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Depression and Bipolar Support Alliance

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NATIONAL NETWORK of DEPRESSION CENTERS

Investigating Care Models to Support Older Adults with Depression and Health Comorbidities

Recommendations for Promoting and Supporting Collaborative Relationships Between Peers and Researchers

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THE VALUE AND IMPORTANCE OF PEER-CENTRIC RESEARCH

Recent years have seen an acceleration in patient-centered care and peer-centric research. The cornerstone of patient-centered care is emphasizing an individual's needs, and his or her desired outcomes when determining the best course of treatment, and whether that treatment has been successful.

The importance of patient-centered care is evidenced by the fact that people with the lived experience of mood disorders can often hold unique perspectives regarding the impacts of their condition, their experiences of care, and their treatment goals. Research reveals that these perspective may not always align with clinician or researcher perceptions.

For example, one online survey of people with mood disorders and healthcare providers found that patients reported more mood, physical, and cognitive symptoms, and a higher impact on psychosocial functioning in the post-acute and remission phases than the healthcare providers reported. These individuals also reported worse Quality of Life and greater levels of functional impairment than providers.[1]

Additionally, the perceived impact of treatment may not be adequately represented by traditional ideas on improvement based on symptom change. In one study, almost half of patients meeting criteria for symptomatic remission did not subjectively consider themselves to be in remission.[2]

These results underscore the importance of peer-centric research grounded in the meaningful involvement of people with the lived experience across the continuum of the research process. This begins with the

- identification of research questions,
- through shaping the design and conduct of research, all the way
- to the dissemination of findings.

The recognition of perception discrepancies between the researcher and clinician community and the patient and peer community prompted the Depression and Bipolar Support Alliance and the National Network of Depression Centers to partner on a project titled "Investigating Care Models to Support Older Adults with Depression and Health Comorbidities" to better understand how the community of stakeholders can identify potential best practices in engagement around peer-centric research. The Patient-Centered Outcomes Research Institute (PCORI) provided funding for this work through a Eugene Washington Engagement Award (EASC-23195).

Engaging peers upstream in research supports:
- Identifying peer-centric research topics and questions
- Shaping the design of the project
- Disseminating findings to larger audiences

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[1] Baune, B.T., Christensen, M.C., 2019. Differences in perceptions of major depressive disorder symptoms and treatment priorities between patients and health care providers across the acute, post-acute, and remission phases of depression. *Front Psychiatry* 10, 335.

[2] Zimmerman, M., Martinez, J.A., Attiullah, N., Friedman, M., Toba, C., Boerescu, D.A., Rahgeb, M., 2012. Why do some depressed outpatients who are in remission according to the Hamilton Depression Rating Scale not consider themselves to be in remission? *J. Clin. Psychiatry.* 73, 790–795.

PROJECT BACKGROUND

Depression is often linked to late in life health conditions such as cancer, diabetes, and heart disease. A few approaches to improving late life depression and health comorbidities in primary care have been tested. They include IMPACT (Improving Mood Promoting Access to Collaborative Treatment) and PROSPECT (Prevention of Suicide in Primary Care Elderly – Collaborative Trial). While these models use clinical management and patient follow-up, they fail to address the importance of a holistic approach in supporting patients' physical and mental health rooted in patient engagement and reducing isolation and self-stigma due to depression.

Patient-centered care aims to place individuals, their values, preferences, life, and health goals at the heart of the care process and to actively involve patients in care decisions. However, there remain few comparative effectiveness research (CER) studies specific to patient defined outcomes for older adults with depression and health comorbidities.

Recognizing the positive impacts of peer engagement in research, DBSA and NNDC convened the following stakeholder communities:

- peers and caregivers,
- clinicians and researchers, and
- patient advocacy organizations.

The goal was to elicit recommendations from these stakeholder communities that can foster and facilitate the development of collaborative relationships when implementing (CER) projects. To elicit feedback, the convening agenda acknowledged established principles of peer-centric research used to:

- generate user-focused research objectives and research questions,
- refine study methods (including recruitment strategies),
- include peer-centered interpretation of results, and
- support enhanced implementation and dissemination of research findings.

Participants were educated about these guiding principles prior to the open discussion and feedback gathering components of the convening.

PURPOSE OF THIS DOCUMENT

Increasing stakeholder engagement in research has the potential to improve patient-centered care.

Twenty-eight individuals participated in a virtual convening held by DBSA and NNDC in August 2022. Invitations were extended to create an environment of equal representation between the peer and patient advocacy communities, and the clinician and researcher communities.

The convening agenda included a presentation from PCORI to educate participants on the value and characteristics of CER. This session was followed by a panel discussion among a peer, a patient advocacy organization staff member, and a researcher. All had participated as stakeholders in PCORI CER projects.

The panelists shared their own experiences of best practices when engaging as a collaborative stakeholder. Topics included what worked, challenges that arose, and solutions to mitigating those challenges.

Feedback from the stakeholder community was elicited through

- large group discussions,
- breakout group discussions,
- reports from the breakout groups,
- individual lists of recommendations, and
- group voting on the individual recommendations.

This document contains six recommendations for promoting and supporting collaborative relationships among the previously identified stakeholders. When implemented, these recommendations have the potential to improve engagement among the identified stakeholder communities, resulting in CER projects that have the potential to improve patient-centered care. This report is provided as guidance and is derived from the generous input of convening participants.

The guidance provided in this document is divided into three sections:

- Recommendations for researchers
- Recommendations for patient advocacy organizations
- Recommendations for peers

During the panel discussion, participants were asked to provide observations about questions raised or thoughts about their own personal experience as a stakeholder in CER projects. This feedback was used to develop questions for the small group discussions.

Participants were also asked to rate their knowledge and or experience around the concept of best practices in peer-centric research before and after the panel discussion. Participants demonstrated a 24% increase in the response “Very Knowledgeable about Best Practices” after listening to the panel discussion.

90%

of convening participants rated their knowledge of best practices in peer-centric research as very knowledgeable or more aware after listening to a panel discussion on the topic.

RECOMMENDATIONS FOR RESEARCHERS

1. Think about who you have not engaged from the peer community; what voices might be missing.

There was consensus among stakeholder participants that more diversity in CER stakeholder collaboration is needed. Participants recognized that outreach to historically underrepresented communities requires humility, cultural responsiveness, and an acknowledgment that there has been a history of exclusion.

Using the principles of community-based participatory research was recognized as a starting point. Stigma and mistrust of the medical research community was raised by participants as a barrier. Solutions offered included working in the community to build trust, long before making the request for CER stakeholder engagement. This strategy includes broadening the scope of partner organizations from traditional patient advocacy organizations to local organizations serving the needs of the community.

2. Engage patient and community partners early in the process to decide on the study's purpose or objective and allow time for relationship-building.

As researchers build relationships based on mutual respect and trust, it is important to strengthen these relationships by demonstrating a desire for collaboration through action. Recommendations include recognizing that peers are experts in research priority topics. The peer and patient advocacy community should be included upfront in research proposal development. This includes identification of the research topic, study design, and patient recruitment.

Once a proposal has been accepted, peer advisory councils should be more than an approver of decisions already made. Recommendations for collaborative engagement include providing:

- equitable compensation for participation on the stakeholder or peer council commensurate with their expert by experience status;
- active participation in developing research questions; and
- opportunity to identify recruitment and participation barriers that living with the condition can impose.

Community advisory councils are a valuable resource to engage the stakeholder communities early and often in the study design, implementation, and dissemination process.

RECOMMENDATIONS FOR PATIENT ADVOCACY ORGANIZATIONS

1. Educate peers about the research process and opportunities.

Patient advocacy organizations have a distinctive role in mentoring peers and developing awareness about:

- serving on peer advisory councils,
- criteria for effective council collaboration, as well as,
- participation in a research project.

Recognizing that researchers often turn to patient advocacy organizations for peer council and research participant recommendations, patient advocacy organizations should put in place systems that support a diverse pool of suggested candidates including previously under-served communities and the most ill or disabled members of the community. Enlarging patient advocacy databases supports eliminating the potential for self-selection bias and overuse of the same advocates.

Additionally, patient advocacy organizations can deploy the organization's communication strategies to create awareness about websites which facilitate the matching of research participants to clinical trials.

2. Create approaches to engage peers from communities.

Patient advocacy organizations often sit between the peer community and the research community. This unique role provides opportunities to bridge the relationship from peer to researcher and vice versa. Recommendations from convening participants include developing bottom-up surveys. This provides opportunity for peers to have a direct pipeline to researchers on the impact of living with the condition, desired treatment outcomes and how they measure progress.

> When sharing peer-designed surveys with researchers, patient advocacy organizations support education around peer-centric language, identification of peer priorities, and draw researchers closer to the peer community.

RECOMMENDATIONS FOR PEERS

1. Clearly define the relationship and what you want from it going into the CER project.

As a partner in collaboration, it is important for peers to demonstrate leadership in their expert by experience status. Recommendations include researching academic institutions to find those a peer wants to work with. Once a good match has been identified, peers should feel empowered to speak up. Recommendations include:

- contact researcher or research department,
- provide an introduction and overview of the area of interest,
- clearly state lived experience and personal goals around future stakeholder engagement opportunities.

When invited to participate on a peer council, address any specific accommodations needed, including attendance at meetings, compensation, and whether an opportunity exists to be listed as an author on any academic papers that result from the project.

2. You don't need to be an expert in the research, your lived experience is just as valuable as other project team members.

Stigma has the potential to keep peers from recognizing their own expertise. Lack of education about the process can be intimidating. Current peer leaders can seek out opportunities to share their knowledge with other peers. Convening participants recommended peers ask people they trust to educate them about the process. Trusted sources included:

- patient advocacy organizations,
- local leaders such as ministers and neighborhood elected officials, and
- members of the medical community.

Peers should be encouraged to claim their authority as an expert in research topics designed around the conditions they live with.

CONCLUSION

The polling results from the convening demonstrate that providing education about best practices for collaboration can increase stakeholder knowledge. While a range of frameworks to help foster, evaluate, and report on patient and public research are available[1], this field remains immature.[2] Productive stakeholder collaboration has the potential to provide better research outcomes and improve patient care. Research on the value and methods for providing stakeholder education around collaboration is recommended. In the meantime, implementing recommendations provided in this guidance report has potential to improve the peer-centric research process.

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[1] Greenhalgh et al. 2019

[2] Domecq et al., 2014

THANK YOU

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APPENDIX I

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