

Lessons Learned from Challenges in MoodNetwork Recruitment: Stigma and Mental Health

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Project Aims

How does your project benefit from using PCORnet infrastructure and resources?

By bringing together a large, diverse group of individuals with mood disorders interested in focusing on patient-reported outcomes and patient priorities in research, MoodNetwork has the potential to both investigate the factors that cause and maintain stigma. This network hopes to change the conversation about mental health conditions, and reduce uncertainty about these conditions.

Having stakeholder involvement in our projects improves our understanding of what is important to research. PCORnet's people-centered research model allows us to continue to prioritize this important goal.

It is paramount that every PCORnet community understands the best methods for reducing core barriers to engagement, including stigma, so that they may grow their communities.

How does your project benefit the further development of PCORnet?

This project will help communities enhance the engagement of their stakeholders. This will contribute to PCORnet's sustainability, given that engagement is crucial to sustaining an active and vibrant network, as well as assisting with dissemination throughout PCORnet.

Methods

How is PCORnet being used to advance this project?

PCORnet has given us the resources to expand beyond the MoodNetwork platform and develop partnerships with PPRNs that have different experiences but also face stigma.

How does your project reflect research done differently?

Unlike past research, our work through PCORnet on MoodNetwork brings together patients, providers, researchers, and caregivers to open up a dialogue about stigma. The online nature of our study allows members to communicate with others across the globe, while also allowing them to maintain their desired level of privacy. This is particularly important to break down barriers regarding stigma.

List all PCORnet collaborators, including patient groups.

Anxiety and Depression Association of America (ADAA), Depression and Bipolar Support Alliance (DBSA), International Bipolar Foundation (IBPF), and the National Organization for People of Color Against Suicide (NOPCAS).



Objectives

Why is this project important? How is it "people-centered"? Describe the role patients play in forming the research question/objectives.

A nearly unavoidable aspect of living with bipolar disorder is experiencing stigma. This project examines how we can open up conversations that may decrease the burden that people with bipolar disorder—and mood disorders more generally—encounter. It became clear early on that people were reluctant to associate their name with an organization focusing on mood disorders. For this reason, we decided to explore the best ways to reduce stigma among our MoodNetwork registrants.

Progress or Results

What is your progress so far or key results?

We identified four strategies for reducing stigma: simplifying website and recruitment material language, removing messaging that separates researchers from patients, focusing on wellness and positive messaging, and increasing the accessibility of MoodNetwork materials. However, we have found that recruiting and reducing stigma among marginalized communities, e.g., people of color (POC), LGBTQ+ communities, has posed additional challenges.

Figures

Preferred Research Topics for MoodNetwork

Topic	Votes (N)	Votes (% of total)
1. Reducing stigma	187	11.7%
2. Alleviating symptoms	173	10.9%
3. Alternative treatments	151	9.5%
4. Reducing barriers to care (improving access to care)	150	9.4%
5. New medications	143	9.0%
6. Genetic studies to identify responders to treatment	124	7.8%
7. Improving assessment and diagnosis	120	7.5%
8. Healthy lifestyle	100	6.3%
9. Managing side effects	96	6.0%
10. Educating families and friends	84	5.3%
11. Effects of psychotherapy	78	4.9%
12. Educating people with mood disorders	76	4.8%
13. Treatments for adolescents and young adults	51	3.2%
14. Effects of peer support	39	2.4%
15. Treatments for children	20	1.2%

Strategies for Reducing Stigma and Increasing People to Speak Out

Strategy	Steps taken to address these strategies
Simplify the website and recruitment materials	Changed the layout and format of the website to make it easier to navigate. Reduced language/words in all materials and website.
Collaborate with patients and other stakeholders	Conduct focus groups to receive additional patient stakeholder feedback on MoodNetwork. Removed language from our website and materials that separates researchers and clinicians from patients and caregivers ("us" versus "them").
Focus on wellness and positive messaging	We have posted blogs, forum posts, and Facebook posts to promote the idea of living well with mood disorders (e.g., "curing" mood disorders is not part of our mission). Encouraging patient stakeholders to write about their strengths opposed to focusing only on negative aspects of living with mood disorders.
Improve access to materials	We have been working to publish papers and articles to describe MoodNetwork in the public domain. Creating a dashboard for participants to view aggregated data from all MoodNetwork participants.
Targeting specific sub-populations in recruitment efforts	We have tailored messages for specific sub-populations (e.g., worked with the National Organization for People of Color Against Suicide to recruit individuals from African American fraternities, colleges)

DISCLOSURES

Dr. Nierenberg is a consultant for the Abbott Laboratories, Alkermes, American Psychiatric Association, Appliance Computing Inc. (Mindsite), Basilea, Brain Cells, Inc., Branded University, Bristol Myers Squibb, Clintara, Concept, Dey Pharmaceuticals, Dainippon Sumitomo (now Sunovion), Eli Lilly and Company, EpiQ, L.P./Mylan Inc., Forest, Genesance, Genentech, GlaxoSmithKline, Hoffman LaRoche, Infomedic, Intra-Cellular Therapies, Lundbeck, Janssen Pharmaceutica, Jazz Pharmaceuticals, Medavante, Merck, Methylation Sciences, Nurex, NeuroRx, Novartis, Otsuka, PamLabs, Pfizer, Pfizer, PGx Health, Ridge Diagnostics Shire, Schering-Plough, Somerset, Sunovion, Takeda Pharmaceuticals, Targacept, and Teva; consulted through the MGH Clinical Trials Network and Institute (CTNI) for Astra Zeneca, Brain Cells, Inc., Dainippon Sumitomo/Separacor, Johnson and Johnson, Labopharm, Merck, Methylation Science, Novartis, PGx Health, Shire, Schering-Plough, Targacept, and Takeda/Lundbeck Pharmaceuticals. He receives grant/research support from American Foundation for Suicide Prevention, AHRQ, Brain and Behavior Research Foundation, Bristol-Myers Squibb, Cederroth, Cephalon, Cyberonics, Elan, Eli Lilly, Forest, GlaxoSmithKline, Janssen Pharmaceutica, Intra-Cellular Therapies, Lichtwer Pharma, Marriott Foundation, Mylan, NIMH, PamLabs, PCORI, Pfizer Pharmaceuticals, Shire, Stanley Foundation, Takeda, and Wyeth-Ayerst. Honoraria include Belvoir Publishing, University of Texas Southwestern Dallas, Branded University, Bristol-Myers Squibb, Hillside Hospital, American Drug Utilization Review, American Society for Clinical Psychopharmacology, Baystate Medical Center, Columbia University, CRICO, Dartmouth Medical School, Health New England, Harold Grinspoon Charitable Foundation, IMDEX, Israel Society for Biological Psychiatry, Johns Hopkins University, MJ Consulting, New York State, Medscape, MBL Publishing, MGH Psychiatry Academy, National Association of Continuing Education, Physicians Postgraduate Press, SUNY Buffalo, University of Wisconsin, University of Pisa, University of Michigan, University of Miami, University of Wisconsin at Madison, World Congress of Brain Behavior and Emotion, APSARD, ISBD, SciMed, Slack Publishing and Wolters Kluwer Publishing, ASCP, NCOEJ, Rush Medical College, Yale University School of Medicine, NNDc, Nova Southeastern University, NAMI, Institute of Medicine, CME Institute, ISCTM. He was currently or formerly on the advisory boards of Appliance Computing, Inc., Brain Cells, Inc., Eli Lilly and Company, Genentech, Johnson and Johnson, Takeda/Lundbeck, Targacept, and Infomedic. He owns stock options in Appliance Computing, Inc., Brain Cells, Inc., and Medavante; has copyrights to the Clinical Positive Affect Scale and the MGH Structured Clinical Interview for the Montgomery Asberg Depression Scale exclusively licensed to the MGH Clinical Trials Network and Institute (CTNI).

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