Participating in and Maintaining a PCOR Team

CFReSHC Eugene Washington Award Team

CFReSHC

Cystic Fibrosis Reproductive and Sexual Health Collaborative

Housekeeping

Before we get started with the training, please:

- Turn on your video

- Mute to your microphone when you are not speaking to reduce ambient noise

- Use the "Chat" feature during the presentation for questions or comments

  Message **Erin T** with logistics or Zoom related questions

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

Partnering in Patient-Centered Outcomes Research
- 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.

What we will cover today

By the end of this training, you will be able to:

1. Describe elements for successful PCOR team dynamics
2. Describe how to create conditions for patient-partners to be active participants within a PCOR team
3. Identify barriers to successfully functioning PCOR teams and articulate potential solutions to address those barriers
4. Review strategies to maintain confidentiality of patient-partners when part of the research team

Describe elements of successful PCOR team dynamics

Learning Objective #1

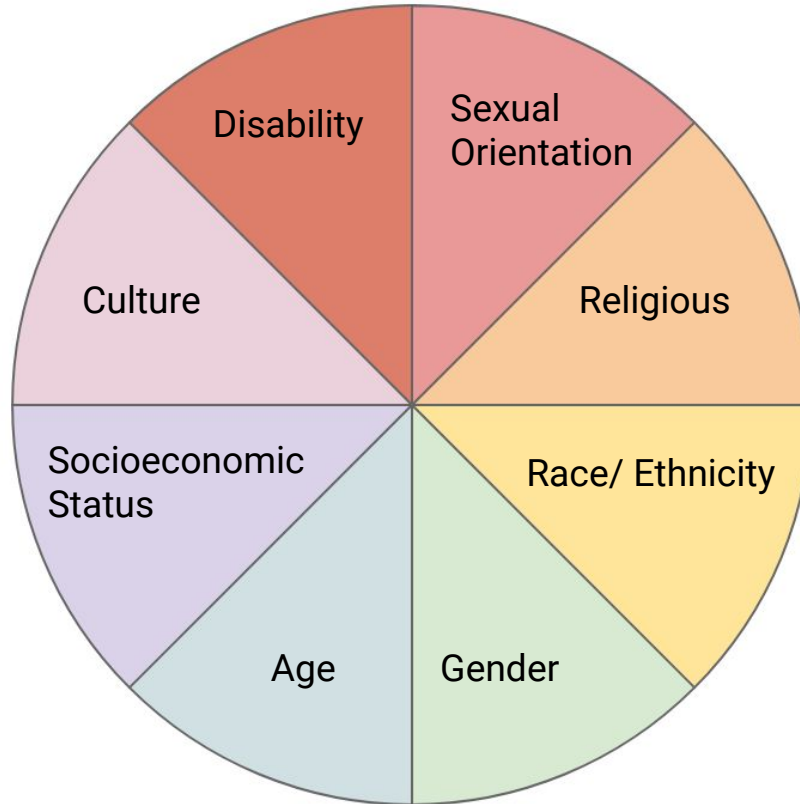# PCOR Embodies Six Engagement Principles
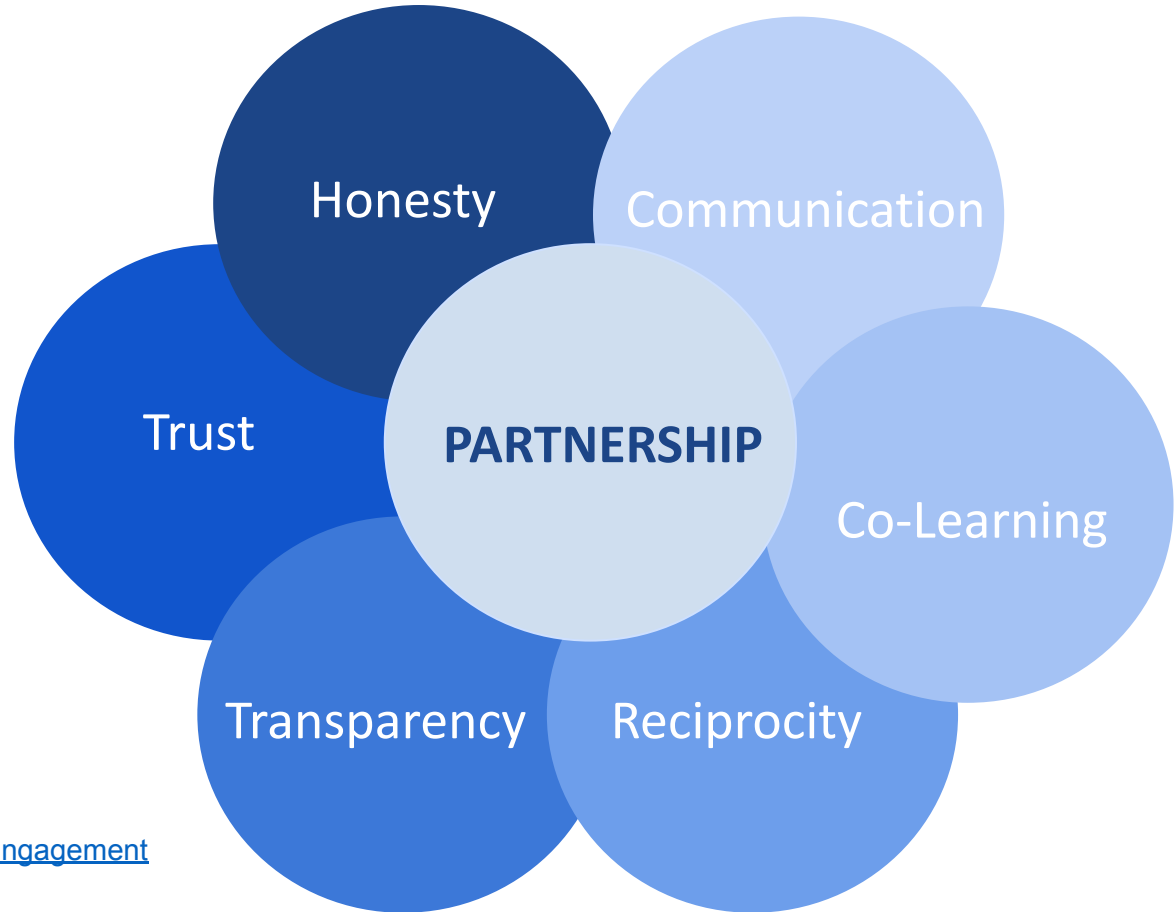
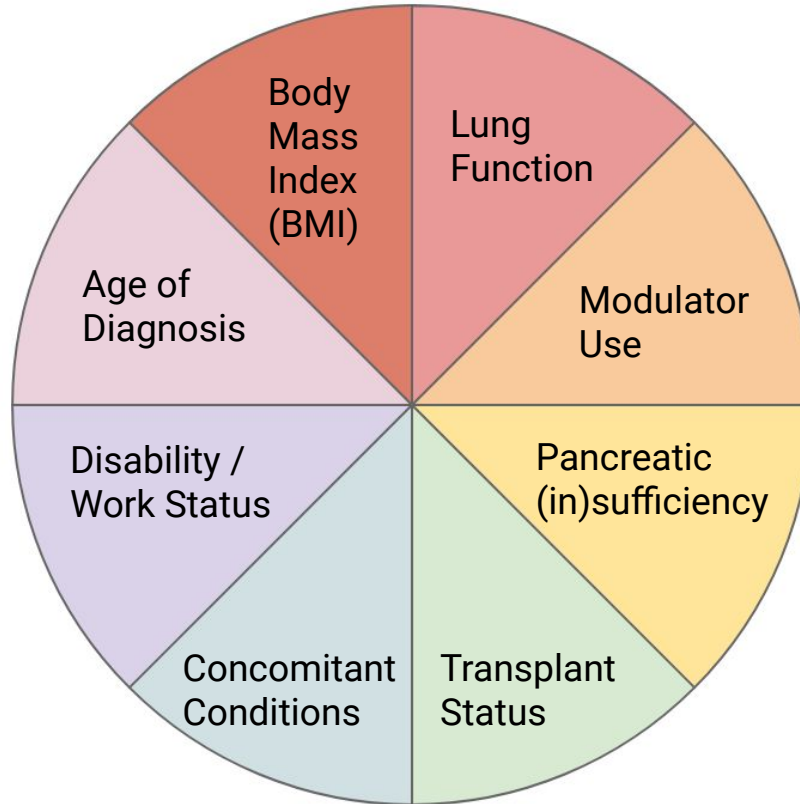# Maintain an Inclusive and Respectful Space

CF Diversity

PARTNERSHIP

Describe how to create conditions for patient-partners to be active members of a PCOR team

Learning Objective #2

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: Lavallee 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.

Assemble Your Stakeholder Team

PARTNERSHIP

1. Recruit and interview potential partners

2. Find a meeting space

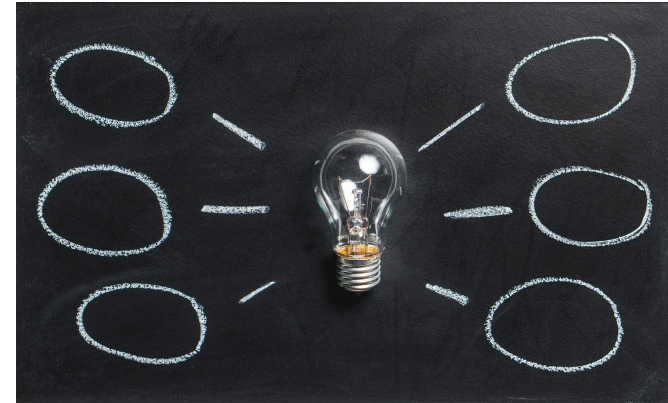3. Know partner scheduling availability

4. Respect each other's time

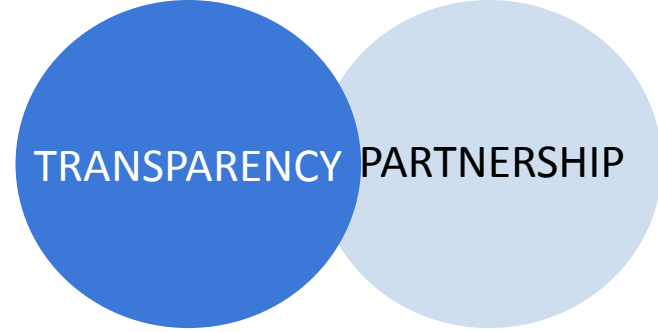# Supporting Success

TRANSPARENCY PARTNERSHIP

- Supportive Structures
  - Mission Statement
  - Project Goals
  - Realistic Timelines
  - Regular meetings
  - Meeting Ground Rules
  - One-on-one check-ins
  - Lead by Example
  - Stay focused but flexible

Create Open Communication Channels

- Choose good communication tools for your group and project
- Set ground rules for communication
  - (e.g., which types of mediums to use for which types of communication)

Adapted from:
https://www.extension.harvard.edu/professional-development/blog/challenges-managing-virtual-teams-and-how-overcome-them

Pick your tech

COMMUNICATION

Document sharing
Dropbox, Google Docs.

Communication tools
E-mail, Slack, WhatsApp.

Project management software
Asana, Trello

Scheduling
Doodle, Calendly

Workflow Automation
Zapier, Microsoft Flow, Monday

Video Conferencing software
Zoom, Bluejeans, WebEx, Skype, GoTo Meeting, Google Hangouts, Facetime, WhatsApp

Manners Matter-- especially online

- Turn on video during conferences
- Help all team members learn technology
- Be thoughtful about your communication
- Include all team members in communication
- Address language
  - Making sure people avoid acronyms

Acronyms

Online Miscommunication

Thursday, June 13th

What could go wrong here?

Create a Welcoming Environment

RECIPROCITY

PARTICIPATION BEST PRACTICE GUIDELINES

+

FACILITATOR ENCOURAGES PARTICIPATION FROM ALL PARTNERS

→

LEVELED POWER DYNAMIC

Participation Best Practice Guidelines

- Use I-statements (e.g., I think, I believe)
- State your goal
- Pros and cons to your point of view
- Contextualize (where is your point of view coming from?)
  - From your experience? Peer-reviewed journals?

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

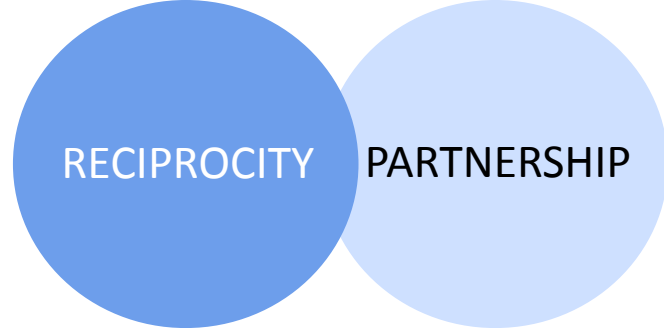# Facilitator Encourages Participation From All Partners

- Ask for input from those not speaking up
- Practice empathy
- Listen attentively
- Reflect back what you heard
- Don't offer advice, suggestions, or interrupt with own experience
- Ask open-ended questions

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

Leveled Power Dynamic

RECIPROCITY

- Acknowledge and actively address power differentials
- Only using first names
  - Disallow formal titles at meetings (i.e. Doctor, Professor)
- Recognize and appreciate different talents and experience members bring to the project
- Allow patient partners to take a lead in activities
  - Invite patient partners to co-present or co-author publications

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

Compensation for Contributions

RECIPROCITY PARTNERSHIP

- Another way to level the hierarchical structure is to <u>compensate</u> everyone (including patient-partners) for their contributions to the project
- Consider individual needs related to:
  - Supplemental Security Income
  - Social Security Disability
- Offer alternatives to income
  - Reimburse travel expenses to a conference, for example
- Consider different schedules for payment, deferred payments

Evaluating Engagement

TRANSPARENCY | HONESTY

For example, ask team members about their agreement with the following statements:

1. People in the group respected my opinion
2. I spoke as much as I wanted to in the group
3. There was enough time to discuss all the relevant issues
4. The facilitator ensured that all opinions were considered and I understood the issues well enough to participate as much as I wanted to

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

Identify barriers to successfully functioning PCOR teams and articulate potential solutions

Learning Objective #3

Potential Barriers to Open Communication

Barriers to having a respectful space during meetings:

- Telling jokes
- Using sarcasm
- Making snide remarks
- Being silent
- Cutting people off
- Changing the subject rather than providing candid opinion
- Lack of attention
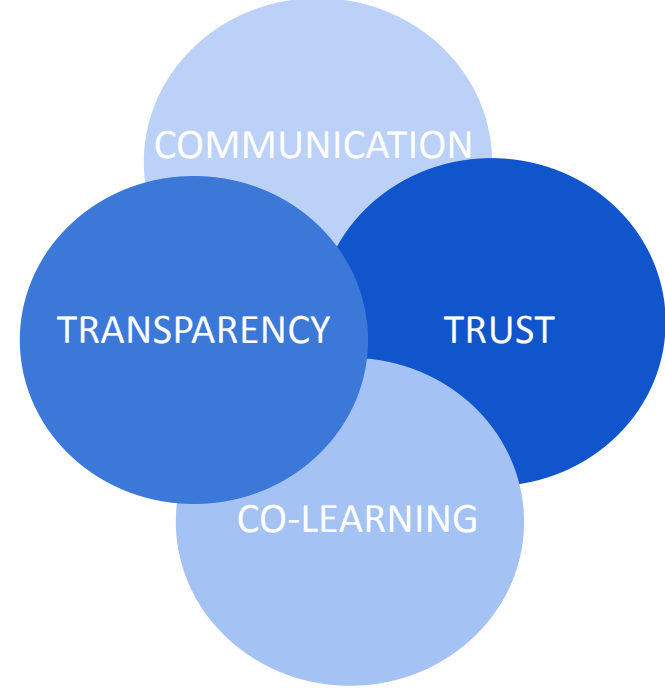- Not sharing video
- Extensive side conversations in "chat"
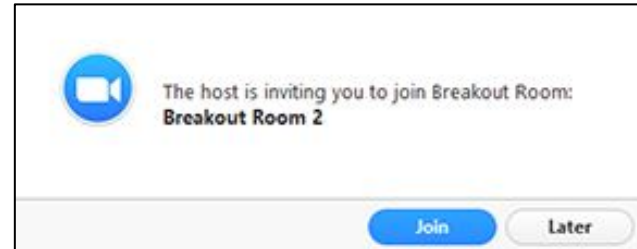
Small Group Activity - 15 min

Case 1:

How to create a respectful space for collective sharing and open collaboration

Case 2:

How to build and maintain trust among team members

COMMUNICATION

TRANSPARENCY

TRUST

CO-LEARNING

To join the breakout room click "Join":

The host is inviting you to join Breakout Room:
Breakout Room 2

Join   Later

Large Group Activity - 8 min

➢ Discuss key points related to maintaining a respectful space during meetings

➢ Discuss key points related to creating and maintaining trust throughout the engagement process

Respectful Space for Collective Sharing

Co-Learning

As a group:

1. Announce ground rules prior to each meeting
2. Identify guidelines for facilitating meetings
3. Share agenda in advance, finalize agenda as a group
4. Find ways to reduce hierarchy

Adapted from:
https://www.extension.harvard.edu/professional-development/blog/challenges-managing-virtual-teams-and-how-overcome-them

Maintaining an Inclusive, Respectful Space

- Maintain open lines of communication
- Create clearly defined roles, but flexible tasks
- Use first names
- Solicit feedback from members (e.g., google forms)
- Welcome and encourage all questions
- Continuously learn from one another
- Provide ongoing support for online engagement

Building Trust

TRUST

As a group:

1. Create mission and vision statement
2. Set expectations for communication and collaboration
3. Identify shared goals
4. Establish roles
5. Make time for ice breakers/personal updates before each meeting
6. Support team building with online activities

https://www.extension.harvard.edu/professional-development/blog/challenges-managing-virtual-teams-and-how-overcome-them

Characteristics of an Effective Research Team

- Effective leadership and management skills
- Self- and other-awareness
- **Trust is established among team members**
- **Strategies developed for communicating openly**
- Effective building of a team, including shared expectations and defining roles and responsibilities
- Creating, sharing and revisiting a shared vision
- Making provisions for appropriate recognition and credit
- Promoting disagreement while containing conflict
- Learning each others' languages
- Enjoying the science and the work together

Review strategies to maintain confidentiality of patient-partners when part of the research team

Adapting Working Relationships

RECIPROCITY

Examples:

1. Role Reversal

2. Incorporating Patient-Partners

3. Common Goals

Addressing Concerns about Confidentiality

- What do we mean by "confidentiality"
  - Patient information is protected through HIPAA*
  - In PCOR, patient partners are not research subjects

- Responsibility for confidentiality for all team members and opinions shared
  - Community Individual Investigator Agreement

*HIPAA = Health Insurance Portability and Accountability Act of 1996

Human Subjects Research

Any research team member who engages in research that involves human subjects must undergo training to learn about conducting research that is ethical and safe.

Institutional Review Board (IRB)

- Ethical review at organizations (e.g., universities)

Collaborative Institutional Training Initiative (CITI)

- Human subjects research ethics training
- Patient-partners can complete CITI training

Community Partners Research Ethics Training

- University of Pittsburgh training for community partners

In Summary

- PCOR is one of several modalities in which people with CF can participate in research

- PCOR embodies six engagement principles

- Use technology to enable frequent and open communication

- Create respectful space and build trust with ground rules, first names only, ice-breakers, check-ins, specific roles, and team goals

- Keep clinic dynamics out of PCOR interactions

- IRB training may be necessary

Questions?

Thank you for attending today's session!

- Erin will email the link to our post-training survey and a list of additional resources for reference.
- You will receive a $15 Amazon gift card after you complete the post-training survey!

Please note: The University of Washington requires us to record full names, permanent addresses and social security numbers of all people who wish to receive gift cards. Your information will be stored in REDCap, a secure, HIPAA compliant database.

CFReSHC
Cystic Fibrosis Reproductive and Sexual Health Collaborative

Case Scenario: Overcoming Barriers

Provide example of barrier, have participants work in small groups to come up with ways to overcome the barrier

Group Activity

- What are ways to ensure that patient-partner input is empowered and heard?

Let's play a game!

Imagine: aliens just landed on earth and brought with them a new virus

Act now! How will you save our healthcare system from disaster

What did you learn?

➢ Did all team members contribute?

➢ Did you have fun?

➢