Establishing partnerships with people with lived experience of mental illness for stigma reduction in low- and middle-income settings

Gurucharan Bhaskar Mendon[1], Dristy Gurung[2], Santosh Loganathan[3], Sisay Abayneh[4], Wufang Zhang[5], Brandon A. Kohrt[6], Charlotte Hanlon[7], Heidi Lempp[8], Graham Thornicroft[9], Petra C Gronholm[10]*

Abstract

Social contact refers to the facilitation of connection and interactions between people with and without mental health conditions. It can be achieved, for example, through people sharing their lived experience of mental health conditions, which is an effective strategy for stigma reduction. Meaningful involvement of people with lived experience (PWLE) in leading and co-leading anti-stigma interventions can/may promote autonomy and resilience. Our paper aimed to explore how PWLE have been involved in research and anti-stigma interventions, to improve effective means of involving PWLE in stigma reduction activities in LMICs. A qualitative collective case study design was adopted. Case studies from four LMICs (China, Ethiopia, India and Nepal) are summarized, briefly reflecting on background for the work, alongside anticipated and experienced challenges, strategies to overcome these, and recommendations for future work. We found that the involvement of PWLEs in stigma reduction is commonly a new concept in LMIC. Experienced and anticipated challenges were similar, such as identifying suitable persons to engage in the work

This peer-reviewed article has been accepted for publication but not yet copyedited or typeset, and so may be subject to change during the production process. The article is considered published and may be cited using its DOI.
10.1017/gmh.2024.69

and sustaining their involvement. Such an approach can be difficult, because PWLE might be apprehensive about the negative consequences of disclosure. In many case studies, we found that long-standing professional connectedness, continued encouragement, information sharing, debriefing and support helped the participants' involvement. We recommend that confidentiality of the individual, cultural norms and family concerns be prioritized and respected during the implementation. Taking into account socio-cultural contextual factors, it is possible to directly involve PWLEs in social contact-based anti-stigma interventions.

Impact Statement

Establishing partnerships with people with lived experience (PWLE) of mental illness is essential for stigma reduction in mental health across the world. Involving PWLEs in stigma reduction efforts through strategies based on social contact is an effective and recommended approach to reduce mental health-related stigma. Additionally, involving PWLEs in such activities can benefit in other ways, such as improved self-confidence and self-esteem. However, there has been little written on how to practically go about doing this in economically underserved settings and in different cultural contexts. Across low- and middle-income countries (LMICs), limited access to mental health care, variable protections of human rights, limited opportunities for empowerment of PWLE and their caregivers, and differing explanatory models of mental health conditions provide contextual challenges requiring different approaches. To begin to address this gap, in this paper we reflect on researchers' and mental health experts' perspectives on establishing partnerships with PWLEs across four LMIC countries as part of efforts to reduce mental health related stigma. This is the first study of its kind to present a number of examples of anti-stigma research involving partnerships with PWLEs in LMICs. Hence, this paper provides important insights on the practical challenges in implementation, and reflections to inform future anti-stigma activities and strategies to ensure PWLEs are meaningfully involved with anti-stigma intervention and research.

Introduction

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Social contact refers to ways in which is people with lived experience (PWLE) of mental health conditions have direct or indirect contact with people who do not have such experiences. Direct (face to face, individual to individual) and indirect (e.g. active or passive interaction, e-contact or imagined contact; such as recorded personal testimonials and narratives of lived experience and recovery) social contact can effectively reduce stigma and discrimination (Thornicroft *et al.* 2016, 2022a; White *et al.* 2021) and can reduce self-stigma through empowering individuals with lived experience (Corrigan *et al.* 2013). In addition to involving PWLEs in anti-stigma activities through social contact strategies, PWLEs' involvement can be extended to other aspects of mental health care and 'anti-stigma activities. Indeed, PWLE is crucial in reducing stigma and promoting mental health worldwide (Sartor 2023b; Thornicroft *et al.* 2022a).. The involvement of PWLE can also bring unique expertise in developing mental health policy and legislation, planning and designing mental health programmes, and service provision (Lempp *et al.* 2018).

Involving PWLE as partners must be equitable, including contributing to decision-making, transparency, and appropriate compensation at regional, national and international levels (Sartor 2023b). However, evidence from low- and middle-income countries (LMICs) shows that there is often little or no involvement of PWLE in mental health-related research or anti-stigma activities. For example, lack of mental health awareness, stigma associated with mental illness, minimal empowerment of PWLE, structural barriers, or lack of clarity on involving PWLE in stigma reduction or policy development (Lempp *et al.* 2018a; Petersen *et al.* 2017; Samudre *et al.* 2016; Stuart 2016). This contributes to the gap in understanding how PWLE can be involved in 'anti-stigma activities, considering that most of the research evidence is from high-resource western countries, which might not be transferable (Kohrt *et al.* 2021; Ryan *et al.* 2019). However, there is emerging evidence also from LMIC settings that stigma-reduction approaches focused on social contact through PWLE involvement can be effectively delivered (Thornicroft *et al.* 2022b). This has been demonstrated, for example, through Time to Change Global, where social contact-based stigma reduction principles from England's Time To Change anti-stigma program were successfully delivered in Ghana and Kenya (Potts and Henderson 2021). Also studies like Reducing Stigma among Healthcare Providers (RESHAPE) in Nepal, and the Systematic Medical Appraisal, Referral and Treatment (SMART) Mental Health project in India have shown that stigma reduction through social contact and PWLE involvement was feasible despite some

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

challenges (Gurung *et al.* 2023; Kaiser *et al.* 2022; Kaur *et al.* 2021; Maulik *et al.* 2019; Rai *et al.* 2023). Notably, the SMART Mental Health project reported positive effects of their anti-stigma campaign even at 2-year follow up (Maulik *et al.* 2019). To expand on this evidence-base, the Lancet Commission on Ending Stigma and Discrimination in Mental Health emphasized that the involvement of PWLEs should be an integral feature of stigma reduction and promotion of mental health globally, through culturally appropriate social contact strategies (Thornicroft *et al.* 2022b). Furthermore, PWLEs are key stakeholders who need to be supported to lead or co-lead interventions using social contact (Gronholm *et al.* 2023, 2024; Sartor 2023a; Thornicroft *et al.* 2022b).

The aim of this paper is to explore the factors which contribute to the active involvement of PWLE in stigma reduction in LMICs (Hanlon 2017; Kaiser *et al.* 2020; Lempp *et al.* 2018).

Methods:

A qualitative collective case study design (Baxter and Jack 2015)was adopted to address the knowledge gap on engaging PWLE in stigma reduction. The case studies were selected from four LMICs. Specifically, these studies were case study 1. Experience using Photovoice in Nepal: a voice to be seen (Nepal); case study 2. A social contact-based education intervention to reduce stigma among community health care staff in Beijing, China; case study 3. Experience from 'Stories Against Stigma'- a Walking Tour of a Tertiary Mental Health Care facility, Bengaluru, India; and case study 4. Using participatory action research for service user and caregiver involvement in mental health system strengthening in primary care in Ethiopia. Further detail on these studies is provided in Table 1. Ethical approval was granted for this work at the respective institutions.

Table 1 about here

For the reflections reported on in this paper, a team in each site shared their thoughts on: i) a detailed local situation analysis; ii) anticipated challenges in involving PWLE; iii) experienced

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

challenges; iv) strategies to overcome these challenges; and v) what they have learned from PWLE and what they would recommend.

These case study examples are provided below, followed by reflections on key insights and commonalities in these to identify recommendations for mental health stigma reduction efforts in future that are meaningful partnerships with PWLEs.

Results

Case Study 1. Experience using Photovoice in Nepal: a voice to be seen.

Background to the work

In Nepal, stigma poses a significant barrier to mental health treatment access (Luitel *et al.* 2017). The Transcultural Psychosocial Organization (TPO) collaborated with people with lived experience (PWLE) in projects like RESHAPE, a stigma reduction initiative. RESHAPE involves PWLE sharing recovery stories through Photovoice, a participatory research approach using photography (Kohrt *et al.* 2020; Rai *et al.* 2023). Trained PWLE then go on to co-facilitate mental health training for primary healthcare workers, where they share experiences and dispel myths. PWLE receive compensation, including 1000 Rupees per session, travel reimbursement, and food. This approach effectively addresses stigma among healthcare workers.

Ethical clearance for this work was obtained from the Nepal Health Research Council (Ref: 441/2020).

Anticipated challenges

In intervention, we had anticipated that disclosure of mental illness would be a major challenge for most of the PWLE as part of the recovery narrative. In the community, mental health conditions were much stigmatized and identifying oneself living with this condition could lead to job loss, exclusion from family and community, and problems in marriage. Secondly, as the photovoice training was of 10-12 sessions and 5-6 hours each, we anticipated a challenge in participation of PWLE as it could disrupt their household or fieldwork, jobs, or other chores.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Experienced challenges

As anticipated, some PWLEs were discontinued or dropped out. An unforeseen challenge was that due to fear of increased stigma from disclosure, PWLE had to make excuses to their family members and caregivers while participating in the training, which led to increased mistrust and drop-outs in some cases (Rai *et al.* 2018).

Another challenge was the low literacy rate among PWLE, and perceived self-stigma induced low self-confidence among PWLE, making it difficult for them to participate in the intervention. Speaking in front of the audience, such as health workers was anxiety-inducing especially when asked intrusive questions. Further, recounting painful past experiences (lived experience and stigma experience) sometimes increased their distress.

Strategies for overcoming challenges

1. Caregivers play an active role in all aspects of PWLE's treatment and recovery, including their daily activities. Without their involvement, it was difficult for PWLE to participate in the training and intervention. Hence, we actively involved caregivers in all aspects of participation such as the consent process, participation in the training, and narrating recovery stories to health workers (Rai *et al.* 2018). This approach helped reduce drop-out from the program as they helped PWLE travel to and from training venues and manage time for the training.
2. Instead of viewing information sharing and consent as a one-time event, we stressed that this must be an ongoing process where we checked in on the PWLE and caregiver's understanding of the intervention in each session. Information sharing put PWLE and caregivers at ease during their early stages of involvement as they narrate recovery stories in front of an audience was a daunting concept for them without practice and preparation.
3. Training and preparation will be needed for PWLE before their involvement in anti-stigma interventions to help them understand the program and process better which equips them to deal with disclosure and distress.
4. As recalling and narrating past experiences of illness and stigma was distressing for some PWLEs, we involved psychosocial counsellors throughout the training and intervention

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

process. The counsellors monitored any signs of distress among the PWLE and checked in on their psychosocial well-being. Their presence helped to reduce the concern of creating more distress and harm to PWLE.

5. The research team extensively discussed the process and consent before recruiting the PWLEs. In Nepal, we asked the PWLE to invite one caregiver (family member, close relative, or friend) who had disclosed their condition to the training. Hence, along with the PWLE, the caregiver was also involved throughout the training process. A counsellor was present in each session of the photovoice training to check in with the PWLE and caregiver and to manage any distress that could come up during the training session. Each training session began with checking in and discussion with the participants regarding the benefits and harm of their participation in the program.
6. Disclosure of mental illness and safety of PWLEs were key ethical concerns of our team. We involved a caregiver (a person PWLE felt comfortable with and consented to participate) in the entire training and intervention process. We also included safe disclosure and handling difficult question sessions in the photovoice training.

Key learning points and recommendations

Caregivers can play a vital role in the involvement of PWLE in anti-stigma intervention programs – especially in a collectivist community like Nepal. Their involvement would ease PWLE to manage time, reducing external stress such as travelling to the training venues. It also helped in the involvement of PWLE with low levels of functioning.

Continuous information sharing and consenting processes where PWLEs are made aware that their involvement is voluntary and it ensures safety and reduces intimidation among PWLEs. Involvement of mental health professionals throughout the process will help to ensure early detection and management of negative consequences of involvement or signs of distress.

Case Study 2. A social contact-based education intervention to reduce stigma among community health care staff in Beijing, China

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Background to the work

Peking University Sixth Hospital in Beijing, China, focuses on clinical treatments, practitioner training, and mental health research. In Chinese culture, there's significant stigma associated with mental health issues, affecting both the general public and community mental healthcare staff (Lam *et al.* 2010; Li *et al.* 2014; Lv *et al.* 2013). A collaborative initiative with King's College London, "Reducing Mental Health Stigma in Chinese Healthcare Practitioners" took place from 2016 to 2019. In this groundbreaking study, involving 4 people with lived experience (PWLE) and 121 community mental health workers, PWLE were actively engaged for the first time in mainland China's mental health stigma reduction interventions (Zhang *et al.* 2022). There were no monetary benefits to the participants (PWLE's) during the training. However, during the social contact, each PWLE received 300 yuan of labor fee.

The study was approved by the Peking University Institutional Review Board (Year 2017, No. IRB00001052-16077),

Anticipated challenges

These comprised identifying PWLE who fulfilled the inclusion criteria - having a full-time job; good at storytelling; able to speak fluently at a moderate pace; not exhibiting obvious side-effects of treatment, getting good narratives without further worsening stigma was expected to be difficult. Moreover, PWLE would be potentially apprehensive about disclosing their stories to the community workers and may not be intrinsically motivated in mental health stigma reduction activities.

Experienced challenges

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

When suitable PWLE's were identified by research team, many refused to participate because training was normally held on weekdays and most had difficulty applying for medical leave as their condition was often concealed from their managers and colleagues.

The initial attempts of PWLE to write and narrate stories using the recovery story checklist were characterized by a tendency to record only the treatment process rather than the impact of their mental health conditions on their personal and family lives, or their feelings in the recovery process. During the intervention implementation, PWLE felt anxious speaking in front of community staff and expressed signs of worry.

Strategies to overcome challenges

To overcome challenges, the inclusion criteria was widened to include PWLE with different work status. PWLE known by the research team were approached first, followed by PWLE who had past experience of stigma and discrimination and had demonstrated a strong motivation to help reduce mental health stigma and discrimination.

PWLE and their family members were supported by psychiatrists, psychotherapists, general practitioners and social workers throughout the intervention. Measures to avoid pictures/videos was taken unless there was prior consent obtained.

During the initial training, PWLE's wrote their stories with the help of family members and the research team. Further, each PWLE rehearsed their stories and received feedback from the research team. At implementation, PWLE were allowed to read from the script if they forgot any part of their story and they were accompanied by family members who could provide additional perspectives to the stories.

Research team discussed disclosure and answered any questions with PWLEs and their family members/caregivers before disclosure decisions were made. PWLEs were monitored for potential harm over time through continued professional contact with the lead organizer. The communities that PWLE participate in training were not the localities in which they live.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

To support PWLEs' involvement, the local ethics board suggested to involve also family members.

Key learning points and recommendations

We found that PWLE cherished these opportunities and took the anti-stigma intervention seriously, arriving early at the research site every time and feeling satisfied with themselves after completing their work. Their testimonies encouraged the team to continue such endeavors in the future. Interventions of this kind can empower PWLE to strengthen their confidence. The work also showed that it is possible to recruit participants who are willing to share their recovery stories, and contribute towards reducing mental health stigma.

Case Study 3. Experience from 'Stories Against Stigma'- a Walking Tour of a Tertiary Mental Health Care facility, Bengaluru, India

Background to the work

NIMHANS (National Institute of Mental Health and Neurosciences), established in the mid-19th century, provides modern training, research, and mental health services. Despite commendable efforts to raise awareness through group sessions, TV programs, and publications, stigma persists. PWLE face stigma affecting various aspects of their lives. To combat this situation, NIMHANS introduced a groundbreaking "Walking Tour" in 2018, inviting the public to interact with mental health professionals, explore the institute, and hear PWLE share their recovery stories. Two PWLEs participated, and the event garnered positive feedback from the public, featured in national media (Meena *et al.* 2023).

One of the PWLE who took part was offered travel allowance and another was admitted as an inpatient and was managing well during the tour, hence no compensation was provided.

Anticipated challenges

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

The team anticipated that, involving PWLE is sensitive because they and their family members often fear the disclosure of their mental health condition to the community. They worry that disclosure might lead to losing their job, or detrimentally affecting marriage prospects or exclusion from their extended family members. Apart from our experience, we were also uncertain of PWLE's perspectives about participating in a tour and the training process.

Experienced challenges

PWLE with active symptoms were unable to provide informed consent or reflect on / represent recovery. Therefore, an experienced psychiatrist was involved in identifying and inviting individuals to participate in the tour. Another difficulty was obtaining consent from family members of PWLE who were willing to take part in this public event. The families were uncomfortable with the idea of the person speaking openly about illness experience and recovery.

Strategies for overcoming challenges

To overcome the above-mentioned challenges, recovered and highly motivated individuals, who had indicated their interest in raising awareness during their clinical visits were considered. A therapeutic and working relationship with the treating psychiatrist was crucial to garner the trust of PWLE. In addition, the long-standing cordial relationship, rapport and ensuring trust and confidence among the PWLE and their family members strengthened their participation.

The team discussed disclosure and answered any questions regarding this with PWLEs and their family members/caregivers before making disclosure decisions. As per the caregivers' request, disclosures were pseudonymised (not using the person's real name or photo). Opportunities to debrief about disclosure were offered to PWLEs and their family members/caregivers. PWLEs were monitored for potential harm over time through continued professional contact with the lead organizer.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Sharing recovery stories without pictures and names of PWLE in the public domain alleviated concerns of their family members. Two service users participated in the walking tour and the treating psychiatrist carried out a pre-event briefing to explain the nature and expectations of the tour. The narratives of PWLE were edited for brevity and to emphasize the recovery process.

The walking tour was one of a first of a kind initiative taken by the institute and having PWLE come in and share their narratives during the tour was suggested by psychiatrists who were also part of organizing the tour. The entire tour was carried out under the supervision of mental health professionals including psychiatrists and psychiatric social workers who suggested involving family members along with PWLEs.

Key learning points and recommendations

It was easy to work with motivated and trained volunteers to deliver their recovery stories, which was crucial. Since PWLEs do not necessarily have experience in delivering their recovery stories in public, they may express many details about their lived experience and can get emotionally distressed. Understandably, this situation requires empathetic listening and validation from the team, but at the same time the content of their stories needs to be carefully edited to make a strong and meaningful impact to the audience and to minimize over-disclosure and distress.

We are considering PWLE to take initiative to carry out future tours and provide one-to-one interaction with the public. However, the confidentiality of the individual, cultural norms and family concerns must be acknowledged and respected. Strategies such as keeping the media informed about what to report (using proxy names & not publishing their pictures), and debriefing sessions for PWLE after the event, are useful in addressing such concerns. The team suggest offering appropriate remuneration to PWLE and the caregivers for their time and travel along with providing them insights about the impact of their work through discussion during booster sessions afterwards which would make them feel significant.

Case study 4. Using participatory action research for service user and caregiver involvement in mental health system strengthening in primary care in Ethiopia

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Background to the work

In the Ethiopian mental health system, involving PWLEs is challenging due to stigma and lack of awareness about experiences of and impact of mental distress. To address this situation, researchers from Addis Ababa University conducted participatory action research between April 2017 and August 2019 in Sodo district, south-central Ethiopia. Service users, including people with schizophrenia, epilepsy, alcohol use disorder, or depression, formed a Research Participant Group (RPG). They underwent ten days of face-to-face empowerment training based on 'Emerging mental health systems in low-and-middle-income countries' (Emerald) empowerment manual (Abayneh *et al.* 2017a) and the RESHAPE curriculum, receiving compensation of 300 Ethiopian Birr per session, along with tea and food during breaks (Abayneh *et al.* 2017b, 2020, 2020, 2022a, 2022b; Lempp *et al.* 2018).

Each participant was compensated with 300 Ethiopian Birr per session.

Ethical approval was obtained from the Institutional Review Board of Addis Ababa University College of Health Sciences (Protocol number: 027/16/Psy).

Anticipated challenges

Although we intended to recruit recovered service users, there was a concern about relapse, lack of adequate transport and long-distance travel, particularly for service users coming from rural areas could affect participation. Stigma and low community expectations of what PWLE could meaningfully contribute were expected to be an impediment to PWLE's willingness and confidence to actively participate and openly share their lived experiences. Heterogeneity in the PWLE group, for example, diagnosis, gender, or educational level, might have undermined common understandings because of their different experiences of recovery.

Experienced challenges

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

During the participatory action research (PAR) process, staff noticed that some PWLE became distressed while sharing their lived experiences of mental health stigma and discrimination, challenges with accessing mental healthcare, and associated costs and social burdens. The low educational level of service users meant that they could not fully engage in activities that involved writing. Many of the experienced challenges were in relation to sustaining PWLE involvement, and people coming from rural areas during the rainy season struggled to attend meeting sessions on time. The PWLE had concerns about operational expectations to sustainable involvement beyond the life of the project, including where they would meet and adequate funding to cover engagement-related costs. They also mentioned systemic and organizational constraints (e.g., lack of national-level regulatory mechanisms to enforce service-user involvement in mental health policy and mental health legislation) (Abayneh *et al.* 2022a).

Strategies for overcoming challenges

We identified the following key strategies for overcoming challenges, like PWLE with varying levels of literacy, utilized natural discussion, PowerPoint presentations or didactic lectures were not used which helped the team to make the training and PAR process more inclusive and participatory. When writing was required, participants were assisted by family members and research assistants. Their caregivers also supplemented the discussion process by providing additional explanations about PWLE's stories.

Equipping PWLE for participation ahead of time (through photovoice and empowerment training) (Abayneh *et al.* 2022b) was important. In addition, they mentioned that active and energetic facilitation of the PAR process helped to obtain their active engagement and involvement throughout the activities and sessions (Abayneh *et al.* 2022a).

Pre-planned strategies included: (i) preparatory training of participants on crisis management, identifying and capitalizing one`s inner strengths, and (ii) The research process was facilitated by a mental health professional with extensive experience working with people with mental health problem. Arrangement of a convenient, central place and time (during the weekend or holidays) for the training and PAR processes, which assisted to maximize participation was essential.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

There was critical reflection with the research participants and the research team at the beginning and end of every day. In addition, two psychosocial professionals (one male and one female) attended throughout the study to provide any needed support, which was of value in our research to handle some actual challenges, e.g. causal attribution between a caregiver and service user about illness.

The research team was conscious of vulnerability of service users and arranged the necessary capacity-building and safeguarding measures before and during working with PWLEs.

Key learning points and recommendations

Making use of participatory strategies in the research process was a key mechanism to supporting PWLE involvement, including establishing the small RPG that met regularly, utilized techniques to ensure everyone's voice was heard and the commitment to involvement from the beginning to set research priorities. The narrative of lived experiences was found to require careful planning. Preparatory training for strategic disclosure and crisis management for PWLE, and necessary precautions in the selection of the content of recovery stories to be adapted to ensure the participants did not feel distress during the intervention process was an important consideration.

The combined use of visual data (photos) together with individual and group reflective sessions (voice) can facilitate genuine, active participation, co-creating/co-production of knowledge, and provides a powerful means for marginalized groups to communicate their lived experiences.

The PWLE expressed satisfaction with their personal involvement, valued the experiences gained from the PAR process, and demanded various support for greater and sustained contribution. This initiation led to the establishment of a service user association and a strengthened voice of the PWLE in community.

Discussion

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

In this paper, we have presented experiences in the form of case studies from various anti-stigma programmes implemented in four different countries (China, Nepal, India, and Ethiopia) of LMICs. In general, all these programmes had active involvement of PWLE. These sessions were held at places where stigma towards mental illness was a major concern, and was influenced by culture (Loganathan and Murthy 2011, 2008). For example, Chinese culture had a high level of stigma related to mental disorders (Lv *et al.* 2013; Phillips *et al.* 2002). Additionally, the involvement of a PWLE in stigma reduction is a new concept in most of the case studies which is similar to existing evidence that despite interest in achieving greater involvement of PWLE, experiences and awareness of practical applications of this kind of engagement is limited in LMIC countries (Semrau *et al.* 2016).

The RESHAPE module was commonly applied to train PWLE in three case studies (China, Nepal, Ethiopia), and they received photovoice training, where individual narrate their recoveries with a photograph (Kohrt *et al.* 2020, 2021). Most of the research programmes summarised in these case studies found that direct contact with the public had positive effect in reducing stigma and discrimination, as outlined in Table 1. This is similar to existing evidence that the positive effect was stronger with the direct contact (London and Evans-Lacko 2010; Nguyen *et al.* 2012; Nyblade *et al.* 2019; Stubbs 2014).

In all case studies, the programme coordinating team anticipated that identifying PWLE would be difficult because their participation needs time, which may disrupt their household, jobs, or other daily chores. Another anticipated challenge was that PWLE would be apprehensive about disclosing their stories of mental illness because of the negative consequences and experience of stigma, similarly to what has been reported as potential barriers by previous studies (Lempp *et al.* 2018; Thornicroft *et al.* 2022). Cultural diversity and lifestyle differ among people from LMIC and high-income countries. Thus, during the process of planning and implementation the team encountered minimal involvement of the PWLE due to lack of empowerment and uncertainty on engaging PWLE (Kohrt *et al.* 2021; Petersen *et al.* 2017). PWLE need to be involved from the beginning, in leadership positions wherever possible (Thornicroft et al. 2022). Given the lack of experience of involvement in our countries, our efforts fell short of this recommendation. The authors intend that this case reports can help to catalyse greater and meaningful involvement of

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

PWLE. However, each country team recognise that this will need explicit attention to reduce power differentials and create safe spaces for learning and development (Thornicroft *et al.* 2022a).

In addition, identification of suitable PWLE and refusal to take part due to work and fear of disclosure were the major challenges. Whereas service users had to make excuses to their family and caregivers while involving in the training, led to increased mistrust and dropouts in some cases as reported in the study by (Rai *et al.* 2018).

The families were uncomfortable with the idea of the person speaking out openly about their mental illness experiences and recovery (India) in similar with earlier study results, such as concerns about marriage, autonomy, social devaluation, fear of rejection, uneasiness about disclosure, feelings of shame and embarrassment about their condition. These were identified as factors having an adverse social impact of the illness on the person diagnosed, and their caregivers (Charles *et al.* 2007; Thara and Srinivasan 2000).

During the initial phase of the intervention implementation, PWLE felt anxious and expressed signs of worry as they were uneasy about their ability to handle the new situation, commonly linked with a low literacy rate, perceived self-stigma and low self-confidence. However, better support and time to develop trusting relationships in Ethiopia for example, PWLE's gained their confidence (Abayneh *et al.* 2022b) which is in line with the existing finding that self-stigma can be reduced when the person with mental illness recovers and shares his/her experiences of illness and the successful recovery process (Corrigan *et al.* 2013). In LMICs, the components, attributing factors, focus, and implementation processes of various anti-stigma interventions varied based on their feasibility and acceptability in the respective social and cultural environments (Hanlon 2017). Further, PWLE were asked to recall their lived experience with mental health conditions and stigma (Nepal and Ethiopia). This recounting of painful past experiences sometimes increased their distress expressing the need for appropriate support and adequate preparation (Kaiser *et al.* 2020).

Different strategies were employed to overcome challenges involving PWLE in stigma reduction towards mental health care. Service users with varied educational backgrounds, who were recovered, with past stigma experience and strong motivation to reduce stigma were considered. PWLE known by the research team were approached first due to long-standing cordial relationship, rapport, trust, and confidence among the service users and their family members,

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

which helped the participants (China, India) in similar with the guiding principles for the involvement of lived experience in decision-making (Sartor 2023b). Continued encouragement, information sharing, debriefing and support for family members by the multidisciplinary team play an essential role in the involvement of PWLE of mental health conditions (China, India).

Furthermore, having a psychosocial counsellor or mental health professionals throughout the training was useful when PWLE became distressed due to recalling past painful experiences (Nepal, Ethiopia) (Abayneh *et al.* 2020). Similarly to the existing work by Rai *et al.* 2018, writing recovery narrations, family members' help, rehearsal of stories, and regular training was crucial (narration), and the involvement of family members (China, Nepal, Ethiopia) helped in reducing dropout from the program. Structuring, planning and delivery of contact situation influence the effectiveness of the intervention (Chen *et al.* 2016). Quality of professional contact included in the intervention plays a significant role in improving relationships with people with lived experience (Carrara *et al.* 2021). Speakers, messages, and interactions are found to be the primary constructs in designing the contact situation similar to the existing literature by (Chen *et al.* 2016; Stuart 2016; Stuart *et al.* 2014). A convenient place and time (during the weekend or holidays) for the training was found to be necessary.

The case studies found that PWLE were willing to participate and valued the opportunities to get involved in anti-stigma activities. It also strengthened their confidence, and they felt satisfied after the training, which was similar to what was found by (Abayneh *et al.* 2022b). Caregivers of PWLE's also play a vital role in the anti-stigma intervention programs by managing time and reducing external stress. Empathetic listening and validation by the team, and the content of their stories need to be carefully edited to make a strong and meaningful impact among audience and to minimize over-disclosure and distress (India and Ethiopia) was in line with structured testimonial that are important in stigma reduction (Kohrt *et al.* 2021). The author recommends confidentiality of the individual, cultural norms and family concerns to be prioritized and respected during the implementation of activity. In China, PWLE would not be sharing their stories in their own community or the district where they were living so that the trainees (community mental health workers) would not know or interact with them later in their lives.

Strategies like informing the media about what to report (e.g. using proxy names and not publishing PWLE's pictures), and debriefing sessions for PWLE, are useful in addressing such

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

concerns (Thornicroft *et al.* 2022a). Offering appropriate remuneration to PWLE and the caregivers for their time and travel and providing them insights about the impact of their work would make them feel significant (Sartor 2023b; Thornicroft *et al.* 2022a). Combined visual data (photos) and individual and group reflective sessions (voice) can facilitate genuine, active participation, co-creating of knowledge, and provides a powerful means for marginalized groups to communicate their lived experiences. In addition, the findings support the need for an explicit "transformative shift' of attitude towards global mental health, as mentioned by (Ryan *et al.* 2019). The study outcome provides further knowledge published by (Semrau *et al.* 2016), namely that the involvement of service users can take place at various levels, e.g. in training health care personnel on mental health, peer review of policy planning and implementation.

These barriers, facilitators and strategies reported across the four study sites all case studies are summarized in Table 2.

Table 2 about here

As the evidence-base for collaborating with PWLE in stigma-reduction activities in LMICs is growing, a valuable next step would be for programs to routinely carry out implementation and process evaluations of this work. This would yield standardized insights on practical barriers and facilitators of implementation, and the role of contextual factors, which could inform the development of step models to guide best practice in the field. An important consideration of such guidance would be how to assess when the potential harms of PWLE involvement could outweigh its benefits, and how to flexibly plan activities so that this risk is mitigated.

Strengths and Limitations

We present case studies from a diverse range of settings, reflecting different PWLE contexts. PWLEs were involved in these initiatives because the existence of stigma and discrimination towards PWLE's in their culture. Another strength is, PWLEs were trained using a standard an established module in LMICs (RESHAPE) across 3 case studies which represents the quality of social contact. On other hand, we present the finding from four case studies from different countries, with insightful reflections and these allow for comparisons between different contexts.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Case studies are not generalisable; however, they illustrate important learning and detailed insight from different settings with similar and different perceptions. Any research or anti-stigma activities will have its strengths and limitations in the implementation process, which need to be taken into account when interpreting the findings. Considering this work as an important start in this area of research, we acknowledge and are aware of the potential critiques of our work i.e., the initiatives were not led by PWLE, clinicians/clinical settings were predominant in selecting the PWLE in sharing individuals' recovery narration.

The authors have implemented the social contact strategy in each setting to reduce power differentials and equip PWLE to take on and commit to increasingly active roles in the anti-stigma activities process. Additionally, a key limitation is the lack of involvement of PWLE in writing up this paper as the case studies were obtained from different countries and the PWLE were from varied educational background

Conclusions

Involving PWLE to reduce mental health related stigma and discrimination is an essential strategy worldwide. Despite the socio-cultural barriers, it is possible to involve PWLEs in social contact-based anti-stigma interventions and other mental health activities. Training PWLEs to narrate their condition or recovery and build skills to facilitate social contact-based interventions is likely to enhance the intervention's effectiveness. Developing or adapting cultural and contextual-based training modules to train PWLE is crucial. Debriefing and providing adequate information about the training, intervention, and role of PWLE and their family in anti-stigma intervention will highlight the value of their involvement and its impact at the community level or the general public. Involving multi-disciplinary mental health staff throughout the process of recruitment, and training is important, as is PWLEs leading or co-leading anti-stigma initiatives, alongside support to reduce the risk of disclosure consequences and emotional distress or discomfort due to lived experience sharing.

References:

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Abayneh S, Hanlon C and Lempp H (2017a) *Developing Service User & Caregiver Involvement in Mental Health System Strengthening*. Ethiopia: Addis Abab University. Retrieved from https://www.mhinnovation.net/innovations/emerald

Abayneh S, Lempp H, Alem A, Alemayehu D, Eshetu T, Lund C, Semrau M, Thornicroft G and Hanlon C (2017b) Service user involvement in mental health system strengthening in a rural African setting: Qualitative study. *BMC Psychiatry* **17**(1). https://doi.org/10.1186/s12888-017-1352-9.

Abayneh S, Lempp H and Hanlon C (2020) Participatory action research to pilot a model of mental health service user involvement in an Ethiopian rural primary healthcare setting: study protocol. *Research Involvement and Engagement* **6**(1), 2. https://doi.org/10.1186/s40900-019-0175-x.

Abayneh S, Lempp H, Kohrt BA, Alem A and Hanlon C (2022a) Using participatory action research to pilot a model of service user and caregiver involvement in mental health system strengthening in Ethiopian primary healthcare: a case study. *International Journal of Mental Health Systems* **16**(1). https://doi.org/10.1186/s13033-022-00545-8.

Abayneh S, Lempp H, Rai S, Girma E, Getachew M, Alem A, Kohrt BA and Hanlon C (2022b) Empowerment training to support service user involvement in mental health system strengthening in rural Ethiopia: a mixed-methods pilot study. *BMC Health Services Research* **22**(1). https://doi.org/10.1186/s12913-022-08290-x.

Baxter P and Jack S (2015) Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers. *The Qualitative Report*. https://doi.org/10.46743/2160-3715/2008.1573.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Carrara BS, Fernandes RHH, Bobbili SJ and Ventura CAA (2021) Health care providers and people with mental illness: An integrative review on anti-stigma interventions. *International Journal of Social Psychiatry* **67**(7), 840–853. https://doi.org/10.1177/0020764020985891.

Charles H, Manoranjitham SD and Jacob KS (2007) Stigma and Explanatory Models Among People With Schizophrenia and Their Relatives in Vellore, South India. *International Journal of Social Psychiatry* **53**(4), 325–332. https://doi.org/10.1177/0020764006074538.

Chen S-P, Koller M, Krupa T and Stuart H (2016) Contact in the Classroom: Developing a Program Model for Youth Mental Health Contact-Based Anti-stigma Education. *Community Mental Health Journal* **52**(3), 281–293. https://doi.org/10.1007/s10597-015-9944-7.

Corrigan PW, Kosyluk KA and Rüsch N (2013) Reducing self-stigma by coming out proud. *American Journal of Public Health* **103**(5), 794–800. https://doi.org/10.2105/AJPH.2012.301037.

Gronholm PC, Bakolis I, Cherian AV, Davies K, Evans-Lacko S, Girma E, Gurung D, Hanlon C, Hanna F, Henderson C, Kohrt BA, Lempp H, Li J, Loganathan S, Maulik PK, Ma N, Ouali U, Romeo R, Rüsch N, Semrau M, Taylor Salisbury T, Votruba N, Wahid SS, Zhang W and Thornicroft G (2023) Toward a multi-level strategy to reduce stigma in global mental health: overview protocol of the Indigo Partnership to develop and test interventions in low- and middle-income countries. *International Journal of Mental Health Systems* **17**(1), 2. https://doi.org/10.1186/s13033-022-00564-5.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Gronholm PC, Kline S, Lamba M, Lempp H, Mahkmud A, Morales Cano G, Vashisht K, Vera San Juan N and Sunkel C (2024) Exploring perspectives of stigma and discrimination among people with lived experience of mental health conditions: a co-produced qualitative study. *eClinicalMedicine* **70**, 102509. https://doi.org/10.1016/j.eclinm.2024.102509.

Gurung D, Kohrt BA, Wahid SS, Bhattarai K, Acharya B, Askri F, Ayele B, Bakolis I, Cherian A, Daniel M, Gautam K, Girma E, Gronholm PC, Hanlon C, Kallakuri S, Ketema B, Lempp H, Li J, Loganathan S, Ma N, Magar J, Maulik PK, Mendon G, Metsahel A, Nacef F, Neupane M, Ouali U, Zgueb Y, Zhang W and Thornicroft G (2023) Adapting and piloting a social contact-based intervention to reduce mental health stigma among primary care providers: Protocol for a multi-site feasibility study. *SSM - Mental Health* **4**, 100253. https://doi.org/10.1016/j.ssmmh.2023.100253.

Hanlon C (2017b) Next steps for meeting the needs of people with severe mental illness in low- and middle-income countries. *Epidemiology and Psychiatric Sciences* **26**(4), 348–354. https://doi.org/10.1017/S2045796016001013.

Kaiser BN, Gurung D, Rai S, Bhardwaj A, Dhakal M, Cafaro CL, Sikkema KJ, Lund C, Patel V, Jordans MJD, Luitel NP and Kohrt BA (2022) Mechanisms of action for stigma reduction among primary care providers following social contact with service users and aspirational figures in Nepal: an explanatory qualitative design. *International Journal of Mental Health Systems* **16**(1), 37. https://doi.org/10.1186/s13033-022-00546-7.

Kaiser BN, Varma S, Carpenter-Song E, Sareff R, Rai S and Kohrt BA (2020) Eliciting recovery narratives in global mental health: Benefits and potential harms in service user

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

participation. *Psychiatric Rehabilitation Journal* **43**(2), 111–120. https://doi.org/10.1037/prj0000384.

Kaur A, Kallakuri S, Daniel M, Yatirajula SK, Devarapalli S and Maulik PK (2021) Directly engaging with People with lived experiences of mental illness from the communities in India. *SSM - Mental Health* **1**, 100024. https://doi.org/10.1016/j.ssmmh.2021.100024.

Kohrt BA, Jordans MJD, Turner EL, Rai S, Gurung D, Dhakal M, Bhardwaj A, Lamichhane J, Singla DR, Lund C, Patel V, Luitel NP and Sikkema KJ (2021) Collaboration with People with Lived Experience of Mental Illness to Reduce Stigma and Improve Primary Care Services: A Pilot Cluster Randomized Clinical Trial. *JAMA Network Open* **4**(11). https://doi.org/10.1001/jamanetworkopen.2021.31475.

Kohrt BA, Turner EL, Rai S, Bhardwaj A, Sikkema KJ, Adelekun A, Dhakal M, Luitel NP, Lund C, Patel V and Jordans MJD (2020) Reducing mental illness stigma in healthcare settings: Proof of concept for a social contact intervention to address what matters most for primary care providers. *Social Science and Medicine* **250**. https://doi.org/10.1016/j.socscimed.2020.112852.

Lam CS, Tsang WHH, Corrigan PW, Lee YT, Angell B, Shi K, Jin S and Larson JE (2010) Chinese lay theory and mental illness stigma: Implications for research and practices. *Journal of Rehabilitation* **76**(1), 35–40. https://research.polyu.edu.hk/en/publications/chinese-lay-theory-and-mental-illness-stigma-implications-for-res

Lempp H, Abayneh S, Gurung D, Kola L, Abdulmalik J, Evans-Lacko S, Semrau M, Alem A, Thornicroft G and Hanlon C (2018a) Service user and caregiver involvement in

mental health system strengthening in low- and middle-income countries: a cross-country qualitative study. *Epidemiology and Psychiatric Sciences* **27**(1), 29–39. https://doi.org/10.1017/S2045796017000634.

Lempp H, Abayneh S, Gurung D, Kola L, Abdulmalik J, Evans-Lacko S, Semrau M, Alem A, Thornicroft G and Hanlon C (2018b) Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: A cross-country qualitative study. *Epidemiology and Psychiatric Sciences* **27**(1), 29–39. https://doi.org/10.1017/S2045796017000634.

Li J, Li J, Thornicroft G and Huang Y (2014) Levels of stigma among community mental health staff in Guangzhou, China. *BMC Psychiatry* **14**(1). https://doi.org/10.1186/s12888-014-0231-x.

Loganathan S and Murthy RS (2011) Living with schizophrenia in India: GendeR perspectives. *Transcultural Psychiatry* **48**(5), 569–584. https://doi.org/10.1177/1363461511418872.

Loganathan S and Murthy S (2008) Experiences of stigma and discrimination endured by people suffering from schizophrenia. *Indian Journal of Psychiatry* **50**(1), 39. https://doi.org/10.4103/0019-5545.39758.

London J and Evans-Lacko SE (2010) Challenging mental health-related stigma through social contact. *European Journal of Public Health* **20**(2), 130–131. https://doi.org/10.1093/eurpub/ckq014.

Luitel NP, Jordans MJD, Kohrt BA, Rathod SD and Komproe IH (2017) Treatment gap and barriers for mental health care: A cross-sectional community survey in Nepal. *PLoS ONE* **12**(8). https://doi.org/10.1371/journal.pone.0183223.

Lv Y, Wolf A and Wang X (2013) Experienced stigma and self-stigma in Chinese patients with schizophrenia. *General Hospital Psychiatry* **35**(1), 83–88. https://doi.org/10.1016/j.genhosppsych.2012.07.007.

Maulik PK, Devarapalli S, Kallakuri S, Tripathi AP, Koschorke M and Thornicroft G (2019) Longitudinal assessment of an anti-stigma campaign related to common mental disorders in rural India. *British Journal of Psychiatry* **214**(2), 90–95. https://doi.org/10.1192/bjp.2018.190.

Meena KSM, Latha K, Mendon GB, Ballani Y, Tandon J, Dasgupta M, Pravitha MR, Yadav C, Cherian AV, Chaturvedi SK and Loganathan S (2023) Narratives Against Stigma: The Walking Tour at a Neuropsychiatric Hospital with a Baseline Assessment of Public Attitudes and Stigma. *Indian Journal of Psychological Medicine*. https://doi.org/10.1177/02537176231180279.

Nguyen E, Chen TF and O'Reilly CL (2012) Evaluating the impact of direct and indirect contact on the mental health stigma of pharmacy students. *Social Psychiatry and Psychiatric Epidemiology* **47**(7), 1087–1098. https://doi.org/10.1007/s00127-011-0413-5.

Nyblade L, Stockton MA, Giger K, Bond V, Ekstrand ML, Lean RM, Mitchell EMH, Nelson LRE, Sapag JC, Siraprapasiri T, Turan J and Wouters E (2019) Stigma in health facilities: Why it matters and how we can change it. *BMC Medicine* **17**(1). https://doi.org/10.1186/s12916-019-1256-2.

Petersen I, Marais D, Abdulmalik J, Ahuja S, Alem A, Chisholm D, Egbe C, Gureje O, Hanlon C, Lund C, Shidhaye R, Jordans M, Kigozi F, Mugisha J, Upadhaya N and Thornicroft G (2017) Strengthening mental health system governance in six low- and middle-income countries in Africa and South Asia: Challenges, needs and potential

strategies. *Health Policy and Planning* **32**(5), 699–709. https://doi.org/10.1093/heapol/czx014.

Phillips MR, Pearson V, Li F, Xu M and Yang L (2002) Stigma and expressed emotion: A study of people with schizophrenia and their family members in China. *British Journal of Psychiatry* **181**(DEC.), 488–493. https://doi.org/10.1192/bjp.181.6.488.

Potts LC and Henderson C (2021) Evaluation of anti-stigma social marketing campaigns in Ghana and Kenya: Time to Change Global. *BMC Public Health* **21**(1), 886. https://doi.org/10.1186/s12889-021-10966-8.

Rai S, Gurung D, Kaiser BN, Sikkema KJ, Dhakal M, Bhardwaj A, Tergesen C and Kohrt BA (2018) A service user co-facilitated intervention to reduce mental illness stigma among primary healthcare workers: Utilizing perspectives of family members and caregivers. *Families, Systems, & Health* **36**(2), 198–209. https://doi.org/10.1037/fsh0000338.

Rai S, Gurung D and Kohrt B (2023) The PhotoVoice method for collaborating with people with lived experience of mental health conditions to strengthen mental health services. *Cambridge Prisms: Global Mental Health* **10**, e80. https://doi.org/10.1017/gmh.2023.73.

Ryan GK, Semrau M, Nkurunungi E and Mpango RS (2019) Service user involvement in global mental health: what have we learned from recent research in low and middle-income countries? *Current Opinion in Psychiatry* **32**(4), 355–360. https://doi.org/10.1097/YCO.0000000000000506.

Samudre S, Shidhaye R, Ahuja S, Nanda S, Khan A, Evans-Lacko S and Hanlon C (2016) Service user involvement for mental health system strengthening in India: A qualitative study. *BMC Psychiatry* **16**(1), 1–11. https://doi.org/10.1186/s12888-016-0981-8.

Sartor C (2023a) Mental health and lived experience: the value of lived experience expertise and participation in global mental health matters. *Cambridge Prisms: Global Mental Health* 1–11. https://doi.org/10.1017/gmh.2023.24.

Semrau M, Lempp H, Keynejad R, Evans-Lacko S, Mugisha J, Raja S, Lamichhane J, Alem A, Thornicroft G and Hanlon C (2016) Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: systematic review. *BMC Health Services Research* **16**(1), 79. https://doi.org/10.1186/s12913-016-1323-8.

Stuart H (2016) Reducing the stigma of mental illness. *Global Mental Health* **3**, e17. https://doi.org/10.1017/gmh.2016.11.

Stuart H, Chen S-P, Christie R, Dobson K, Kirsh B, Knaak S, Koller M, Krupa T, Lauria-Horner B, Luong D, Modgill G, Patten SB, Pietrus M, Szeto A and Whitley R (2014) Opening Minds in Canada: Background and Rationale. *The Canadian Journal of Psychiatry* **59**(1_suppl), 8–12. https://doi.org/10.1177/070674371405901S04.

Stubbs A (2014) Reducing mental illness stigma in health care students and professionals: A review of the literature. *Australasian Psychiatry* **22**(6), 579–584. https://doi.org/10.1177/1039856214556324.

Thara R and Srinivasan TN (2000) How stigmatising is schizophrenia in India? *International Journal of Social Psychiatry* **46**(2), 135–141. https://doi.org/10.1177/002076400004600206.

Thornicroft G, Mehta N, Clement S, Evans-Lacko S, Doherty M, Rose D, Koschorke M, Shidhaye R, O'Reilly C and Henderson C (2016) Evidence for effective interventions

to reduce mental-health-related stigma and discrimination. *The Lancet* **387**(10023), 1123–1132. https://doi.org/10.1016/S0140-6736(15)00298-6.

Thornicroft G, Sunkel C, Alikhon Aliev A, Baker S, Brohan E, el Chammay R, Davies K, Demissie M, Duncan J, Fekadu W, Gronholm PC, Guerrero Z, Gurung D, Habtamu K, Hanlon C, Heim E, Henderson C, Hijazi Z, Hoffman C, Hosny N, Huang FX, Kline S, Kohrt BA, Lempp H, Li J, London E, Ma N, Mak WWS, Makhmud A, Maulik PK, Milenova M, Morales Cano G, Ouali U, Parry S, Rangaswamy T, Rüsch N, Sabri T, Sartorius N, Schulze M, Stuart H, Taylor Salisbury T, Vera San Juan N, Votruba N and Winkler P (2022a) The Lancet Commission on ending stigma and discrimination in mental health. *The Lancet* **400**(10361), 1438–1480. https://doi.org/10.1016/S0140-6736(22)01470-2.

White FA, Borinca I, Vezzali L, Reynolds KJ, Blomster Lyshol JK, Verrelli S and Falomir-Pichastor JM (2021) *Beyond* direct contact: The theoretical and societal relevance of indirect contact for improving intergroup relations. *Journal of Social Issues* **77**(1), 132–153. https://doi.org/10.1111/josi.12400.

Zhang W, Henderson C, Magnusdottir E, Chen W, Ma N, Ma H and Thornicroft G (2022) Effect of a contact-based education intervention on reducing stigma among community health and care staff in Beijing, China: Pilot randomized controlled study. *Asian Journal of Psychiatry* **73**, 103096. https://doi.org/10.1016/j.ajp.2022.103096.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Author contribution statement:

GBM led on the writing of the article. GBM, PCG, BAK and CH conceptualized the article. PCG conceptualized methodology and provided modification, WZ, SA, DG, CH, SL provided site case studies and reviewed full article. PCG, BAK, HL, GT shaped the article and reviewed multiple times, provided experts opinion and reading materials. All authors have revied and approve of the final submission of this work.

Financial Support

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

WZ is supported by Beijing Health Technologies Promotion Program (BHTPP2022027)

PCG is supported by the UK Medical Research Council (UKRI) for the Indigo Partnership (MR/R023697/1) award.

GT is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care. GT is also supported by the UK Medical Research Council (UKRI) for the Indigo Partnership (MR/R023697/1) awards.

CH receives support from the National Institute for Health and Care Research (NIHR) for the SPARK project (NIHR200842) and through the NIHR Global Health Research Group on Homelessness and Mental Health in Africa (HOPE; NIHR134325) using UK aid from the UK Government. CH also receives support from WT grants 222154/Z20/Z and 223615/Z/21/Z. The views expressed in this publication are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Conflict of Interest statement

Conflicts of Interest: None

Ethics statement

The process of collating reflections on the case studies reported on in this manuscript does not warrant ethical approval. Ethical approval was granted as relevant for the activities reported on in this manuscript at the respective institutions where the case study projects were carried out.

Data availability statement

The case study reflections synthesized in the current study can be made available upon reasonable request to the corresponding author.

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

Table 1. Overview of anti-stigma programs				
Case study		**Type of stigma targeted**	**Details**	**Impact**
1	**Experience using Photovoice in Nepal: a voice to be seen**	Public Stigma, Family stigma	Stigma attitudes of primary healthcare workers were targeted through social contact of photovoice trained PWLE*. For some PWLEs, family stigma was also addressed on an ad hoc basis.	Through a pilot cluster-randomized control trial, improved attitudes of primary healthcare workers and improved detection of cases at primary healthcare facilities were seen in the intervention arm compared to implementation as usual arm. On occasions, at the PWLEs request, counsellors facilitating the programme provided psychoeducation or family counselling to PWLEs' family members who were stigmatising towards them. However, this was not formally evaluated as a part of the training.
2	**A social contact-based education intervention to reduce stigma among community health care staff in Beijing, China**	Public stigma	Public attitudes towards primary care and community health care staff; attitudes and intended behavior to people with mental health conditions	RCT trial, evaluated by scales. The "education and contact" group showed a significantly greater improvement in clinicians' attitudes and intended stigma-related behaviours than the "education only" group, but the between group differences disappeared at 1 month and 3 months follow-up points. The positive effects on stigma levels (knowledge, attitudes and behaviours) in both groups were sustained at 3 months.
3	**Experience from 'Stories Against Stigma'- a Walking Tour of a Tertiary Mental Health Care facility, Bengaluru, India**	Public stigma	Public attitudes towards a tertiary mental health care centre; stigma associated with the medical model of treatment for mental health conditions	In the pre-assessment, 36.4% took part in the health care facility tour to know more about mental illness, about 27.3% were interested in knowing about the mental health care facility, and the remaining 27.3% wanted to improve their knowledge. In post assessment, the majority (79.4%) agreed that the tour was responsible for bringing about a positive shift in their attitude toward mental health.
4	**Using participatory action research for service user and caregiver involvement in mental health system**	Self-stigma, public stigma	Public stigma among health professionals, self-stigma among service users and caregivers, and public stigma through community perceptions about service user and	In our qualitative studies, the service users and caregivers reported a sense of achievement being part of the research team, contribution and agency for establishing service user association, improved opportunity to get out of home and interact with other people. The general public reported improved social acceptance and improvement in public attitudes towards people with mental health problem. The health

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

	strengthening in primary care in Ethiopia		caregiver involvement in mental health system strengthening.	professionals improved their receptiveness towards involvement of service users in developing and improving services as well as their attitude towards mental healthcare service delivery.
*PWLE = people with lived experience of mental health conditions				

1
2

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

1 **Table 2:** Barriers, facilitators and strategies in establishing partnership with PWLEs.

Barriers	**Facilitators**	**Strategies to mitigate barriers/strengthen facilitators**
● Refusal to Participate (*) ● Discontinued or dropout (*)	● Recovery stage (*) ● Volunteer (**) ● Motivation (*)	● Involved PWLE who are doing well, or symptoms are well controlled with their treatment and attained recovery stage (****) ● Identify PWLEs through known contacts who would be willing to be engaged (***) ● Identify the interested PWLE's through engaging with community health workers and local psychiatric facilities (Government and private) (*) ● As per the caregivers' request, disclosures were pseudonymized (not using the person's real name or photo) (*) ● The team discussed disclosure and answered any questions with PWLEs and their family members/caregivers before disclosure decisions were made (***) ● Thanking the PWLEs (*)
● PWLE employment status (*)	● Flexibility in work pattern (*)	● PWLEs known by the research team were approached (**) ● Planned training on weekends/ holidays (*)
● Self-stigma (**) ● Low self-esteem/ confidence (*)	● Strong motivation (*)	● Involvement of family members or caregivers in training (***) ● There was critical reflection on self with research participants and the research team at the beginning and end of every day (***).
● Fear of disclosure of mental illness in their own community/ district (***) ● Fear of negative consequence of disclosure of mental illness (**)	● Opportunity to disclose (*)	● Planned disclosure and Pre-event briefing (***) ● Each session of the training began with checking in and discussion with the participants regarding the benefits and harm of their participation in the program (*) ● The communities that PWLE participate in training were not the communities in which they live (*) ● PWLEs were monitored for any potential harm over time through continued professional contact with the lead organizer (**)

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

		• Cultural norms and family concerns need to be prioritized and respected (*)
• Confusion about what to share or what not to reveal about mental illness (*) • Lack of public speaking skills (worry & anxiousness) (*) • Lack of public speaking skills (*) • Limited experience of public speaking (*)	• Readiness and commitment to participate in social contact (*) • Existing training module (**)	• PWLE wrote their stories about mental illness with the help of family members (*) • Family members helped in the narration of recovery stories (***) • Adequate training to prepare recovery narration and disclosure of mental illness (***) • Review of PWLE motivation and confidence, and debrief from the research team (*) • Use of photographs for recovery narration (**) • Trained PWLEs on disclosure, recovery narration and public speaking skill, and team ensured PWLEs disclosed at varied levels and practiced before presenting to general public (**)
• Low level of education (**)	• Different level of literacy (*)	• Utilization of discussion and participatory approach in training PWLE's (**)
• Family stigma (**) • Lack of support from family (**)	• Family support system (*) • Trust and confidence with a MHP (**) • Long-standing cordial relationship (*)	• Information sharing and consent to participate in social contact (**) • Asked the PWLE to invite one caregiver (family member, close relative, or friend) who had disclosed their condition to the training session (*) • Avoid pictures and names of PWLEs (*) • PWLEs were monitored for any potential harm over time through continued professional contact with the lead organizer (****) • Training team (Mental health professionals) psychoeducating the family members or care givers on PWLEs' mental health problem to reduce family stigma (*)

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press

		• Encouraging caregiver to be involved in the training and participate along with the PWLEs in community programmes (**).
• Recounting painful experience (**) • Emotional breakdown (*)	• Meaningful story about lived experience (*) • Appropriate content for recovery story (*)	• Support from a mental health professional [Empathetic listening and validation] (**) • Minimize over disclosure (*) • A counsellor was present in each session of the photovoice training to check in with the PWLE and caregiver and to manage any distress during the training session (**) • Group therapy format was adopted for each session where the participants reflected on their issues and ensured peer support for each other's and ensured therapeutic benefits (*)
• Travel and Transportation (**)	• Session to be held in mutually convenient place (**)	• Honorarium for participation (**) • PWLE is accompanied by caregiver (***) • Organizing training in a convenient or central place and time (***)
• Active symptoms/ Presenting symptom of mental illness (*) • Relapse of mental illness (*)	• Various diagnoses of mental health problems (*)	• Mental health experts are involved throughout the training and disclosure process which helped research team to identify early sign/symptoms of mental illness and provide appropriate treatment and decide on when PWLEs can be involved in the stigma reduction activity (****) • Careful planning of training sessions for PWLE (**) • Preparatory training on crisis management and identifying strengths is provided to PWLEs and their care givers (*)
• Other		• Meaningful engagement of PWLEs at the initial period when planning and developing a stigma reduction programme (***) • Disseminating the lived experience recovery story through audio/video materials are another best strategy for stigma reduction in LMICs (***)
Element present in *one case study; ** two case studies; ***three case studies; ****four case studies		

1

https://doi.org/10.1017/gmh.2024.69 Published online by Cambridge University Press