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## **Peer and Non-Peer Academic Scientists and Peer Support Specialist Community of Practice:**

### **Stakeholder Engagement to Advance the Science of Peer Support**

**Karen Fortuna, PhD, LICSW,**

Geisel School of Medicine, Dartmouth College, Hanover NH, USA

**Mbita Mbao, LICSW,**

Simmons University, Boston MA, USA

**Arya Kadakia,**

Dartmouth College, Hanover NH, USA

**Amanda Myers, MPH,**

Brandeis University, Waltham MA, USA

**Daniel Fischer, PhD,**

National Empowerment Center, Boston MA, USA

**Sandi MacDonald,**

International Association of Pre-Menstrual Disorders, Nova Scotia, CA

**Sheila Brunchet,**

International Association of Pre-Menstrual Disorders, Nova Scotia, CA

**Iga Hintz,**

National Empowerment Center, Poland

**Rebecca Rossom, MD,**

HealthPartners Institute, Minneapolis MN, USA

**Jessica Brooks, PhD,**

University of Wisconsin-Madison, Madison WI, USA

**Joseph Kalisa,**

University of Rwanda, Kigali, Rwanda

**Claver Haragirimana,**

Opromamer, Rwanda

**Marianne Storm,**

University of Stavanger & Molde University College, Norway

**George Mois, LISW,**

University of Georgia, Athens GA, USA

**Emre Umucu,**

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klfortuna@gmail.com .

University of Texas at El Paso, El Paso TX, USA

**Margaret Almeida, PhD,**

Mental Health Center of Greater Manchester, Manchester NH, USA

**Jennifer Rivera,**

Boston College, Boston MA, USA

**Yaara Zisman Ilani,**

Temple University, Philadelphia PA, USA

**Maria Venegas,**

Veterans Affairs, USA

**Robert Walker, COAPS**

Department of Mental Health, Boston MA, USA

## Abstract

Community of Practice, a community-engagement method that encourages a group of people to interact regularly towards a common goal, may promote satisfying experiences in patient-outcomes research among marginalized populations. Peer support specialists are increasingly being involved in peer-informed mental health research due to their lived experiences of mental illness and are an asset in co-designing healthcare programs along with researchers. In 2015, ten scientists and ten mental health service users joined as a Community of Practice that trained to engage in patient-centered outcomes research. The group has so far has presented at 20 conferences, published three book chapters and 30 peer-reviewed publications, and developed two smartphone applications. Of note are the co-production of a smartphone application, a digital peer support certification program, an app decision support tool, and an instrument to assess the value of patient-research partnerships. Future research will assess the feasibility of incorporating more stakeholders to enhance research outcomes.

## Keywords

peer support specialists; community of practice; marginalized populations; PeerTECH

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## I. Introduction

Serious mental illness (SMI; a diagnosis of schizophrenia spectrum disorder, bipolar disorder, or major depressive disorder) is a leading disability globally. While smartphone applications designed to support recovery from SMI have shown promise in clinical settings, they have limited engagement when implemented in the real world. Partnering with people with SMI to co-design smartphone apps may therefore improve engagement, adoption, and consequently mental health outcomes.

Co-design partnerships include various participatory stakeholder methods including focus groups, community engagement studies, and community-based participatory research [14]. Bucci et al. (2019) suggest that digital tools such as a smartphone application with high acceptability and likelihood to fit the needs of service users will have to consider the

end-users' perspectives to increase uptake [32]. This is especially important in digital mental health because vulnerable groups such as people with SMI often disengage from recovery-oriented technologies before improved outcomes are achieved [30, 31]. Within the realm of smartphone app interventions, the application of a participatory research approach and usercentered design throughout the software development lifecycles has shown promising evidence of leading to the highest levels of engagement among people with SMI [13].

However, working with people with SMI as partners in the software development lifecycle can be challenging as individuals in this vulnerable population report high levels of mistrust in the traditional mental health system and its associated technologies. After deinstitutionalization on the global stage (i.e., closing state mental health hospitals), patients came to reject the traditional mental health system due to experiences within institutionalization and challenges in reintegrating within their community such as forced medication and restraints. As a result of this history, engaging, hiring, and working with people with SMI is impacted and requires a specialized approach in the software development lifecycle. Moreover, patient-centered outcomes research (PCOR) often leaves research-naïve stakeholders feeling overburdened and disenfranchised, leading to premature disengagement from PCOR [8]. Stakeholders may be expected to relive past emotionally painful memories, compelled by a huge responsibility to keep sensitive information confidential, made to do tremendous work that can lead to relapse, at risk of public media exposure through their work, and can be frustrated by their limited involvement in the research [8]. This is particularly important to engaging historically marginalized and disadvantaged populations in PCOR/CER, such as service users of the mental health system, who already experience high mistrust of research.

### **Community of Practice**

Wenger and Trayner (2015) define Community of Practice (CoP) as groups of people who share a concern or passion for something they do and learn how to do it better through regular interaction. Three characteristics of a successful CoP include (1) identity of the group defined by a shared domain of interest, (2) engagement in joint activities and discussions, helping each other and sharing information, and (3) shared resources, experiences, and ways of addressing recurring problems. one community engagement method that may promote satisfying experiences in the software development lifecycle. Preliminary evidence indicates that incorporating community-engaged research in the software development lifecycle produces more relevant research, increased engagement, and uptake of technologies, and improves clinical outcomes compared to traditional research [13]. The goals of CoP vary and can be based on the exchange of resources, transferring of skills, or meeting disparities. Academic partnerships have been documented in several disciplines to meet global health disparities [10], such as in business to accelerate innovation [9] and in behavioral health research to develop and implement mHealth interventions [14].

### **Description of peer support specialists**

Peer support specialists are defined as people with lived experience of mental health and/or substance use challenges employed and accredited by their respective states to offer Medicaid reimbursable support services [26,27]. Peer support specialists are practitioners

working in various settings including but not limited to primary care offices, emergency rooms, inpatient facilities, mental health clinics, and recovery centers [10]. In many settings, peer support specialists work as part of a team with other professionals. In addition to the practitioner role, several studies have engaged peer support specialists as active research partners, involved in all phases of research, from conceptualizing research projects to reporting, validation, and dissemination of findings [14]. Whereas few studies exist that are led by peer specialists, emerging researchers in the field are engaging and developing a mental health peer-informed research and continue to engage peer support specialists with some having principal investigators as mental health peers.

### Current Academic Partnership

This manuscript delineates the CoP partnership between peer support specialists and academic researchers, outlining the history of the partnerships, projects undertaken, and future goals. The goal of this CoP was to bring a group of practitioners together with similar interests to learn from each other and collaborate on projects and research based on their shared interest in advancing the science of digital peer support. Hence, this research furthers the agenda of Information and Communications Technology for Development (ICT4D) and Humanitarian Technologies by promoting the utilization of technology to benefit those with lived experiences of mental illness. For instance, certified peer support specialists were trained by researchers to utilize the PeerTECH smartphone application, a platform that allowed them to connect with others with SMI to support them in illness management, goal obtainment, and recovery. Another example that highlights this partnership is the co-production of a decision support tool that helped peer support specialists and service users select appropriate and valid mental health apps to aid in their recovery. This current research is necessary to further assess the relationship between the peer specialists and academic experts to determine the underlying mechanisms that benefit the partnership as well as the scope of future research that can be undertaken using this CoP.

This paper will first highlight how the relationship between the peer specialists and the scientists was formed in the community of practice. It will explore their individual roles as well as the shared goals and outcomes of the collaborations before identifying the key activities that they engaged in together. It will finally outline the future work in community engagement and the role of peer support specialists in research collaboration in Rwanda.

## II. Methodology

The partnership includes ten scientists (with or without a lived experience of mental illness) representing diverse fields of study (i.e., medicine, biology, implementation science, social work, psychology, engineering, computer/data science) and ten patients, peer support specialists, family, or caregivers of people with SMI trained in PCOR and actively engaging in PCOR (Figure 1). Our team has been engaged in solidifying a patient perspective on current research and future directions for the past six years through weekly project meetings, online discussion forums, open meetings, and surveys. Discussion topics vary, and each group member can present a case for shared learning. Topics that group members have discussed include research relationships with the community; (4) encourage community

self-determination; (5) partner with the community; (6) respect community diversity and culture; (7) activate community assets and develop capacity; (8) maintain flexibility; and (9) commit to long-term collaboration [14]. These goals were based on the CDC principles of community engagement and the integration of an accountability tool, which encouraged reciprocal learning in the knowledge production process. The foundation of the partnership involved gaining knowledge of peer support specialists' roles. In this critical phase, the academic researchers conducted preliminary research to understand the peer support specialists. The academic researchers conducted formal and methodology, project management, and grant writing. A group member may present their project to the rest of the group to obtain feedback. The group members then collaborate on research projects and help each other learn from their individual insight. The relationships developed by this group have extended beyond the monthly meetings. They have even created a text message group with all group members to interact and help build relationships that foster connection.

### Development of partnership

The partnership between academic researchers and peer support specialists was developed in line with principles of community engagement research and has been thoroughly documented in Fortuna et al., 2019. The methodological approach of the co-partnership was inspired by the Academic Researchers-Certified Peer Specialists mHealth Research Continuum [14]. The goals were to (1) develop a clear understanding of the purpose, goal, and population involved in community change; (2) become knowledgeable about all aspects of the community; (3) interact and establish informal research to gain insight into the role of peer support specialists and understand potential challenges that such a partnership would create [14]. The partnership was guided by the following principles: fairness, empowerment, inclusion, and self-determination. In developing peer research capacity, training in research methodology and technology was offered to peer support specialists. Learning was experiential, giving peer support specialists opportunities to practice the research skills they were learning. In this partnership, peer support specialists are equal partners involved in all aspects of the collaboration, including grant application, identifying, and defining the research problems, recruiting research participants, conducting research, disseminating research findings, and training. The advantage of such a methodological approach is enabling those with lived experiences to produce products that are designed for their demographic. Collaborative work in the Community of Practice helped make sure that the research was not only relevant to the population but was also accessible despite the cognitive and social challenges that they faced. Moreover, by treating the individuals with lived experiences as equal partners in the research process, they offered insight into the multiple dimensions of mental health and contributed to the standards of digital mental health that were traditionally established by expert groups [34]. Nevertheless, the disadvantage to this methodology lay in the fact that peer specialists had limited research training. Hence, the initial stages of the knowledge production were slow, repetitive, and was contingent on the individual capacities of the peer specialists and patients. It was also held back by the barrier between the scientists and patients, the latter being unfamiliar with the jargon and technical knowledge used in academia. However, over time, such barriers were negligible as scientists and patients developed a better understanding of their tasks and specialized role in the research process.

The partnership has already engaged in numerous activities together. This paper will outline four projects as part of the CoP. First, peer support specialists participated in a single-arm pilot study that assessed the feasibility, acceptability, and preliminary effectiveness of the PeerTECH application. Along with offering peer support to patients, they engaged in focus groups with the researchers to ascertain the utility of the app through qualitative analysis. Second, peer support specialists co-produced a Digital Peer Support Certification and training with researchers. They conducted a pre-post study to examine the impact of audit and feedback with a supportive management structure on the ability of peer specialists to utilize technology. Next, they worked on the design, production, and testing of a digital support tool that helped people with serious mental illnesses choose smartphone applications to benefit their recovery. Their feedback was collected through cognitive interviews across three testing phases. Lastly, peer support specialists supported the production of the Quality of Patient-Centered Outcomes Research Partnerships Instrument (QPCOR) that assessed the partnership between researchers and service users using an iterative co-production technique. They participated in testing and cognitive interviews to produce a viable tool.

A particular ethical issue that needs to be noted is the lack of formal ethics training undertaken by the peer specialists. As part of the PCOR parent study, a few peer specialists were identified using a convenience sample framework to conduct an online research ethics course [25]. While qualitative analysis demonstrated that they considered research ethics education an opportunity to share their lived experiences, participants also struggled with the cognitive complexity of the content and with learning and retaining new information [25]. Limited insight into research ethics could consequently lead to complications while interacting with their patients about sensitive issues. Nevertheless, the rights of the partnered peer specialists were maintained as much as possible. For instance, their mental health diagnoses were kept confidential as part of the Americans with Disabilities Act. Furthermore, peer specialists were reimbursed completely for their time regardless of the success of their projects, were involved in every stage of the process to make sure they made informed decisions and were given the freedom to withdraw from projects if needed.

### III. Results and Discussion

#### Maintaining the partnership

The partnership of peers and academic researchers is committed to the dissemination of results and has achieved many milestones in the development of new projects including journal articles, conferences, webinars, and training. Group members are committed to their projects, and they all can assume ownership to lead various projects. The group has maintained momentum by engaging in monthly seminar meetings as well as regular informal and weekly formal check-ins with group members to maintain focus on goals for the partnership. The group is also committed to presenting results to agency senior leadership, policymakers, and state legislators to ensure that they are well informed while making priority decisions regarding funding, programming, policy, and workforce development initiatives.

## Studies Conducted by the Partnership

The partnership has conducted several activities over the years and has won a series of federally funded grants to expand the CoP research. The following information provides examples of activities that the partnership has undertaken. Each study was conducted in the United States using a combination of in-person activities and teleconference debriefs, focus groups, and interviews. All studies received IRB approval prior to them being conducted.

**A. PeerTECH Smartphone App**—Our team conducted a small single-arm pilot study in 2020 and established the preliminary feasibility and acceptability of PeerTECH [14], a digital peer support integrated medical and psychiatric self-management intervention smartphone application. The PeerTECH mobile technology platform includes a smartphone application and a peer support specialists' care management dashboard. The smartphone application is designed for people with SMI to reinforce skills learned from in-person sessions with a peer support specialist. The smartphone application includes: (a) access to personalized self-management support; (b) intervention components that correspond to patients' needs and goals; (c) a HIPAA-compliant encrypted chat feature for use between peer support specialists' care management dashboard and patients' smartphone application; and (d) an on-demand library of peer-led self-management narrative videos.

The study used a pre/post design, in which  $n = 10$  adults (Mean age of 68.8 years;  $SD=4.9$ ) with SMI and medical comorbidity received PeerTECH interventions in their homes by peer specialists. Participants also completed the Herth Hope Index, Empowerment Scale, Medical Outcomes Study Social Support Scale, Illness Management and Recovery Scale, Self-Rated Abilities for Health Practices Scale, and Self-Efficacy for Managing Chronic Disease Scale before and after the study. The study demonstrated high levels of patient engagement and promising clinical effectiveness. PeerTECH appears to be feasible for both peers and patients with SMIs. Eight people (80%) participated in 10 or more in-person meetings, consistent with the study definition of adequate exposure [14]. On average, 74% to 88% of participants engaged weekly with the smartphone application, and 33% to 47% engaged daily. The study provided evidence that PeerTECH was associated with statistically significant improvements in psychiatric self-management ( $p < .001$ ). Improvements were found in self-efficacy for managing chronic health conditions, social support, hope, quality of life, medical self-management skills, and empowerment (however, a limited demographic of participants may have influenced results).

Qualitative findings revealed the need to modify PeerTECH content to consider peer specialists' professional practice standards. Specifically, peer specialists indicated that focusing on social goals was a necessary and effective means to improve self-management behaviors.

**B. Digital Peer Support Certification**—This 2020 study aimed to explore the Digital Peer Support Certification impact on peer support specialists' capacity to use digital peer support technology.

The Digital Peer Support Certification was co-produced with peer support specialists and included an education and simulation training session, synchronous and asynchronous

support services, and audit and feedback. Participants included 9 certified peer support specialists between the ages of 25 and 54 years (mean 39 years) who were employed as peer support specialists for 1 to 11 years (mean 4.25 years) and had access to a work-funded smartphone device and data plan. A pre-post design was implemented to examine the Digital Peer Support Certification impact on peer support specialists' capacity to use technology over a 3-month timeframe. Data was collected at baseline, 1 month, 2 months, and 3 months. Overall, an upward trend in peer support specialists' capacity to offer digital peer support occurred during the 3-month certification period.

The Digital Peer Support Certification shows promising evidence of increasing the capacity of peer support specialists to use specific digital peer support technology features. Our findings also highlighted that this capacity was less likely to increase with training alone and that a combined knowledge translation approach that includes both training and management would likely be more successful.

**C. Decision Support Tool**—This 2021 study [29] aimed to create a decision-support tool for peer support specialists and service users to implement technologies in promoting recovery and well-being for people with mental health and substance use challenges. The Decision Support Tool for Peer Support Specialists and Service Users (D-SPSS) offered, for the first time, a tool to choose between technologies aimed at peers and service users, including an iterative co-production process on The International Patient Decision Aid Standards (IPDAS) and the Academic-Peer Partnership Model for Community Engagement. As service users and peer support specialists have stated, not being included in the decision-making regarding technology selection for clinical care, utilizing DSPSS may positively impact recovery.

The first version of the decision-support items on digital peer support competencies, barriers, and facilitators to using technologies, as identified by service users and peer support specialists. The initial decision-support tool included the following domains: (1) principles of recovery (2) privacy and security; (3) cost; (4) usability; (5) accessibility; (6) inclusion and equity; (7) personalized for service users' needs; and (8) device set-up. Each domain included various checklists pertaining to the themes in the domain.

The study included item formulation and three group cognitive interviews. The initial items were assessed in phase one with (N = 9) peer support specialists and service users. The refined items were evaluated in phase two (N = 9), and in phase three, the final set of items were tested with another group (N = 4) to assess the acceptability, ease of use, and relevance of the items. Even though the study was limited by its sample size and biases in verbal probes, the involvement of peer support specialists and service users in the design, co-production phase, the pilot testing of a decision-support tool is feasible and can empower both peer support specialists and service users. This could lead to potential increase engagement in using technologies to promote individuals' recovery and conventional clinical methods. In future research, it is necessary to consider the clinical benefits of this tool in terms of recovery outcomes.



**D. Partnership Instrument**—This 2021 study aimed to improve community engagement research practices by measuring the degree to which researchers partnered with psychiatric patient stakeholders (N=22) through an instrument that went through initial item development, cognitive testing, and a pilot study. The Quality of Patient-Centered Outcomes Research Partnerships Instrument (QPCOR) includes an iterative co-production technique based on research methodology to develop instruments [28].

Phase one was the initial item formulation which focused on the core aspects - analysis of the principles of community engagement in research and challenges for people with mental health conditions. Essential elements of community engagement in research include purpose, goals within the population, self-determination, shared decision-making, establishing relationships, respect of diversity, community assets, co-learning, and developing the capacity to become knowledgeable about the community. Conducting two phases of cognitive interviews based on an evidence-based method. Wanting to know how individuals would interpret items and assessed their views regarding whether the item aligned well with principles of community engagement. There were further modifications made to items in phase three. In phase four, a pilot study with a final set of items by a different group (N=15) of peer support specialists and a patient currently involved in PCOR research projects to assess the acceptance, ease of use, and relevance of items. After cognitive interviews, the final items were tested on a small sample of patient stakeholders and found that QPCOR was feasible and acceptable among psychiatric patient stakeholders.<sup>28</sup>

While the study was limited by bias in verbal responses and sample size, the QPCOR can potentially lead to higher quality, lasting partnerships, novel research questions, techniques, improved clinical outcomes, best practices, clinical guidelines, research-informed practices for end-users, and better uptake of results.

### Limitations

These studies were limited by small sample sizes. Therefore, such preliminary findings cannot be utilized to assess clinical significance, effectiveness, and generalizability. Nevertheless, these studies were not targeted towards such goals and therefore data saturation could not be realistically obtained. Instead, since most studies were pilot endeavors, they offer valuable insight into the potential utility of co-production partnerships and the *emerging* significance of these relationships.

### Future Work

In Rwanda, there has been less engagement of peer support specialists in research activities with a few being engaged only as subjects for researchers to implement their research projects. With the burden of mental health-related difficulties resulting from the 1994 Genocide against the Tutsi and a small functioning mental health workforce [23], community researchers have shifted to harnessing grassroots initiatives including the engagement of people with lived experience in the provision of mental health support services. In 2020, the University of Rwanda, which is the single public university in the country, under its Centre for Mental Health entered into collaboration with

peer support specialists from an association of people with mental health difficulties, “*Organisation pour la Promotion et la Solidarité des Malades et Handicapés Mentaux au Rwanda (OPROMAMER)*” [24] to collaborate in research activities. This collaboration is a pioneering partnership between academic and peer support specialists in the country of Rwanda.

Inspired by the CoP experience, the team at the Centre for Mental Health is working together with OPROMAMER to also carry out practice-based research building on already established community engagement psychosocial support work being done by practitioners at the Centre who have been working with peer support specialists in offering mental health support for some groups of OPROMAMER.

#### IV. Conclusion and Recommendations

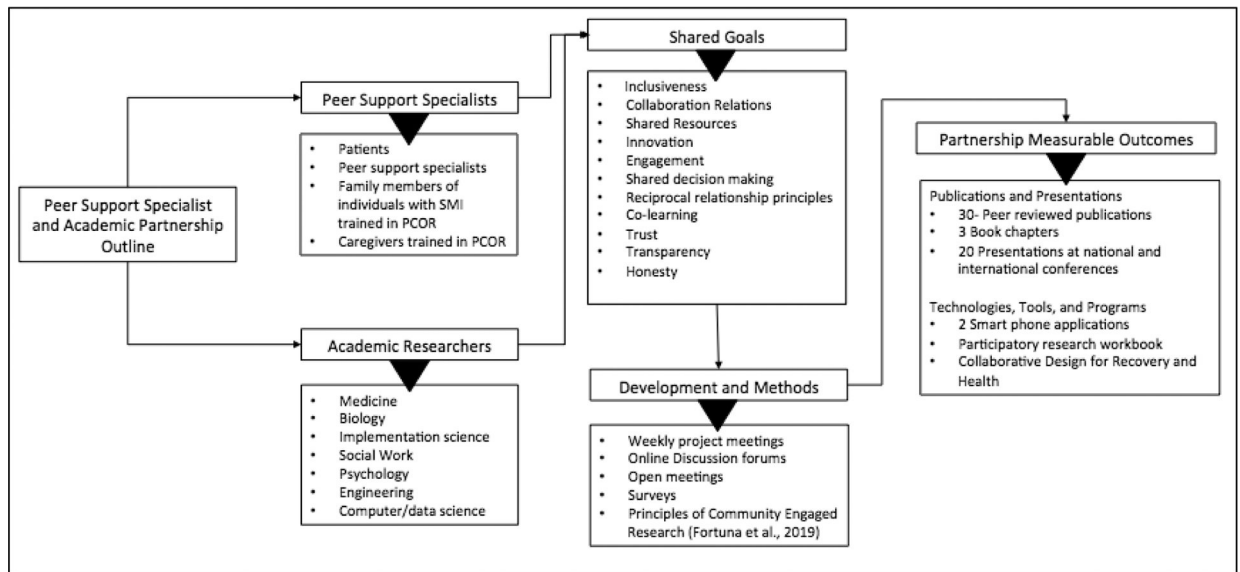
We recommend utilizing a humanistic lens to understand how these CoPs can systematically benefit every stage of the research process. Such an approach requires a careful examination of the epistemology motivating patient-centered research, increasing accountability by a continuous appraisal of the partnerships, and selecting the most appropriate participatory method for research [33]. The next steps would involve furthering the CoP by involving more stakeholders in the research process. This can include other individuals with lived experiences of mental illness who haven’t gone through certified training as well as non-academic professionals such as counselors, therapists, patient navigators, and group facilitators (such as for 12-step programs like AA). Future research would also require an accurate assessment of the feasibility of these partnerships as well as a comparative approach to better ascertain what unique benefits such partnerships have. The use of surveys at multiple time points throughout a study can offer opportunities for continuous improvement through patient-reported perspectives, ensuring that the most appropriate participatory framework is employed [33].

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**Fig. 1:**  
Overview of the Peer Support Specialist and Academic Partnership