

# Amplifying Peer Priorities in Mood Disorders Research

## Peer Priorities for Mood Disorders Research

**October 2021**

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

**Depression and Bipolar Support Alliance**

Suggested citation: Dardess, P., Foxworth, P., Abraham, M., Patel, U., & Bernstein K. (2021, October). *Peer Priorities for Mood Disorders Research*.



Depression and Bipolar  
Support Alliance

# Introduction

## Background

Mood disorders affect over 21 million people in the U.S.<sup>1</sup> 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."<sup>2</sup> 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. 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 a description of peer priorities for mood disorders research compiled from (1) a review of survey data previously collected by DBSA and (2) a multi-stakeholder Convening. The goal is for these priorities to inform conversations and collaborations between researchers, clinicians, peers, and mental health advocacy organizations as future mood disorders research is conceptualized and planned.

The document is divided into two sections:

- Peer priorities for research topics
- Peer priorities for how research is conducted, disseminated, translated, and funded

## How Peer Priorities Were Identified

The project consisted of two primary activities designed to elicit and understand peer priorities.

**Supporting Wellness Survey.** DBSA has a ten-year initiative focused on eliciting peer perspectives and priorities to ensure that peer-desired treatment outcomes are incorporated in the delivery of mental health care throughout the entire health care ecosystem. In 2018, DBSA partnered with the Milken

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<sup>1</sup> Depression and Bipolar Support Alliance. (2020). Retrieved from <http://www.dbsalliance.org/about>

<sup>2</sup> Office of Disease Prevention and Health Promotion. (2020). Mental health and mental disorders. Retrieved from [www.healthypeople.gov](http://www.healthypeople.gov)

Institute Center for Strategic Philanthropy to develop and implement a survey of peers to gather information to guide research prioritization. The Supporting Wellness survey, which was developed in conjunction with peers, generated over 6,400 responses from the peer community. While the survey addressed broader topics related to wellness, an open-ended question asked respondents to specify “questions about your health and experience with depression and/or bipolar that you would most like research to help answer.” As part of this project, our team reviewed, coded, and analyzed 2,930 responses to this open-ended question to identify peer priorities for additional research.

**Multi-stakeholder Convening.** The themes identified from the analysis of the Supporting Wellness survey item were shared with a group of approximately 30 mental health advocacy organizations, peers, clinicians, and researchers during a virtual Convening in June 2021 (see Appendix 1 for participant list). Over a series of two virtual sessions, Convening participants provided additional input on the peer priorities and provided recommendations for future mood disorders research based on their experiences, expertise, and perspectives.

During the Convening, participants noted the value of the 2018 Supporting Wellness survey, but also noted that the survey sample was skewed in ways that point to systemic issues in mood disorders research (i.e., the sample was skewed towards White females). The survey sample also consisted primarily of individuals who already had a diagnosis or awareness of their mental health condition. Convening participants noted the importance of ensuring that traditionally under-represented and underserved populations are well-represented in efforts to address peer priorities moving forward.

## Peer Priorities for Research Topics

Survey respondents and Convening participants highlighted eight topics reflecting peer priorities for future mood disorders research:

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

Each of these topics is described in more detail below. More specific research questions related to each of the topics are presented in Appendix 2.

## Causes

Survey respondents expressed a desire for research to increase the understanding of the specific causes of mood disorders, including how various factors might contribute. In many cases, understanding the causes was viewed as a pathway to diagnosis and more clarity around options for treatment. Survey respondents also wanted research to address questions about why certain people are more prone to mood disorders and why and how a mood disorder can manifest differently in people with the same diagnosis.

## Diagnosis

Survey respondents and Convening participants expressed the importance of being able to obtain earlier, more accurate, and more definitive diagnoses. Avoiding misdiagnosis was also viewed as critical. Survey respondents and Convening participants noted the importance of receiving information as part of the diagnostic process to help inform discussions between peers, family members, and health care providers around treatment options. The need to diagnose correctly and at an earlier point in time was seen as important for all individuals, but particularly for children, adolescents, and individuals with bipolar. Convening participants noted that obtaining an accurate and timely diagnosis comes with additional layered challenges for traditionally underserved populations and those with complex medical conditions.

## Access

Survey respondents and Convening participants highlighted access to mental health care as a critical issue. Access was described as a multi-faceted topic that involves understanding the mental health system, navigating insurance coverage or lack of, and confronting individual and societal stigma around mental health. For traditionally underserved populations, particularly individuals who are un- or under-insured, the burdens associated with lack of access were noted as being particularly high.

*"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*

Survey respondents and Convening participants also linked access to receiving high quality care, noting that the goal is not just to find "any mental health provider," but to find a high-quality provider that can address an individual's specific needs and circumstances. Survey respondents also noted that having a "continuing relationship with mental health services without having a dire need" was important for long-term health and wellness, as was continuity of care to avoid "being bounced back and forth, doctor to doctor, for the treatment of mental illness."

## Treatment Options and Outcomes

Survey respondents expressed a strong desire for more research into treatments for mood disorders, with the goal of identifying more effective treatments, matching treatments to individual needs, and learning how various treatments work in conjunction each other. Survey respondents also wanted more information about which treatment approaches were most appropriate for crisis, maintenance, and remission.

Medications were a particular point of focus for additional research, particularly with regard to improving the often-lengthy process of identifying effective medications and finding medications without significant negative side effects. In addition, survey respondents wanted more information about the effectiveness of counseling, peer support and other programs, and “alternative” treatments. This included how various forms of treatment might be used in combination to help people achieve desired outcomes.

*“Much treatment focuses on short-term depression. I would like to see more research and better treatment options for my long-term depression. I have been living with depression and anxiety for 34 years. I would love to see research that looks at the linkages between mental and physical health. And that looks at being on medication very long term. And at living with this disease, rather than just trying to get past the worst episodes.” – Survey respondent*

Survey respondents and Convening participants also emphasized that treatment outcomes need to address peer priorities by including aspects of functioning and wellness. This includes functional issues, the impact that living with a mood disorder has on someone’s day-to-day life, and outcomes including well-being, quality of life, social interaction, productivity, and employment.

*“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

Survey respondents and Convening participants noted the importance of research that emphasizes whole-person perspectives on mental health treatment, with the goal of incorporating people’s diverse backgrounds and circumstances into models of treatment, care, and support. A whole-person approach was described as integrated physical and mental health care that includes care coordination and communication between health care providers.

*“Whole person means both lifespan development issues and...also thinking about other conditions. It has a cascading impact.” – Advocacy organization*

In terms of models of care, Convening participants noted peer support as an area that would benefit from additional research to build the evidence base around benefits these services provide as it relates to access, navigating the health care system, and treatment. Convening participants also noted the need for research about interventions that include families as an integral component of treatment and that provide support and mentoring for families themselves. With the increase of virtual care due to the COVID-19 pandemic, telehealth was described as an important area, including how it can help address issues of access. Finally, survey respondents and Convening participants noted the need for more research into how to deliver more inclusive, responsive, and culturally competent mental health care across all types of care models, interventions, and programs.

## Education and Training

Survey respondents and Convening participants described education and training as critical building blocks for peers and health care professionals and an area where further research could help identify best practices.

For individuals with mood disorders and their families, survey respondents noted that education is needed at multiple points in the process, including around seeking and accessing care, diagnosis, treatment, and self-advocacy. This included ensuring that information about advances in treatments is communicated in accessible ways to individuals with mood disorders. Convening participants echoed the importance of peer education but noted that the lack of payment mechanisms can present a barrier—for example, lack of clinician reimbursement for providing education and funds to support education by public mental health agencies and advocacy organizations.

In recognition that patient-provider relationships are a key element of achieving desired outcomes, survey respondents and Convening participants also noted that education and training is needed for health care professionals to facilitate the provision of patient- and family-centered care. Training also was described as an important part of counteracting stigmas and perceived stereotypes in the medical community with regard to mood disorders. Convening participants emphasized opportunities to include peers in provider education to deepen providers' understanding of peer experiences and perspectives.

*"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*

In addition, Convening participants noted that credentialed peer support specialists can be an important part of the education and training process for both providers and peers. Given their background, experience, and expertise, peer support specialists are uniquely positioned to offer guidance to peers while also helping providers understand the needs and perspectives of peers.

## Underserved Populations

Both Convening participants and survey respondents noted additional challenges related to diagnosis, access, treatment, stigma, and receiving support for traditionally underserved populations. Addressing these issues requires understanding how racism, discrimination, stereotypes, and bias affect people's experiences and perspectives. Because of this, Convening participants emphasized the importance of looking at all research topics and priorities through an equity lens, with purposeful inclusion of individuals, communities, and populations that have been historically under-represented and underserved.

*"Our BIPOC communities have such great need, but also varying ways that the symptomatology or the feelings, behaviors, expressions, can sometimes be different. I think that needs a lot more research." – Peer*

Convening participants and survey respondents noted a variety of groups that would benefit from additional attention as future research is planned, including (but not limited to) communities of color; LGBTQ+ individuals; low-income individuals; Veterans; older adults, particularly those who have lived with a mood disorder for a long time; young adults (18-25); children and adolescents; and women, particularly related to reproductive health.

## Effects of the COVID-19 Pandemic on Living with or Acquiring a Mood Disorder

Convening participants noted that the COVID-19 pandemic has “put a spotlight on the weaknesses in our society” and “poked vulnerabilities” in multiple aspects of people’s lives, with a significant impact on mental health. COVID-19 was seen as both a negative disruptor (for example, in terms of burdens on mental health) and a potentially positive disruptor (for example, decreasing barriers to care through the adoption of telehealth). Participants noted the importance of examining how COVID-19 has affected the prevalence of mood disorders, specific diagnoses, access to care, treatment methods and modes, and 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*

## Peer Priorities for How Research is Conducted, Disseminated, Translated, and Funded

Survey respondents and Convening participants noted the need to consider and address peer priorities not only for research topics, but also for how research is conducted, disseminated, and adopted into practice.

### Conducting and Disseminating Research

Convening participants emphasized that peers are a critical part of the research process, and should be included as members of research teams, with meaningful roles in planning, conducting, and disseminating research.<sup>3</sup> This partnership begins with involving peers as a primary source for identifying research topics and approaches that meet the needs and concerns of affected populations, rather than setting priorities and trying to fit community feedback into researchers’ existing priorities and plans.

*“It’s not just taking our priorities and then someone goes and researches them, but also saying is this research focused on the outcomes that patients care about? And did patients help design and participate in the research? Those are the things we’re pushing for.” – Peer*

*“You can’t just expect that [underserved communities] are going to come adapt to your project. With that mentality, you’re going to miss a lot of pieces.” – Advocacy organization*

Partnering with and learning directly from peers was highlighted as a particularly important strategy for addressing the needs and concerns of underserved populations. Convening participants noted that underserved populations are often labeled as “hard to reach,” when appropriate outreach does not occur. Engaging underserved populations in research requires a specific plan for

<sup>3</sup> 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). *Amplifying Peer Priorities in Mood Disorders Research: Recommendations for Creating and Sustaining Meaningful Partnerships Between Researchers and Peers.*

including under-represented voices, an outreach strategy grounded in meeting people where they are, and a willingness to listen openly and adjust plans accordingly. Beyond partnering with underserved communities, Convening participants noted that all research should also collect and report information on the extent to which underserved groups are represented in the study population.

## Translating and Implementing Research Results

To be useful for improving outcomes, Convening participants noted that research findings need to be translated into policy and practice. This requires upfront consideration of how research outcomes and recommendations will be implemented. In particular, Convening participants highlighted the importance of considering from an early stage how programs or treatments might ultimately be paid for and adopted and building relationships to facilitate that process. In addition to researchers, clinicians, and peers, key stakeholders to engage and involve include insurance companies, policymakers, government payers, pharmaceutical organizations, health systems, and advocacy organizations.

*"Once the research is done, some of the findings will need to be translated into policy, and it will be a good idea to have those stakeholders who would be helpful in getting policy implemented involved as well. A lot of the issues that peers brought up as priorities, it's going to require policy changes and interventions that require other stakeholders to be involved. The earlier you involve them, the more likely you're going to be able to address issues without significant pushback in the process. At the end of the day, you want something that is patient- or peer-centered. But it will be helpful to have those other stakeholders involved." – Advocacy organization*

## Funding Research

Convening participants described several ways in which funders, including PCORI, can support and advance research that is peer-led, innovative, and that listens to and addresses peer priorities.

First, participants noted that many of the topics identified by peers as priorities for future research seem to "fall into a funding gap between agencies." Convening participants advised that it would be helpful for government agencies, foundations, and other organizations that provide funds for mood disorders research to collaborate in describing their areas of interest and ensure that topics of importance to peers do not get overlooked. In particular, there was a desire for more coordination and clarity across PCORI, NIH, and NIMH.

Second, the traditional structure of and evaluation criteria for funded research projects also can make it difficult to address peer priorities or for peer-led organizations to assume lead roles on research projects. For example, Convening participants noted that peers have expressed the need for longer-term and longitudinal research, but that current funding mechanisms make this type of research challenging. In addition, Convening participants spoke specifically about peers' desire for research that adopts a "whole-person" lens, noting that a comprehensive, broad approach including multiple elements and modalities may be the "way to treat depression or mood disorders," but does not always translate to a "clean" research design that is appealing to reviewers and funders. Furthermore, funders' criteria sometimes act to minimize peer voices and expertise. For example, Convening participants noted that funders require

*"If they [funders] invite peers and advocacy groups to give voice to what their networks want to research, they need to prioritize and weight that input." – Advocacy organization*



evidence of the significance of the problem or issue being addressed through research, but do not give equal weight to peer priorities as “evidence.” A related challenge is scoring criteria that prioritize investigators’ research experience, making it more difficult to include peers or mental health advocacy organizations as co-investigators.

Finally, funders can advance peer priorities for research, particularly priorities expressed by underserved communities, by supporting diversity among researchers and within research studies. Convening participants spoke clearly about the need for funders to create development pipelines or other mechanisms that support new voices, including “Black researchers, POC researchers, and people who identify with lived experience.” Convening participants also noted the need for funders to require diversity in research study populations, intentionally and from the start. This takes outreach to underserved populations, the engagement of community partners, and funding to support this type of outreach and engagement.

## Conclusion

Addressing peer priorities requires attention to the topics that are being researched, the types of interventions that are planned, how research findings will be disseminated, plans for translating research to practice, and mechanisms for funding research. The input in this document represents input from nearly 3,000 survey respondents along with a multi-stakeholder group of leading experts that represent the perspectives of researchers, clinicians, peers, and mental health advocacy organization. The work of advancing peer priorities will take continued collaboration among stakeholders. This collaboration will need to include meaningful roles for peers to ensure that their perspectives and priorities continue to guide the work forward.

*"It's about the lifecycle of the research, it's not just the beginning part. It's not just the middle part. But it's also what do you do at the end with this research? Is the research actually beneficial to the peer community? And if it is, is it going out to organizations that serve those folks? You have to look at the entirety and how you engage with [peers] during and throughout the process.— Advocacy organization*

## Appendix 1. Convening Participants

Convening participants are listed in alphabetical order. We acknowledge and thank all of these individuals for their expertise, active participation, thoughtfulness, and contributions.

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## Appendix 2. Specific Peer Priorities for Research by Topic Area

The following topics were suggested by survey respondents and Convening participants as priority topics for further research.

Topic Area	Specific Peer Priorities
<b>Causes</b>	<ul style="list-style-type: none"> <li>• Learning more about hereditary aspects of mood disorders, including whether they are genetically predetermined and how a genetic predisposition is “activated”</li> <li>• Understanding what changes in the brain cause depression and shifts in mood, including understanding how the chemical makeup of the brain differs between individuals with and without mood disorders</li> <li>• Identifying contributors to the development of mood disorders, including environmental factors, societal influences, exposure to chemicals and specific medications, hormonal imbalances, childhood events, trauma, poverty, isolation, and the co-occurrence of other conditions and diseases</li> </ul>
<b>Diagnosis</b>	<ul style="list-style-type: none"> <li>• Developing better pathways toward obtaining an accurate and timely diagnoses as a critical part of starting treatment</li> <li>• Including education and expectation-setting related to both treatment options and outcomes as part of the diagnostic process</li> <li>• Addressing age-related gaps in diagnosis, particularly related to diagnosing mental health conditions in young people</li> </ul>
<b>Access to Care</b>	<ul style="list-style-type: none"> <li>• Understanding how various factors affect access, including sex, gender, disability, race, ethnicity, age, religion, cultural beliefs, employment status, income, health insurance coverage, geographic location, prior military service</li> <li>• Developing programs that increase timely access to care and reduce barriers, particularly for underserved populations</li> <li>• Determining how to provide mental health care and treatment options at lower costs to larger segments of the population</li> <li>• Delineating the linkages between access, coverage, cost, and outcomes</li> </ul>
<b>Treatment</b>	<p><u>General priorities around treatment</u></p> <ul style="list-style-type: none"> <li>• Understanding why individuals experience variability in symptoms and identifying factors that contribute to improved or worsening symptoms</li> <li>• Researching individualized care delivery models, including which forms of treatment are most appropriate for specific individuals or types of individuals, including those with complex conditions (e.g., treatment-resistant depression), chronic pain, ADHD,</li> </ul>

	<p>trauma, PTSD, substance use, metabolic disorders, autoimmune disorders, migraine, sleep, and PCOS</p> <ul style="list-style-type: none"> <li>• Identifying how various types of treatments work in conjunction with each other, and which combinations are most effective for specific individuals and diagnoses</li> <li>• Identifying which treatments are most appropriate for specific points in one’s mood disorder, including crisis, maintenance, and remission</li> <li>• Learning how to manage mood disorders as a chronic condition, including preventing recurrences (i.e., “relapse prevention”) or the progression of mood disorders in terms of severity</li> </ul> <p><u>Priorities around medication-related treatment</u></p> <ul style="list-style-type: none"> <li>• Finding more effective medications—particularly for bipolar and treatment-resistant depression—that have fewer and less undesirable side effects</li> <li>• Reducing the trial and error associated with finding effective medications</li> <li>• Understanding the long-term effects of antidepressants and mood stabilizers, including the effects of being on medications for a significant period of time</li> <li>• Developing a better understanding of drug interactions, including medications that for mental and physical health conditions</li> <li>• Understanding which medications are most appropriate for use in pregnancy and post-partum</li> </ul> <p><u>Priorities around non-medication-related treatment and support</u></p> <ul style="list-style-type: none"> <li>• Understanding the effectiveness of various types of therapy, including therapy that involves family members</li> <li>• Developing community-based interventions to reduce social isolation and build support into individuals’ everyday experiences</li> </ul> <p><u>Priorities around alternative treatments</u></p> <ul style="list-style-type: none"> <li>• Learning more about the effectiveness of alternative treatments including diet and nutrition; exercise and physical activity; cannabis/CBD; psychedelics; spiritual practices; meditation and mindfulness; dietary supplements; massage; and sleep</li> <li>• Developing the evidence base for “non-traditional” treatments to facilitate wider adoption of and payment for these treatments</li> </ul>
<p><b>Models of Care</b></p>	<ul style="list-style-type: none"> <li>• Fortifying research around peer support models to facilitate wider adoption of and payment for peer support services, including researching the effectiveness of various peer support models (e.g., virtual versus in-person, placement of peer supporters in emergency departments) and the key elements of these programs for driving outcomes</li> <li>• Developing evidence to facilitate the wider adoption of and payment for family peer support (i.e., families helping other families)</li> <li>• Learning how best to incorporate families into an individual’s treatment, including development of payment models for family integration</li> </ul>

	<ul style="list-style-type: none"> <li>• Understanding how to most effectively deliver telehealth services in ways that work to address the needs of individuals with mood disorders and that are reimbursable</li> <li>• Developing flexible models for integrated and coordinated care, including different modes of delivery (e.g., virtual, in-person, hybrid, peer-led)</li> </ul>
<b>Education and Training</b>	<p><u>Education and Training for Peers</u></p> <ul style="list-style-type: none"> <li>• Providing effective education around self-advocacy, diagnosis, participating in treatment, asking questions, and accessing appropriate care</li> <li>• Ensuring that advances in treatments are communicated broadly to peers in addition to health care providers, and understanding how to effectively communicate advances to all individuals in equitable ways</li> <li>• Integrating education into treatment and identifying opportunities to increase reimbursement for education</li> </ul> <p><u>Education and Training for Providers</u></p> <ul style="list-style-type: none"> <li>• Developing provider education and credentialing around providing patient-centered care for individuals with mood disorders</li> <li>• Providing training to family medicine and primary care physicians to help them recognize mood disorders</li> <li>• Addressing stigmas held amongst medical professionals with regard to mood disorders</li> <li>• Delineating the importance and effects of patient-provider relationships, including key elements and the impact on treatment outcomes</li> <li>• Building best practices and evidence for including individuals with lived experience in provider education</li> </ul>
<b>Underserved Populations</b>	<ul style="list-style-type: none"> <li>• Understanding the concerns of specific clinical and demographic populations with regard to access and treatment to develop a better understanding of how current systems and approaches are or are not meeting needs</li> <li>• Examining whether and how evidence-based treatments can be adapted to address the needs and concerns of underserved populations</li> <li>• Researching the intersection of poverty, racism, discrimination, health, and mental health</li> <li>• Understanding how previous negative experiences with and treatment by the medical community impact the ability to seek and acquire effective care</li> </ul>
<b>Effects of COVID-19</b>	<ul style="list-style-type: none"> <li>• Understanding how COVID-19 has impacted the mental health of individuals, communities, and populations</li> <li>• Examining disruptions to treatment as a result of COVID-19 and the impact on outcomes</li> <li>• Identifying positive aspects of changes to mental health care resulting from COVID-19, for example, the increased use of telehealth</li> </ul>