# Amplifying Peer Priorities in Mood Disorders Research

# Recommendations for Creating and Sustaining Meaningful Partnerships Between Researchers and Peers

**October 2021**

**Institute for Patient- and Family-Centered Care**

**Depression and Bipolar Support Alliance**

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

**DBSA**

**Depression and Bipolar Support Alliance**

# Introduction

## Background

Mood disorders affect over 21 million people in the U.S.[1] While there is increased interest in mood disorders research related to diagnosis, treatment, access, and education, significant knowledge gaps remain. Mental health "...is complex, and it is important that interventions be relevant to the target audiences."[2] One issue is that many studies are initiated and led by researchers, with limited engagement from those with lived experience of a mood disorder and their family members (peers). Understanding how peers define the burden of the condition, impact on their lives, preferred treatment outcomes, and improvement or progress towards wellness is critical for ensuring that research addresses priorities most relevant to those affected. Research that is peer-centric focuses on outcomes of interest to peers, provides desired information to inform decision-making, and can contribute to better health outcomes.

With this background, the Institute for Patient- and Family-Centered Care (IPFCC) partnered with the Depression and Bipolar Support Alliance (DBSA) on a project titled "Amplifying the Peer Voice in Behavioral Health Research to Drive Transformation" to build a better understanding of peer priorities and develop recommendations for ways in which future mood disorders research can better address these priorities.[3] The Patient-Centered Outcomes Research Institute (PCORI) provided funding for this work through a Eugene Washington Engagement Award (EACC-18757).

## Purpose of this Document

This document contains recommendations for promoting and supporting meaningful partnerships between peers and researchers. **Meaningful partnerships are those that reflect substantive roles and 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.**

These recommendations are the result of input from approximately 30 participants in a virtual Convening held by IPFCC and DBSA in June 2021. Convening participants included peers, mental health advocacy organizations, clinicians, and researchers. This document is not intended to be a "how to" guide, but to raise issues that should be discussed and considered for effective peer-researcher partnerships. The document is divided into three sections:

- Recommendations for researchers (9 recommendations)
- Recommendations for peer and mental health advocacy organizations (3 recommendations)
- Recommendations for funders (4 recommendations)

---

[1] Depression and Bipolar Support Alliance. (2020). Retrieved from http://www.dbsalliance.org/about
[2] Office of Disease Prevention and Health Promotion. (2020). Mental health and mental disorders. Retrieved from www.healthypeople.gov
[3] For more information, see the companion document developed as part of this project: Dardess, P., Foxworth, P., Abraham, M., Patel, U., & Bernstein K. (2021, October). *Peer Priorities for Mood Disorders Research.*

## Recommendations for researchers and research organizations

Engaging peers as partners on research projects requires individual commitment combined with institutional structures and systems that facilitate partnership. Researchers can help by creating meaningful opportunities, demonstrating respect for peer perspectives, and creating appropriate supports for peer partners.

1. **Acknowledge the strengths, experience, knowledge, and perspectives of peers.**

   In many cases, researchers may be a step removed from peer communities. As a result, researchers may not have a complete understanding of existing peer-led work or the knowledge and capacities that exist within the peer community. It is critical for researchers to approach community-based, partnered work with openness, a desire to learn directly from and listen to peers, and respect for the perspectives and experience that peer partners offer.

2. **Identify substantive, not tokenistic, opportunities to partner with peers.**

   Peers are well-positioned to make significant contributions to research teams. However, people with lived experience often are asked to serve in more limited roles, such as project advisory boards. Convening participants noted that constraining peers to limited roles by only asking them to conduct periodic reviews of project plans and materials, or asking them to "educate people about their suffering" can be tokenizing. Substantive opportunities for peers are those that include the ability to help plan, recruit, implement, interpret, and disseminate the research, for example, by serving as paid co-designers and full members of the research team. Without these types of meaningful roles, one Convening participant noted that peers will "continue to be underserved."

3. **Actively seek new peer voices and perspectives.**

   Several Convening participants highlighted the tendency for researchers and others seeking the peer perspective to contact the same small group of individuals (i.e., "the usual suspects"). While peers appreciated the inclusion, they also noted that repeatedly seeking the same voices "leads to total exhaustion and discourages new people coming in." Identifying new subject matter experts, peer leaders, and individuals with lived experience is important for increasing representation and diversifying the voices and perspectives that are included. This process of networking needs to begin months and even years before a team is assembled to respond to funding announcements.

4. **Invest time and effort in building relationships with peer partners.**

   Establishing ongoing relationships with peer team members involves a dedicated investment of time beyond the initial outreach. Clear communication, along with feedback to encourage peers and help them understand the value of their contributions, helps build trust and respect.

   > "I think giving feedback helps [peers] to really get, 'Wow, I do have something to contribute here, and my lived experience, my stories, are just as important as this person with all these letters after their name." — Peer

5. **Structure teams in ways that address potential power imbalances between peers and other stakeholders.**

When peers are included on research projects in small numbers or as the sole individual with lived experience, situations can arise where peer perspectives are outweighed by those of clinicians, researchers, and other stakeholders. Multiple Convening participants had personal experiences with these types of situations, describing them as frustrating and demoralizing. Researchers can help address power imbalances by moving beyond the mere inclusion of peers to more equitable approaches. This means structuring teams that have multiple peers in meaningful, substantive, decision-making roles.

> *"The vision we had was that people living with mental health conditions would be co-designing or leading the research. It's not equitable when you sit people in a room and you have four patient stakeholders, but then the hospitals, psychiatrists, psychologists, they all outnumber us in voting." – Peer, mental health advocacy organization*

6. **Develop guidelines and systems for peer payment.**

Developing clear guidelines for peer payment ensures that peers are compensated for their time, knowledge, and expertise. Equity means that the economic value of peer knowledge is just as valuable as the economic value of scientific knowledge and recognizes that peers have advanced degrees in lived experience. Guidelines should include appropriate levels of compensation for various roles and activities, plans for timely payment, and processes that minimize burden on peers. Convening participants also noted that there has been little consistency in peer payment across projects and institutions, and encouraged sharing of compensation guidelines to develop best practices.

7. **Provide preparation, training, and mentorship for peer partners.**

While no specific education or training is required for peers to participate as research team members, providing them with preparation and mentorship can help them communicate, engage, and feel supported. This includes helping peers understand unique vocabulary associated with research or the topic being studied, providing background information as appropriate about the project and study design, and outlining key questions and project decisions. Providing a mentor or support person also can help peers feel more comfortable with their experience working on research teams.

> *"In working with patients and families who wanted to partner in research, one thing they said was, 'We don't need to become researchers, but we need enough information so that when we walk in those rooms and sit at those tables, we can actually communicate and understand." – Mental health advocacy organization*

8. **Provide support for the mental health of peer partners.**

The specific expertise that peers contribute to research teams is their lived experience. Acknowledging and respecting the strength of this lived experience requires putting structures in place to support peers' mental health. As one Convening participant noted, "What happens if you are having a mental health slip-up or relapse or crisis? How can we make sure that if [peers] need time to step away that we have this as an expectation versus a lot of shame?" Another Convening participant advocated for a trauma-informed approach to partnership that recognizes the impact of previous trauma and incorporates communication about peers' continued well-being to avoid re-traumatization.

9. **Model visible partnership in all aspects of the work.**

Convening participants encouraged researchers to lead by example, with the goal of spreading best practices and educating others about the value and impact of partnered research. This includes ensuring that peer partners are visible as "equal partners and equal collaborators," for example, by always including peers as co-presenters or co-authors in disseminating research processes and results.

## Recommendations for mental health advocacy organizations

Peer and mental health advocacy organizations can facilitate peer partnerships in research by developing relationships with researchers, investing in professional development, and exploring opportunities to assume lead roles on research projects.

1. **Develop relationships with researchers and research organizations.**

Peer and advocacy organizations can put themselves in a better position to partner in research by seeking and developing research connections in advance of specific funding announcements. Convening participants noted that having existing relationships with researchers allows advocacy organizations to pro-actively identify opportunities and advocate for collaboration. Convening participants also suggested that peer organizations be "strategic about their board members" and "put leading researchers on your board to facilitate connections."

2. **Develop a basic understanding of research processes and funding mechanisms.**

Investing in professional development can help peer and mental health advocacy organizations better understand funding opportunities and mechanisms, the research process, and research methodologies. Peers and advocacy organizations do not need to become research experts, but having a basic understanding of research practices and terminology can facilitate conversations and planning discussions with both researchers and funders.[4]

---

[4] PCORI's Research Fundamentals is a free, online resource about the health research process and opportunities to become involved in patient-centered outcomes research. Available at: https://www.pcori.org/engagement/research-fundamentals. PCORI's Learning Resources for Research Teams provides information and resources to help multi-stakeholder teams work effectively together. Available at: https://research-teams.pcori.org/best-practices#Creating%20a%20Shared%20Vision

3. **Explore arrangements to maximize peer ownership of projects.**

Most typically, peer and mental health advocacy organizations are included as subcontractors or consultants on research projects, as opposed to the primary research awardee. Convening participants suggested that there is strength in flipping this traditional arrangement to have peer organizations serve as primes and research organizations/researchers as sub-awardees or consultants. Convening participants noted that having a peer-led application would shift "the power and the priority."

> *"I would encourage [peer and advocacy organizations] to be the prime. I'm saying that as a researcher of an academic institution. As a reviewer, I would only see the strength of the proposal. It speaks to the organization's level of interest and capacity to be a true partner in the research." – Researcher*

## Recommendations for funders

Funding organizations play a critical role in supporting and encouraging peer partnerships through funding requirements, incentives, direct support, and revisiting traditional funding mechanisms and systems. Funders also can help collect, share, and disseminate knowledge about effective partnership practices.

1. **Define expectations for meaningful partnerships and provide incentives for researchers to engage peers.**

Convening participants highlighted PCORI's mandate to include patients in research, but noted that this is not a standard requirement and suggested that more funders could include partnership with peers as a requirement for funding. In addition, there can be a difference between "including" peers in a project and identifying meaningful roles for them. Funders can help by providing clear guidance that prioritizes roles in which peers and advocacy organizations have an equitable say in design, implementation, and dissemination, along with equitable compensation. Proposal evaluation processes should be structured to include examination of partnership plans, with points awarded for projects that demonstrate meaningful peer partnership.

2. **Provide development support to smaller and/or less experienced peer and advocacy organizations.**

While some mental health advocacy organizations are well-funded, newer and smaller organizations would benefit from development support to help them to pursue research partnerships. For example, smaller and less experienced organizations may not understand how to identify funding opportunities or navigate the proposal-writing process. Convening participants noted this as a particular opportunity for increasing representation and addressing issues related to diversity, equity, and inclusion.

3. **Revisit funding mechanisms and processes.**

Submitting research applications involves a significant amount of effort. For some peer and mental health advocacy organizations, this effort is prohibitively burdensome and serves as a barrier to pursuing research projects and funding. Convening participants noted that funders have the ability to change or diversify funding opportunities to encourage peer-led and partnered research. This includes not only revisiting funding mechanisms, but also re-examining scoring processes.

> *"Funders can flip the script, which is what we've always asked. That means looking at all the systems, looking at where systemic inequity exists for elevating the patient voice, and flipping that on its head to create an equal playing field." — Mental health advocacy organization*

4. **Share learning around peer engagement and partnership to build skills and capacity.**

Organizations that fund community-based participatory research or partnered research of any kind have the opportunity to collect lessons learned from grantees, assist in the development and promotion of best practices, and build capacity in the broader research community. Specific opportunities noted by Convening participants included training for first-time investigators, learning collaboratives, and the development and dissemination of case studies to share best practices and avoid researchers "starting from scratch."