Partnering with Individuals with Lived Experience in Mood Disorders Research

Peer Priorities for Research and Recommendations for Meaningful Partnerships

Presenters:
Pam Dardess, IPFCC
Phyllis Foxworth, DBSA
Kate Boyd, PCORI

Peer Panelists:
Kimberly Allen
Melinda Hasbrouck

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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Agenda

- Introduction to the project
- Overview of PCORI
- Peer priorities for research
- Recommendations for partnership
- Peer panel

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Introduction to the Project

“Amplifying the Peer Voice in Behavioral Health Research to Drive Transformation”

Funded by a PCORI Eugene Washington Engagement Award

The Importance of Peer Priorities

Engaging Peers in Research

- Identify research questions
- Shape the design and conduct of research
- Disseminate findings
- Translate findings into real-world change

Creates Potential

- Generate user-focused research objectives and questions
- Refine study methods
- Interpret results
- Enhance dissemination and implementation of findings

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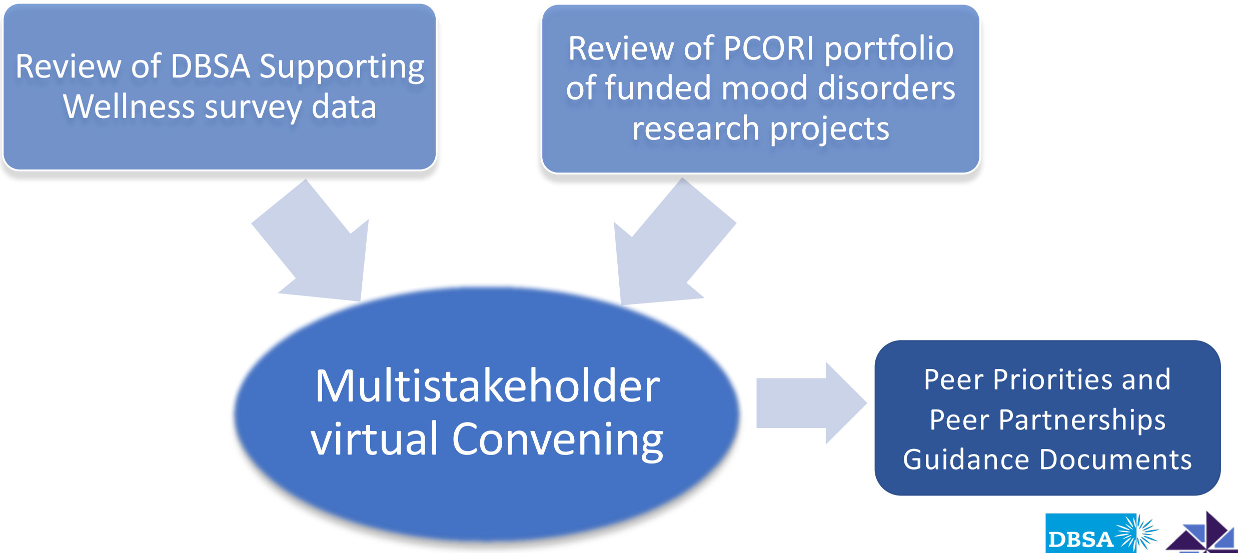
Project Goals

Amplify peer voices in mood disorders research, particularly comparative effectiveness research and patient-centered outcomes research

Key Questions

- What topics are important to peers?
- What are the gaps between research that has been funded by PCORI and peer priorities?
- What are priority areas for future research?
- How can researchers, clinicians, and peers best collaborate?

Project Tasks



Review of DBSA Supporting Wellness survey data

Review of PCORI portfolio of funded mood disorders research projects

Multistakeholder virtual Convening

Peer Priorities and Peer Partnerships Guidance Documents

Getting to Know PCORI:

Opportunities for Involvement and Partnering in Patient-Centered Research

Kate Boyd
Program Officer, PCORI

Presentation Overview

- About PCORI
- Engage and get involved with PCORI

About PCORI

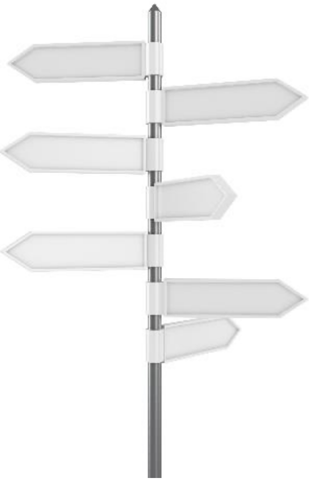
- **The Patient-Centered Outcomes Research Institute (PCORI)** was authorized by Congress in 2010 and is governed by a 21-member Board of Governors representing the entire healthcare community
- PCORI funds **comparative clinical effectiveness research (CER)** that engages patients, caregivers, and other stakeholders throughout the entire research process
- What works best for **YOU**

What is Comparative Clinical Effectiveness Research (CER) ?

- CER generates and synthesizes evidence **comparing** benefits and harms of at least two different methods
- Patient-Centered Outcomes Research (PCOR) investigates what works, for whom, under which circumstances
- We **engage** patients, caregivers, and other stakeholders throughout the entire research process
    - This ensures we are answering questions that help patients and other healthcare stakeholders make **better-informed decisions** about health and healthcare options

How is PCORI's Work Different?

- We focus on **answering questions most important to patients** and those who care for them.
- We aim to produce evidence that can be easily applied in **real-world settings**.
- We engage patients, caregivers, clinicians, insurers, employers, and other stakeholders throughout the research process.

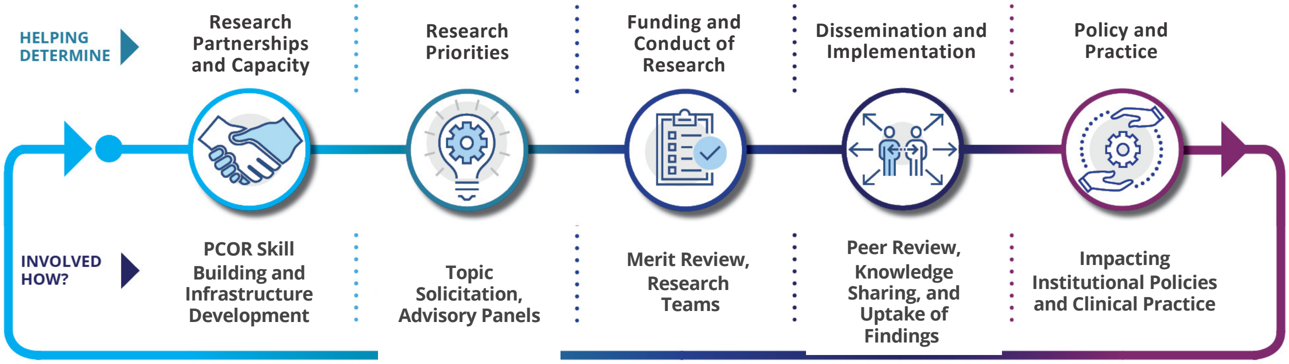


Getting Involved with PCORI

PCORI Engagement Awards

https://www.pcori.org/engagement/eugene-washington-pcori-engagement-awards

Engagement: A Foundation for Everything PCORI Does



Other PCORI Engagement Opportunities

- **Merit Reviewers**
  - PCORI invites patients, caregivers, clinicians and other stakeholders who are passionate and committed about PCOR to serve as merit reviewers.
  - Applications are accepted on a rolling basis.
  - Learn more: www.pcori.org/engagement/engage-us/become-merit-reviewer
- **Ambassador Program**
  - The PCORI Ambassador Program is a national, volunteer network of healthcare stakeholders aiming to shift the culture of health research to be more patient centered.
    - There are no educational or certification requirements to become a PCORI Ambassador.

Contact Information

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Thank You!

2021 PCORI Annual Meeting
November 17-19, 2021
https://www.pcori.org/2021-annual-meeting

Priorities for Mood Disorders Research: What Topics are Important to Peers?

Methodologies for Collecting Input

- Supporting Wellness Survey
    - First of its kind peer developed survey focused on priorities of well-being and research
- Multi-stakeholder Convening
    - Peers
    - Family
    - Researchers
    - Clinicians

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Research Priority Topics

- Causes of mood disorders
- Diagnosis of mood disorders, including process and timing
- Access to care
- Treatment options and outcomes
- Models of care and support
- Education and training, for peers and health care professionals
- Underserved populations
- Effects of the COVID-19 pandemic on living with or acquiring a mood disorder

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Causes

- Understanding factors around condition that lead to better:
  - Pathways to diagnosis
  - Clarity around treatment options
- Individual susceptibility or risk factors
- Variabilities in the way individuals are affected

Diagnosis

- Timely and accurate
- Emphasis on youth, adolescents, and underserved populations
- Information provided at time of diagnosis around treatment options

Access to Care

- Understanding the mental health care system
- Navigating the complex world of health insurance
- Addressing stigma as a barrier to care

> *"Finding the right provider is hard. It's even harder when you are a part of a community that providers don't understand generally, battling a system that has traditionally tried to change who you are. How do you battle that access to find affirming and supportive care?"*
> *– Advocacy organization*

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More Effective Treatment Options and Outcomes

- Addressing issues related to medications
    - Lengthy trial and error process
    - Side effects
- Incorporating non-clinical options
    - Peer support
    - Alternative treatments
- Emphasizing well-being
    - Improved functionality
    - Personal definition of wellness

> *"We're so often looking to get rid of the negative impacts of mental health issues, but we're not seeking to make someone in a space of thriving. Let's focus on the positives of what treatment can do that creates the flip from just being neutral to having a positive life and outcome."*
> *– Advocacy organization*

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Models of Care and Support

- Peer support
- Role of and support for families
- Telehealth

Education and Training

- Individuals
  - Accessing care
  - Diagnosis
  - Treatment
  - Self advocacy
- Health care professionals
  - Patient- and family-centered care
  - Stigma towards patients
- Peer specialists
  - Educating clinicians
  - Providing support to patients and family members

> *"For physicians who were trained a long time ago and they're still in practice, a lot of them don't adhere to patient-centered principles. And they're kind of top-down paternal. We struggle with that a great deal."*
> *-Clinician*

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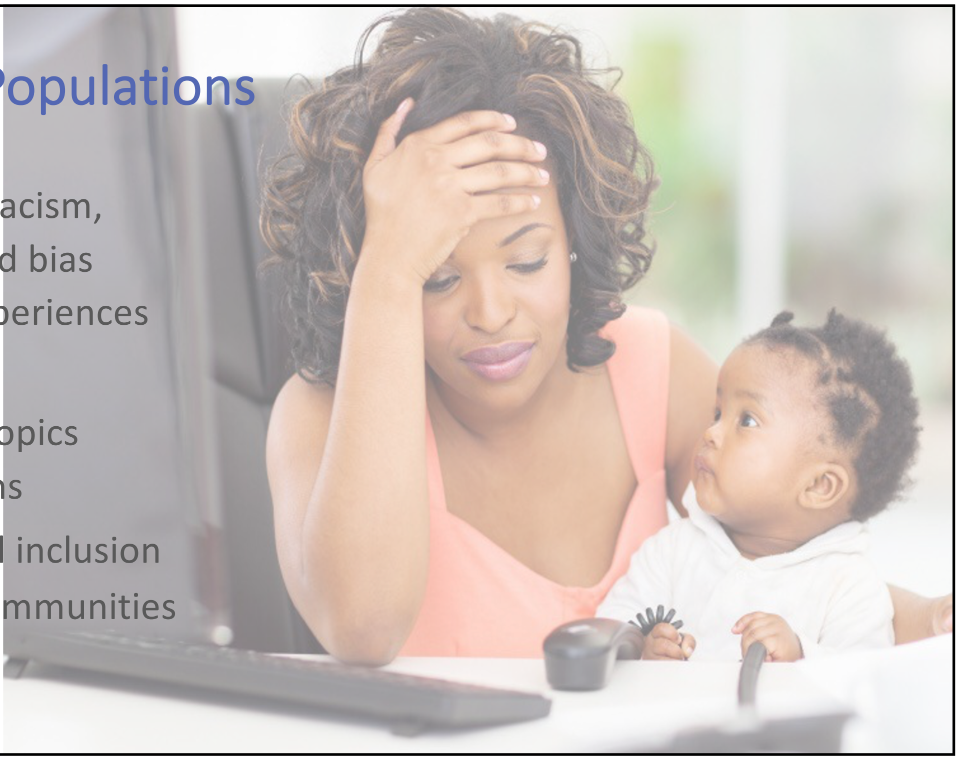
Underserved Populations



- Understand how racism, discrimination, and bias affect people's experiences and perspectives
- Review research topics through equity lens
- Initiate purposeful inclusion of underserved communities

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Effects of COVID-19 Pandemic

- Prevalence or increase in diagnosis
- Effects on:
  - ○ Access to care
  - ○ Treatment methods/options
  - ○ Treatment outcomes

> *"I live alone and I became even more isolated during COVID. My depression went to a real low. I lost a lot of people that have committed suicide, overdosed, or went back to drugs. COVID caused a big mental health overload."*
> *– Peer*

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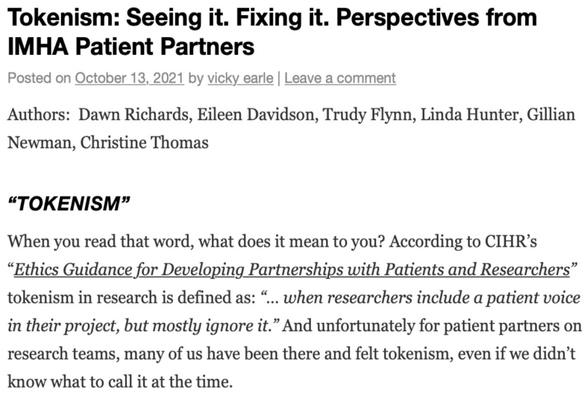
Partnership Themes

Developing and Sustaining Meaningful Partnerships Between Peers and Researchers

“Meaningful partnerships are those that reflect substantive opportunities for peers to contribute as members of the research team throughout a research project from design to recruitment to implementation to reporting and dissemination of results.”

Dardess, P., Foxworth, P., Abraham, M., Patel, U., & Bernstein K. (2021, October). *Amplifying Peer Priorities in Mood Disorders Research: Recommendations for Creating and Sustaining Meaningful Partnerships Between Researchers and Peers.*



Tokenism: Seeing it. Fixing it. Perspectives from IMHA Patient Partners

Posted on October 13, 2021 by vicky earle | Leave a comment

Authors: Dawn Richards, Eileen Davidson, Trudy Flynn, Linda Hunter, Gillian Newman, Christine Thomas

“TOKENISM”

When you read that word, what does it mean to you? According to CIHR’s “*Ethics Guidance for Developing Partnerships with Patients and Researchers*” tokenism in research is defined as: “*… when researchers include a patient voice in their project, but mostly ignore it.*” And unfortunately for patient partners on research teams, many of us have been there and felt tokenism, even if we didn’t know what to call it at the time.

https://blogs.ubc.ca/imhablog/2021/10/13/tokenism-seeing-it-fixing-it-perspectives-from-patient-partners/

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Partnership is Central to PCORI's Mission

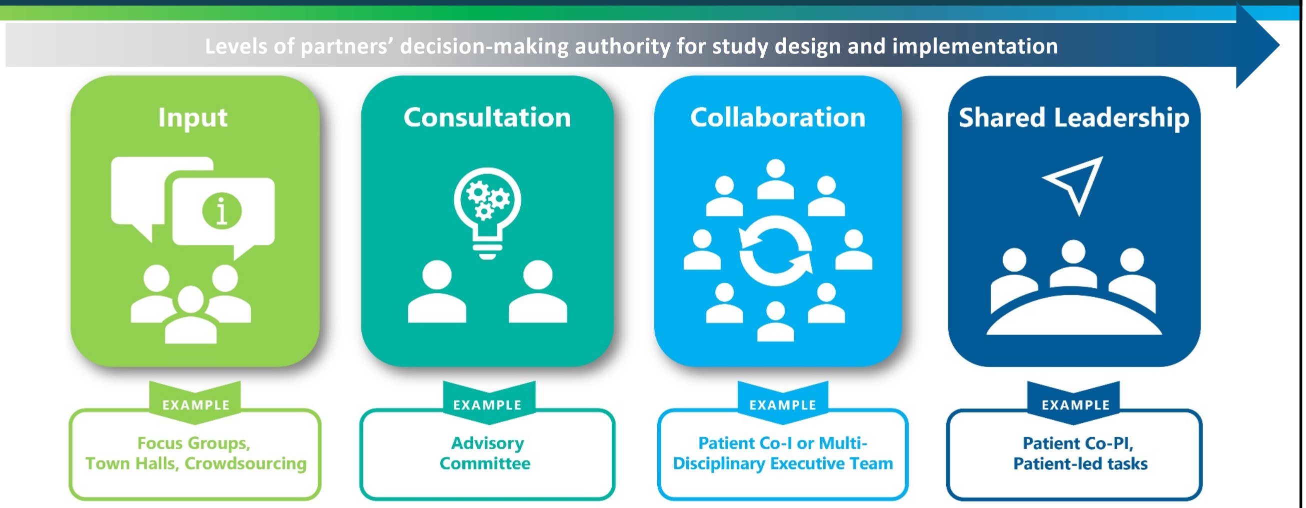
"Patient-centeredness"

- Addresses outcomes (both benefits and harms) that are important to patients
- The interventions proposed for comparison are currently available to patients
- Study design is low-burden to participants

"Patient and stakeholder engagement"

- Patients and stakeholders are partners in research, not only "subjects"
- Can occur by building upon existing relationships, or developing new ones
- Leverages the expertise of patients, clinicians and other stakeholders for the purpose of improving study design and conduct
- Includes a range of engagement approaches: input, consultation, collaboration, shared leadership

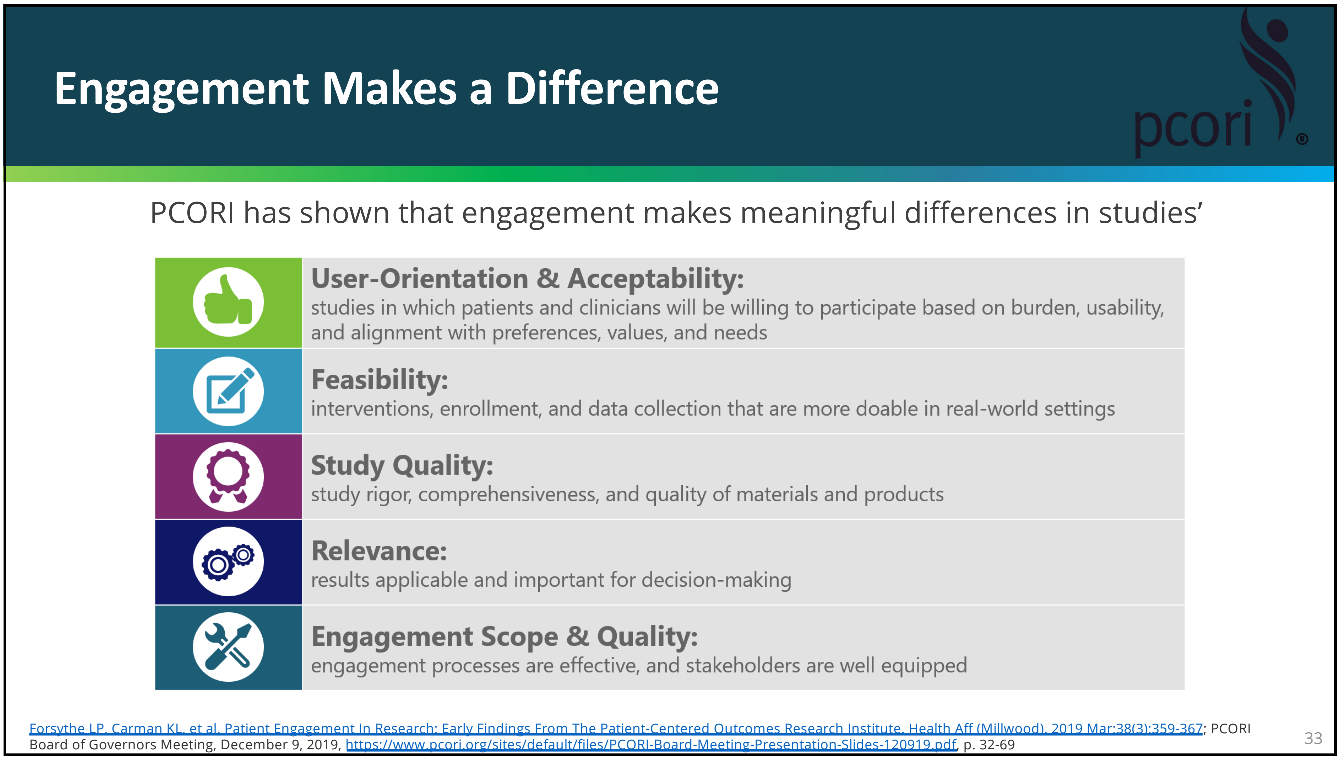
There Is A Continuum Of Engagement Practices



Levels of partners' decision-making authority for study design and implementation

Input	Consultation	Collaboration	Shared Leadership
EXAMPLE	EXAMPLE	EXAMPLE	EXAMPLE
Focus Groups, Town Halls, Crowdsourcing	Advisory Committee	Patient Co-I or Multi-Disciplinary Executive Team	Patient Co-PI, Patient-led tasks

Adapted from:
Hanley et al. (2004). Involving the public in NHS, public health and social care research.
Carman et al. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs, 32*(2), 223–231.
Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association, 35*, 216–24



Engagement Makes a Difference

PCORI has shown that engagement makes meaningful differences in studies'

User-Orientation & Acceptability:
studies in which patients and clinicians will be willing to participate based on burden, usability, and alignment with preferences, values, and needs

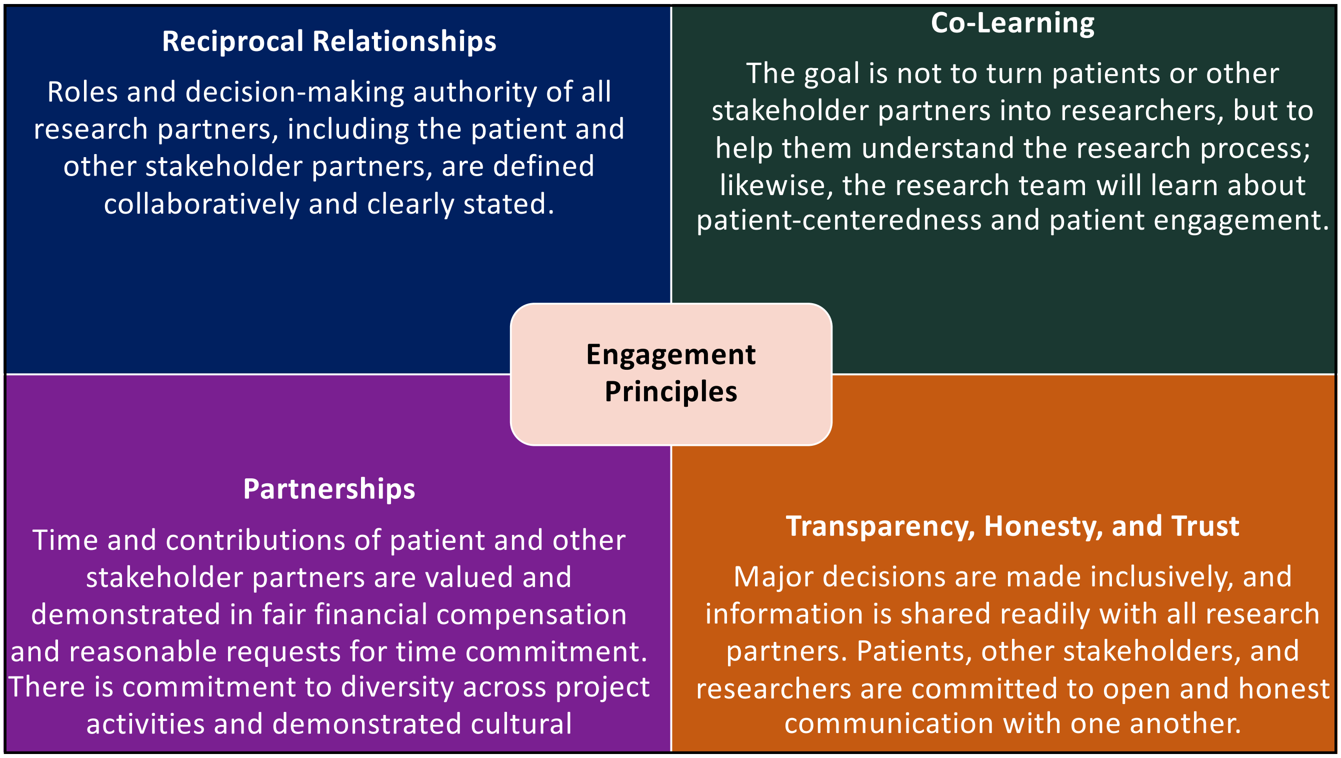
Feasibility:
interventions, enrollment, and data collection that are more doable in real-world settings

Study Quality:
study rigor, comprehensiveness, and quality of materials and products

Relevance:
results applicable and important for decision-making

Engagement Scope & Quality:
engagement processes are effective, and stakeholders are well equipped

Forsythe LP, Carman KL, et al. Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute. Health Aff (Millwood). 2019 Mar;38(3):359-367; PCORI Board of Governors Meeting, December 9, 2019, https://www.pcori.org/sites/default/files/PCORI-Board-Meeting-Presentation-Slides-120919.pdf, p. 32-69



Reciprocal Relationships

Roles and decision-making authority of all research partners, including the patient and other stakeholder partners, are defined collaboratively and clearly stated.

Co-Learning

The goal is not to turn patients or other stakeholder partners into researchers, but to help them understand the research process; likewise, the research team will learn about patient-centeredness and patient engagement.

Engagement Principles

Partnerships

Time and contributions of patient and other stakeholder partners are valued and demonstrated in fair financial compensation and reasonable requests for time commitment. There is commitment to diversity across project activities and demonstrated cultural

Transparency, Honesty, and Trust

Major decisions are made inclusively, and information is shared readily with all research partners. Patients, other stakeholders, and researchers are committed to open and honest communication with one another.

Recommendations for researchers

1. Acknowledge peers' strengths, experience, knowledge, perspectives
2. Identify substantive, not tokenistic, opportunities for partnership
3. Actively seek new voices and perspectives
4. Invest time and effort in building relationships
5. Structure teams to address power imbalances
6. Develop guidelines and systems for peer payment
7. Provide preparation, training, mentorship
8. Support the mental health of peer partners
9. Model visible partnership in all aspects of work

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Recommendations for advocacy organizations

1. Develop relationships with researchers and research organizations
2. Develop a basic understanding of research processes and funding mechanisms
3. Explore arrangements to maximize peer ownership of projects

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Phyllis Foxworth, DBSA: pfoxworth@dbsalliance.org

Additional Resources

Links to Resources

Organizational Websites

- Institute for Patient- and Family-Centered Care: www.ipfcc.org
- Depression and Bipolar Support Alliance: www.dbsa.org
- Patient-Centered Outcomes Research Institute: www.pcori.org

Resources from IPFCC

- Mood Disorders Research Project: https://ipfcc.org/bestpractices/partnerships-in-research/mood-disorder-research.html
- Guidance Documents:
  - Recommendations: https://ipfcc.org/resources/Recommendations_for_Creating_and_Sustaining_Meaningful_Partnerships_Between_Researchers_and_Peers.pdf
  - Peer Priorities: https://ipfcc.org/resources/EACC-18757_Guidance_Peer_Priorities.pdf
- Partnerships in Research Projects: https://www.ipfcc.org/bestpractices/partnerships-in-research/index.html

Resources from PCORI

- Information on PCORI Engagement Awards: https://www.pcori.org/engagement/eugene-washington-pcori-engagement-awards
- Research and Results: www.pcori.org/research-results
- Engage with PCORI: https://ipfcc.org/resources/Engage_with_PCORI.pdf
- PCORI Compensation Framework: www.pcori.org/document/compensation-framework
- PCORI Research Fundamentals: https://pcori.org/research-fundamentals
- PCORI Annual Conference: https://www.pcori.org/2021-annual-meeting

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Other Resources

- Blog by Dawn Richards: Tokenism: Seeing it. Fixing it. Perspectives from IMHA Patient Partners: https://blogs.ubc.ca/imhablog/2021/10/13/tokenism-seeing-it-fixing-it-perspectives-from-patient-partners/
- Article by Dawn Richards in PXJ From 2018: *Patient partner compensation in research and healthcare*: https://pxjournal.org/journal/vol5/iss3/2/
- 2019 Guidelines for Patient-Partner Compensation from the Child-Bright Network and SPOR https://www.child-bright.ca/compensation-guidelines

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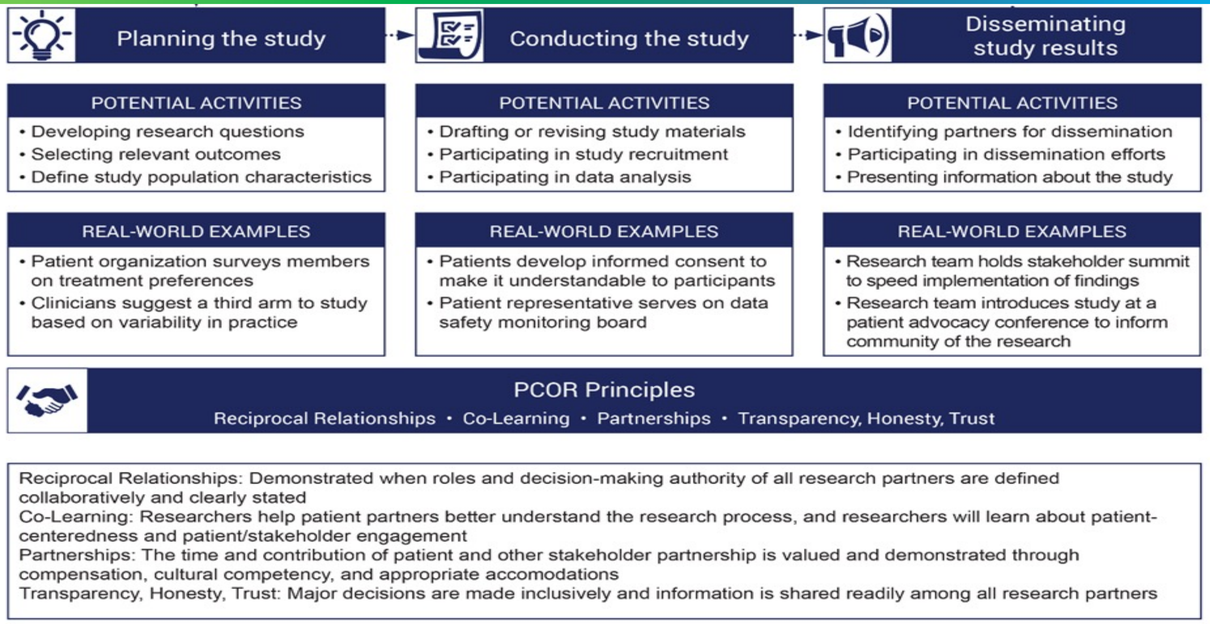
Resource: PCORI Engagement Rubric Overview



Planning the study	Conducting the study	Disseminating study results
POTENTIAL ACTIVITIES • Developing research questions • Selecting relevant outcomes • Define study population characteristics	**POTENTIAL ACTIVITIES** • Drafting or revising study materials • Participating in study recruitment • Participating in data analysis	**POTENTIAL ACTIVITIES** • Identifying partners for dissemination • Participating in dissemination efforts • Presenting information about the study
REAL-WORLD EXAMPLES • Patient organization surveys members on treatment preferences • Clinicians suggest a third arm to study based on variability in practice	**REAL-WORLD EXAMPLES** • Patients develop informed consent to make it understandable to participants • Patient representative serves on data safety monitoring board	**REAL-WORLD EXAMPLES** • Research team holds stakeholder summit to speed implementation of findings • Research team introduces study at a patient advocacy conference to inform community of the research

PCOR Principles

Reciprocal Relationships • Co-Learning • Partnerships • Transparency, Honesty, Trust

Reciprocal Relationships: Demonstrated when roles and decision-making authority of all research partners are defined collaboratively and clearly stated

Co-Learning: Researchers help patient partners better understand the research process, and researchers will learn about patient-centeredness and patient/stakeholder engagement

Partnerships: The time and contribution of patient and other stakeholder partnership is valued and demonstrated through compensation, cultural competency, and appropriate accomodations

Transparency, Honesty, Trust: Major decisions are made inclusively and information is shared readily among all research partners

https://www.pcori.org/sites/default/files/Engagement-Rubric.pd

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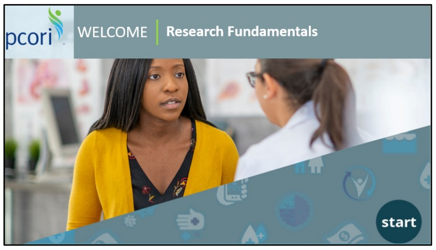
Learning Packages to Support Multi-Stakeholder Research Teams



Research Fundamentals

- Provides **foundational knowledge in PCOR/CER** to **nonscientist participants** on research and other projects.
- **Free and publicly available at** https://pcori.org/research-fundamentals

Building Effective Multi-Stakeholder Research Teams

- For **new and experienced researchers and stakeholder partners**, offers **practical guidance and resources to support multi-stakeholder teams** in effectively working together.

PCORI Ambassador Program

- PCORI Ambassadors are members of an online, volunteer community of PCOR supporters who are committed to **shifting the culture of health research to be more patient-centered**.
  - Learn more about the diversity of our membership and their PCOR experience with the networking tool **"The Ambassador Center"** or check out the website.
- We encourage PCORI-funded study team members and partners to **become Ambassadors!**
  - It is as easy as completing an online **interest form** and optional online training.
  - Ambassador membership spans the spectrum of health care stakeholders.
  - There are no educational, training, or time requirements to join.
- **Become a part of the PCORI Ambassador Community!** Be on the lookout for materials to circulate with research staff and partners to consider joining!