients and families and involve them in developing the responses to issues and problems identified (i.e., start with the satisfaction survey in "Assess Your Program" [pg.18]).

⌘ 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, for 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 virtual support groups or email 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. Essential Allies: Families as Advisors. Bethesda, MD: Institute for Patient- and Family-Centered Care; 1994. Revised 2005.

Additional resources are available through the CF Foundation (CFF.org) or the Institute for Patient- and Family-Centered (ipfcc.org):

Webster PD, Johnson BH. Developing and Sustaining a Patient and Family Advisory Council. Bethesda, MD: Institute for Patient- and Family-Centered Care; 2000. Blaylock B, Ahmann E, Johnson BH. Creating Patient and Family Faculty programs. Bethesda, MD: Institute for Patient- and Family-Centered Care; 2002.

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CASE STUDY

Improving Patient and Family Involvement with CF Family Advisory Council

Nemours – Alfred I. duPont Hospital for Children

Kerry Doyle-Shannon, JD – Parent of a Person With CF
Kim York, MSW – CF Social Worker

Meeting with former Governor Markell and Eileen Miley, Mid-Atlantic executive director, CF Foundation.

INTRODUCTION

In September 2008, Kerry Doyle-Shannon, JD (parent of a person with CF) and Kim York, MSW (CF social worker) founded the CF Family Advisory Council (FAC) at the Nemours – Alfred I. duPont Hospital for Children in Wilmington, Del. The group was formed in accordance with the Cystic Fibrosis Foundation's and Nemours' goals to promote family-centered care. The CF FAC addresses patient care issues and quality improvement in addition to patient and family support. The CF FAC expanded to include several parents with the CF social worker serving as the hospital-based facilitator. The CF social worker identified other family members of individuals with CF for inclusion on the CF FAC. Presently, the CF FAC is comprised of many active parents of children with CF, with the CF social worker and the CF nurse coordinator serving as facilitators. The CF FAC meets on a quarterly basis, with two meetings occurring outside the hospital and two meetings held in the hospital where the facilitators are also present. The CF FAC was the first condition-specific council formed at Nemours – Alfred I. duPont Hospital for Children. It is viewed as the premier FAC at Nemours, and is often utilized as a resource and model for other condition-specific groups that have been created since 2008. Mrs. Doyle-Shannon is also a member of the hospital-wide FAC and was also the first parent to present to the Nemours Foundation Board of Directors, during which she discussed her family's experiences at the hospital and her experience working on the CF and hospital-wide FACs.

METHOD/STRATEGY

Families new to our CF center are invited to participate in the CF FAC in several ways. Both the CF team and CF FAC have closed Facebook pages in which new CF families are invited to participate. CF FAC brochures are included in our CF care center's binder of information provided to patients new to our clinic. The brochures are also available on the inpatient hospital unit and the outpatient clinical areas where CF patients are seen. CF FAC parent members also provide direct phone or in-person support and mentorship to parents of children newly diagnosed with CF or families seeking help and guidance regarding their child or teen with CF.

CF FAC parent members are actively involved with the multidisciplinary CF care team and are included in the interview process for new hospital CF care team members. CF FAC members work with staff to advocate for patients in many ways. They were instrumental in advocating for the retention of high-salt, high-fat, high-calorie diet options on the inpatient hospital menu and in various outpatient locations (e.g., vending machines, cafeteria, and gift shop) when nationally low-fat, low-calorie menu options for "healthier diet" are being

promoted. It is important to allow families affected by CF, who are often facing the most challenging times in their lives, to make their own decisions about what they eat, and have snacks or meal options available to their children at all hours. CF and oncology teams joined this advocacy effort. Later in 2015, the CF nutritionist created a menu supplement for CF patients staying in the hospital and sought and received feedback on the supplement from both patients and families before it was implemented hospital-wide. Additional ways the CF FAC members have worked with staff to advocate for CF patients, including several QI and patient care initiatives, are outlined.

The patient and quality care initiatives/accomplishments of the CF FAC in conjunction with the CF multidisciplinary team are:

- ⌘ Organizing patient and family advocacy within our institution and in the larger community, including government officials (e.g. CF team, parent, and CF Foundation local chapter meeting with state governor)
- ⌘ Hosting Lunch and Learn events with topics ranging from 504 Plans and individualized education plans (IEPs), to CFRD, to status of research in CF Therapeutics Pipeline
- ⌘ Presenting on CF Education Days to new nursing and respiratory staff
- ⌘ Participating in all phases of design and construction of inpatient hospital expansion
- ⌘ Aiding in development of educational materials for patients and families (e.g., PFT information sheet, New CF Patient Family Binders of Information)
- ⌘ Assisting in planning CF Family Education Day
- ⌘ Working with CF team to move lab work for patients from outpatient lab to clinic exam rooms to promote increased completion of annual testing in addition to improved infection control measures
- ⌘ Addressing pain management in the outpatient CF clinic (e.g., this was the first outpatient clinic to utilize distraction box as well as child life therapists on a regular basis)
- ⌘ Posting bulletin board with relevant information in outpatient waiting area
- ⌘ Circulating newsletters to families
- ⌘ Writing articles for Nemours newsletters on CF FAC projects and accomplishments
- ⌘ Advocating for and assisting CF dietitian with institution of a new inpatient menu supplement to provide high-salt, high-fat, high-calorie diet options for CF patients in the hospital
- ⌘ Working with Interventional Radiology and CF staff to streamline the PICC line process, which significantly improved patient and family satisfaction during inpatient admissions
- ⌘ Continuously working with CF clinic and hospital staff on the issue of infection control
- ⌘ Working with inpatient nursing staff and physical therapist to obtain exercise equipment to be stored on inpatient unit for use by only CF patients who are confined to their rooms
- ⌘ Working on QI projects with CF team in CF FUN LLC2 and beyond
- ⌘ Hosting a staff appreciation luncheon for CF team
- ⌘ Creating clinic worksheet for patients and families to use to keep track of information provided during CF clinic visits
- ⌘ Networking with other hospital groups and families
- ⌘ Becoming members of hospital committees (e.g., Inpatient Satisfaction, Hospital/Estate Collaboration)

CF team with Collaborative Award. Pictured with inpatient nurses and Kerry Doyle-Shannon.

Assessing Your Practice Discoveries and Actions

Know Your Patients	Discoveries	Actions Taken
1. Age Distribution	1. 30 percent of our patients >65 years old.	1. Designated special group visits to review specific needs of this age group including physical limitations, dietary considerations.
2. Disease Identification	2. We do not know what percentage of our patients have diabetes.	2. Staff reviewed coding/billing data to determine approximate numbers of patients with diabetes.
3. Health Outcomes	3. We do not know what the range of HgA1C is for our patients with diabetes or if they are receiving appropriate Americans with Disabilities Act-recommended care in a timely fashion.	3. Staff conducted a chart audit with 50 charts during a lunch hour. Using a tool designed to track outcomes, each member of the staff reviewed five charts and noted their findings on the audit tool.
4. Most Frequent Diagnosis	4. We learned we had a large number of patients with stable hypertension and diabetes, seeing the physician frequently. We also learned that during certain seasons we had huge volumes of acute diseases such as upper respiratory tract infections, pharyngitis, and poison ivy.	4. Designed and tested a new model of care delivery for stable hypertension and diabetes optimizing the RN role in the practice using agreed upon guidelines, protocols, and tools.
5. Patient Satisfaction	5. We don't know what patients think unless they complain to us.	5. Implemented the "point of service" patient survey that patients completed and left in a box before leaving the practice.
Know Your Professionals	**Discoveries**	**Actions Taken**
1. Provider FTE	1. We were making assumptions about provider time in the clinic without really understanding how much time providers are OUT of the clinic with hospital rounds, nursing home rounds, etc.	1. Changed our scheduling processes, utilized RNs to provide care for certain subpopulations.
2. Schedules	2. Several providers are gone at the same time every week, so one provider is often left and the entire staff works overtime that day.	2. Evaluated the scheduling template to even out each provider's time to provide consistent coverage of the clinic.
3. Regular Meetings	3. The doctors meet together every other week. The secretaries meet once a month.	3. Entire practice meeting every other week on Wednesdays.
4. Hours of Operation	4. The beginning and the end of the day are always chaotic. We realized we are on the route for patients between home and work and they want to be seen when we are not open.	4. Opened one hour earlier and stayed open one hour later each day. The heavy demand was managed better and overtime dropped.
5. Activity Surveys	5. All roles are not being used to their maximum. RNs only room patients and take vital signs, medical assistants doing a great deal of secretarial paperwork, and some secretaries are giving out medical advice.	5. Roles have been redesigned and matched to individual education, training, and licensure.
Know Your Processes	**Discoveries**	**Actions Taken**
1. Cycle Time	1. Patient lengths of visits vary a great deal. There are many delays.	1. The staff identified actions to eliminate, steps to combine, and learned to prepare the charts for the patient visit before the patient arrives. The staff also holds daily "huddles" to inform everyone on the plan of the day and any issues to consider throughout the day.
2. Key Supporting Processes	2. None of us could agree on how things get done in our practice.	2. Detailed flow charting of our practice to determine how to streamline and do in a consistent manner.
3. Indirect Patient Pulls	3. The providers are interrupted in their patient care process frequently. The number one reason is to retrieve missing equipment and supplies from the exam room.	3. The staff agreed on standardization of exam rooms and minimum inventory lists that were posted inside the cabinet doors. A process was also determined on WHO and HOW the exam rooms would be stocked regularly and through the use of an assignment sheet, a person was identified and held accountable.
Know Your Patterns	**Discoveries**	**Actions Taken**
1. Demand on the Practice	1. There are peaks and valleys of the practice depending on day of the week, session of the day, or season of the year.	1. Resources and roles are matched to demand volumes. Schedules are created that match resources to variation.
2. Communication	2. We do not communicate in a timely way, nor do we have a standard form to communicate.	2. Every other week hold practice meeting to help communication and email use of all staff to promote timely communication.
3. Cultural	3. The doctors don't really spend time with non-doctors.	3. The staff meetings heightened awareness of these behaviors has helped improve this.
4. Outcomes	4. We really have not paid attention to our practice outcomes.	4. Began tracking and posting on a data wall to keep us alert to outcomes.
5. Finances	5. Only the doctors and the practice managers know about the practice money.	5. Finances are discussed at the staff meetings and everyone is learning how we make a difference in our financial performance.

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Assessing Your Practice High-Yield Wastes

Common High-Yield Wastes	Recommended Method to Reduce Waste	Traps to Avoid
1. Exam rooms not stocked or standardized — missing supplies or equipment	• Create standard inventory supplies for all exam rooms. • Design process for regular stocking of exam rooms with accountable person. • Standardize and utilize all exam rooms.	• Don't assume rooms are being stocked regularly — track and measure. • Providers will only use "their own" rooms. • Providers cannot agree on standard supplies; suggest "testing."
2. Too many appointment types, which create chaos in scheduling	• Reduce appointment types to two to four. • Utilize standard building block to create flexibility in schedule.	• Frozen schedules of certain types. • Use one time (e.g., 10-15 minute "building blocks").
3. Poor communication amongst the providers and support staff about clinical sessions and patient needs	• Conduct daily morning "huddles" to provide a forum to review the schedule, anticipate needs of patients, and plan supplies and information needed for a highly productive interaction between patient and provider.	• People not showing up for scheduled huddles. Gain support of providers who are interested, test ideas, and measure results. • Huddles last longer than 15 minutes, use a work sheet to guide huddle. • Don't sit down.
4. Missing information or chart for patient visit	• Review patient charts BEFORE the patient arrives — recommended the day before to ensure information and test results are available to support the patient.	• Avoid doing chart review when patient is present. • If you have computerized test results, don't print the results.
5. Confusing messaging system	• Standardize messaging processes for all providers. • Educate/ train messaging content. • Utilize a process with prioritizing methods such as a "bin" system in each provider office.	• Providers want their "own" way — adding to confusion to support staff and decreases ability for cross coverage. • Content of message can't be agreed upon — test something.
6. High prescription renewal request via phone	• Anticipate patient needs. • Create "reminder" systems in office (e.g., posters, screensavers). • Standardize the information support staff obtain from patients before the provider visit — include prescription information and needs.	• Doesn't need to be the RN — medical assistants can obtain this information.
7. Staff frustrated in roles and unable to see new ways to function	• Review current roles and functions using activity survey sheets. • Match talent, education, training, and licensure to function. • Optimize every role. • Eliminate functions.	• Be sure to focus on talent, training, and scope of practice, not individual people.
8. Appointment schedules have limited same-day appointment slots	• Evaluate follow-up appointments and return visit necessity. • Extend intervals of standard follow-up visits. • Consider RN visits. • Evaluate the use of protocols and guidelines to provide advice for homecare (icsi.org). • Consider phone care.	• Don't set a certain number of same-day appointments without matching variations throughout the year.
9. Missed disease-specific and preventive interventions and tracking	• Utilize the flow sheets to track preventive activities and disease-specific interventions. • Utilize "stickers" on charts to alert staff to preventive and disease-specific needs. • Review charts before patient visits. • Create registries to track subpopulation needs.	• Be alert to creating a system for multiple diseases and not having many stickers and many registries.
10. Poor communication and interactions between members	• Hold weekly staff meetings to review practice outcomes, staff concerns, and improvement opportunities. • Encourage education and development.	• Hold weekly meetings on a regular day, time and place. • Do not cancel — make the meeting a new habit.
11. High no-show rate	• Consider improving same-day access. • Institute reminder systems.	• Automated reminder telephone calls are not always well-received by patients.
12. Patient expectations of visit not met, resulting in phone calls and repeat visits	• Evaluate patient at time of visit to see if their needs were met.	• Use reminders to question patient about needs being met. • New habits are not easily made.

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GLOSSARY

5P Framework: Puts improvement themes into context and is a great place from which to start your improvement work. Use global aim template.

Action Plan: Detailed "next steps" and "to do" with clearly identified and accountable people and time line.

Agenda: Meeting process that includes meeting roles to result in productive meetings with timed segments and clear objectives.

Aim (Global): Puts improvement themes into context and is a great place from which to start your improvement work. Use global aim template.

Aim (Specific): Detailed focus and includes measurable outcomes with specific dates. Use specific aim template.

Algorithm: A sequence of specified actions to reach a goal.

Benchmarking: To 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.

Best Practices: A process that is generally accepted as preferred to any alternatives.

CF Clinical Mesosystem: People with CF and interdisciplinary health professionals coming together with families and care teams in multiple microsystems (two or more) across the continuum of care.

CF Learning Network (CFLN): A system to make it easier for everyone in the CF community to work together at scale to improve health care and costs for people with CF.

CF Patient and Family Experience of Care (PFEC) survey: Learn about the experience of care from the viewpoint of the patients and families to inform improvement and redesign of care and services.

Change Concepts: Stimulants for developing and designing detailed and specific change ideas to test.

Change Ideas: Generated from literature review, best practices, benchmarking, and change concepts to select a change idea to test.

Checklist: Comprehensive list of items and actions to be taken in a specific order.

Chronic Care Model (CCM): Comprised of six interrelated systems meant to make patient-centered, evidence-based care easier to accomplish.

Clinical Mesosystem: Two or more microsystems: A patient pathway.

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.

Co-design: Users as "experts" of their own experience become central to the design and improvement process.

Communication Plan: Clear actions to share improvement progress.

Conceptual Definition: The conceptual definition tells what will be measured (e.g., patient waiting for CF clinic visit).

Continuous Quality Improvement: A management philosophy that is a preventive, proactive process to continuously improve and learn how current processes and systems are performing.

Contributing Units: Clinical units (microsystems) 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.

Coproduction: Effective participation of people with CF, their families, and health care providers in the design and improvement of care.

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: Total time from the beginning to the end of a process.

Dartmouth Microsystem Improvement Ramp: A disciplined and organized improvement process including PDSA to guide improvement.

Data Owner: Accountable person to oversee specific data collection and display.

Data Transparency: Full public disclosure of performance and outcomes that can be a driver of accountability.

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.

Decision-Making Criteria: A set of criteria to help individuals select an improvement idea to test. Usually includes: don't need permission to work on, can start right away, doesn't cost money, and will have the biggest impact on needed improvement.

Driver Diagram: A tool to organize and track multiple improvements to achieve the "Global Aim" of the "Theme" of improvement. It also shows the relationships among the theme, global aim, specific aims, measures, and PDSA cycles in a quick, visual way.

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

Fishbone Diagram: An analysis tool that depicts the possible causes that contribute to a single effect. Also called a "cause-and-effect" or Ishikawa diagram.

Flowchart: Graphic representation of a process using symbols and arrows.

Gantt Chart: A chart in which a series of horizontal lines shows the amount of work done or production completed in certain periods of time in relation to the amount planned for those periods.

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.

IHI: Institute for Healthcare Improvement (IHI), an independent not-for-profit organization based in Cambridge, MA., that is a leading innovator in health and health care improvement worldwide.

Improvement Model: Developed by Associates in Process Improvement, is a simple yet powerful tool for accelerating improvement with two parts: three fundamental questions and the Plan-Do-Study-Act (PDSA) cycle.

Improvement Sciences: An emerging concept that focuses on exploring how to undertake quality improvement well. It inhabits the sphere between research and quality improvement by applying research methods to help understand what impacts quality improvement.

Lead Improvement Team: Interdisciplinary team of a microsystem leading improvement actions and strategy.

Measurement and Monitoring (Ticks and Tallies): Observational data tracking through documenting frequency with a "Tick" or hash mark and then a total "Tally" of the individual hash marks.

Measurement Triangle: The model of disciplined improvement measurement linked to The Dartmouth Microsystem Improvement Ramp.

Metrics that Matter (MTM): 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_1).

Microsystems: Front-line units that provide day-to-day health care. A small group of people who work together on a regular basis to provide care to discrete populations of patients. It has clinical and business aims, linked processes, and a shared information environment and it produces performance outcomes.

North American Cystic Fibrosis Conference (NACFC): Annual meeting that provides a collaborative and educational forum for CF professionals to help advance CF research and care.

OneCF Learning and Leadership Collaborative (OneCF LLC): A program that merges pediatric and adult resources and processes to provide a transition "bridge" from pediatric to adult care.

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GLOSSARY (CONTINUED)

Operational Definition: Defines how metrics will be measured (e.g., time elapsed from patient appointment time until time patient enters exam room in minutes).

Outcomes: Short- and long-term changes that occur as a direct result of "processes" on inputs.

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

Pace of Improvement: Consideration of operational and seasonal impacts that affect the pace of improvement like vacations, snow storms, The Joint Commission, or CF Foundation site visits.

Patient and Family Advisory Group: Group to assist in planning, implementing, and evaluating improvement projects and needed improvement of the CF program.

Patient Experience Maps: The lived care experience of people with CF and families as experienced through their own visit. What did the experience feel like? How does the experience compare to the "mechanical" process map of the CF clinic?

Patient Registry: An organized system to collect uniform data (clinical or other) to evaluate specified outcomes for a population defined by a particular diagnoses and serves a predetermined scientific, clinical, or policy purpose.

Patient Satisfaction Survey: Patient evaluation of care to provide opportunity for improvement, monitor health care performance, and provide benchmarking information.

Patients: One of the 5Ps, patients are at the core of quality improvement work in a CF center microsystem. Their top diagnoses, age distribution, and satisfaction with current care are a few measures.

Patterns: One of the 5Ps, patterns are repeating predictable cycles and behaviors that can be observed and articulated (e.g., meeting frequency, communication and relationships, 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.

Performance Dashboards: Provide at-a-glance view of the CF microsystem key performance, process, and clinical outcomes to create actionable information environments to facilitate continuous improvement.

Personal Skills Assessment Tool: Documents strengths and development topics to determine quality improvement education and training needs.

Pilot Test: Small-scale test of a proposed solution.

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: One of the 5Ps, a process is any activity that is a series of steps with a beginning and end resulting in products or outcomes.

Professionals: One of the 5Ps, professionals are members of the frontline team including anyone who has the privilege to provide care and services; administrative staff, lead MDs, nurses, therapists, social workers, dietitians, etc.

Purpose: One of the 5Ps, this is the common aim and reason to come together to strive and be accountable for achieving.

QI Learning and Leadership Collaboratives (QI LLC): Contribute to creating cultures of improvement at the front line of care through a blend of face-to-face and virtual learning sessions to increase improvement capabilities.

Reaccreditation Site Visit: Every 3-5 years, the accreditation site visit is conducted by CF Care Center Accreditation Committee who review the four explicit standards: physician leadership, multidisciplinary team, participation of the CF clinic and meeting of clinical teaching, and research requirements.

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.

Rhythm of Improving: Disciplined improvement supported by regular meetings, monthly all-staff meetings, and annual retreats to plan and execute improvement.

Scatter Plot Display: Used to plot data points on a horizontal and a vertical axis in the attempt to show how one variable is affected by another.

SDSA (Standardize-Do-Study-Act Cycle): Steps taken when PDSA Cycle has been successfully done to achieve the original aim. Purpose is to hold the gains that were made using PDSA cycles and standardize process in daily work.

Self-Management: Individual control and management of health care.

Senior Leaders: The "C Suite:" Chief Executive Officer, Chief Nursing Officer, Chief Operating Officer, Chief Quality Officer.

Shadowing: Following a patient/family through their care experience to inform improvement and redesign of care processes and systems.

Small Pilots: Small-scale preliminary study conducted in order to evaluate feasibility, time, cost, adverse events, and impact to improve upon the study design prior to performance of a full-scale research project.

Smart Change Ideas: Best practices.

Snapshot of the Data: Small sample in a set time rather than an exhaustive collection of data.

SPC (Statistical Process Control): Developed by Dr. Walter Shewhart and further expanded upon by Dr. W. Edwards Deming to monitor process variation to improve quality.

Staff Satisfaction Survey: Employee affective and cognitive satisfaction with the workplace.

Standard Operating Procedures (SOP): See Playbooks.

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

Subpopulations of Patients: A specific group of individuals with common patient characteristics (e.g., race/ethnicity, age, risk factors).

Sustaining Improvement: Utilizing SDSA and playbooks to sustain improvement while creating conditions in the microsystem to continue to provide care and improve care.

Systems Within Systems: Bertalanffy, the founder of the scientific, mathematical "Theory of Systems," defined a system as a set of interacting, interrelated, or interdependent elements that work together in a particular environment to perform the functions that are required to achieve the system's aim.

Target Value: The measured output of the desired process results.

Tests of Change: See PDSA.

Theme: Focus of improvement after review of information and data of a clinical microsystem.

Through the Eyes of the Patients: Direct real-time observation of people with CF in their care experience — process and interactions.

Transition and Transfer Process: Specific to transition from pediatric to adult care with all processes to ensure smooth seamless transfer from pediatric care, services, and staff to adult care, services, and staff.

Trend Charts (Run Charts): Used to show trends in data over time.

Unplanned Activity: Interruptions, waits, and delays in the processes of providing smooth and uninterrupted patient care.

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