



CFReSHC

Cystic Fibrosis Reproductive and Sexual Health Collaborative

Bringing Patient-Centered Outcomes Research to the and the CF Community

CFRI PODCAST
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Patient-Centered Outcomes = Stakeholder-Driven Research Research Institute

From the Affordable Care Act, 2010

“The purpose of the Institute is to **assist patients, clinicians, purchasers, and policy-makers in making informed health decisions** by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appropriately be prevented, diagnosed, treated, monitored, and managed **through research and evidence synthesis...and the dissemination of research findings** with respect to the relative health outcomes, clinical effectiveness, and appropriateness of the medical treatments, services...”



PCORI's Mission

PCORI helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from **research guided by patients, caregivers and the broader health care community.**



Shaping CFF's Program-Level Initiatives

- Broad feedback from community members helps shape CFF's overarching research priorities



Giving input on specific research projects

- Through surveys and focus groups, community members can provide their input on key study-related questions, and researchers can direct their projects towards the topics that matter most to the community



Sitting on a review committee

- Community members can review grants and protocols to ensure they are feasible and aligned with the community's needs



Working on guidelines and quality improvement

- Community members can partner with researchers and clinicians to co-create clinical care guidelines and apply the latest evidence to improvements in CF clinical care



Participatory Research and Patient Engagement

- Community members and researchers can collaborate as equal partners throughout the entirety of a research project

People with CF can help shape research in many different ways.

Community members can become engaged with this work through Community Voice and other venues.

Who are Our Stakeholders?

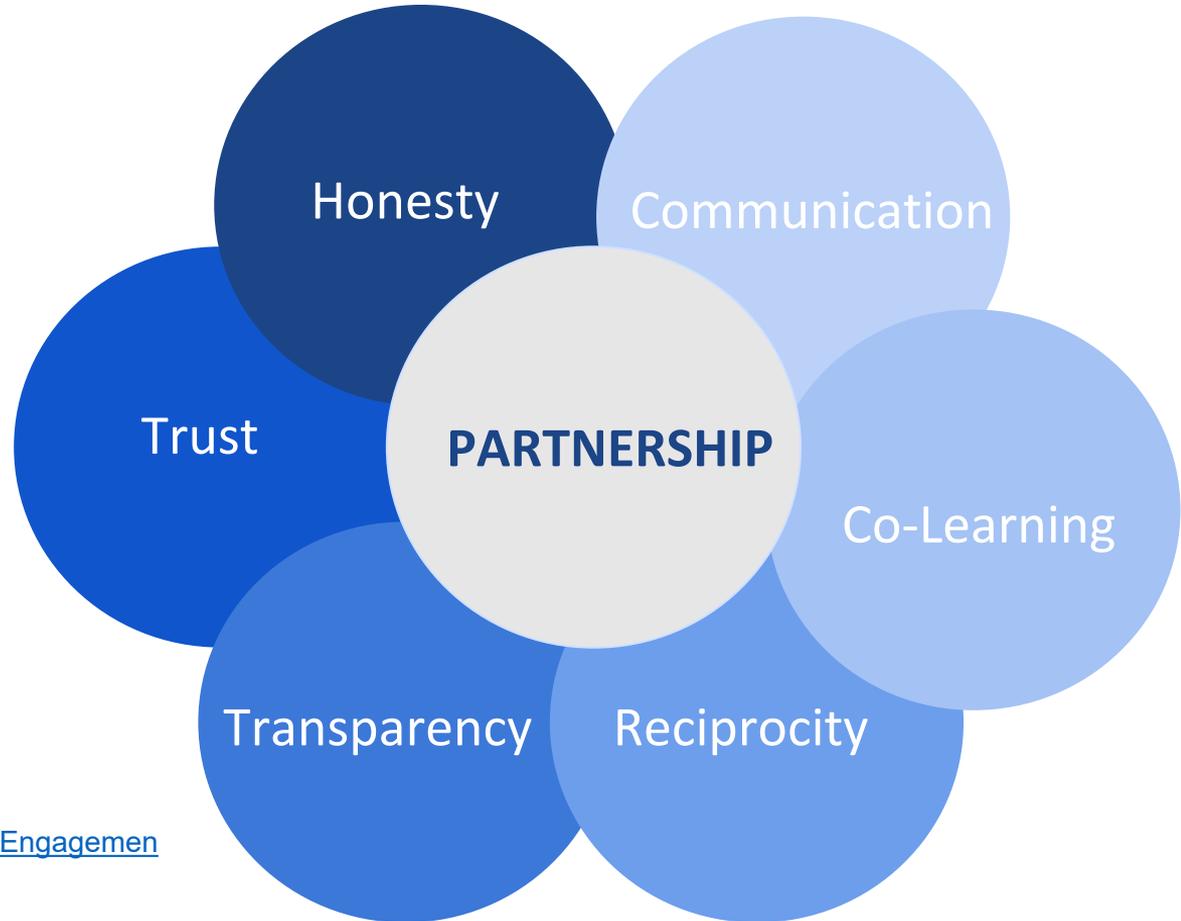


Why Engage?

- To influence research to be patient-centered, relevant, and useful
- To establish trust and a sense of legitimacy in research findings
- To encourage successful uptake and use of research results



PCOR Embodies Six Engagement Principles



Adapted from:

<https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf>

Tips for Effective Engagement

1

Assemble your stakeholder team

2

Create open communication channels

3

Address hierarchy and create a level playing-field

4

Create a welcoming environment and build relationships

5

Evaluate engagement

Adapted from: Lavalley DC, Gore JL, Lawrence SO, Lindsay J, Marsh S, Scott MR, Wernli K. Initiative to Support Patient Involvement in Research (INSPIRE): Findings from Phase I Interviews [Internet]. September 2016. Available from: http://www.becertain.org/partner/patient_advisory_network/resources.

Create a Welcoming Environment

RECIPROCITY

**PARTICIPATION
BEST PRACTICE
GUIDELINES**



**FACILITATOR
ENCOURAGES
PARTICIPATION
FROM ALL
PARTNERS**



**LEVELED POWER
DYNAMIC**

Compensation for Contributions

- PCORI recommends compensation of **all** persons contributing to the research team
 - Compensation can be in the form of:
 - Cash
 - Conference expenses
 - Access to services
 - Items needed for the work (like headphones)
 - Consider individual needs related to:
 - Supplemental Security Income
 - Social Security Disability
 - Consider different schedules for payment, deferred payments

Potential PCOR Barriers



- Avoiding ***tokenism***
- Supporting patients as ***credible participants*** especially those from vulnerable or marginalized populations
- Understanding the role of patients/caregivers on the research team as ***equal partners***
- Identifying ***ethical issues*** in having patients/caregivers on the research team
- Equitably and sustainably ***compensating*** patient/caregiver partners

Tips for Developing Research Partnerships

Engage Early.

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

Plan ahead.

- Establishing and building trust takes time. Allow for extra time to work with partners before the proposal deadline and during the study.
- Think in advance about how to financially support early engagement activities that may occur prior to receiving study funding.

Foster positive partnerships.

- Ensure that the work is a good fit with partners' interests and abilities.
- Create a welcoming environment for partners by encouraging, listening to, and valuing their input.
- Explain the research process.
- During proposal development, be open about the realistic expectation about funding.

Partnering in Research

Plan the Study

- Identify the research question
- Identify outcomes
- Craft study design
- Specify inclusion criteria
- Develop study materials

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Conduct the Study

- Assist with recruitment
- Collect and synthesize data
- Make decisions about study adjustments
- Revise informed consent materials

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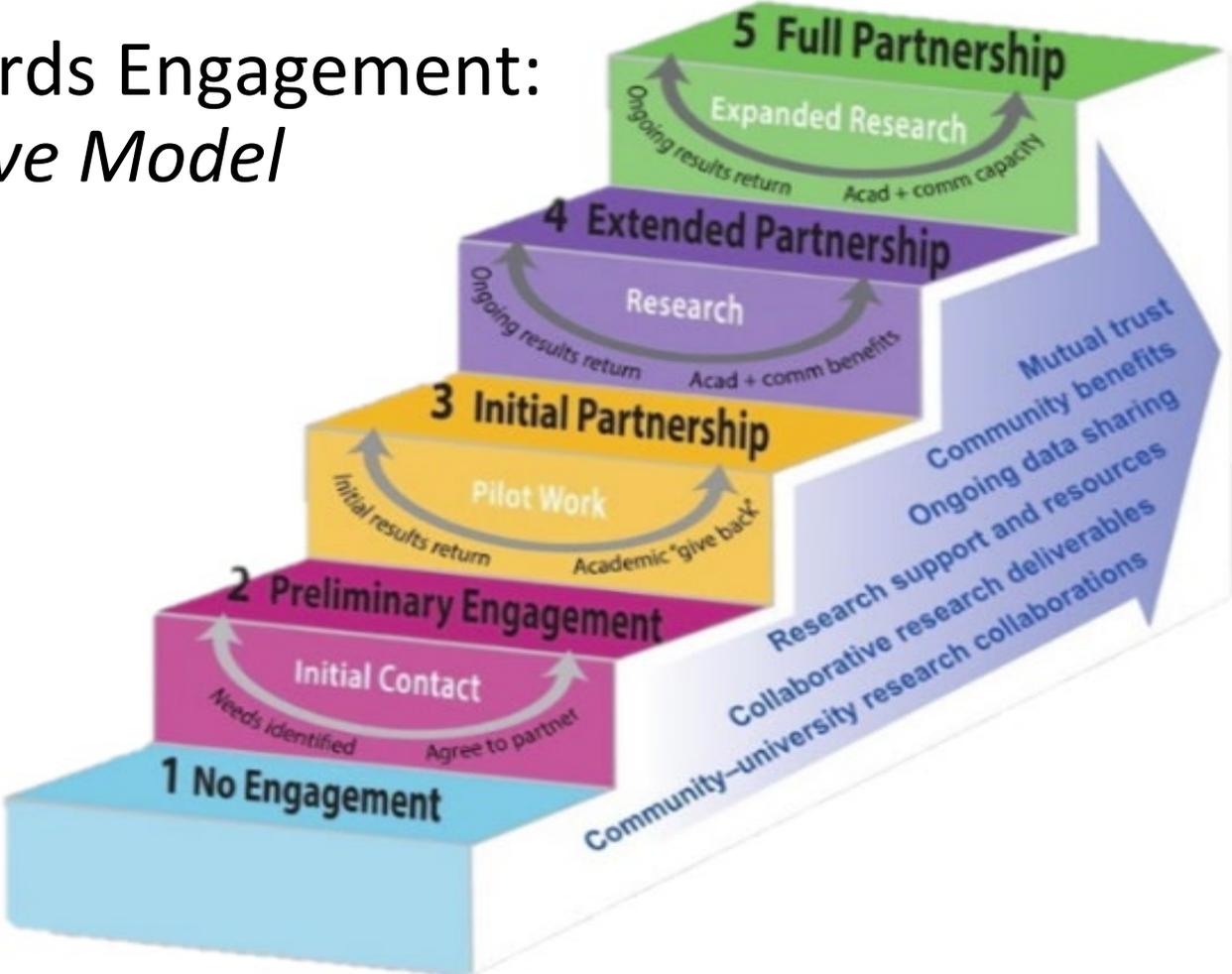
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Disseminate the Results

- Co-author and co-present in traditional formats
 - Develop non-traditional formats and methods
 - Begin planning for dissemination when planning the study
- 

Steps Towards Engagement: *A Progressive Model*



What we learned when we surveyed the community...



86%

of patients, caregivers, health care providers, researchers and research staff are interested in learning about PCOR

Top three training topics included how to...

Patient/Caregivers

- Openly communicate with researchers
- Build trust with researchers/providers
- Share expertise with researchers

Researchers/Healthcare providers

- Include outcomes that matter to patients/caregivers
- Partner with patients/caregivers
- Select relevant research topics

PCOR Training Program Sessions

As part of our PCORI Eugene Washington Engagement Award, we have developed 4 PCOR trainings for the CF community:

1. Research 101 (for CF patients/caregivers only)
2. PCOR 101 (for all participants)
3. PCOR Team Dynamics (for all participants)
4. Designing and Implementing a PCOR Study
(for researchers/ healthcare providers only)

Summary:

- Patient-engaged research can improve your life with CF
- Patient engagement enhances your research
- PCOR embodies six engagement principles
 - Create respectful space and build trust with ground rules, first names, ice-breakers, check-ins, specific roles, and team goals
- Maintain commitments to all partners: responsibilities, compensation
- Research and utilize resources offered by PCORI
- Sharing the PCOR experience with others
 - PCOR training for the CF Community. An invitation.
 - Best Practices for Online Engagement in PCOR