CF PCOR Training Manual

Step 2: Launch

This section is tailored primarily to CF researchers and the steps they should take after preparing their teams and institutions for PCOR. These are essential first steps in creating a successful PCOR team. For the purposes of this document, when the term "partners" is used, it is inclusive of patient and caregiver partners.

This table of contents is a starting list for this stage, which you can adapt for your needs.

Launch Activities

DEVELOPING RESEARCH PARTNERSHIPS

Engage Partners Early

Start engaging partners as future team members and gathering ideas for research questions and studies early, before the grant opportunity is identified. Early engagement also allows the team to discuss team agreements and communication, which are detailed below.

HELPFUL HINT

- **Engage partners early, preferably before or while developing a research proposal.**
- **Use a variety of sources to find and reach out to potential partners.**

For an overview of Best Practices in Engaging Stakeholders, see PCORI's "Preparing Team Members for Partnership." https://research-teams.pcori.org/stakeholders#Practicing%20Effective%20Team%20Communication

INVITING PARTNERS ONTO THE RESEARCH TEAM

Decide on the Number of Partners to Have

Research teams should consider the number of partners to include on their team. Including several partners on a single research team can help diversify the patient voice and avoid tokenism.

Time off needed by partners is another consideration regarding how many partners to include on a research team. People with CF may have other circumstances that affect the amount of time they can dedicate to your team. Teams will want to have good partner representation should one stakeholder become unavailable.

A partner on a PCOR team was hospitalized and missed a month of developing a product for the team. Luckily, the team had a community advisory board that could represent the patient voice in the project, and the grant was not delayed.

The number of partners also depends on team resources. In general, we recommend starting small, with 2-3 partners. Teams can grow as agreements and processes are established, specific needs to conduct the research are identified, and funding is secured.

Create a Flyer to Recruit Partners

Create a flyer that outlines the partner's role on the CF Center research team. The flyer should include information about partner expectations, compensation, and time commitment. It should also include frequency of meetings and the amount of work that will be needed between meetings. It should be written in clear, easy to understand language and all acronyms should be defined.

Choose Partners

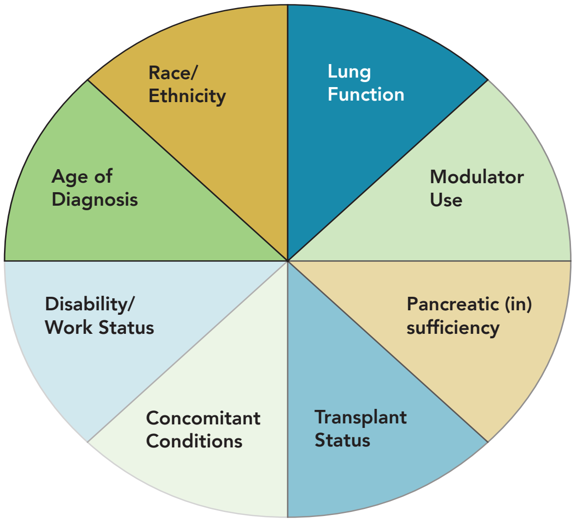
Diversifying your team can lead to new ideas and open others' eyes to different experiences that relate to the study.

Possible activities for selecting diverse partners include:

- Run an informal focus group with multiple partner applicants to see how partners interact and what skills they add to the team (i.e. some people are better at facilitation, tech, identifying research questions, etc.).
- Work with CF care centers to identify partners. Speak to potential partners to ensure the work is a good fit with their interests and abilities.*
- Generate a questionnaire that asks about basic demographic information (see fig 1). Additionally, the questionnaire can ask partners to report their skills and strengths.

*Ideas for places to recruit partners are located in the "Where to Find Partners" supplement on page 9.

Figure 1. Types of Diversity in CF



Approaching Partners in Your Own CF Center

As a physician/researcher, it may not be appropriate to ask your own patients to join your PCOR team. Some patients may feel pressured to join, and this may affect how they participate and whether they feel comfortable being honest with the group.

If you do decide to ask patients within your own CF Center, consider:

- How do you make the question as pressure free as possible? How can you show your patients that saying "no" will not affect their relationship with you or their quality of care?
- What is the best timing? It may not be appropriate to ask during a formal clinical visit.
- Think about who is best suited to address your patients. Consider medical assistants, receptionists, research coordinators, or existing team partners as potential team members to invite new partners onto your team.
- Introducing the invitation as part of an overview of the visit and following up in a few days. The end of a visit may not be the most appropriate time to invite partners because patients are often tired and mentally drained after a long day at the CF clinic. They are eager to get home to pick up children, eat, rest, or attend to other responsibilities.
- A patient who has known you longer and/or knows you better may be more comfortable being honest with their feelings about being invited to join a PCOR team.
- When you approach them, explain PCOR thoroughly. Let your partner know exactly what it is and what you are asking of them, and why you think they would be a good fit.

A research coordinator wanted to recruit a patient for a study. The CF physician/researcher suggested that the research coordinator come in and explain the study to the patient while the physician was performing a nasal exam. The research coordinator opted to come back later in the visit when the physician was not there, so the patient would not feel coerced.

CREATING A SPACE FOR EFFECTIVE PARTNERSHIP

Onboarding Partners

Onboarding partners helps to ensure that everyone, including the partners, share common language and understanding. This sets the stage for teams to co-create successfully. Onboarding for partners includes basic research training. See Table 1 in the Prepare Guide for basic research training and PCOR training resources.

The Cystic Fibrosis Learning Network (CFLN) offers helpful resources for patient/caregiver onboarding. Information about the CFLN is included in the list of Active Learning Programs facilitated by Cincinnati Children's Hospital. For more information, contact Kathy Sabadosa (ksabadosa@cff.org) at the Cystic Fibrosis Foundation. https://www.cincinnatichildrens.org/research/divisions/j/anderson-center/learning-networks/active-emerging

Create a Welcoming Environment

https:www.pcori.org/sites/default/files/TeamScience-SWOG-Field-Guide.pdf

Figure 2. Leveling a power differential on a PCOR team

To ensure honest and open input from partners, they need to feel welcome on the research team. Knowing their voices will be heard and respected encourages participation. Developing skills to create welcoming environments helps researchers obtain participation from all team members (See "Facilitation Skills" in the Prepare Guide supplement page 8).

Clarify How Equal Partnerships Will Be Established

In PCOR, patients and caregivers are active partners in research, but they may often be intimidated to speak in front of researchers. Thus, teams should incorporate processes to level the playing field so that partners feel comfortable to actively participate and offer feedback on researchers' ideas.

> *When we first started our PCOR team, partners were reluctant to speak freely in front of researchers and clinicians due to the fear that something said would get back to their CF Care Team. As a solution, only the designated PCOR champion met with partners for the first several years. The PCOR champion acted as a liaison between the researcher group and the partners until the partners felt comfortable speaking with all the researchers.*

HELPFUL HINT

Below are some questions your team may want to review to create a welcoming environment:

- **What concerns do you have about patients/caregivers as equal members of the research team?**
- **What are ways research team members can level the power dynamic?**

Some ways to create a sense of equality with partners:

- Use first names (avoid formal titles like Dr. or Professor)
- Recognize and appreciate different talents and experiences verbally or in writing
- Encourage partners to lead activities:
    - ◊ Assign partners regular team roles, such as meeting facilitator, note-taker, and timekeeper
    - ◊ Co-present with partners at conferences
    - ◊ Empower partners to write about the project/research for non-peer-reviewed publications for CF patients

Build Relationships

Building stronger relationships can help develop partners' comfort on the team. When partners are comfortable, they may give more information about their experiences. Building relationships creates team cohesion and helps avoid miscommunication. Strong relationships allow the PCOR team to work together better.

Start building relationships on your team as soon as possible. The entire team should participate in relationship building.

Relationship building can be achieved through a variety of methods. For some examples of activities you can do with your team, see the "Building Relationships" supplement on page 10.

HELPFUL HINT

Use this checklist below as a starting point for team agreements.

- **Communicate need/benefits of PCOR** – PCOR increases quality of research, trust between patients/caregivers & providers, empowers everyone in the community, and leads to greater health equity
- **Outline practices that counterbalance resistance to change** – How do we recognize that being able to speak about the lived experience of having CF is an important aspect of research?
- **Create policies that enhance accountability** – Make sure there are several CF partners on each research team to avoid tokenism. Ensure members of the research team are trained in facilitation to make sure everyone feels welcome. Include IRB policies and how to reimburse partners who are not research subjects.

Teams are motivated by passionate leaders. Share your passion about CF (care, research, patients, communities). Passionate leaders make the work more enjoyable. They help motivate their teammates to work harder and feel appreciated. The result is that every team member feels a stronger sense of satisfaction. Encouraging strong relationships and maintaining positive leadership will also promote a sense of fun and enjoyment.

It can be harder to build relationships virtually because body language is harder to read and small talk is more difficult. Consult the Guideline for Online PCOR Engagement for tips to enhance relationships online at https://familymedicine.uw.edu/pcor-guide/

HELPFUL HINT

Think about the best teams you were a part of.

- **How did you build relationships?**
- **What was most effective?**
- **When was your team most productive?**

ESTABLISHING TEAM AGREEMENTS

Team guidelines can be established through team agreements, a team charter, or a governance document. The team charter or governance document is co-created with researchers and partners and can be updated as needed.

Documenting team agreements is important before your PCOR team begins their work. A list of items to include in your governance document is in the "Generating a Governance Document" supplement on page 12.

HELPFUL HINT

For grant applications, an effective team charter, team agreements or governance document can translate into an engagement plan. Having established agreements in place shows potential funders that the engagement team is already established and is a high-functioning partnership.

Are you unsure of what your governance document should look like? Below is a table with links to governance documents from previous PCORI awardees.

Table 1. Example Governance Documents from Previous PCORI Awardees

Title	**Contents**
Governance document for Patient Outcomes Research to Advance Learning (PORTAL) Network (see appendices B, C, D) https://www.pcori.org/sites/default/files/521-PORTAL-Governance.pdf	Governance Document outlining roles, responsibilities, and decision-making
Inborn Errors of Metabolism Collaborative (IBEMC) QUEST Project Governance Document https://www.pcori.org/sites/default/files/QUEST-Governance-Document.pdf	Governance document outlining roles and expectations within the team
Patient-Centered Network of Learning Health Systems (ADPCPRN) Governance Policy https://www.pcori.org/sites/default/files/512-AD-PCPRN-Governance-Policy.pdf	Governance policy outlining roles, expectations, and study processes

Address Concerns About Confidentiality

What do we mean by "confidentiality"?

- Patient information is protected through the Health Insurance Portability and Accountability Act (HIPAA). However, when those patients and caregivers volunteer to be a partner on a research team, they are not covered by HIPPA. During your work together, they may disclose personal or confidential information about themselves as a way of sharing their experience as someone living with the disease. This information may not be shared outside the team unless partners have given explicit permission to do so (ideally in writing).

- Team agreements should articulate partner preferences for disclosure of their name and/ or photo outside the team.

A newly formed interdisciplinary research team asked three patient partners how they would feel if their names and photos were included on the institutional departmental Facebook website. One patient partner was happy to list her name and post her photo. The other two did not want their names or photos posted, because their disease was confidential from their workplace and they feared discrimination if their employers found out that they had CF. Thus, the team agreements stated that partners had to agree, in writing, to having their name and photos used on public facing websites prior to posting.

Articulate How Decisions Will Be Made

Team agreements should also include how decisions will be made.

Power and team dynamics have a strong influence on how teams make decisions and whether those decisions are made equitably. Teams should discuss approaches to decision making and agree on a process. Are there some areas where partners make decisions, but other areas where the researchers do? Groups may make decisions by voting, consensus, or a blended process. Practicing your process early and often will support the team when making decisions as a group becomes difficult.

Keep in mind that consensus is different from majority rule. Through consensus, an agreement is made that reflects compromise between all members of the group. Consensus should strive to be "win-win" and provide a decision that everyone involved can agree to. For more information about consensus see Seeds for Change's explanation on consensus decision making at https://www.seedsforchange.org.uk/shortconsensus

Write A Mission Statement

Effective teams have a shared understanding of the project, its structure, and commitments. Successful teams share a mission and purpose for the work they have come together to do.

Create A Communication Plan

A communication plan outlines how your team shares information, along with the software, that will be used for meetings and messaging. Consult the "Guideline for Online PCOR Engagement" for tips on software or programs that can enhance your team's functionality at https://familymedicine.uw.edu/pcor-guide/

Traditionally PCOR teams communicate in-person, but for CF PCOR teams in particular, communicating online allows teams to include more than one partner, avoiding tokenism. Additionally, teams meeting virtually can include members from distant locations.

A written communication plan in the team agreements includes:

- How to best communicate with partners about questions and concerns that arise between meetings. Examples include Email, Slack, WhatsApp, or Microsoft Teams.
- Ways collaborative documents will be shared with all team members. Examples include Google Docs or Microsoft Teams.
- Decisions about where to meet, virtually or in person. It is understood that most CF teams with patient partners will meet virtually. Thus, teams may also need to agree on their conferencing platform for team meetings. Examples include Zoom or BlueJeans.

Establish Meeting Times

Partners often have other responsibilities and may not be able to meet during typical business hours. Since CF is a complex disease, PCOR teams also may encounter absences due to illness. Agreements should stress that partners' health is a priority and outline how the team will navigate alternate ways to engage for partners who take time off for CF exacerbations and other health-related matters.

Ways to engage partners in regular team meetings:

- Switch up the time the team meets, or consider meeting in the evening or on weekends
- Be conscious of time zones
- Agree on earliest and latest times all members of the team are able to meet
- Record team meetings that can be watched later and commented on by partners
- Meet individually with partners, outside of meeting times
- Provide written materials about what occurred in the meeting

Other Agreements Related to Compensation and Institutional Processes

Team agreements should also include:

- Amounts and ways in which partners will be compensated.
  - ◊ The amount a partner is paid should be reflective of their contributions to the team or grant project. For examples, see the "Sample Stakeholder Engagement Plan" supplement on page 13, or PCORI's Compensation Framework at https://www.pcori.org/sites/default/files/PCORI-Compensation-Framework-for-Engaged-Research-Partners.pdf
  - ◊ Consider including compensation for work done between meetings for partners who miss meetings due to illness or scheduling conflicts.
  - ◊ Delineate how partners will invoice or be paid according to institutional policies.
  - ◊ Also see "How to Compensate Outside Community Members" in the Prepare Guide.
- Institutional processes related to IRB training or IT security (see appropriate sections in the Prepare Guide).

You have completed the Launch section.

Where to Find Partners

1. CF Listservs and nonprofit organizations
    1. Cystic Fibrosis Research Institute (CFRI) Weekly newsletter
    2. Cystic Fibrosis Foundation Community Voice
    3. Attain Health
    4. Boomer Esiason Foundation
    5. CF Roundtable blog and quarterly newsletter
2. General Research Listservs (you may need to budget these into your grant)
    1. Rare Patient Voice
    2. Savvy Cooperative
    3. WEGO Health
3. Social Media
    1. Build relationships with moderators of closed and secret Facebook groups populated by people with CF -- there are tons! You can ask your patients/caregivers for recommendations and an introduction. Some groups will not allow researchers, but your partners may post for the team.
    2. Some advice: Do not post a link to an application or survey on a public Facebook or Instagram page-- it will immediately be filled by spam bots.
4. CF Care Centers
    1. Take the time to call less-engaged patients and families. You should never feel like you are coercing patients into joining your team. If you do, we suggest having a research coordinator or other staff member approach the patient or caregiver instead
    2. Recruiting at care centers can target a diverse population of people who are not plugged into CF organizations
    3. Use caregivers to engage the unengaged (e.g. spouses, parents)

Building Relationships

Below are ideas for how to build relationships on your CF PCOR team

1. **Have social meetings to get to know one another, especially when integrating new team members.**
    a. One way to accomplish this is to regularly schedule unstructured social meetings during normal meeting times in which you agree to talk about anything but the project. This would not be a working meeting, but a meeting to get to know each other.

    b. Another way is through structured social meetings, or "team-building events." There are many ideas online for games to play in virtual meetings, questions to lead discussions, and activities to do together.

2. **Share personal information.**
    a. Researchers: do not be afraid to be vulnerable. It will help level the playing field, create a bond that keeps partners invested in the research, and humanize you as a person who exists outside of the context of the project.

    b. It shows that other team members can be vulnerable as well. This is particularly important for patient/caregiver-partners who may share deeply personal experiences and feelings about CF. Vulnerability shows that your meetings and your project are a safe and open space for everyone.

    c. Social meetings are an opportunity for this vulnerability. You can talk about your family, hobbies, or a struggle you have had.

3. **Start each meeting with ice-breaker questions.**
    a. Ask icebreaker questions at the beginning of your meetings. They are a good way to get to know one another. They help to start meetings with energy and fun and makes it easier to maintain momentum, investment, and interest as the meeting progresses. This is also a great moment to check-in with your team and see how everyone is doing.

    b. Finding icebreakers is as easy as doing a quick google search. Finding icebreakers can be a task shared and rotated throughout the team.

Example icebreakers:

- What is your favorite or most used emoji?
- If you could travel to any place in the world, without restrictions, where would you go?
- If you could have any superpower, what would it be?
- What is your favorite item you have bought this year?
- If you had to delete all but three apps on your smartphone, which ones would you keep?
- As a child, what did you want to be when you grew up and why?

If your team does not have time for an icebreaker at the beginning of meetings, consider other ways to get to know one another. An example of this may be quick bios that you share with one another. These bios should not have experience, titles, or educational background on them. Instead, they should include fun facts. You can use some of the icebreaker questions as ideas for questions to ask on these bios.

4. **Address one another by first name, no titles allowed**.

    a. Titles will make the team hierarchical and one of the main tenets of PCOR is that patient/caregiver-partners are equal members of the team.

    b. Leveling the playing field can mean that team members are more honest about their thoughts on the project and their feedback. This is particularly important in the realm of feedback. It can be difficult to provide honest feedback on a hierarchical team. We encourage continuous feedback to improve the team and team experiences.

5. **Skill share**

    a. Everyone brings experiences and skills to your team, and this includes partners. Ask team members to teach everyone their skill on a video call as a team-building event.

    b. The best way to find out about skills your team members may have is to just ask. After discussing parts of the project that need to be completed, ask if anyone has the skills to do it.

6. **Create a shared language.**

    a. Learn to communicate to the level of partners. Partners may have some training but will need time and information given to them in an appropriate manner for their level of understanding.

    b. The use of lingo and jargon can be both confusing and intimidating to patient/caregiver-partners. This is particularly important to consider as we think about partners' comfort contributing to the team. Defining acronyms like CFLN (CF Learning Network) as you speak and providing a list of acronyms partners can refer to can ensure all team members understand what is being said. The PCOR champion should also check in with partners regularly to make sure they understand everything.

    c. Foster a culture of questioning. Take the time to answer partner questions about an acronym or concept they don't understand, either verbally or in the chat box of your video conference software. If you won't have time to go over it, the PCOR champion can meet with the partner after to ensure they understand everything.

Generating a Governance Document

A governance document should include the following:

1. A Team mission statement
2. Guidelines about creating inclusive and respectful space (i.e. meeting ground rules)
3. Agreement on how the team will communicate -- this includes video conferencing software, document sharing platforms, instant messaging, email, etc.
    a. See our User Guide on the types of platforms and how to pick ones that meet your team's needs at https://familymedicine.uw.edu/pcor-guide/
    b. Identify a member to serve as a tech lead
4. Address hierarchy and create a level playing field (this includes things like being on a first name basis)
5. Sometimes people with CF get sick and team members have to be flexible when medical issues come up

Consider: The first line of an agreement should be that the team will honor partners' health

6. Frequency and length of meetings
7. Identify areas where patient/caregiver-partners will take a lead in activities (such as publishing in non-peer reviewed publications)
8. Discuss partner and other stakeholder compensation. Given the institutional barriers at the funding researchers' institution identified under the Prepare phase.
9. Evaluation
    a. Discuss how frequently you will evaluate the team dynamic
    b. Discuss if team members have other components they would like to evaluate.

HELPFUL HINT

Create processes up front to allow for make-up work, a meeting surrogate, or other ways the team can move forward without leaving the person taking time for their health behind.

This is considered a living document, and one that the group should re-visit on a regular basis. Make sure that all stakeholders have an opportunity to discuss and comment on the group vision, mission, philosophy, outcomes, expectations and roles

Sample Stakeholder Engagement Plan

Below is an example of how partners can participate on research teams at different levels of engagement. The table also outlines how partners can be compensated, depending on their level of engagement.

Engagement level	Participant Role	Responsibilities	Compensation
Occasional	Any interested person with CF	• Give occasional feedback on CF project ideas and progress; • Chat on public Facebook page, or answer online surveys. • Vote on priority areas for research.	None
Medium	Engaged researchers, consultants, and other stakeholders	• Meet with research team to discuss patient research questions. • Help translate these questions/ideas into fundable research questions. Provide feedback on the CF project progress. • Provide ideas for how to reach the greater CF community.	$20/meeting
High	Equal partner	• Drive overall direction and vision of the project. • People with CF help generate research questions. • Meet regularly during CF project. Provide input on grant applications. Attend regular project meetings, provide input into recruitment plans & materials, how to display research findings. • Help disseminate findings to CF community.	$30/meeting