Involving People with Lived Experience in the Evaluation of a Mental Health Peer Support Project in Uganda

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Declaration of work

I, Grace Kathryn Ryan, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Despite mounting calls to increase the involvement of people with lived experience in global mental health (GMH) research, there are few examples from low- and middle-income countries (LMICs). This thesis draws on a Theory of Change-driven evaluation of the Brain Gain II peer support project at Butabika Hospital in Kampala, Uganda, to document and derive lessons from efforts to involve peer workers at various stages of the research process.

This is a paper-style thesis comprising three published articles and two manuscripts under preparation. First, an 18-month rapid review reports an increase in the rate of publication on involvement in mental health systems strengthening in LMICs, but identifies only one possible example of involvement in the actual conduct of research. Second, a critical review of the literature on psychosis in sub-Saharan Africa highlights the material consequences of exclusion from GMH research. Third, a protocol documents how peer workers were involved in conceptualising and collecting data for a quasi-experimental study evaluating the effectiveness of Brain Gain II's peer support. The fourth paper shares findings of the Brain Gain II knowledge, attitudes and practices survey, which was developed in collaboration with peer workers. Finally, a qualitative study explores the benefits and unintended consequences of efforts to involve peer workers in data collection for Brain Gain II.

This thesis demonstrates that it is possible to involve people with lived experience in carrying out mental health research in a low-resource setting and highlights a number of possible benefits. However, Brain Gain II peer workers were often in exceptionally vulnerable situations, skirting a fine line between empowerment and exploitation. GMH research projects that seek to involve people with lived experience should critically reflect on how involvement is ultimately experienced and share their insights in order to avoid either "reinventing the wheel" or repeating past mistakes.

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List of abbreviations

BELL:	Butabika-East London National Health Service Trust Link
BGII:	Brain Gain II Project
BREC:	Butabika Recovery College
CBR:	Community-Based Rehabilitation
CHIME:	Connectedness, Hope, Identity, Meaning, Empowerment
CI:	Confidence Interval
CONSORT:	Consolidated Standards of Reporting Trials
COPSI:	Care for People with Schizophrenia in India
Covid-19:	Coronavirus Disease 2019
CRT:	Community Recovery Team
DALYs:	Disability-Adjusted Life Years
DID:	Difference-in-Differences
DSM:	Diagnostic and Statistical Manual of Mental Disorders
Emerald:	Emerging Mental Health Systems in Low- and Middle-Income Countries
ELFT:	East London National Health Service Foundation Trust
EMPOWER:	Empowering People Affected by Mental Disorders to Promote Wider Engagement with Research
EURIKHA:	Explorations in User Research, Impact, Knowledge and Activism
GBD:	Global Burden of Disease
GMHPN:	Global Mental Health Peer Network
HICs:	High-income countries
HOPE:	Homelessness and Mental Health in Africa
HR:	Human Resources
ICD:	International Classification of Diseases
INTREPID:	International Research Programme on Psychoses in Diverse Settings
KAP:	Knowledge, Attitudes and Practices
LEAP:	Lived Experience Advisory Panel
LL:	Lower Limit
LMICs:	Low- and Middle-Income Countries
M&E:	Monitoring and Evaluation
M&E Buddy:	Monitoring and Evaluation Buddy
mhGAP:	Mental Health Gap Action Programme
MIND ME:	Mental Health Information and Monitoring and Evaluation
MRC:	Medical Research Council
MSG:	Monthly Advisory Support Group
NSUN:	National Service User Network
NHS:	National Health Service
PANUSP:	Pan-African Network of Users and Survivors of Psychiatry
PCO:	Psychiatric Clinical Officer
PhD:	Doctorate of Philosophy
PPI:	Patient and Public Involvement
PRIME:	Programme for Improving Mental Health Care
PROMISE:	Psychosis Recovery Orientation in Malawi by Improving Services and Engagement
PSW:	Peer Support Worker
PSW+:	Frequent users of psychiatric inpatient care who have access to a peer support worker
PSW-:	Frequent users of psychiatric inpatient care who do not have access to a peer support worker
RECOLLECT:	Recovery Colleges Characterisation and Testing

RESHAPE:	Reducing Stigma among Healthcare Providers to Improve Mental Health Services
RISE:	Community-Based Rehabilitation Intervention for People with Schizophrenia in Ethiopia
Health RPC:	Health Research Programme Consortium
SD:	Standard Deviation
SE:	Standard Error
STARS-C:	Starting from the Bottom: Using Participatory Action Research to Re-Imagine Local Mental Health Services in Colombia
STROBE:	Strengthening the Reporting of Observational Studies in Epidemiology
SUCCEED Africa:	Support, Comprehensive Care and Empowerment of People with Psychosocial Disabilities in sub-Saharan Africa
ToC:	Theory of Change
UBACC:	University of California, San Diego Brief Assessment of Capacity to Consent
UGX:	Ugandan Shillings
UK:	United Kingdom
UL:	Upper limit
UN:	United Nations
UPSIDES:	Using Peer Support in Developing Empowering Mental Health Services
US:	United States
USD:	United States Dollars
USP Kenya:	Users and Survivors of Psychiatry Kenya
WEF:	World Economic Forum
WHO:	World Health Organization
WHO-AIMS:	World Health Organization Assessment Instrument for Mental Health Systems
WHODAS 2.0:	WHO Disability Assessment Schedule, Version 2.0
WPA:	World Psychiatric Association
W-SOHO:	Worldwide Schizophrenia Outpatient Health Outcomes
YLDs:	Years Lived with Disability
YLLs:	Years of Life Lost

1. Introduction

> *We have potentials, abilities, talents and each of us can make a great contribution to the world* […] *There can be no mental health without our expertise. We are the knower's* [sic] *and yet we remain the untapped resource in mental health care* […] *We invite you to walk beside us. We know where we want to go.* (PANUSP 2011, n.p.)[1]

Involvement in research positions people with lived experience as active "partners" as opposed to "passive subjects" (Trivedi, et al. 2002 pp.468); in other words, research is done "with" or done "by", rather than done "to" or done "for" people with lived experience (INVOLVE 2012, pp.6).[2, 3] Lived experience involvement in mental health research originated with the psychiatric user and survivors movement of the 1960s and '70s,[4] gained traction within the emancipatory disability research paradigm of the 1980s and '90s,[5] and ultimately became an important driver for the development of policy, practice and guidance on what the UK currently refers to as "patient and public involvement" ("PPI").[6] Historically, much of this momentum has been constrained to high-income countries (HICs). Recent developments in Global Mental Health, a field which grew primarily out of concern over disparities between HICs and low- and middle-income countries (LMICs),[7] call for further attention to involvement in mental health research in low-resource settings.

A 2018 *Lancet* Commission asserts that Global Mental Health is experiencing a "transformational shift" toward "nothing about us without us" (Patel, et al. 2018 p.1557).[8, 9] Critics have positioned involvement as a necessary pre-requisite to begin addressing long-standing critiques of the field; namely, that Global Mental Health risks exporting problematic explanatory, treatment and service models, marginalising local conceptualisations of and responses to mental ill-health in the process, and ultimately contributing to the oppression of those it claims to serve.[10, 11] A recent editorial from Global Mental Health researchers at University of Edinburgh calls for a "slow research movement" (Chiumento, et al. 2024, n.p.). centred in lived experience expertise to reinvigorate the field.[12]

Global advocacy groups for people with lived experience have organised regional chapters in the Global South, such as Transforming Communities International Asia and the Pan-African Network of Users and Survivors of Psychiatry (part of the World Network of Users and Survivors of Psychiatry).[1, 13] Meanwhile, national and grassroots organisations are also gaining traction in LMICs.[14] Headquartered in South Africa, the Global Mental Health Peer Network (GMHPN) has begun producing policies and guidelines to help facilitate lived experience involvement, including in research (though the latter is a brief document mainly describing GMHPNs' consultancy service).[15] Prominent funders of LMIC mental health research are also raising the bar; for example, Wellcome Trust now employs an in-house Lived Experience Team (which includes members from LMICs) responsible for ensuring that "lived experience expertise is embedded in […] the research we fund" (Wellcome 2024).[16, 17] Wellcome is also financing a new *Lancet Psychiatry* Commission on Lived Experience in Mental Health Research[18] and recently announced a call for "innovative approaches to lived experience in mental health science" (2024, pp.1) with three aims, one of which is explicitly focused on LMICs.[19]

Yet there are few documented examples of lived experience involvement in the actual conduct of empirical mental health research in LMICs.[20-22] Further, there is no evaluation of these efforts which might otherwise provide important lessons on how best to facilitate lived experience involvement, or to what end.[16] What outcomes might research involvement achieve in a low-resource setting, and are there any potentially negative consequences that need to be mitigated? Those conducting mental health research who are looking for ways to involve people with lived experience for the first time are faced with daunting theoretical, ethical, and practical questions,[23] and it is unclear to what extent any answers derived from HIC research may (or may not) apply to low-resource settings. Indeed, a prominent user-led research initiative that originally sought to map lived experience knowledge around the world ultimately splintered over a North-South divide and "positions on racialisation [that] became entrenched in a very strong way" (Rose 2021, n.p.).[24-26] Similar questions asked of the decolonisation of Global Mental Health could also be applied: are there any risks in exporting a tradition of lived experience involvement developed in a handful of HICs to the rest of the world?

1.1. Origins of my PhD research

In 2014 our research group at the Centre for Global Mental Health was approached by representatives of the Butabika-East London NHS Link who were looking for a consultant to evaluate their newest peer support project in Uganda, Brain Gain II. I admired their commitment to co-production and did not wish to undermine the project's values by side-lining peer workers from its evaluation. Further, as it was funded by the UK Tropical Health Education Trust as a capacity-building project, not a research project, the Link simply could not afford to recruit a large team of external data collectors. In fact, I saw a number of ways in which involving peer workers could help to facilitate some of the basic tasks of an evaluator: understanding how a programme is intended to work; identifying and prioritising outcomes for measurement; designing contextually appropriate measurement tools; even interpreting results.[27] Drawing on the Link's experience in co-production in Uganda[28-30] and my own experience in mental health monitoring and evaluation (M&E) in Nigeria,[31-33] we agreed to take a risk and "learn by doing" together. While I had expected to submit results of our evaluation in fulfilment of the requirements of a PhD, I ultimately found our process to be more edifying than the outcome, and potentially a more useful contribution to this "transformational shift" that my field claims to be undertaking.[34]

Instead, this doctoral thesis draws on our evaluation of Brain Gain II to document and derive lessons from efforts to involve peer workers with lived experience at various stages of the research process—from overall study design to the development of questionnaires, the collection of M&E and research data, and the interpretation of study results. The thesis is divided into four parts: (1) a background section, offering an overview of several key concepts and terminology, before turning to the setting of this research and my positionality as a researcher; (2) an overview of the rationale, objectives and methods of the thesis; (3) the five research papers that make up the body of the thesis; and (4) a discussion section drawing together key findings, and also reflecting on the implications and limitations of this research.

My research papers comprise three published articles and two manuscripts under preparation (Table 2). First, an 18-month rapid review of the literature reports an increase in the rate of publication on user involvement in mental health systems strengthening in LMICs, which may support the notion of a nascent “shift” in GMH. However, it identifies only one possible example of user involvement in the actual conduct of an empirical research study. Second, a critical review of the literature on psychosis in sub-Saharan Africa highlights the material consequences of exclusion from Global Mental Health research, calling for more involvement of people with lived experience. Third, the Brain Gain II evaluation protocol documents how peer workers were involved in conceptualising and collecting data for a quasi-experimental study. The fourth paper shares findings of the Brain Gain II knowledge, attitudes and practices (KAP) survey developed in collaboration with peer workers and includes their feedback from an interpretation session held at Butabika. Finally, a qualitative study explores experiences of involvement in the Brain Gain II evaluation, from the perspectives of hospital staff and the peer workers involved.

In sum, this thesis aims to both further and complicate the argument for increasing involvement in mental health research in LMICs, by highlighting the scale and consequences of inaction (papers 1-2), offering proofs of concept for involvement in various stages of the research process (papers 3-4), and exploring what is at stake for those involved—including risks as well as benefits (paper 5). I make no claim that ours was the right or only way to involve people with lived experience in the Brain Gain II evaluation, and in fact highlight many opportunities to improve upon our efforts. However, I hope that my thesis might serve as a jumping-off point for other researchers who find themselves—as I did—eager to respond to mounting calls for involvement in Global Mental Health research, but unsure where to begin.

2. Background

Papers 1-2 review the literature on psychoses in sub-Saharan Africa (which represent the majority of cases at Butabika[35]) and involvement in mental health systems strengthening in LMICs. However, to provide sufficient context for the thesis as a whole, it is important to begin with an orientation to several key concepts and terminologies. I start first by introducing the mental health-related terminology used in this thesis. Second, I provide some background on research involvement and the recovery paradigm in which Butabika’s interventions and my PhD research are embedded. Third, I attempt to “set the scene” for the reader by briefly describing the research setting, adding to the contextual information provided in Papers 3-5. Finally, I briefly summarise my positionality and theoretical orientation toward this research (i.e., my epistemological and ontological stance). To minimise duplication, I refer to relevant sections of the research papers included in this thesis for further information, where appropriate.

2.1. Mental health terminology

2.1.1. Mental health and mental disorders

> *The language used to talk about mental health also creates barriers because the way in which we understand, and subsequently express, experiences can be easily misinterpreted and consequently negative assumptions are made about others. It is*

> *therefore imperative to obtain clarity in the distinction between terms such as ‘mental health’ and ‘mental illness’.* (Sunkel and Sartor 2022, pp.161)

As GMHPN advocates Sunkel and Sartor argue above,[36] imprecise language is an obstacle to lived experience involvement, so it is important that I clarify here how several key terms are used in this thesis. The World Health Organisation (WHO) describes mental health as “more than the absence of mental disorders”; rather, it is both “a complex continuum” and “a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community” (WHO 2022).[37] The WHO definition reflects a conscious move away from deficit-based language and psychiatric labelling, a move which is on the one hand essential for stigma-reduction[38] and promoting a “values-based climate” (Richards 2018, pp. 461),[39] and on the other hand, stubbornly difficult to operationalise.

In paper 2,[i] I discuss some of the nuances in the language surrounding “psychosis”, “psychoses” and “severe mental health conditions”, and reflect on discomfort with common terms used in the clinical and academic research literature,[40] referencing guidance originally prepared for development professionals.[41] In this paper and elsewhere in the thesis, I begrudgingly use terms like “mental disorders” at times for accuracy; for example, when describing other studies that employ this terminology or when discussing groups identified according to ICD (international Classification of Disease)[42, 43] or DSM (Diagnostic and Statistic Manual) criteria for various “disorders”. However, a keen-eyed reader may notice discrepancies in my evaluation protocol (paper 3), which I drafted in 2016 before coming to grips with the politics of language in Global Mental Health. Unfortunately, I ended up inadvertently replicating the clinical language to which I had been exposed as a Master’s student as a result. In more recent papers, I try to follow my own guidance and apply “person-first” language focused on “lived experience” (see below) of either “mental health conditions” (an imperfect though hopefully less medicalised term than “disorders”) or “psychosocial disabilities” (the product of societal barriers in interaction with [perceived] impairments related to mental health[44]) (Ryan, et al. 2019, pp.10).[41] As mentioned in paper 2, this will hopefully soon be replaced by new guidelines co-produced by academic, clinical and peer researchers from SUCCEED Africa (SUpport, Comprehensive Care and Empowerment of pEople with psychosocial Disabilities in sub-Saharan Africa).[40]

2.1.2. Lived experience

In the preface to a special issue of *Nature Mental Health*, the editors define “lived experience” as “the core qualia of a mental health condition as it is perceived and inhabited by an individual” and situate the development of a “lived experience movement” within the wider Disability Rights Movement and its commitment to “nothing about us without us” (2023, pp.145).[9, 45] There are numerous terms used synonymously with “person with lived experience” in the research literature (e.g., “consumer”, “user”, “survivor”, “peer”, “patient”) each with its own nuances, adherents and critics.[6, 45, 46] At a practical level, the

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[i] I should take pause here to acknowledge an anonymous peer reviewer who encouraged us to add an extra section on terminology to our paper. It spurred some much-needed discussion among the co-authors as a group, and for me personally, a deep-dive into the literature on psychosis.

language of “experience” side-steps concerns over identifying people primarily in relation to their diagnosis and/or relationship with mental health services. The phrasing of “lived experience” also positions it as equivalent to “professional experience” or “educational experience”, different though sometimes overlapping routes toward achieving substantial expertise (e.g., as “experts by experience”). Hence, this terminology proves especially useful in involvement research, and I have tried to adopt it in this thesis. However, as described above, I occasionally use other terms in order to remain faithful to other research under discussion (for example, paper 1 updates a previous review on “service user and caregiver involvement”[47]). My evaluation protocol (paper 3) was also written early in my PhD studies and rather uncritically employed the term “users” for recipients of peer support.

2.2. Research involvement

In most of my research, I talk about and even advocate for lived experience involvement without really defining or interrogating it as a concept. Here, I briefly describe research involvement, its benefits and drawbacks as documented in the HIC literature, and some of the very few available examples of lived experience involvement in mental health research in LMICs.

2.2.1. Participation, engagement and involvement

In the context of research, involvement and engagement represent two distinct subclasses of participation.[48] (For instance, I refer to involvement in the development of a survey tool and interpretation of results as examples of “participatory methods” in paper 4.) However, to avoid the common pitfall of misrepresenting participation as a research subject as an example of PPI, the UK’s INVOLVE guidelines narrowly define participation as “tak[ing] part in a research study”, which is distinct from sharing “information and knowledge about research” (engagement) and “actively involv[ing members of the public] in research projects and organisations” (INVOLVE 2012, pp.7).[3] In the context of mental health research, involvement typically refers not to members of the public in general, but to people with lived experience specifically (sometimes extending to family members). For the purposes of this thesis, I use “involvement” as shorthand to refer to the involvement of people with lived experience.

Involvement can take many forms and may vary across the different stages of the research process.[49, 50] The INVOLVE guidelines depict involvement as a continuum, ranging from consultation (e.g., advisory panels) to collaboration (e.g., co-production) and control (e.g., user-led research).[3, 49, 50] Sweeney and Morgan (2009) propose that an additional level should be inserted between consultation and collaboration to capture “significant and meaningful *contribution* [emphasis added] to research” (pp.29), for instance, where a person with lived experience acts as a member of a research team (e.g., as a data collector), but has little influence over decision-making within the team.[50] Indeed, where on the involvement continuum a particular research activity may be located is mainly determined by its approach to power-sharing between “traditional researchers” and those with lived experience (Table 1). As research projects are composed of many different activities, each of which can take different approaches to involvement with different levels of power-sharing, it is often difficult to qualify an entire research project as, for example, “co-produced”.[51, 52]

Table 1. Mapping PPI concepts on a continuum of power
(adapted from INVOLVE [2012] and Sweeney and Morgan [2009])

Locus of power	**Level**	**Description**
Professional experience	Participation*	“Where people take part in a research study” (pp.7).[3]
	Engagement	“Where information and knowledge about research is provided and disseminated” (pp.7).[3]
	Involvement	“Where members of the public are actively involved in research projects and in research organisations” (pp.7).[3]
	Consultation	“Service users and survivors are invited to comment on the research, but crucially, the power to act, or not, on those comments resides with traditional researchers” (pp. 28).[50]
	Contribution	“Research where service users/survivors make a significant and meaningful contribution to research but with power and decision-making still residing with traditional researchers” (pp.29).[50]
Shared	*Collaboration*	“Power is genuinely shared between service users/survivors and traditional researchers, with decisions taken jointly” (pp.29).[50]
Lived experience	*Control*	“User-controlled research… refers to research where service users/survivors have absolute control over the process” (pp.30).[50]

*Note: INVOLVE (2012) uses a narrow definition of participation,[3] while other conceptual frameworks subsume involvement and engagement under the category of research participation.[48]

2.2.2. Benefits and drawbacks

The heterogeneity of research involvement aside, reviews of HIC studies suggest possible benefits. An analysis of more than 300 studies from the UK’s Mental Health Research Network portfolio showed that involvement improved the likelihood that studies would achieve their recruitment targets.[53] A systematic review examining comparative studies on the involvement of people with lived experience in mental health service delivery and evaluation concluded that involvement in evaluation was feasible, though participants were more likely to report dissatisfaction with services to lived experience interviewers when compared to other interviewers,[54, 55] which could be indicative either of social desirability bias or, conversely, greater validity of data collected by interviewers with lived experience.[56] This same finding was echoed by a Cochrane review on lived experience involvement in health care, though the effect of using lived experience interviewers was small, and the evidence was of low quality.[57]

A more recent study by Gillard, et al. (2010) supports the notion that lived experience and “traditional” researchers will carry out the same tasks in slightly different ways. In a secondary analysis of interview transcripts from a study of psychiatric patients detained under the UK Mental Health Act, the authors found that lived experience interviewers were more likely to ask follow-up questions focused on experiences and feelings, and less likely to focus on agency, medical and behavioural approaches. Interviewees also reported that they were "more comfortable" (pp.191) with the lived experience researcher, but they were unsure how this may have impacted their responses.[58] Lived experience researchers' attention to experiences and feelings was even more pronounced when it came to qualitative coding, while "traditional" researchers were more likely to emphasise detention processes and procedures in their coding of the same interview transcripts.[58]

More broadly speaking, Davidson, et al. (2009) have portrayed lived experience involvement in mental health research as something potentially transformative both for "the research itself" and for those involved, with the capacity to improve "the quality, relevance and utility of mental health research" (pp. 89), while at the same time contributing to "the overall process of the restoration of their [persons' with lived experience] full citizenship in society" (pp. 93).[59] These wider benefits are perhaps more challenging to measure than, say, recruitment rates. Yet they feature prominently in much of the discourse surrounding lived experience involvement. INVOLVE's (2012) briefing notes give a number of examples of how involvement might improve individual research studies (e.g., by increasing the accessibility of language used for recruitment and consent forms, data collection tools, dissemination and other engagement materials) as well as the broader research endeavour (e.g., by promoting democratic approaches to research and focusing limited resources on answering questions of particular salience to those most affected).[3] For people with lived experience, involvement in research can offer exposure to new learning, and even a stepping-stone into other employment.[60] Patterson, Trite and Weaver (2014) offer an emotive summary of the less tangible benefits reported by lived experience survey respondents in the UK (pp.73):

> *Many wrote that involvement and investment in research activity provided a sense of purpose and belonging, giving meaning to their 'suffering', reduced self-stigma and enhanced self-respect. Facing up to the challenges of research was described as leading to discovery of internal resources and development of self-management strategies that promoted mental well-being. Being occupied and active intellectually were considered health promoting by several and respondents commonly reported deriving a sense of pride in their achievements and developing (or renewing) confidence in their place in community.*[61]

On the other hand, lived experience involvement may also have drawbacks. For instance, colleagues from the London School of Hygiene and Tropical Medicine have written about the "dark side of co-production" in health research generally,[52] which they argue is "not free [of] risk or cost" (Oliver, Kothari and Mays 2019, n.p.). In fact, the authors present an extensive list of these costs in the main figure of their paper: practical (financial) costs, such as increased overheads; personal and professional costs to ("traditional") researchers, such as potential reputational damage, stress and burnout, particularly when co-production isn't working well; costs to the other stakeholders involved, such as time away from other responsibilities; costs to the research itself, namely, the opportunity cost of investing so much time and effort in relationship management with no guarantee of a good outcome; and finally, potential costs to the research profession, for example by undermining the credibility of research and researchers when "evidence become[s] just another voice" (Oliver, Kothari and Mays 2019, n.p.). A systematic review of the outcomes and experiences of involving patients as "co-researchers" in HIC health research (in which mental health was one of the main topics covered) found that although studies generally extolled the benefits of involvement, this was often at the expense of methodological rigour, and was extremely time- and resource-intensive.[62] A second review focused on the views of HIC mental health researchers reported reluctance to "co-research"; many researchers preferred that user involvement be limited to consultation, and that this take place mainly at the early stages of the research process.[49]

In the context of mental health research involvement, the stakes may be especially high for people with lived experience. The discomfort of navigating multiple roles, identities and power imbalances, the resentment of feeling used, and disillusionment with mental health research and services, are just some of the many potentially distressing consequences of research involvement gone wrong.[60, 61] Meanwhile, workplace mental health is exceptionally poor both in academic[63] and clinical settings,[64] where existing policies and systems may not offer adequate supports.[61, 65] There are also material costs. While lived experience researchers may be in extremely vulnerable financial situations, they are often inadequately compensated for their efforts.[60, 66] Paradoxically, receiving compensation can actually add to financial insecurity by threatening welfare benefits, though this is more common in HICs with more heavily regulated benefits systems.[61, 67] Despite these challenges, Patterson, Trite and Weaver (2014) reported that of 124 respondents with lived experience who had been involved in mental health research in the UK, only 14 said that research involvement had an overall negative effect on their mental health; over 60% (n=80) stated the opposite, that involvement was unambiguously positive.[61]

2.2.3. Examples from low- and middle-income countries

Until quite recently, with the advent of several new research projects and consortia that have made an explicit commitment to involvement, examples from LMICs have been fairly piecemeal. In some instances, involvement of people with lived experience from LMICs has taken place at a very high international level: co-leading global surveys for *The Lancet*;[68, 69] contributing to multi-site participatory research on the ICD-11;[70] or co-writing a "bottom-up review" on psychosis for the journal of the World Psychiatric Association (WPA).[71] More often, lived experience involvement in LMICs is quite limited or even tokenistic, if it happens at all.[22]

A case study of the EMPOWER project inadvertently highlights the lack of literacy on lived experience involvement among many global mental health researchers. EMPOWER engaged organisations of mental health service users in India, Kenya, Nepal and Zambia to develop communications about mental health research. The authors correctly state that user-led research is characterised by user control at all stages of the research process, but miscategorise EMPOWER as "a mixed approach of collaborative and user-led" (Gupta and Roberts 2014, n.p.) when involvement was restricted to research dissemination alone. Then again, there may be knock-on effects even of this fairly limited, late-stage involvement; one of the researchers quoted in the paper said that their close interactions with people with lived experience on EMPOWER gave them pause to reflect on the research questions they might want to ask in future.[72]

My rapid review (Paper 1) identified only one possible example of lived experience involvement in the conduct of a LMIC research study.[21] This was a survey on psychosocial disability in North India in which three of the eleven data collectors identified as having disabilities, including psychosocial disabilities (though this was not made clear in the original text).[73] In my rapid review, I had originally referenced Semrau, et al.'s (2016) report of two Portuguese publications on a participatory qualitative evaluation of Brazilian centres for psychosocial care.[47, 74, 75] Later, I discovered that the researchers focused on involving family members, not people with lived experience, in data analysis and interpretation. This means that at the time I was starting my PhD research, there was even less lived experience involvement happening in LMICs than I had thought. However, in the years that have elapsed since our reviews were completed, I have come across a few new initiatives worth highlighting, specifically in the areas of Participatory Action Research, collaboration with lived experience researchers, and user-led research.

2.2.3.1. Participatory Action Research

Participatory Action Research is one area where Global Mental Health researchers have shown growing interest in recent years. Burgess, et al. (2022) have published a protocol for the STARS-C pilot study using Participatory Action Research "informed by co-production principles" to "co-design", "co-implement" and "co-evaluate" (n.p.) a group intervention aimed at improving community mental health services in Colombia.[76] However, it is unclear to what extent people with lived experience, specifically, will be involved. Rather, the authors emphasise public involvement, with "potential service users" included among the "everyday citizens" involved, though they mention efforts to include "people with previous experience of mental health services" in Theory of Change (ToC) workshops (Burgess, et al. 2022, n.p.).

In Ethiopia, Abayneh and colleagues have used a Participatory Action Research approach to pilot a model of involvement that claims to empower people with lived experience of mental health conditions.[77, 78] They brought together two stakeholder groups to identify priorities for research on involvement in mental health systems strengthening, and like Burgess, et al. (2022), they also used Theory of Change workshops to help facilitate involvement at the design stage.[77] In addition, people with lived experience and health professionals were provided with training to support collaboration.[79] However, people with lived experience represented only half of the members of the "research participant group" and a small minority of the "research advisory group" (five of 26) involved.[78] It is unclear whether any data collectors had lived experience, and there was no involvement in analysis, as stated in the protocol: "We expect that it will be challenging to involve service user [sic] in the data analysis, in the true sense of the word, hence the principal investigator will lead the data analysis, and results of the data analysis will be fed back to the participants for member checking" (Abayneh, et al. 2020 n.p.). In a subsequent publication, the authors clarify that the main challenge to involvement in data analysis was literacy.[78]

In North India a Participatory Action Research approach was used to develop a visual recovery tool for the Burans project.[80] An Experts by Experience group was established, comprising four people with psychosocial disabilities and four carers, who joined in a series of meetings and workshops in which a variety of participatory methods were applied (e.g., story-telling, generating and/or discussing photographs, pictures and symbols, carrying out focus groups and participant observation) to develop and refine the domains of the recovery tool, provide feedback on pictures representing these domains, and advise on the process of administering the tool. As in the Ethiopian example above, “traditional” researchers appear to have taken the lead in analysing transcripts of workshops and additional in-depth interviews conducted with group members, but fed their initial results back for discussion with the group. Unlike the Ethiopian example, they include an Expert by Experience group member as a co-author and reflect critically on an instance in which they failed to consult the group ahead of dissemination: “For the researcher group, who believed we were using empowering approaches, we were surprised to become aware we had inadvertently made several unilateral decisions (e.g. in submitting a conference abstract). This challenge was surprising and uncomfortable” (Mathias, et al. 2020, pp.496). Another reported challenge was that group members felt “unqualified to challenge or engage with the power relations in the co-production process” (Mathias, et al. 2020, pp.496) due to low education and literacy, lack of prior engagement in the user movement and lack of confidence in their expertise. The authors recommend a longer research timeline, more explicit conversations around hopes, expectations and ownership at the outset, and more opportunities for critical reflection as a project unfolds.

2.2.3.2. Collaboration with lived experience researchers

Less common in Global Mental Health is the involvement of people with lived experience as researchers in their own right. However, I am aware of at least three initiatives that have formally employed “peer researchers” in sub-Saharan Africa to contribute to different stages of the research process, alongside other consultation (e.g., Theory of Change workshops, advisory groups) and engagement efforts. In 2019 the SUCCEED Africa consortium began a six-year programme of research to co-produce the design and evaluation of a community-based intervention for people with lived experience of psychosis in Malawi, Nigeria, Sierra Leone and Zimbabwe.[40, 81] The consortium involves people with lived experience of psychosis at different levels: in-country, as key stakeholders in Local Advisory Groups and peer researchers embedded in research teams; cross-consortium, as members of a Lived Experience Advisory Panel (LEAP) also represented in the Consortium Advisory Group; and externally, as consultants contributing to specific areas where additional lived experience expertise is needed.[ii] Through these various mechanisms, it aims to involve people with lived experience at each stage of the research process. One of SUCCEED Africa’s final outputs will be a retrospective evaluation of its efforts at co-production, though peer researchers have already presented a number of benefits, challenges and recommendations at a conference in 2023.[82][iii]

In 2021 a participatory research project investigated recovery priorities and the impact of Covid-19 on people with psychosocial disabilities in Ghana and Indonesia.[77, 83] Four peer researchers with lived experience were embedded in the in-country research teams and involved in recruiting study participants,

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[ii] One of SUCCEED Africa’s consultants is a former peer worker from Brain Gain II who advises on issues related to human rights, recovery and peer support in African contexts.

[iii] I should probably disclose here that I am SUCCEED Africa’s Research Manager and supported the peer researchers to develop their conference abstract and presentation.

developing topic guides, conducting interviews, contributing to a participatory thematic analysis process, producing case study narratives and filming participatory videos to disseminate preliminary findings. Peer researchers also worked on radio dramas and social media activities to raise awareness and presented their work to policy-makers and practitioners at local conferences. However, opportunities for collaboration at earlier stages (e.g., study design) were curtailed by the extremely short timeframe of the project, as only six months of funding was offered in the first instance. On the other hand, this short timeframe allowed the project to document reflections on their process, which may prove instructive for other collaborative research that is still ongoing.

Both of these initiatives—and Abayneh's research,[77-79, 84] described above— have informed the collaborative approach behind HOPE,[85] a new consortium focused on homelessness among people with severe mental health conditions in Ethiopia, Ghana and Kenya. HOPE also involves people with lived experience as advisors and as peer researchers, though to my knowledge this approach has not yet been formally documented.

2.2.3.3. User-led research

The EURIKHA Project stands out as a rare example of user-led research in Global Mental Health.[iv] EURIKHA aimed to "map the knowledge produced by service users, survivors and persons with psychosocial disabilities globally" (Rose and Kalathil 2019, n.p.), including those from LMICs.[24-26] It appears that EURIKHA was ultimately unsuccessful in fulfilling this aim, due in part to tensions between lived experience researchers from the "Global North" and those from the "Global South",[24] as mentioned in the background to this thesis. However, it did produce thought-provoking critiques of a Eurocentric "rational, racialized science" as an obstacle to co-production, preventing people with lived experience—and particularly those of colour— from "overturn[ing] the hierarchy of methods in general or question particular ones" (Rose and Kalathil 2019, n.p.) and consequently, from effecting real change. EURIKHA also published uncomfortable reflections on the power dynamics within the project and on co-production between white and racialised people with lived experience, generally: "Racialised peoples are not just treated oppressively by psychiatry; they are epistemically ignored or suppressed by their white peers" (Rose and Kalathil 2019, n.p.). EURIKHA reminds us that efforts to increase involvement must also be aligned with efforts to decolonise Global Mental Health,[10, 86] paying special attention to intersectionality and power dynamics not only between "traditional" and lived experience researchers, but among those with lived experience themselves.

2.3. Recovery

> *Recovery, as consumers define it, comprises hope, empowerment, social connectedness, meaning/purpose, aspirations, contributions to society, satisfaction with life, building on personal strengths and resources, well-being, positive sense of self, roles and life beyond the mental health system, respect, connections, self-determination and spiritual*

[iv] I apologise for any possible inaccuracies in my discussion of EURIKHA and the challenges that it encountered. As the EURIKHA website is now defunct, I am relying entirely on descriptions of the project embedded in a series of publications led by the Principal Investigator.

> *development. It is a way of life, attitude, or way of approaching the day's challenges rather than a point-in-time outcome; the journey is nonlinear in nature. Not synonymous with cure, mental health recovery may involve ongoing symptoms, treatment, or supports.* (Del vecchio and Blyler 2009, pp. 107)

While my fourth research paper offers a brief definition of personal recovery (what I refer to simply as "recovery" in this thesis) as distinct from clinical recovery, I prefer Del vecchio and Blyler's (2009) description above.[87] It evokes the deeply personal, multifaceted and dynamic nature of recovery that on the one hand, makes it so compelling, and on the other hand, so intimidating. How can this concept be operationalised, serviced, measured? Is it universal, portable (with some modifications), or constrained to a particular set of social norms, values and privileges? Perhaps most vexing: is it too good to be true? These questions are mostly unresolved, but not for lack of effort.

The concept of recovery originated with the psychiatric users and survivors movement and evolved over several decades before it started appearing in government policies around the turn of the 21st century.[88] A number of different definitions, models, frameworks and measurement tools were developed to help create a shared language and understanding across research, policy and services.[89, 90] In an attempt to corral together the common elements of recovery across this diverse landscape, Leamy, et al. produced the CHIME conceptual framework in 2011, based on a systematic review and narrative synthesis.[90, 91] CHIME stands for Connectedness, Hope, Identity, Meaning and Empowerment, the five core processes of recovery identified across 87 studies from 13 countries (all high-income). The reviewers also identified 13 characteristics of the "recovery journey": It is an (1) individual and unique, (2) multidimensional, (3) active, (4) non-linear, (5) gradual process of (6) trial and error; it can occur without (7) cure or (8) professional intervention, though may be aided by a (9) supportive and healing environment; it is a (10) journey, with different (11) stages or phases; and it can be a (12) struggle, but ultimately a (13) life-changing experience (Leamy, et al. 2011, pp. 448).

CHIME is perhaps the most commonly used recovery framework internationally,[92] but does not necessarily represent a global consensus. Among the critiques of CHIME are that it is based on concepts published in academic literature from barely a dozen very wealthy countries in the Global North with relatively little research on recovery in ethnic minority groups.[93-95] CHIME has been accused of furthering a "monocultural" (Slade, et al. 2014, pp.17), "decontextualise[d] and overindividualise[d] recovery" that leaves little room for consideration of the "social locations that individuals with lived experience may be occupying" (Karadzhov 2023, pp.212).[93, 95, 96]

Global mental health researchers have raised similar critiques of the concept of recovery as a whole, based on work in a number of LMICs (e.g., India,[97] Colombia[98]). In HICs, people with lived experience have protested against the "co-opt[ion]" of recovery by professionals as a neoliberal tool of "discipline and control" which burdens individuals in vulnerable situations with responsibility for their own recovery and shames those who are "unrecovered" (RITB 2016, n.p.).[99, 100] In contrast, peer workers in Uganda appear to have embraced the concept of recovery and made it their own.

The Brain Gain II project began with a series of “listening events” with people with lived experience (including peer workers) and people with professional experience, facilitated by the Sharing Stories Venture. [101] During these events, participants were asked to define recovery and what helps or hinders it in the Ugandan context. Facilitators noted several commonalities with recovery concepts emphasised in HICs, such as “hope, empowerment and having meaning in life”, as well as “striking differences”, most notably the importance of personal finances as both a marker and facilitator of recovery in a low-resource setting (Parker 2015, n.p.). Recovery themes from these listening events were later incorporated into the training syllabus of the Brain Gain II Recovery College (discussed further below).

2.3.1. Recovery-oriented interventions

While recovery remains a contested concept,[99] the WHO encourages all member states to adopt recovery-oriented approaches[102] and highlights a number of recovery-oriented interventions in its *Guidance on Community Mental Health Services*.[103] According a review of HIC literature, recovery-oriented interventions can be organised into four categories: (1) psychoeducational interventions focused explicitly on recovery (e.g., Recovery Colleges); (2) peer support and peer-led programmes; (3) social inclusion interventions (e.g., supported employment); and (4) recovery-oriented training directed at professionals and members of the public (e.g., Mental Health First Aid).[89] These interventions are expected to impact recovery by providing information and skills, promoting a working alliance between users and providers, role modelling recovery, and increasing choice, access and resources.[89] There is also evidence from HICs that recovery-oriented interventions can have an effect on mental health providers, improving recovery-related knowledge and attitudes.[104]

However, recovery-oriented interventions have not yet gained much traction in LMICs. A 2023 scoping review identified no examples of recovery-oriented mental health programmes in sub-Saharan Africa,[96] underscoring the unique contribution that our evaluation of Brain Gain II can make to the academic literature.[v] In order to put Brain Gain II’s recovery-oriented interventions into context, I briefly summarise the literature on peer support and Recovery Colleges below, focusing on evidence from LMICs where possible.

2.3.1.1. Peer support

Paper 3 offers a fairly broad definition of peer support as “social emotional support that is mutually offered or provided by […] people with lived experience” (Ryan, et al. 2019), explaining the distinction between formal and informal peer support in slightly more detail. This distinction matters, because the latter has been a feature of many LMIC mental health programmes for several decades (as described further below). However, the Brain Gain II project was among the first to employ formal peer support in any LMIC setting, and the first in sub-Saharan Africa.[105]

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[v] I do question the findings of this review, as I am aware of relevant publications from Brain Gain I and II that were not included, but nevertheless agree that there are not yet many examples of recovery-oriented interventions in this region.

Efforts to employ people with lived experience in mental health care settings date back at least as far as the French Revolution.[106, 107] A colleague of Philippe Pinel's, Jean-Baptiste Pussin promoted the benefits of work, both from a therapeutic perspective and as a pragmatic response to their economic vulnerability.[106] Patients who could not rely on family support often starved to death as a result of food shortages in hospitals.[106] Pussin therefore adopted a policy of hiring patients as servants and noted their aptitude as psychiatric nurses.[106] Shalaby and Agyapong (2020) suggest this may be the first instance of formal peer employment on record.[107] However, it was not until the tail end of the 20th century that peer support services began to gain traction in community mental health, mainly in high-income countries.[107]

Self-help groups are the cornerstone of several models of care developed for use in LMICs in the late 1990s and early 2000s. For example, the BasicNeeds Model for Mental Health and Development relies on self-help groups as a means of providing informal peer support alongside material benefits, such as access to credit.[108, 109] Similarly, community-based rehabilitation (CBR) programmes frequently use self-help groups to support livelihoods and social reintegration of people with psychosocial disabilities, in many LMICs.[33, 110-114] These have been tested in randomized controlled trials for people with schizophrenia in India (COPSI) and Ethiopia (RISE), with mixed results. For COPSI, improvements in primary outcomes (disability and symptom severity) were statistically significant at rural study sites in Tamil Nadu, but not at sites in Goa and Satara, where there is better access to specialist care.[114] The RISE trial concluded that CBR was effective in improving disability outcomes, but only seven of the 24 included subdistricts managed to organize family support groups (self-help groups for people with schizophrenia and their family members).[115] More research is needed to understand the role that informal peer support plays in improving outcomes as part of complex mental health interventions in low-resource settings, and what barriers people with lived experience may face in accessing and benefitting from self-help groups and similar activities.

The introduction of formal peer support for severe mental health conditions in LMICs is a more recent development. Uganda claims to be the first LMIC to train people with severe mental health conditions as peer support workers, as part of the 2011 Brain Gain I project that preceded my PhD research.[28] Other early examples include: the QualityRights Gujarat Initiative in India, which developed a new cadre of public hospital-based peer support volunteeers;[116] Users and Survivors of Psychiatry (USP) Kenya's user-led peer support programme in Nairobi, which has a strong focus on legal rights;[117] and RedeAmerica's multinational Critical Time intervention, which includes a peer support component for people with severe mental health conditions, in high- (Chile, Argentina) and middle-income (Brazil) Latin American countries.[118] However, the effectiveness of these interventions in improving peer outcomes has not yet been established. At least one multisite randomized controlled trial of formal peer support for people with severe mental health conditions (UPSIDES) has recently been conducted in a range of low- middle- and non-Anglophone high-income countries (Germany, India, Israel, Tanzania, Uganda), though results have not yet been published.[119] Yet even without gold-standard evidence of effectiveness, peer support is already considered by the WHO to be a best practice for the promotion of person-centred and rights-based approaches in community mental health services.[103]

2.3.1.2. Recovery Colleges

Recovery Colleges originated in the United States in the 1990s and rapidly spread internationally, with the first British Recovery College opening its doors in 2009.[120, 121] 221 Recovery Colleges are now in operation across 28 countries, though LMICs are under-represented, and Uganda remains the only country in sub-Saharan Africa with a Recovery College.[122] As discussed in Papers 3-4, Recovery Colleges use educational approaches as opposed to traditional treatment approaches.[121, 123] People with personal and professional experience co-produce the curriculum and co-deliver Recovery College sessions. While Recovery Colleges are not accredited institutions, they do provide a platform for learning and skills development, as well as a supportive community where people with lived experience and people with professional experience can interact with one another on equal footing. However, there is some variation in how Recovery Colleges operate internationally; for example, the international RECOLLECT consortium found that Recovery Colleges in Asia were rated lower in terms of their commitment to co-production and tailoring to individual students, when compared to those in England.[122]

Thériault, et al. (2020) identify a number of potential benefits of Recovery Colleges reported by empirical studies published in peer-reviewed journals: high student satisfaction; improved quality of life and well-being; increased knowledge, self-management skills and attainment of recovery goals; reduction in service use; and change in the attitudes, beliefs and practices of service providers.[124] Other reviews have identified similar benefits for students and service providers as reported in both grey and published literature.[125, 126] However, longitudinal and comparative studies of the effects of Recovery Colleges are lacking, and no results have been published from LMICs.[121, 124] A co-created scoping review also found surprisingly little involvement of people with lived experience in the evaluation of Recovery Colleges. Out of the 43 evaluations included in the review, 32 provided no indication at all of any sort of co-development or co-production of the evaluation.[127]

2.4. Setting

2.4.1. Uganda

Uganda is a low-income country in East Africa bordered by the Democratic Republic of the Congo, the Sudan, Kenya, Rwanda and Tanzania.[128] At the time of the last census, carried out in 2014 just before the start of the Brain Gain II project, Uganda had a population in excess of 34.6 million, with over half (55%) under the age of 18.[129] Over 20% were living in urban areas, including more than 4% in Kampala alone. According to 2019 estimates, 42% were living in poverty.[128] Its geographic proximity to recent and ongoing conflict has resulted in the fourth largest population of refugees in the world: as of 2019, Uganda was hosting over 1.7 million refugees and other migrants.[130] Uganda’s own history has also been marked by violence,[131] which Golooba-Mutebi (2008) attributes in part to a colonial legacy of “weak state apparatus, ethnic division, skewed development, elite polarisation and a narrow economic base” (pp.1), exploited by a series of authoritarian leaders including the current President Yoweri Museveni, who has been in power since 1986.[132]

2.4.1.1. Mental health

Given that poverty and other forms of social inequality, urbanization, a young population, high levels of migration and exposure to violence are all important factors affecting mental health,[133, 134] the relatively high prevalence of mental health conditions in Uganda is perhaps unsurprising. A recent systematic review calculated the pooled prevalence of mental disorders among adults in Uganda at approximately 24%, though this was based mainly on studies of anxiety, depression, and post-traumatic stress.[135, 136] Meanwhile, the global prevalence of common mental disorders is 17.6%.[137] Among inpatient populations, severe mental health conditions are more prevalent. In 2018, 63% of all new patients at Butabika National Psychiatric Referral Hospital were diagnosed with schizophrenia and related psychoses or a mood disorder (e.g., bipolar affective disorder) with psychotic symptoms.[35]

Mental health conditions are heavily stigmatised in Uganda, in part due to explanatory models that place responsibility on individuals and families.[138] Mental health conditions may be seen as punishment for sinful behaviour or the result of witchcraft, often a retributive curse. They may also be considered hereditary or contagious, contributing to social exclusion. However, cultural and religious beliefs are not the only factors at play. For example, Ssebunya, et al. (2009) have identified stigma as an important mediator of the mutually reinforcing relationship between poverty and poor mental health, causing a desperate downward spiral that can threaten even basic survival.[139] Stigma also extends into healthcare settings, with deleterious effects on quality of care.[138, 140] A survey of Ugandan medical students found that while more than three-quarters of respondents had a high level of knowledge about mental health, less than half had positive attitudes (49.29%) or perceptions (46.92%).[141]

Help-seeking behaviours reflect pluralistic approaches to mental health in Uganda, ranging from traditional and religious healing to allopathic medicine.[142] Traditional healing in this context typically involves herbal remedies, spiritual divination or a combination of the two.[143] Religious healers draw on their Christian or Islamic faith, offering “prayer, deliverance and counselling” (Teuton, et al. 2007, pp. 12510).[142] While healers will often refer patients for medical care,[143] medical providers rarely reciprocate, and traditional and religious healers may view one other with suspicion.[142] Consequently, families are often left to themselves to navigate the available treatment options. Nsereko, et al. (2011) suggest the pathway to care commonly starts with traditional healers before moving on to religious healers, ending with allopathic medicine as a last resort.[144] As described in Paper 4, human rights watchdogs have catalogued examples of abusive practices at Ugandan psychiatric hospitals as well as traditional and religious healers’ compounds.[145-147]

2.4.1.2. Mental health system

Uganda’s formal mental health system is severely under-resourced, particularly in rural areas. The most recent WHO-AIMS (Assessment Instrument for Mental Health Systems) report in 2006 estimated the ratio of human resources for mental health at 1.13 per 100,000 population, with the majority of the workforce comprised of nurses (0.78), only 4% of whom were specialised in mental health.[148, 149] Including supplemental funding from the African Development Bank, mental health spending was equivalent to 4% of Uganda’s overall health expenditure, but more than half (55%) was spent on just one psychiatric hospital:

Butabika (which we will turn to shortly). While mental health is included in the National Minimum Health Care package, meaning that mental health care should be made available at all levels of the health system, decentralisation is an ongoing challenge.[131] At the time of the WHO-AIMS report, 62.4% of psychiatric beds were located in or near Kampala, and only a small number of primary health care facilities had treatment protocols in place for any mental health conditions.[148, 149]

While organisations like Mental Health Uganda have been advocating for decades,[150] there has been little involvement of people with lived experience in mental health system strengthening activities such as policy development, implementation and research.[22, 151] Where involvement has occurred, it is often externally driven by funding organisations, not solicited by the Ministry of Health or other local stakeholders.[151] Mugisha, et al. (2019) identify a number of barriers to involvement at the individual, community and institutional level, respectively, though stigma and resource limitations (including poverty) appear to be cross-cutting themes.[151]

2.4.2. Butabika

Butabika, Uganda's main psychiatric hospital and the headquarters of Brain Gain II, is a disconcerting and inescapable presence in this research, impossible to convey through the brief, factual descriptions included in Papers 3-5. Butabika opened its doors in 1955, following a decades-long effort to move away from the prison-asylum system established under colonial rule and toward "what were framed as 'modern' and 'scientific' psychiatric services" (Kitafuna 2022, pp.830).[152] However, the word "Butabika" retains a more sinister connotation, akin to the English "bedlam".[153] Alma Ionescu (2023) has described its location sequestered on the outskirts of the city as a physical manifestation of the stigmatization of mental health.[154] This tension, with Butabika on the one hand poised as a regional leader in specialist mental health care, training and research, and on the other, a local bogeyman, is one of many incongruities.

Figure 1. Gates of Butabika Hospital. Photograph Courtesy of the Butabika-East London NHS Link, 2015.

Inside the hospital gates is a lush green campus containing a series of modest but tidy, mostly single-story buildings (Figure 1). The male, female and children's wards are each housed in separate buildings and adjoined by outdoor enclosures surrounded by chain-link fencing.[145] The male and female wards are further subdivided into admission, acute and "sick" wards. There is also a separate forensics ward, a drug and alcohol unit and a private wing. Staff and patients complain of poor conditions on the wards, with patients often sleeping two to a bed and subsisting on *posho* (maize porridge) and beans, with little privacy or personal space and limited attention from the heavily outnumbered staff. The hospital is patrolled by *askaris* (security guards) to keep order, sometimes by force. Toward the end of the Brain Gain II evaluation, when we were carrying out the qualitative data collection for Paper 5, a peer worker brought a court case to challenge the hospital's use of seclusion rooms, described rather harrowingly in a 2017 human rights report:[145]

> *They are concrete, single rooms, approximately two metres x four metres in size, containing concrete plinths that are the only place to lie down* […] *all the rooms had heavy metal doors without windows; the only ventilation and light came from small circular portals above the door. Dirty water, possibly urine, was visible on the floors* […] *Scratch marks were clearly visible on the walls and metal doors*. (MDAC 2017, pp.20-21)

Against this backdrop, where many peer workers had spent some of their worst days and were still receiving outpatient care, the Recovery College was set up in a small office and larger training room in a building occupied by the Community Recovery Team. Peer workers used the training room to hold yoga classes and beading groups and to co-deliver training sessions on recovery to inpatients, who would often linger to use one of the College's computers, check out books to read, or have a chat. In the Recovery College office, peer workers, volunteers and staff involved in Brain Gain II would meet to manage the project's M&E, finances, scheduling and other administrative tasks. The Recovery College was also down the hall from one of the hospital's canteens, another place where peer workers would mix with staff and volunteers. The effect generally was of a congenial, lively space, where visitors would constantly pop in with greetings— a contrast to the tedium, alienation and sometimes outright hostility reported on the wards.[145]

2.5. Researcher positionality

The irony (and extreme discomfort) of preparing this thesis as someone who does not identify as a person with lived experience by most definitions, and who is not from the country in question, is not lost. Disability activist Julie Gosling gives a sharp reminder that writing about lived experience involvement is never neutral: "One of the most upsetting outcomes is where involvement becomes an opportunity for theft or piracy by professional and academic treasure seekers—the colonizers who write clever books about our ideas and then promote themselves as 'experts' in involvement" (2010, pp. 35).[155] Although Gosling uses the term "colonizers" metaphorically, the image she paints is particularly discomfiting to someone working in Global Mental Health at a British institution with a long legacy of supporting—and benefitting from—the exploitation of colonized peoples.[156] Further, the requirements of a PhD demand that students position themselves as experts making unique and novel contributions to science. Collaboration is treated as suspect. My own Faculty requires an official "Statement of Conjoint Work" (Appendix 1) to be submitted in advance of examination entry, detailing the student's role on any co-authored research outputs that may be included in the thesis. All of this is antithetical to the spirit of research involvement, and it keeps me up at night. However, there is a second quote by Gosling that offers some comfort: "Positive results can and do spring from a variety of motivations and even when underlying principles and practice have less apparent integrity and are more control driven, involvement can and does make a difference" (2010, pp. 35).[155] I shall hope this is the case.

2.5.1. Personal and professional experience

In addition to my position as a doctoral student, there are several other aspects of my personal and professional experience that have bearing on this research and its theoretical orientation. I have previously been included in an international lived experience advisory group on the basis that I have experience of family-based interventions in the United States for a close family member with a severe mental health condition, though in reality, my role was more as an interlocutor supporting the group to communicate their position to experts by profession.[157] I have many formative memories of family visits to psychiatric wards, group homes and juvenile hall, but I am not a "carer", per se; nor do I have first-hand experience of actually being in the custody of these services. To claim a lived experience perspective feels to me like an insult to true experts by experience. However, I do believe that my personal background is pertinent to the insider-outsider[158] perspective that I bring to this research, and requires some disclosure. These experiences have contributed to my own fairly ambivalent attitude toward mental health services and my ardent desire for change—and specifically, for people with lived experience to drive this change. Writing this thesis has forced me to confront some of my preconceptions of lived experience involvement as a self-evident, unquestionable "good" and make space for consideration of unintended consequences.

I am also a white, cisgender, heterosexual American woman in a position of exceptional privilege, which has inevitably shaped my research. Over the course of my academic career, I have spent several years (four in total, if memory serves) in West and East Africa, either in the capacity of a student ethnographer (Ghana), an applied qualitative researcher (Rwanda) or as a M&E specialist (Nigeria, Uganda). In all of these roles, I have been affiliated with a highly regarded university (Harvard University, London School of Hygiene and Tropical Medicine, Kings College London) or non-governmental organization (Inshuti Mu Buzima/Partners In Health, CBM Global). As such, I have been granted access to people, places, information and resources and entrusted with highly specialized tasks that frankly would not have been offered to an early career researcher locally. Often, I have been treated as a potential benefactor or gatekeeper to other opportunities (e.g., research degrees, grants, publications), and this has most certainly coloured my interactions with both research collaborators and participants. To return once more to Gosling, involvement should be a "two-way street" (2010, pp. 38) that comes with personal responsibilities to those involved, but this may not be readily apparent or even permissible in heavily boundaried work environments.[155] This is another source of guilt which I imagine could influence my research, as positive results have material benefits and are among the few things that I feel I can give back to Brain Gain II.

2.5.2. Theoretical orientation

Although my undergraduate training was in social anthropology, this PhD follows more than a decade of study in a research group mainly preoccupied with the design, evaluation and "scale-up"[159, 160] of complex mental health interventions in LMICs. This is an awkward fit with my subject matter, as the history of research involvement in HICs is closely intertwined with the rise of anti-psychiatry and "Mad Studies",[6, 10, 161] which tend toward a post-structuralist perspective, viewing mental health as a social construct and psychiatry as social control.[162] While the field of Global Mental Health also has roots in cross-cultural psychiatry and medical anthropology,[163] those who come from a strongly relativist position have complained of being "othered" within the Centre for Global Mental Health.[164]

The reader may sense this conflict in my research. In Paper 2, I seek to challenge the dominant narrative surrounding the epidemiological and economic "burden" of mental health conditions in sub-Saharan Africa by essentially fighting fire with fire (or positivism with data, as it were). Instead of furthering a values-based argument that we should reject the conclusions of supposedly "evidence-based" exercises in global priority-setting, I mainly pick holes in the evidence. But I do not simply speculate, "These assumptions might be wrong, these models could be improved with more data." Rather, my co-authors and I suggest that the "failure"[165] of supposedly global exercises is symptomatic of a much bigger problem; that is, epistemic oppression.[166, 167] We argue that righting wrong conclusions requires, as a starting point, more inclusive processes of knowledge production. Ultimately, Paper 2 helped to clarify my ontological and epistemological stance toward this research: a critical-realist view that there is a measurable, intransitive reality, but that this reality is ultimately unknowable in isolation from the transitive reality that we construct.[162, 168, 169] Whose subjectivity is granted license to shape the realities produced through empirical research is of profound importance. Ultimately, this is what's at stake in efforts to promote research involvement.

However, it is worth noting Pilgrim's (2014) claim that critical realism "is not reconcilable with psychiatric positivism", particularly in relation to psychiatric diagnoses.[162] I do not entirely eschew psychiatric categories such as "psychoses" (paper 2), and in fact include diagnosis as a potentially important confounder in my analytic model for the quasi-experimental study (paper 3). Unfortunately, there is no escape from these categories in the mental health research literature, and proposing a viable alternative would make for a sizeable PhD thesis in its own right.

3. Project rationale, aims and objectives

Growing recognition that psychosocial disability is not a direct consequence of mental health conditions, but rather the product of psychosocial impairment and a disabling environment,[170] has led to calls for more holistic approaches to mental health that go beyond biomedical treatment to tackle social inequalities, promote inclusion and empower people with lived experience.[8] Consequently, mental health services are increasingly being encouraged to embrace the spirit of "nothing about us without us"[9] in all their functions, including service design, delivery and evaluation.[102] Yet in most LMICs, involvement of people with lived experience of mental health conditions rarely extends beyond consultation, if it happens at all.[22, 47]

The field of global mental health has also come under criticism for the relative lack of involvement of people with lived experience in research.[171-173] A 2016 systematic review of user and carer involvement in mental health systems strengthening identified only one previous example of involvement in evaluation research.[47] This example came from Brazil, an upper-middle-income country with a long history of participatory action research,[174] and mainly involved families at a very late stage of research when all of the data had already been collected.[74, 75] The same review concluded that there was little evidence from LMICs on how best to involve people with lived experience in mental health systems strengthening, noting the quality of existing studies is generally low, and few studies actually evaluate the process or outcomes of involvement. The authors called for the empowerment of people with lived experience to deliver mental health services and document best practice.[47]

The overall aim of this PhD thesis is to help generate evidence on the involvement of people with lived experience in research in LMICs, focusing on the evaluation of the Brain Gain II project in Uganda. This thesis includes a protocol for the first comparative study of a formal peer support intervention in sub-Saharan Africa that is also (to the best of my knowledge) the first to explicitly engage people with lived experience in data collection. It also includes results of the first African survey of recovery-related knowledge, attitudes and practices (KAP), which was designed through a participatory process with peer workers, and may offer a way forward for evaluators seeking to understand the impact of recovery-oriented interventions on staff in diverse settings. Qualitative research explores the perspectives of peer workers involved in data collection, considering both the benefits and potential risks of involvement in a low-resource setting. Specific objectives are listed below and summarised in Table 2, which provides an overview of the five main papers—three of which have been published separately in academic journals.

Objective 1

To understand the current state of the literature on involvement of people with lived experience in mental health service delivery and research in LMICs, by carrying out a rapid review updating a previous systematic review published in 2016 (Paper 1).

Objective 2

To explore the implications of exclusionary, top-down approaches to mental health research, drawing on a critical review of the literature on psychoses in sub-Saharan Africa to challenge problematic assumptions of global priority-setting exercises (Paper 2).

Objective 3

To involve people with lived experience in the design and conduct of a quasi-experimental study evaluating the impact on service users of a formal peer support programme engaging people with lived experience of MNS conditions in mental health service delivery in Uganda (Paper 3).

Objective 4

To involve people with lived experience in designing and interpreting the results of a cross-sectional survey exploring the impact of Brain Gain II interventions (the peer support programme and Recovery College) on staff knowledge, attitudes and practices (Paper 4).

Objective 5

To explore the perspectives of people with lived experience on their involvement in data collection for the Brain Gain II evaluation (Paper 5).

Table 2. Summary of key papers and methods, organised by research objective

Objectives	**Methods**	**Paper**
(1) To understand the **current state of the literature on involvement of people with lived experience** in mental health service delivery and research in LMICs.	Rapid review updating a previous systematic review, published in 2016.[21]	Paper 1: “Service user involvement in global mental health: What have we learned from recent research in low- and middle-income countries?”
(2) To explore the **implications of exclusionary, top-down approaches to mental health research** in sub-Saharan Africa.	Critical review of the evidence on psychoses from sub-Saharan Africa used to inform global priority setting, published in 2023.[40]	Paper 2: “Reprioritising global mental health: Psychoses in sub-Saharan Africa”
(3) To **involve people with lived experience in the design and conduct of a quasi-experimental study** evaluating the impact on service users of Brain Gain II’s peer support component.	Participatory ToC-driven approach to designing a multi-method evaluation including a quasi-experimental study, published in 2019.[175]	Paper 3: “Peer support for frequent users of inpatient mental health care in Uganda: Protocol of a quasi-experimental study”
(4) To **involve people with lived experience in designing and interpreting**	Participatory workshops to design KAP survey tool for cross-sectional survey and	Paper 4: “Recovery-Oriented Interventions and the Knowledge, Attitudes

results of a cross-sectional survey exploring the impact of Brain Gain II interventions (peer support and Recovery College) on staff knowledge, attitudes and practices (KAP).	interpret initial results, unpublished manuscript.	and Practices of Psychiatric Hospital Staff in Kampala, Uganda: A Cross-Sectional Survey”
(5) To **explore the perspectives of people with lived experience involved** in data collection for the Brain Gain II evaluation.	Qualitative methods (focus groups and interviews) with peer workers, reflecting on experiences of involvement, unpublished manuscript.	Paper 5: “An opening of one’s heart”: Lived experience involvement in data collection for the evaluation of a mental health peer support project in Uganda

4. Overview of methods

Papers 3-5 detail the specific methods related to different components of this thesis, which are also briefly summarised according to objective in Table 2 above. However, it is important to situate these methods within the overall approach to evaluation of the Brain Gain II project in order to understand where they originated and how they fit together.

During initial stakeholder meetings before the launch of Brain Gain II, the Ministry of Health of Uganda requested that a research evaluation of these activities be carried out in order to assess whether recovery-oriented interventions might represent a valuable addition to the decentralized mental health services being rolled out nationally. This was the motivation for the Butabika-East London NHS Link to reach out to the Centre for Global Mental Health at London School of Hygiene and Tropical Medicine for technical support in designing and executing the Brain Gain II evaluation. Researchers at the Centre for Global Mental Health have pioneered the application of ToC to the Medical Research Council (MRC) Framework for Complex Interventions,[176] notably through the five-country PRIME (PRogramme for Improving Mental health carE) consortium,[177, 178] which included a site in Uganda.[131] PRIME had a robust stakeholder engagement component,[179] and it was a strategic decision for Brain Gain II to build on this by also adopting a ToC-driven approach that would be familiar to the Ministry of Health.

A ToC-driven approach typically starts with one or more stakeholder workshops in which participants are asked to first consider the impact they would like to see, then work backward to articulate the pathway by which it can be achieved.[176] Indicators are eventually assigned to each step on the pathway, creating a roadmap for the evaluation of process and outcomes. The Brain Gain II project team felt that a ToC workshop would offer an opportunity to engage peer workers and staff in co-producing the design of the evaluation. However, this presented several practical challenges, mainly in terms of managing a large group with different needs as well as different levels of education and experience (i.e., professional versus lived experience). Further, we faced an all too common problem of sequencing. There were no resources to carry out the ToC workshop as part of the Brain Gain II funding application; rather, the workshop was funded as an activity of the project. Therefore, the final ToC had to align with several pre-determined, non-negotiable deliverables to the funder. In light of these constraints, we adjusted the typical workshop format in four ways, which have been described previously at a conference on Global Mental Health.[180]

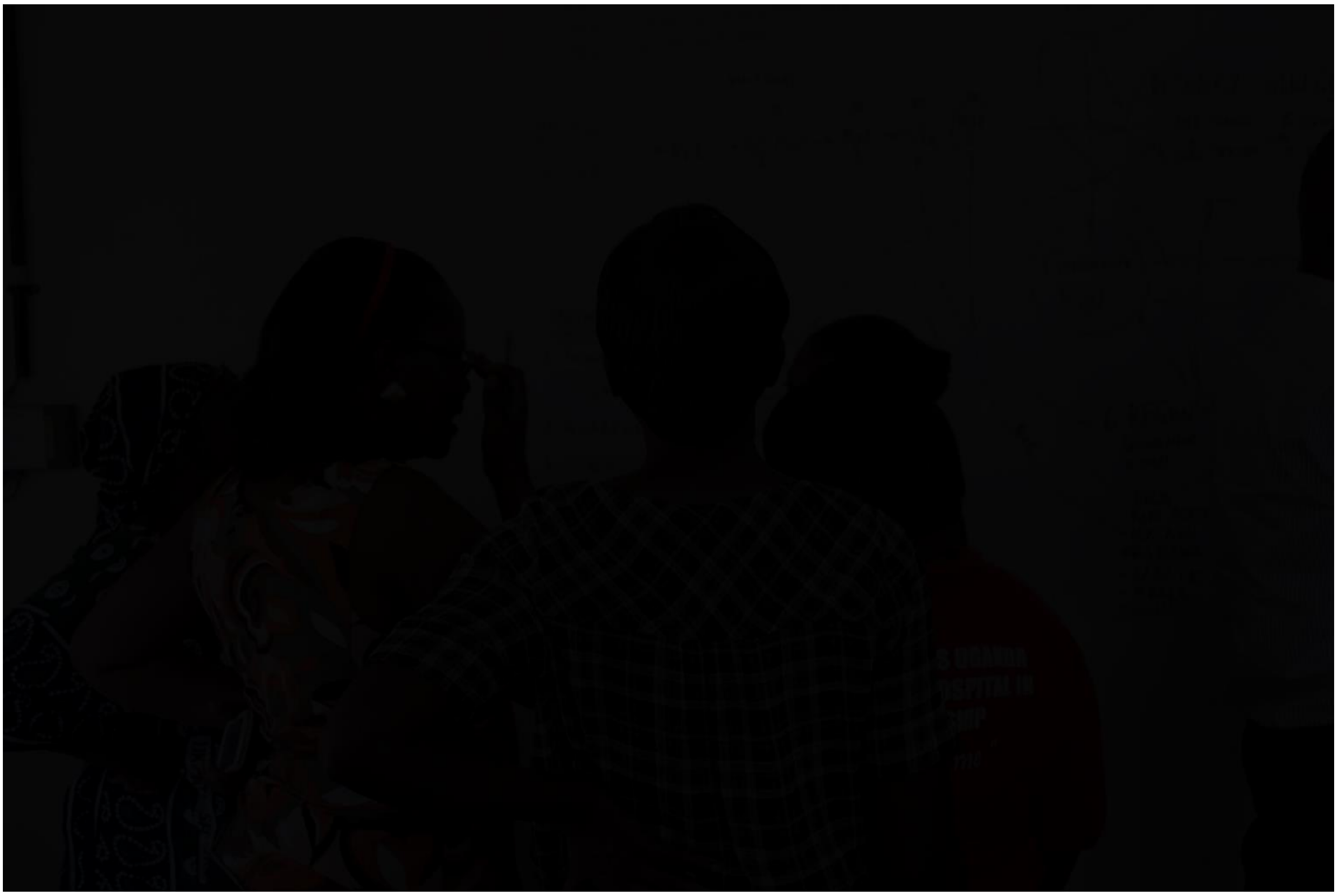

Figure 2. Butabika staff and peer workers review a diagram of the Brain Gain II project. Photograph courtesy of the Butabika-East London NHS Link, 2015.

First, we preceded the workshop with an interactive review of the application, including discussion of a large visual diagram of the project as it had been described to the funders (Figure 2). Second, a lived experience consultant from the UK suggested a visioning exercise, in which workshop participants were first asked to write down what they would like to see the project achieve on slips of paper. They were then paired, comparing what they had written with the other participant and coming up with a joint vision. This pair met with another pair, and the process continued until there were two broad visions to discuss as a group. The discussion that resulted helped to clarify the long-term impact for the ToC map and suggest some other important outcomes on the pathway (Figure 3). We found this exercise especially helpful in ensuring that all participants were able to contribute, and those who initially felt confused or had trouble coming up with ideas were able to seek support from their partners.

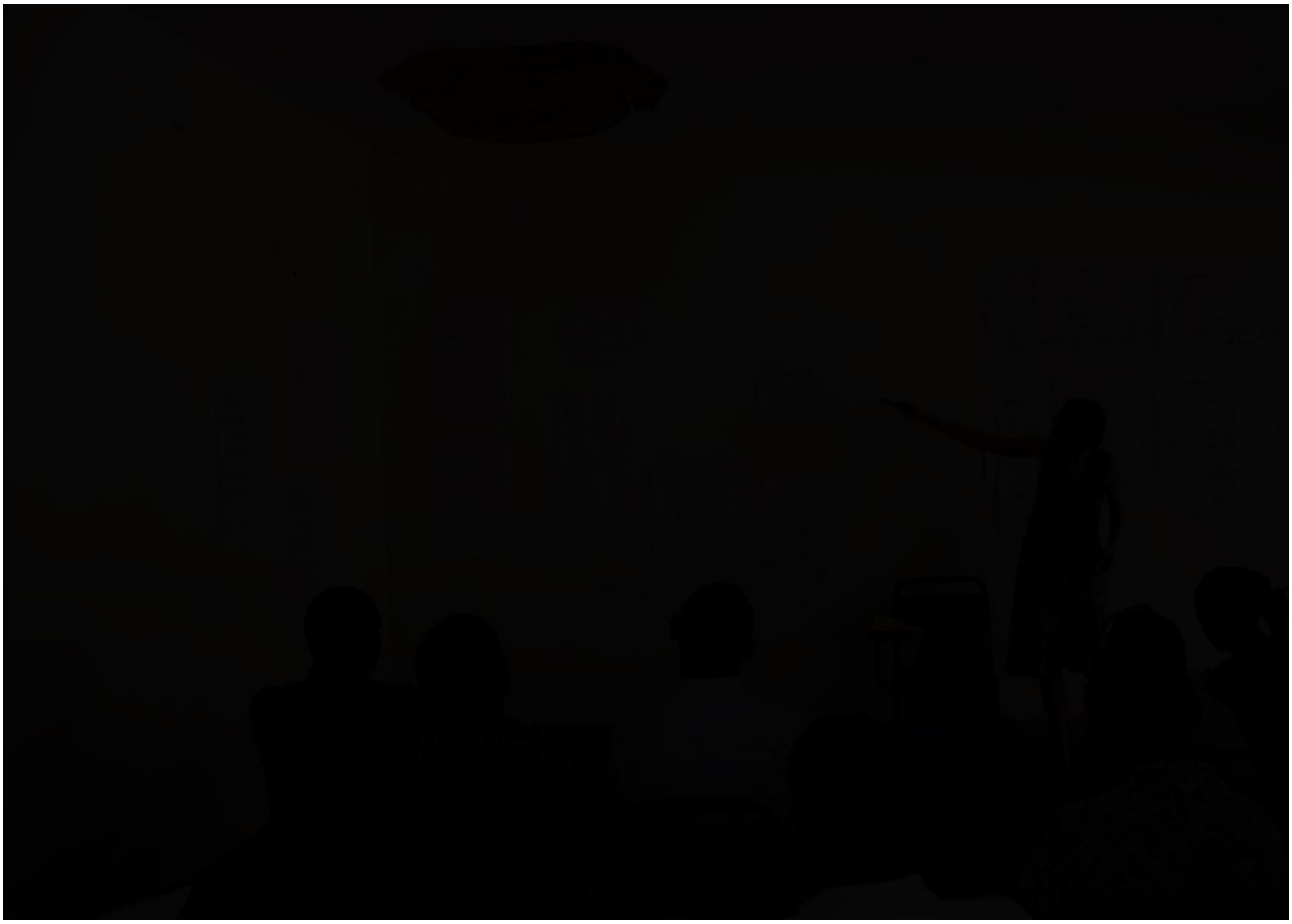

Figure 3. Reviewing long-term outcomes and impact. Photograph courtesy of the Butabika-East London NHS Link, 2015.

Third, we split the workshop over two days, allowing for reasonable start and end times and long breaks, including tea and lunch. This was especially important for the comfort of peer workers, many of whom struggle with fatigue, difficulty concentrating, and side effects causing hunger and thirst. The break also allowed me to consolidate notes from a very lively, fast-paced discussion with many participants (Figure 4) in order to produce a draft ToC map for review on the second day (Figure 5). Fourth, we recognised the need to document and appreciate participants' contributions, while ultimately producing a workable ToC that fit within the scope of activities agreed with the funder. So on the second day, we broke participants in small groups to scrutinise different sections of the map and decide which elements fit within Brain Gain II and which we might consider "parking" for future funding applications.

Figure 4. Notes from Theory of Change workshop. Photograph courtesy of the Butabika-East London NHS Link, 2015.

Figure 5. Reviewing a draft ToC map on second day of workshop. Photograph courtesy of the Butabika-East London NHS Link, 2015.

The initial M&E training that was carried out several months later offered an opportunity to review a revised, streamlined ToC map, including proposed indicators and methods for evaluation (Appendix 3.1). The result was a multi-method design incorporating several different elements: (1) a quasi-experimental study comparing readmissions among “revolving door” service users receiving peer support to those in catchment areas not covered by Brain Gain II (Paper 3); (2) a nested before-and-after study examining change in disability and other psychosocial outcomes among those receiving peer support; (3) a cross-sectional survey of hospital staff investigating the association between contact with Brian Gain II interventions and recovery-oriented KAP (Paper 4); and (4) qualitative research, including focus groups an semi-structured interviews, to explore the process by which Brain Gain II interventions achieved impact. Questions related to the collection of M&E and evaluation data were integrated into discussion guides for the qualitative component, allowing for further exploration of peer workers' experiences of research involvement in the evaluation (Paper 5).

4.1. Ethical approvals

The Brain Gain II evaluation protocol (including the KAP survey and the qualitative component for papers 4 and 5) was submitted for approval by two Ugandan hospital boards—Butabika National Referral Hospital and Mengo Hospital Research and Ethics (Ref 906/7)—the Uganda National Council of Science and Technology (Ref HS12ES) and the London School of Hygiene and Tropical Medicine Ethics Committee (Ref 10,705).

4.1.1. Permissions for photographs

The Butabika-East London NHS Link sought permission from workshop participants for photographs to be used in promotional materials related to Brain Gain II. However, given the sensitive nature of this topic, I have opted against including any images in which participants' faces are clearly recognisable and intend to redact photographs from the final version of this manuscript that will be made publicly available via London School of Hygiene and Tropical Medicine's online repository.

5. Role of candidate

I served as M&E Consultant on the Brain Gain II project from 2015-2017, taking a participatory ToC-driven approach to designing an evaluation focussed mainly on the peer support component of the project. Brain Gain II was a capacity-building project, with the expectation that I would help to upskill the local team as well as international volunteers and students in the process. Key responsibilities included:

- **Study design:**
    - Leading a two-day participatory ToC workshop at Butabika, designing and feeding back the resulting ToC map (Appendix 3.1);
    - Designing all research protocols, M&E tools and processes needed to capture data against key process and outcome indicators on the ToC map;
    - Carrying out sensitivity analysis in Stata to estimate necessary sample size for quasi-experimental study (Appendix 3.2);
    - Leading two participatory workshops and a review session for the development of a KAP survey tool (Appendix 4.2).
- **Capacity-building:**
    - Developing and delivering training to all staff involved in conducting the evaluation, including “M&E buddies”, the project M&E Officer, Psychiatric Clinical Officers and nurses;
    - Providing remote supervision to the project M&E Officer, with support from an on-site M&E Volunteer.
- **Data collection and management:**
    - Conducting English-language interviews and either co-facilitating or observing focus group discussions;
    - Proofreading and anonymizing transcripts from qualitative data collection, checking against the original audio files where possible;
    - Designing the Excel spreadsheets and quality checks for data entry by the project M&E Officer and Volunteer, and conducting some (limited) double data entry as needed;
    - Cleaning M&E and research data for analysis and preparing codebooks in Stata.
- **Data analysis:**
    - Coding and analysing all qualitative data (I initially planned to double-code with a member of the project team, though upon review of sensitive comments made in transcripts, I ultimately decided against this);

    - Developing initial working model (exposure, outcomes, confounders, etc.) for analysis of quasi-experimental study data and consulting experienced statisticians to advise on data analysis plan;
    - Re-running analysis of KAP survey data in Stata to address limitations of an analysis originally carried out by a MSc student as part of a summer project[181] on which I was supervisor (no do-files were shared and student is acknowledged as co-first author of the final manuscript) (Appendices 4.3-4.4).
- **Dissemination:**
    - Lead author responsible for writing protocol paper (paper 3), with critical feedback from co-authors;
    - Senior co-lead author responsible for rewriting KAP results paper (paper 4) in a journal article format, addressing limitations of the summer project described above,[181] with critical feedback from co-authors.

Outside of my role as M&E Consultant, I also led an update of a previous systematic review on the involvement of people with lived experience in mental health systems strengthening (including service delivery and research) in LMICs,[47] in my capacity as Implementation Work Package Co-Lead of the UPSIDES (Using Peer Support In Development Empowering mental health Services) research consortium.[182] This was in response to an invitation by the journal *Current Opinion in Psychiatry*, which requires a specific format reflecting on recent developments in research (within the past 18 months). For this rapid review (paper 1), I re-ran the searches from the original review, restricting results to the time period of interest (Appendix 2.1); carried out all screening, data extraction (Appendix 2.2) and synthesis; and wrote the manuscript with supervision from the lead author of the original review, and contributions to the discussion by two other co-authors.[21]

As Research Manager for SUCCEED Africa,[183] I also led the Technical Bid of our funding application and led an initial ToC workshop in which we discussed the evidence surrounding psychoses in sub-Saharan Africa and the contributions that lived experience involvement could make to strengthen this evidence base. In the workshop, participants highlighted and expanded upon several of the gaps in the evidence that I had noticed while preparing the Technical Bid, and decided that a critical review of the literature was needed. I led the literature review and preparation of the resulting manuscript (paper 2), with the exception of the “Implications and Recommendations” section, which was drafted by the co-first author (a clinical researcher) and second author (a peer researcher with lived experience). I then copy-edited the full document for consistency, with critical feedback from co-authors.

Further information is available in the “authors’ contributions” sections of two published manuscripts (this was not required by *Current Opinion in Psychiatry*) and in my Statement of Conjoint Work on file with the Faculty of Epidemiology and Population Health (Appendix 1).

6. Service user involvement in global mental health: what have we learned from recent research in low and middle-income countries? (Research Paper 1)

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SECTION A – Student Details

Student ID Number	lsh375171	**Title**	Ms
First Name(s)	Grace		
Surname/Family Name	Ryan		
Thesis Title	Involving People with Lived Experience in the Evaluation of a Mental Health Peer Support Project in Uganda		
Primary Supervisor	Karen Devries		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	Current Opinion in Psychiatry		
When was the work published?	July 2019		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	N/A		
Have you retained the copyright for the work?*	No	Was the work subject to academic peer review?	**No**

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Where is the work intended to be published?	
Please list the paper's authors in the intended authorship order:	
Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I replicated the search strategy of a systematic review previously published by the second author, restricting the results to an 18-month time period. I was solely responsible for screening, data extraction and synthesis. I drafted the full paper, with the exception of a paragraph on mental health advocacy and legislation in Uganda, then revised the full paper for submission.

SECTION E

Student Signature	
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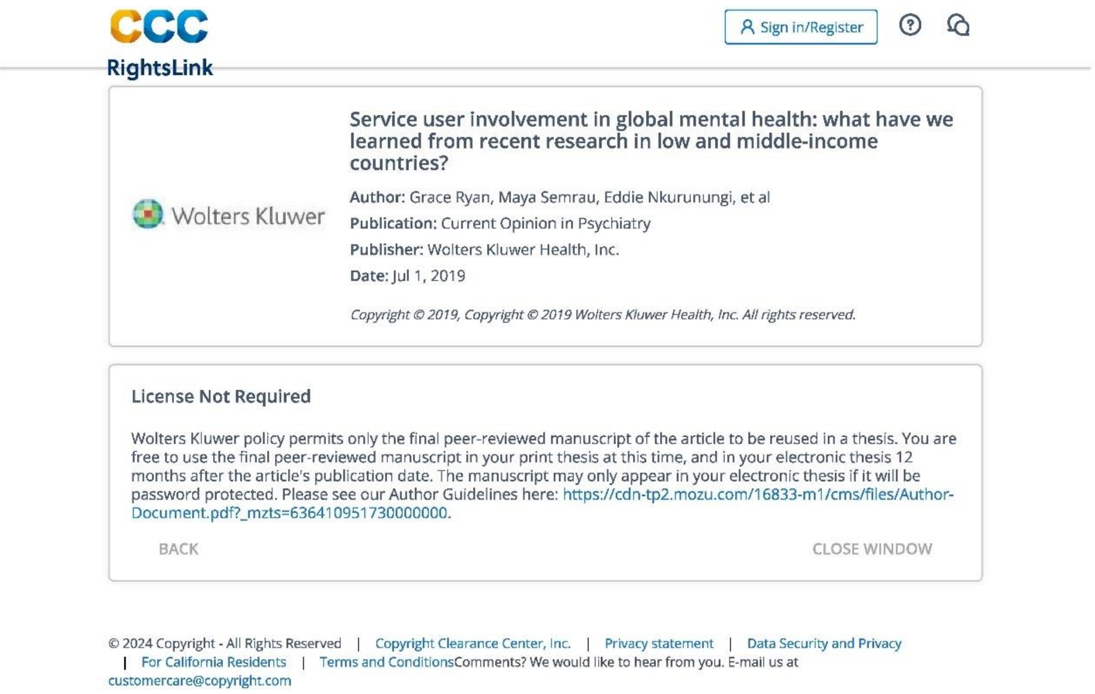
Supervisor Signature	
Date	



Service user involvement in global mental health: what have we learned from recent research in low and middle-income countries?

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Publisher: Wolters Kluwer Health, Inc.
Date: Jul 1, 2019

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Current Opinion in Psychiatry (2019)

Service user involvement in global mental health: What have we learned from recent research in low- and middle-income countries?

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Funder

No funding was received for work on this review.

Abstract

Purpose of Review

The *Lancet* Commission on global mental health and sustainable development claims the field of global mental health is undergoing a “transformational shift” toward an ethic of “nothing about us without us”. Yet a systematic review published in 2016 identified few examples of meaningful participation by service users in mental health systems strengthening in low- and middle-income countries (LMICs). To investigate whether this is still the case, we conducted a rapid review of primary research published between June 2017 and December 2018.

Recent Findings

We identified 10 studies reporting on user involvement in LMICs, including three in mental health policy and planning, three in mental health services or capacity-building, and three in treatment decision-making. An additional study was identified as having involved users in data collection, although this was unclear from the original text. Included studies were mostly qualitative and conducted as part of a situation analysis, pilot study or other formative research. Few reported the results of efforts to improve involvement, suggesting this shift remains at an early stage.

Summary

While the number of studies published on user involvement is rapidly increasing, the potentially “transformational” effects of this shift in global mental health are not yet being felt by most users in LMICs.

Key Words

global mental health, user involvement, psychosocial disabilities, disability rights

Introduction

The 2018 *Lancet* Commission report on global mental health and sustainable development identifies four "transformational shifts" in the history of global mental health to-date. Commissioners describe the fourth shift, dubbed "nothing about us without us", as a "fundamental, rights-based component of the ethos of mental health-care provision and research" (pp.1557).[1] They cite as evidence of this shift a study on the involvement of service users[i] in mental health system strengthening in Nepal.[2]

Yet the field of global mental health has also come under scrutiny for a relative lack of involvement of people with lived experience of mental health conditions in low- and middle-income countries (LMICs), compared to efforts made in high-income countries—which are already deemed insufficient by many critics. Indeed, the United Kingdom's Global Ministerial Mental Health Summit, where the *Lancet* Commission was officially launched in October 2018, drew criticism for failing to meaningfully engage a wide enough range of user representatives, particularly at early stages of planning:

> *While a few networks were approached to provide 'experts by experiences' to attend panels on themes already decided on, there has been no meaningful consultation or involvement of user-led and disabled people's organisations not already signed up to the 'Movement for Global Mental Health' agenda or funding to enable a wide range of representatives to attend* (National Survivor User Network [NSUN], 2018, "Global Ministerial Mental Health Summit-Open Letters", para. 3).[3]

This apparent contradiction—between the "transformational shift" described by Commissioners[1] and the observations of advocates at the report's launch[3]—led us to question to what extent the principle of "nothing about us without us" is reflected in the literature on mental health in LMICs.

A systematic review published in 2016 as part of the Emerald (Emerging mental health systems in LMICs) programme identified twenty papers reporting on experiences of involving service users and caregivers in mental health systems strengthening in LMICs.[4] None of the papers was more than ten years old at the time, suggesting that user and caregiver involvement in global mental health is an area of recent and growing interest. However, most papers reported on the involvement of service users and caregivers as research subjects participating in the evaluation of services, not as direct participants in policy or service development, delivery of services or training of service providers, or the actual conduct of research.

To investigate whether this is still the case, we conducted a rapid review of the academic literature published between June 2017 and December 2018, applying search terms from Emerald's 2016 review[4] across eight electronic databases: Medline, Embase, PsycINFO, Web of Science, LILACS, SciELO, Global Health and the Cochrane Database of Systematic Reviews [see Web Appendix 1 for search terms]. We included primary research conducted in LMICs using any kind of study design, so long as it reported on the involvement of people with mental, neurological or substance use conditions in mental health policy, services or research [Figure 1]. We excluded editorials, systematic reviews and other secondary research. As this was a rapid review conducted by researchers in English-speaking countries, we were unable to consider non-English texts. Titles, abstracts and full-texts were reviewed be a single screener, who was also responsible for data extraction [See Web Appendix 2 for data extraction table].

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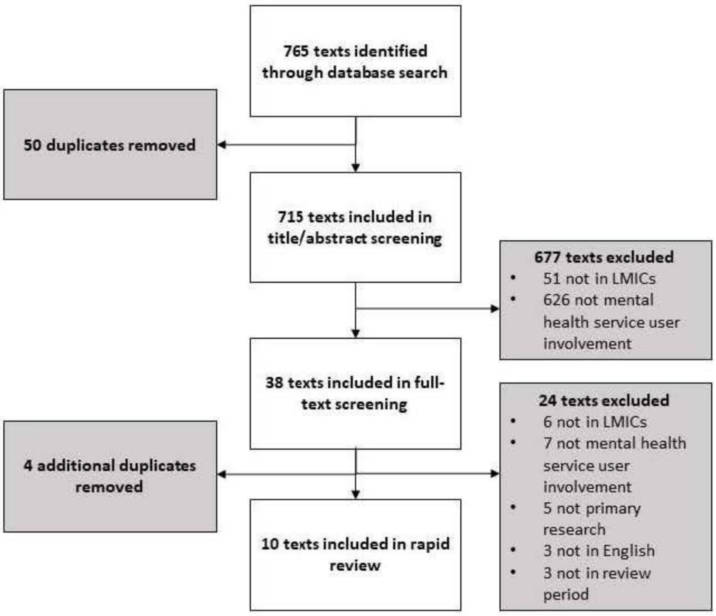
[i] Although we are aware of the many critiques of the term "service user", we have chosen to employ it for the purposes of this review, as it was the term most commonly used in the texts under discussion.

Figure 1: Flow Chart for Rapid Review



Our rapid review returned 10 studies from nine countries across Asia (China,[5] India,[6-8] Malaysia,[9] Nepal[6,10,11]), Africa (Ethiopia,[6,11-13] Nigeria,[6,11] South Africa,[6] Uganda[6]) and Europe (Lithuania[14]). The majority of included studies were qualitative and conducted as part of a situation analysis, pilot study or other formative research. Three reported on user involvement in mental health policy and planning,[6,11,12] three on user involvement in mental health services or capacity-building of service providers,[5,7,10] and three on user involvement in treatment decisions.[9,13,14] Upon further consultation with the corresponding author, an additional study was identified as having involved users in data collection.[8]

Involvement in Mental Health Policy and Planning

The Emerald consortium conducted research in six LMICs (Ethiopia, India, Nepal, Nigeria, South Africa, Uganda) and has recently published country-specific[12] and cross-country[6,11] qualitative studies reporting on the state of user and caregiver involvement in mental health system strengthening. These studies generally report little to no involvement of users in national, regional or district-level mental health policy or planning. Petersen, Marais, Abdulmalik et al. (2017) indicate that user involvement may be more advanced in India but provide no further details: "With the exception of India, a lack of service user participation was identified across all six countries, with the general uncertainty on how to engage service users" (pp.704).[6] Lempp, Abayneh, Gurung et al. (2017) conclude that although many stakeholders in Ethiopia, Nepal and Nigeria recognise its importance, user involvement remains extremely limited and often appears tokenistic.[11] In Ethiopia specifically, Hanlon, Eshetu, Alemayehu et al. (2017) report that district health officials and heads of mental health facilities are more receptive to the idea of user involvement in less strategic activities, such as awareness-raising and service development, than in policy or planning.[12]

Involvement in Mental Health Services and Capacity-Building

In keeping with Hanlon, Eshetu, Alemayehu et al.'s (2017) observations,[12] our review identified more examples of user involvement in mental health services than in policy or planning. Two studies evaluate mental health programmes involving self-help groups (India)[7] and formal peer support (China).[5] Researchers are also piloting a training module on mental health stigma co-facilitated by service users and delivered to primary care workers (Nepal).[10]

Mathias, Mathias, Goicolea and Kermode (2017) present a case study of the Burans mental health project in India, which aims to improve community mental health competence through a variety of community-level interventions, including self-help groups for users and caregivers.[7] Participants report benefits of self-help groups, such as improved social inclusion, though outcomes are not assessed quantitatively. However, self-help groups are widely used in LMICs and their effectiveness has already been investigated in previous studies, including in India.[15-17]

Fan, Ma, Ma et al. (2018) describe a rather more innovative peer support programme in China, in which users are recruited as peer providers.[5] These peer providers lead group sessions with service users focused on developing key skills (daily life skills, social skills, fine motor skills), promoting emotional well-being (emotional support, self-image), and providing health education (mental health literacy, healthy lifestyle) as well as entertainment. Peer providers are recruited, trained and supervised by mental health care providers, and sessions are held in community-based health facilities such as rehabilitation centres and health centres. This is one of very few examples of formal peer support being delivered in a LMIC, and we believe Fan, Ma, Ma et al. (2018) represents the first evaluation of formal peer support in a LMIC to report any quantitative, user-level outcomes. However, there are many limitations to the study design that call into question its overall positive assessment of the programme. For example, outcomes are self-reported at a single time-point, with no comparison group, in response to a series of yes/no questions that leave little room for nuance in participants' responses. More rigorous evaluation is needed.

Rai, Gurung, Kaiser et al. (2018) appear to be setting the foundation for a robust, cluster-randomised controlled trial of a user co-facilitated training to be delivered alongside other mental health Gap Action Programme training modules in Nepal as part of the RESHAPE pilot study.[10] RESHAPE uses participatory research methods such as PhotoVoice, which helps participants shape a personal narrative through photography, to address stigmatising attitudes of care providers.[18] Much like Souraya, Hanlon and Asher (2018) in Ethiopia,[13] Rai, Gurung, Kaiser et al. (2018) focus on the roles of caregivers in facilitating users' involvement in RESHAPE. They conclude that caregiver involvement should be adopted as best practice in the conduct of any anti-stigma interventions involving users in this setting.

Involvement in Treatment Decisions

Three qualitative studies (Malaysia,[9] Ethiopia[13] and Lithuania[14]) report on user involvement in decision-making regarding their treatment. All three studies describe hierarchical relationships between service providers and users in which providers' expert opinions generally prevail. These studies recommend providing more accessible information on treatment options to improve user involvement in decision-making.

In Malaysia, Zaini, Bharathy, Sulaiman et al. (2018) report on formative research informing the development of a tool for shared decision-making in the treatment of major depression.[9] The authors suggest Malaysia may be in a process of transition "from a traditional 'paternalistic' model of clinical decision making into a current 'informed' decision making model" (pp.9)—a transition which can be better supported by creating standardised tools and procedures for clinicians to follow. However, they note that patients still value clinicians' experience and are less interested in evidence of efficacy from the scientific literature than in examples of cases seen by the clinician previously.

In Ethiopia, Souraya, Hanlon and Asher (2018) investigate the roles of users and caregivers in making treatment decisions in the context of a pilot community-based rehabilitation programme for schizophrenia.[13] They describe a prevailing culture of collectivist decision-making that results in caregivers often taking responsibility for treatment decisions. Users' roles in decision-making are limited and may also be mediated by social and economic factors, such as gender and poverty. The study concludes that community-based rehabilitation workers can promote user involvement, for example by providing information about treatment options, listening to users' needs and showing respect for their opinions—essentially mediating between users, caregivers and providers, while remaining sensitive to users' autonomy. However, the authors also observe that systems-level resource limitations affect the affordability and availability of different treatment options, and thereby constrain user decision-making.

This point is further illustrated by Sumskiene, Petruzyte and Klimaite's (2018) evaluation of Lithuania's mental health system.[14] In Lithuania, a scarcity of human resources for mental health has translated into a predominantly biomedical approach to care. Psychotherapy is rarely available and therefore not presented as a treatment option. Those who can afford it may turn to the private sector for psychotherapy. Those who cannot must make do with medication alone. The authors posit that overreliance on medication contributes to the "passive position of the patient", due in part to the potentially debilitating effects of overmedication. They also suggest that psychotherapy requires the user to take a more active role in the treatment process. In this context, the limited number of treatment options available not only diminishes the user's opportunity to exercise choice, but also reinforces the user's "passive position".

Involvement in Research

None of the studies included in this review clearly reported involvement of service users in any capacity other than as research subjects. Three of eleven data collectors involved in a survey on psychosocial disabilities and barriers to participation in North India were identified as people with disabilities.[8] In personal correspondence, the lead author confirmed that some of these data collectors had psychosocial disabilities, although this was not apparent from the study text.

What does recent research tell us?

For many years, the field of global mental health has focused on narrowing the "treatment gap" in LMICs as one of its central concerns.[1] While studies from Ethiopia, Nepal and Nigeria mention improving access to affordable treatment as an important strategy to help lift barriers to involvement,[11-13] the case of Lithuania reminds us that the kind of treatment matters.[14] Overmedication and potentially debilitating side effects of some psychotropic drugs can impede meaningful participation.

Providing a wider variety of treatment options, including non-pharmaceutical options, and more information about these options— for example by using a shared decision-making tool, as in Malaysia,[9] or engaging community-based rehabilitation workers in treatment planning, as in

Ethiopia[13]—may be steps in the right direction. However, these interventions are still at the early stages of development and piloting; their effectiveness in improving involvement in decision-making has not yet been demonstrated.

Psychosocial interventions like self-help groups in India[7] and peer support in China[5] can help empower users to take charge of their own recovery while supporting others. These interventions can also become conduits into higher-level advocacy and involvement in policy and planning. Several of the authors of this review (EN, GR, RM) have witnessed peer support workers and Recovery College trainers in Uganda go on to successfully challenge discriminatory legislation and advocate for more humane and dignified treatment of service users. For example, laws that previously referred to users in Uganda as "idiots, imbeciles and lunatics" have adopted the term "people with psychosocial disabilities" in line with the United Nations Convention on the Rights of Persons with Disabilities.[19-21]

However, Rai, Gurung, Kaiser et al. (2018) and Souraya, Hanlon and Asher (2018) recognise that users' power to effect change can also be curbed by unsupportive caregivers and healthcare providers.[10,13] In Nepal, the RESHAPE trial will test whether user involvement in training could be an answer to widespread stigmatization by providers, while making a concerted effort to engage caregivers in the process.

Finally, while there is evidence that cultural factors—such as gender roles and collectivist approaches to decision-making—can weigh on user involvement, most of the studies included in this review highlight the importance of resource limitations as crucial barriers to meaningful participation. What does shared decision-making really mean in a community where there are virtually no affordable treatment options available? What can a user advocacy group be expected to achieve in terms of policy change, if its members cannot afford the time or transport costs to attend a meeting? In low-income countries especially, where the median mental health expenditure is just $0.02 USD per person per annum,[22] new funding is needed to tackle these sorts of barriers, or we will not see change.[11]

Conclusion

Over the past 18 months, researchers have asked challenging questions about the current state of user involvement in LMICs. In some cases, they are already developing and testing new strategies to improve user involvement in LMICs in future.[5,7,9,10,13] Yet few results have been published, and none of this research appears to be user-led. Only rarely does it actively engage users in any research capacity other than as research subjects. The one exception we note is in India, where a very small number of data collectors with disabilities may have had psychosocial disabilities, though this could not be verified from the text.[8]

Our aim in this review was to investigate whether the purported "transformative shift" in global mental health toward an ethic of "nothing about us without us" represents rhetoric or reality,[1] by drawing on the recent literature. We conclude that this field is at the early stages of such a shift, as evidenced by the rapidly increasing number of studies being published on user involvement in LMICs. However, the potentially transformative effects of this shift are not yet being felt by most users in LMICs. If the field of global mental health is going to make the principle of "nothing about us without us" a fundamental component of its ethos, then this principle must be extended to calls to governments and other funders to increase the resources available for mental health in LMICs.

Key points

- Although the number of studies published on mental health service user involvement in LMICs appears to be growing, much of this is formative research.
- Few recent studies report results of efforts to improve mental health service user involvement in LMICs.
- Mental health service users in LMICs are rarely involved in research in any capacity other than as research subjects.
- Resource limitations are important barriers to mental health service user involvement in LMICs which must be addressed.

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Conflicts of interest

EN, GR and RM are collaborators on the evaluation of the Brain Gain II peer support programme operated by the Butabika-East London Link and funded by the Tropical Health Education Trust. EN, GR and RM are also collaborators on the UPSIDES consortium funded by the European Union's Horizon 2020 research and innovation programme under grant agreement n° 779263. MS is supported by the NIHR Global Health Research Unit for Neglected Tropical Diseases at the Brighton and Sussex Medical School. MS served as Scientific Coordinator of the Emerald programme funded by the European Union's Seventh Framework Programme under grant agreement n° 305968.

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    *This study investigates community-based rehabilitation workers’ roles in improving involvement in decision-making as part of the RISE trial pilot in Ethiopia. Results suggest community-based rehabilitation workers can mediate between people with schizophrenia, their caregivers and healthcare providers, in order to improve involvement of people with schizophrenia in decision-making. It also highlights the important role of caregivers in making treatment decisions.
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7. Reprioritising global mental health: psychoses in sub-Saharan Africa (Research Paper 2)

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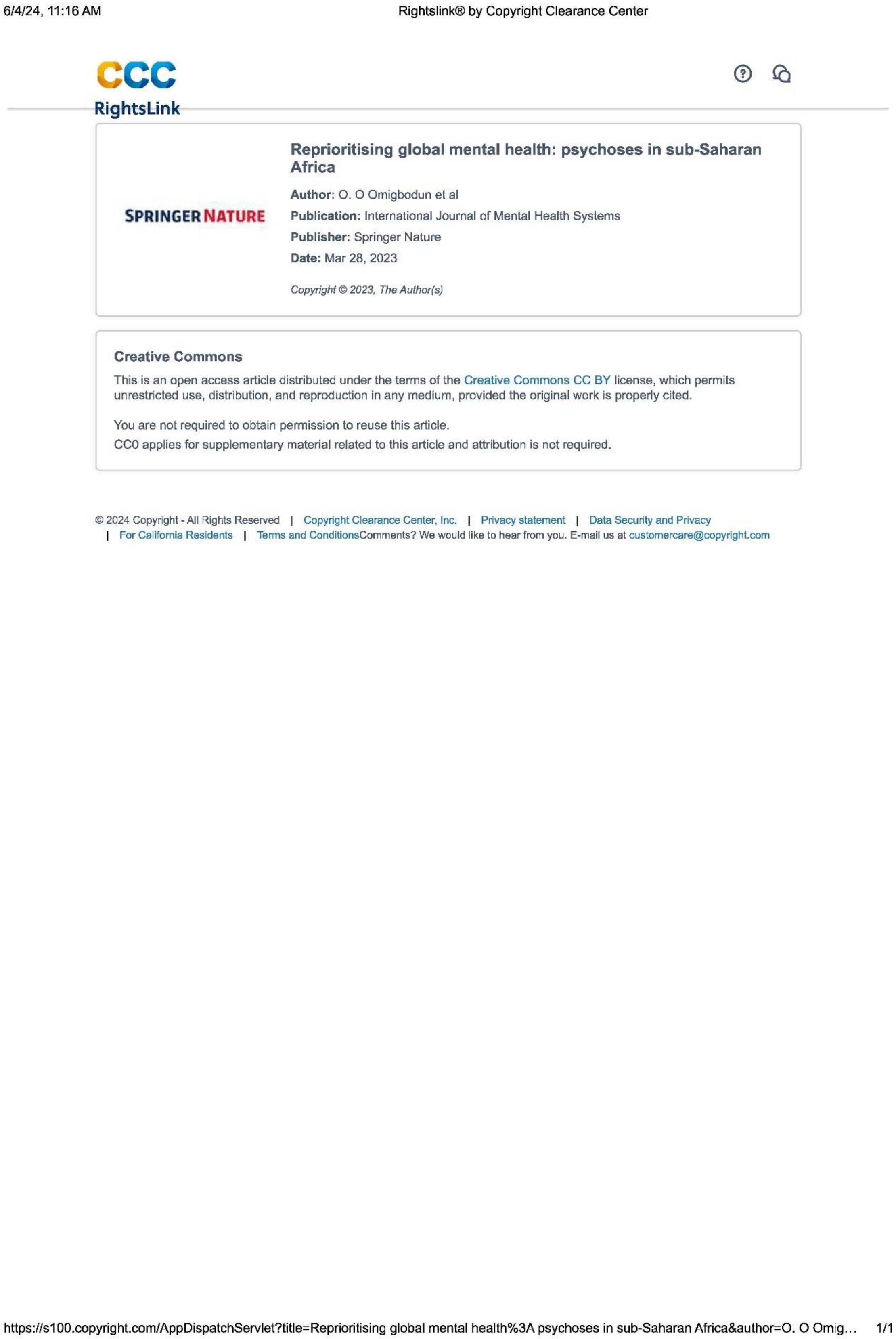

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Reprioritising global mental health: psychoses in sub-Saharan Africa

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Abstract

Arthur Kleinman's 2009 *Lancet* commentary described global mental health as a "moral failure of humanity", asserting that priorities should be based not on the epidemiological and utilitarian economic arguments that tend to favour common mental health conditions like mild to moderate depression and anxiety, but rather on the human rights of those in the most vulnerable situations and the suffering that they experience. Yet more than a decade later, people with severe mental health conditions like psychoses are still being left behind. Here, we add to Kleinman's appeal a critical review of the literature on psychoses in sub-Saharan Africa, highlighting contradictions between local evidence and global narratives surrounding the burden of disease, the outcomes of schizophrenia, and the economic costs of mental health conditions. We identify numerous instances where the lack of regionally representative data and other methodological shortcomings undermine the conclusions of international research carried out to inform decision-making. Our findings point to the need not only for more research on psychoses in sub-Saharan Africa, but also for more representation and leadership in the conduct of research and in international priority-setting more broadly—especially by people with lived experience from diverse backgrounds. This paper aims to encourage debate about how this chronically under-resourced field, as part of wider conversations in global mental health, can be reprioritised.

Keywords Sub-Saharan Africa, Psychosis, Global Mental Health, Human Rights

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Introduction

Box 1. Excerpt from "Global mental health: a failure of humanity"

Ground zero in global mental health is not the 15% [sic] of the global burden of disease accounted for by the cost of mental disorders… Globalised cultural changes have brought about important reductions in the discrimination, fear, and isolation surrounding depression and anxiety disorders in many countries…. [yet] conditions for people with psychosis, dementia, and mental disability remain horrendous most everywhere. (Kleinman 2009, p. 603)

In 2009 Arthur Kleinman [1] published a commentary criticising "the moral failure of humanity" that has allowed people with severe mental health conditions to live under some of the worst possible conditions in all countries of the world and throughout history (p. 604). Kleinman argued that "ground zero" in global mental health should not be the epidemiological or economic arguments that tend to favour common mental health conditions such as mild to moderate depression and anxiety [2], but instead urged for action to protect the basic rights of those in the most vulnerable situations.

More than a decade later, depression remains the most commonly studied mental health condition in global mental health and an "implicit priority" of the field (Misra et al. 2019, p.1) [3]. Depression appears in more than twice as many empirical studies on global mental health (29.7%) compared to psychoses (12.6%) [3]. High-profile efforts in global mental health in recent years have explicitly focused on depression; for example, the 2016 World Bank-World Health Organization (WHO) event "Out of the Shadows: Making Mental Health a Global Priority", as well as the Wellcome Trust's 2019 announcement of a £200 million Mental Health Priority Area (though this has since been expanded to include psychosis as well as depression and anxiety) [4–6]. The editors of *Lancet Psychiatry* (2020) have observed that even prior to the Coronavirus outbreak, "offering desperately needed help to those experiencing severe mental illness was too often secondary to the more prominent discourse around easily scaled and delivered talking therapies for common mental disorders" (pp. 463) [7].

We do not wish to criticise action on depression—a condition with which the authors have substantial personal and professional experience and agree is deserving of attention (not least of all because symptoms of depression and psychosis so frequently co-occur) [8]. However, it does appear that people with severe mental health conditions like schizophrenia and bipolar disorder are at risk of being left behind in global mental health and in international development more broadly [9–12]. Epidemiological and economic data should not be the sole basis for priority-setting, which must also take into account arguments around human rights and social justice [1]. But it certainly does not help the case for psychoses that those data are often based on controversial, outdated studies [13, 14] and blunt models [15] that may not reflect the present-day realities of mental health in sub-Saharan Africa [16].

Sara Cooper (2014) has argued that in our enthusiasm for promoting evidence-based medicine, following a hierarchy of evidence that privileges larger-scale and more resource-intensive quantitative methodologies over more localised and often qualitative study designs, we may be neglecting other approaches to thinking about mental healthcare in sub-Saharan Africa [17, 18]. In this paper, we attempt to highlight some of the contradictions between local evidence and global narratives that privilege common mental health conditions, pointing out the omissions and methodological weaknesses of large-scale research on the Global Burden of Disease, the epidemiology of schizophrenia, and the economic costs of mental health conditions. In the process, we draw on research and experience from sub-Saharan Africa to make the case for more attention to psychoses in this region. We focus mainly on severe mental health conditions like schizophrenia, schizoaffective disorder and similar primary psychotic disorders, as well as bipolar disorder, which is frequently accompanied by psychosis [19].

Methods

We carried out a narrative review of literature on psychosis in low and middle income countries (LMICs) as part of the initial scoping and development of a new Health Research Programme Consortium (RPC), SUCCEED Africa (Support, Comprehensive Care and Empowerment of People with Psychosocial Disabilities in sub-Saharan Africa) between 2018 and 2020 [20]. In the process, we identified several landmark studies whose conclusions appeared to contradict evidence and experience from the region, as observed by SUCCEED's local Principal Investigators and managers (for example during a 2019 RPC Theory of Change workshop) and other scholars of mental health in sub-Saharan Africa (e.g., Oye Gureje [16], Jonathan Burns [14]). This critical review is the result of subsequent efforts to investigate these contradictions and make recommendations for further research, by an international, multidisciplinary group of SUCCEED researchers with either professional or lived experience of psychosis in sub-Saharan Africa.

Key concepts, terminology and scope

The term "psychosis" is a phenomenological concept operationalised by various diagnostic classification systems to describe an individual's experience of symptoms (e.g., delusions, hallucinations, disorganised thinking) that characterise a number of "psychotic disorders" [21], but may also occur in individuals with other mental and neurological disorders (e.g., depressive and anxiety disorders, bipolar type I and II [19, 22, 23]), or even in the absence of any diagnosable mental disorder (e.g., as a result of sleep deprivation, certain physical health conditions like HIV/AIDS, malaria and typhoid, some medications like chloroquine and corticosteroids, alcohol and illicit drug use, etc. [24–26]). The plural "psychoses" is often used as a catch-all referring to some or all of these varied categories, further blurring the lines between different states of being, symptoms and diagnoses.

On the one hand, this ambiguity may allow for more inclusive discussions of psychosis in the mental health literature, acknowledging concerns around "labelling" with a particular (or indeed any) mental disorder as well as long-standing debates surrounding the validity and reliability of psychiatric diagnoses, both of which are magnified when taking a cross-cultural perspective [27, 28]. On the other hand, trying to represent profoundly diverse experiences under the heading of "psychosis" or "psychoses" may have a homogenizing and ultimately reductionist effect. Even our attempt to limit this review to specific diagnostic categories is undermined by ongoing concerns regarding the clinical and biological heterogeneity of conditions like schizophrenia and bipolar disorders, reified by recent findings in genomics and neuroimaging [29–33]. These issues are further compounded when attempting to speak about an entire class of disorders. For example, the International Classification of Disease's "schizophrenia and psychotic disorders" groups together conditions as diverse as "acute and transient psychotic disorder" (in which episodes typically last from as little as a few days to one month) and "continuous schizophrenia" (in which symptoms are present for a minimum of one year, with very little reprieve) [21]. Painting these conditions with the same brush obscures crucial differences in risk factors, treatment and care, outcomes and measurement [34], in the experiences, needs and priorities of those affected, and ultimately in the barriers they face in making their voices heard—with important implications for mental health research, advocacy, programming and policy.

Although cognisant of these limitations, we concentrated our review of "psychoses" in sub-Saharan Africa on primary psychotic disorders and bipolar disorder for pragmatic reasons. WHO groups together psychosis and bipolar disorder under the "psychoses" module of its mental health Gap Action Programme (mhGAP) Intervention Guide [35]. This ambiguity originally served a functional purpose, allowing for non-specialists to identify and treat psychotic symptoms following a common algorithm, without necessitating a formal diagnosis [36]. However, mhGAP also has a complicated "social life" that extends beyond its clinical application [18]. Increasingly, this group of psychoses is used to frame broader discourses in global mental health, sometimes under the heading of "severe mental disorders" (a category which also includes moderate to severe depression by WHO's definition [37], though in practice is often used interchangeably with "psychoses"). As outlined above, it is our aim in this paper to question the implicit prioritisation of common over severe mental health conditions by unpicking the evidence that is selected for "global" studies and further knowledge translation by international bodies like WHO; hence, we focus on the diagnoses that tend to feature most prominently in these.

On a related note, as members of a consortium that co-produces mental health research in sub-Saharan Africa, we wish to preface this critical review by expressing our discomfort with the overuse of deficit-based language in the mental health literature [38]. We generally feel obligated to replicate this terminology in order to accurately represent the research under discussion. Where possible without substantially altering the original meaning of the text, we adopt person-first language that emphasises individuals' lived experience (which may refer to past or present experience) and use the more general terms "mental health conditions" and "psychosocial disabilities", as opposed to "disorders" or similar. This is in keeping with guidance that two of the authors (GR, JE) have produced for international development organisations [9]. However, we recognise that these alternatives may not be accepted by all readers, or even by all members of our consortium (for example, several authors question the distinction of certain conditions as "severe" by WHO). Terminology remains an ongoing discussion within SUCCEED, which includes team members from different cultural traditions and professional backgrounds across five countries. We are still in the process of developing our own consensus-based style guide for research communications.

Results

Global burden of disease: can we trust the DALY?

The Global Burden of Disease (GBD) metric ("Disability-Adjusted Life Years", or "DALYs") combines disability ("Years Lived with Disability", or "YLDs") and mortality data ("Years of Life Lost", or "YLLs") to rank health conditions in terms of their "disease burden" at a population level [39]. The 1990 GBD study that attributed more than 10% of DALYs to psychiatric conditions [40] is often credited with catalysing the development of global mental health as a field [41–44]. In particular, the inclusion of unipolar depression among the top five greatest contributors to the global disease burden shocked the international development community and continues to feature heavily in advocacy and communications about global mental health.

Yet the use of GBD metrics to define priorities in global mental health is increasingly under criticism. First, advocates have argued on semantic grounds that the language of "burden" implies that people with mental health conditions are problems that need fixing [42]. Second, methodologists have questioned the data sources and modelling techniques employed to calculate the GBD. Since the 1990s, critics like Richard Cooper and colleagues have argued that in the absence of sufficient data from sub-Saharan Africa, the GBD numbers are "guesstimates… constrained largely by the need to avoid conflict with previous estimates" (1998, pp. 208) [45]. Of regional GBD estimates published in 1997, Cooper et al. complain that mortality data was based on vital registrations from South Africa alone, representing just 1.1% of the population of sub-Saharan Africa [45–47]. While advancements in health and demographic surveillance systems have helped to improve mortality estimates over the past two decades, they cannot substitute for adequate civil registration and vital statistics system [45–48]. As of 2003, only five countries in sub-Saharan Africa were able to report "useable" mortality data from their vital registrations to the WHO [48, 49].

The lack of regionally-representative data continues to call into question the validity of GBD results for mental health, specifically. Brhlikova, Pollock and Manners (2011) report that the national estimates used in 2000 to calculate the GBD for depression came from just 40 of 191 WHO member countries. While studies from 15 of 52 European countries (28.85%) were included in this dataset, there were only three studies from 46 African countries (6.52%), and each of these three covered a single village or town, as opposed to a nationally representative sample [50]. Examining the data sources for schizophrenia in the 2019 GBD study [51], there are five studies from three countries in sub-Saharan Africa: Botswana, Ethiopia and Zanzibar (United Republic of Tanzania) (Table 1). Four of these studies are more than twenty years old, two come from the same district in Ethiopia, and none uses a nationally representative sample.

Prevalence and incidence

Why does the lack of timely, regionally-representative epidemiological data matter for psychoses, specifically? There is a common misconception that rates of psychoses are fairly consistent between countries, perhaps obviating the need for further epidemiological research, but this is not the case. Global meta-analyses estimate < 1% lifetime prevalence of psychotic disorders, but reviewers repeatedly highlight the heterogeneity of this data [57–59]. Hairong He and colleagues' (2020) analysis of the changing GBD of schizophrenia from 1990–2017 found the greatest rise (> 130%) in both incident cases and DALYs was in sub-Saharan Africa (specifically, Central and Western Africa) and was only partially attributable to population growth [60]. However, they again caution that data from the least-developed countries tend to have the greatest data limitations.

Indeed, this is the central premise behind the research of the INTREPID consortium [61, 62]: without more research from LMICs, we cannot claim to know the most basic facts about the global epidemiology of psychoses, rendering the calculation of more sophisticated measures (such as the DALY) highly suspect. INTREPID has recently published results of epidemiological studies comparing rates of untreated psychotic disorders at study sites in Nigeria (Ibadan), India (Kancheepuram) and northern Trinidad [62]. Overall, age- and sex-standardised rates were approximately three times higher in northern Trinidad compared to the other two sites. However, participants from the Nigerian and Indian sites were more likely to meet diagnostic criteria for schizophrenia (51% Nigeria, 47% India, 39% Trinidad), while brief and affective psychoses were much more common

Table 1 Sources of data on schizophrenia as causes of death and illness in sub-Saharan Africa, Global Burden of Disease Study, 2019

Author (year)	Country	Sample
Awas et al. (1999) [52]	Ethiopia	501 community members from Butajira district (predominantly rural)
Fekadu et al. (2015) [53]	Ethiopia	359 people with schizophrenia from Butajira district (predominantly rural)
Kebede et al. (1999) [54]	Ethiopia	1,420 people with a suspected mental health condition from one administrative division of Addis Ababa (urban)
Bondestam et al. (1990) [55]	Zanzibar (United Republic of Tanzania)	10,766 community members from Unguja (mixed rural and urban) and Pemba (predominantly rural) islands
Ben-Tovim et al. (1986) [56]	Botswana	2,526 community members from six villages in the Chobe region (rural)

in northern Trinidad. The authors conclude that research on psychoses should not be generalised from high-income countries (HICs) to LMICs, though it's worth noting that there were statistically significant differences in rates of psychoses between the two LMIC sites as well.

Morbidity and mortality

While an examination of prevalence data helps to illustrate critiques regarding the representativeness of GBD estimates, further consideration of co-morbidities and mortality data highlights the limitations of the GBD studies' approach to modelling. According to evidence from mainly HICs, people with severe mental health conditions have 10–20 years shorter average lifespan compared to the general population [15, 63], and this gap may be worsening [64]. In Southern Ethiopia, people with schizophrenia or bipolar disorder die approximately 30 years younger than the general population, mainly from infectious diseases [53]. A recent analysis of World Health Survey data shows there is a statistically significant difference ($p < 0.0001$) in the prevalence of multi-morbidities (two or more physical health conditions) between people with diagnosed psychotic conditions (36.0%), subclinical psychosis (21.8%) and general population controls (11.4%) in LMICs specifically [65, 66]. Around the world, people with severe mental health conditions are more likely to experience physical health conditions, they often receive a lower standard of health care for these conditions, and they have more difficulty adhering to treatment, resulting in poorer health outcomes [63, 67]. Unsanitary conditions and abusive practices in institutions [68, 69], as well as polypharmacy [70, 71] and inadequate management of the sometimes dangerous side effects of anti-psychotic medications and mood stabilisers [37, 67], also present serious health risks. Meanwhile, people with severe mental health conditions are also at greater risk of suicide and are more likely to be victims of violence [63, 67, 72–74]. For example, among women with schizophrenia attending an outpatient clinic in Southern Nigeria, 75% had experienced intimate partner violence [66, 75]. Yet calculations of YLLs do not account for all of the 14.3% of deaths worldwide that may be attributable to mental health conditions [76].

Daniel Vigo and colleagues (2016) have shown that when the attribution of mortality to severe mental health conditions and other methodological limitations are addressed, the disease burden for mental health conditions (13.03% DALYs) is roughly on a par with that of cardiovascular and circulatory disease (13.5% DALYs), currently the number one contributor to total GBD [15]. The team responsible for the calculation of GBD estimates for mental and substance use disorders, Whiteford, Ferrari and Vos (2016), agree that the standard of attributing deaths solely to their direct cause is a limitation [77]. For example, they have stated that there is not yet sufficient data "to the standard required for inclusion in the GBD" (pp. 403) to identify what proportion of non-lethal self-harm to attribute to mental disorders [77]. In a separate analysis by Ferrari et al. (2014), schizophrenia had the third highest risk of suicide (pooled relative risk of 12.6%), exceeded only by major depression (19.9%) and cocaine dependence (16.9%) [78]. After accounting for suicide, schizophrenia moved up four places in the 2010 GBD rankings, from the 43rd biggest cause of disease burden to the 39th. However, the authors acknowledge that there were no data on the distribution of suicides attributable to mental and substance use disorders in sub-Saharan Africa, again limiting the generalizability of their results. This is undoubtedly due in no small part to the widespread stigmatization of suicide in the region, and particularly the criminalization of suicide in several countries [79].

The WHO schizophrenia studies: are outcomes really better in sub-Saharan Africa?

Over nearly three decades, the WHO carried out several large international studies of schizophrenia, starting with the International Pilot Study of Schizophrenia launched in 1967 [80], and later followed by the "Ten Country Study" [81] and the International Study of Schizophrenia [82, 83]. The legacy of the WHO schizophrenia studies continues to shape how we think about psychoses as a public health issue in LMICs. One enduring message is that outcomes for people with schizophrenia in LMICs seem to be better than in HICs, fuelling arguments that efforts to improve mental health care for psychoses in LMICs are at best futile, and at worst arrogant and imperialistic—perhaps even damaging. Yet the WHO studies have been critiqued on many fronts, and a 2012 meta-analysis found that after excluding these studies, the difference in clinical and social recovery outcomes in low- and lower-middle income countries, compared to upper-middle income countries and HICs, was no longer statistically significant ($p = 0.632$) [84]. One of the most glaring issues with the WHO studies—and with the more recent 36-country Worldwide Schizophrenia Outpatient Health Outcomes (W-SOHO) study that claims to support the WHO studies' findings [85] is lack of representation from sub-Saharan Africa. In the first two WHO studies, Ibadan, Nigeria was the only African site; in the last WHO study and the W-SOHO study, there were no African sites [14, 86]. As Jonathan Burns highlights, the rapidly changing social, political and economic landscapes in African countries and subsequent changes to risk and protective factors render these decades-old studies in Nigeria obsolete [14]. There were also other methodological shortcomings, mostly rooted in the heterogeneity of psychosis discussed above, which may have resulted in the over-representation of participants with acute conditions with better outcomes. In addition to inconsistencies between sites, including diagnostic differences and the potential for selection bias, these surveys did not account for attrition bias [13, 14]. Yet attrition can be high in studies of people with schizophrenia [13, 87], due to a wide range of factors: impairments related to the condition itself; social barriers, such as stigma; structural barriers, such as high rates of homelessness and incarceration; and poor physical health outcomes, including premature mortality [88].

In a 2008 review of the literature on schizophrenia outcomes in LMICs, Alex Cohen and colleagues argue that the picture is "far more complex" than the WHO studies might suggest (pp. 229) [13]. This review identified four African studies in addition to the WHO study in Ibadan. In Butajira, Ethiopia, 10.3% of a schizophrenia cohort with an 84.4% follow-up rate died over the 1–4 year follow-up period [89–91]. In Ilesa, Nigeria, 7.8% died in a study with an 81.0% follow-up rate over 2.1–3.2 years [92]. Though mortality rates were not reported, follow-up rates were similar for a thirteen-year retrospective study conducted in Abeokuta, Nigeria (85.7%) [93], as well as a prospective study with a two-year follow-up in Cape Town, South Africa (84.2%) [94]. Meanwhile, the Ibadan, Nigeria site included in the WHO studies had only a 69.0% follow-up rate over two years, and mortality was not reported [81]. As Cohen and colleagues argue, premature mortality is surely among the worst possible outcomes of schizophrenia, and it is unwise to draw any conclusions from studies with high and unexplained attrition rates. Further, their review highlights the dangers of generalizing the WHO study results not only across LMICs generally or sub-Saharan Africa specifically, but even within countries, as follow-up rates varied greatly between the WHO study in Ibadan and the two other studies with Nigerian samples.

Care for people with psychoses in sub-Saharan Africa

The controversial assumption that outcomes of psychoses might be better in LMICs than HICs is sometimes credited to the care available for people with psychoses in these countries—whether from the formal mental health system, traditional or religious healers, or families and communities. While recognising that each of these resources can play a crucial and often very supportive role, we would caution against overly romanticised views of the care currently available.

Medical care

Although not a panacea, clinical interventions do exist for the management of psychoses and can be delivered in LMIC settings [2]. However, access to treatment is often limited, as are treatment options [66]. In a given year, only 31% of people with schizophrenia in LMICs receive treatment; in low-income countries, it is just 11% [95]. As Laura Asher (2018) notes in a review of recent evidence on schizophrenia in LMICs, qualitative studies from Ethiopia [96] and Tanzania [97] reported erratic supply chains and difficulties paying for medication as substantial barriers to engagement with formal mental health care [66]. In the case of long-acting injectable antipsychotics, which many consider to be more convenient and discrete than oral medications [91, 98], there is speculation that commercial interests may be interfering with global supplies (see, for example, the US pharmaceutical company Lannett's 1,650% increase in the price of fluphenazine [99]).

A population-based study in rural Ethiopia found that more than 90% of those identified with schizophrenia or bipolar disorder had never received treatment [100]. Even after integrating mental health care into primary care in a nearby area, less than a third (29.8%) of people with psychoses who accessed these services received minimally adequate treatment, defined by the programme as at least one prescription at a "therapeutic level" plus four or more follow-up appointments [101]. Many African countries rely heavily on first-generation anti-psychotic medications with few alternatives available for those who experience distressing side effects, so even this definition of "minimally adequate treatment" (derived from previous studies in HICs [100]) is perhaps over-generous. Critics of the prevailing biomedical paradigm in mental health would also take issue with any implication that medication alone is adequate for people with psychoses.

Traditional healing

Local healing traditions (e.g., traditional or spiritual healing) are ubiquitous in many LMIC settings, and often the first port of call for help-seeking. Evidence from sub-Saharan Africa indicates that approximately half of people seeking mental health care first visit a traditional or spiritual healer [102]. However, even these alternatives can be inaccessible to many. For example, the Nigerian Survey of Mental Health and Well-being found only 8% of people with "seriously disabling disorders" had received any form of clinical treatment or alternative care over the past 12 months [103]. Further, it is important to note recent findings of a meta-analysis suggesting that the solutions offered by healers have less efficacy for psychoses than for common mental disorders [104]. Consequently, there is a tendency for people with psychoses to be subjected to more drastic and sometimes abusive practices, such as shackling and physical assault, over much longer periods of time [68]. In the Ilesa study described above, more than half of recorded deaths took place at traditional healers' compounds [13, 92]. Burns (2012) also cites his own previous studies from KwaZulu-Natal, in which those who attributed first-episode psychosis to supernatural causes or consulted a traditional healer before presenting to formal mental health services had more negative symptoms and spent longer without formal treatment [14, 105, 106]. On the other hand, recent studies of collaboration between healers and formal health care providers have shown promising results for people with psychoses in Ghana [107] and Nigeria [108].

Informal care from families and communities

In the absence of adequate services, including social welfare, much of the caring responsibility for people with psychoses falls on families and particularly on women and girls [66]. The purported difference in outcomes between LMICs and HICs is often attributed to greater social acceptance, the tolerance of the extended family, and the quality of human relationships, especially in rural areas [13]. Yet from her work in rural Ghana, anthropologist Ursula Read suggests that the picture is more varied [109]. Read shares examples of desperate families, fearful of extremes of behaviour such as violence and vagrancy, shackling people with severe mental health conditions in their family compounds. While she emphasises that families are typically pushed to shackling as a last resort in rural areas where few alternatives are available, she also observes instances where restraint can serve as a form of punishment. Family support has its limits, as noted by Cohen et al. (2008) in reference to a retrospective study of social outcomes of people with schizophrenia in Abeokuta, Nigeria: 4% of subjects were homeless or in unstable housing [13, 93]. The original authors Gureje and Bamidele (1999) were surprised by the finding, but concluded that prolonged illness could lead to breakdown of family support networks [93]. In Ethiopia, Senair Ghebrehiwet and colleagues (2020) have also identified important gender differences, with families offering less social support to women with schizophrenia, compared to men [110]. In a review of recent evidence on schizophrenia in LMICs, Asher (2018) highlights two small-scale but in-depth qualitative papers from South Africa that contest some key assumptions around the nature and availability of informal care for people with schizophrenia in LMICs: families did provide care, but sometimes felt obliged to do so; care was not always available due to caregiver employment, sickness or death; and caregivers found it very hard to support medication adherence, particularly given factors such as violence, substance use and difficulties ensuring food supplies [66, 111, 112].

We share these examples not to demonise families or devalue their important contributions to care, but rather to emphasise that their contributions should not be taken for granted. People with psychoses in sub-Saharan Africa deserve more and better options, as do their families.

The economic "burden": are we focusing on the right costs?

Compounding the limitations of the Global Burden of Disease studies with the many assumptions necessary for top-down economic modelling, in 2011 the World Economic Forum (WEF) calculated the economic "burden" of neuropsychiatric conditions based on the previous year's DALY estimates [113]. Neuropsychiatric conditions accounted for more money lost from the global economy than any other non-communicable diseases, including cardiovascular diseases: $16.3 US trillion between 2010 and 2030, with $7.3 US trillion coming from LMICs, mainly due to losses in economic productivity. These figures have featured prominently in communications for global mental health advocacy. While they are not disaggregated by condition, they are generally interpreted as making an economic argument mainly for common mental health conditions—as explained by Vikram Patel in his article on Universal Health Coverage for schizophrenia (2016, pp.885–6):

> *The best available interventions [for schizophrenia] are neither curative nor lifesaving, rendering them less attractive when compared with interventions such as antidepressants or antiretrovirals. It is therefore not surprising that of all the mental disorders, depression, which is associated with high burden and cost-effective interventions and for which the counter-factual case of the cost of inaction is compelling, has attracted most attention [2].*

What goes unsaid in Patel's article is how cynicism regarding the productive potential of people with psychoses may also contribute to a less "compelling" "counter-factual". Psychosis typically onsets in adolescence or early adulthood [114] and can evolve into a chronic, life-long condition. This means that precisely at the time when young people are preparing to enter the workforce or further their education, their professional development is interrupted [115]. One figure commonly cited in reports by UN agencies (though based on US research by the National Institute of Mental Health) is that the unemployment rate for people with severe mental health conditions is 70–90%, higher than virtually any other group of persons with disabilities [10, 116]. There is very little research on employment and mental health-related workplace discrimination in LMICs, though at least one cross-cultural study comparing the US and China claims that American employers may actually be less hesitant about hiring people with psychoses [117]. What this means for unemployment rates in sub-Saharan Africa, however, we should not speculate.

African economies are largely informal and heavily agricultural, which could feasibly offer more flexible opportunities for people with mental health conditions to contribute economically, for example by helping to cultivate a family farm. But these contributions are extremely difficult to measure and model, and are often left out of employment figures. Findings of a systematic review by Huey Yi Chong et al. (2016) suggest that in African studies (both from Nigeria [118, 119]), indirect costs such as losses to productivity by people with schizophrenia account for a much smaller percentage of the economic burden of schizophrenia than in HICs and in LMICs in other world regions (Table 2) [120]. More research is needed, from more countries, to understand whether these trends are artefacts of methodological differences or reflective of a very different economic reality for people with psychoses in sub-Saharan Africa.

Either way, we must be careful not to export discriminatory beliefs (and unrepresentative data) about the potential of people with lived experience of psychoses from HIC to LMIC economies. Indeed, Lisa Cosgrove and others have criticised the imposition of capitalist economic arguments altogether, expressing resentment over the “neoliberalization of mental health” that “promotes an ethics of utility rather than an ethics of care” and frames distress as “economically burdensome” (2019, n.p.) [43]. Even if we put aside these broader critiques, it is undeniable that the costs of providing inappropriate, ineffective or inadequate care for psychoses are substantial, not just to individuals, but also to health systems and families.

Table 2 Differences in the ranges of direct vs. indirect costs attributed to schizophrenia across major world regions and income levels, adapted from Chong et al. (2016)

Region	Income level	Cost contribution to total cost (percentage range)		
		Direct medical cost	Direct nonmedical cost	Indirect cost
Africa	LMICs	73[a]–85%	2%[a]	12–27%
Americas	HICs	19–35%	< 0.1–14%[b]	50–81%
Asia	LMICs	18–32%	0.1–10%	71–82%
	HICs	14–28%	< 0.1–1%	72–85%
Europe	HICs	24–87%	2–12%[b]	8–76%

[a] Amoo and Ogunlesi (2005) include some direct nonmedical costs in their calculation of direct medical costs, and do not report direct nonmedical costs separately

[b] Some studies’ direct nonmedical costs reported as “not applicable”

Costs to health system

Inpatient psychiatric care is the most expensive mental health service, and 80% of government mental health expenditure in LMICs is spent on psychiatric hospitals [121]. The WHO estimates that for schizophrenia the cost of hospital-based mental health care is 33–55% higher when compared to a community-based service model [2, 122, 123]. People with psychoses are among those most likely to be admitted for inpatient psychiatric care—often involuntarily [124] and to be readmitted after leaving inpatient care [125, 126]. For example, at Uganda’s only psychiatric referral hospital, nearly two-thirds (62.7%) of patients are diagnosed with a psychotic disorder at first contact [127]. In Nigeria, a diagnosis of schizophrenia is a predictor of psychiatric readmission [128], and the average cost of a single psychiatric hospital admission ($3675 USD) is equivalent to the cost of 90 outpatient visits [129, 130]. Action on the deinstitutionalization and decentralization of mental health care for people with psychoses could increase coverage, lower per capita costs, and help to address some of the most egregious human rights violations that occur in institutions [131].

Costs to families

In 43% of African countries—the largest percentage of any world region—families pay mostly or entirely out of pocket for mental health care [121]. Meanwhile, most caregivers for people with schizophrenia in sub-Saharan Africa are female and unemployed, despite many being of working age (mean age 46.3), and report that the severity and duration of the illness has a negative impact on their own employment and income [132]. A study from Ghana found that the average monthly cost of care for a person with a severe mental health condition was $160.00 USD per patient, in addition to indirect costs at $133.31 USD per month. Meanwhile, the average monthly income reported by households of people with mental health conditions was just $184.48 USD [133]. Another study carried out in Nigeria found that over half (55.8%) of families of people with schizophrenia or a major affective disorder reported that caring for their relative had a moderate to major financial impact on their households [134]. Consequently, nearly a quarter (23.2%) resorted to either selling property or taking loans. The extreme poverty faced by people with psychoses and their families can threaten their very survival. In a rural district of Ethiopia, people with schizophrenia or bipolar disorder are nearly three times more likely (odds ratio 2.8) to experience severe household food insecurity [66, 135]. Confronted with these harsh realities, it is difficult to understand why severe mental health conditions like psychoses do not feature more heavily in discussions on poverty reduction in sub-Saharan Africa.

Discussion

Key findings

To summarise, there are a number of reasons why psychoses in sub-Saharan Africa may have historically been deprioritised in global mental health, some of which are perhaps rooted in the constraints of international research carried out to inform "evidence-based" decision-making. We don't really know the true prevalence or incidence of psychoses in sub-Saharan Africa, their outcomes or their costs—and what little we know about morbidity and mortality is not necessarily taken into account when calculating the "burden" of psychoses in either epidemiological or economic terms.

In 2020, Nanna Weye and colleagues from Canada and Denmark published an editorial declaring, "These [Global Burden of Disease] methods have been good for mental health—*but not good enough*" (pp. 103, italics authors' own) [136]. The same is true of psychoses in sub-Saharan Africa. While the disability weights employed by the GBD studies do favour conditions like schizophrenia, they have not historically been based on empirical research into the lived experiences of people with psychoses around the world (though this is starting to change) [137]. The relative dearth of high-quality epidemiological studies from this region means that we cannot count on the basic prevalence and incidence data so essential for the calculation of DALYs. This issue is further compounded by rudimentary methods for the attribution of mortality, which are especially consequential for psychoses. According to a global meta-analysis, the pooled relative risk of mortality among people with psychoses (2.54) is significantly higher ($p < 0.05$) than among those with other mental health conditions, such as mood disorders (1.86) and anxiety (1.43) [76].

A further example of the detrimental effects of unrepresentative and methodologically flawed epidemiological research is the conclusion drawn from the WHO schizophrenia studies that outcomes are more favourable in LMICs than in HICs. Several researchers have questioned this, calling for more rigorous studies of the long-term course of psychoses in LMICs [138]. As researchers, clinicians, and people with lived experience in sub-Saharan Africa today, this picture of a better outcome does not reflect our experience. We take pride in the resourcefulness and dedication of those who provide care—both formal and informal—for people with psychoses in these challenging circumstances. However, we cannot condone what medical anthropologists like Paul Farmer have deemed the employment of culture as an excuse for inaction in global health [139]. This does not mean that we believe in the superiority of HIC mental health care. Rather, we agree with former WHO Director of the Department of Mental Health and Substance Abuse Shekhar Saxena [140]: "When it comes to mental health, all countries are developing countries. No country has mental health care services worked out quite satisfactorily" (Davies 2018, pp. 1509).

Finally, the weaknesses of the GBD studies are quantified in dollars and cents through top-down economic modelling that does not necessarily take into account high unemployment rates or the importance of the informal economy in sub-Saharan Africa, and might not value the ways in which people with psychoses, their families and community organisations might contribute to society—economically or otherwise. Meanwhile, we know the cost of care as it is currently provided is not affordable to either health systems or households, and that it drives people in already vulnerable situations toward catastrophic health expenditure and extreme poverty.

Implications and recommendations

Our findings point to the need not only for more research on psychoses in sub-Saharan Africa, but also for more representation and leadership from the region in the conduct of this research and in international priority-setting more broadly. Decolonising global mental health is a vital end unto itself [141, 142], but we also trust these efforts will lead to more cautious interpretation and application of supposedly "global" evidence that all too often treats geographic disparities in mental health research as a mere methodological shortcoming. The consequences are very real, shaping the narratives that drive decision-making in a chronically under-resourced field—and ultimately the lived experiences of people with mental health conditions around the world. Their voices, especially, should be at the forefront of global mental health research, service development, training and advocacy, as argued by the Pan African Network of People with Psychosocial Disabilities in their 2011 Cape Town Declaration [143]: "There can be no mental health without our expertise. We are the knowers and yet we remain the untapped resource in mental health" (PANUSP 2014, pp. 385). Tapping this resource will require more targeted funding for inclusive psychosis research led by African researchers and more support for people with lived experience to be involved—including as leaders of their own research. These efforts must also recognise and embrace the incredible diversity that exists among those with lived experience of psychosis, acknowledging that some voices are harder to hear than others.

This is not to say that we would encourage research for research's own sake. On the contrary, we agree with calls from African disability advocates for "no survey without service" (Schneider et al. 2002, pp. 182) [144], particularly for people with psychosocial disabilities, who are often exceptionally underserved and marginalised even within the global disability movement. Further—and in line with a social model of disability—we would argue that these services should extend beyond clinical treatment and toward ensuring full participation in society. While African countries appear to be leading the way in research on the integration of mental health into non-specialist health care via mhGAP [145, 146], critics have questioned whether mhGAP goes far enough in addressing the diverse needs of people with schizophrenia, bipolar disorder and other severe mental health conditions [147]. The good news is that there are, increasingly, promising examples of innovation upon which we can draw in this region: collaborative care spanning traditional, spiritual and allopathic medicine in Nigeria and Ghana [107, 108]; formal peer support for people with severe mental health conditions in Kenya, Tanzania and Uganda [148–151]; community-based rehabilitation for people with schizophrenia in Ethiopia [152, 153]; and many more.

Moreover, we believe that much can be achieved by improving access to opportunities that already exist in other sectors. To illustrate: an evaluation of the Malawi Incentive Programme's conditional cash transfer scheme not only showed improvements in mental health outcomes, but that recipients with the poorest mental health had the greatest improvements (approximately four times the average effect size) [154]. Yet people with severe mental health conditions are often excluded from poverty-reduction interventions [10, 155]. Peer researchers on SUCCEED have also highlighted the importance of increasing accessibility in schools and workplaces, for example by offering more flexible study opportunities and working hours to allow for daily self-care, as well as longer interruptions when needed. The empowerment of people with psychosocial disabilities to claim their own rights is essential to identify and address these and other instances of exclusion in the region.

Conclusions

We agree with Kleinman [1] that our starting point in global mental health should be more about the human rights of people in the most vulnerable situations, and less about the big numbers generated to guide global decision-making—not only because failure to do so perpetuates a long-standing "moral failure of humanity" (2009; pp. 604), but because the numbers themselves are deeply flawed. Over twenty years ago, Richard Cooper [45] and colleagues wrote of the early GBD studies, "If these data are wrong, the consequences are likely to be most damaging for the very populations unrepresented in the fact-gathering process" (1998; pp. 210). In this paper, we have examined the GBD and other landmarks in international mental health research that may have inadvertently undermined action on psychoses, drawing on mounting—if sometimes fragmented—evidence about psychoses in sub-Saharan Africa. In the process, we call for more research on psychoses to be focused on sub-Saharan Africa and driven by African researchers and people with lived experience, in particular. However, we also agree with Kleinman that action to promote the rights of people with psychoses is well overdue and cannot wait any longer. Research must be coupled with concrete efforts to increase access to holistic services within and beyond the heath sector, and to address the many barriers to full and equal participation in society faced by people with psychoses and other psychosocial disabilities in the region.

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Author contributions
All authors contributed to the conceptualisation of this paper and to the process of revising it for intellectual content. GKR conducted the literature review, drafted and revised the body of the paper with supervision from OO and JE. BF and OO co-drafted the implications and recommendations section. All authors read and approved the final manuscript.

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Availability of data and materials
All data generated or analysed during this study are included in this published article.

Declarations

Ethics approval and consent to participate
The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008.

Competing interests
The authors declare no competing interests.

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8. Peer support for frequent users of inpatient mental health care in Uganda: protocol of a quasi-experimental study

(Research Paper 3)

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Primary Supervisor	Karen Devries		

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For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	As the Brain Gain II M&E Consultant, I was the main investigator responsible for all aspects of the study design and write-up of the protocol for ethical approval and dissemination. I led the Theory of Change workshops and produced the subsequent Theory of Change map identifying outcomes for evaluation. I conducted the desk-based background research to the protocol and developed the study procedures (e.g., for recruitment, consent, data collection, etc.) and original study tools (e.g., information sheets, consent forms, M&E forms). I drafted the manuscript and revised for publication with feedback from co-authors.

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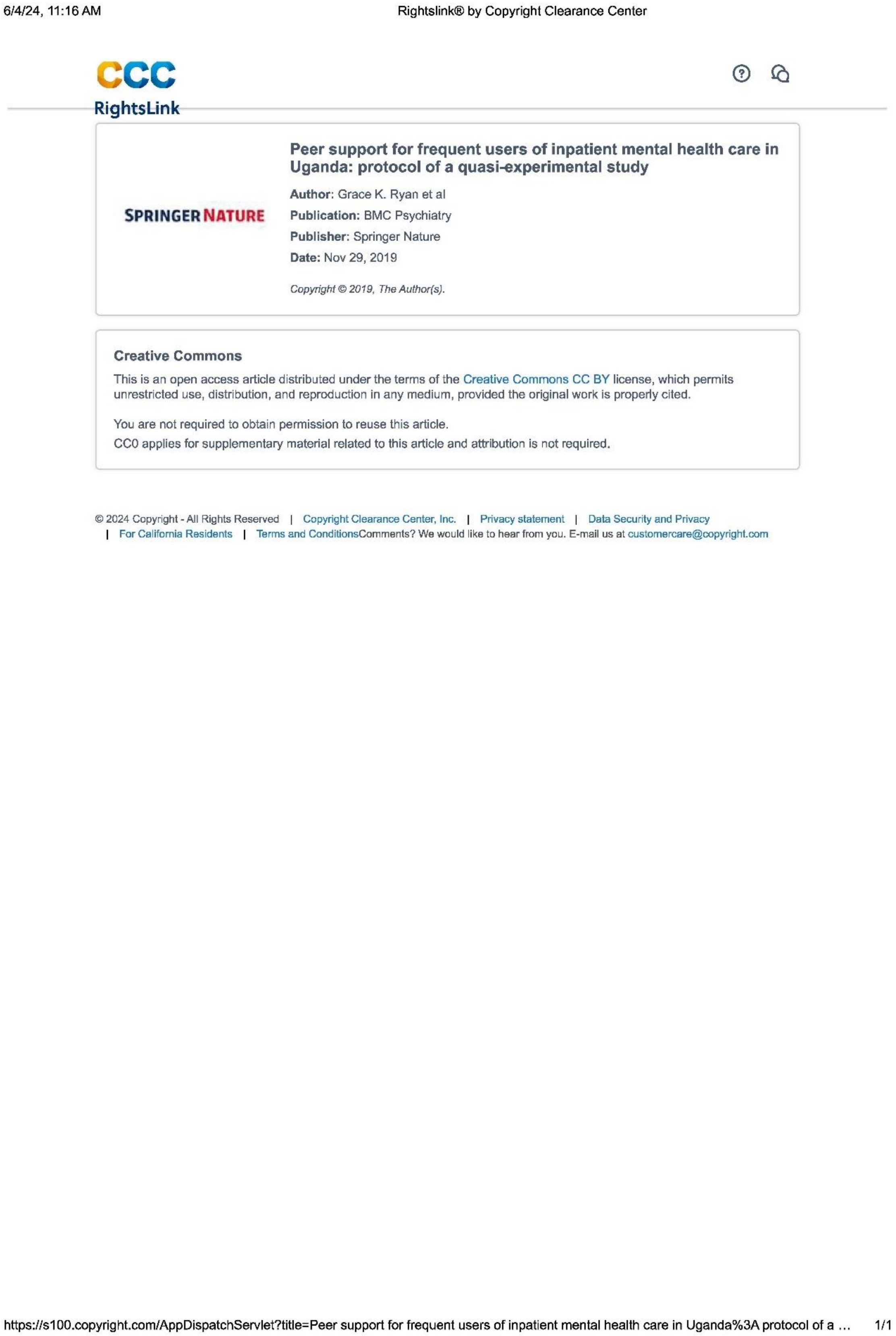

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Peer support for frequent users of inpatient mental health care in Uganda: protocol of a quasi-experimental study

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Abstract

Background: Reducing readmissions among frequent users of psychiatric inpatient care could result in substantial cost savings to under-resourced mental health systems. Studies from high-income countries indicate that formal peer support can be an effective intervention for the reduction of readmissions among frequent users. Although in recent years formal peer support programmes have been established in mental health services in a few low- and middle-income countries (LMICs), they have not been rigorously evaluated.

Methods: This protocol describes a quasi-experimental difference-in-differences study conducted as part of a broader evaluation of the Brain Gain II peer support programme based at Butabika National Referral Hospital in Kampala, Uganda. The primary objective is to investigate whether frequent users of psychiatric inpatient care who have access to a peer support worker (PSW+) experience a greater reduction in rehospitalisation rates and number of days spent in hospital compared to those who do not have access to a peer support worker (PSW-). Frequent users, defined as adults diagnosed with either a mental disorder or epilepsy who have had three or more inpatient stays at Butabika over the previous 24 months, are referred to Brain Gain II by hospital staff on five inpatient wards. Frequent users who normally reside in a district where peer support workers currently operate (Kampala, Jinja, Wakiso and Mukono) are eligible for formal peer support and enter the PSW+ group. Participants in the PSW+ group are expected to receive at least one inpatient visit by a trained peer support worker before hospital discharge and three to six additional visits after discharge. Frequent users from other districts enter the PSW- group and receive standard care. Participants' admissions data are extracted from hospital records at point of referral and six months following referral.

Discussion: To the best of our knowledge, this will be the first quasi-experimental study of formal peer support in a LMIC and the first to assess change in readmissions, an outcome of particular relevance to policy-makers seeking cost-effective alternatives to institutionalised mental health care.

Keywords: Global mental health, Community mental health, Service user involvement, Peer support

Background

Frequent users of psychiatric inpatient care, sometimes referred to as "revolving-door", "high-frequency" or "heavy" users, consume a disproportionate amount of the limited resources available for mental health care [1, 2]. A systematic review of mostly high-income country (HIC) studies estimated 10–30% of users of psychiatric care consume 50–80% of service resources [3].

More recent studies from low- and middle-income countries (LMICs) observe high rates of readmission and large numbers of frequent users among psychiatric inpatient populations [1, 4–9]. In Nigeria, for example, 41.4% of psychiatric inpatients at a university teaching hospital were readmitted within five years. Among those readmitted, mean number of admissions was 2.9 [6]. Meanwhile, the average cost of a single admission to a

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Nigerian psychiatric hospital is $3675 USD, equivalent to the cost of 90 outpatient visits [10]. Reducing readmissions among frequent users could result in substantial cost savings to under-resourced mental health systems in LMICs.

While there is very little LMIC research investigating service user perspectives on readmission, it is generally acknowledged that readmission can be a profoundly disruptive and demoralising experience [11]. In overstretched psychiatric facilities, experiences of inpatient care may be particularly distressing. Human rights watchdogs have documented overcrowding, unsanitary conditions, abusive practices and other human rights violations at psychiatric inpatient facilities in a number of LMICs [12–16]. According to a survey of people with mental health conditions in LMICs, psychiatric facilities are the fourth worst setting in terms of human rights violations; prisons, by comparison, are sixth [17].

There is evidence from HICs that formal peer support can reduce readmissions [18–21]. Notably, a randomised controlled trial conducted in the United States showed that frequent users receiving formal peer support in addition to standard care had an average of 0.64 fewer readmissions and nine fewer days in hospital than those receiving standard care alone [22]. It is unknown whether similar outcomes can be expected in low-resource settings, as patterns in utilisation of inpatient care can differ substantially from those in high-income countries [23]. There have been no studies to-date on the effectiveness of formal peer support as an intervention to reduce readmissions in a LMIC setting.

Broadly defined, peer support is social emotional support that is mutually offered or provided by “peers”, people with lived experience of mental, neurological or substance use disorders [21, 24]. While peer support encompasses a wide range of different interventions, distinctions are made between formal peer support and informal peer support (or “naturally occurring” peer support, as described by Repper and Carter [2011, pp.393]) [24, 25]. Formal peer support is provided through peer-led programmes or by peers recruited to support roles in traditional mental health or social services [25]. Those offering formal peer support may refer to themselves as “peer support workers” (PSWs) [26], though peer support roles can vary greatly. (For example, the American trial described above employed “peer mentors” to deliver formal peer support [22].) Regardless of their role specifications, PSWs are generally considered to be further along on the road to recovery—able to manage their illness and pursue fulfilling lives—and thus able to leverage their personal experience of recovery to support others [18, 19, 24, 25, 27, 28].

The study described in this protocol is part of a broader evaluation of the Brain Gain II project in Uganda, one of the first LMICs to establish a formal peer support programme [29–31]. The aim of this study is to understand the impact of a formal peer support intervention delivered by trained PSWs on service users’ readmissions. The objective is to investigate whether frequent users of inpatient care who have access to peer support (PSW+) experience a greater reduction in rehospitalisation rates and number of days spent in hospital compared to those who do not have access to peer support (PSW-).

Methods

As this is not a randomised trial, we first developed our protocol in accordance with STROBE (Strengthening The Reporting of Observational Studies in Epidemiology) guidelines [32], and then checked it against Reeves and Gaus’ (2004) adaptation of the CONSORT (Consolidated Standards of Reporting Trials) checklist for non-randomised studies [33]. Other components of the Theory of Change-driven evaluation have been protocolised and described elsewhere [34, 35]. These include: a cross-sectional survey of recovery-related knowledge, attitudes and practices among Butabika staff; a cost analysis to estimate money saved as a result of reduction in readmissions; a multi-method process evaluation; and additional qualitative methods comprising focus groups and interviews with study participants, PSWs, Butabika staff and other key stakeholders of the Brain Gain II project.

Setting

Butabika National Referral Hospital (“Butabika”) is a tertiary psychiatric facility with approximately 430 staff and 550 beds [36], though the number of inpatients often exceeds 750 and can approach nearly 1000 [15]. Butabika is located in a largely suburban area of southeastern Kampala, but patients from across Uganda access its services. Standard adult care consists primarily of on-site psychiatric and psychological interventions, and in some cases vocational training, as prescribed by hospital staff. Users in extremely vulnerable situations may be referred to a social worker for additional assistance. After discharge, users typically return to Butabika for outpatient services, attend one of four monthly community outreach clinics (each located within a 20 km radius of the hospital), or access mental health services at district hospitals closer to their homes.

Brain Gain II is a project of the Butabika Link in Uganda—a partnership between Butabika and the East London National Health Service Foundation Trust (ELFT) in the United Kingdom [31]. Brain Gain II aims to reduce the burden on inpatient care at Butabika by promoting recovery among service users on the hospital wards and following discharge. The two main components of Brain Gain II include: (1) establishing an on-campus Recovery College at Butabika, where people with lived and/or professional experience of mental or neurological disorders co-design and co-deliver a recovery-oriented training curriculum; and (2) offering formal peer support by trained PSWs to frequent users of psychiatric inpatient care at Butabika, on five hospital wards and in local communities in four districts [37].

The Butabika Recovery College (BREC) is located in the Community Recovery Team building adjacent to the Forensic Ward. Recovery Colleges are educational (as opposed to clinical) spaces that operate similarly to unaccredited adult education colleges, though with a focus on meaningful involvement of people with lived experience in all aspects of their functioning [38]. At BREC, people with lived experience (mostly PSWs) and people with professional experience (Butabika staff) co-deliver regular teaching sessions on recovery-related topics. Most teaching sessions focus on “what helps” and “what hinders” recovery, identified through a series of Recovery Listening Events held in Uganda by the Sharing Stories Group at the start of Brain Gain II [39]. However, BREC also hosts yoga, bead-making and other skills-based teaching sessions. Most students are current inpatients, though BREC is also open to outpatients, family members and hospital staff.

The Peer Support Office sits within BREC, and acts as the coordinating centre for both Recovery College trainers and PSWs. PSWs operate on five hospital wards, including the forensic ward, acute admissions wards (male and female wards), and long-stay rehabilitation wards (male and female wards). The four districts where PSWs carry out community visits include Kampala, Jinja, Wakiso and Mukono. These are located in the Central and Eastern regions of Uganda and within approximately two hours’ drive of Butabika. Communities in these districts are typically urban or suburban, and English and Luganda are widely spoken.

Study design

In keeping with Brain Gain II’s emphasis on co-production, it was agreed that both PSWs and staff should be involved in the design and conduct of the project’s evaluation. “A theory of how and why an initiative works” that can be empirically tested (Weiss 1995, p. 86 cited DeSilva et al. 2014, n.page), theory of change is increasingly recognised as a useful tool for involving diverse stakheholder groups in evaluation design [40–42]. Two days of Theory of Change workshops were carried out at Butabika, convening PSWs, Butabika staff and representatives of ELFT. Through guided discussions facilitated by the first author, short-, medium- and long-term outcomes were backward-mapped onto a “pathway of change”, which was further refined in consultation with the project leads at Butabika and ELFT [see Additional file 1]. Indicators were assigned to each outcome and methods proposed to measure each indicator, in order to build up the evaluation design. Methodological decisions were made with a focus on feasibility, understanding that PSWs and staff would be responsible for much of the data collection. As this was funded as a project evaluation, with limited budget for research, there was little scope for hiring external data collectors with the time and specialist expertise required to administer complex measurement tools.

For the evaluation of user-level outcomes of peer support, it was not considered appropriate by stakeholders to adopt an experimental design, in which frequent users in extremely vulnerable situations who could otherwise benefit from peer support in their local communities might not receive PSW visits. Hence, a quasi-experimental difference-in-differences (DID) study design was proposed in which the comparison group consists of those who are referred to the PSW programme but live outside of the four districts that comprise its current catchment area, and therefore do not have access to formal peer support. This design was modelled on a previous evaluation of community-based rehabilitation for people with severe mental disorders in India [43], and compares the change in number of rehospitalisations and hospital days among frequent users who have have access to a PSW (PSW+) to that of frequent users who do not have access to a PSW (PSW-).

Participants

Eligibility criteria

In order to be eligible for inclusion in the study, a service user must: (1) be age 18 years or older; (2) be a Ugandan national currently residing in-country; (3) have been diagnosed with either a mental disorder or epilepsy; (4) have had three or more inpatient stays at Butabika in the previous 24 months; (5) be referred to the peer support programme from one of five participating hospital wards at Butabika; (6) agree to participate in the study (assent) at baseline; and (7) provide either informed consent or guardian consent within the six-month follow-up period (Fig. 1). Although Butabika’s Alcohol and Drug Unit is not one of the hospital wards participating in this study, service users with mental or neurological disorders who also have co-morbid substance use disorders will not be excluded.

Selection

Over a six-month recruitment period, staff from the five participating hospital wards will refer frequent users of inpatient care by completing referral forms with users’ demographic information, contact details, diagnoses, and admissions histories, extracted from patient records. As

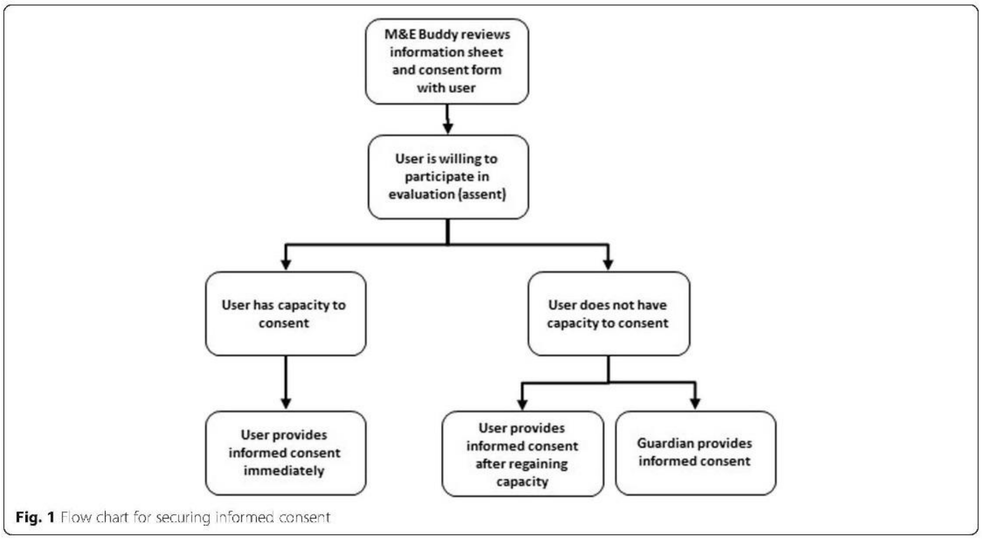

Fig. 1 Flow chart for securing informed consent

making referrals represents an additional unpaid administrative burden for already overstretched Butabika staff, Brain Gain II will offer a performance-based incentive to ward staff of 10,000 UGX (approximately $2.50 USD equivalent) for each referral form that is filled out completely and accurately. The Monitoring and Evaluation (M&E) Officer will review each form to confirm data quality before authorising a cash payment to be made directly to the staff member. Referral forms of sufficient quality will then be used to identify potential patients who meet the study criteria. Patients residing in Kampala, Jinja, Wakiso and Mukono will be eligible to receive the intervention, and patients residing elsewhere will form a comparison group.

Consent

The M&E Officer will assign specialised PSWs called "M&E Buddies" to visit potential participants on the hospital's wards. M&E Buddies receive enhanced training in research procedures and ethics, including the use of the University of California, San Diego Brief Assessment of Capacity to Consent, a structured tool designed to assist research workers in assessing capacity to consent [44]. During the visit, a M&E Buddy will review the study information sheet and consent form with the participant in either English or Luganda and answer any questions.

All potential participants must assent before baseline data can be collected. Informed consent must also be secured in order for this data to be included in the evaluation. If the M&E Buddy suspects that a potential participant may not have capacity to consent, a guardian can consent as a substitute. Alternatively, a potential participant can provide informed consent at any point over a six-month follow-up period if he or she regains capacity. This provision is made to ensure that potential participants are empowered as much as possible to make their own decisions regarding participation. The process of securing informed consent is illustrated in Fig. 1.

Peer support

All participants receive standard adult care and may have some contact with PSWs via the Recovery College. Additionally, participants in the PSW+ group receive face-to-face visits from a trained PSW. Each participant in the PSW+ group is assigned a PSW from a nearby community by an administrator in the Peer Support Office. Peer support visits are offered for up to six months after a PSW is assigned to a user. A recipient of peer support will be visited by a PSW at least once on the ward before discharge, and at least three times after discharge. For particularly vulnerable cases (i.e. three or more inpatient stays in the past 12 months), up to six visits can be made. The PSW visits occur per the recipient's preference, either at home, at a meeting point in the community, or at the hospital when the recipient returns for outpatient visits. The carer may also be engaged in peer support visits, where possible.

The peer support visits delivered by PSWs are flexible and unstructured, and may consist of any or all of the following:

- **Befriending** (social contact, supportive listening and encouragement);
- **Role-modelling** (sharing personal experiences of illness and recovery);
- **Psychoeducation** (education on recovery principles);
- **Problem-solving** (discussing current challenges and possible solutions, liasing with providers to resolve issues with medical and social care as needed).

The qualifications, training, supervision and compensation of PSWs as well as quality assurance for peer support visits are detailed in Table 1.

Table 1 Brain Gain II Peer Support Workers

Qualifications
PSWs must be adults (age 18+) with lived experience of mental or neurological disorders who are numerate, literate in at least one language and able to communicate in basic English. There is no minimum educational or professional qualification required to become a PSW.
Training
Thirty PSWs from communities in Kampala and nearby districts identified by the user-led organisation HeartSounds Uganda were trained in 2012, prior to the start of Brain Gain II. The five-day training was delivered in Kampala by three mental health professionals from the UK with experience managing peer support programmes. Training covered principles of peer support work, recovery and wellness, communications skills, techniques for managing aggression and using Tree of Life as a tool to positively reframe personal narratives of illness and recovery [31]. In March 2015 the trained PSWs participated in an additional Training of Trainers as part of Brain Gain II, to help build the capacity of new cohorts of PSWs [37]. The Training of Trainers has since been manualised and is available upon request.
Supervision
Group supervision is provided via Monthly Advisory Support Group meetings at Butabika. These meetings create opportunities for PSWs to discuss their work with one another and with Butabika staff, creating a forum for shared learning and problem-solving. If a particularly challenging medical or social issue is encountered, a PSW may request that a trusted staff member—usually a social worker or a nurse from Butabika's Community Recovery Team—participate in the next visit. Monthly Advisory Support Group meetings are also opportunities to monitor the well-being of PSWs and provide additional support to those who are struggling. A PSW's caseload may be redistributed to other PSWs from nearby communities, if necessary. A PSW recovering from a relapse is assessed by a psychiatrist at Butabika before resuming peer support visits.
Quality Assurance
At each visit, the PSW completes a structured follow-up form, which documents essential information such as the user's up-to-date contact information and details about what took place. Forms are reviewed regularly by a M&E Officer to identify any inconsistencies which might suggest that a visit has not taken place, in which case an additional visit may be conducted by a Butabika staff member, to investigate.
Compensation
Although PSWs are not salaried hospital staff, they receive a lunch and travel stipend of 20,000 UGX (approximately $5 USD equivalent) for each day of activity.

Outcomes

For variables to be included in the primary analysis, Table 2 summarises the time-points for assessment, the form used and the data collector responsible.

There are two primary outcomes for this study, both related to change in frequent users' utilisation of inpatient care at Butabika. The first is change in the number of hospital days over the previous six months. The second is change in the number of rehospitalisations over the previous six months. The index hospitalisation during which the participant was recruited into the study is excluded from both calculations. The study flow chart in Fig. 2 further illustrates the sequence of assessments in each group.

Hospital days

Hospital days are the number of days spent in psychiatric inpatient care at Butabika over the previous six months. In order to calculate the number of hospital days, dates of entry and departure are extracted from the patient file at the point of referral and six months from referral. An entry may be the result of formal admission or return to the hospital's premises following an escape. Similarly, a departure may be the result of formal discharge or escape from the hospital's premises.

Number of rehospitalisations

Number of rehospitalisations is the overall number of inpatient stays at Butabika over the previous six months. An inpatient stay is defined as a period of time spent in psychiatric inpatient care at Butabika and is also derived from the entry and departure data extracted from the patient file at the point of referral and six months from referral.

Potential confounders

Our initial working model described in Fig. 3 suggests four confounders from previous research on risk of re-admission in other sub-Saharan African countries [6, 45], two from HICs [46–50], and four proposed by the investigators: baseline values for the number of rehospitalisations and hospital days; baseline values for disability and family support; demographic factors, including gender, age, marital status, education level and employment; and diagnosis.

However, DID is designed to adjust for time-invariant and group-invariant confounders [51]. Age, gender, diagnosis, education level, employment and marital status are unlikely to change substantially between groups within the six-month follow-up period. We also observe cautions by Glymour et al. (2005) regarding adjustment for baseline measures of outcome variables (hospital days and rehospitalisations) [52]. Therefore, we plan to include only the remaining two proposed confounders

Table 2 Assessment of Outcome Variables and Confounders for Primary Analysis

Variable type	Variable	Assessment	Time point	Data source	Method of Assessment
Outcomes	• Hospital days • Rehospitalisations	Baseline	Point of referral	Secondary data from paper-based records	Data extracted from patient file and entered into referral form by ward staff, then checked by M&E Officer
		Follow-up	Six months from referral	Secondary data from paper-based records	Data extracted from patient file and entered into six-month admissions form by M&E Officer
Confounders	• Disability • Family support	Baseline	Initial ward visit after referral	Primary data collected via questionnaire (based on WHODAS 2.0 and MIND ME)	Reported by user to M&E Buddy using baseline form

(disability and family support) as pre-specified covariates in the adjusted analysis.

The M&E Buddy collects data on these two potential confounders by administering a baseline form to the study participant while he or she is still on the hospital wards [Table 2]. For those in PSW+ group, it is completed before any PSW visits take place.

Disability

Disability score is assessed using the 12-item World Health Organisation Disability Assessment Scale 2.0 (WHODAS 2.0) [53]. WHODAS originated as a tool for use in psychiatric inpatient settings. WHODAS 2.0 has been validated in diverse cultural contexts and settings, and is considered to be an acceptable cross-cultural measurement tool [53–55]. A Luganda version has been developed and used in primary care settings in Uganda by the PRIME research project [56]. We will use the unweighted "simple scoring" technique manualised by Ustun et al. (2010) to calculate disability scores from the WHODAS Likert scales.

Family support

Family support is measured using two separate three-item Likert scales: one for family's attitude, and one for family's willingness to help. Face validity of these scales

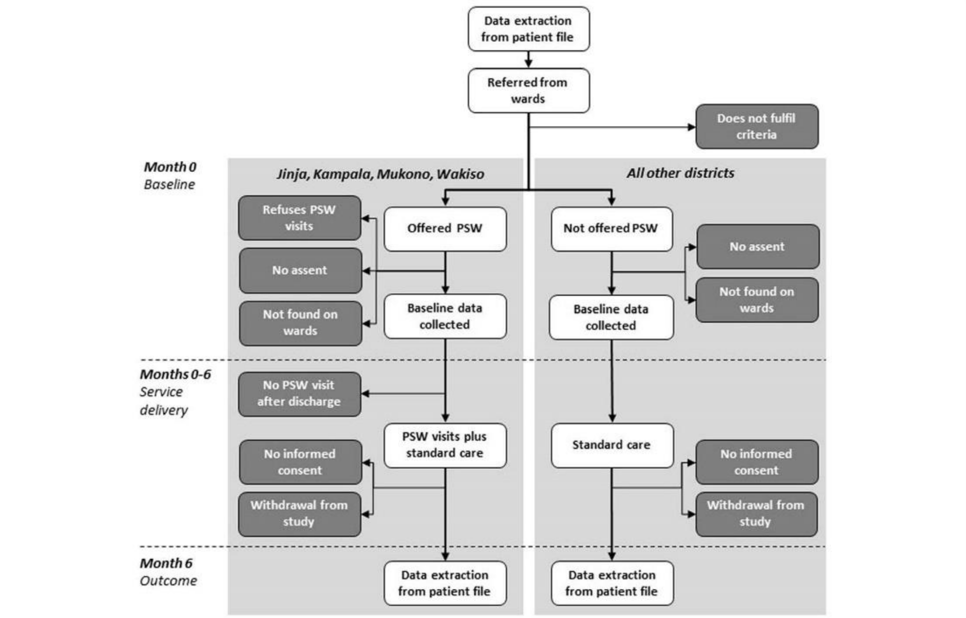

Fig. 2 Flow chart for quasi-experimental study

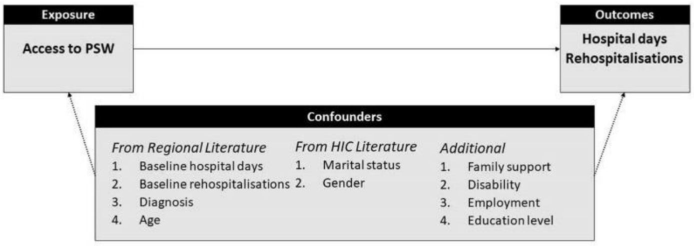

Fig. 3 Initial working model

was examined during the development of the Mental health Information aND Monitoring and Evaluation (MIND ME) Nigeria toolkit, and these measures have since been integrated into routine data collection for monitoring and evaluation of three Nigerian mental health programmes [57–59]. As with the "simple scoring" technique for WHODAS, we plan to sum these Likert scales in order to produce overall family support scores.

Bias

Although this is not a blinded study, neither M&E Buddies, PSWs or the Peer Support Office Administrator responsible for assigning PSWs have access to participants' admissions data. Admissions data are extracted from hospital records by ward staff at baseline and by a M&E Officer at follow-up [Table 2]. To reduce the risk of bias in the collection of additional data, a participant's M&E Buddy will not also be assigned as his or her PSW.

Study size

Brain Gain II aims to enrol 180 users into peer support over six months. Assuming at least a 15% refusal rate and 15% loss-to-follow-up [60], we expect a maximum of 126 participants to complete follow-up in the PSW+ group. With this estimate in mind, we conducted a sensitivity analysis exploring a variety of different scenarios relating to power, effect size and intraclass correlation, allowing for both balanced and unbalanced samples, at 0.05 alpha (see Additional file 2). Results suggest it is possible to detect a clinically meaningful effect (20% as per Cohen [1998]) with 80% power, or a larger effect (30%) with 90% power, if an additional 87 users are followed up in the PSW- group [61]. We therefore aim to recruit at least 129 users to the PSW+ and 101 to the PSW- group.

Analysis

A detailed a priori statistical analysis plan has been drafted in consultation with a biostatistician and covers the baseline, primary and exploratory analyses described below. The plan will be finalised before any data are analysed and is available from the authors upon request. Any departures from the statistical analysis plan must be itemised and clearly justified in study reports.

We will use Stata/SE v15.1 for statistical analysis. All analyses will be performed at the level of the individual. Significance tests will be carried out with two-sided alpha of 0.05, and results will be reported with 95% confidence intervals.

Baseline

Descriptive statistics will be tabulated at baseline for both study groups (PSW+ and PSW-) [Table 3]. The mean, standard deviation and number of observations will be presented for all continuous variables. Numbers and percentages will be presented for categorical variables. Significance tests will not be performed to test for baseline differences between the study groups, as DID already presumes that study groups are unequivalent at baseline [51].

Primary

The primary analyses will compare the six-month change in primary outcomes (hospital days and number of rehospitalisations) between the PSW+ and PSW- groups. We will carry out both intention-to-treat and per-protocol DID analyses for the two primary outcomes, presenting adjusted and unadjusted results [62]. To be included in the per-protocol analysis, participants in the PSW+ arm must receive at least one recorded ward visit and three recorded community visits during the six-month follow-up period [62]. As described above, disability and family support are potential confounders and will be included as covariates in the adjusted analysis.

We will use multivariable linear regression unless the distribution is skewed, in which case we may consider a Poisson or negative binomial regression, or another appropriate method. The impact of the peer support programme on hospital days and rehospitalisations will be estimated through mixed effects models with a

Table 3 Baseline characteristics for descriptive analysis

Variable type	Variable	Time point	Data source	Method of Assessment
Demographic	• Age • Gender • District of residence	Point of referral	Secondary data from paper-based records	Data extracted from patient file and entered into referral form by ward staff, then checked by M&E Officer
	• Education level • Occupational category	Initial ward visit after referral	Primary data collected via questionnaire (based on WHODAS 2.0)	Reported by user to M&E Buddy using baseline form
Family	• Family support • Marital status • Number of children	Initial ward visit after referral	Primary data collected via questionnaire (based on MIND ME and WHODAS 2.0)	Reported by user to M&E Buddy using baseline form
Clinical	• Diagnosis	Point of referral	Secondary data from paper-based records (based on MIND ME)	Data extracted from patient file and entered into referral form by ward staff, then checked by M&E Officer
	• Disability	Initial ward visit after referral	Primary data collected via WHODAS 2.0	Reported by user to M&E Buddy using baseline form
	• Years lived with mental health problem	Initial ward visit after referral	Primary data collected via questionnaire	Reported by user to M&E Buddy using baseline form
Service use	• Ward of referral • Hospital days • Rehospitalisations	Point of referral	Secondary data from paper-based records	Data extracted from patient file and entered into referral form by ward staff, then checked by M&E Officer
	• Previous Recovery College attendance • Satisfaction with hospital services	Initial ward visit after referral	Primary data collected via questionnaire	Reported by user to M&E Buddy using baseline form

random effect to account for correlations among users with the same PSW and fixed effects for access to peer support (PSW+ group versus PSW-group), time (baseline versus follow-up) and the interaction between access to peer support and time. The interaction estimating the change from baseline to follow-up in the PSW+ group relative to change in the PSW- group is the key effect of interest. We will tabulate the results at follow-up and differences from baseline by group with corresponding 95% confidence intervals.

Exploratory

Further exploratory analyses will be carried out to help contextualise the results of the main analyses and generate hypotheses for future testing. As primary data collection from the PSW- group is not possible at six-month follow-up, exploratory analyses are limited to the PSW+ group.

Disability, service satisfaction and family support outcomes Likert scale data on disability, satisfaction with services and family support will be collected from the PSW+ group by M&E Buddies at both baseline and six-month follow-up. For both disability and family support, we will calculate summary scores at baseline and follow-up in the PSW+ group [53], then perform a one-sample paired t-test. If the data distribution is skewed, we will consider the Wilcoxon signed-rank test or another non-parametric alternative. For the five-item Likert scale question on service satisfaction, we will use chi-squared tests to test the significance of the difference between baseline and follow-up in the PSW+ group.

Other psychosocial outcomes Retrospective data on a number of other psychosocial outcomes will be collected from the PSW+ group by M&E Buddies at six-month follow-up. These are categorical variables labelled “improved”, “no change” or “worsened”. We will present descriptive statistics showing proportion of participants in the PSW+ group who reported “improved” or “worsened” outcomes, for the following:

- Marriage or romantic relationship
- Parenthood
- Relationship with main caregiver
- Relationship with other family members
- Relationship with hospital staff (not PSWs)
- Social relationships (e.g. friends, neighbours)
- Work or income
- Education or training
- Housing
- Hobbies or recreation
- Physical health

Missing data

We expect attrition to be low, as the primary outcome data are derived from hospital records, meaning no follow-up contact with participants is required for the main analyses. The most likely reason for missing outcome data is loss of hospital records, which is not expected to affect the study groups differentially.

As per Schafer's (1999) guidance, we will consider up to 5 % missing data to be inconsequential [63]. However, if more than 5 % of data is missing, then we will select appropriate principled missing data methods (e.g. multiple imputation), taking into consideration the data distribution and the mechanism, rate and pattern of missing data [64].

Data quality

Although this study was not resourced to enable double data entry, we will undertake a number of other precautions to improve data quality. As described above, forms used for data collection are routinely checked for quality by the Brain Gain II M&E Officer, and performance-based incentives are also offered to staff for complete and accurate extraction of admissions data. Data validation rules are programmed into the spreadsheet used for data entry. We will carry out additional range and consistency checks during data cleaning.

At the conclusion of the six-month follow-up period, we will also perform a data quality audit. The primary investigator will sample every fourth participant file and check each paper form against a checklist for missing, illegible or illogical data. Data quality issues will be disaggregated by type and tabulated by data collector and question, to identify any common patterns. At the stage of data analysis, we will use either box-plots or z-scores to identify outliers. Where outliers are clearly the result of spurious data, corrections will be made if possible; otherwise, outliers resulting from spurious data may be treated as missing data.

Ethics

This study was approved as part of a broader evaluation protocol for Brain Gain II. Institutional approval was received from the Research and Training Committee of the Butabika National Referral Hospital in Uganda. Ethics approval was secured from the London School of Hygiene and Tropical Medicine Research Ethics Committee in the United Kingdom (Ref 10,705) and Mengo Hospital Research and Ethics in Uganda (Ref 906/7). The evaluation protocol was also approved by the Uganda National Council of Science and Technology (Ref HS12ES). Additional details on the ethical considerations and procedures for this study are available from the study authors upon request.

Discussion

This study will contribute to the evaluation of one of the first formal peer support programmes to be established in a LMIC. Given the high cost of inpatient care, the outcomes are particularly relevant to mental health policy in Uganda and other LMICs, where most government expenditure on mental health continues to be spent on psychiatric hospitals [23].

The use of a quasi-experimental study design is an improvement over previous evaluations of formal peer support in LMICs. Although formal peer support programmes have been established in statutory services in other LMICs such as China [65] and India [66], to the best of our knowledge, only one has published a quantitative evaluation of user-level outcomes. These outcomes were limited to change in mood and social communication skills, assessed retrospectively at a single time-point, with no comparison group [65, 67].

This is also one of remarkably few examples in which the manpower and unique expertise of people with lived experience of mental and neurological disorders is harnessed for the purposes of conducting evaluation research in a LMIC. A systematic review published in 2016 identified only one previous example; it came from Brazil, an upper-middle income country, and users were not involved until data had already been collected [68, 69]. A 2017 survey on psychosocial disabilities and barriers to participation in North India may have involved data collectors with psychosocial disabilities, although this is unclear from the study's text [67, 70]. While engagement of M&E Buddies in data collection is desirable from an inclusion perspective, and may be more sustainable than relying on external evaluators, the use of M&E Buddies has not yet been tested in this context. Future publications will report not only on the outcomes of peer support in Uganda, but also on learning from the engagement of peers in the conduct of this study.

Unfortunately, a randomized control trial was not deemed acceptable for the purposes of this study. Indeed, researchers in HICs have pointed out that randomisation may be in opposition to the principles of self-determination embraced by peer support programmes [71], though some have carried out successful randomised-controlled trials nonetheless. DID is designed to control for time-invariant and group-invariant confounders, but does not entirely eliminate the possibility of confounding or other types of bias. As noted by Wing, Simon and Bello-Gomez (2018): "The DID design is not a perfect substitute for randomized experiments, but it often represents a feasible way to learn about causal relationships" (pp.453).

The study design outlined in this protocol introduces a risk of bias, as the two study groups differ by district of residence. There is a possibility that unmeasured time- and group-variant factors may differ between districts and confound the relationship between peer support and use of inpatient care. Peer support is only available in four districts of the relatively prosperous Central and Eastern regions near the country's capital city, Kampala, where Butabika is located. Further, this is not a blinded study, though PSWs responsible for delivering the intervention do not collect study data from their assigned peers, and neither PSWs, M&E Buddies nor the Peer Support Office Administrator have access to admissions data.

In addition, the outcomes compared between groups are limited to those which can be assessed using the hospital's routinely collected data. Loss-to-follow-up after discharge from inpatient care is a significant issue for Butabika, which PSWs help to remedy through regular visits to the community. The comparison group does not have contact with PSWs after discharge. Therefore, stakeholders deemed it unfeasible to collect primary data from a significant number of participants in the comparison group. The Indian evaluation upon which this study is based faced similar challenges; outcomes could not be assessed in about a third of all participants in the comparison group [43].

Finally, it is worth acknowledging that formal peer support can be challenging to implement [72]. For example, there is a risk that formalisation of peer support roles may actually reinforce hierarchical relationships in statutory services and ultimately undermine core peer support values [73]. At the same time, PSWs may be expected to serve as "carriers of a recovery culture into mental health systems" (Ibrahim 2019, n.page), resulting in conflict between PSWs and organisations resistant to change [72]. These are tricky relationships for PSWs to negotiate, even in relatively well-resourced settings. Meanwhile, resource limitations have been identified as major barriers to service user involvement in mental health systems strengthening in Uganda [74] and in LMICs more broadly [75]. While the Brain Gain I pilot demonstrated that it is feasible to deliver formal peer support in Uganda [31], there is always the possibility of "implementation failure" (Patton 2008, pp. 310) leading to null results [76]. In this case, our multi-method, Theory of Change-driven approach to the broader programme evaluation (described elsewhere [34, 35]) may help to identify "what went wrong" on the anticipated pathway of change and make targeted recommendations for future implementation.

In conclusion, this is a quasi-experimental DID study subject to a number of different constraints and potential biases, which should be followed up with more robust research, assessing more outcomes with locally validated measures, and ideally using a randomised design. Due caution will need to be taken in the interpretation of results. However, given the paucity of research currently available from LMICs, this study represents a crucial next step toward the development of a global evidence base for peer support.

Supplementary information

Supplementary information accompanies this paper at https://doi.org/10.1186/s12888-019-2360-8.

Additional file 1. Brain Gain II Theory of Change map.

Additional file 2. Sensitivity Analysis for Primary Outcomes.

Abbreviations

BELL: Butabika-East London National Health Service Foundation Trust Link; DID: Difference-in-differences; ELFT: East London National Health Service Foundation Trust; HICs: High-Income Countries; LMICs: Low- and Middle-Income Countries; M&E: Monitoring and Evaluation; MIND ME: Mental Health Information and Monitoring and Evaluation; PSW-: No Access to Peer Support; PSW: + Access to Peer Support; PSWs: Peer Support Workers; STROBE: Strengthening the Reporting of Observational Studies in Epidemiology; UGX: Uganda Shillings; USD: United States Dollars; WHO: World Health Organisation; WHODAS: World Health Organisation Disability Assessment Schedule

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Authors' contributions

GKR designed the study and wrote the original Brain Gain II protocol with supervision from JM, MJD and RM, and critical input from MK, DB, CH, EN and CN. SDR advised on the sample size calculation, and along with KMD assisted GKR in revising the manuscript for publication. All authors read and approved the final manuscript.

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Availability of data and materials

Not applicable.

Ethics approval and consent to participate

Informed consent must be confirmed via signature or thumb-print by the participant or guardian following the procedures described in this protocol, which were approved by the London School of Hygiene and Tropical Medicine Research Ethics Committee in the United Kingdom (Ref 10705), Mengo Hospital Research and Ethics in Uganda (Ref 906/7), and the Uganda National Council of Science and Technology in Uganda (Ref HS12ES).

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Publisher's Note

9. Recovery-Oriented Interventions and the Knowledge, Attitudes and Practices of Psychiatric Hospital Staff in Kampala, Uganda: a Cross-Sectional Survey (Research Paper 4)

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First Name(s)	Grace		
Surname/Family Name	Ryan		
Thesis Title	Involving People with Lived Experience in the Evaluation of a Mental Health Peer Support Project in Uganda		
Primary Supervisor	Karen Devries		

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SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I conceptualised this paper and co-facilitated the workshops with peer workers to develop questions for the survey and integrated these into a draft tool. I also co-facilitated (with the last author) the review sessions in which the tool was finalised. I designed and co-facilitated the training of data collectors, and co-supervised data collection, splitting responsibilities for data entry. I am listed as a joint first-author in order to acknowledge a former student of our Global Mental Health MSc, who carried out an initial analysis of the dataset as part of a summer project that I supervised. In response to recommendations from the examiners and from a feedback session that East London NHS Link members led at Butabika, we ultimately decided that I should re-analyse the dataset and draft a new manuscript. I cleaned the dataset, performed my own analysis in Stata and produced the new draft, which I circulated to co-authors and revised accordingly.

SECTION E

Student Signature	
Date	

Supervisor Signature	
Date	

9.1. Abstract

Background

People with lived experience are best-placed to identify the knowledge, attitudes and practices (KAP) that help or hinder recovery in mental health care settings. Yet they are rarely involved in mental health research in low- and middle-income countries (LMICs). We used participatory methods to investigate staff KAP at Butabika Hospital in Uganda, one of the first psychiatric hospitals in sub-Saharan Africa to begin implementing recovery-oriented interventions. We sought to: (1) describe staff characteristics and exposure to recovery-oriented interventions; (2) involve peer support workers (PSWs) in developing a KAP survey tool; (3) use this tool to explore staff KAP; (4) test whether staff KAP differs by exposure to recovery-oriented interventions.

Methods

The survey tool was developed through two PSW workshops followed by a review panel. 97 staff were randomly selected to participate in a cross-sectional survey. Descriptive statistics were calculated. Bivariate analysis and simple linear regression were employed to compare two exposure groups (direct versus no direct exposure to recovery-oriented interventions) and investigate relationships between KAP and other factors. Multiple linear regression tested the association between exposure and KAP when adjusting for participant characteristics. Two discussion sessions were held with PSWs and clinical staff to aid in the interpretation of results.

Results

62 staff responded (50% clinical staff, 61% female). 77% were directly exposed to at least one recovery-oriented intervention. Mean KAP was 56 points out of 84 possible. Most staff demonstrated positive knowledge and attitudes, though responses related to violence and treatment were often at odds with international discourses on rights and recovery. Crude results indicated that participants with direct exposure to a recovery-oriented intervention scored six points higher than those without direct exposure ($p = .017$). This was no longer statistically significant ($p = .088$) after adjusting for participant characteristics. Staff type remained a significant predictor of KAP in the adjusted analysis, with clinical staff scoring nearly nine points higher ($p < .001$).

Conclusion

While crude results were promising, the association between KAP and exposure to recovery-oriented interventions was confounded by staff type. Results should inform the design of more rigorous, participatory evaluations of recovery-oriented interventions in LMICs.

9.2. Background

"Promote recovery" is part of the World Health Organization's (WHO's) Comprehensive Mental Health Action Plan adopted by the 66th World Health Assembly in 2013.[102] In this context, the term "recovery" refers not to clinical recovery, or the resolution of symptoms, but rather a personal and subjective process of regaining meaning, purpose and control over one's life.[94, 102, 184] Efforts to promote a recovery approach in mental health services have led to the development of a wide range of recovery-oriented interventions, such as recovery planning and trialogue.[89, 94, 184] Measurement tools have also been developed to evaluate their individual- and service-level outcomes, including the recovery-related knowledge and attitudes of service providers, as well as the recovery orientation of their practices.[89, 94, 104, 184, 185] However, much of this work to-date has been limited to high-income countries (HICs).[94, 96, 184] If the WHO Action Plan is to be made a reality worldwide, more research on recovery and recovery-oriented interventions is also needed from low- and middle-income countries (LMICs).

Researchers and practitioners have recently begun exploring concepts of recovery and the factors that either help or hinder it in LMICs (e.g., Colombia,[98] India,[186-189] South Africa,[190-193] Thailand,[194] Uganda[195]).[196, 197] A crucial next step is to examine to what extent existing mental health interventions and services promote (or fail to promote) recovery in these contexts, to identify future directions for mental health care reform. Investigating the recovery-related knowledge, attitudes and practices (KAP) of service providers may yield important insights into the current state of mental health care and readiness for change. Indeed, resistance to change among health care providers has been a well-documented stumbling block to mental health care reform in LMICs,[198] and "organisational culture" is the factor most commonly described as either a facilitator or barrier to the implementation of recovery-oriented interventions like peer support.[199]

KAP surveys were originally developed for family planning and population studies in the 1950s and later adapted for use in different areas of health research around the world.[200, 201] KAP surveys are commonly used in LMIC settings to collect structured data on what is known, thought and practiced in relation to a specific health condition or set of conditions, and may be applied to the general population in a defined area[202-205] or to a sub-population, such as healthcare workers.[206-209] While research on the mental health-related knowledge and attitudes of health workers in sub-Saharan Africa dates back at least as far as the 1970s,[210] these studies often fail to apply representative sampling strategies[207, 211, 212] and may limit their investigation to knowledge and/or attitudes, with less attention to behaviour or practice.[210, 211] However, there are notable exceptions. In Ethiopia, for example, Deribew and Tesfaye (2005) have assessed the KAP of psychiatric nursing staff of health centres and hospitals across Jimma Zone using a cross-sectional survey design.[213] In Kenya, Ndetei et al. (2011) have carried out a cross-sectional KAP survey of providers across ten health care facilities selected to represent the various levels of the healthcare system, from primary through to tertiary care, in both rural and urban settings.[208]

Despite growing interest in the mental health-related KAP of health workers in sub-Saharan Africa, and the broader impetus to generate evidence on recovery in LMIC settings, there has not yet been any research published to-date on the recovery-related KAP of mental health service providers in this region. Further, research on mental health systems strengthening often fails to meaningfully involve people with lived experience of the mental health conditions and services under investigation.[21, 22, 47] Not only does this call into question the relevance of research findings to those most affected,[84] it also highlights a missed opportunity to model core principles of the recovery approach promoted by WHO, such as values-based practice and "working alongside people" (2019, pp.27).[214] The aim of this cross-sectional survey was to investigate the KAP of staff at one of the first psychiatric hospitals in sub-Saharan to begin implementing recovery-oriented interventions, Butabika National Referral Hospital ("Butabika") in Kampala, Uganda. Specifically, we sought to: (1) describe staff characteristics and exposure to recovery-oriented interventions; (2) involve people with lived experience in developing a survey tool to assess recovery-related KAP of staff; (3) use this survey tool to explore the recovery-related KAP of staff; and (4) test whether staff KAP differs by exposure to recovery-oriented interventions. Results will help to inform future programming for staff and further research at Butabika and in similar low-resource settings.

9.3. Method

9.3.1. Study design

We carried out a cross-sectional survey in March 2017, administering a KAP survey tool designed using participatory methods to a random sample of Butabika staff. The survey took place toward the end of the implementation phase of Brain Gain II (BGII), a recovery-oriented mental health project sited at Butabika,[175] allowing us to also measure participants' exposure to BGII's recovery-oriented interventions and to carry out an exploratory analysis of the association between KAP, exposure and other participant characteristics.

9.3.2. Setting

Located in south-eastern Kampala, Butabika is the second largest hospital in Uganda and the country's only psychiatric referral hospital. Butabika carries out over 100,000 consultations each year, primarily to patients with severe mental health conditions such as schizophrenia and bipolar disorder.[146] Approximately two-thirds of Butabika's patients are diagnosed with a psychosis-related condition at first contact.[35] Although the hospital is reported to have around 430 staff and 550 beds,[215] the number of inpatients can at times near 1,000,[145] resulting in overcrowding and shortages of specialist care, among other challenges. Limited access to psychological and psychosocial interventions, overmedication, coercive practices and instances of violence and abuse have been reported by human rights watchdogs, mental health advocates, academics and the media.[145, 152, 216-219] Human rights reports have also highlighted positive efforts to involve people with lived experience of mental health conditions in service delivery at Butabika,[145, 146] for example through the Brain Gain I and II projects described further below.

9.3.3. Brain Gain II interventions

With funding from the Tropical Health Education Trust's Health Partnership Scheme, the Brain Gain projects were developed through a 16-year collaboration ("BELL") between Butabika and the East London National Health Service Foundation Trust.[28, 175, 220] BELL's 2012-2013 Brain Gain I project trained 30 people with lived experience of mental health conditions in Central and Eastern Uganda as peer support workers (PSWs).[28, 220] Although these PSWs did engage with patients at the hospital and operated a satellite office out of Butabika's occupational therapy building, peer support mainly took place in local communities and was coordinated off-site by the user-led organisation HeartSounds Uganda. Contact with Butabika staff was ad hoc and mostly limited to the clinicians who were directly involved either in BELL's management or in the care of individuals receiving peer support. Reflecting the hospital administration's growing interest in promoting a recovery approach, the 2015-2017 BGII project brought hospital-based peer support and Africa's first Recovery College onto the grounds of Butabika.[175]

Initiated in July 2015, the BGII peer support intervention was delivered across the forensic, acute admissions and long-stay rehabilitation wards by 33 trained PSWs. 17 psychiatric nurses working on the targeted hospital wards were trained to refer frequent users of psychiatric inpatient care to the peer support programme, and PSWs aimed to provide at least one visit to referred patients before hospital discharge. Subsequent peer support visits took place either in the community, at the hospital coinciding with outpatient appointments, or on the wards during longer inpatient stays or following readmission. Because BGII explicitly targeted frequent users with three or more inpatient stays over a 24-month period, readmissions were common and resulted in substantially more peer support visits taking place at the hospital and more contact between PSWs and staff than in Brain Gain I.

Established in October 2015 in the community recovery team building adjacent to the forensic ward, the Butabika Recovery College offered a new headquarters for the peer support programme as well as an educational space where staff and people with lived experience ("peer trainers") could co-produce and co-deliver trainings on "what helps" and "what hinders" recovery.[195] Five clinical staff and 22 people with lived experience (mostly PSWs) participated in a six-day training of trainers covering learning aims and objectives, lesson planning, leading group discussions, co-production and teaching recovery themes. For the duration of the BGII project, clinical staff and peer trainers co-delivered five trainings per week, mainly to inpatients—though outpatients, family caregivers and hospital staff were also encouraged to attend. The Recovery College's central location near several offices, meeting and training rooms and a popular canteen also helped to increase contact between staff, PSWs and peer trainers.

9.3.4. Development of the survey tool

The decision to investigate staff KAP emerged out of a series of Theory of Change workshops led by one of the authors (GR) in March 2015, as described in a previous protocol.[175] Brain Gain I PSWs, Butabika staff and representatives of BELL came together to map out the "pathway of change" by which BGII interventions were expected to impact individual- and service-level outcomes and discuss how these outcomes would be measured as part of a multi-method project evaluation. "Changes in knowledge, attitudes and practices of hospital staff" was identified as an indicator of a long-term outcome, "Quality of services provided at the hospital is improved."

The KAP survey tool was then developed through two gender-mixed workshops led by two of the authors (GR, MK) in July 2015, with approximately 10 PSWs per workshop (10 female, nine male), followed by a review panel. PSWs were asked to discuss gaps in KAP related to recovery at Butabika and to propose potential survey questions. Specifically, they were asked to imagine the change they would like to see among staff as a result of the project, and what questions they could pose to assess whether this had been achieved. Informed by discussion points from the workshops, the study team adapted several additional questions from a public knowledge, attitudes and behaviour questionnaire originally developed in England.[221]

The draft survey tool was then reviewed for face validity by a panel consisting of two Ugandan PSWs (one male, one female), two Ugandan staff members (one male, one female), and two members of the international research team (two female) from the BGII Management and Advisory Committee in Uganda. After adapting or removing questions on the advice of the panel, the final survey tool consisted of 18 five-item Likert scale questions, with answers ranging from “Strongly Disagree” to “Strongly Agree”, and three multiple choice questions, taking approximately 20-30 minutes to complete [Appendix 2].

9.3.5. Survey Participants

9.3.5.1. Eligibility criteria

Eligible participants for the KAP survey were hospital staff currently employed at Butabika Hospital. Volunteers, family caregivers and occasional staff (those working less than once per month since the introduction of BGII) were not included.

9.3.5.2. Selection

The Butabika Human Resource (HR) Department compiled a sampling frame of all 386 staff on its payroll. Staff were stratified into four groups: clinical (e.g., psychiatrist, nurse), security (“askaris”), administrative (e.g., secretary, medical records) and other support staff (e.g., cleaner, cook) [Appendix 1]. 25% of staff from each stratum were randomly selected without replacement by the lead author (GR) using a random number generator (n = 97 total).

9.3.6. Data collection

Although involvement of PSWs and peer trainers in data collection was an important feature of the broader BGII evaluation,[175] this was not considered appropriate for the KAP survey—in part due to the likelihood of response bias, but also because the survey tool included questions measuring contact with PSWs and peer trainers, which might prove confusing for respondents. Instead, five Ugandan Psychiatric Clinical Officers (PCOs) with prior research experience were recruited as data collectors. The PCOs had completed work placements as part of their qualifications, but were not on Butabika’s payroll at the time of the study. They were trained in the use of the participant consent form and KAP survey tool through a one-day training session led by three members of the research team (GR, MK, RM). Competence was assessed through role-plays.

Over a two-week period, PCOs approached potential participants at Butabika to review the study consent form with them. The office of the Executive Director of Butabika Hospital issued letters to potential participants, giving permission for staff to participate during work hours. The letter briefly explained the purpose of the study and reassured staff that participation was optional, confidential, and would not affect their employment in any way. Those who consented had the option of completing the paper-based KAP survey tool either alone or with the assistance of the PCO. Two members of the research team (CN and GR) then entered the collected data into an electronic spreadsheet, using Microsoft Excel 2013 for Windows.

9.3.7. Variables

9.3.7.1. Exposure to Brain Gain II interventions

Exposure to BGII interventions was measured through self-report in the background section of the KAP survey tool [Appendix 2 and 4]. For each intervention (Recovery College and PSW), exposure was first categorized as “none”, “heard of”, “met/attended”, or “worked with/co-delivered”, and then recategorized as a binary variable for direct (“met/attended”, “worked with/co-delivered”) versus no direct exposure (“none”, “heard of”). For the purposes of analysis, direct exposure to either intervention was treated as a single binary variable.

9.3.7.2. Recovery-related KAP

For our descriptive analysis, responses to each survey question were classed as desirable (i.e., “disagree” or “strongly disagree” for statements that were not recovery-oriented, “agree” or “strongly agree” for statements that were recovery-oriented) or undesirable. To analyse the relationship between overall KAP score, participant characteristics and exposure to BGII interventions, a discrete variable was generated by attaching a 0-4 score to each five-item Likert scale questions (e.g.,“strongly disagree”=0, “disagree”=1, “neither agree nor disagree”=2, etc.) and three multiple choice questions (each choice scored incorrect=0, correct=1) and generating the sum, for a total possible score of 84, with higher scores indicating better overall KAP [Appendix 2 and 4].

9.3.7.3. Participant characteristics

Gender was binary (male vs. female), and age was a discrete variable (years); both were captured via self-report on the KAP survey form. Years of service was a continuous variable calculated by dividing the number of days between date of hire (reported on the Human Resources records used for sampling) and survey start date (29 March 2017) by 365.25. Staff type was recorded as a four-item unordered categorical variable via self-report (clinical, security, administrative, or support staff), and recategorized as a binary variable (clinical vs. non-clinical staff) for analysis [Appendix 2-4].

9.3.8. Data analysis

Data cleaning and analysis were carried out in Stata version 16.1 (StataCorp LLC, Texas) by two international researchers: one internal (GR) and one external (SV) to the BGII project, with supervision from an external biostatistician (SR) and epidemiologist (KD). Missing data and data inconsistencies were checked prior to analysis. As these were found to be scarce and did not exceed 5% of the total sample, they were not considered to be a substantial source of bias [222].

A descriptive analysis was first conducted to examine participant characteristics (age, gender, years of service, staff type), exposure to recovery-oriented interventions, overall KAP scores and responses to individual KAP survey questions. The range, mean and standard deviation were calculated for all discrete and continuous variables. Frequencies and proportions were used for binary and categorical variables.

We then carried out a series of bivariate analyses to compare participant characteristics across the two exposure groups. Visual inspection of histograms for age and years of service suggested the distribution of age was approximately normal, while years of service was positively skewed. We selected the two-sample independent t-test for age, and Wilcoxon-Mann-Whitney *U* test as a nonparametric alternative for years of service. Pearson's chi-squared tests were used for both gender and clinical vs. non-clinical staff type.

We used linear regression to investigate the relationship between overall KAP score and gender, age, years of service and clinical vs. non-clinical staff type, respectively. A simple linear regression model was also used to examine the crude association between overall KAP score and exposure to BGII. For our adjusted analysis, we included covariates for age, gender, years of service, and clinical vs. non-clinical staff type in a multiple regression model. We graphed quantile-quantile plots to test the assumption of normally distributed residuals.

9.3.9. Interpretation

To ensure that those involved in the development of the KAP survey tool had the opportunity to remain engaged in subsequent steps of the research process, one of the authors (DB) led two brief discussion sessions in October 2019, with assistance from students of a professional diploma course in tropical medicine. A lay summary of key findings prepared by the first authors (GR and SV) was shared first with two clinical staff from the original review panel (1 female, 1 male), and then to a group of eight PSWs (5 female, 3 male). During these sessions, clinical staff and PSWs were asked for feedback; for example, whether any results surprised them, what they thought might help to explain these results, and what recommendations could be made to improve staff KAP, based on these results. Feedback from this session fed into the interpretation of results and was incorporated into the discussion section of this manuscript.

9.4. Results

9.4.1. Participant characteristics

Of the 97 staff selected from the sampling frame, 62 responded to the KAP survey. Reasons for non-response were not systematically recorded, though data collectors reported difficulty locating potential participants who were frequently off campus for leave, training and community work. Table 1 presents participant characteristics for the total sample and for each exposure group. There was no statistically significant difference between those who were directly exposed to BGII interventions and those who had no direct exposure, in terms of age, years of service, gender, or staff type (clinical vs. non-clinical). However, the latter was near the $p < .05$ cut-off for statistical significance ($p = .068$).

Table 1. Participant characteristics and differences between exposure groups

		Exposure to BGII interventions			
Characteristics	Total sample	No direct exposure[a]	Direct exposure[b]	Test statistic	*p*
Age					
Mean (SD)	39.0 (8.5)	39.3 (9.3)	38.9 (8.4)	*t* (59) = 0.13, 95% CI [-*4.89*, *5.59*]	.894
Range	22-58	25-58	22-57		
Years of service					
Mean (SD)	15.4 (10.0)	13.7 (9.3)	16.0 (10.2)	$Z = -0.809$	.419
Range	1.1-38.2	1.1-28.1	1.5-38.2		
Gender *n* (%)					
Female	38 (61.29%)	10 (26.32%)	28 (73.68%)	X^2 (1) = 0.78	.376
Male	24 (38.7%)	4 (16.67%)	20 (83.33%)		
Staff type *n* (%)					
Non-clinical	31 (50.00%)	10 (32.26%)	21 (67.74%)	X^2 (1) = 3.32[c]	.068
Security	8 (12.90%)	3 (37.50%)	5 (62.50%)		
Support staff	17 (27.42%)	6 (35.29%)	11 (64.71%)		
Administrative	6 (9.68%)	1 (16.67%)	5 (83.33%)		
Clinical	31 (50.00%)	4 (12.90%)	27 (87.10%)		

Note. SD = standard deviation; CI = confidence interval.

[a] No direct exposure to either BGII intervention (PSW or Recovery College).
[b] Direct exposure to at least one BGII intervention (PSW or Recovery College).
[c] Chi-squared test comparing exposure in non-clinical versus clinical staff.

9.4.2. Staff KAP

Overall KAP scores ranged from 32-71, with a mean score of 56.05 (SD = 8.3). Table 2 ranks each survey question by the percentage of participants who provided desirable responses. More than 80% of Butabika staff in our sample demonstrated knowledge of key concepts related to recovery (e.g. Question 31, 32), and more than 90% indicated positive attitudes regarding the possibility of recovery (e.g. Question 12, 13). However, over 80% also accepted the use of terminology that PSWs had identified as derogatory (Question 30). Responses related to mental health care and practices at Butabika were also inconsistent. For example, while 83.87% reported that patients were informed about side effects (Question 24), far fewer said that patients were involved in discussing treatment options (Question 27, 50.00%) or that they usually understood their diagnosis and symptoms (Question 23, 37.10%). Similarly, 59.68% of respondents acknowledged there may be other effective treatments besides medication (Question 20), but only 27.42% disagreed that people with mental health diagnoses must take medication for life (Question 22).

Appendices 3-4 show the frequency of responses by staff type, for each question. Among the non-clinical staff, administrative staff scored highest overall, followed by support staff and security staff. No security staff scored above the mean. Non-clinical staff responses to questions related to violence were particularly striking. Less than half of participants disagreed that most people with mental health conditions are violent (Question 15, 40.32%). However, among security staff, 87.50% agreed with Question 15, compared to 41.18% of support staff, 33.33% of administrative staff and 12.91% of clinical staff. While 83.87% of participants disagreed that it is sometimes necessary to beat people with mental health conditions (Question 19), half (50.0%) of administrative staff, 37.50% of security staff and 5.88% of support staff agreed; no clinical staff agreed.

Table 2. Percentage of staff with desirable KAP responses, by question and exposure group

		Total sample	No direct exposure[a]	Direct exposure[b]
Question		*n* (%)	*n* (%)	*n* (%)
13.	A person who has suffered from a mental illness can have a “normal life”, for example: a house, a family and a job.	61 (98.39%)	14 (22.58%)	47 (75.81%)
16.	There are people suffering from mental illnesses whom I consider to be my friends.	60 (96.77%)	13 (20.97%)	47 (75.81%)
12.	It is possible for someone to recover from a mental illness.	57 (91.94%)	11 (17.74%)	46 (74.19%)
28.	Anyone who has suffered from a mental illness should not be allowed to take public office.	54 (87.10%)	12 (19.35%)	42 (67.74%)
25.	People suffering from mental illnesses should not be given any responsibility.	53 (85.48%)	9 (14.52%)	44 (70.97%)

32.	Which of the following are examples of "peer support" for mental illness?	52 (83.87%)	12 (19.35%)	40 (64.52%)
24.	Patients at Butabika are usually informed about the possible side effects of their medication.	52 (83.87%)	11 (17.74%)	41 (66.13%)
19.	At times it may be necessary to beat a person who has a mental illness.	52 (83.87%)	10 (16.13%)	42 (67.74%)
31.	What does "recovery" from mental illness mean?	51 (82.26%)	12 (19.35%)	39 (62.90%)
29.	I would not want to live next door to someone who has suffered from a mental illness.	49 (79.03%)	8 (12.90%)	41 (66.13%)
14.	I would be comfortable having someone who has suffered from a mental illness as a co-worker.	49 (79.03%)	10 (16.13%)	39 (62.90%)
18.	A person who has suffered from a mental illness can manage money well.	45 (72.58%)	10 (16.13%)	35 (56.45%)
26.	People who have suffered from mental illnesses can have a bad influence on each other.	41 (66.13%)	4 (6.45%)	37 (59.68%)
20.	There are other effective treatments for mental illness besides medication.	37 (59.68%)	8 (12.90%)	29 (46.77%)
15.	Most people who are suffering from a mental illness are violent.	37 (59.68%)	6 (9.68%)	31 (50.00%)
27.	Patients at Butabika play an active role in discussing treatment options with their care providers.	31 (50.00%)	6 (9.68%)	25 (40.32%)
21.	I would advise my brother or sister against marrying someone who has suffered from a mental illness.	26 (41.94%)	4 (6.45%)	22 (35.48%)
23.	Patients at Butabika do not usually understand their diagnosis or symptoms.	23 (37.10%)	3 (4.84%)	20 (32.26%)
22.	A person who has been diagnosed with a mental illness must take medication for life.	17 (27.42%)	3 (4.84%)	14 (22.58%)
17.	If a person who has suffered from a mental illness begins to show any signs of relapse, he or she should be admitted to the Hospital immediately.	13 (20.97%)	2 (3.23%)	11 (17.74%)
30.	Which of the following other phrases are acceptable when speaking about a person with mental illness?	11 (17.74%)	2 (3.23%)	9 (14.52%)

Note. For Likert scale questions, "desirable" responses include responses of "Strongly agree" or "Agree" to recovery-oriented statements and "Strongly disagree" or "Disagree" to statements designed to reflect a lack of recovery orientation. For each multiple-choice question, "desirable" responses include any response where a recovery-oriented option was selected (participants were allowed to select multiple options). Missing responses are not counted as "desirable" but are included in the denominator (*n* = 62) for the percentage calculation.

[a] No direct exposure to either BGII intervention (PSW or Recovery College)

[b] Direct exposure to at least one BGII intervention (PSW or Recovery College)

9.4.3. Association Between Exposure to Brain Gain II interventions and Staff KAP

Table 3 presents regression results before and after adjusting for staff age, gender, years of service, and staff type. According to the crude analysis, participants with direct exposure scored 6.0 marks higher than those with no direct exposure to BGII interventions (*p* = .017). Total KAP was also affected by gender and staff type, but not by age or years of service. On average, female staff scored 4.6 marks higher than males ($p = .039$), while clinical staff scored 10.6 marks higher than non-clinical staff ($p < .001$).

A multiple linear regression was calculated to adjust for the effects of age, years of service, gender and staff type. In the adjusted analysis, staff type was the only significant predictor of KAP ($p < .001$), with clinical staff scoring 8.7 marks higher than non-clinical staff. Those who were directly exposed to BGII interventions appeared to have slightly higher KAP (3.7 marks) than those who were not directly exposed, but this did not quite meet the $p < 0.05$ cut-off for statistical significance ($p < .088$).

Table 3. Association between KAP and exposure to recovery-oriented interventions

Variables	Coefficient	95% CI		*p*
		LL	*UL*	
Crude analyses				
BGII exposure[a]	6.04	1.11	10.96	**.017***
Intercept	51.50	47.23	55.78	<.001
Age[b]	0.22	-0.24	0.28	.867
Intercept	55.32	44.80	65.40	<.001
Years of service[c]	0.13	-0.09	0.35	.246
Intercept	54.04	49.96	58.13	<.001
Gender[d]	-4.61	-8.98	-0.23	**.039***
Intercept	57.91	55.13	60.69	<.001
Staff type[e]	10.64	7.22	14.05	**<.001***
Intercept	50.83	48.43	53.22	<.001
Adjusted analysis				
BGII exposure[a]	3.66	-0.56	7.88	.088
Age[b]	-0.21	-0.56	0.14	.226
Years of service[c]	0.18	-0.13	0.50	.250
Gender[d]	-2.07	-5.93	1.79	.287
Staff type[e]	8.71	4.88	12.54	**<.001***
Intercept	55.43	44.07	66.78	<.001

Note. SE = standard error; CI = confidence interval; *LL* = lower limit; *UL* = upper limit.

***** = statistically significant at $p < .05$. [a] 0 = no direct exposure to either BGII intervention (PSW or Recovery College), 1 = direct exposure to at least one BGII intervention (PSW or Recovery College). [b] age in years. [c] years since hire date. [d] 0 = female, 1 = male. [e] 0 = non-clinical, 1 = clinical.

9.5. Discussion

9.5.1. Key findings

Although the overwhelming majority of Butabika staff (more than three quarters) had been exposed to recovery-oriented interventions and demonstrated some positive attitudes and knowledge about recovery, a closer analysis of their responses revealed several caveats with implications for recovery-oriented practice at the hospital. Further, while our crude analysis suggested there was a significant association between KAP and exposure to recovery-oriented interventions, our adjusted analysis showed evidence of confounding by staff type. These findings are discussed further below, and a summary of recommendations is presented in Box 1.

9.5.1.1. Medicalised perspectives

Several survey questions reflect the biomedical focus of services provided at Butabika, which has been noted in previous human rights reports.[145, 146, 217, 218] More than half (62.90%) of respondents agreed that patients must take medication for life (Question 22) and that a person showing any signs of relapse should be admitted to the hospital immediately (Question 17, 70.97%). Even among clinical staff, 48.39% agreed about life-long medication and 53.33% agreed about immediate hospitalisation. Further, nearly a quarter of clinical staff (23.33%) disagreed that there are other effective treatments besides medication (Question 20). The importance given to medication may also affect how recovery-oriented interventions are implemented. All but three participants selected “educating one another on the need to take medication” as an example of peer support work in the multiple-choice section of the survey.

Medicalised perspectives on mental health are indeed quite common in treatment settings in Uganda and in LMICs generally, and reflect the realities of providing care with extremely limited resources for psychosocial interventions.[218, 223] However, these responses are at odds with international discourses on recovery and disability rights that emphasise the importance of individual agency in making treatment decisions, the right to live independently and be included in the community, and that medication may not be the whole or only solution for people with mental health conditions.[91, 170] The disconnect between these international discourses and local realities is already the subject of ethnographic research in LMICs like India and Colombia,[97, 98] as well as a recent scoping review,[196, 197] but would be worth exploring further in a Ugandan context.

9.5.1.2. Expectations of violence

Although the majority of staff offered recovery-oriented responses to questions on violence, a third of respondents agreed with the statement, “Most people who are suffering from a mental illness are violent” (Question 15, 32.26%). While security and other support staff were more likely to expect violence from patients, administrative and security staff were the most likely to accept violence toward patients. Expectations of violence in treatment settings are reflective of broader issues in Uganda’s mental health policy, legislation and governance.[218] For example, the 2011 Mental Health Treatment Bill was criticised for failing to define or explicitly prohibit inhumane treatment.[146] A 2017 human rights investigation by the Mental Disability Advocacy Centre identified a number of gaps at Butabika, such as the use of seclusion rooms and other forms of restraint, noting that “staff, residents and the public more widely may not immediately recognise some of these practices as harmful” (pp.3).[145] Through BELL, Butabika has previously offered training in aggression management to security staff but identified high turnover among this cadre as a potential barrier to long-term uptake. Given the important role that administrators play in defining and enforcing policies and procedures, our results highlight the need to include administrative staff and other cadres in future trainings on violence at the hospital.

9.5.1.3. Evidence of confounding by staff type

Perhaps the most compelling finding from this study is that Butabika staff with direct exposure to BGII interventions had higher recovery-related KAP scores, compared to those without direct exposure, but these differences were smaller and no longer statistically significant after adjusting for other participant characteristics— namely, staff type. Although the relationship between staff type and exposure narrowly missed the $p < 0.05$ benchmark for statistical significance, it cannot be ruled out as a confounding factor. The study authors involved in implementing the BGII project note that fostering relationships between PSWs, peer trainers and clinical staff was core to its model of co-production. For example, non-clinical staff were not invited to become Recovery College trainers alongside peer trainers or carry out home visits alongside PSWs. Meanwhile, clinical staff may be better-equipped to offer the “right” answers to survey questions as a result of prior education, training and experience. A previous study of Butabika’s psychiatric nursing students found that the majority were motivated to pursue careers in mental health after encountering people with mental health conditions in their communities whom they wished to help, and that they had positive attitudes about psychiatric nursing despite their communities’ negative attitudes.[224] It is possible that the same factors influencing career choices could also influence KAP and interest in engaging with recovery-oriented interventions, even before taking into consideration more proximal factors such as clinical training and patient contact.

It is also important to note that during the discussion session held to assist in the interpretation of KAP survey data, staff and PSWs involved in the delivery of BGII interventions questioned the first authors' initial interpretation of "null" findings. They felt this was at odds with marked changes they had witnessed over the course of the project, and highlighted the stark differences in responses between the two exposure groups across several key questions. Indeed, given evidence of confounding and the many other limitations described above, the fact that our adjusted analysis produced a near-significant effect ($p = .088$) may actually seem quite promising. Further research is needed, ideally using a longitudinal study design with an appropriate sample size and taking into consideration other important variables related to staff type, such as years of education, training and experience in mental health, and personal factors which could plausibly impact KAP—as discussed further below.

9.5.2. Limitations

This survey was funded as part of a time-limited project evaluation as opposed to a scientific research study and faced several limitations as a result. First, there are inherent limitations to any KAP survey,[200, 201] which could perhaps be overcome with more resources to triangulate findings. The use of self-report to measure KAP is subject to numerous biases. Regarding the cross-cultural application of KAP, another important critique concerns the unequal power dynamics in terms of who defines knowledge and the attitudes and practices that may be deemed either desirable or problematic, often from a Western-centric, biomedical perspective. We sought to engage PSWs, lay people from surrounding communities who have lived experience of mental health conditions, in developing KAP survey questions. However, the panel that finalized the survey tool also included Ugandan and international medical professionals and researchers. More open-ended observational methods such as ethnography could be used to help triangulate and go beyond the KAP survey findings, to better understand the recovery "culture" at Butabika.[200] Second, project timelines meant that a baseline survey and validation study could not be carried out to enable a longitudinal comparison. Third, the sample size was relatively small and may not be representative. In the absence of a validation study or previous examples of recovery-related KAP surveys carried out with hospital workers in similar contexts, it was not possible to make a realistic sample size calculation. We took into consideration Wilson Van Voorhis and Morgan's (2007) recommendation of a minimum 50 survey participants for correlation analysis and roughly doubled this to account for refusals and other factors that might affect the statistical power of the study,[225] but ultimately the 62 staff who completed the survey may not have been sufficient. It is also important to note that the hospital is reportedly staffed by more than 400 workers,[215] yet this was not reflected in the HR Department's records at the time of the survey in March and April 2017. This is likely due to the high number of occasional and volunteer workers who are excluded from Butabika's official payroll. However, PCOs reported that several staff selected for participation were unavailable at the time of the survey and may no longer be actively working at the hospital, perhaps indicating that HR records are also out of date.

9.5.3. Implications

Conceptual models of peer support highlight the cyclical and mutually reinforcing relationship between peer support and organisational change.[226] By modelling co-production and mutual learning between people with lived experience and people with professional experience, Recovery Colleges, too, are expected to bring about organisational change, though research on the facilitators and barriers to their implementation is scant.[227, 228] Gaps in recovery-related KAP could either indicate a failure of BGII to bring about organisational change as part of efforts to improve services or represent important barriers to the successful implementation of recovery-oriented interventions in this setting—or both. Unfortunately, it is not possible to conclude from this study whether BGII was successful in improving staff KAP; nor can we benchmark the survey results to conclude whether Butabika staff have “good” or “bad” KAP, compared to staff in other settings. However, understanding where there is room for improvement can help future projects promoting a recovery approach to focus their attention and resources where they can make the most impact. Involving PSWs in the process of defining “desirable” staff KAP, the questions posed to assess this, and the interpretation of results helps to ensure the relevance of research findings and recommendations to the lived experience of patients. Key recommendations that emerged from this study are listed in Call-Out Box 1, below.

Box 1. Summary of Key Recommendations

For Butabika

1. Consider introducing regular, mandatory staff (clinical and non-clinical) trainings on recovery- and rights-related topics, ideally delivered at the Recovery College.
2. Offer clinical staff training on nonpharmaceutical approaches to mental health care and on safe and evidence based reduction and discontinuation of psychotropic medication.
3. Establish mandatory training in the management of actual and potential aggression at induction and regular follow up for all staff, particularly security personal (*askaris*, who are subject to high turnover) but also administrators responsible for management decisions related to patient safety.
4. Update HR records of formally employed staff and keep additional records of volunteer staff.

For future research

1. Formally validate the KAP survey tool for use in Uganda and similar settings.

2. Use a comparative longitudinal study design with an appropriate sample size to assess the effect of recovery-oriented interventions on KAP with greater confidence.
3. Consider powering future studies to stratify analysis by staff type (clinical vs. non-clinical).
4. Measure other factors among staff which could plausibly impact KAP, such as years of education, training and experience in mental health, and personal and family history.
5. Use multi-method/mixed-method research to triangulate findings on KAP, ideally using observational methods to investigate reported vs. actual behaviour.
6. Involve people with lived experience of the conditions and services under investigation in the design and interpretation of KAP studies.

9.6. Conclusion

This study investigated the recovery-related KAP of staff at one of the first psychiatric hospitals in sub-Saharan Africa to begin implementing recovery-oriented interventions. In the process, it identified several gaps in KAP (particularly related to medication, hospitalization and violence) that can inform future programming at Butabika and other organisations working to promote a recovery approach in similar settings. It also offered an important opportunity to explore the relationship between staff KAP and exposure to recovery-oriented interventions. While crude results were promising, it is not possible to conclude from this study whether the BGII project affected the KAP of Butabika staff. However, we have demonstrated a participatory methodology that could easily be adapted for use in more rigorous evaluations of similar interventions, and offer several recommendations to improve on our study design. Given the dearth of evidence from LMICs on recovery[94, 184] and the involvement of people with lived experience in service delivery[21, 47] evaluating projects like BGII is essential— especially to the WHO's ongoing efforts to document person-centred, rights-based approaches to mental health in diverse settings.[103] This study reinforces that it is possible to "work alongside people" with lived experience not only in the delivery of these services, but in their evaluation as well (pp.27).[214]

10. "An opening of one's heart": Lived experience involvement in data collection for the evaluation of a mental health peer support project in Central and Eastern Uganda

(Research Paper 5)

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Student ID Number	lsh375171	**Title**	Ms
First Name(s)	Grace		
Surname/Family Name	Ryan		
Thesis Title	Involving People with Lived Experience in the Evaluation of a Mental Health Peer Support Project in Uganda		
Primary Supervisor	Karen Devries		

If the Research Paper has previously been published please complete Section B, if not please move to Section C.

SECTION B – Paper already published

Where was the work published?	N/A		
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Where is the work intended to be published?	BMC Psychiatry
Please list the paper's authors in the intended authorship order:	Grace K. Ryan,* Sonia Vallentin,* Maurica Kamuhiirwa, Carter Newman, Dave Baillie, Cerdic Hall, Sujit D Rathod,1 Benon Kabale, Eddie Nkurunungi, James Mugisha, Karen Devries, Richard Mpango
Stage of publication	**Not yet submitted**

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)	I conceptualised this paper and co-facilitated the workshops with peer workers to develop questions for the survey and integrated these into a draft tool. I also co-facilitated (with the last author) the review sessions in which the tool was finalised. I designed and co-facilitated the training of data collectors, and co-supervised data collection, splitting responsibilities for data entry. I am listed as a joint first-author in order to acknowledge a former student of our Global Mental Health MSc, who carried out an initial analysis of the dataset as part of a summer project that I supervised. In response to recommendations from the examiners and from a feedback session that East London NHS Link members led at Butabika, we ultimately decided that I should re-analyse the dataset and draft a new manuscript. I cleaned the dataset, performed my own analysis in Stata and produced the new draft, which I circulated to co-authors and revised accordingly.

SECTION E

Student Signature	
Date	

Supervisor Signature	
Date	

10.1. Abstract

Background

Despite calls to increase involvement of people with lived experience in Global Mental Health, there remain exceptionally few examples of lived experience involvement in mental health research in low- and middle-income countries (LMICs). The 2015-2017 Brain Gain II project involved peer workers in data collection for the evaluation of peer support in four districts of Central and Eastern Uganda. This qualitative study explores the benefits and unintended consequences of lived experience involvement from the perspectives of peer workers, in order to draw lessons for evaluators working in similar contexts.

Methods

Two gender-specific focus groups (10 male, 10 female) and five in-depth interviews (3 male, 2 female) were carried out with peer workers in 2017. Participants were selected using purposive sampling with an aim to maximise variation. The facilitators and interviewer followed semi-structured discussion guides, and discussions were audio-recorded and transcribed for analysis. Transcripts were coded by the first author in Nvivo-12 Plus using a combination of inductive and deductive techniques for a reflexive thematic analysis taking a critical realist approach.

Results

This paper explores three overarching themes: (1) *Opening hearts: The lived experience connection*, captures peer workers' unique connection to peers and their families, including its perceived benefits and potential drawbacks; (2) *Making the work meaningful: Valuing monitoring and evaluation*, considers the personal, practical, and symbolic importance of monitoring and evaluation to peer workers; (3) *Also vulnerable: Empowerment or exploitation?* examines a recurring tension in peer workers' accounts, in which involvement was poised on the one hand as a valuable opportunity, and on the other, a sacrifice demanded of people in vulnerable situations.

Discussion

Findings of this analysis echo several key arguments for the involvement of people with lived experience in mental health research as described in literature from high-income countries. However, some of the potential risks and other drawbacks to those involved may be magnified in low-resource settings. Evaluators should be mindful of the challenges faced by lived experience collaborators and make certain that there are sufficient practical, material and

psychosocial supports in place to ensure that well-meaning efforts toward empowerment do not give way to exploitation.

10.2. Introduction

In 2011, the World Psychiatric Association (WPA) Task Force on Best Practice in Working with Service Users and Carers published a set of ten recommendations based on a literature review and consultation with international stakeholders, including people with lived experience from India, Kenya, Laos and Sri Lanka.[229] One of the key WPA recommendations is that "education, research and quality improvement in mental health care require *collaboration* [emphasis added] between users, carers and clinicians" (Wallcraft, et al. 2011, pp. 233). The World Health Organisation's Comprehensive Mental Health Action Plan 2013-2020 also advocates for the involvement of people with lived experience in mental health research, monitoring and evaluation (M&E) in all member states.[102] More recently, the *Lancet* Commission on Global Mental Health and Sustainable Development has declared a radical "fourth shift" toward an ethic of "nothing about us without us" in mental health care and research (Patel, et al. 2018, pp.5). Yet despite growing enthusiasm, there remain exceptionally few examples of lived experience involvement in mental health research and M&E in low- and middle-income countries (LMICs), beyond participation in Theory of Change workshops or advisory groups.[21, 47, 230] More collaborative approaches are rare and often poorly described in the research literature, making it difficult to critically assess or build on these initial efforts.[21]

This paper explores the experiences of peer workers involved in the evaluation of the 2015-2017 Brain Gain II project in Uganda, one of the first projects to begin delivering recovery-oriented mental health interventions in a low-income country.[96] As described previously, Brain Gain II brought peer support workers with lived experience of mental health conditions to Butabika, Uganda's only psychiatric referral hospital, and established the first Recovery College in sub-Saharan Africa.[175] Brain Gain II may also be the first project in sub-Saharan Africa to train peer workers as data collectors, with peer support workers collecting routine M&E data during their visits with peers, and specialised "M&E Buddies" collecting more in-depth baseline and endline data during a 12-month "enhanced evaluation period". This paper asks two related questions: what did the involvement of peer workers in data collection bring to the Brain Gain II evaluation, and what did the evaluation, in turn, bring to these peer workers? The aim is to document some of the benefits and unintended consequences of lived experience involvement in the Brain Gain II evaluation from the perspectives of the peer workers involved, in order to draw lessons for evaluators working in similar contexts.

10.3. Material and methods

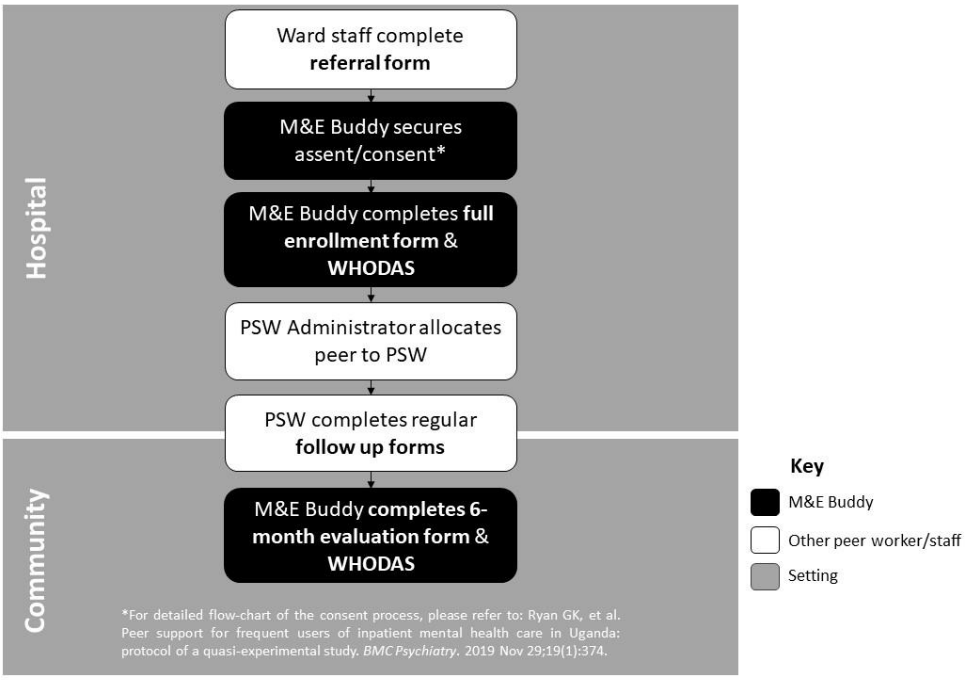
This paper presents a reflexive thematic analysis[169] of qualitative data collected in August-September 2017 as part of the Brain Gain II project evaluation. Qualitative data collection took place at Butabika Hospital in Kampala, Uganda, though peer workers were involved in collecting quantitative data from peers in four districts of Central and Eastern Uganda (Kampala, Jinja, Wakiso and Mukono).[180] The wider evaluation included semi-structured interviews and focus group discussions with key stakeholders, including: peer workers (peer support workers [PSWs], Recovery College trainers and peer administrators), peers (people with lived experience who had received peer support), project staff (volunteers and hospital staff with formal roles on the project) and other hospital staff involved in the project (hospital administrators, Community Recovery Team and ward nurses). In keeping with recommendations by Telford and Faulkner (2014, pp.551) to recognise “fundamental differences in stakeholder viewpoints” and “consider the motives of academic and clinical researchers and the motives of service users separately”,[231] I have limited this analysis to the perspectives of peer workers and intend to analyse other stakeholders’ perspectives separately.

10.3.1. Participants

In March 2015, 33 peer workers were recruited to Brain Gain II’s first cohort on the basis of having lived experience of a mental health condition. These were typically severe mental health conditions that had resulted in one or more periods of hospitalisation, though the project did not restrict eligibility by diagnosis or history of service use. All peer workers were originally trained as Peer Support Workers (PSWs) responsible for carrying out one-to-one visits to peers. They were subsequently trained to co-deliver educational sessions at Butabika Hospital’s Recovery College. The majority of peer workers opted to carry out both activities, though some preferred to work exclusively as either PSWs or Recovery College Trainers. Two peer workers with higher-level education and relevant professional experience also served on the project management team as Peer Administrators. Peer workers received peer supervision from the Peer Administrators as well as Monthly Advisory Support Group (MSG) meetings attended by PSWs, project staff and nurses from the Community Recovery Team (CRT). CRT nurses also carried out “shadow visits” to observe and support PSWs in the field. M&E forms were submitted to the Peer Administrator as evidence of work for travel reimbursement and were reviewed for quality by either the project M&E Officer or the international M&E Volunteer.

Brain Gain II peer workers received four half-days of training on M&E and research ethics in July-August 2015, to prepare for the collection of routine M&E data during peer support visits and become familiar with the tools and procedures that would take place during a year-long “enhanced evaluation period”. The training concluded with short written quizzes on data quality and ethics. The ten peer workers with the highest combined scores (which including the two Peer Administrators) were invited to train further as M&E Buddies who would be responsible for securing informed consent and collecting baseline and endline data during the “enhanced evaluation period” using the 12-item version of the World Health Organisation’s Disability Assessment Schedule (WHODAS 2.0)[232] as well as a project-specific questionnaires.[233] The responsibilities for M&E Buddies, other peer workers and ward staff during the enhanced evaluation period are outlined in Figure 1, below.

Figure 1. Data collection responsibilities during the Brain Gain II "enhanced evaluation" period



*For detailed flow-chart of the consent process, please refer to: Ryan GK, et al. Peer support for frequent users of inpatient mental health care in Uganda: protocol of a quasi-experimental study. *BMC Psychiatry*. 2019 Nov 29;19(1):374.

M&E Buddies received a three-day training in May 2016, which included refresher sessions on M&E and ethics, as well as more intensive practice and role-plays with WHODAS 2.0, the Brain Gain II questionnaire and consent materials, including the University of California, San Diego Brief Assessment of Capacity to Consent (UBACC).[234] Completed consent forms and questionnaires were submitted to the project M&E Officer or international M&E Volunteer for review. M&E Buddy Meetings were arranged on a regular basis by the Brain Gain II M&E Officer, M&E Volunteer and Peer Administrators, to troubleshoot any issues. As the project’s M&E Consultant, I facilitated both M&E trainings and periodically observed M&E Buddy meetings during field visits.

Following the close of the “enhanced evaluation period”, two gender-specific focus groups were organised with ten PSWs each. Participants were selected by the project’s PSW Administrators using purposive sampling, with an aim to maximise variation in terms of age, years of experience in peer support, and perceived performance as a PSW. Five M&E Buddies (three male, two male) were among those selected. To capture more in-depth information related to M&E, I organised in-depth interviews with the remaining five peer workers who had trained as M&E Buddies (three male, two female), including the two Peer Administrators (both male). Potential participants were notified by phone in advance of the proposed interview or focus group discussion. On the appointed day, the facilitator or interviewer reviewed the informational letter and consent form with the potential participants and reassured them that their participation would in no way impact their current or future roles on the project. There were no refusals, though subsequent review of the focus group transcripts indicates that two female and four male PSWs did not elect to speak during their group discussions.

10.3.2. Data collection

I developed semi-structured discussion guides for both the focus groups and in-depth interviews. In focus groups, peer workers were asked about their experience using M&E forms, what they liked or disliked about M&E, what their peers seemed to like or dislike about M&E, and what changes they might like to see. Interview guides went more-in depth, talking through the relevant processes in which M&E Buddies were involved (e.g., recruiting eligible peers, securing consent, collecting routine data during peer support visits where applicable, collecting baseline and endline data for evaluation, etc.). Additional questions were added to explore M&E Buddies' perspectives in different ways, for example by asking participants to reflect on their experiences (e.g., "What motivates you to do your job well? What demotivates you?") and to consider some different hypothetical scenarios (e.g., "Would you rather be a M&E Buddy or a PSW, or both—if given the choice?).

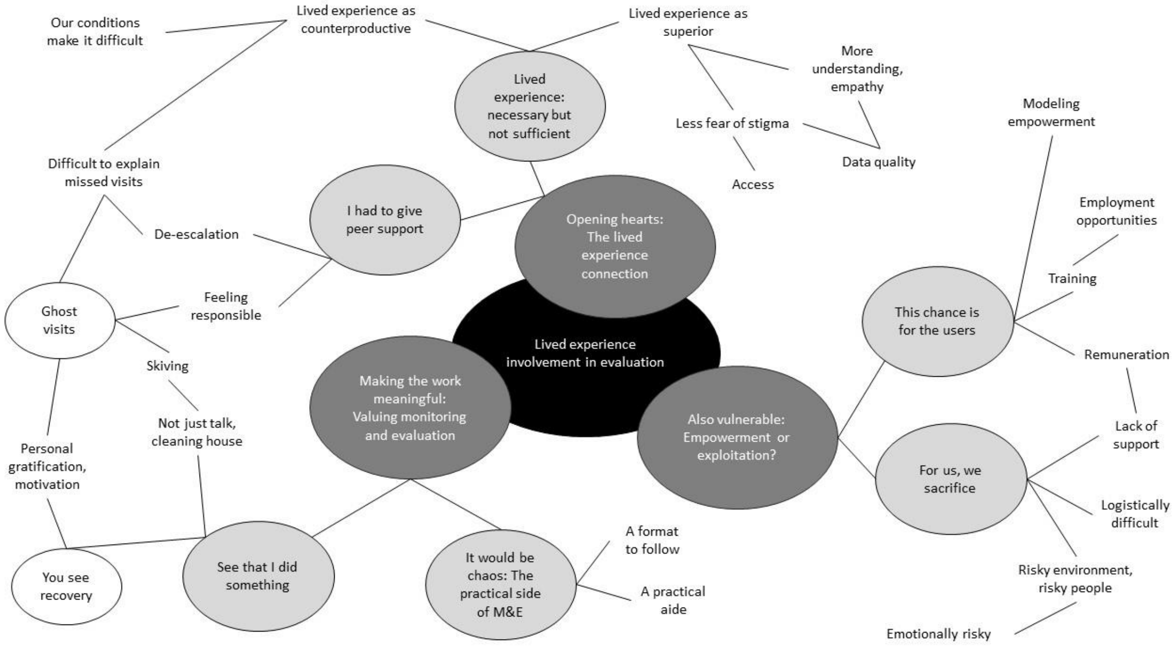
All data collection was carried out in English, as this is one of Uganda's official languages and the main language used in the conduct of the Brain Gain II project. It also conserved the project's limited resources for translation for the focus groups and interviews that were held with recipients of peer support as part of the broader evaluation. Focus group discussions took place in a meeting room near the Recovery College at Butabika Hospital. Interviews were carried out in private, either after-hours in the Recovery College office or in meeting areas of the Postgraduate Halls. Both interviews and focus group discussions were audio-recorded with participants' consent. An all-female team led the female PSW focus group. I co-facilitated along with the project's M&E Officer, and a research assistant took notes to aid in identification of speakers when preparing the transcript. A male social worker with formal training in qualitative research led the male PSW focus group, which I observed along with the research assistant taking notes. I conducted all interviews individually and took brief notes in case of equipment failure. Interviews ran for approximately one hour on average, while focus groups ran for slightly over two hours each.

All interviews and focus group discussions were transcribed, incorporating the research assistant's notes to help identify speakers. I checked all transcripts against the original audio for accuracy and to ensure that I was correctly interpreting the tone of the conversation (for example, adding notes to capture laughter). I did not conduct repeat interviews or return transcripts to participants for review prior to analysis, though I intend to seek participants' approval before publication, as this is a small sample, and it may not be possible to guarantee anonymity.

10.3.3. Data analysis

I carried out a reflexive thematic analysis[169] using a combination of inductive and deductive coding techniques in Nvivo 12 Plus[235] and kept a reflective journal to record insights as the analysis progressed. Following an initial stage of data familiarisation, including listening back to all audio recordings and reading all transcripts, I first coded the transcripts inductively, producing a combination of latent and semantic codes. I later refined my coding by first checking all codes against the original data extracts and then combining codes with similar latent meanings. I organised my codes under a set of candidate themes and sub-themes, then reviewed my proposed framework against the coded data, against the dataset as a whole, and in relation to my overall research question. At this stage, I recognised three of the candidate themes as overarching themes that served to orient the remaining themes and sub-themes in relation to the research question, and revised my thematic framework accordingly (Figure 2). I do not make claims of having achieved data saturation, as this is incompatible with the reflexive thematic analysis approach outlined by Braun and Clarke (2022).[169, 236]

Figure 2. Revised thematic map



10.3.4. Positionality

I am a white cisgender American living in the UK with more than a decade of experience in global health, including both higher education and professional experience at research institutes and international non-governmental organisations headquartered in high-income countries (United States, United Kingdom). Although I am open about my personal motives for studying lived experience involvement, I do not identify as someone with lived experience. I was therefore in a position of immense privilege even before joining the project as M&E Consultant—a rather imposing title in and of itself. Brain Gain II's ethic of co-production helped to facilitate more egalitarian working relationships between peer workers and other staff, and I developed friendships with several peer workers over the course of many field visits in the lead-up to this study. However, I was still recognised as someone in a position of authority over the project's M&E and as a possible conduit into further education and employment. This is particularly salient, as qualitative data were collected towards the end of the project, when the future of Brain Gain II's peer workers was very uncertain. I expected participants would try to minimise some of the challenges related to M&E, either to spare my feelings or to present themselves as eager candidates for future work, and was surprised by the candour and nuance in many of their accounts. Ultimately, this challenged me to confront my initial assumptions surrounding lived experience involvement as an indisputable best practice for mental health research and a boon to empowerment. Below, the results of my analysis paint a more complicated picture of involvement in a low-resource setting.

10.4. Theory

This study is informed by a critical approach to Global Mental Health.[10, 164, 237, 238] Critical Global Mental Health does not represent a distinct theoretical position or sub-field; rather, it draws on a variety of different disciplines such as anthropology, transcultural psychiatry and Mad Studies to interrogate the various ways in which power is asserted and reproduced within and by the emerging field of Global Mental Health. A Critical Global Mental Health lens highlights concerns with intersectionality and epistemological injustice that call for close attention to the voices of people with lived experience, particularly those in formerly colonised, low-income countries. Hence, I have chosen to adopt an experiential orientation to the dataset, characterised by a hermeneutics of empathy that seeks to capture meaning in ways that participants might recognise.[169] I take a critical realist approach that combines a realist ontological position with a relativist epistemological stance, requiring further consideration of my positionality in relation to this research, as discussed above and in the Limitations section below.[162, 169]

10.5. Results

My analysis generated three overarching themes. The first, *Opening hearts: the lived experience connection*, captures peer workers' unique connection to peers and their families, including its perceived benefits and potential drawbacks for the purposes of the evaluation. The second, *Making the work meaningful: valuing monitoring and evaluation*, considers the personal, practical, and symbolic importance of monitoring and evaluation to peer workers, which ultimately became a source of judgment and discord within the project. Finally, *Also vulnerable: empowerment or exploitation?* examines a recurring tension in peer workers' accounts, in which involvement was poised on the one hand as a valuable opportunity, and on the other, a sacrifice demanded of people in vulnerable situations.

10.5.1. *Opening hearts: the lived experience connection*

While M&E Buddies generally positioned their lived experience as an asset to the evaluation, in some cases it was also considered a potential liability, and experience alone was not enough to form strong connections with peers and family members. Peer workers explained how they drew on their interpersonal skills in combination with their lived experience to forge a connection, sometimes under extremely challenging circumstances. This lived experience connection was valued both as a practical tool with the power to secure access to peers, elicit information, and diffuse tense situations, and as an extension of peer support, particularly for peers and families who had not been adequately supported. These nuances are explored further below under the themes *Lived experience: necessary but not sufficient* and *I had to give peer support*, with quotes and anecdotes from three peer workers (“M&E Buddies”) responsible for baseline and endline data collection.

10.5.1.1. Lived experience: necessary but not sufficient

> *In the eyes of the researcher, it could be different, but also on the ground, they don’t have the experience the peers have to feel what is really going on. Someone will come in, with their skill, do what they have to do* […] *But is there a connection—or it is not necessary to have a connection with what you are doing and how you are doing it? Is it about just the professional work?*
>
> (Interview 002, Female)

In interviews, M&E Buddies repeatedly described their role in data collection as distinct from and in some ways superior to that of a “professional” researcher, the main distinguishing factor being a unique “connection” rooted in lived experience “on the ground”. According to two of the M&E Buddies, their shared identity as people with lived experience allayed fears of stigmatization, established trust that they would understand what participants had to say, and allowed them to empathise with participants’ experiences of data collection and respond accordingly—with implications for the quality of the data that participants were then willing to provide:

> *They will receive me better than you* [a researcher] […] *Because this one* [the researcher] *has not suffered* […] *immediately they will know you are stigmatizing them. But for me, they will know they are fitting under me* [are like me]*, so they feel like, “Wow!” So even if the person is giving you information, they are not giving you the right information, this one will not get the clear information, because they* [the peers] *are fearing, yeah they are fearing.*
>
> (Interview 015, Female)
>
> *I mean, in the mental health, usually, we build walls around us* […] *but if I’m asking you, “I’ve been there you see, I know how you feel, you don’t have to answer anything,” there is a relationship that builds, which someone without an experience might not be able to hit* […] *Most families are ashamed of having peers with mental health challenges* […] *there is an opening of one’s heart when they hear that you’ve experienced what they are going through, and they are able to open more.*
>
> (Interview 002, Female)

Although lived experience was considered essential to creating a connection, it was not necessarily sufficient—and could even prove problematic during data collection. One M&E Buddy, a soft-spoken man who came across as more detached and analytical compared to his outgoing colleagues, described his “personality” and “moods” as barriers to forming connections with peers, reducing the interaction to a “struggle” to extract data (or, “to get what you want out of them”):

> *Some of our colleagues can easily interact with these peers, yet for some of us, it’s a bit difficult* […] *you just struggle with them until you get what you want out of them* […] *We* [peer workers] *have different personalities* […] *and at times it is even the mood, you find that you are a bit low* […] *You find that you cannot easily approach them, you are very slow in doing your things* […] *our conditions actually are the ones that make it a bit difficult for us. And at times you’ll find it very easy, because our moods are always high and low, in-between.*
>
> (Interview 008, Male)

The same M&E Buddy suggested that researchers might be more readily accepted by family members in some cases; namely, when peers had not received the intervention as intended. In these instances, the peer worker could be held accountable for the failure of the project to provide support, or else dismissed as a “user”, someone whose grip on reality was inherently suspect:

> *When you look at the carers—there is no way you can explain to them that you are, say, a peer support worker who is going to collect data from their patient and you are a user and even inform them that somebody has been coming to visit their peer, yet this person has never been visited. So, just imagine the image they get when you give them such information* […] *I think when you are a researcher, it will not give them a bad image as if you are a user or a peer support worker.*
>
> (Interview 008, Male)

10.5.1.2. I had to give peer support

In contrast, the two other M&E Buddies described scenarios in which they deployed exceptional interpersonal skills to create connections with peers and family members, even when peer support visits had been missed and their lived experience was perceived as a threat—or when they, in turn, felt threatened. In the anecdote below, a peer’s mother feared the potentially corrupting influence of “fellow patients” on her son and forbade the PSW from visiting their home. The M&E Buddy managed to bring the family around by modelling a “normalize[d]” state in which a person with lived experience can act “like any other persons”:

> *He* [the peer] *was positive towards the support, the peer support. But when I called them for evaluation, the mom said, “I don't want patients to follow up fellow patients.”* […] *So, I spoke politely, because she said, “No, I don't want, what? Patients to follow fellow patients”* […] *When I called the person* [the

> PSW]*, he said, "Eh! Don't tell me, that person* [the mother] *was about to even kill me on the phone! Me, I can't go there."*
>
> […]
>
> *For me, I felt like supporting this guy, because I had seen him* [the peer] *on the ward, and we talked at large, because I did M&E on him. So I said, "No, I must go there. Maybe these people didn't understand." So when I told them, this lady said, "They are going to cut you* [beat you] *from there." I said, "Me, let me go there and they cut me." I felt like I should go and make people aware of what is meant of this programme.*
>
> […]
>
> *Then I explained to them* [the family] *everything. They actually started crying, saying, "We are sorry, we didn't know this program is there, this guy* [the peer] *didn't tell us."*
>
> […]
>
> *So I did M&E and they were great. Actually, they were very happy. They gave me even a Coke, and they gave me a drive up to my home.*
>
> […]
>
> *Now, what I did, I told them about the project* […] *I shared my experience. They were saying, "Ah! Really?"* […] *So I told them that the person can normalize and be like any other persons. So, I told them, "I'm also working, you can see me, can you tell that I am a patient? No, so* [peer name]*, you also will be* [like me]*." Now I started, like, peer supporting him, when I had gone to do what? M&E.*
>
> (Interview 015, Female)

While this peer worker demonstrated courage in reaching out to a family that had not been receptive, she was not in real danger. However, this wasn't always the case. Another M&E Buddy described multiple instances in which she connected with peers in an effort to de-escalate aggressive behaviour. In the anecdote below, she vividly recounts how she positioned herself as "a service user like you", someone on the peer's side who was "just here to understand", and in the process, turned a near-fight into a new friendship:

> *I also met a violent peer* […] *this peer had not got peer support work* […] *the state in which the peer was—was not a state in which you would evaluate, so I had to give peer support. "You know,"* [I said,] *"I see you like this,"* [and he responded,] *"You want to take me to hospital! Where are you coming from?" He almost wanted to fight, but I would engage him with my eyes and tell him, "I am a service user like you. You have to calm down, I am not here to take you to hospital. I'm just here to understand, to share your story. How do you feel? Is there any way I can help?"*
>
> […]

> *I was already there, and the man had engaged me and I shared my story, so I stayed to share a bit of who I am. We are now friends* […] *but I couldn't evaluate him, I didn't even want him to see me writing down his name, because he had so many questions, so many doubts* […] *so, like, okay, we'll sit down in the garden, have a chat, the chat was so long sometimes, but at least I left his mood a bit lifted* […] *But that was a bit of a challenge, I didn't expect to find someone very energetic, so I had to engage him. My heart was beat, beat—but on the inside. But on the outside, I had to stay calm and tell him who I was.*
>
> […]
>
> *Finally I balanced the situation and he is a good guy when he is okay* […] *on the ward, he* […] *was always waiting when the* [Recovery College] *classes are coming so he could engage and then he talks to me.*
>
> (Interview 002, Female)

These two anecdotes also highlight another way in which M&E Buddies mobilised their lived experience connection in the context of the Brain Gain II project: as an extension of peer support. Even when data collection remained the main purpose of the encounter, as in the first anecdote—and conversely, when data collection was entirely impossible, as in the second—M&E Buddies felt compelled to share their stories in order to uplift, inspire and befriend peers and their families.

10.5.2. *Making the work meaningful: valuing monitoring and evaluation*

PSWs voiced their appreciation of M&E as a way of helping to structure and evidence their work. For M&E Buddies specifically, endline data collection was especially meaningful as an opportunity to witness and document the positive effects of peer support. However, meeting peers in the community also exposed shortcomings. PSWs who missed visits with peers were treated with suspicion, and in some cases denounced as cheats undermining the project's efforts. Below, I draw on excerpts from focus group discussions with PSWs and interviews with M&E Buddies to explore the value (and values) attached to data collection captured by two themes, *It would be chaos: the practical side of M&E* and *See that I did something*, along with the sub-themes *You see recovery* and *Ghost visits.*

10.5.2.1. It would be chaos*: the practical side of M&E*

Focus group discussions focussed mainly on the practical benefits of routinely collecting M&E data from peers. In the context of peer support, a flexible intervention that varies from person to person, M&E offered PSWs "processes" and a "format" or "formula" to follow, quelling the "chaos" of otherwise unstructured work: "Yeah it's good for learning. It is really important. I prefer [to have] processes." (Male FGD, R2)

> *I think it gives us a format to follow. If we from [out of] the blue, you begin asking questions without any format, it would be chaos. That is what I think. It gives us a formula to follow.*
>
> (Female FGD: R3)

Some PSWs were less effusive, but still identified ways in which M&E helped to facilitate their work; for example, by standardizing the process for capturing contact information in order to trace peers in the community and making it easier to interface with the hospital's information system:

> *For me, the forms I think they are okay, they are brief, I think they are okay. And beginning* [M&E] *in the hospital is really essential. It's an introduction to this patient, and it's the only chance that we have to know where these people stay.*
>
> (Female FGD, R3)
>
> *I think I like it, because there is a peer we brought from the community, he was on the streets, so when we reached the OPD* [outpatient department] *they wanted the IP* [patient's identification number], *and because I am the peer support worker for that* [peer]*, it helped us get his file so quick.*
>
> (Female FGD, R5)

10.5.2.2. See that I did something

For one PSW, filling out forms had more of a symbolic quality. Documenting peer support visits made her work concrete and verifiable (or in her words, "meaningful"), distinguishing her from someone who might "talk[] when there is no evidence":

> ***Respondent 6:*** *And another good thing, it makes the work meaningful. Yeah, filling in the forms, yeah it makes the work meaningful.*
>
> **Facilitator:** *What do you mean by "meaningful"?*
>
> ***Respondent 6:*** *That you are doing things which are documented, or written down. If it was just me— if they check my work, they can see that I did something* [rather] *than talking when there is no evidence.*
>
> (Female FGD, R6)

In a separate interview, one of the M&E Buddies echoed this notion of separating out "real" peer support from just "talk[]" through the process of evaluation:

> *I want to go and find out, was this person really visited? Yeah, did he get the real services we give?*
>
> […]

> *You are there, but when you evaluate, you know that really there is something going on* […] *there is something improving in this project.”*
>
> (Interview 015, Female).

A PSW administrator who had trained as a M&E Buddy gave a similar account of the evaluation as an opportunity to sense-check and bring “all the dirt” to light in order to “clean house”:

> *Evaluation is good, because it checks you, it shows you where you're going wrong* […] *Otherwise if you keep saying, like—we say that a child without going out will always think their mother is the best cook. So we shall think of, “We’re the best, we’re the best, we’re the best!” But yet, there is so much we need to do within our own house.*
>
> […]
>
> *In Brain Gain II, we had a lot of evaluation, so that there was some scientific way of checking things. And so that brought out a lot of dirt* […] *You know like when you're sleeping in the house, sometimes you can just hoover around, but when you do an overhaul and bring out all the dirt, you know, you do a good job. So Brain Gain II brought out all the dirt* [laughter] […] *and then we had a very clean house.*
>
> (Interview 016, Male)

10.5.2.3. You see recovery

Independent of its role in evaluating the project, witnessing change in those who received peer support was valued by M&E Buddies as a source of personal gratification and motivation:

> *Yeah some of these peers that will get M&E, have actually appreciated the work we have done. The peers themselves have appreciated, then the carers themselves have also appreciated the work we are doing* […]*They are very happy and so you don’t find much difficulty dealing with them.*
>
> (Interview 008, Male)
>
> *I love seeing people’s lives transformed after meeting peer support workers in the community* […] *you see recovery in people’s eyes and* [in] *their family, because the family members, in most cases, have met the peer support workers, so, there is positivity, you see. They feel there is hope. You see hope in the family’s eyes and* [in] *the peers, which is really encouraging.*
>
> (Interview 002, Female)

10.5.2.4. Ghost visits

Conversely, when M&E Buddies discovered that PSWs had not visited peers as intended, this was extremely demotivating, particularly for those who held dual roles as M&E Buddies and PSWs. As in the quotes above and in the two longer anecdotes presented earlier, M&E Buddies felt that missed PSW visits made the task of collecting endline data much harder and required them to go above and beyond their roles as data collectors. It also undermined the wider effort to evaluate “the exact impact” of peer support:

> *Some peers that have not done peer support—that is something very bad about peer support, because it is not very easy to continue doing peer support when some peer support workers are not doing the work. So, like the monitoring and evaluation* [M&E Buddy] *finds it a bit tricky continuing with peer support or to know the exact impact of peer support yet* [when] *some peers are not peer supporting. If all these peers were peer-supported, actually it would be very easy to find out the exact impact.*
>
> (Interview 008, Male)

Within the project missed visits were often referred to as “ghost visits”, evoking “something very bad” indeed: an apparition that seems real at the time, but ultimately has no substance. Technically “ghost visits” referred to those visits recorded on M&E forms (presumably to validate the PSW’s request for transport allowance) that could not then be verified with the peer or their family members at endline. Yet it was frequently used within the project as shorthand for any missed visit. Interestingly, the term “ghost visit” was rarely mentioned in the peer worker dataset, though missed visits were discussed in every interview. For example, a peer support administrator trained in M&E explicitly avoided using the term while at the same time acknowledging the phenomenon itself as “an issue”:

> ***Interviewer:*** *Could you give me an example of an issue?*
>
> ***Respondent:*** *I think mainly focussing on people who were like, you know—I wouldn’t call them “ghost visits”, but you know, people making reports that are not really genuine* […]
>
> (Interview 013, Male)

There was considerable stigma associated with “ghost visits”, which is perhaps why peer workers were so judicious in their use of the term. A second peer support administrator trained in M&E described PSWs “not doing the work” as “skiving”, while at the same time recognising there may be legitimate reasons for missed visits that the evaluation failed to address:

> *Later on some people were skiving, but those who did the work developed very good relationships with their peers.*
>
> […]
>
> *We did not address those issues, “Why is it?” Like in the evaluation we did of not doing the work, where the visits aren’t being made, some of the questions could be, “What is supporting you? How could this be done?” You know, in a way—to find out how this could happen.*

> (Interview 016, Male)

Ultimately, missed visits (and “ghost visits”, especially) undermined peer workers’ personal and collective efforts to make an intangible, unsupervised intervention like peer support *real* (or “meaningful”) through documentation and evaluation. On a more practical level, they made M&E Buddies’ jobs more challenging and also deprived them of the personal rewards of data collection. Unsurprisingly, they were widely condemned. However, concessions were made for the vulnerability of PSWs—and the failure of the project to adequately support them—as discussed further in the next section.

10.5.3. *Also vulnerable: empowerment or exploitation?*

Peer workers described involvement in M&E as an important opportunity to develop new skills, to participate in remunerated activities, and to demonstrate the capabilities of people with lived experience. At the same time, they catalogued the many risks and discomforts of data collection, complained of inadequate remuneration and safeguarding, and questioned whether skilled researchers would put up with the same treatment. Central to this tension, with involvement poised on the one hand as empowerment, and on the other as exploitation, was the self-avowed “vulnerability” of peer workers. Excerpts from focus group discussions with PSWs and interviews with M&E Buddies help to further illustrate this tension under the themes *This chance is for the users* and *For us, we sacrifice*.

10.5.3.1. This chance is for the users

In a context of high unemployment, poverty and discrimination against mental health conditions at school and in the workplace, involvement in data collection was considered a rare “chance […] to get trained” for people who might otherwise “be left redundant” and a potential pathway into future employment that side-stepped the usual expectations of previous educational attainment:

> *The chance is for the users themselves to get trained. You never know* [if] *they would be picked on to do research somewhere else or to do monitoring and evaluation on something else. But at least if they have done enough training of the kind, it would be better for them—it’s beneficial to them and they shouldn’t be left redundant, that is what I think.*
>
> (Interview 008, Male)
>
> […] *one: we are not earning some money, because people are not giving us jobs. We are stigmatized. Secondly, when you were recruiting* [for M&E Buddies] […] *you didn't like, have a class* […] *that they want, like Senior 6 Levels or this qualification* […] *thirdly: since people are not working, they are low earners and others are not working at all, they just take the money.*

> (Interview 015, Female)

This second quote also stresses the financial incentive to work as a M&E Buddy. Due to restrictions imposed by the funding agency, peer workers had to be treated as volunteers and reimbursed through a daily travel allowance, a flat rate of 20,000 Ugandan shillings (UGX). As we will discuss further, this was considered paltry compensation for their efforts, but by cobbling together extra days of work (e.g., for baseline or endline data collection) and finding ways to cut expenses (e.g., by walking instead of using transport), peer workers could sometimes bring home a little money to their families:

> *The mere fact that I'll be given transport refund is some kind of motivation. I can't hide that it gives me motivation, because if you are doing it on a voluntary basis and you find all these difficulties, it would be very difficult actually to continue doing it. But the mere fact that I know that when I visit, I will be refunded my transport, so we just go ahead and do it.*
>
> (Interview 008, Male)

Beyond its material value, for some peer workers involvement served as an opportunity to model "empowerment", showing that people with lived experience could keep up with the times and handle data just as well as "professionals" (or "normal people").

> *In the older time, there was no routine records, but now these days, we have to move with the system. So that we can show these people that even mental—peer support workers who have mental health challenges can have their records also, a bit like normal people* […] *you're supposed to do the consent, the record-keeping, and doing everything systematically as the world is moving on* […] *so that we are also living more like other people live.*
>
> (Male PSW FGD, R5)
>
> *I mean, learning to work with data, you know? That is a skill we have got from the project, and a skill we can build on, you know? The professionals have started it, they know it well, they can do their work because they have learned to do it. But this is an opportunity to show that even the peer support workers have the ability to do some of these things, and once we are empowered, we can be more better every day. So, trusting us, with sensitive information, to me, was a high level of empowerment, you know?*
>
> (Interview 002, Female)

10.5.3.2. For us, we sacrifice

Involvement in M&E exposed peer workers to new opportunities, but it also increased M&E Buddies' exposure to risk, as underscored by the two anecdotes in the first section of this analysis. To help mitigate bias, M&E Buddies were assigned to peers whom they had not supported. As such, endline data collection often required travel to meet peers and families whom they didn't know very well (if at all) in unfamiliar homes and neighbourhoods far from where the M&E Buddies lived ("A risky environment filled with risky people"):

> *Because you are going to a home you don't know, maybe this person* [the PSW] *even never went there* […] *You know this place, this work is risky, you enter into someone's home, you don't know how these people—whether they hit people, and we are dealing with dangerous people. You may reach there and a person slaughters you and pierces you, because you may find a person is in an aggressive state, people are not there, you reach there, he becomes a different person. So we are working in a risky environment filled with risky people.*
>
> (Interview 015, Female)

Baseline data collection also required navigating the hospital's wards in order to locate new peers who were typically very unwell, then introduce them to the project and the evaluation. M&E Buddies were sometimes met with suspicion:

> *Yeah, in the female admission* [ward] […] *one of them grabbed me by the collar from admission when I called the name, "I'm looking for so and so!" She came and just grabbed me by the neck! "Why do you have my name? What have I done? Why are you looking for me? I want to see the sheet that has my name." I came back with a half-done sheet. She wanted to sit* […] *in my mind I'm like, "I don't* [won't] *do any baseline with this one!"* [laughter] […] *but you expect that on the ward.*
>
> (Interview 002, Female)

Working on the wards was presented as emotionally risky for peer workers who were already struggling with their mental health, especially when women were asked to visit the male wards, though some appeared to take it in stride:

> *They went on the ward and they got a shock. They were first being shocked by the men who are nude and all that, saying, "No, I can't take this. It's not good for my health,"* […] *Especially on the wards, where you go and find the men who are disturbed, it torments you, it means you also need therapy after that.*
>
> (Interview 016, Male)
>
> *Then one time, they teased me. I was asking for someone and they pointed me, "He's over there!" And when he came, he was all naked, and I was in a boys' ward and I'm like, "I don't think he is the one, maybe we try and get him clothes?" He was out of this world, but I was not shocked, I was like, "Were they trying to tease me? I hope they don't bring a worse joke!"* [Laughter]
>
> (Interview 002, Female)

Whether in the community or on the wards, the work of M&E Buddies could be taxing: in some cases “hectic” and “confusing”, in others, tedious and time-consuming. For one M&E Buddy, the daily stresses of data collection were described as taking an emotional toll (“you feel like crying”):

> […] *that work is too hectic. Actually, you reach there and you feel like crying* […] [to do] *M&E, I'm here in Butabika, I'm going to Entebbe. You find all the transport is done, you need to eat, you don't know the place, because they’ve directed you, you get boda bodas* [private-hire motorcycles] *inside, there is a lot of confusion in that thing.*
>
> (Interview 015, Female)
>
> *You go to the ward, you ask them for their consent to participate. At times you might find* [peers] *when they are not in the mood, somebody might refuse to speak, so getting some of this information from them is not easy* […] *it takes a lot of time, and then the WHODAS itself also takes a lot of time. Some of these questions are not very easy for some of these peers, depending on the mood you found them in. So, I find, please— it is not always very easy doing M&E as compared to peer support* […]
>
> (Interview 008, Male)

Frustrations surrounding data collection were bound up with a more general critique that peer workers were undervalued by the project. An internal evaluation of Brain Gain I had already demonstrated the positive impact of peer support on peer support workers’ recovery; hence, the Brain Gain II evaluation focused on generating evidence of the impact on peers. Many peer workers felt that concern for their own well-being had been lost in this transition. Meanwhile, longstanding challenges surrounding remuneration were amplified, as M&E Buddies found their work to be more difficult and to require more transport than peer support—as in the quote above—though they were still paid the same travel allowance:

> *But in Brain Gain II, I don't know whether it's because it was target-focussed that you need to score these numbers or whatnot* […] *it’s like a teacher marking an assignment, homework, whether you work. “How many have done this?” And so people come primarily because there is a token of income to take home, but they don't feel empowered.*
>
> […]
>
> *But that care of supporting you, as someone who is also vulnerable supporting other vulnerable people, was not provided for in Brain Gain II strongly. What was provided was not strong enough for us. So these people were looked at as research fellows who are competent research fellows that don't need any*

> *support apart from remuneration. There's even no remuneration, it's just transport refund.*
>
> (Interview 016, Male)

It is perhaps unsurprising, then, that the decision to involve peer workers was sometimes interpreted as being financially motivated, rather than rooted in the values of the project:

> *M&E Buddies, when you use peer support workers, it is so cheap, because there is no one you can pay 20,000* [Ugandan shillings] *for that work* […] *you want to employ someone from outside, you get a person and you give 20,000 or even 30,000, all that they can't accept. Because they will be qualified people, and for us, we are not qualified* […] *but you can't get someone who is educated and you give that person something like this. They can't eat, it becomes so expensive* […] *They can't. But for us, we know our people, for us we sacrifice.*
>
> (Interview 015, Female)

Despite the "sacrifice" required, when asked whether they would prefer to stop doing M&E and have professional researchers hired instead, most M&E Buddies advocated strongly for the status quo: "I love the peers doing this and I really love the peers to continue […] the service users, they need the opportunity." (Interview 002, Female)

> *I wouldn't prefer it that way. I think for them* [researchers]*, they would be better to take on other researches* [and] *leave alone this one, because there are very many researches, and then this chance will be given to the users.*
>
> (Interview 008, Male)

This contradiction highlights a core tension within the peer worker dataset. The vulnerability of peer workers was at once a rationale for their involvement—on the positive side, a rare "chance" or "opportunity" to get ahead and signal their "empowerment", on the more cynical side, an expedient cost-saving measure—and a major caveat, requiring a level of support and safeguarding that the project had struggled to provision to peer workers generally.

10.6. Discussion

My analysis explored what peer workers brought to evaluation and conversely, what involvement in evaluation brought to peer workers, in the context of a recovery-oriented mental health project in Uganda. The first two overarching themes map roughly onto these questions, while the third paints a more complicated picture of the interaction between the vulnerabilities that peer workers carry into their work and the opportunities and risks presented by the evaluation. Below, I consider what these insights might add to the existing literature on lived experience involvement in mental health research and make recommendations for other evaluators seeking to involve peer workers in low-resource settings.

In accounts of the *lived experience connection*, successful M&E Buddies knew how to deploy their lived experience in order to form strategic connections for the purposes of the evaluation. As in previous studies of research involvement from HICs, these M&E Buddies sensed that peers and families were more comfortable speaking to them as people with lived experience, and that this had positive effects in terms of research participation and data quality.[53-58, 239] Even when their lived experience was initially stigmatized by family members, they used connection as a tactic to overcome barriers to accessing peers. Establishing a connection was also a vital strategy for conflict resolution that helped M&E Buddies stay safe during data collection. However, not everyone felt they had the right personality or affect to make a connection, and in these instances, data collection could be a struggle. In their guidance for the involvement of service users as paid researchers, Delman and Lincoln (2009) highlight the diversity of “interests, skills and needs” (pp.147) among people with lived experience and the importance of a tailored approach that matches individuals’ strengths with particular research stages or tasks.[239] Although my analysis could be interpreted as admonition for what some M&E Buddies did *not* bring to evaluation (i.e., an ability to connect), I would argue the reverse: the evaluation did not adequately identify and accommodate this diversity among M&E Buddies. The analytical skills needed to master written quizzes are not necessarily indicative of the interpersonal skills needed to make a connection, and this should be taken into consideration when recruiting peer workers for data collection. Offering a wider variety of opportunities for involvement would help to ensure that peer workers do not feel they are missing out if they refuse an unsuitable task.

Considering the *value* that the evaluation brought to peer workers (or perhaps more accurately, the value peer workers placed on the evaluation) helped to make sense of the overwhelming concern with missed or “ghost visits” across the peer worker dataset. In the context of largely unstructured, unsupervised and highly individualised interactions with peers, M&E forms were something that PSWs could hold onto—both figuratively and literally. M&E also had a performative quality, signalling that PSWs were doing real, “meaningful” work (not “skiving”). On a larger scale, the evaluation itself was valued as an opportunity to generate evidence on PSWs’ collective impact. This was especially important for Brain Gain II, as there was no evidence of the effectiveness of formal peer support for people with mental health conditions from any LMIC at the time,[105] which made it difficult to advocate for government funding of peer worker roles. “Ghost visits”, then, were a violation of these efforts, calling the credibility of PSWs’ M&E into question, hampering M&E Buddies’ attempts at data collection, and threatening the overall findings of the evaluation and future sustainability of peer support in Uganda. The discord that this sowed within the project was an unintended but perhaps unsurprising consequence of the design of the evaluation, in which M&E Buddies were essentially tasked with validating the claims of fellow peer workers. Evaluators should be aware of the sizeable “emotional labour” (Faulkner and Thompson 2021, pp.537) that research involvement entails and seek to promote a cohesive working environment.[240]

Finally, discussions with peer workers conveyed the high stakes of involvement in a low-resource setting, which could be framed as either *empowerment* or *exploitation*, even within the same interview. In this environment of extreme insecurity, learning new skills was presented as a tactical advantage, with the potential to counter stigma by showcasing peer workers’ abilities and hopefully improve job prospects down the line. In high-income settings, too, skills development, employment opportunities and financial rewards are important inducements for research involvement.[241] For M&E Buddies, there was an incentive to accrue extra travel allowance, though in reality this didn’t always result in much additional income, which left some feeling shortchanged. I have written previously with colleagues from the UPSIDES project about the extremely precarious situation of Ugandan peer support workers in the context of the Covid-19 pandemic: unsalaried, insecure employment leaves peer support workers with little financial buffer or institutional support for periods of illness, bereavement, family leave, or other personal issues.[242] Indeed, the insufficient compensation of lived experience collaborators is a problem in Global Mental Health generally, which advocates are fighting to remedy.[66] Providing adequate compensation and support is already a major preoccupation of research involvement in high-income countries;[231, 240] in fact, an entire chapter of the WPA’s *Handbook of Service User Involvement in Mental Health Research* is bluntly titled, “Money”.[243] In low-resource settings, where poverty and unemployment rates are especially high and social protection is even less accessible, peer workers have very little power to negotiate for basic entitlements such as fair pay and safe working conditions, or to refuse any possible opportunity that may be presented, which can easily tip the scale toward exploitation.

In sum, the findings of this qualitative analysis appear to support several key arguments for the involvement of people with lived experience in mental health research and evaluation that have previously been identified in literature from high-income countries. However, some of the potential risks and other drawbacks to those involved may be magnified in low-resource settings. Evaluators should make certain that there are sufficient practical, material and psychosocial supports in place to ensure that well-meaning efforts toward empowerment do not ultimately translate into exploitation. In the context of a peer-delivered intervention, it is also important to weigh the convenience of conducting an internal evaluation—upskilling experienced peer workers who already have an interest in the project—against any potentially deleterious effects on interpersonal dynamics among peer workers.

10.6.1. Limitations

While insightful and reflexive engagement of the researcher is the key benchmark of quality in reflexive thematic analysis,[169] readers from a more positivist background might question the potential for bias in this study and the replicability of the analysis. As previously mentioned, my status as the M&E Consultant for Brain Gain II, and as someone from a different cultural, educational and professional background, most certainly shaped my interactions with peer workers. However, my position also brought a level of nuance and behind-the-scenes knowledge that would be difficult to find in an external interviewer or coder, and interviewees often spoke of sensitive interpersonal dynamics that I would hesitate to disclose to other members of the project team. Further, coding reliability approaches are considered to be at-odds with the qualitative orientation of reflexive thematic analysis.[169] As such, I chose not to engage a second coder. However, close involvement of a co-researcher from the same cultural background—and ideally, the same experiential background—would have undoubtedly improved the validity of the analysis. I intend to circulate this manuscript and a summary of the coding to participants for member checking, and to work closely with collaborators to revise for publication.

Another major limitation of this study is that discussion guides were not pilot-tested ahead of data collection. As is perhaps evident from the results above, interviews with M&E Buddies ultimately proved to be the richest data source for this analysis. Questions related to M&E appeared rather far down on the focus group discussion guide, and focus group discussions lasted much longer than the 90 minutes I had originally anticipated. Perhaps as a result of fatigue, discussion of M&E was comparatively thin. When reviewing the transcripts, I also noted instances where facilitators could have used more open-ended questions and probes to encourage in-depth discussion during focus groups. In addition, the decision to carry out focus group discussions in English might have affected some participants’ confidence in speaking about more technical topics related to M&E. My presence, as well, could have affected the course of focus group discussions, as participants might be uncomfortable expressing dissatisfaction in front of the M&E Consultant.

10.6.2. Conclusion

This study harnessed a unique opportunity to learn from one of very few examples of involvement of people with lived experience of mental health conditions in data collection in a LMIC. While peer workers echoed many of the purported benefits of involvement that have previously been identified in high-income settings, risks may be amplified in low-resource settings. In Uganda, peer workers are often living and working in extremely precarious situations, with little social protection or alternative routes into paid employment. Meanwhile, data collection may involve navigating environments and interactions that expose them to additional hazards. However, most M&E Buddies were adamant that the opportunities afforded by involvement in evaluation should rightfully be claimed by people with lived experience. Their voices must be at the forefront of efforts to make “nothing about us without us” a reality and ensure that empowerment does not give way to exploitation.

11. Overarching discussion

11.1. Key findings

This thesis initially sought to provide an argument and proof-of-concept for the involvement of people with lived experience in different facets of mental health research in low-resource settings. Paper 2, a narrative review of the literature on psychoses in sub-Saharan Africa, highlights the risks of exclusion from research that ultimately guides priority-setting and resource allocation on a global scale. With no obvious forum to bring lived experience to bear on methodological concerns or to contradict the questionable conclusions of supposedly global research, there has been little redress of the “moral failure of humanity” (2009, pp. 603) that Arthur Kleinman identified nearly 15 years ago.[165] Photographs of men and women who have become profoundly unwell being chained to trees or held in cages[244] are still met with calls to scale-up low-intensity interventions for common mental health conditions.[245] Meanwhile, *Lancet* Commissioners have claimed “nothing about us without us”[9] as a core principle of Global Mental Health, placing the voices of people with lived experience at the heart of a “transformational […] fourth shift” that has not yet been realised (Patel, et al. 2018, pp.1557).[8] The rapid review presented in Paper 1 highlights the dearth of lived experience involvement in LMIC mental health research, returning just one probable example of involvement in data collection. Unfortunately, it was impossible to tease out from this paper any lessons specific to data collectors with psychosocial disabilities.

With few published examples available from which to learn, this thesis also sought to document the involvement of peer workers in various aspects of the Brain Gain II evaluation. Paper 3 outlines the methods for a quasi-experimental study in which peer workers served as data collectors, and briefly describes how they were also involved in the ToC process that informed the study design. While ToC is commonly used for the design and evaluation of complex interventions in Global Mental Health,[176, 177, 230] people with lived experience are not always included in ToC workshops, and we found it necessary to modify the workshop format in order to improve accessibility—as described in the Overview of Methods. The decision to involve peer workers as data collectors also required additional methodological considerations, for example: introducing UBACC, a tool to aid non-clinical research workers in assessing capacity to consent;[234] selecting outcomes that could be measured using routine data (i.e., hospital admissions) and tools administered by non-clinicians (i.e., WHODAS 2.0[232]); and ensuring that the same peer worker was not selected to provide support and collect evaluation data from the same peer (though this had important implications for peer workers’ experiences of endline data collection, as discussed in Paper 5).

Paper 4 presents a survey designed in collaboration with peer workers who also contributed to (and in fact contested) the interpretation of results. Asking peer workers what they would like Brain Gain II to change at Butabika produced an array of revealing survey questions, for example on attitudes toward violence against patients and on the language used by staff. Indeed, improving the relevance of research tools is often cited as a motive for increasing lived experience involvement in HIC research.[241] Responses to survey questions varied significantly between different types of providers, with clinical staff demonstrating more recovery-oriented KAP compared to non-clinical staff, and security personnel scoring exceptionally low on the whole. After adjusting for staff type, we originally interpreted the results as evidence of no association between exposure to Brain Gain II interventions and staff KAP. However, peer workers and staff rejected this interpretation, as it directly contradicted their experiences on the project. This ultimately led us to engage more critically with the results and limitations of the study design and to consider the possibility of confounding. While "traditional" researchers sometimes prefer that involvement be limited to the early stages of the research process,[49] in the case of the Brain Gain II KAP survey, involvement in interpretation helped to produce a more nuanced analysis.

In all four of these papers, there is an overt assumption that lived experience involvement in global mental health research is a straightforward, self-evident *good*. However, the qualitative analysis of peer workers' perspectives in Paper 5 paints a more complicated picture. On the one hand, involvement in data collection for the Brain Gain II evaluation was seen as a valuable opportunity; on the other, it was risky and required a great deal of personal sacrifice. Involvement of people with lived experience was described as a way of getting more in-depth and honest responses from study participants, and at the same time a potential liability that could interfere with data collection. It rallied peer workers around a collective effort to demonstrate the value of their work, while also castigating those who underperformed. Many of these tensions are echoed in HIC literature, though even in the Global North there is a dearth of empirical evidence on the benefits and potential "disbenefits" (Faulkner 2009, pp.18) of lived experience involvement in mental health research, particularly among racialised groups.[240, 241]

There is risk in documenting downsides, as Faulkner and Thompson (2023) have written: "In surfacing the emotional challenges represented by bringing lived experience into research, we are potentially problematising the entire involvement 'project' with the risk of discouraging people from embarking on it" (pp. 543).[240] Since completing my fieldwork in 2017, I have participated in a number of different initiatives aimed at increasing lived experience involvement in Global Mental Health and witnessed firsthand the personal, professional and material costs of involvement gone wrong—some of which were reported in an auto-ethnographic account that ultimately contributed to the disbanding of a global research commission.[157] As observed by

Mathias and colleagues (2019) when carrying out participatory action research in North India, a great deal of critical, ongoing reflection and concrete action are needed in order to make these initiatives a success, [80] but that doesn't mean they aren't worth doing. I trust that by being open and transparent about the unintended consequences of our early efforts, mistakes are less likely to be repeated as involvement in Global Mental Health research begins to gain momentum.

11.2. Limitations

There are three main limitations of this research as a whole which merit further discussion. The first is simply that it did not go far enough. I initially approached research involvement from the perspective of an evaluator seeking to upskill non-specialists—in this case, peer workers—so that they could carry out their own M&E. I did not come to Uganda with a background in research involvement from the UK, for example. If I had, I might have drawn on the INVOLVE guidelines[3] or similar to consider the full spectrum of opportunities for involvement, from consultation to control, at every step in the research process and for each individual study included in this thesis. As it stands, involvement was fragmented, taking place at the design stage through a ToC workshop, in data collection for the quasi-experimental study, and in the development of tools and interpretation of results for the KAP survey. Partially because of the requirements of this PhD, I also had to carry out my own analyses and serve as a lead author, although I did try to ensure at least one person with lived experience was included as a co-author on each paper (with the exception of the final qualitative paper, which was prepared on a short timescale for the purposes of this thesis; I intend to engage co-authors in the process of participant checking, reviewing my coding, and revising for publication).

Sweeney and Morgan (2009) would likely situate these efforts somewhere between consultation and collaboration, in which "there is a commitment to involvement", but the contribution made by those with lived experience is still "contained" by traditional researchers (pp.29).[50] As the Brain Gain II M&E Consultant, I had final say on all methodological and editorial decisions, while collaborative research should aim to share the power of decision-making (though this is notoriously difficult to achieve in practice).[50] I sincerely wish that this same research had been user-led, not only because I suspect that someone with lived experience would have made different and better decisions, but also to ensure that the benefits of conducting research would be shared more equitably. Encouragingly, at least one peer worker has recently begun publishing his own work, so the future of user-led research in Uganda may not be far off.[152, 219] However, at the time of the 2015-2017 Brain Gain II project, even consultation was a radical departure from the status-quo in many LMICs, and there are still very few examples today of hands-on involvement in the actual conduct of Global Mental Health research.

A second and related limitation is that I did not adequately engage with the literature on lived experience involvement in HICs until rather late in my PhD studies, as the focus of my thesis had originally been on evaluating Brain Gain II's peer support intervention, not on the ways in which we might harness peer workers' lived experience for the purposes of the evaluation. I will also admit to having some hesitation about whether and how far I should delve into it. On a practical level, this is a vast body of literature spanning decades, and the grey literature is especially diverse and difficult to navigate. On a more philosophical level, I was well aware of the strong anti-psychiatry contingent within the user movement in HICs, which seemed to contradict the messages I had heard from people with lived experience during fieldwork in sub-Saharan Africa.

Instead of advocating for freedom *from* psychiatry, the people I met were more often desperate *for* psychiatry, or indeed any service which might offer some hope under difficult circumstances. I wasn't sure how useful or appropriate it would be to carry concerns derived from research involvement in a handful of wealthy countries into this very different setting. However, as the evaluation progressed and we began to encounter challenges, I realised my mistake. We were certainly not the first to have problems contracting or paying peer workers, or supporting people in carrying out emotionally demanding research, or navigating tricky interpersonal dynamics. More regard for the existing literature would have better prepared me for this work. Indeed, Trivedi (2014) argues that the field of Global Mental Health generally would benefit from more engagement with people with lived experience in HICs, as there are a number of overlapping areas of concern for people with lived experience around the world, with the caveat that those from HICs must be mindful of their position and keep those from LMICs "at the forefront" (n.p.).[173] Rose and Kalathil (2019) also call for greater recognition of geographic and racial inequalities as well as other forms of intersectionality that affect people with lived experience involved in co-production efforts.[25]

Perhaps a more concrete example of where this research might have benefitted from findings in HICs was in the selection of measurement tools for the Brain Gain II evaluation. Although this was not a major topic of the qualitative study in Paper 5, M&E Buddies did complain about WHODAS 2.0 during training and over the course of the evaluation. Some questions were confusing or redundant (e.g., being able to walk a kilometre while confined at a psychiatric hospital) and others presumed an unrealistic level of numeracy and recall (e.g., quantifying how many days that difficulties were present over the past month). When preparing the background section of this thesis, I later learned that WHODAS 2.0 was one of the most poorly rated mental health outcome measures by people with lived experience in the UK.[246] Yet it remains a common go-to in Global Mental Health research. In fact, the Wellcome Trust requires that any mental health research into mood disorders captures WHODAS 2.0 as one of its "common metrics" and advocates for other members of the International Alliance of Research Funders to adopt the same. [247] [248] If I'd had better command of the HIC literature at the time, I would have tried to involve peer workers in a more thorough review of the different possible measurement tools—or perhaps in generating a new one, as we did for staff KAP.

A third recurring limitation is the under-resourcing of this research. As described previously, Brain Gain II was funded as a capacity-building project, not a research project. Only a fraction of my time was funded, and only for two years; I had to make up the shortfall with other work, which split my attention and extended the timeline of this PhD significantly. We had to rely a great deal on international students and volunteers to assist in carrying out research activities for Brain Gain II, unable either to delegate large quantities of uncompensated work to Butabika staff who were already overstretched with clinical responsibilities, or to overcome the funders' restrictions on payments to peer workers. Although several team members from Butabika and peer workers had a strong interest in research, played key roles in M&E and made important contributions to the evaluation, they were not always granted the same level of ownership and recognition that, say, a Principal Investigator might have. Especially given the cross-cultural nature of Global Mental Health research and mounting calls to decolonise Global Health,[249] this is a significant shortcoming. However, there was some redress in the form of a subsequent application for the UPSIDES project, which funded a local Principal Investigator and largely autonomous research team based at Butabika.

Other limitations specific to the individual components of this PhD research are covered in Papers 3-5. However, as the journal format did not allow for a limitations section, I should also acknowledge some of the limitations of the rapid review from Paper 1 here. I was invited to prepare this article for *Current Opinion in Psychiatry*, which asks authors to discuss recent developments in their field, drawing on research published within the previous 12-18 months. Rather than cherry-pick a few recent articles for consideration, I tried to take a more systematic approach, using this as an opportunity to help update the systematic review by Semrau, et al. (2016) on user and caregiver involvement in mental health systems strengthening in LMICs.[47] However, there was a significant gap between Semrau et al.'s literature search, which ended in December 2013, and my search which covered the 18-month period between June 2017 through December 2018. As this was an unfunded research activity, I could not afford to bring on board a second reviewer to improve reliability or a translator to help identify texts in languages other than English, and did not conduct a grey literature search. Finally, the search strategy of the original review was not adequately tailored to lived experience involvement in research, specifically, as I later discovered when supervising a Master's student's scoping review on co-production in psychosis research.[51] For the scoping review, we included terms like "co-design" and "participatory research" that had been omitted from Semrau, et al.'s (2016) original search strategy, but learned from peer reviewers that even this more tailored search strategy may not have adequately captured all of the terminology used to describe research involvement internationally. I later supported the lived experience advisory group of a now defunct *Lancet* Commission to develop a more comprehensive search strategy on lived experience involvement in psychosis research, but that review is still ongoing. In short, it is very possible that examples of mental health research involvement in LMICs have been missed by the reviews published to-date, though I did try to identify a few recent ones in the background to this thesis.

11.3. Implications and Recommendations

Despite the various limitations of our efforts and the challenges encountered in involving peer workers in the Brain Gain II evaluation, we have demonstrated that it is possible to do. Social contact is one of the most effective interventions for reducing stigma and discrimination,[250] and this may be a mechanism by which even relatively modest efforts toward lived experience involvement could lead, eventually, to systemic change. As reported by Gupta and Roberts (2014), even when limited to research dissemination, collaboration between “traditional” researchers and people with lived experience generated new ideas for future research.[72] My own experience on Brain Gain II gave me the confidence to apply for funding for the much more ambitious SUCCEED Africa project,[81, 82] on which a former peer worker currently serves as a consultant. Another PhD project by Sisay Abayneh has also informed the involvement element of the HOPE consortium in Ethiopia.[77-79, 84, 85] Change may appear to be slow and incremental, but as in the famous Hemingway quote,[251] it often happens in “two ways […] gradually and then suddenly” (1926, pp.136). Recent developments, such as new funding from the Wellcome Trust,[18, 19] suggest we may be approaching a tipping-point.

This thesis also underscores the many important considerations to keep in mind when involving people with lived experience in research, particularly in low-resource settings. How will power be shared, at what stages and across which elements of the research? What resources, safeguarding and other precautions are needed to ensure that people with lived experience themselves do not become collateral damage? What can we learn from previous efforts, and how do we document and share our efforts in order to help others? Many of these questions are also being grappled with in HICs.[231, 240, 241] Fostering international communities of practice, perhaps linked to GMHPN or similar, is an important first step to harness and share learning across these different settings. While I would also recommend routinely and systematically evaluating efforts at involvement in LMICs, and can attest to the power of open-ended, qualitative methods to uncover unexpected consequences, I fear this simply will not happen quickly enough. It is important to note that this thesis was finally completed nearly seven years after data collection, and I have been warned on many occasions that it takes an average of seventeen years to translate research into practice.[252] Involvement research calls for more efficient strategies of knowledge exchange that go beyond publication in academic journals. Researchers must also think critically about their motivations and what values or guiding principles might be useful in troubleshooting the challenges that will inevitably arise in their work, as there will be situations in which there simply is no relevant prior experience on which to draw.

Finally, if Global Mental Health research is to move beyond consultation and contribution, toward collaboration and control by people with lived experience, there must be more inclusive and accessible pathways into this field. Mental health conditions frequently onset in adolescence or early adulthood, interrupting critical years for educational advancement and career development.[253] Particularly in LMICs, where secondary education often comes with school fees attached, people with lived experience may not have the qualifications required for graduate or postgraduate-level training. These issues are compounded by the cyclical relationship between poverty and poor mental health,[254] in which stigma, too, plays a critical role.[139] Meanwhile, opportunities for education and employment in Global Mental Health are largely concentrated in HICs with increasingly hostile immigration policies.[255] While at the Centre for Global Mental Health, I have seen overseas students with lived experience cobble together studentships and other funding, receive exemptions from admissions teams, and overcome immigration issues in order to study on our Global Mental Health MSc. But they are not many. Creating more in-country capacity-building opportunities for people with lived experience as part of ongoing research projects may be a more viable alternative, and indeed the opportunity to train was an important motivator for peer workers, as seen in Paper 5.

11.4. Conclusion

This PhD evolved as part of my own journey as a researcher and advocate of lived experience involvement in Global Mental Health. When I was first approached to work on Brain Gain II as someone with experience of M&E in African mental health care settings, the decision to involve peer workers was mainly a pragmatic one. However, I recognised that involvement might bring unexpected challenges and sought out advice and examples from others working in LMICs. To my dismay, I found none. This thesis offered an opportunity to document and derive lessons from our attempts to involve peer workers in study design, the development of study tools, data collection and interpretation, to help inform future efforts to promote research involvement in Global Mental Health. Ultimately, many of the experiences of peer workers involved in data collection were echoed in HIC literature on research involvement, though peer workers were often in exceptionally vulnerable situations, skirting a fine line between empowerment and exploitation. I recommend that LMIC research projects involving people with lived experience should critically reflect on the experience of involvement itself and share their insights, though empirical research may not always be the most efficient way of doing this. More support is needed to develop international communities of practice and other mechanisms of knowledge exchange on research involvement, in order to respond effectively to mounting calls to increase lived experience involvement in Global Mental Health and avoid either “reinventing the wheel” (Regan 2014, n.p.) or repeating past mistakes.[256]

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Appendices

Appendix 1. Statement of conjoint work

Student:

Grace Kathryn Ryan (lsh375171)

Supervisor (Dept/Faculty):

Prof. Karen Devries (DPH/EPH)

Thesis:

"Involving People with Lived Experience in the Evaluation of a Mental Health Peer Support Project in Uganda"

Statement:

The main body of this paper-style thesis is comprised of five chapters, each of which is the product of collaborative work on one or more of three research projects focused on evaluating peer support interventions in sub-Saharan Africa: Brain Gain II Uganda, on which I was a Co-I and Monitoring and Evaluation Lead; UPSIDES, on which I was a Co-I and Co-Lead of the Implementation Work Package; and SUCCEED Africa, on which I am Co-I and Research Manager. My role on each of these papers is outlined below.

1. **Narrative review of the literature on psychoses in sub-Saharan Africa**
    - **Citation:** Ryan GK*, Omigbodun OO* (joint first authors), Fasoranti B… Eaton J. Reprioritising global mental health: psychoses in sub-Saharan Africa. *Int J Ment Health Syst*. 2023 Mar 28;17(1):6. doi: 10.1186/s13033-023-00574-x.
    - **Role:** I am listed as joint first-author of this paper, though in reality I led on the conceptualization and coordination of the paper, carried out the literature review and critical appraisal myself, and drafted the full manuscript with the exception of the "implications and recommendations" section (as we felt this would be better co-produced by a peer researcher and Regional Research Director), with minimal supervision. Other authors contributed to the discussions that led to its conceptualization at a Theory of Change workshop (which I facilitated), reviewed drafts, provided critical feedback, and approved the final manuscript for submission. This division of responsibility is reflected in the "Contributions" section of the published manuscript.
2. **Rapid review of the literature on user involvement in mental health systems strengthening in low- and middle-income countries**
    - **Citation:** Ryan GK, Semrau M, Nkurunungi E, Mpango RS. Service user involvement in global mental health: what have we learned from recent research in low and middle-income countries? *Curr Opin Psychiatry*. 2019 Jul;32(4):355-360. doi: 10.1097/YCO.0000000000000506.
    - **Role:** For this rapid review, I replicated the search strategy of a systematic review previously published by the second author, restricting the results to an 18-month time period as per the journal's requirements. I was solely responsible for screening (again adopting the eligibility criteria of the previous review), data

extraction and synthesis. I drafted the full paper, with the exception of a paragraph on mental health advocacy and legislation in Uganda, which was co-produced by the former Operational Lead of Brain Gain II (last author) and a peer support worker administrator (fourth author). All authors reviewed drafts, provided critical feedback, and approved the final manuscript for submission.

3. **Protocol for quasi-experimental study involving peer workers in data collection**
    - **Citation:** Ryan GK, Kamuhiirwa M, Mugisha J… Mpango R. Peer support for frequent users of inpatient mental health care in Uganda: protocol of a quasi-experimental study. BMC Psychiatry. 2019 Nov 29;19(1):374. doi: 10.1186/s12888-019-2360-8.
    - **Role:** As the Brain Gain II M&E Consultant, I was responsible for all aspects of the study design and write-up of the protocol for ethical approval and dissemination. I led the Theory of Change workshops and produced the subsequent Theory of Change map identifying outcomes for evaluation. I conducted the desk-based background research to the protocol, for example identifying an appropriate primary outcome measure (WHODAS) and the parameters used in similar studies for my sensitivity analysis (which was supervised by my PhD supervisor and an advisory board member, both listed as co-authors). I developed the study procedures (e.g., for recruitment, consent, data collection, etc.) and original study tools (e.g., information sheets, consent forms, M&E forms). Authors from Butabika advised on how these procedures might work (e.g., how to collect baseline admissions data from hospital records, how to trace participants after discharge from inpatient care) and helped to facilitate the in-country ethics approvals. Authors from the East London NHS Link advised on similar research on peer support in high-income settings and provided missing details on the background to the Brain Gain projects. All authors critically reviewed drafts and approved the final manuscript for submission. My responsibilities are reflected in the “Contributions” section of the published manuscript.
4. **Results of Knowledge, Attitudes and Practices survey developed in collaboration with peer workers**
    - **Citation (anticipated):** Ryan GK*, Vallentin S* (joint first authors), Kamuhiirwa M… Mpango R. Recovery-oriented interventions and the knowledge, attitudes and practices of psychiatric hospital staff in Kampala, Uganda: A cross-sectional survey (manuscript in preparation).
    - **Role:** I conceptualised this paper as a way of involving peer workers in evaluating the impact of the Brain Gain II project on the hospital. I co-facilitated (with the third author) workshops with peer workers to develop questions for the survey and integrated these into a draft tool alongside additional questions suggested by volunteers from the East London NHS Link. I also co-facilitated (with the last author) the review sessions in which the tool was finalised. As with the quasi-experimental component of the Brain Gain II evaluation (see above), I was responsible for designing study tools and procedures with advice from other co-authors. I co-facilitated (with the last author) the training of data collectors, and co-supervised data collection with the in-country M&E team, splitting responsibilities for data entry with the volunteer. I am listed as a joint first-author of this paper in order to acknowledge a former student of our Global Mental Health MSc, who carried out an initial analysis of the dataset as part of a summer project that I supervised. In response to recommendations from the examiners and from a feedback session that East London NHS Link members led at

Butabika, we ultimately decided that I should re-analyse the dataset and draft a new manuscript (rather than simply editing down the student’s project for publication). I cleaned the dataset, performed my own analysis in STATA and produced the new draft with oversight from my PhD supervisor and a member of my advisory committee (both listed as co-authors). All co-authors critically reviewed drafts and approved the final manuscript.

5. **Qualitative study of experiences involving peer workers in data collection**
    - **Citation (anticipated):** Ryan GK, Kamuhiirwa M, Newman C… Mugisha J. Lived experience involvement in the evaluation of a recovery-oriented mental health project in Uganda: A qualitative analysis of barriers, facilitators and recommendations (manuscript in preparation).
    - **Role:** As with all other aspects of the Brain Gain II evaluation, I was responsible for designing the study tools and procedures for this qualitative research. I carried out all English-language interviews and female focus group discussions myself. The third and last authors led non-English (Luganda) interviews and focus group discussions. Although we used external transcription services, I checked all transcripts against the original (English-language) audio where possible, and reviewed and copy-edited all translated transcripts as needed. I carried out all coding and analysis myself in Nvivo, and drafted the manuscript for review by co-authors. However, at this stage co-authors have not had the opportunity to critically review the manuscript. I expect to circulate the draft before submitting my thesis.

Supervisor Signature and Date:

I declare the above to be correct and true to the best of my knowledge.

Student Signature	**Date**	**Supervisor Signature**	**Date**
[redacted]	09/02/24	[redacted]	**14/02/24**

Appendix 2. Supplementary material for Paper 1

Appendix 2.1 Search terms adapted from Semrau, et al. (2016)

Service users

#1 Search: (exp Patient Participation/ OR exp Consumer Participation/) OR (patient involvement OR client involvement OR service user involvement OR client participation OR service user participation OR patient participation OR service user engagement OR patient engagement OR service user co-production OR patient co-production).mp.

Health system and services / research

#2 Search: (exp Delivery of Health Care/ OR exp Health Policy/ OR exp Health Services/ OR exp Mental Health Services/ OR exp Community Mental Health Services/ OR exp Community Health Planning) OR (delivery of health care OR health care delivery OR health system strengthening OR health policy OR health policies OR health system OR health systems OR health services OR mental health system OR mental health systems OR mental health services OR community mental health services).mp.

OR

Exp Research/ OR research.mp.

Mental health

#3 Search: (exp Mental health/ OR exp Mental Disorders/) OR

("drug abuse" OR "drug addict*" OR "drug depend* *" OR "drug dependence*" OR "drug withdrawal" OR "drug abuse") OR

("addictive disease*" OR "addictive disorder*") OR

("alcoholic patient*" OR "alcoholic subject*" OR alcoholism OR "alcohol dependent*" OR "alcohol dependence*" OR "fetal alcohol*" OR "prenatal alcohol*" OR "chronic ethanol*" OR "chronic* alcohol*" OR "alcohol withdrawal" OR "ethanol withdrawal") OR

("caffeine dependent*" OR "caffeine dependence" OR "caffeine addiction" OR (caffeine AND addict*) OR "caffeine withdrawal") OR

(((cocaine OR heroin OR cannabis OR mdma OR ecstasy OR morphine*) AND (abuse OR depend* OR dependent* OR dependence* OR addict* OR addicts OR addicted OR addiction* OR withdrawal) OR methadone) OR

(addiction OR addictive OR "substance abuse" OR "withdrawal syndrome" OR psychoactive*) OR

((schizophrenia OR schizophrenic) OR Schizotyp* OR ((Delusional OR paranoid) AND disorder*) OR hallucination* OR Psychotic OR Schizoaffective OR psychosis) OR (((manic OR bipolar OR mood) AND disorder*) OR (depressive AND (disorder* OR episode*)) OR "depressive symptom*" OR hypomania OR mania* OR ((major OR psychotic OR disorder*) AND depression) OR "suicide attempt*" OR suicidal* OR cyclothymia OR Dysthymia) OR

(((anxiety OR panic OR "Obsessive-compulsive" OR adjustment OR conversion OR dissociative OR Somatoform OR Somatization OR neurotic) AND disorder*) OR ("hypochondriasis*" OR "body dysmorphic disorder*" OR "pain disorder*") OR agoraphobia OR "social phobia*" OR "Post-traumatic stress" OR "stress disorder*") OR

("Eating disorder*" OR "Anorexia nervosa" OR "Bulimia nervosa" OR "sleep disturbance" OR (sexual AND (disorder* OR dysfunction)) OR ((postnatal OR postpartum) AND depression) OR ((antidepressant* OR

laxative* OR analgesic* OR psychotropic* OR vitamin* OR steroids OR hormone*) AND abuse) OR

((insomnia OR sleepiness OR "sleep disturbance") NOT (apnea OR "side effect*" OR parkinson* OR alzheimer OR neurodegenerat* OR cancer OR obesity OR obese*)) OR (hypersomnia NOT narcolepsy) OR ((sleep OR night) AND terror*) OR nightmare* OR

((disorder* AND (personality OR identity OR impulse* OR impulsive* OR impulsivity)) OR asocial OR antisocial OR psychopathic OR anxious OR narcissi* OR "Pathological gambling" OR pyromania* OR Trichotillomania OR Psychosexual OR ("Munchhausen syndrome")) OR

("Pervasive developmental disorder*" OR autism OR autistic* OR "Rett* syndrome" OR "Asperger* syndrome") OR

((Hyperkinetic OR Conduct OR Emotional OR tic) AND disorder*) OR (anxiety AND (separation OR phobic OR social)) OR (hyperactivity AND (disorder* OR syndrome)) OR "Tourette syndrome" OR " Tourette's syndrome") OR

((Mental AND (disorder* OR illness OR health OR health condition OR distress)) OR "psychological distress" OR "psychiatric disorder ") OR

(Nervousness OR "nervous tension" OR Irritability) OR anorexia OR (neurosis OR neuroses OR psychoses) OR (("mental confusion*") OR ("mental disability*") OR ("mental capacity*") OR ((psychiatric OR mental) AND (comorbidity OR comorbid)) OR psychiatry OR psychology))

LMICs

#4 Search:

(developing OR less developed OR under developed OR underdeveloped OR middle income OR low income OR lower income).mp. AND (countr* OR nation* OR population* or world).mp.

OR

(transitional OR developing OR less developed OR lesser developed OR under developed OR underdeveloped OR middle income OR low income OR lower income).mp. AND (economy OR economies).mp.

OR

((low*).mp. AND (gdp OR gnp OR gross domestic OR gross national).mp.) OR (lmic OR lmics OR lamics OR lamic OR third world OR lami countries OR lami country).mp. OR (transitional country OR transitional countries).mp.

OR

Exp Developing Countries/

OR

(Afghanistan or Albania or Algeria or Angola or Antigua or Barbuda or Argentina or Armenia or Armenian or Aruba or Azerbaijan or Bangladesh or Benin or Byelarus or Byelorussian or Belarus or Belorussian or Belorussia or Belize or Bhutan or Bolivia or Bosnia or Herzegovina or Hercegovina or Botswana or Brazil or Bulgaria or Burkina Faso or Burkina Fasso or Upper Volta or Burundi or Urundi or Cambodia or Khmer Republic or Kampuchea or Cameroon or Cameroons or Cameron or Camerons or Cape Verde or Central African Republic or Chad or Chile or China or Colombia or Comoros or Comoro Islands or Comores or Mayotte or Congo or Zaire or Costa Rica or Cote d Ivoire or Ivory Coast or Croatia or Cuba or Cyprus or Czechoslovakia or Czech Republic or Slovakia or Slovak Republic or Djibouti or French Somaliland or Dominica or Dominican Republic or East Timor or East Timur or Timor Leste or Ecuador or Egypt or El Salvador or Eritrea or Estonia or Ethiopia or Fiji or Gabon or Gabonese Republic or Gambia or Gaza or Georgia Republic or Georgian Republic or Ghana or Gold Coast or Grenada or Guatemala or Guinea or Guam or Guiana or Guyana or Haiti or Honduras or India or Maldives or Indonesia or Iran or Iraq or Jamaica or Jordan or Kazakhstan or Kazakh or Kenya or Kiribati or Korea or Kosovo or Kyrgyzstan or Kirghizia or Kyrgyz or Kirghiz or Kirgizstan or Lao PDR or Laos or Latvia or Lebanon or Lesotho or Basutoland or Liberia or Libya or Lithuania or Macedonia or Madagasca or Malagasy or Malaysia or Malaya or Malay or Sabah or Sarawak or Malawi or Nyasaland or Mali or Marshall Islands or Mauritania or Mauritius or Agalega Islands or Mexico or Micronesia or Middle East or Moldova or Moldovia or Moldovian or Mongolia or Montenegro or Morocco or Ifni or Mozambique or Myanmar or Myanma or Burma or Namibia or Nepal or Netherlands Antilles or New Caledonia or Nicaragua or Niger or Nigeria or Mariana Islands or Oman or Muscat or Pakistan or Palau or Palestine or Panama or Paraguay or Peru or Philippines or Philipines or Phillipines or Phillippines or Romania or Rumania or Roumania or Russia or Russian or Rwanda or Ruanda or Saint Kitts or St Kitts or Nevis or Saint Lucia or St Lucia or Saint Vincent or St Vincent or Grenadines or Samoa or Samoan Islands or Navigator Island or Navigator Islands or Sao Tome or Senegal or Serbia or Montenegro or Seychelles or Sierra Leone or Slovenia or Sri Lanka or Ceylon or Solomon Islands or Somalia or Somaliland or Sudan or Suriname or Surinam or Swaziland or Syria or Tajikistan or Tadzhikistan or Tadjikistan or Tadzhik or Tanzania or Thailand or Togo or Togolese or Tonga or Trinidad or Tobago or Tunisia or Turkey or Turkmenistan or Turkmen or Uganda or Ukraine or Uruguay or USSR or Soviet Union or Union of Soviet Socialist Republics or Uzbekistan or Uzbek or Vanuatu or New Hebrides or Venezuela or Vietnam or Viet Nam or West Bank or Yemen or Yugoslavia or Zambia or Zimbabwe or Rhodesia).mp.

Limits

Years 2017-2018 only

Appendix 2.2. Data extraction from included studies

Author, Year	Countries involved	Funder	Description of study	Study methods	Participant group and sample size	Description of involvement	Summary of key findings
Fan, Ma, Ma, et al. (2018)	China	Beijing Health Development Research Project, National Natural Science Foundation of China	Quantitative evaluation of community-based peer support service.	**Quantitative:** Structured interviews (yes/no questions) with consumers and caregivers in two of four communities served and with all peer providers ("peers"), reporting on outcomes related to service satisfaction and perceived benefit.	21 consumers, 15 caregivers and 12 peer providers (66.67% male) Sex reported for peer providers only.	Peer providers deliver peer support activities such as skills training, psychoeducation and emotional support.	Consumers: 79.2% (p<0.001) satisfied with peers, 70.8% (p=0.005) wanted to continue. 41.7% (p=0.827) reported improved communication skills. Caregivers: 93.3% (p=0.001) wanted consumers or peers to continue, 33.3% (p=0.197) reported improvement in mood, 40% (p=0.197) reported observing improved communication skills among consumers or peers. Peers: 85.7% (p=0.059)

							reported improved working skills, 57.1% (p=0.507) reported improved communication skills.
Hanlon, Eshetu, Alemayehu, et al. (2017)	Ethiopia	EU	Situation analysis to inform mental health systems strengthening in Ethiopia through Emerald.	**Qualitative:** In-depth, semi-structured interviews with national/ regional leaders and planners, district level planners and health facility managers.	National/ regional level: 3 planners, 4 leaders involved in service development. District level: 2 planners, 8 health facility managers. Sex not reported.	Study reveals lack of service user involvement in policy and planning.	Particularly at district level, respondents were receptive to idea of user and caregiver involvement, but recognised it was not practiced.
Lempp, Abayneh, Gurung, et al. (2017)	Ethiopia, Nepal, Nigeria	EU	Cross-country situation analysis on involvement of users and caregivers in mental health systems strengthening.	**Qualitative:** In-depth, semi-structured interviews with users, caregivers, heads of mental health centres and policy-makers.	Ethiopia: 13 service users, 10 caregivers, 8 heads of primary care facilities and 8 policy-makers. Nepal: 14 service users, 10 caregivers. Nigeria: 10 service users, 10 caregivers. Sex not reported.	Study concludes involvement “is still in its infancy in LMICs” (pp.9) across the board.	Four key themes discussed, related to participants’ experience of involvement, barriers to and perceived benefits of involvement, and strategies to increase involvement. Key recommendation is for further investment to improve user

							and caregiver involvement.
Mathias, Mathias, Goicolea and Kermode (2017)	India	Private donation	Case study evaluating the Burans project.	**Qualitative:** focus group discussions and participant observation. **Quantitative:** analysis of routinely collected project data.	Unclear. People with psychosocial disabilities, carers, Burans team and other community members participated.	Focus of project is on building community mental health competence generally, however people with psychosocial disabilities and caregivers targeted for participation in support groups, some of which are led by people with psychosocial disabilities.	Participating in support groups helped to improve social support and inclusion of people with psychosocial disabilities.
Mathias, Pant, Marella, et al. (2018)	India	CBM	Survey assessing prevalence of psychosocial disabilities and barriers to participation.	**Quantitative:** cross-sectional survey of a population-based random sample in Sahaspur block, Dehradun District, using Rapid	2,441 community members (51.6% male).	Survey reveals lack of involvement in consultations at community level. Three of the eleven data collectors for this survey had either physical or	2.5% more people with psychosocial disabilities reported lack of information about consultations, compared to general

				Assessment of Disability survey tool and adapted Kessler scale.		psychosocial disabilities.	population; however, finding was not statistically significant (p=0.50). Outcomes of involvement in data collection not reported.
Petersen, Marais, Abdulmalik, et al. (2017)	Ethiopia, India, Nepal, Nigeria, South Africa, Uganda	EU	Cross-country situation analysis inform mental health systems strengthening across all Emerald countries.	**Qualitative:** In-depth, semi-structured interviews with national/ regional, provincial and district level stakeholders including policy-makers, planners and managers.	Ethiopia: 7 policy-makers, 10 district planners and managers India: 20 national policy-makers, 6 provincial planners, 7 district planners and managers Nepal: 17 national policy-makers, 11 district planners and managers Nigeria: 6 national policy-makers, 4 provincial planners, 20 district planners and managers South Africa: 4 national policy-	Study reveals lack of service user involvement in policy and planning across all participating countries, but notes India may be an exception; further information on involvement in India not provided.	Study concludes there is poor participation of users in the development of policies and plans, and recommends strategies be developed to support development of user groups and build capacity to improve collaboration between of both users and managers.

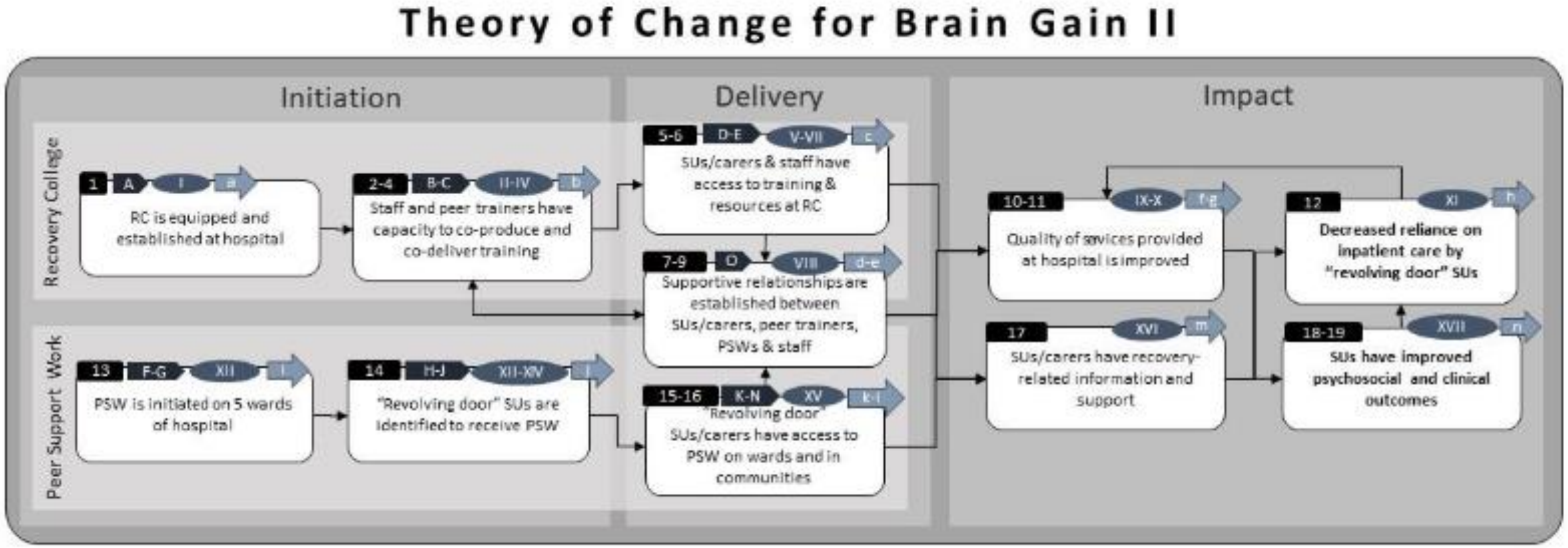
					makers, 5 provincial planners, 8 district planners and managers Uganda: 8 national policy-makers, 8 district planners and managers Sex not reported.		
Rai, Gurung, Kaiser, et al. (2018)	Nepal	DFID, NIMH	Formative research to inform the RESHAPE trial.	**Qualitative:** key informant interviews of users selected as training co-facilitators and their carers.	9 service users (33.33% male) and 8 caregivers (37.5% male).	Service users have been selected as co-facilitators of an anti-stigma training delivered to primary care workers alongside mhGAP.	Engaging with caregivers is crucial to facilitating involvement of service users. Study reports on benefits as well as burdens of and barriers to involvement of service users, primarily from the caregivers' perspective.
Souraya, Hanlon and Asher (2018)	Ethiopia	DFID, LSHTM, Wellcome Trust	Qualitative study investigating community-based rehabilitation workers' roles in improving involvement in decision-making, conducted as	**Qualitative:** focus group discussions with community-based rehabilitation workers and in-depth interviews with people with schizophrenia,	Focus groups: 10 CBR workers. Interviews: 6 people with schizophrenia (66.67% male), 7 caregivers, 2 health officers, 1 supervisor, 1	Community-based rehabilitation workers attempt to mediate between people with schizophrenia, their caregivers and healthcare	Although community-based rehabilitation workers can be mobilised to improve involvement in decision-making, involvement

			part of RISE trial pilot.	caregivers and a community-based rehabilitation worker.	community-based rehabilitation worker. Sex reported for people with schizophrenia only.	providers, in order to improve involvement of people with schizophrenia in decision-making regarding their treatment.	remains limited due to social, cultural and practical constraints in this setting.
Sumskiene, Petruzyte and Klimaite (2018)	Lithuania	No funder reported	Qualitative study evaluating treatment available via Lithuania's mental health care system.	**Qualitative:** semi-structured interviews with patients of two mental health centres (one primary care-level, one secondary-care level) and experts.	30 patients (40.0% male) and 20 experts. Sex reported for patients only.	Study reveals lack of involvement of patients in decision-making regarding treatment, particularly in relation to biomedical versus psychotherapeutic treatment.	Human resource shortages in the public sector have contributed to an overreliance on biomedical treatment, which may in turn hinder involvement of patients in decision-making, partly due to disabling side effects of medication.
Zaini, Bharathy, Sulaiman, et al. (2018)	Malaysia	University of Malaya	Formative research to inform development of a shared decision-making tool for depression.	**Qualitative:** focus group discussions with patients diagnosed with major depressive disorder and doctors involved in psychiatric outpatient care.	11 patients (9.09% male) and 19 doctors (53.6% male).	Involvement as research subjects in formative research to develop a shared-decision making tool that aims to ultimately increase participation in	Development of tools and processes intended to promote shared decision-making require patient involvement. Six key themes identified as important for

						decision-making on treatment of major depression.	decision-making: presentation of treatment options, instructions on how to take medications, side effects, cost, pharmacist input and examples of previous patients' experiences.

Appendix 3. Supplementary material for Paper 3

Appendix 3.1. Brain Gain II Theory of Change Map



■ **INDICATORS**

1. Building refurbishment completed by target date
2. Number of attendees completing TOTs, disaggregated by attendee type
3. Proportion of attendees able to develop and execute a lesson plan during TOT demonstration
4. Mean improvement in peer assessment score between first and second TOT
5. Average number of RC trainings held per month after opening
6. Average RC training attendance, disaggregated by attendee type
7. Qualitative data collected from SUs, peer trainers and staff
8. Difference in family support scores at 6 month follow-up
9. Qualitative data collected from SUs, PSWs, staff and hospital administrators
10. Change in knowledge, attitudes and practices of hospital staff
11. Difference in patient satisfaction score
12. Change in number of inpatient days at 6 month follow-up
13. Proportion of identified wards accepting initial PSW visits
14. Average number of appropriate referrals to PSW per month, disaggregated by ward
15. Proportion of appropriate referrals receiving at least 1 ward and 3 community PSW visits
16. Average number of contacts with a PSW, disaggregated by contacts with SU alone, carer(s) alone, or SU and carers together
17. Perceptions of SUs and PSWs as discussed in focus groups
18. Difference in WHODAS 12-item disability score
19. Self-reported change in psychosocial circumstances, disaggregated by change in employment, education, relationships

RATIONALES

a. Location at hospital ensures accessibility and decreases stigmatization of Butabika
b. Co-production and co-delivery increase social contact between staff and peer trainers and role-model principles of equality to trainees, reducing stigma and building relationships
c. Creating a space for staff, SUs and carers to use increases social contact, reducing stigma and building relationships
d. Having relationships with SUs, peer trainers and PSWs encourages staff and carers to treat SUs as equals
e. PSWs add to SUs and carers social support network in the community
f. Quality services will better prepare SUs to manage in the community, decreasing likelihood of readmission
g. Quality services will improve outcomes of SUs leaving hospital
h. High patient load negatively impacts quality of care
i. Adult admissions wards are included except for drug and alcohol unit, as PSWs have not yet been trained to address addiction
j. "Revolving door" SUs are more likely to have issues managing their illness in the community, which PSWs aim to support
k. Having PSWs on wards increases social contact with staff, allows PSWs to help problem-solve when issues with inpatient care arise, and allows PSWs provide transitional support back to community at a point when SUs are particularly vulnerable
l. Having PSW in community helps to bolster social support network and problem-solve in the community, partially through interaction with carer
m. Adopting a recovery-oriented approach to care encourages illness management in the community and may improve outcomes
n. If outcomes are better, SUs will not require as much inpatient care

ASSUMPTIONS

I. Hospital staff and administration are willing and able to make a facility available for RC
II. Trainers are willing and able to collaborate
III. Trainers are willing and able to attend TOTs
IV. TOTs build sufficient capacity
V. Trainers are willing and able to produce and deliver regular trainings
VI. SUs, carers and staff are willing and able to attend RC without compensation
VII. Programme has sufficient human and material resources to keep RC open regularly for project duration
VIII. Interventions delivered through RC and PSW are sufficient to change relationships
IX. Interventions delivered and supportive relationships built through RC and PSW are capable of changing the quality of services
X. Reduction in client load from "revolving door" SUs is sufficient to enable hospital staff to take on quality improvement measures
XI. Better outcomes and access to quality services, information and support are sufficient to change illness management behavior
XII. PSWs from Brain Gain I are willing and able to deliver service on wards
XIII. Hospital staff and administration are willing to have PSWs on the wards
XIV. Ward staff are willing and able to identify and refer "revolving door" SUs
XV. PSWs, SUs and carers are willing and able to complete full course of visits
XVI. RC and PSW interventions are sufficient to equip SUs and carers
XVII. Information, support and quality services are sufficient to improve outcomes

INTERVENTIONS

A. Purchase equipment (furniture, computers, books, teaching supplies) and refurbish community building
B. Recruit staff from wards and peer trainers from existing PSWs and former peers from Brain Gain I
C. Conduct two TOTs for staff and peer trainers to attend collaboratively
D. Develop educational films on recovery and common questions about MNS disorders, as resources for RC
E. Conduct bi-monthly, co-produced and co-delivered trainings on recovery-related topics for a variety of attendee types
F. Recruit Brain Gain II PSWs from existing PSWs trained in Brain Gain I
G. Initiate mutual support groups for supervision
H. Conduct trainings of trainers for ward in-charges to learn to use referral forms
I. Ward in-charges train and supervise ward staff to make referrals
J. Monitoring and Evaluation Officer works with hospital staff to confirm "revolving door" status by examining patient records
K. PSWs are assigned correctly referred SUs in their respective catchment areas
L. PSWs conduct a minimum of 1 ward visit and 3 community visits to each assigned SU, interfacing with carers and ward staff as needed
M. During visits, PSWs role-model, educate on principles of recovery, aid in problem-solving, and/or offer encouragement, as needed
N. Ongoing monitoring and evaluation is carried out to confirm that SUs are receiving visits as intended
O. Staff accompany PSWs on visits for specialist assistance on an as-needed basis

Appendix 3.2. Sensitivity analysis for primary outcomes

						Receiving PSW Visits			**Receiving Standard Care**			**Combined**
Variable	Power	Alpha	ICC	Ratio	Effect Size	Mean	SD	Sample	Mean	SD	Sample	Total Sample[6]
Hospital Days	0.90	0.05	0.01	3:1	20%	47.72	28.07	261	59.65	28.07	78	339
					30%	41.76	28.07	**111**	59.65	28.07	**35**	**146***
				2:1	20%	47.72	28.07	192	59.65	28.07	88	280
					30%	41.76	28.07	**82**	59.65	28.07	**39**	**121***
				1:1	20%	47.72	28.07	127	59.65	28.07	117	244
					30%	41.76	28.07	**54**	59.65	28.07	**52**	**106***
			0.04	3:1	20%	47.72	28.07	396	59.65	28.07	78	474
					30%	41.76	28.07	**126**	59.65	28.07	**35**	**161***
				2:1	20%	47.72	28.07	268	59.65	28.07	88	356
					30%	41.76	28.07	**92**	59.65	28.07	**39**	**131***
				1:1	20%	47.72	28.07	164	59.65	28.07	117	281
					30%	41.76	28.07	**59**	59.65	28.07	**52**	**111***

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[6] Asterisk indicates a feasible sample size based on programme targets and assumptions.

	0.80	0.05	0.01	3:1	20%	47.72	28.07	189	59.65	28.07	58	247
					30%	41.76	28.07	**81**	59.65	28.07	**26**	**107***
				2:1	20%	47.72	28.07	140	59.65	28.07	66	206
					30%	41.76	28.07	**60**	59.65	28.07	**29**	**89***
				1:1	20%	47.72	28.07	**93**	59.65	28.07	**87**	**180***
					30%	41.76	28.07	**40**	59.65	28.07	**39**	**79***
			0.04	3:1	20%	47.72	28.07	246	59.65	28.07	58	304
					30%	41.76	28.07	**90**	59.65	28.07	**26**	**116***
				2:1	20%	47.72	28.07	176	59.65	28.07	66	242
					30%	41.76	28.07	**66**	59.65	28.07	**29**	**95***
				1:1	20%	47.72	28.07	**112**	59.65	28.07	**87**	**199***
					30%	41.76	28.07	**43**	59.65	28.07	**39**	**82***
Rehospitalisations	0.90	0.05	0.04	3:1	20%	1.32	0.24	**27**	1.65	0.24	**8**	**35***
				2:1	20%	1.32	0.24	**18**	1.65	0.24	**9**	**27***
				1:1	20%	1.32	0.24	**12**	1.65	0.24	**12**	**24***

Appendix 4. Supplementary material for Paper 4

Appendix 4.1. Description of staff types

Staff type	Specific occupations	Description
Clinical staff	• Psychiatrists • Clinical psychologists • Psychiatric clinical officers • Occupational therapists • Psychiatric nurses • Nursing officers • Laboratory technicians • Pharmacists	In direct contact with patients, varying levels of medical training.
Administrative staff	• Accountants • Managers • Secretaries • IT technicians	No direct contact with patients. No medical training required, although a small number of formerly clinical staff have been promoted into management roles.
Support staff	• Cleaners • Cooks • Hospital drivers	In direct contact with patients. No medical training.
Security	“Askaris”	In direct contact with patients. No medical training.

Appendix 4.2. Knowledge, Attitudes and Practices (KAP) survey tool and scoring

A. ADMINISTRATIVE INFORMATION

1. **Name of person administering the survey:**
2. **Date the survey was administered** (DD/MM/YY):
3. **Gender of respondent** (circle one): Male Female
4. **Age of respondent:**

B. BACKGROUND INFORMATION

Suggested script: *Thank you for agreeing to take part in this survey. Before we begin, I would like to ask you for some background information.*

5. **What best describes your role at Butabika Hospital?** (Choose one):
   a. Security (i.e. “Askari”)
   b. Support staff (i.e. cleaner, caterer)
   c. Administrator (i.e. secretary, records keeper)
   d. Clinical professional (i.e. social worker, occupational therapist, nurse, doctor, psychologist, psychiatric clinical officer, psychiatrist)
6. **Have you ever heard of the Recovery College at Butabika Hospital?**
   Yes No
   (If “No”, skip to 9.)
7. **Have you ever attended a Recovery College Training at Butabika?**
   Yes No
8. **Have you ever co-delivered a Recovery College Training at Butabika?**
   Yes No
9. **Have you ever heard of Peer Support Workers at Butabika?**
   Yes No
   (If “No”, skip to 12.)
10. **Have you ever met a Peer Support Worker at Butabika?**
    Yes No
11. **Have you ever worked with a Peer Support Worker at Butabika?**
    Yes No

C. KAP INFORMATION: Yes/No Questions

Suggested script: *Thank you for providing some background information. For this next section, I am going to read several phrases. I’d like you to tell me whether you agree or disagree with each statement, and how strongly.*
Marking instructions: Recovery-oriented responses are underlined.

12. **It is possible for someone to recover from a mental illness** (choose one):
    1-Strongly disagree
    2-Disagree
    3-Neither agree nor disagree
    4-Agree
    5-Strongly agree
13. **A person who has suffered from a mental illness can have a “normal life”, for example: a house, a family and a job** (choose one):
    1-Strongly disagree
    2-Disagree
    3-Neither agree nor disagree
    4-Agree

5-Strongly agree

14. **I would be comfortable having someone who has suffered from a mental illness as a co-worker** (choose one):
1-Strongly disagree
2-Disagree
3-Neither agree nor disagree
4-Agree
5-Strongly agree

15. **Most people who are suffering from a mental illness are violent** (choose one):
1-Strongly disagree
2-Disagree
3-Neither agree nor disagree
4-Agree
5-Strongly agree

16. **There are people suffering from mental illnesses whom I consider to be my friends** (choose one):
1-Strongly disagree
2-Disagree
3- Neither agree nor disagree
4-Agree
5-Strongly agree

17. **If a person who has suffered from a mental illness begins to show any signs of relapse, he or she should be admitted to the Hospital immediately** (choose one):
1-Strongly disagree
2-Disagree
3- Neither agree nor disagree
4-Agree
5-Strongly agree

18. **A person who has suffered from a mental illness can manage money well** (choose one):
1-Strongly disagree
2-Disagree
3- Neither agree nor disagree
4-Agree
5-Strongly agree

19. **At times it may be necessary to beat a person who has a mental illness** (choose one):
1-Strongly disagree
2-Disagree
3- Neither agree nor disagree
4-Agree
5-Strongly agree

20. **There are other effective treatments for mental illness besides medication** (choose one):
1-Strongly disagree
2-Disagree

3- Neither agree nor disagree
4-Agree
5-Strongly agree

21. **I would advise my brother or sister against marrying someone who has suffered from a mental illness** (choose one):
1-Strongly disagree
2-Disagree
3- Neither agree nor disagree
4-Agree
5-Strongly agree

22. **A person who has been diagnosed with a mental illness must take medication for life** (choose one):
1-Strongly disagree
2-Disagree
3-Neither agree nor disagree
4-Agree
5-Strongly agree

23. **Patients at Butabika do not usually understand their diagnosis or symptoms** (choose one):
1-Strongly disagree
2-Disagree
3-Neither agree nor disagree
4-Agree
5-Strongly agree

24. **Patients at Butabika are usually informed about the possible side effects of their medication** (choose one):
1-Strongly disagree
2-Disagree
3-Neither agree nor disagree
4-Agree
5-Strongly agree

25. **People suffering from mental illnesses should not be given any responsibility** (choose one):
1-Strongly disagree
2-Disagree
3-Neither agree nor disagree
4-Agree
5-Strongly agree

26. **People who have suffered from mental illnesses can have a bad influence on each other** (choose one):
1-Strongly disagree
2-Disagree
3-Neither agree nor disagree
4-Agree
5-Strongly agree

27. **Patients at Butabika play an active role in discussing treatment options with their care providers** (choose one):

1-Strongly disagree
2-Disagree
3-Neither agree nor disagree
4-Agree
5-Strongly agree

28. **Anyone who has suffered from a mental illness should not be allowed to take public office** (choose one):
    1-Strongly disagree
    2-Disagree
    3-Neither agree nor disagree
    4-Agree
    5-Strongly agree

29. **I would not want to live next door to someone who has suffered from a mental illness** (choose one):
    1-Strongly disagree
    2-Disagree
    3-Neither agree nor disagree
    4-Agree
    5-Strongly agree

D. KAP INFORMATION: Multiple Choice Questions

Suggested script: *Thank you for answering those questions. For this next section, I am going to read several questions and several possible answers for you to choose from.*

30. **Which of the following other phrases are acceptable when speaking about a person with mental illness?** (Choose all that apply.)
    a. “Kataala”
    b. “Mulwadde wa mute”
    c. “Zonto”
    d. “Mularu”
    e. None of the above

31. **What does “recovery” from mental illness mean?** (Choose all that apply.)
    a. Never using drugs or alcohol anymore
    b. Not experiencing any symptoms of mental illness anymore
    c. A personal journey of positive change in someone’s life
    d. None of the above

32. **Which of the following are examples of “peer support” for mental illness?** (Choose all that apply.)
    a. People with lived experience of mental illness educating one another on the need to take medication
    b. People with lived experience of mental illness sharing personal stories with one another about their illness
    c. People with lived experience of mental illness helping staff to dispense medication on the ward
    d. None of the above

Appendix 4.3. Responses to Likert scale questions, by staff type

Question	Staff type	*Strongly disagree*		*Disagree*		*Neither agree nor disagree*		*Agree*		*Strongly agree*	
		n	%	*n*	%	*n*	%	*n*	%	*n*	%
12.	Clinical	0	0.00	0	0.00	0	0.00	15	48.39	16	51.61
	Security	0	0.00	0	0.00	1	12.50	6	75.00	1	12.50
	Support staff	0	0.00	0	0.00	3	17.65	11	64.71	3	17.65
	Administrative	0	0.00	0	0.00	1	16.67	2	33.33	3	50.00
13.	Clinical	0	0.00	0	0.00	0	0.00	6	19.35	25	80.65
	Security	0	0.00	0	0.00	0	0.00	3	37.50	5	62.50
	Support staff	1	5.88	0	0.00	0	0.00	9	52.94	7	41.18
	Administrative	0	0.00	0	0.00	0	0.00	4	66.67	2	33.33
14.	Clinical	1	3.23	2	6.45	2	6.45	16	51.61	10	32.26
	Security	0	0.00	3	37.50	0	0.00	3	37.50	2	25.00
	Support staff	0	0.00	2	11.76	2	11.76	9	52.94	4	23.53
	Administrative	0	0.00	1	16.67	0	0.00	3	50.00	2	33.33
15.	Clinical	5	16.13	19	61.29	3	9.68	3	9.68	1	3.23
	Security	0	0.00	1	12.50	0	0.00	4	50.00	3	37.50
	Support staff	1	5.88	8	47.06	1	5.88	7	41.18	0	0.00
	Administrative	1	16.67	2	33.33	1	16.67	2	33.33	0	0.00
16.	Clinical	0	0.00	0	0.00	0	0.00	14	45.16	17	54.84
	Security	0	0.00	0	0.00	1	12.50	6	75.00	1	12.50
	Support staff	0	0.00	1	5.88	0	0.00	9	52.94	7	41.18
	Administrative	0	0.00	0	0.00	0	0.00	3	50.00	3	50.00
17.	Clinical	0	0.00	11	36.67	3	10.00	15	50.00	1	3.33
	Security	0	0.00	0	0.00	0	0.00	3	37.50	5	62.50
	Support staff	1	6.25	0	0.00	0	0.00	6	37.50	9	56.25
	Administrative	0	0.00	1	16.67	0	0.00	3	50.00	2	33.33
18.	Clinical	0	0.00	1	3.23	0	0.00	22	70.97	8	25.81
	Security	0	0.00	3	37.50	1	12.50	3	37.50	1	12.50
	Support staff	1	5.88	5	29.41	3	17.65	6	35.29	2	11.76
	Administrative	1	16.67	2	33.33	0	0.00	2	33.33	1	16.67
19.	Clinical	12	38.71	17	54.84	2	6.45	0	0.00	0	0.00
	Security	0	0.00	4	50.00	1	12.50	3	37.50	0	0.00
	Support staff	7	41.18	9	52.94	0	0.00	1	5.88	0	0.00
	Administrative	1	16.67	2	33.33	0	0.00	3	50.00	0	0.00
20.	Clinical	3	10.00	4	13.33	0	0.00	9	30.00	14	46.67
	Security	1	12.50	2	25.00	1	12.50	3	37.50	1	12.50
	Support staff	5	29.41	3	17.65	3	17.65	4	23.53	2	11.76
	Administrative	1	16.67	1	16.67	0	0.00	3	50.00	1	16.67
21.	Clinical	3	9.68	9	29.03	7	22.58	8	25.81	4	12.90
	Security	0	0.00	0	0.00	2	28.57	1	14.29	4	57.14
	Support staff	1	5.88	7	41.18	3	17.65	5	29.41	1	5.88
	Administrative	1	16.67	5	83.33	0	0.00	0	0.00	0	0.00
22.	Clinical	2	6.45	9	29.03	5	16.13	12	38.71	3	9.68
	Security	0	0.00	2	25.00	0	0.00	3	37.50	3	37.50
	Support staff	0	0.00	0	0.00	1	5.88	11	64.71	5	29.41
	Administrative	0	0.00	4	66.67	0	0.00	1	16.67	1	16.67
23.	Clinical	2	6.45	11	35.48	1	3.23	16	51.61	1	3.23
	Security	0	0.00	3	37.50	2	25.00	1	12.50	2	25.00
	Support staff	1	5.88	4	23.53	2	11.76	7	41.18	3	17.65
	Administrative	0	0.00	2	33.33	1	16.67	2	33.33	1	16.67
24.	Clinical	0	0.00	3	9.68	0	0.00	14	45.16	14	45.16
	Security	1	12.50	1	12.50	1	12.50	4	50.00	1	12.50
	Support staff	0	0.00	2	11.76	1	5.88	7	41.18	7	41.18
	Administrative	1	16.67	0	0.00	0	0.00	3	50.00	2	33.33
25.	Clinical	21	67.74	9	29.03	0	0.00	1	3.23	0	0.00
	Security	2	25.00	4	50.00	0	0.00	2	25.00	0	0.00
	Support staff	4	23.53	9	52.94	2	11.76	2	11.76	0	0.00
	Administrative	2	33.33	3	33.33	1	16.67	1	16.67	0	0.00
26.	Clinical	11	35.48	13	41.94	4	12.90	3	9.68	0	0.00
	Security	1	12.50	3	37.50	0	0.00	4	50.00	0	0.00
	Support staff	1	5.88	7	41.18	3	17.65	5	29.41	1	5.88
	Administrative	1	16.67	4	66.67	0	0.00	1	16.67	0	0.00
27.	Clinical	2	6.45	11	35.48	4	12.90	13	41.94	1	3.23
	Security	0	0.00	1	12.50	3	37.50	3	37.50	1	12.50
	Support staff	2	11.76	3	17.65	3	17.65	9	52.94	0	0.00
	Administrative	1	16.67	1	16.67	0	0.00	4	66.67	0	0.00
28.	Clinical	14	45.16	15	48.39	1	3.23	1	3.23	0	0.00
	Security	1	12.50	5	62.50	1	12.50	0	0.00	1	12.50
	Support staff	2	11.76	13	76.47	0	0.00	2	11.76	0	0.00
	Administrative	2	33.33	2	33.33	1	16.67	1	16.67	0	0.00

29.	Clinical	14	45.16	15	48.39	1	3.23	1	3.23	0	0.00
	Security	0	0.00	3	37.50	2	25.00	2	25.00	1	12.50
	Support staff	4	23.53	9	52.94	3	17.65	1	5.88	0	0.00
	Administrative	2	33.33	2	33.33	2	33.33	0	0.00	0	0.00

Appendix 4.4. Responses to multiple-choice questions, by staff type

Question	Staff type	Option a.		Option b.		Option c.		Option d.		Option e.	
		n	%	*n*	%	*n*	%	*n*	%	*n*	%
30.	Clinical	0	0.00	26	86.67	0	0.00	0	0.00	4	12.90
	Security	1	12.50	6	75.00	1	12.50	2	25.00	2	25.00
	Support staff	0	0.00	14	82.35	0	0.00	0	0.00	3	17.65
	Administrative	2	33.33	3	50.00	1	16.67	1	16.67	2	33.33
31.	Clinical	6	19.35	12	38.71	24	77.42	0	0.00	-	-
	Security	5	62.50	7	87.50	7	87.50	0	0.00	-	-
	Support staff	9	52.94	10	58.82	14	82.35	1	5.88	-	-
	Administrative	1	16.67	1	16.67	6	100.00	0	0.00	-	-
32.	Clinical	30	96.77	24	77.42	4	12.90	0	0.00	-	-
	Security	8	100.00	8	100.00	3	37.50	0	0.00	-	-
	Support staff	15	88.24	17	100.00	1	5.88	0	0.00	-	-
	Administrative	6	100.00	3	50.00	2	33.33	0	0.00	-	-

Note. Participants were allowed to select multiple responses for each question. Missing responses included in denominator for calculation of percentage.