Partnering with Individuals with Lived Experience in Mood Disorders Research

Peer Priorities for Research and Recommendations for Meaningful Partnerships

Presenters:
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Peer Panelists:
Kimberly Allen
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Agenda

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

Dissemination Initiative
- Up to $250,000
- Up to 2 years

Capacity Building
- Up to $250,000
- Up to 2 years

Stakeholder Convening Support
- Up to $100,000
- Up to 1 year

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

Engagement: A Foundation for Everything PCORI Does

Helping Determine
- Research Partnerships and Capacity
- Research Priorities
- Funding and Conduct of Research
- Dissemination and Implementation
- Policy and Practice

Involved How?
- PCOR Skill Building and Infrastructure Development
- Topic Solicitation, Advisory Panels
- Merit Review, Research Teams
- Peer Review, Knowledge Sharing, and Uptake of Findings
- Impacting Institutional Policies and Clinical Practice
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](http://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
  o First of its kind peer developed survey focused on priorities of well-being and research

• Multi-stakeholder Convening
  o Peers
  o Family
  o Researchers
  o Clinicians

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
Causes

• Understanding factors around condition that lead to better:
  o Pathways to diagnosis
  o 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

More Effective Treatment Options and Outcomes

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

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
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.”


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

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.

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

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
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.
Engagement Makes a Difference

PCORI has shown that engagement makes meaningful differences in studies’ outcomes.

### 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.

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**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.

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**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.

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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

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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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:
• 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 Research Fundamentals: https://pcori.org/research-fundamentals
- PCORI Annual Conference: https://www.pcori.org/2021-annual-meeting

Other Resources

- Article by Dawn Richards in PXJ From 2018: Patient partner compensation in research and healthcare: https://pxjournal.org/journal/vol5/iss3/2/
Resource: PCORI Engagement Rubric Overview

- Planning the study
  - POTENTIAL ACTIVITIES
    • Developing research questions
    • Selecting relevant outcomes
    • Define study population characteristics
  - REAL-WORLD EXAMPLES
    • Patient organization surveys members on treatment preferences
    • Clinicians suggest a third arm to study based on variability in practice

- Conducting the study
  - POTENTIAL ACTIVITIES
    • Drafting or revising study materials
    • Participating in study recruitment
    • Participating in data analysis
  - REAL-WORLD EXAMPLES
    • Patients develop informed consent to make it understandable to participants
    • Patient representative serves on data safety monitoring board

- Disseminating study results
  - POTENTIAL ACTIVITIES
    • Identifying partners for dissemination
    • Participating in dissemination efforts
    • Presenting information about the study
  - 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 accommodations.
Transparency, Honesty, Trust: Major decisions are made inclusively and information is shared readily among all research partners.


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 PCOR-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!