

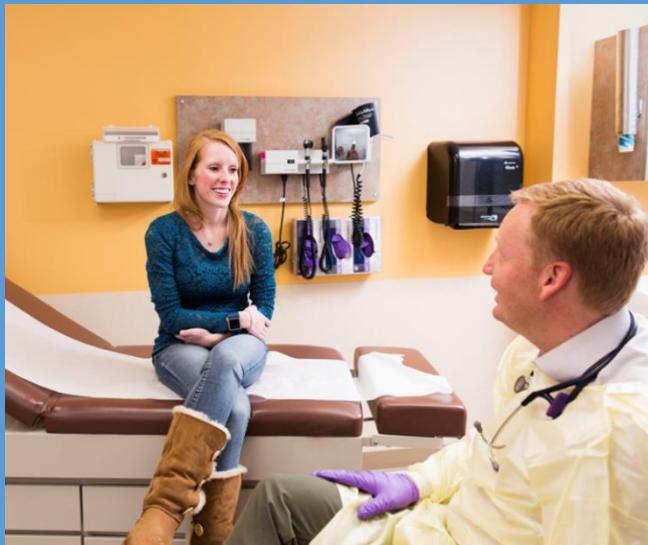


PARTNERSHIPS FOR SUSTAINING DAILY CARE

Understanding Patient-Clinician Communication:
A Comprehensive Pilot Project Report
June 2016



Inpatient multidisciplinary team meeting at Boston Children's Hospital



Ivy Landin, adult with CF, converses with physician Dave P. Nichols, M.D. at National Jewish Health

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Partnerships for Sustaining Daily Care

Communications Executive Summary

Adherence to prescribed treatments is critical to ensuring health outcomes that support individuals with cystic fibrosis (CF) to live full lives. Research has shown that higher rates of adherence correspond to higher lung function, fewer pulmonary exacerbations and lower health care costs. Adherence to treatments, however, is not always easy. A combination of financial, practical and psychosocial issues contribute to the challenges of sustaining daily CF care, which, can take up to two hours a day to complete.

Acknowledging that these barriers prevent people with CF from fully benefiting from efficacious treatments, the Cystic Fibrosis Foundation's (CFF) strategic plan on adherence aims to discover and develop effective ways to help people with CF successfully manage their prescribed therapies. As a result, the Partnerships for Sustaining Daily Care (PSDC) program was created to explore this multidimensional topic of treatment adherence in the context of daily life. A key premise of this initiative is that people with CF, families and care teams work in partnership to create a treatment plan that is optimal, both medically and practically.

Insights from the CF community reveal that non-judgmental, problem-solving conversations about CF treatment regimens lay the foundation of such partnerships. These conversations allow for open discussions about what is working and what is not. Finding the right words and approach to use in discussing the challenges of sustaining the burdensome treatment regimen can be difficult for many patients and families and their care teams. With this insight in mind, the CF Foundation and its team of stakeholders conducted a pilot project focused on learning about the one-on-one conversations between care team members and adults with CF.

Six adult CF programs, along with patient representatives, participated in this initiative to learn more about the one-on-one conversations that happen between care teams and patients. Together, these teams developed ideas and materials designed to trigger conversations and discussions about sustaining daily care. The materials included a poster, tent card, hospital ID badge, sticky-note pad and magnet (examples to the right). The questions tested were: "How are your spirits? What would help you today? [How] are you balancing your life and your care plan?"



Timeline

The pilot was developed from July-October 2015 and was launched from November 2015-February 2016.

Participating Care Centers

The sites involved consisted of six adult programs spread across the country:

1. Northwestern University Adult CF Program – Chicago, IL
2. University of Kansas Medical Center Adult CF Program – Kansas City, KS
3. Boston Children's/Brigham & Women's Adult CF Program – Boston, MA
4. Johns Hopkins Adult CF Program – Baltimore, MD
5. Women and Children's Hospital of Buffalo Adult CF Program – Buffalo, NY
6. National Jewish Health Adult CF Program – Denver, CO

Evaluation Methods

The pilot was evaluated by three methods:

- ❖ A survey administered to patients
- ❖ A survey administered to participating care team members
- ❖ Site visits conducted by CF Foundation staff at five sites (+ one virtual site)

Patient Surveys	Care Team Surveys
<ul style="list-style-type: none"> • 10-minute, 10-item survey • Completed after receipt of materials • \$10 Amazon or CVS gift card provided • Paper or online option (Survey Monkey) 	<ul style="list-style-type: none"> • 10-minute, 18-item survey • Completed at the end of the pilot • No additional incentive offered outside grant • Paper or online option (Survey Monkey)

Results

Overall, patients valued their participation in this pilot project. Many were eager to provide feedback on the conversation materials and felt that the pilot offered them a unique opportunity to share their thoughts on something that could have a real impact in helping them discuss adherence issues with their care team. Care team members similarly expressed enthusiasm in their interviews and survey responses, reporting that they wanted to learn more about how to support their patients and to build stronger relationships to address concerns or difficulties in sustaining daily care and balancing busy lifestyles.

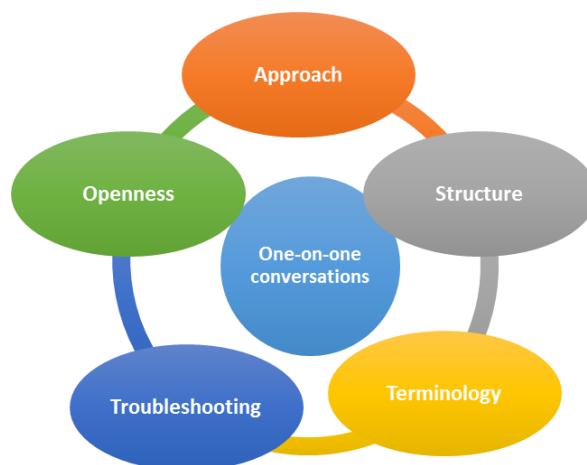
Care teams revealed that, although components of the materials could be improved, the concept and intent behind the materials were effective at triggering conversations to reveal the presence and nature of barriers to adherence. They found that deliberately asking their patients about their challenges to balancing care and life, and subsequently addressing those challenges, led to productive conversations and a better understanding of the root causes of suboptimal follow-through on the daily regimen.

Feedback about the communications pilot provided evidence that the communications tools successfully triggered adherence conversations during a care center visit. Patients indicated that they were interested in improving their adherence rates by having productive conversations with their care team members. Care teams reported interest in building and strengthening relationships with their patients and a need for better tools to do so.

Key Themes

A few main themes emerged from this communications pilot about the one-on-one conversation between clinicians and patients. These themes indicated that there are behaviors and styles of interaction that the care teams and patients can employ in their conversations with each other.

- Approach refers to the way the clinician approaches the conversation with a patient from the start—contextualizing CF within the larger picture of a patient's life.
- Structure refers to the order and intent of the care center visit conversation between the clinician and



patient/family—being deliberate to ask open-ended questions and give the patient/family the opportunity to contribute to the conversation.

- Terminology refers to the types of language and phrasing that care teams could use to normalize the sustaining daily care process for patients in terms of a cycle rather than a binary—adherence versus nonadherence.
- Troubleshooting refers to the ability of a care team to problem solve with the patient and to tap into the shared expertise of the full care team and the patient/family to find the best solutions possible.
- Finally, openness refers to the personality and style of the care team member that can impact the full range of the relationship between the care team member and a patient: being open and approachable allows for a patient to connect with a real person and not just a clinician. These themes all indicate that building stronger relationships between care teams and patients requires a multifaceted approach and requires all parties involved to be full participants in the conversation and care planning process.

The Partnership

Although the conversations between care teams and patients are important, being able to discuss abilities to sustain daily care go beyond those one-on-one conversations in the care visit. This pilot project underscored the importance of relationships. Partnerships and relationships are built over time, through multiple touchpoints and conversations between members of the care team and people living with CF. While the feedback from this pilot provided insights into how to have productive conversations, patients and care teams also shared insights about what a partnership looks like and how to strengthen those relationships between members of the care team and people with CF.

- ❖ **Patients want to be supported in building partnerships with their care teams:**
 - They want more support and education on how to feel confident in opening up discussions with their care partners.
 - They don't want their CF to define their life—interventions need to be something that can fit into their lifestyles and with their personalities.
 - They think that building relationships with care teams depends on personality, number of touch-points (how often you see them) and time (longevity of relationship).
- ❖ **Care teams want to be supported in building partnerships with their patients:**
 - They want to connect with patients in a more productive way and uncover the true barriers and concerns patients have about their treatment regimen.
 - They want more tools and training to build partnerships because interpersonal skills vary from person to person, and some may have more confidence in these skills than others.
 - They want the care center environment to adopt and embrace a holistic approach to addressing concerns of sustaining daily care.
- ❖ **Maintaining a partnership requires multiple touchpoints over time:**
 - Patients and care teams suggest using clinic time to begin and reinforce relationships and/or partnerships over time in the care center visit.
 - Patients and care teams recommend supplementing in-person conversations through email (or preferred outside-of-clinic communication).

Conclusion

Overall, this pilot project yielded a number of insights and implications that address the one-on-one conversations that occur between a patient and a member of a care team. Patients and care team members understand the importance of partnering with each other to achieve optimal health outcomes, but they do



not always feel confident in their ability to further these conversations and to strengthen that partnership. Also, patients and care team members have identified that strong relationships are critical to setting the stage for a productive conversation about adherence and barriers. Although patients and clinicians have a shared goal of promoting positive health outcomes and want to work together, there is always room for improvement in achieving that goal.

Moving forward, community stakeholders will be engaged to further apply these pilot learnings into interventions as part of the PSDC initiative. This iterative, community-based approach in developing interventions with input from care team members, people with CF and family members is critical. Embedding these interventions into routine CF clinical practice and patient self-care requires continuous discovery, measurement and refinement of tools, resources and training — all done with mutual respect, flexibility, acknowledged expertise and sustainability in mind — as partners work toward the shared goal of improving the health and total well-being of all people living with CF.

ADHERENCE — A CRITICAL FACTOR FOR MORE TOMORROWS

Introduction

Cystic fibrosis (CF) is a complex chronic illness requiring individuals with CF to follow a multifaceted, time-intensive, daily treatment regimen. Research demonstrates that consistent adherence to CF treatments is crucial for better health—leading to improved lung function, fewer pulmonary exacerbations and lower health care costs. A combination of financial, practical and psychosocial issues contributes to the treatment burden of CF, which, can take up to two hours a day to complete. The challenges faced by the growing number of adults with CF and family caregivers present significant barriers to sustained adherence¹ to prescribed therapies over the long term.

Acknowledging the complex barriers that prevent people with CF from fully benefiting from efficacious treatments, the CF Foundation brought together a committee of stakeholders² to create a multi-pronged strategic initiative to discover and develop effective ways to help people with CF successfully manage their prescribed therapies. The Partnerships for Sustaining Daily Care (PSDC) program has been formed to address the multilayered barriers that can affect sustained daily care. A key premise in this program is that people with CF, families and care teams work together in partnership to create a treatment plan that is optimal, both medically and practically.

The following report details the development and background of the pilot project and communications initiative. It features information about the methods and evaluation techniques employed throughout the process. It also includes specific information about the results from the surveys and interviews administered as part of the project. The report concludes with highlights, emphasizing key themes synthesized from the participant feedback. The index features examples of the training and evaluation tools that were made available to the participants in this project.

OVERVIEW OF THE COMMUNICATIONS PLAN

Background

Insights from the CF community reveal that non-judgmental, problem-solving conversations about CF treatment regimens lay the foundation for patient and family and care team partnerships. Originally conceived as a national campaign imparting the importance of adherence, feedback collected over a two-year period from PSDC stakeholders highlighted the need to focus on the intricacies of the conversations that occur between members of the care teams and patients and families. These conversations allow open discussions about what is working and what is not in CF care. However, finding the right words and approach to discussing the challenges of sustaining the burdensome CF treatment regimen can be difficult for many patients and families and their care teams. With this insight in mind, CF Foundation and its team of stakeholders conducted a pilot project through the PSDC initiative, and focused on learning about the one-on-one conversations between care team members and adults with CF.

²The stakeholder group consisted of adults with CF, parent caregivers, members from adult and pediatric multidisciplinary care teams, representatives from specialty pharmacies, pharmaceutical manufacturers and CF Foundation leadership.

Findings from people with CF and family caregivers indicated that the "take your meds" message, or what one person with CF called "the dreaded adherence talk," often falls flat. Care center teams agreed with individuals with CF and family caregivers that it is not easy to have an open, honest conversation about sustaining the full range of daily CF care: medications, nutrition, exercise and airway clearance techniques (ACTs). For example, care team members and adults with CF both recalled times when they wanted to address the issues pertaining to sustaining daily CF care, but were unsure of how to initiate the conversation or if it was even their place to do so.

Literature

The literature on patient-provider communication supports the community's feedback that these one-on-one conversations in health care settings can affect adherence to treatments: "The quality of patient-provider communication has been identified as an important and potentially modifiable factor associated with improved patient outcomes."³ In this instance, patient-provider communication — defined as shared-decision making, patient-centeredness and empathic support — is associated with improved adherence in patients with chronic diseases.⁴

Patients who report having adequate communication with their providers are more likely to be satisfied with their care and to adhere to the prescribed treatments.⁵ In addition, research suggests that it is not solely the physician-patient relationships that are important, but also the relationships patients have with various health care team members.⁶ This applies to CF care centers where patients and families experience a range of conversations with the multidisciplinary care team members through their care experience.

A Communications Pilot Is Born

To ensure that the voice and perspectives of the partners in the care conversations were heard, the CF Foundation brought together adults with CF, family members, care team members and experts in a collaborative effort to create, design and test language and materials over the course of several months. The aim of this pilot was to determine if patient-provider conversation centered on the topic of sustained adherence to daily CF care could be influenced by a collection of communications tools and, more broadly, to collect additional information on how these conversations currently take place between adults with CF and their care team members.⁷

Care team members and adults with CF reported that there have been times when someone may have wanted to say something about issues pertaining to sustaining daily CF care, but they were unsure of how to start the conversation.

³Schoenthaler, A., Allegrante, J. P., Chaplin, W., & Ogedegbe, G. (2012). The effect of patient-provider communication on medication adherence in hypertensive black patients: Does race concordance matter? *Annals of Behavioral Medicine*, 43(3): 372–382. doi: 10.1007/s12160-011-9342-5. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3665951/pdf/nihms462927.pdf>

⁴Haskard-Zolnierk, K. B. & DiMatteo, M. R. (2009). Physician communication and patient adherence to treatment: Meta-analysis. *Medical Care*, 47(8): 826–834. doi:10.1097/MLR.0b013e31819a5acc. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2728700/pdf/nihms109392.pdf>

⁵Ha, J. F., & Longnecker, N. (2010). Doctor-patient communication: A review. *The Ochsner Journal*, 10(1), 38–43. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3096184/>

⁶Carlisle, A., Jacobson, K. L., Di Francesco, L., & Parker, R. M. (2011). Practical strategies to improve communication with patients. *Pharmacy and Therapeutics*, 36(9), 576–589. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3278143/pdf/ptj3609576.pdf>

⁷The dyad between adults with CF and their adult care teams was chosen for this first pilot to understand the intricacies of the patient-care team relationship.

Six care center sites—all members of the Success with Therapies Research Consortium (STRC)⁸ and varying in size, geography and patient populations—volunteered to participate in this pilot project. There were also six different types of materials utilized in this project, allowing for versatility in use and greater exposure to the language on the materials. Each center was able to implement this program according to their own preferred clinic flow. Throughout the pilot, patient and care team feedback was solicited. The following pages will describe the process in which the design, goals, implementation and findings were set for this pilot.

COMMUNICATIONS PILOT PROJECT

The pilot project was designed to test the potential impact that a collection of communications tools, or “triggers,” could have on conversations between care team members and adults with CF during the care center visit. A community-based participatory research approach⁹ was used to create the communications tools, employing the expertise and practical input of CF clinicians and individuals living with CF. This pilot was grounded in communications best practices,¹⁰ taking on an innovative approach as it was being introduced to the CF community for the first time. Quality improvement methods were applied throughout the design and implementation process to reflect the style and preferences of each care center. Multiple evaluation measures were used to collect data throughout the duration of the pilot.

Timeline Summary



Tool Development and Logistics

The six adult CF care programs from the STRC who volunteered received a grant for their participation.

1. Johns Hopkins Cystic Fibrosis Center – Baltimore, MD
2. Boston Children’s/Brigham & Women’s Adult CF Program – Boston, MA
3. Women and Children’s Hospital of Buffalo Adult CF Program– Buffalo, NY
4. Northwestern University Adult CF Program – Chicago, IL
5. National Jewish Hospital Adult CF Program – Denver, CO
6. University of Kansas Medical Center Adult CF Program – Kansas City, KS

An adult with CF and care team member were appointed as representatives and project leaders, respectively, from each site to lead the pilot project development and implementation process at each care program. Project leaders represented members of the multidisciplinary care team and included social

⁸ The Success with Therapies Research Consortium (STRC) is the research arm of the Partnerships for Sustaining Daily Care initiative. For more information on the STRC, visit our website: <https://www.cff.org/Our-Research/For-Researchers/Success-With-Therapies-Research-Consortium/>

⁹ Community-based participatory research enlists the expertise and experience of community members to inform and direct programmatic elements. For this pilot, the language and structure of this pilot project were created and implemented by the community members who were the focus of this pilot project.

¹⁰ American Academy of Family Physicians Division of Medical Education, Family Medicine Interest Group. *Tips on building doctor/patient relations*. Retrieved from: http://www.aafp.org/dam/AAFP/documents/medical_education_residency/fmig/tips_relationships.pdf

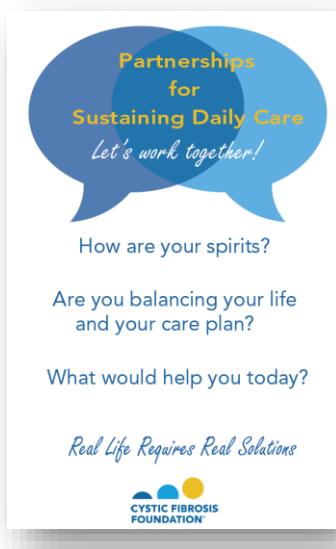
workers, physicians, nurse coordinators and respiratory therapists. The working groups were charged with informing the development of the communications tools through a series of conference calls and web chats.

The materials were designed to trigger a conversation around sustaining daily care between the adult patients and members of their care team during a clinic visit. Ongoing discussion among participants at the participating CF programs was facilitated through Yammer (an Office 365 social media platform) and moderated by CF Foundation program leaders. Through the “Prototype Review” group on Yammer, adults, clinicians and CF Foundation staff were able to comment on the tools in real time.

The final iterations of the tools were produced and distributed to the project leaders at each care center and to all of the adults with CF in the working groups. The intended audience and the suite of material were as follows:

For use by care center teams in the care center environment:

1. Poster (Format: 11" × 17", laminated; Quantity: 5-10 to each site)
2. Tent card (Format: laminated, three-sided; Quantity: 5-10 to each site)
3. ID badge (Format: two-sided, plastic; Quantity: 3-5 to each site)



For use by adult patients (given by a care team member during visit):

4. Sticky-note pad (Format: 3" × 4", color;
Quantity: 75 to each site)
5. Magnet (Format: 3.5" × 5", laminated;
Quantity: 75 to each site)



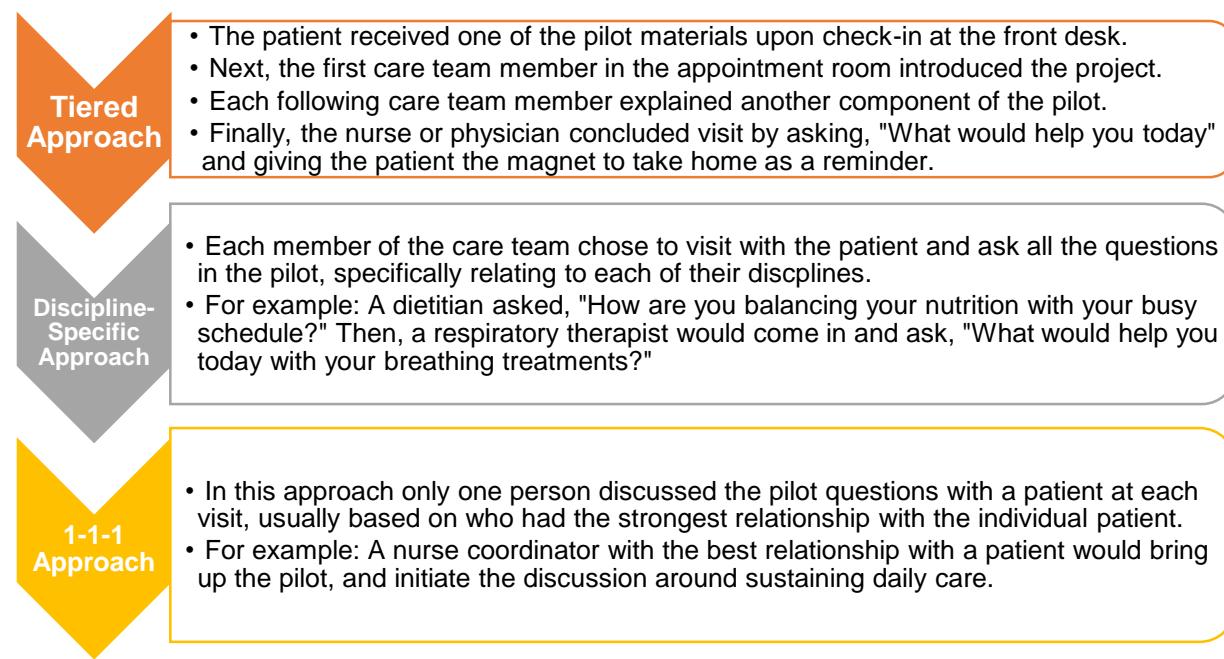
An instruction guide was included with the materials to help project leaders orient their team members to the pilot. Informed by the literature on patient-provider communication, the guide provided an example of scenarios of how to use the messages featured in the tools. Care team members were encouraged to adapt the materials to their specific styles, needs and preferences, and to apply to each of their patients with CF.

Launch

With the instruction guide and communications tools in hand, the working groups and members of their respective care teams from all six pilot sites took part in a video conference. In this, the groups reviewed the materials and their intended use, implementation logistics, tips for communicating with patients, the instruction guide and any outstanding questions implementing teams had concerning the pilot. During the video conference, care teams were coached on how to implement the project using the 1-1-1 method: where one provider reached one patient per one clinic day. However, because of the variation in clinic flow at each site, teams were encouraged to implement the pilot into their clinic workflow and make it fit with their style. The pilot project launched on November 17, 2015, after the video conference.

Implementation

The actual implementation at the centers occurred in three distinct ways:



Care center teams reported that implementing the pilot was gradual and required an iterative approach. There were different reactions to the materials from the various care team members. Some felt that they were able to confidently administer the materials and initiate conversations, whereas others felt that they needed more training to do so. Many care team members reported that these conversations required more time in the appointments, and as a result, the pilot was hard to implement with every patient due to limited amount of time available in clinic. When patient volume was high, the pilot was not implemented with every patient. Additional barriers to implementation were addressed as they arose: for instance, if care teams were unable to use all of the materials in their shared clinic space, such as the posters, they were given more of the materials that they could use and easily transport, such as the tent card or ID badges.

Project leaders at each care center were asked to provide updates throughout the duration of the pilot. Team members were encouraged to share pictures and exchange ideas of how the tools were used, the nature of the sustaining daily care conversations they had, and any questions that arose, which they could share through the Yammer platform. (Emails were used by those who could not access Yammer.)

Evaluation

The pilot was evaluated with three methods: a patient survey, a care team survey and in-person interviews during site visits.

Surveys were designed to collect feedback from adult patients and care team members who represented the patient-clinician “partnership.” The aim was to describe the one-on-one conversation around sustaining daily care, what the partners regarded as a productive or unproductive conversation, and whether they felt the communications materials were effective at triggering these conversations. Survey items included specific questions about the individual materials, conversation preferences around sustaining daily care and perceived self-efficacy for having productive conversations for clinicians. The following is a breakdown of each survey design:

Patients	Care Team
<ul style="list-style-type: none"> • 10-minute, 10-item survey • Completed after receipt of materials • \$10 Amazon or CVS gift card provided • Paper or online option (Survey Monkey) 	<ul style="list-style-type: none"> • 10-minute, 18-item survey • Completed at the end of the pilot • No additional incentive offered outside grant • Paper or online option (Survey Monkey)

A 20 percent response rate (100 completed surveys out of approximately 500 materials deployed) was the anticipated goal for patients, and a 60 percent response rate of care team member surveys from each site (five respondents out of 8 to 10 at each site) was anticipated.

Site visit debriefing guides were developed based on quality improvement and program evaluation best practices. The aim was to learn how the project was implemented and what environmental factors contributed to the pilot results. In-person interviews were conducted during the site visits with members of the care teams, both individually and as a collective, and with the individual patients during a typical care center visit.

Results

Of the six pilot sites, on-site interviews were successfully completed with five care center programs. An in-depth interview with the project leader and supporting members of the care team at the sixth site was conducted using BlueJeans, a video conferencing platform.

As the pilot concluded toward the end of January 2016, results were collected and synthesized. The main themes and ideas are further addressed in the following sections.

Results Summary
60 interviews were conducted during the site visits.
127 patient surveys were completed (25.4 percent response rate).
19 care team surveys were completed (63.3 percent response rate).

FEEDBACK

Feedback about the communications pilot supported evidence that the communications tools had some traction in triggering a conversation around sustaining daily care during a care center visit. Both sides of the partnership indicated that they desired to have productive conversations about sustaining daily care with the other party. Patients indicated that they were interested in improving their adherence rates by having productive conversations with their care team members. Care teams reported interest in building and strengthening relationships with their patients and reported the need for better tools to do so.

The Communications Bottom Line

The communications pilot triggered conversations about sustaining daily care and revealed barriers that could prevent productive conversations from occurring between adults with CF and members of their care teams. For patients, barriers included circumstances or events in their lives that impacted their schedule or physical ability to complete their treatments. These particular barriers were ones that their care teams would not necessarily know about unless they asked directly.

Care teams revealed that although components of the materials could be improved, the concept and intent behind the materials were effective at triggering conversations with patients to reveal the presence and overall nature of barriers to adherence. Care team members found that deliberately asking their patients about their challenges to balancing care and life, and subsequently addressing those challenges, proved to be a successful way to promote productive conversations. This led to an overall better understanding of the root causes of challenges in sustaining the daily treatment regimen.

Patient Reactions to the Tools

Overall, patients valued their participation in this pilot project as reported in surveys and interviews. Many were eager to provide feedback on the tools and felt that the pilot offered them a unique opportunity to share their thoughts on something that could have a real impact in helping them discuss adherence issues with their care team. Highlights from their feedback about the communications tools are as follows:

PILOT MATERIALS	MATERIAL DESIGN	PILOT WORDING
They were generally helpful and appealing.	Graphics could be more modern.	Verbatim script was unnatural, especially "How are your spirits?"
Magnets should have contact information. People don't use sticky notes that much anymore.	Messaging of graphics was unclear.	Care team member delivery worked better when it was organic and not forced.
They were eye-catching and interesting to look at in exam rooms.	The word bubbles indicating partnership were appealing.	Wording should be personalized per patient.

"With patients it [has] uncovered stuff that it wouldn't have otherwise ... it brought up topics [and] we were able to [help] them be more compliant by addressing those topics."
- Respiratory Therapist. University of Kansas

Care Team Reactions to the Tools

Care team members similarly expressed enthusiasm in their interviews and survey responses, reporting that they wanted to learn more about how to support their patients and to build stronger, more personal relationships to address concerns or difficulties in sustaining daily care and balancing busy lifestyles. Highlights from their responses are as follows:

PILOT CONCEPT	MATERIAL TYPES	PILOT FORMAT
Care teams liked the intent and idea behind the materials.	Sticky notes felt like giving patients "homework."	The wording had a mixed reception — some people loved it and others hated it.
They found the delivery a bit awkward as they did not know whether to deliver wording by script or to weave into conversation.	Magnets were more appealing than the other items.	Care teams would like to use this on a periodic basis, not every clinic visit.
Materials were eye-catching and served as triggers to open up conversation.	Those who can hang posters found them useful and appealing.	Liked multiple material options — each care team had a different preference for materials.

FINDINGS AND IMPLICATIONS

The ultimate goal of this initiative was to learn more about conversations in care center visits to better understand the partnership that exists between patients and care teams. The feedback from this pilot project not only provided rich information on the specific conversation starters tested, but it also uncovered feedback on the relationships between care teams and patients. From this feedback, some main themes emerged that provided insight about how these conversations are best supported in clinic visits.



Customize the Approach

During implementation of this pilot project, care team members took different approaches to initiate these conversations. Patients and care teams shared their feedback about these various approaches and indicated several areas where they worked well and where they could be improved.

First, patients and care team members indicated that prior to having these conversations, it is important that the care team member have context into the patient's life. Patients report coming to care centers anxious and worried about their test results

and health status, and some days they may feel confident about their health whereas other days they may not. They reported that they want their care team to understand what is happening in their lives and tune in to how they are feeling during each visit so team members can adjust how they approach the patient

accordingly. Care teams echoed this sentiment stating that to build strong relationships with patients, it is important to understand where each patient is coming from so the team member can better provide resources and support that truly take into account each patient's perspective and personality.

Second, to feel comfortable knowing the patient's perspective, care team members reported that preparation is key. When they were able to learn about what was happening in a patient's life during a multidisciplinary team meeting, care team members were able to better contextualize why a patient may be struggling with sustaining their treatments. Conversing with other team members, especially those who have the best relationships with the patient, before a clinic visit is critical to help frame the mindset of the clinicians to better understand the needs of the patient.

Key Takeaways on Approach

- *Know the person before the patient*
 - As preparation for each patient visit, care teams can brief each other to learn something personal and non-medical about the patient (like a family pet's name or the patient's major in college) that helps put the patient's life into perspective as it relates to his or her ability to manage CF.
 - Clinic schedules tend to be busy and, at times, chaotic, but if care team members are able to connect with the patients on one or more non-CF-related topics, then they can learn more about the patients and the context of their CF within the greater context of their life.
 - Examples of such details are "*Sarah is getting married next month and is very stressed.*" or "*Sam started a new job and may be struggling to do all of his treatments because he has a 2-3 hour commute each day.*"
 - Having just one way to connect with a patient outside of their CF and to contextualize how the patient views their CF as part of a larger life, can lead to deeper connections and more productive conversations.

- ❖ Try to follow the patient's life
- ❖ Try to understand the patient's perspective
- ❖ Put the visit in the context of the patient's

"It is important to understand the patient's lifestyle if you are going to understand their wishes for their care."

- Care team member at Women and Children's Hospital of Buffalo

Structure of the Visit (Who and When)

Overall, care teams and patients agree that in-person care center visits provide the best opportunity to have productive conversations around adherence. They also agree that the order and continuity in which these conversations take place during the course of the visit are important.

When care team members initiated the conversations with patients when they first entered the room, they reported that they had more successful discussions with patients. By uncovering barriers in their patients' lives at the beginning of a visit, care teams were afforded more time to address those barriers throughout the course of the visit. Similarly, patients reported that when the care team member started the conversation

“with a hand on the door,” they felt less comfortable bringing up new concerns. Care teams agreed that when the questions were asked at the end of a visit, they did not elicit the best responses.

In addition, the order and structure of each individual care team member entering the room and having these conversations matters. Patients reported that continuity between clinicians — each team member being able to share with each other and communicate priority topics — was important in helping them feel confident in their partnership with their team. Although the sequencing of members seeing the patient varied by site, some care team members recommended that each clinician touch base, as much as possible, with each other to share what they learned from their own conversation with the patient. This helps frame the next conversation and provides a level of continuity for patients throughout their care center visit.

“It would help if talking about how I’m doing emotionally/mentally was made a part of each clinic visit. I often feel like I’m there strictly to talk about my physical symptoms and my CF as it’s presenting itself, but not how I’m handling everything else that having this disease entails. So if that was brought up to me by my care team on a regular basis, I might start feeling like that was something they cared about, too.”

- Adult with CF

Key Takeaways on Structure

Patients and care teams both remarked on the importance of structuring the care visit to ensure that these sustaining daily care conversations can happen with enough time to discuss possible realistic solutions, without feeling rushed.

- *Start conversations when entering the room*
 - Care team members can “set the stage” of the conversation by using the wording, “How can I help today?” or “How are you balancing everything?” as openers. These open-ended questions frame the conversation to reinforce that the care team member is there to partner with the patients and to help put them at ease about the concerns of their visit.
- *Apply quality improvement (QI) best practices*
 - Care teams can apply established QI methods to inform ways to efficiently integrate conversations around sustaining daily care into the current clinic flow. Using QI best practices can reinforce the way clinic is structured and the ability of the care team members to make the most of their clinic time. It can help with small tests of change and tweaks in behavior or flow to find what works best for the team and the patient/family.
- *Leverage unique relationships and roles*
 - Care teams can work together to identify who among them has the best relationship with individual patients or is best positioned to initiate the discussion on sustaining daily care.
 - Care teams can take advantage of pre-clinic huddles to provide each other with quick briefings on each patient. They can also connect between team member visits to reinforce a collaborative zone within the center, which, as a result, supports the whole team and fosters efficient practices.

- ❖ Order of conversation matters
- ❖ Maximize clinic time by sharing with each other
- ❖ Deliberately structure the clinic visit

- *Care teams can share with each other*
 - Care centers can share with each other about their challenges and successes with difficult topics and conversations with their patients. Understanding that other centers may be facing similar issues helps contextualize each site's problems and gives them the tools to troubleshoot and learn from each other.
 - Having a fully accessible team and a strong team dynamic supports a cohesive and continuous environment in which patients feel confident and comfortable being open and honest with all members of the care team.
 - For example, it may be hard for a patient to connect with a team member they only consult with once or twice a year. Those team members who see patients at every visit may be better able to establish and nurture these relationships.

Terminology: Words Matter

Discussing complicated matters with patients can be a sensitive area for care team members. Asking the right questions can trigger a conversation in which patients provide valuable insights into how they are managing their daily treatments. The words and how they are emphasized can affect the way a patient responds.

Feedback from both patients and care teams indicated that the response to the wording used in the materials varied. Some patients reported that delivery of some questions, such as "How are your spirits?" seemed contrived and unnatural coming from most clinicians. Some care team members found that a few questions were more effective, such as "How are you balancing everything?" and "What would help you today?" These questions, when delivered in a welcoming tone, elicited positive and honest responses from patients, according to care team members.

When discussing the subject of sustaining daily care, care team members reported that acknowledging adherence in terms of "good" or "bad" days rather than "compliance" or "non-compliance" led them to have more productive conversations with patients. When the care team recognized that sustaining daily care has cycles of ups and downs, it put patients at ease to where they felt understood rather than judged.

Patients are interested in having these discussions, but sometimes have negative associations with the medical terminology used in these conversations. Care teams reported that switching up their language, as well as personalizing their questions, was most successful in helping patients open up.

Key Takeaways on Terminology

Asking the right questions can trigger a conversation in which patients provide valuable insights into how they are managing their daily treatments.

Acknowledging that each patient has good and bad days can minimize instances in which the patient feels as if he or she is always being judged and makes it easier for the care team member to work with the patient on potential solutions that enable the patient to overcome barriers in each visit.

Using words and phrases to normalize the lived experience of someone with CF can have positive effects. Care teams can use language that helps the patient feel less alone and that they are not the only ones struggling with managing

- ❖ Word choice and delivery of words matter
- ❖ Conversations are a two-way street
- ❖ Recognize cycles in adherence

everything. Some phrases could be, “A lot of patients struggle with...” or “Many patients do not like the taste of this medicine, so they have a hard time taking it regularly.” Using language to create a safe zone for a patient to admit they are not 100 percent adherent, because no one is, can lead to positive conversations and outcomes, as reported by patient and care team respondents.

- *Acknowledge that 100 percent is a goal, not a given*
 - Care teams can help promote a judgment-free zone by acknowledging that no one is 100 percent adherent all of the time.
 - Patients may not feel comfortable sharing their drawbacks if they think they'll be judged or that they'll disappoint their clinician.
- *Care teams can use different language to describe adherence that fosters a sense of realism rather than judgment.*
 - Instead of using “adherence” try “sustaining daily care.”
 - Instead of asking why they aren’t doing something, ask what is getting in the way of their ability to do something.
- *Ask the right questions and become better listeners*
 - Care teams can adopt some of the more successful wording from this pilot, such as “How are you balancing everything?” or “What would help you today?” and can share the results of those conversations with other care team members, presenting a rich opportunity for sharing.
 - In addition, training to develop specific listening and response skills can help care team members foster a more non-judgmental “zone” by being able to pick up on certain cues that would inform a more helpful response.

“How are your spirits? is a question that we don’t typically ask and I think people responded to it and gave us info that was useful and that we wouldn’t otherwise hear back.”

- Physician, Johns Hopkins Adult CF Center

Troubleshooting: Being Prepared for the Unexpected

During care center visits, care team members may not always feel prepared to address certain issues as they arise due to a variety of factors, such as busyness of clinic, nonchalance of the patient or joint misunderstanding of root causes. However, as patient survey respondents indicated, there is value in acknowledging when issues are complicated so that patients feel validated and encouraged to work with their care team member to identify realistic solutions, leaving them feeling more satisfied with their care.

Care team members reported that difficult conversations often reveal insights into why a patient may not be adhering to recommended treatments. Often these insights included mental health issues that the care teams were not ready to adequately address. Patients reported that they avoided certain topics because they were not able to do everything their care team recommended and often felt guilty that they were unable to do everything. Patients and care teams report that there are a variety of factors for why patients may not be adherent, and, together, they are interested in discussing what patients’ options are to improve their ability to adhere.

Care team members said that it is important to normalize the disease process for patients. As both sides reported, living with a chronic disease is difficult, and everyone struggles with being able to maintain

everything. When care teams offered the opportunity to troubleshoot with patients about the feasibility of some of the prescribed treatments, they reported that patients were more forthcoming with information and were realistic about what they were comfortable doing in their care regimen.

Although some care team members felt comfortable discussing barriers and troubleshooting solutions, others were less confident. They cited a number of barriers for themselves that made it hard for them to conceive of solutions to more complex problems such as not enough time, not enough training, new relationship with patient, etc. As one way to address this, clinicians recommended supporting each other, embracing a team approach with shared expertise to cover different aspects of sustaining daily care.

Finally, care team members recognized the importance of negotiating and setting realistic expectations about what aspects of a care plan a patient is able and/or willing to do. Clinicians felt it was important to learn from patients what their preferred care structure is, what their motivations are, what is happening at home and what they are willing to do. Being able to troubleshoot with patients to determine realistic management of their disease is critical in the conversations about sustaining daily care, as reported by care team members.

Key Takeaways on Troubleshooting

Due to the complex nature of living with CF, issues may arise that require more support than a care team member can provide alone. Knowing when to ask for help can be a critical way that care teams continue to support their relationship with their patients and families and with their colleagues. Working together to address barriers to sustaining daily care can also lead to optimal solutions for those barriers.

- *Leverage the collective expertise of the care team — starting with the patient*
 - Patients are the experts of living with their disease and can help their care team identify barriers to adherence. The shared experience of both the care team and the patient/family can lead to a rich conversation in which a sustainable, realistic treatment plan is achieved.
 - Care team members can leverage each other's clinical expertise and triage to the appropriate team members to follow up with the patient.
 - Additionally, the care team has the benefit of working with many other patients or families – and can pass along these examples to the single patient or family member who may feel isolated in their personal issue.
- *Take advantage of time outside of a care center visit*
 - Care teams can develop action plans beyond the care center visit with patients to address complex issues that require more time or resources.
 - Opportunities for further follow up and action steps can be done via phone, email or text message, depending on individual team capabilities, capacities and patient preference.
- *Leadership buy-in*
 - Leadership has to “buy-into” partnering with patients by fostering a supportive team environment where experienced team members can coach newer members in engaging patients in productive conversations around sustaining daily care.

- ❖ Adherence covers a wide range of topics
- ❖ Normalize disease process for patients
- ❖ Problem solve with patients

- *Remember to be in the moment*
 - Busy clinic days with many different patients can make it hard to connect with individual patients. Use visual cues, such as the communications tools tested in this pilot, as reminders to initiate the conversation in the frame of mind that is most conducive to a productive dialogue on sustaining daily care.

"If you tell me you're doing your treatments four times a day and you're sitting here with a 50 percent drop in your lung function, it's going to be hard for me to figure out what to say or do. But, if you sit here and say, 'Eh, I'm only doing it just three times a week,' I'll say, 'OK, great. That gives me a bigger playing field to figure out where to go and figure out what we are going to do to make it better.'"

- Nurse Coordinator at Northwestern University Adult CF Center

Openness: Setting the foundation for stronger relationships

Interwoven in all of the previous themes is an openness to connect, primarily on the part of the care team members because they have the opportunity to help put the patient at ease and set the tone of the relationship. Patient survey respondents reported that accessible and approachable care team members made the patients feel more comfortable sharing their barriers. Care team members want patients to know that they have a shared interest in the patient's health outcomes. Patients want to know more about their care team members—as people—to help humanize the clinician beyond just someone they see a couple of times a year.

Patients and care teams indicated that a successful partnership to sustaining daily care requires a level of openness and two-way conversation. Patients reported feeling more comfortable discussing barriers to sustaining daily care when they felt that their care team members were more open to suggestions and less judgmental. Conversely, care teams reported that when they connected with patients on a personal level, it helped them foster a judgment-free zone where patients could bring up any questions or concerns.

Care teams can foster a “family” sense for each other in the center by supporting each other in their conversations with patients and in their interactions with each other. Care team members also reported that when they felt a stronger, more collaborative bond with their fellow team members, they were more confident in their ability to successfully meet their patients’ needs. Self-efficacy levels to tailor clinic processes were found to be generally high among care teams; however, individual team members may need greater support and validation from their colleagues to foster a stronger sense of openness among their shared patients.

Both care teams and patients reported that strong relationships take time and trust to build, and are made possible when the other person is personable and open—allowing for free-flowing, honest conversations. Relationships happen between people, and patients and care teams can build deeper relationships by seeing the person behind the title. Care team members can refer to each other by name or share something about each other in conversation with patients to share a more personal side of their role. Care teams and patients cultivate relationships over time and should understand that flexibility and patience are key for both sides to understand and assess each other’s personalities and preferences.



These findings have identified the components that help explain the complexity of the one-on-one conversation around sustaining daily care between adult patients and care team members during the care center visit. Each domain showcases the depth of knowledge that each patient and care team member can bring to the conversation, and identifies ways in which they can both work to help support these partnerships.

CONCLUSION

Overall, this pilot project yielded a number of insights and implications that address the one-on-one conversations that occur between a patient and a member of a care team. Each area explored in these findings comes directly from synthesized patient and care team feedback. Patients and care team members understand the importance of partnering with each other to achieve optimal health outcomes, but they do not always feel confident in their ability to further these conversations and to strengthen that partnership. Also, at the core of productive conversation is a strong relationship, and patients and care team members have identified these relationships as critical to setting the stage for a productive conversation about adherence and barriers. Although patients and clinicians have a shared goal of promoting positive health outcomes, and they want to work together, there is much that can be done to make the most of a care center visit where these conversations take place.

Moving Forward

Moving forward, community stakeholders will be engaged to further apply these pilot learnings into interventions as part of the PSDC initiative. This iterative, community-based approach is critical for being able to hear directly from the care team members and adults with CF for whom these interventions are intended. Embedding these interventions into routine CF clinical practice and patient self-care requires continuous discovery, measurement and refinement of tools, resources and training — all done with mutual respect, flexibility, acknowledged expertise and sustainability in mind – as all partners work toward the shared goal of improving the health and total well-being of all people living with CF.

"Building relationships has to be longitudinal — we have to understand where the patient is each time they come into the clinic, hold them accountable and adjust to fit their needs and to understand more about them as we go. It's got to be nonjudgmental from my side because I only see a snapshot of [their lives] rather than what happens day in and day out. We do everything we can at every point, but not cling onto what we weren't able to do."

- Physician at National Jewish Health

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- Ahmet Uluer, D.O., and Boston Children's Adult CF Program team members
- Sue Sullivan, R.N., and Johns Hopkins Memorial Adult CF Program team members
- Cara Gomez, R.R.T., and National Jewish Health Adult CF Program team members
- Abby Moog, L.M.S.W., and University of Kansas Medical Center Adult CF Program team members
- Carla Frederick, M.D., and Women and Children's Hospital of Buffalo Adult CF Program team members
- Melanie Abdelnour, adult with CF, Boston
- Naomi Feltz, adult with CF, Buffalo
- Anna McVey-Tyson, adult with CF, Denver
- Adam Dennison, adult with CF, Kansas
- Janet Kindred, adult with CF, Baltimore
- Jessica Glowinski, adult with CF, Chicago

The Partnership for Sustaining Daily Care team for support with logistics, planning and evaluation

Additional Resources

All of the tools and materials used in this pilot project are available to those interested in reviewing them. Due to their volume, they have not been included in this report. The following tools are available upon request to Katherine Raymond (kraymond@cff.org) or PSDCteam@cff.org

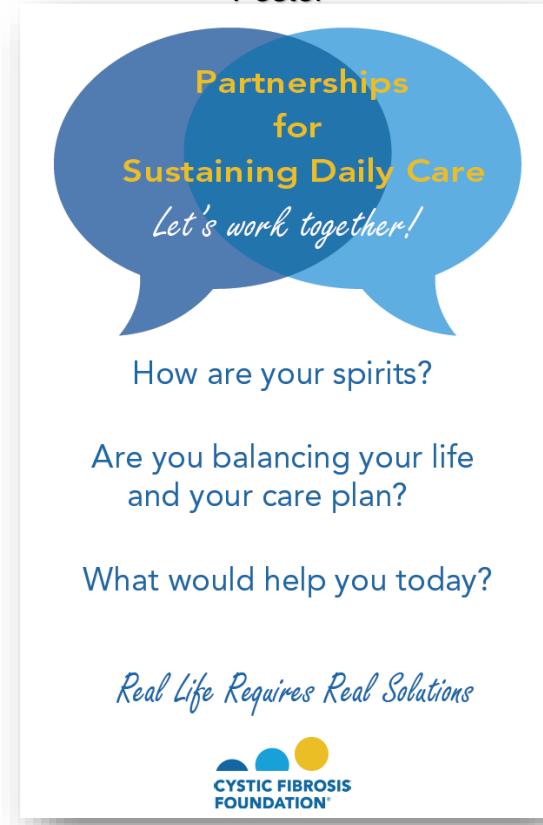
- **Pilot Project Development:** Instruction Guide
- **Evaluation:** Patient Survey, Survey Monkey Survey And Care Team Survey
- **Launch:** Webinar Slides
- **Site Visits:** Site Visit Guide, PSDC Overview
- **Debriefs:** Presentations
- **Survey Responses:** Patient Verbatim And Care Team Verbatim
- **Yammer:** Prototype Review

Index

Materials (*True sizes not shown*):

- 500 sticky note pads – 75 to each site
- 500 magnets – 75 to each site
- 50 posters – 5-10 to each site (depending on preference)
- 30 hospital ID badges – 3-5 to each site (depending on preference)
- 30 tent cards – 5-10 to each site (depending on preference)

Poster



ID badge



Magnet



Tent card



Sticky note



Participating Care Centers



Northwestern University Hospital Team



Brigham & Women's— Multidisciplinary meeting



Johns Hopkins Memorial Hospital Team



University of Kansas Medical Center Adult CF



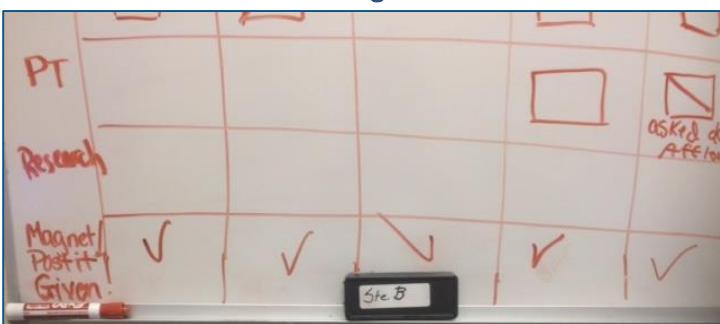
National Jewish Health Hospital Team

(Not pictured) Women and Children's Hospital of Buffalo

How Care Teams Implemented the Project



How Care Teams Tracked Progress



How the Materials Were Organized

