

PROMISE in Action: Fostering Inclusive Research through Lived Experience Engagement in Malawi

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Introduction

Acknowledging lived experience viewpoints as valuable inputs into mental health research and initiatives is gaining considerable traction (World Health Organisation Global Coordination Mechanism Secretariat for NCDs, 2023). The Psychosis Recovery Orientation in Malawi by Improving Services and Engagement (PROMISE) study is committed to ensuring the meaningful inclusion of persons with lived experience (PWLE) to collaborate in the research work of psychosis identification and management systems. This necessitates recalibrating traditional research techniques to establish genuine collaborative partnerships, prevent tokenism and navigate power differentials (Sangill et al., 2019). Involving PWLE in research ensures distinctive findings compared to conventional research and has tangible implications for practice (Rose, 2014; Faulkner, 2004). Researchers with lived experience contribute their expertise and experience to projects, fostering a deeper understanding and raising pertinent questions. Their endeavours are driven by a desire to improve the lives of fellow PWLE. Under-involvement of PWLE and their families in the Global South is one of the most pressing concerns in research on psychosocial disability (Semrau et al., 2016; Ryan et al., 2019). Healthcare reform in high-income countries has benefited from lived experience-led research and co-production, in which PWLE and those with professional expertise collaborate as equal partners and co-creators. Examples of collaboration between researchers and PWLE include cancer research with patient advisory committees (PACs) (Lindberg et al., 2022). The evidence supporting "what works" to increase involvement in the Global South is limited. More Global South evidence and experience must be created to enable disempowered groups to have real input into research if the notion of nothing about us without us is to be given more than simply lip service (Faulkner, 2004; Abayneh et al., 2022).

In Malawi, people with psychosis often experience stigma and discrimination, have long delays in accessing appropriate care, and may not receive high-quality care in health facilities. Consultation with traditional or religious healers for mental health concerns is commonplace, owing to the alignment of these approaches to causal attributions held by community members, as well as limited awareness of biomedical explanations of psychosis and the ease of access compared to centralised and distant mental health services (Kokota et al., 2023). The PROMISE study is a collaboration between researchers in Malawi, UK and Australia that endeavours to build upon existing community and health service structures to establish and evaluate a sustainable system for the community-based identification, referral, and management of psychosis to promote recovery. In developing the intervention, PROMISE seeks to comprehend the perspectives on psychosis among persons with lived experience, caregivers, and key health stakeholders in Malawi, and the influence of these perspectives on help-seeking behaviours. PROMISE is initially implementing the project in two districts in Malawi: Chiradzulu in the Southern Region and Salima in the Central Region (Lawrie, in press).

PROMISE aspires to ensure the meaningful inclusion of PWLE at all stages of the study. The project protocol (Lawrie et al., in press) emphasises the need to have the lived experience expertise contribute to its success; "...co-produce psychosis identification and management systems" (Lawrie et al., in press, Methods

section), "...People with lived experience (PWLE) and caregivers will be closely involved throughout to steer the development of tools and interventions..." (Lawrie et al., in press, Abstract section), "...This sustained and analytic attention to lived experience will ensure that these initiatives are acceptable to and shaped by the communities concerned, and will interface with broader health, social and family support system..." (Lawrie et al., in press, Introduction section), and "...to explore and seek to understand how PWLE can be supported to contribute to the research: both as participants and through ongoing engagement with the research team as stakeholders in the intervention and shapers of this" (Lawrie et al., in press, Methods section). This article discusses how these ambitious goals are being approached in practice.

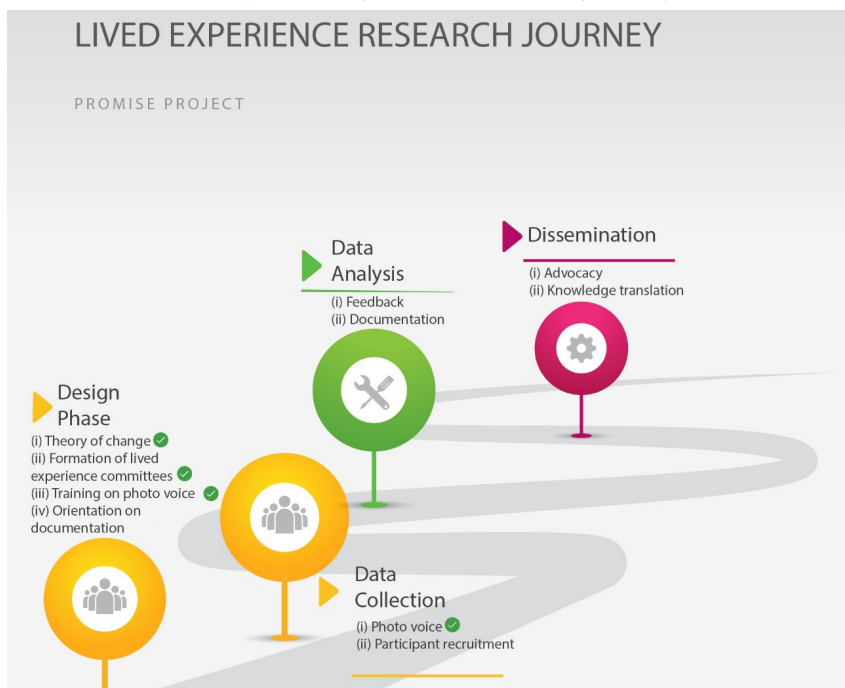
Methods and Results

The PROMISE project has adopted a multifaceted approach to engage persons with lived experience in research activities. A systematic approach to engaging PWLE was adopted from other mental health projects that have demonstrated best practices of lived experience involvement, namely: Support, Comprehensive Care and Empowerment of People with Psychosocial Disabilities in Sub-Saharan Africa (SUCCEED-Africa) (London School of Hygiene & Tropical Medicine, n.d.) and the Study of Context of Psychoses to improve outcomes in Ethiopia (SCOPE) (Hanlon et al., 2023). Key aspects of these projects include that they are both Africa-based and focused on people with psychosis. They are also pioneering engagement and involvement of PWLE (Abayneh et al., 2022)

The initial stages involve efforts to gain a comprehensive understanding of the lived experiences of individuals grappling with challenges related to the experience of psychosis in Malawi. Activities completed or underway include research team training; participatory research using Photovoice; Theory of Change development; and establishing Lived Experience Advisory Structures. The PROMISE project will also build capacity through PhD projects (such as that being undertaken by the first author) that focus on developing skills, knowledge, and resources that will enhance those with lived experience to support the research journey of the project. In other words, a meaningful approach to engaging PWLE will be employed in the project to ensure that people can openly express their views on the issues being discussed without fear and actively participate in project activities and decision-making. The involvement of PWLE to which the project aspires is depicted in Fig.1.

Figure 1

The PROMISE study lived experience research journey.



Research Team Training

Through community engagement training conducted in February 2022, the research team were equipped with the basic requisite skills and knowledge to effectively facilitate engagement with PWLE, including co-designing a Theory of Change (TOC). 16 research team members (5 Kamuzu University of Health Sciences, 7 University of Edinburgh, 1 Kings College London, 1 UK National Health Service (NHS), 1 University of Newcastle, 1 St John of God) took part. Key areas covered included defining participation, involvement, and engagement, along with a review of barriers to inclusion, different levels of participation, and guiding participation principles. In discussions, key barriers to inclusion identified included, similarly to those highlighted in the 2022 Advancing multisectoral and life-course approaches in mental health research workshop cofacilitated by the first author and initiated jointly by the Academy of Science of South Africa and the UK Academy of Medical Sciences (ASSAf & Academy of Medical Sciences, 2023), namely the need for more capacity of those with lived experience, financial resources to engage and train, the invisibility of those with lived experience, and limited research literacy. Specific strategies to mitigate the recognised barriers to engagement were identified, which were subsequently adopted as strategies for the project. These included lived experience capacity building, participation in decision-making processes, advocacy efforts, research activities, and leadership roles in various project components. In addition, it was agreed that there should be sustained efforts to involve mental health user advocacy groups, including Malawi's Mental Health Users and Carers Association (MEHUCA).

Participatory research using Photovoice

Through the participatory approach Photovoice (Wang & Burris, 1997), the project has fostered dialogue with PWLE and their caregiver's personal experiences through use of photographs. This approach provides a platform for meaningful engagement where PWLE and caregivers use mobile phones to take photos that draw attention to, and generate insights into, the challenges they face living with psychosis (or caring for a family member with this condition) and identify their needs and wants from their perspectives. The project engaged six PWLE and caregivers in the Photovoice activity (detailed below). Moreover, the exercise highlighted several key recurring themes from the discussions in the two project districts. These included the significance of holistic support, both in terms of personal relationships and professional assistance, the importance of access to medication and healthcare facilities, the fight against stigma and discrimination, and the need for self-reliance among persons with psychosis and their caregivers. These themes shed light on the diversity of support and aid needed for persons with mental health challenges and the barrier they encounter on their path towards recovery and overall well-being. The outputs of the Photovoice activity form the basis of a short film created by the project that portrays the first-hand experiences of individuals with lived experience.

Theory of Change development

The project identified and involved six persons with lived experience from the two project districts to participate in the development of the project Theory of Change (TOC). Participation in the activity provided those with lived experience a platform to voice their perspectives and influence the development of the study path so that it can better cater to their needs and aspirations. Two key outcomes that can be attributed to the participation of PWLE in the TOC development are:

- a) Empowerment: involvement in the process of conceptualizing the TOC empowered individuals by giving them a sense of agency and ownership over their experiences.
- c) Increased self-awareness: reflecting on personal experiences and contributing to the development of the TOC facilitated greater self-awareness.

Lived Experience Advisory Structures

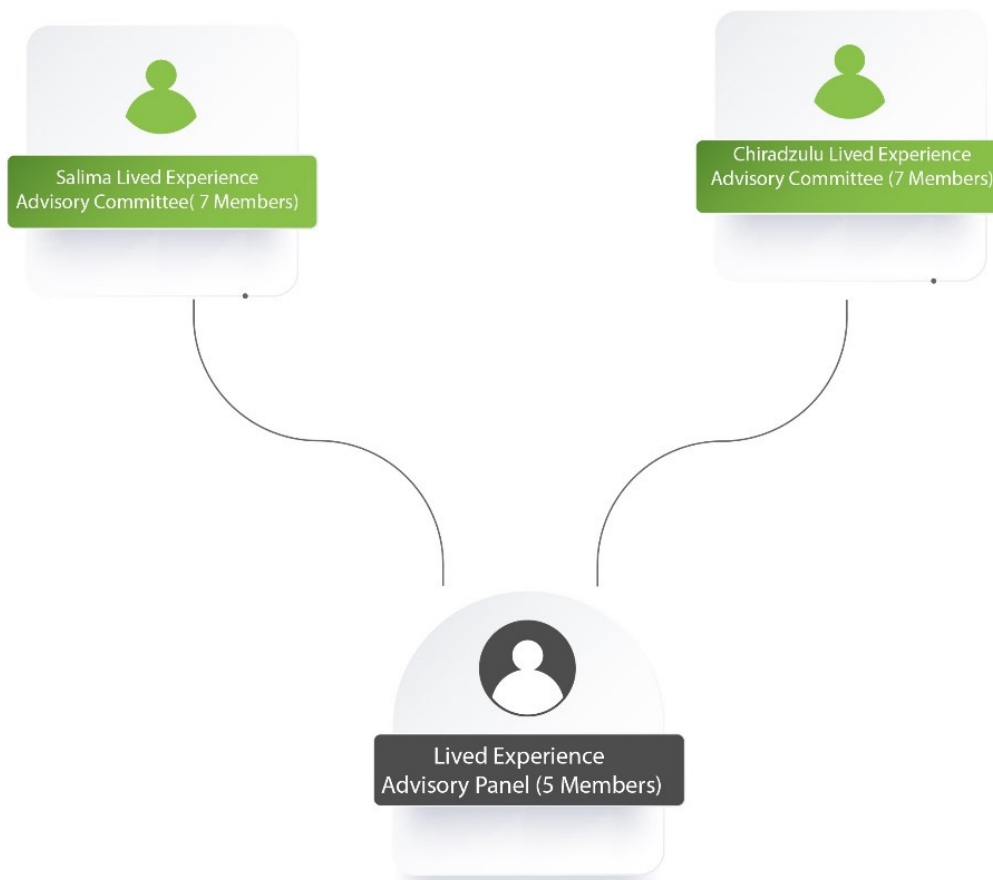
PROMISE will have a two-tier level of advisory arrangement in which those with lived experience will be engaged. At district level, two district Lived Experience Advisory Committees (LEACs) will be formed (with seven members per district). At national level, five members (selected from the two LEACs) will form the

Figure 2

PROMISE Lived Experience Advisory Structure

Lived Experience Advisory Panel (LEAP) (See Fig 2).

LIVED EXPERIENCE ADVISORY STRUCTURE



The LEACs and LEAP aim to improve the representation and active involvement of PWLE in the research project at all levels of PROMISE work. The PROMISE lived experience advisory structure will adhere to the principles of partnership, learning, empowerment, transparency, responsiveness, and respect. In the PROMISE project, empowerment concerns PWLE gaining more control over the things that affect their lives. Through empowerment, people can express their needs, voice their concerns, and become involved in decision-making that will impact them. The objectives of the LEAP and LEAC advisory structures are to:

- Identify common challenges and issues relating to the engagement of PWLE in the PROMISE Project.
- Guide the PROMISE Project to improve the active engagement of PWLE in its work.
- Promote best practices and key considerations for improving the experience of PWLE involved in the PROMISE Project.
- Provide advice on ongoing PROMISE research activities, including nested PhD projects.
- Support advocacy work through various platforms and engaging in discussions with policymakers and stakeholders.

To establish PWLE advisory bodies, the project team identified potential members, ensuring diverse representation across various community segments. Identification processes were conducted in collaboration with MEHUCA in Salima and the District Mental Health Team in Chiradzulu. Requisites for inclusion were that participants fully understand the purpose, procedures, and potential risks and benefits of the research. An assessment employing a simple screening method was conducted to ascertain participants' capacity to comprehend and actively contribute to the research process. Fourteen individuals from the project sites in Salima and Chiradzulu were selected to form the LEACs, with representatives from these forming the LEAP.

Further planned activities

The project will hold orientation sessions on research for PWLE and implement use of adapted methods of documentation by the LEAP members. This is an approach intended to enhance those with lived experience to document their involvement experience in the PROMISE Project. The trained LEAC and LEAP members will assume their PROMISE advisory roles that include interacting with research participants, research assistants and research team leads at district and national level. Advisory team members will be key identifiers of other PWLE, carers, and traditional and faith healers to be part of other components of the project. They will also act as co-facilitators in the training of health surveillance assistants, traditional and faith healers, village health committees and traditional leaders about mental health. They will support PROMISE advocacy activities and later disseminate the project results locally or through other intended dissemination platforms.

Conclusion

The PROMISE Project's commitment to meaningful lived experience engagement is a testament to the advocacy of PWLE and their organisations for the transformative potential of integrating diverse perspectives into mental health research. The project has prioritised the voices and experiences of PWLE in the design of the intervention, and has established the advisory structures that support a comprehensive and inclusive approach. The planned orientation sessions in research data documentation by lived experience advisory team members are anticipated to enrich the research process further. By actively involving PWLE in the research process, the project is seeking to foster a collaborative environment that values inclusivity, diversity, and empathy. The shared experiences and insights by the members will inform the development of tailored interventions that address the unique needs and challenges faced by individuals living with mental health conditions in Malawi. Alongside other projects such as SUCCEED and SCOPE, it is hoped that PROMISE will provide further impetus for future initiatives promoting lived experience-centric approaches to mental healthcare.

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