



# **DEVELOPING SERVICE USER AND CAREGIVER INVOLVEMENT IN MENTAL HEALTH SYSTEM STRENGTHENING IN ETHIOPIA**

**SISAY ABAYNEH**



Dissertation thesis submitted in partial fulfilment of requirement for the Degree of  
Doctor of Philosophy (PhD) in Mental Health Epidemiology, Addis Ababa  
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May 2021



**ADDIS ABABA UNIVERSITY  
SCHOOL OF GRADUATE STUDIES**

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STRENGTHENING IN ETHIOPIA**

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University in partial fulfilment of the requirements for the Degree of Doctor  
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**By**

**Sisay Abayneh**

**Supervisors**

Dr. Charlotte Hanlon  
Dr. Heidi Lempp

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Addis Ababa University, College of Health Sciences, Schools of Medicine and  
School of Public Health, Department of Psychiatry



DISSERTATION APPROVAL  
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Dissertation title:

**Developing Service User and Caregiver Involvement in Mental Health System Strengthening in Ethiopia**

**By**

**Sisay Abayneh**

**APPROVED BY THE EXAMINING BOARD**

----- <b>Chairman, Examining Board</b> -----	----- <b>Date</b> -----
----- <b>Supervisor (Primary)</b> -----	----- <b>Date</b> -----
----- <b>Supervisor (Secondary)</b> -----	----- <b>Date</b> -----
----- <b>External Examiner</b> -----	----- <b>Date</b> -----
----- <b>Internal Examiner</b> -----	----- <b>Date</b> -----
----- <b>Internal Examiner</b> -----	----- <b>Date</b> -----

## Declaration

I, declare that this thesis “*Developing service user and caregiver involvement in mental health system strengthening in Ethiopia*” is my original work and has never been submitted for a degree or examination in any university. All citations of previous research, published or unpublished, have been duly acknowledged in the text and list of references is given. The five co-authored journal articles included in this thesis are directly based on the research for this degree, and constitute work, for which I was the lead author.

Name: .....

Date: .....

Place: .....

Date of submission: .....

This dissertation has been submitted for examination with my approval as university supervisor.

Name: .....

Signature: .....

Date: .....

## **Dedication**

To all people with mental health conditions who, amid lack of access to mental healthcare services and experience of discrimination and stigma, have worked in the past, are working and will work in the future to give voices for their fellow beings for a better world. Particularly, I painfully remember the three service users who gave their time, energy and lived wisdom to the success of this research but did not survive to make the difference that they wished to do.

## List of original papers

This doctoral thesis includes published (Papers 1, 2, &4) and to be published (Papers 3&5) journal articles. The candidate is the lead on all papers.

Paper1. Abayneh S, Lempp H, Alem A, Alemayehu D, Eshetu T, Lund C, et al. Service user involvement in mental health system strengthening in a rural African setting: qualitative study. *BMC psychiatry*. 2017;17(1):1-14.

Paper2. Abayneh S, Lempp H, Alem A, Kohrt BA, Fekadu A, Hanlon C. Developing a Theory of Change model of service user and caregiver involvement in mental health system strengthening in primary health care in rural Ethiopia. *International Journal of Mental Health Systems*. 2020;14(1):1-1

Paper3. Abayneh S, Heidi H, Brandon A. Kohrt BA, Girma E, Getachew M, Alem A, Hanlon C. Empowerment training to support service user involvement in mental health system strengthening in rural Ethiopia: a mixed-methods pilot study

Paper4. Abayneh S, Lempp H, Hanlon C. Participatory action research to pilot a model of mental health service user involvement in an Ethiopian rural primary healthcare setting: study protocol. *Research Involvement and Engagement*. 2020;6(1):1-14

Paper 5. Abayneh S, Heidi H, Kohrt BA, Alem A, Hanlon C. Using Participatory Action Research to pilot a model of service user and caregiver involvement in mental health system strengthening in Ethiopian primary healthcare: A case study

## **ACRONYMS AND ABBREVIATION**

ACT	Assertive Community Treatment
AFFIRM	African Focus on Intervention Research for Mental Health
CAB	Community Advisory Board
CBPR	Community Based Participatory Research
CST	Critical Social Theory
Emerald	Emerging mental health systems in low- and middle-income countries'
FDRE	Federal Democratic Republic of Ethiopia
FENAPD	Federation of Ethiopian National Association of People with Disability
FMOH	Federal Ministry of Health
HDA	Health Development Army
HEP	Health Extension Program
HEW	Health Extension Workers
HIC	High Income Countries
HSDP	Health Sector Development Program
HSTP	Health Sector Transformation Plan
LMICs	Low and Middle Income Countries
MRC	Medical Research Council
mhGAP	mental health Gap Action Programme
OPAL	Optimizing Provider Attitudes and Competence in Learning Mental Health Systems
PAR	Participatory Action Research
PHC	Primary Health Care
PHCU	Primary Health Care Unit
PRIME	Programme for Improving Mental health care .
RAG	Research Advisory Group

RESHAPE	REducing Stigma among HealthcAreProvidErs
RPG	Research Participant Group
SDGs	Sustainable Development Goals
SNNPR	Southern Nation Nationalities and People Region
ToC	Theory of Change
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

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## **Abstract**

**Background:** Service user and caregiver involvement has become an expectation in all aspects of the mental health system, including in policy, planning, service delivery, quality improvement, research and education around the world. Service user involvement is particularly promoted as a strategy to scale-up quality mental healthcare service in low-and-middle-income countries (LMICs). However, little is known about actual involvement experiences and how best to involve service users and caregivers in mental health systems. No study of involvement has been conducted in Ethiopia. Hence, this study aimed to achieve the following objectives.

**General objective:** To develop, pilot and evaluate a model of service user/caregiver involvement in mental health system strengthening in Ethiopia

**The specific objectives of the study were to:**

- explore the experiences, perceived barriers and facilitators regarding service user and caregiver involvement in mental health system strengthening.
- develop an acceptable, sustainable and feasible Theory of Change model of service user and caregiver involvement in the expanding mental health system.
- equip service users and health professionals for greater involvement in mental health system strengthening.
- pilot the feasibility and acceptability of a co-developed model of service user and caregiver involvement in mental health system strengthening.

**Methods:** A predominantly qualitative approach was used, which was conducted in three phases. The study was situated within participatory approaches informed by a critical social theoretical perspectives and social-ecological system theory. The thesis consists of 5 articles, which have been published or are about to be submitted for publication.

Phase 1 provides the context for the thesis, which was a formative qualitative study conducted to explore the experiences of involvement, barriers to, facilitators and capacity building needs for greater involvement from the perspective of key stakeholders (Paper 1). In the study, 39 semi-structured interviews were carried out with purposively selected service users (n=13), caregivers

(n=10), heads of primary care facilities (n=8) and policy makers/planners/service developers (n=8). Thematic analysis was applied.

In Phase 2, a Theory of Change(ToC) model was developed in iterative participatory workshops conducted in (i) Addis Ababa with purposively selected psychiatrists (n=4) and multidisciplinary researchers (n=3), and (ii) a rural district in south-central Ethiopia (Sodo) with community stakeholders (n=24). Information from the workshops (provisional ToC maps, minutes, audio recordings), and inputs from Paper1 were triangulated to develop the detailed ToC map. This ToC map was further refined with written feedback and further consultative meetings with the research team (n=6) and community stakeholders (n=35) (Paper 2). Based on findings from paper 1 and 2, an empowerment training programme was developed, delivered and evaluated for acceptability, feasibility and preliminary impacts using a mixed-methods design in Paper 3 (Chapter 7). The training was delivered separately for service users (n=12) and caregivers (n=12), and health professionals (n=18). The quantitative data consisted of process data, satisfaction questionnaires, and a retrospective pre-test survey. Qualitative data included exit and follow-up in-depth interviews with service users and caregivers. Descriptive statistics were performed for quantitative data, and qualitative data were analysed using a thematic analysis approach. The findings were integrated through triangulation for convergent themes following analysis.

Phase 3 involved Participatory Action Research (PAR) implementation strategy development, piloting the ToC model and a case study of the piloting process and participants' experiences of involvement. Accordingly, a PAR protocol was developed to guide the ToC model implementation process (Paper 4) and the ToC model was piloted using PAR in three stages, each with iterative activities of plan, act, observe and reflect. Two stakeholder groups, a Research Advisory Group (RAG) and Research Participant Group (RPG), were established and collaborated in all stages of the PAR process. Data collection involved process documentation of meetings and activities: attendances, workshop minutes, discussion outputs, and reflective notes, participatory observation of sessions, and in-depth interviews with service users (n=6), caregivers (n=4) and health professionals (n=2) involved throughout the PAR process. Descriptive analysis was used for process data, and thematic analysis was used for qualitative data. Triangulation and synthesis of findings was carried out to develop the case study (Paper 5- Chapter 8).

**Results:** The formative qualitative study showed that the concept of service user involvement is new within the Ethiopian mental health system and that service user participants had little direct involvement in mental health systems strengthening. Several potential benefits were identified, included were improved appropriateness and quality of services, and greater protection against mistreatment and promotion of respect for service users. This study identified key multilevel barriers and facilitators to effective involvement, and many areas of capacity building needs for greater involvement. Stigma was considered to be a pervasive barrier, operating within the health system, the local community and individuals. Low recognition of the potential contribution of service users seemed linked to limited empowerment and mobilization of service users. There was a strong need for awareness-raising and training to equip service users, caregivers, service providers and local community for involvement.

The participatory ToC model co-produced described the causal pathways for greater service user involvement with key components (community, health organisation, service user and caregiver), interventions, preconditions, assumptions and indicators for each component along the pathway to the long-term outcomes and impact. The participatory nature of ToC process raised awareness of the possibilities for service user and caregiver involvement, promoted co-working and stimulated immediate commitments to mobilise support for a grass roots service user organization. The empowerment training content, delivery process and standard of the training program met participants' expectations, improved positive gains in understanding about mental illness, stigma, service-user involvement, and human rights. The training had positive impacts, including increased self-confidence, sense of empowerment, social benefits, and perceived therapeutic benefits. Through active collaboration and involvement the stakeholder groups identified their top research priorities considered as significant problems in their specific settings (particularly the need for public awareness-raising and addressing stigma and discrimination) and developed intervention programmes, action plans and initiated actions that could resolve some of these problems. Key mechanisms used for inclusive participation included capacity building and bringing together diverse stakeholders, anchoring the study in established strong community involvement structures, and making use of participatory strategies and activities during the PAR process. The case study about participants' experiences of involvement in PAR identified and explained about: (i) expectations and motivation, (ii) experiences of the dynamics

of the PAR process, (iii) perceived impacts of involvement in the PAR process, and (iv) implementation challenges and future directions.

**Conclusions:** Service user and caregiver involvement in mental health system strengthening is a complex process, which is affected by multilevel factors that demands interventions that recognize this complexity. This thesis shows that effective involvement could be achieved by empowering key stakeholders for greater involvement. PAR can be a feasible and acceptable approach for empowerment and collaborative engagement of a range of stakeholders in mental health system strengthening. Combining ToC with a PAR approach can provide a more inclusive active involvement model of stakeholders including service users and caregivers. Embedding effective service user and caregiver involvement can be hindered with lack of strategic enabling regulatory infrastructure within the mental health system.

**Implications:** The findings of this thesis can be of practical relevance to researchers and those working in health care settings to develop service user and caregiver involvement in mental health system strengthening. It contributes theoretical understanding for future research and provides practical knowledge for application of participatory action oriented approaches about how to develop participatory models and actively involve key stakeholders in the contexts of low resource setting.



## Chapter one

### 1. Introduction

#### 1.1. Background

The global movement to develop service user involvement in health and social care has a long history. Four key developments have driven the emergence of service user involvement, namely: **(i) social revolutions**, such as civil and individual rights movements, development of democratic government and movements for self-organization and self-determination (1, 2), encapsulated in the call from the disability movement “*nothing about us without us*”(3, 4); **(ii) the Universal Declaration of Human Rights (5), and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)(6)** promoted the idea of individual and collective involvement in issues that affect peoples’ lives. In particular, human rights-based approaches, which pay due attention to rights to non-discrimination, privacy, autonomy, and participation are considered to be imperative in the design, implementation, monitoring and evaluation of mental health policies (7, 8); **(iii) the World Health Organization (WHO)** published several treatises on mental health which emphasised the necessity of involvement of communities, families and service users in different aspects of mental health systems strengthening(9, 10); and **(iv) the global movement to expand access to mental health care** has given impetus to efforts to involve service users in service development, improvement and system strengthening, particularly in low-and middle-income countries (LMICs) (11, 12).

In the past few decades, the health policies of many countries have sought to promote the human rights of people with mental health conditions as per the obligations enshrined in international human rights standards (6, 8). Service user involvement at all levels of mental health system(policy-making, planning, service development and delivery, quality improvement, research, education and training) is becoming a mainstream policy expectation in many countries internationally and has attracted growing research interest as a strategy for achieving people-centered healthcare (6, 10, 13). Likewise in Ethiopia, the protection of people with mental health conditions is included in the National Constitution (14) the proclamation on employment of persons with disability (15) and the nationally ratified UN CRPD(16). More importantly, the

second National Mental health Action Plan for Ethiopia (2020-2025) is aligned with global guidance and recommendations, including the WHO global comprehensive mental health action plan(10),the Sustainable Development Goals(SDGs) and UNCRPD(17). One of the main strategic objectives of the Strategy is to empower individuals, families and other stakeholders to promote their mental health, help protect themselves from risk factors and create enabling conditions that would facilitate target audiences to advance their mental health (17).

Service user involvement can be considered as a complex process with multiple meanings, involving different approaches, various levels, and numerous processes (2, 12, 18). Involvement can take place at (i) direct care or *micro-level* (e.g. individual care plan, choice of treatment decision, assessment and care management),(ii) healthcare agency/local organization or *meso-level*(e.g. local service planning, monitoring and evaluation, advocacy, training and recruitment of staff, input into guidelines, participation in board or committees), (iii) strategic or *macro-level* (e.g.co-deciding policy, national level planning and advocacy) and in service-related research and education (1, 2, 19). Involvement at these levels has potential for multidimensional benefits. Involvement can serve as a key indicator of democratization of health services, helping to increase public accountability and transparency which lead to more accessible and acceptable mental health services, advance the culture and responsiveness of mental health services, and increase the quality of care. Working alongside service users as partners can also help to improve health professionals` attitudes towards service recipients, particularly helping to overcome stigmatizing attitudes. From the service user side, involvement in care can lead to increased treatment engagement, self-esteem and confidence, greater satisfaction with mental health care, and may empower service users to gain control over their own recovery (2, 20-22). Service user involvement has also been proposed as an essential means to ensure equitable scale up of respectful and quality mental healthcare in LMICs (11, 12, 23).

Despite substantial research advances showing the benefits, and recommendations for the importance of service user involvement in mental health system strengthening, actual implementation has been very low, particularly in LMICs. Numerous gaps in policy implementation exist relating to marginalization, stigma, lack of voice, violations of basic human rights, lack of access to care and injustices confronting service users that need attention (7, 12, 24).

## **1.2. Statement of the problem**

Despite increasing international policy and research support for the value of, and need for involving service users and caregivers at all levels of mental healthcare system, the extent of implementation of involvement varies substantially across countries. In many LMICs, actual involvement remains largely aspiration; and low attention has been given to the contributions of service users (11, 12). There are few examples of actual involvement of service users and caregivers in many LMICs (25) and almost none in Ethiopia. Approximately 80% of people with mental health conditions globally reside in LMICs (26). The mental health systems of many LMICs fail to meet the needs of service users (23) and are characterized by human resource shortages (27). Underfunded mental health services and limited access to mental healthcare result in a large treatment gap and a substantial economic burden to service users and caregivers (28). As well as being inaccessible, mental health care may be of poor quality (29). The consequences of poor quality healthcare are a higher burden of mortality as well as morbidity and loss of trust in the health care system (30). Low attention to service user involvement results in underutilization of their potential contributions to drive forwards change and improve weak mental health systems (11, 12).

In addition to the suffering and burden due to mental health conditions, service users may experience an extensive range of human rights violations, including marginalisation from their rights to participation within institutions and in the community. These are powerful barriers to service user involvement in strengthening health systems to deliver quality care (17, 30-32). Other barriers to involvement include high levels of poverty, low levels of education, lack of infrastructure, low level of service development, lack of reliable health information systems, and a lack of models of collaborative working with mental health service users have been documented in many LMICs (33, 34). The effective exclusion of people with mental health conditions from the development and improvement of mental health care is at odds with binding international human right laws, and ratifications of UNCRPD and other international legal documents in many LMICs (31, 32, 35).

In many LMICs, limited attention has been given to empowerment and mobilization of service users to facilitate greater involvement within mental health systems (12, 36, 37). Marginalisation and low levels of empowerment of mental health service users are associated with low levels of

awareness of their rights and low expectations of care (30). In many LMICs there are few service user organizations and those that do exist have little influence on mental health system changes (23, 38). In Ethiopia there is only one association of caregivers and one service user association, which is low even compared to other LMICs in Africa (38). There are legal provisions to protect the rights of persons with disability (39), and there are various organizations and federations of persons with disability operating in Ethiopia (40). However, mental health service users are not members of these organizations, are marginalized and effectively voiceless. This reflects the lack of service user involvement, power and voice at the grassroots level. There are few programmes to equip stakeholders to work together in mental health systems in LMICs (41-43) and no such programmes in Ethiopia.

There is an increasing number of studies from various LMICs which have investigated the value, need, barriers and facilitators to involvement of service users and caregivers, but less is known on how involvement can be acted in practice, actual involvement experiences and impacts (11, 12, 23). Furthermore, although service user involvement is recognized to be a complex process that commonly occurs at, and is affected by, multilevel factors (2, 12, 19), there are few studies that have explored this complexity in relation to contextual and organisational factors in LMICs (12). Systematic reviews of studies from LMICs found little evidence of conceptual framework/models being used to guide inclusive active involvement of service users and caregivers within mental healthcare systems (12, 23). In addition to these gaps, in Ethiopia there has been no empirical study on involvement experience, barriers to involvement, facilitators to involvement, and capacity building needs for greater service user involvement from the perspectives of different stakeholders.

The body of work contained in this thesis addresses some of the key gaps in knowledge and practice with regard to involvement experiences, barriers, facilitators and capacity building for greater involvement. This work makes use of participatory action research methods to develop and assess a theory-driven model for involvement, focusing on implementation processes and outcomes. Hence, this thesis is timely and important to address these gaps in Ethiopia and give insights to other LMICs.

### **1.3. Rationale and significance of the study**

There is strong international policy imperative to improve mechanisms and approaches to empower and actively involve service users and caregivers in efforts to strengthen mental health systems in LMICs (10-12). The global initiative to scale-up of mental health care through integration within general healthcare in LMICs also calls for increased involvement of service users and caregivers as a fundamental element to ensure healthcare quality (11, 44, 45). The findings of this thesis respond directly to these evidence gaps and make contributions in terms of policy, theoretical/knowledge, practical and future research contributions in the context of LMICs in general and in Ethiopia in particular.

In Ethiopia there is national level commitment towards improving access to mental healthcare services for people with mental health conditions. In national level documents pertaining to health care, including the Health Sector Transformation Plan and the second National Mental Health Strategy, there are a set of aspirations concerning system strengthening. These plans envisage the development of partnership as the vehicle for delivery of services using a human-rights approach, with strong focus on the provision of compassionate and respectful care. Moreover, the Federal Ministry of Health identifies the empowerment and involvement of service users and caregivers as an essential component of efforts to scale up the integration of mental health care into primary healthcare in Ethiopia (17, 46). The findings reported in this thesis will outline some benefits that can be achieved through involvement of service users. Development of a model of involvement will help to show how stakeholder partnership can be developed and sustained through creating inclusive participatory space to enable change. This PhD thesis provides examples of how to build collaboration and partnership with local stakeholders and will provide a detailed report on the experience of actively involving service users and other stakeholders. This can contribute to embedding meaningful and equitable engagement of service users and caregivers within service improvement and development activities as scale up proceeds. Evidence on effective empowerment of service users and contextualised training manuals for health professionals and service users gained from this study can contribute towards the strategic objectives set in the mental health strategy.

The findings of this thesis will also make a contribution to development of new knowledge, in terms of: (i) actual service user and caregiver experience of involvement, barriers and

facilitators, and capacity building experiences, (ii) understanding the complexity of service user and caregiver involvement within mental health system strengthening and deeper understanding of the value of active involvement of key stakeholders, and (iii) participatory models and interventions for supporting inclusive active involvement of service users and caregivers in mental health system/service strengthening. It can help better understand participatory action research approaches, including photovoice as a useful strategy to facilitate active involvement of service users and caregivers in mental health system.

The findings of this study will also offer opportunities for health administrators, and clinicians to learn how to work collaboratively with local community stakeholders, in particular to support greater involvement of service users and caregivers in mental health system improvement. Collaborative stakeholder participation can have multidimensional benefits beyond empowering service users to have a say and voice in different endeavors that affect their life. This can bring opportunities for community stakeholders to critically reflect on, and learn about, local resources and assets. This can help to strengthen stakeholder advocacy to improve health systems and to make sure that the rights of all people are cared for and defended. Building on local actions may lead to longer-term social inclusion and sustainability of initiatives to involve service users to improve care.

The findings of the study will also identify areas for further research in relation to how to empower and involve stakeholders to support greater service user and caregiver involvement in mental health system strengthening. These findings can serve as a foundation for future larger-scale evaluation of the model of service user and caregiver involvement and refinement of training interventions and assessment tools to evaluate the impact of involvement in the research context. This study will also provide evidence to integrate the involvement model within mental health care scale up. Further development and manualisation of the training program will enable wider use of the programme and allow evaluation in other LMICs. This work can also be a basis to develop mid-range theories to achieve effective service user and caregiver in mental health system improvement that can provide evidence based policy and practice recommendations transferable to other LMICs (18). Lastly, the personal experiences and knowledge gained throughout the PhD experience has greatly enriched the learning experiences of the researcher with regards to working with people with mental health conditions, their caregivers and community stakeholders in mental health system strengthening for future effective working.

## **1.4. Organization of the thesis**

In my write-up of this participatory research work, I have attempted follow the usual thesis structure, with some adaptation to take into account the nature of the study and better capture the nature of this study design. This thesis is structured into nine chapters including the introduction section.

### **Chapter 1: Introduction**

This chapter presents background to the study by drawing on literature in relation to development of service user involvement in mental health system strengthening, and how a lack of service user involvement in Ethiopia and other low-and middle-income countries provided the rationale for this thesis investigation.

### **Chapter 2: Literature Review**

This chapter provides a scoping review of international literature related to the state of current knowledge on service user and caregiver involvement in mental health systems strengthening. With regards to service user involvement, the review broadly focuses on (i) theories and frameworks or models, (ii) the evidence base for different approaches and methods, (iii) added values/outcomes, and (iv) barriers and facilitators for involvement. The findings from the review inform the conceptual and methodological approaches to address the identified gaps that were used in this study.

### **Chapter 3: Objectives and research questions**

This chapter presents the objectives of the study and research questions.

### **Chapter 4: Research Methodology**

This chapter explains the theoretical, conceptual framing, methodology and methods of the study. First, the methodological choices of participatory approach that locate the philosophical stance of the researcher are reported and justified with references to the ontological and epistemological perspectives associated with knowledge sought to development service user and caregiver involvement. Then, the conceptual framework of the study is described. A general summary of the research design, context and setting, study population, recruitment, consent

procedures, data collection, management and analysis procedures, ethical considerations, and quality assurance procedures and data trustworthiness are provided in each sub-study.

**Chapter 5:** Service user involvement in mental health system strengthening in a rural African setting: qualitative study(Paper1).

This chapter presents a qualitative exploration of the experiences of involvement, barriers and facilitators, and capacity building needs for involvement in mental health system strengthening with multi-level key health system stakeholders in Ethiopia.

**Chapter 6:** Developing a Theory of Change model of service user and caregiver involvement in mental health system strengthening in primary health care in rural Ethiopia(Paper2).

This describes the process and outcomes of a participatory Theory of Change model for service user and caregiver involvement in mental health system strengthening in rural Ethiopia.

**Chapter 7:** Empowerment training to support service user involvement in mental health system strengthening in rural Ethiopia: a mixed-methods pilot study (Paper 3)

This chapter presents the development, implementation and evaluation of the acceptability, feasibility and preliminary impacts of a pilot capacity building training program designed as part of an intervention to pilot the ToC model of service user involvement.

**Chapter 8:** Presents a case study of the piloting process and experiences of the ToC model using PAR in primary healthcare setting (Paper 4&5).

**Chapter 9:** General discussion, conclusion and recommendations.

In the final chapter, the main findings of the studies in the thesis are summarized and discussed. The strengths and limitations, conclusions, and the implications of the study for policy, research and practice will be presented.

## **Chapter 2: Literature review**

This chapter presents a synthesis of the global literature on service user and caregiver involvement in mental health systems strengthening.

### **2.1. Methods**

#### **2.1.1. Review approach**

Existing evidence about service user and caregiver involvement shows that (i) there are numerous terms used to describe people with mental health conditions and little agreement about the most appropriate term (47, 48);(ii) there is a lack of consistent definitions and multiple interchanging terms used to describe the roles of service users and caregivers, including ‘involvement’, ‘participation’, ‘engagement’, ‘co-production’, and so on (1, 2, 49); and (iii) service user and caregiver involvement in mental health system strengthening is an emerging field of research, and the literature is based on a wide range of study methodologies (50). Given these challenges, the approach selected was a systematic scoping review conducted in accordance with a methodological framework developed by Arksey and O’Malley(51) which was augmented by recommendations from Levac et al.(52). A scoping review is particularly useful when a body of literature has not yet been comprehensively reviewed or exhibits a complex or heterogeneous nature not amenable to a more precise systematic review of evidence (53). This approach allows synthesis of a wide range of evidence sources and allows development of insight about the extent, variety and volume of existing literature to inform practice, policy and future research (54, 55). The review process comprised five stages, including (a) identifying the research questions; (b) searching for, and identifying, relevant studies; (c) selecting studies; (d) charting the data; and (e) collating, summarising, and reporting the results.

#### **2.1.2. Review questions**

The review addresses the following questions:

- How has service user and caregiver involvement been defined in the literature?
- What is the level of service user and caregiver involvement reported in the literature?
- In what aspects of the mental health system is service user and caregiver involvement taking place (policy making/development, health care planning, mental health service

delivery, mental health research, monitoring and evaluation or quality assurance, training/education, advocacy activities, self-help or mutual support groups and peer support)?

- What outcomes are associated with service user and caregiver involvement in mental health systems strengthening?
- What methods, strategies/models are used to involve service users and caregivers?
- What is known about barriers and facilitators to involvement of service users and caregivers?

### **2.1.3. Eligibility Criteria**

Eligibility criteria focused on the following key elements:

#### **Population**

This review was focused on studies that included service users or their representatives and caregivers. Service users or their representatives included adults (aged 18+ years) with a diagnosis of mental illness (with particular focus on depression, severe mental illness including any form of psychosis, schizophrenia and related disorders, major depressive disorders, and bipolar disorder). Caregivers included adults who provide support to service users, for example, family members, spouses or community members. Studies focused on the following populations were excluded: children (<18 years) and older adults (>64 years) and non-representative sub-populations (students, forensic/juvenile/offenders, veterans, defense forces/military/police, migrants, and ethnic minorities), humanitarian settings, samples defined by exposure to violence, and people with developmental disabilities or personality disorders).

**Types of studies:** This review was focused on service user and caregiver involvement in the mental health system, including policy making, planning and design, service delivery, quality improvement, research, training and education, advocacy, and peer support. Articles that did not pertain to system level involvement (e.g. self-care, treatment decisions, etc.) were excluded. All study designs were included (qualitative, quantitative, and mixed methods). Theoretical or conceptual papers that described theories or models of involvement were also included. We excluded studies that limited service users to only being sources of data (i.e., the collection of their individual data or respondents to a survey or interview).

**Interventions/exposures:** Included any service user and caregiver involvement activity or action in the area of mental health systems strengthening, including empowerment training, capacity-building training, communication skills, service user/caregiver activation, Photovoice, service user/caregiver organization/mobilization, local community support, involvement in organizational structures (inclusion in committees, boards, peer support), policy and legislation, community inclusion, socioeconomic and livelihood support, logistical support and accessible mental health care.

**Outcomes:** Papers to be included in the review needed to include discussion of the outcomes of participation or link with related studies. Our interest was mainly focused on outcomes that the authors formally evaluated and/or reflected as being associated with /related to the involvement process. Outcomes included improvement or changes in any components of mental health systems, theories, strategies/interventions. In addition, any reported outcome related to service user/caregiver involvement (e.g., functional outcomes, perceived empowerment, self-esteem, sense of community, satisfaction, adherence, social network, level of participation); health professional-related outcomes (e.g., job satisfaction, improved attitudes, communication, reduced burden), health organization outcomes (e.g., improved quality of service, cost-effectiveness, responsiveness and access), and community related outcomes (e.g., awareness).

**Setting/context:** There was no restriction by geographic location (country). The review considered studies in any mental healthcare setting including primary health care, hospitals, community healthcare, and self-help centers or at the interface of such settings.

#### **2.1.4. Search strategy**

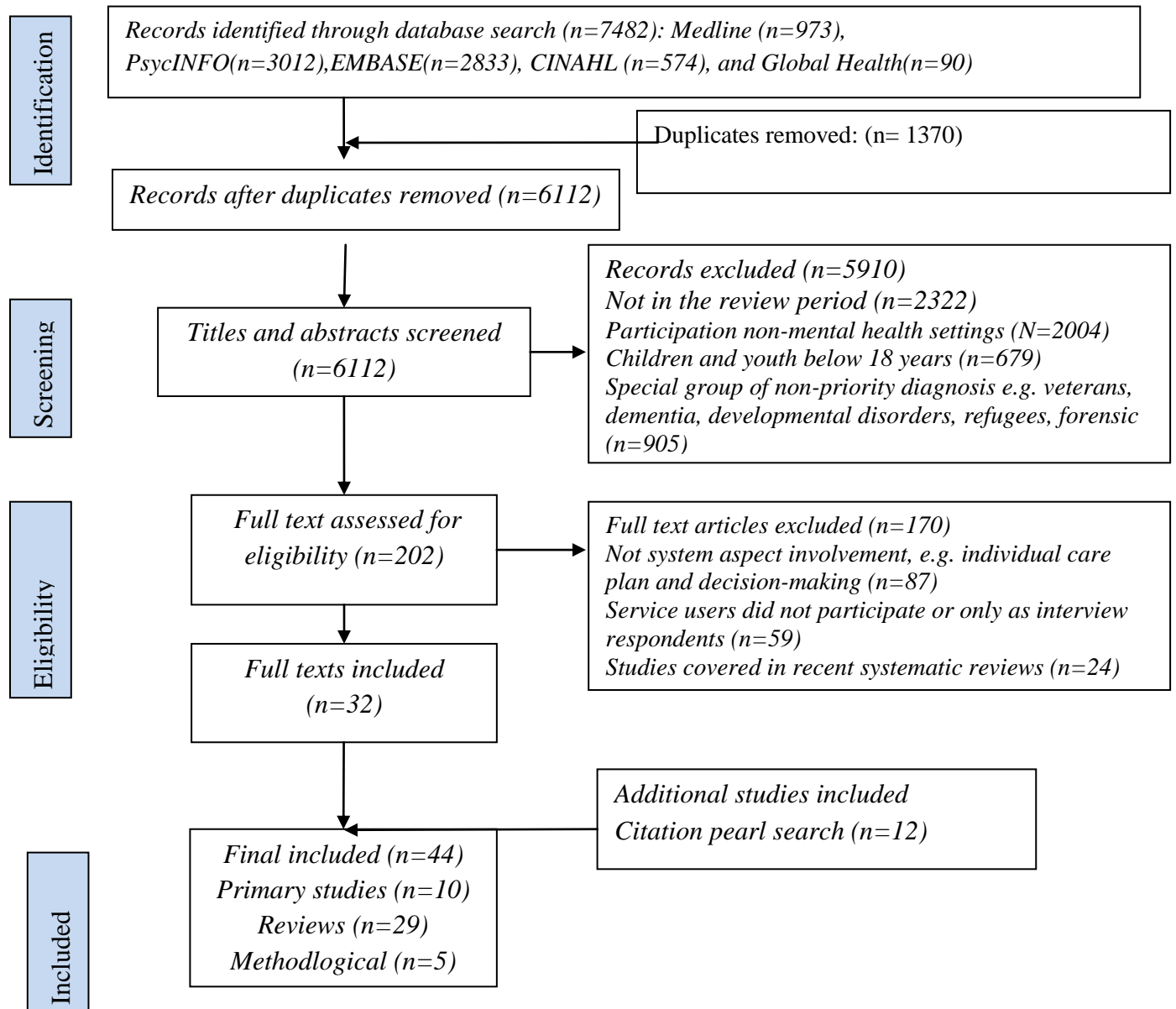
For this thesis, a broad search was undertaken in five databases: Ovid Medline, PsycINFO, Embase, CINAHL and Global Health. The search period was from the inception of databases to the end of March 2021, but the evidence presented largely focuses on the last ten years (from 2011 to 2021) to ensure inclusion of the most recent literature. Selected studies with high relevance and documents regarding models/frameworks, theories/conceptualisations of service user and caregiver were not restricted to the last ten years.

The search strategy incorporated combinations of Medical Subject Heading (MeSH) and free text terms in titles and abstracts, covering synonymous words or phrases in four domains: (i) service user/caregiver (e.g. service user, caregiver, consumer, public, patient), (ii) concept/type of

involvement (e.g. involvement, collaboration, engagement, participation, co-production ), (iii) mental health system activities (e.g. policy-making, health service planning and development, service deliver, quality improvement), and (iv) models or frameworks(e.g. model, strategy, framework). The terms in each set were combined with the logical operator ‘OR’, and each set was combined with the logical operator ‘AND’. The keywords were used in PsycINFO and modified to the specific thesaurus of each database; an example of the search strategy used for Medline is shown in Appendix1.The reference lists of included articles and documents were manually searched to identify additional relevant articles and documents that might meet the inclusion criteria.

### **2.1.5. Study selection**

The reference lists of the database searches were imported, combined and de-duplicated in reference management software (Endnote X7 (56)) prior to screening for relevance. Study selection was completed in a two stage screening process (Fig1). First, all the titles and abstracts were screened against the eligibility criteria to ensure match and relevance. Second, the full texts of articles deemed to be relevant were retrieved, and screened for meeting the screening criteria. Papers which were clearly irrelevant were excluded in the first stage of title and abstract review, and if the eligibility of the paper was not clear, the full text was then reviewed in the second stage.



**Figure 1. Flow chart of systematic review process**

### 2.1.6. Data charting (extraction)

Data abstraction forms were used to facilitate data extraction, including information about year of publication, country/location, study design/type, participants, and health system aspect, methods of involvement, conceptual/theoretical perspectives, and outcomes assessed, findings, barriers and facilitators, and critical comments.

### **2.1.7. Collating and summarising/data analysis**

A narrative approach was used to collate and summarise data using a descriptive approach (57, 58). The synthesis was structured to address the research questions, in relation to: (i) concepts and definitions, (ii) levels of involvement and qualities of reporting, (iii) involvement in aspects of mental health system strengthening and reported outcomes, (iv) strategies/models and methods of involvement, and (v) barriers and facilitators to involvement. This process involved identifying prominent or recurring themes in the literature (relevant to the research questions) and summarizing the findings of different studies under thematic headings using summary tables.

### **2.1.8. Quality appraisal**

Assessing the quality of the studies in a scoping review is not a requirement but can facilitate interpretation of study findings by identifying potential biases (52, 59). In this study, the methodological quality of systematic review papers was performed using the Assessment of Methodological Quality of Systematic Reviews (AMSTAR2) tool, which covers randomised controlled trials and non-randomised studies (60). AMSTAR2 consists of a 16-point critical appraisal assessment with evaluation options “Yes”, “Partially Yes” and “No”. In this review the critical domains suggested by the authors of AMSTAR 2 were identified (Items 2, 4, 7, 9, 11, 13 and 15) for evaluating the included studies. The overall rating confidence was set to four levels: High, moderate, low, and critically low (60).

The methodological quality of each primary study was assessed using Hawker et al.’s general appraisal checklist that systematically reviews disparate forms of evidence and methodologies (61). This instrument consists of nine domains (abstract, background, methodology, sampling, data analysis, ethics, results, transferability /generalizability, and implications) that are applicable to quantitative as well as qualitative studies. Each domain is scored on a four-point scale (ranging from very poor to good). Scores for the various domains are added to give a total score that ranges from nine to thirty six. Studies are categorized into three based on their total score: high quality (score 30-36 points), moderate quality (score 24-29 points) and poor quality (score: 9-23 points) (62).

## **2.2. Results**

### **2.2.1. Included studies**

The database search strategy generated 7482 records. After duplicates were removed automatically and manually (n=1370), 6112 articles remained. Title and abstract screening removed 5910 articles, which resulted in 202 relevant articles for full-text screening. Following full-text screening, a further 170 articles were excluded, and 32 articles were included in the review. An additional 12 articles were identified by hand search of citations and the references of the retained studies. A total of 44 studies were included in the final analysis. The selection process is summarized in Fig 1.

### **2.2.2. Characteristics of the included studies**

The majority of the studies on service user involvement were published from few high income countries, including the United Kingdom (UK), the United States of America (USA), Canada, and Australia (APPENDICES 2A-E). From the studies, 10 were primary studies, 29 were reviews and five were descriptive/methodological papers. Of these studies, five focused on conceptual description and frameworks, seven on policy making, nine on service delivery and evaluation, five on research, nine on education and training and nine on informal care/peer support.

### **2.2.3. Quality of the included studies**

Three of the systematic reviewers were rated as high quality, 12 were rated as moderate quality, eight as low quality and four studies had critically low quality based on the AMASTAR 2 tool (Table 1).

**Table 1. Assessment of methodological quality of included systematic reviews using the AMSTAR 2 tool**

Studies	(1) Question and inclusion	(2) protocol	(3) Study design	(4) comprehensive search	(5) study selection	(6) Data extracts	(7) Excluded studies	(8) Included studies details	(9) Risk of bias	(10) Funding sources	(11) Statistical methods	(12) RoB on meta-analysis	(13) RoB in individual studies	(14) Explanation for heterogeneity	(15) Publication bias	(16) Conflict of interest	Overall quality
<i>Olsson et al., 2020</i>	Y	Y	Y	Y	Y	Y	PY	Y	N	Y	N	NA	N	Y	Y	Y	Moderate
<i>Soon et al., 2020</i>	PY	Y	Y	Y	Y	Y	N	PY	N	Y	N	NA	N	PY	Y	Y	Low
<i>Malterud &amp; Elvbakken, 2020</i>	Y	Y	Y	Y	Y	Y	N	Y	N	Y	N	NA	N	PY	Y	Y	Low
<i>Kang &amp; Joung, 2020</i>	Y	N	Y	Y	Y	Y	N	PY	N	Y	N	NA	N	Y	PY	Y	Low
<i>White et al., 2020</i>	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	Y	Y	Y	Y	Y	High
<i>Ibrahim et al., 2020</i>	Y	Y	Y	Y	Y	Y	N	PY	N	Y	N	NA	N	PY	PY	Y	Low
<i>Charles et al., 2020</i>	Y	Y	Y	Y	Y	Y	N	PY	N	Y	N	NA	N	PY	PY	Y	Low
<i>James et al., 2020</i>	PY	PY	Y	Y	Y	Y	PY	Y	N	Y	N	NA	N	Y	Y	Y	Moderate
<i>Yoma, 2019</i>	PY	N	Y	Y	Y	Y	N	PY	N	Y	N	NA	N	PY	PY	Y	CL
<i>Ryan et al., 2019</i>	Y	N	Y	PY	Y	Y	PY	PY	N	Y	N	NA	N	PY	PY	Y	Low
<i>Sangill et al., 2019</i>	PY	N	Y	Y	Y	Y	PY	PY	PY	Y	N	NA	N	PY	PY	Y	Moderate
<i>Bombard et al., 2018</i>	Y	N	Y	Y	Y	Y	PY	PY	N	Y	N	NA	N	PY	Y	Y	Low
<i>Stomski &amp; Morrison, 2017</i>	PY	N	Y	Y	Y	Y	PY	PY	N	Y	N	NA	N	PY	PY	Y	Low
<i>Semrau et al., 2016</i>	Y	N	Y	Y	Y	Y	PY	PY	PY	Y	N	NA	N	Y	Y	Y	Moderate
<i>Arblaster et al., 2015</i>	PY	N	Y	Y	Y	Y	N	PY	N	Y	N	NA	N	PY	PY	Y	CL
<i>Eassom et al., 2014</i>	Y	N	Y	Y	Y	Y	PY	Y	PY	Y	N	NA	N	Y	PY	Y	Moderate
<i>Brett et al., 2014</i>	PY	PY	Y	Y	Y	Y	PY	Y	Y	PY	N	NA	N	NA	N	Y	Moderate
<i>Domecq et al., 2014</i>	PY	PY	Y	Y	Y	PY	PY	PY	N	PY	N	NA	N	NA	N	PY	Moderate
<i>Happell et al., 2014</i>	PY	PY	PY	Y	Y	Y	N	PY	N	N	N	NA	N	NA	N	N	CL
<i>Lloyd-Evans et al., 2014</i>	Y	N	Y	Y	Y	Y	PY	PY	Y	PY	Y	Y	Y	Y	Y	Y	High
<i>Fuhr et al., 2014</i>	Y	PY	Y	Y	Y	PY	PY	Y	Y	Y	PY	PY	PY	PY	Y	Y	High
<i>Perry et al., 2013</i>	Y	PY	Y	PY	PY	PY	Y	Y	Y	Y	N	NA	PY	NA	N	PY	Moderate
<i>Terry, 2012</i>	PY	PY	Y	Y	PY	PY	PY	Y	Y	N	N	NA	N	NA	N	N	Moderate
<i>Wright-Berryman et al., 2011</i>	PY	N	Y	Y	PY	PY	PY	PY	PY	Y	PY	N	N	N	PY	Y	Moderate
<i>Doughty &amp; Tse, 2011</i>	PY	N	Y	Y	Y	Y	N	PY	PY	N	N	N	N	N	N	N	CL
<i>Crawford et al., 2002</i>	PY	PY	Y	Y	Y	Y	PY	Y	PY	N	N	NA	N	NA	N	PY	Moderate
<i>Simpson &amp; House, 2002</i>	Y	PY	Y	Y	PY	Y	PY	Y	PY	N	N	NA	Y	NA	N	PY	Moderate

Abbreviations: RoB, Risk of Bias. Y=Yes, PY=Partially yes, N=Not, NA=Not applicable, CL=critically low

The quality appraisal of primary studies is presented in Table 2. Five studies were rated as being of high quality, and five had moderate quality based on the assessment tool.

**Table 2. Quality of appraisal of primary studies included in the study**

<i>Studies</i>	<i>Tergesen et al., 2021</i>	<i>Kohrt et al., 2020</i>	<i>Kaiser et al., 2020</i>	<i>Kaseltonyte et al 2019</i>	<i>Tang et al 2016</i>	<i>Pelletier et al., 2015</i>	<i>Leung &amp; Lam, 2014</i>	<i>Chien &amp; Thompson, 2013</i>	<i>Adeponle et al 2009</i>	<i>Malakouti et al., 2009</i>
<i>Abstract and title</i>	3	3	4	4	4	4	2	4	2	2
<i>Introduction and aims</i>	4	4	3	4	4	4	4	4	3	3
<i>Methods and data</i>	3	4	4	3	3	3	3	4	3	4
<i>Sampling</i>	4	2	3	3	2	3	3	3	3	3
<i>Data analysis</i>	4	4	4	3	3	3	3	4	3	4
<i>Ethics and bias</i>	4	3	3	3	3	3	3	3	4	3
<i>Results</i>	4	4	4	3	3	3	3	4	3	3
<i>Transferability</i>	3	3	3	3	3	3	3	3	3	3
<i>Implications and usefulness</i>	4	3	3	3	3	3	3	3	2	4
<i>Total score</i>	33	30	31	29	28	30	28	32	26	29
<i>Quality level</i>	<i>High</i>	<i>High</i>	<i>High</i>	<i>Moderate</i>	<i>Moderate</i>	<i>High</i>	<i>Moderate</i>	<i>High</i>	<i>Moderate</i>	<i>Moderate</i>

#### 2.2.4. Terms and definitions

This review showed that a variety of terms are used to refer to people with mental health conditions, including ‘patient’, ‘client’, ‘consumer’, ‘survivor’, ‘person with lived experience’, ‘service user’ and many others (47, 48, 63). Many of the included studies reported that the plurality, ambiguity and inconsistency in the use of the terms created confusion (50, 64-68). The evidence base indicated that there was no conclusive agreement about how people with mental health conditions prefer to be named (48). There appeared to be a difference in preference among countries; for example, in the UK, the term ‘patient’ was preferred, whereas ‘client’ was preferred in Australia and the USA (69). Systematic reviews, as well as recent primary studies from high income countries, found little or no empirical evidence for whether the use of specific terminology is related to any outcomes in terms of empowerment or stigmatization (48, 70). However, some scholars argued that different terms signify different meanings, power dynamics, and nature of relationships (2, 47, 67). In addition, the terms were noted to constitute metaphors,

which define individuals using the services, how people view mental illness and people with mental health conditions, their roles, the forms and levels of involvement, paths and mechanisms of support, and how service users construct their identity (71). Terms preferred by service users can differ according to their personal interpretation and the associated meaning; hence, it is crucial to consult service users themselves about their preferences and ensure that the term decided upon is inclusive (67, 72). Although there is no consensus in preferred terminology, the term service user was more commonly used than consumer, client, and patient in policy documents and research (20, 67).

Similarly, this review found that a variety of terms are utilized, often synonymously, in relation to the concept of involvement; for example, engagement, participation, patient and public involvement (PPI). In many high income settings, more general terms like PPI were commonly used whereas in many LMICs terms such as community engagement and civic engagement are used (12, 73). However, no unifying definition/conceptualisation exists about the terms used to name the roles of people with lived experience of mental health conditions with mental health systems strengthening (1, 2, 74). This lack of conceptual clarity (referred to as a ‘conceptual muddle’ (75)) has created confusion regarding the goals and mechanisms of involvement, who to involve, how to involve, where to involve, and the overall development and implementation of service user involvement (49, 75, 76).

In Arnstein’s classic paper describing a ladder of participation, service user involvement was conceptualised based on the power relations between service users and service providers, and has been defined as the redistribution of power that enables disadvantaged citizens excluded from the political and economic processes to be intentionally included in the future by providing different inputs (77). Simpson and House have described service user involvement as all ways of involving service users in the delivery and evaluation of services; service users involved as case managers, as client advocates in case management, as peer counsellors or specialists, as trainers, and as interviewers in research (78). Crawford et al. (79) described involvement as methods whereby service users, service user representatives, or the public are involved as active participants in planning, monitoring and developing health services. Tambuyzer et al. have developed a comprehensive definition of involvement based on an analysis of 45 definitions used in the literature (2):

*“Service user and family/carer involvement means the active and meaningful involvement in decision-making and active participation in a range of activities (e.g. planning, evaluation, care, research, training, recruitment) starting from the expertise by experience of the person, in collaboration with and as equal partners of professionals in mental health care system’ (p, 142).*

Similarly, in a evolutionary concept analysis, Millar et al. proposed a comprehensive definition for service user involvement in mental health care (1):

*‘An active partnership between service users and mental health professionals in decision making regarding the planning, implementation and evaluation of mental health policy, services, education, training and research. This partnership employs a person-centred approach, with bidirectional information flow, power sharing and access to advocacy at a personal, service and/or societal level.’ (p. 216)*

Carman et al, in their multidimensional conceptualization of service user and caregiver involvement, define involvement as(19): *“patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system-direct care, organizational design and governance, and policy making-to improve health and health care.”(p. 223)*

### **2.2.5. Levels of involvement**

This review identified some studies that included service users and caregivers at all stages of a specific aspect of mental health systems strengthening. For example, three systematic reviews included service users in the systematic reviews (12, 80, 81). Although there are several frameworks that depict degrees of service user and caregiver involvement in a continuum from the lowest to highest, e.g. International Association of Public Participation(IAP2), Ontario Patient Engagement Framework (74) and evidence based co-production (82), this review identified only a few studies that explicitly stated conceptual or theoretical frameworks to guide the involvement process or to identify the degree of service user and caregiver involvement (20, 83). For example, the Bombard et al.(83) systematic review was informed by frameworks developed by Bate and Robert(82) and Carman et al. (19) to included and evaluate studies that

consulted(lowest level of involvement), involved, partnered, or co-designed(highest level) health services with service users(83). Similarly, Sangill et al. used frameworks that describe a continuum of involvement to identify studies that actually involved service users in a collaborative research in mental health (20).

Many studies provided limited or no information on the level, extent or nature of involvement. Although the description of service user and caregiver involvement was not presented using specific frameworks, many studies described levels of involvement at different stages in the specific component of the mental health system(20, 65, 66, 80, 84-86). In many studies service users and caregivers were involved at the initial stages (consultation in agenda setting and protocol development) and less commonly during the execution and translation of research.(20, 65, 66, 80, 84). Few studies involved service users and caregivers at all stages, starting from planning through to service user-controlled/led-service evaluation, dissemination and adoption of findings (50, 66, 67).

#### **2.2.6. Service user and caregiver involvement in mental health systems strengthening**

The reviewed literature showed that service users and caregivers were involved in many aspects of mental health systems strengthening, including mental health policy, service planning and development, mental health service delivery and quality improvement, mental health research, education and training, and in various types of peer support activities.

##### ***2.2.6.1. Involvement in mental health policy, planning and development of healthcare services***

In relation to this aspect of the mental health system, this review identified 7 publications (5 reviews and a further 2 primary studies) (Appendix 2A). In a relatively recent integrative review, seven relevant studies were identified from six countries, including Canada, UK, USA, Belgium, South Africa and Brazil (64). However, none of the studies actively involved service users, and many of these were based on literature reviews of conceptual analysis (n=2) theoretical articles (n=2) and experience reports (n=1), and qualitative empirical studies where service users were data sources without active involvement (n=2). The reviewers reported that service user and caregiver involvement at the public mental health policy level was an emerging area and there were numerous barriers and facilitators/strategies for involvement. They recommended greater

recognition of the contributions made by movements and associations that are dedicated to defending the rights of service users and promoting their leading participation in this field (64).

There are examples of service user and caregiver involvement in mental health service planning and development aspects of the mental health system. For example, a more recent scoping review and thematic analysis by Olsson et al identified 34 primary studies, including qualitative(n=29), mixed-methods(n=1), and quantitative (n=4) studies examining the impact of adult service user involvement in health service development (50). Of these, 12 were focused on mental health services. The review identified varied impacts of service user involvement in service development that are relevant to health organizations, health professionals, and service users (See Table 3). However, the studies were all from high-income countries. In another primary study conducted in Canada, the feasibility and acceptability of service user partnership was demonstrated in relation to developing an interactive guide to a new medical tool and in developing an intervention to address inequity of access to primary care providers for chronic diseases management and health promotion among people with severe mental illness (87). The authors used a PAR approach to engage service users with severe mental illness, other key community and institutional stakeholders as full partners to develop the strategy for patient-oriented primary care for persons with schizophrenia who also have chronic physical illnesses. Similarly, a cross-sectional study from a non-Western high income setting, China(Hong Kong), reported positive attitudes towards service user involvement in service planning and monitoring, and to a lesser extent in the management of human and financial resources in mental health research (68). The authors reported from their practical experience that successful partnership with service users requires careful leadership and communicative capacity among facilitators and ontological stances embracing multiple realities (68).

A relatively earlier systematic review conducted by Crawford et al. (79) identified 42 studies about service user involvement in health care planning and development, of which 13 studies were in the area of mental health. The authors concluded that there is evidence to support the assumption that involving service user may contribute to positive changes in service development and planning across a range of settings; however, the evidence base for the effects of involvement on use of services, quality of care, satisfaction and health of service users

remains weak, which was considered a potential obstacle for advocating for greater service user involvement. The author also noted that they found some of the most informative studies in the grey literature and that these studies were hard to find in electronic databases and systematic reviews. This review did not identify high quality studies from LMICs that actively involved service users and caregivers at policy/strategic or health service planning and development levels. Two relatively recent systematic reviews (11, 88) also identified very few examples of active involvement of service user and caregivers, and concluded that the evidence base is weak with regard to involvement in mental health system strengthening in LMICs. For example, Semrau et al. identified only five studies that related to the strategic level where participants were consulted on several issues (88). Very few studies (n=4) included explicit evaluative data of service user and caregiver involvement (88). The reviewers reported that there is little evidence in the literature on how best to involve service users and caregivers in the planning or development of services and noted the presence of good experience in using participatory research approaches. Similarly, in a follow-up update of this review, three studies in the area of mental health policy and planning were identified, but they were all formative qualitative studies conducted as a situational analysis or pilot study without direct, active involvement of service users or caregivers (11). The reviewers listed a series of recommendations for future research, including the need for rigorous evaluation of involvement, high quality studies (including RCTs), participatory approaches and case studies to capture the complexities and outcomes of service user and caregiver involvement in mental health systems strengthening in LMICs (11, 88).

In summary, this review identified a growing recognition of the importance of service user and caregiver involvement in mental health policies, planning and development of mental healthcare services. However, the existing evidence shows that actual involvement is very limited across the world, particularly at a strategic policy level of the mental health system and with few studies at lower levels of the mental health systems. The accessed reviews did not review the roles and level of involvement or provided detailed accounts of the processes and outcomes of involvement in a way that could be generalized and replicated in other settings. The existing evidence is concentrated in high income countries whereas evidence from LMICs is scarce.

### ***2.2.6.2. Involvement in mental health service delivery and evaluation***

This review identified 10 (6 reviews and 4 additional primary studies) about service user and caregiver involvement in service delivery and evaluation aspects of the mental health systems (APPENDIX 2B).

A meta-synthesis of peer reviewed qualitative studies over a 15 year period identified 19 studies from high income countries. The reviewers identified few actual involvement experiences and concluded that service user involvement in mental healthcare remains a policy aspiration. They reported several factors that affect service user involvement (APPENDIX 2B)(89). Another systematic review by Bombard et al. identified 48 studies (27 qualitative, 3 quantitative, 13 mixed-methods), which showed that active service user and caregiver involvement can enhance service delivery and governance (83). Although few studies conducted a formal evaluation, increased self-esteem, feeling empowered and independence were reported as impacts of involvement in quality improvement processes. The reviewers concluded that service user involvement can inform service user and provider education, policy, service delivery and governance (83). Another earlier systematic review by Simpson and Houses (78) also identified 12 studies (five controlled trials and seven comparative studies) related to service user involvement in the delivery and evaluation of mental health services. The reviewers concluded that service users with severe mental disorders can be feasibly involved in mental health service delivery with necessary support in the role of employees, trainers or researchers. However, the authors indicated that most of the studies they identified involved only small numbers of service users and were limited by substantial methodological weaknesses (e.g. using non-validated outcome measures, very small sample sizes, geographically too limited) to generalize to other settings.

The systematic review by Simpson and House (78) identified very few studies about caregiver involvement in mental health service delivery and evaluation. Similarly, Eassom et al.'s (65) systematic review of 43 studies, reported low involvement of caregivers because of several factors that hinder caregivers/family involvement in service delivery(See section 2.2.7). In a related study, Kaselionyte et al. developed structured clinical procedures to maximize caregiver involvement in inpatient treatment and tested the feasibility of a single session caregiver

involvement intervention in four acute psychiatric hospital wards in East London (90). The researchers found that caregiver involvement in acute psychiatric ward seems feasible, and that a simple structured approach can facilitate a dialogue among service users, caregivers and clinicians. However, this approach requires, but was complex and challenging phenomenon that needs new ways of thinking and additional support strategies, such as training clinicians, carrying out awareness raising programmes and workshops to ensure buy-in of senior managers. The researchers concluded that the involvement of senior managers and clinical leaders might play a key role in overcoming barriers and supporting front-line clinicians to prioritise and implement caregiver involvement. There are a few promising outcomes of caregiver involvement as case-managers from LMICs (e.g. Iran), which were considered to be of practical importance in a resource poor setting (88). Similarly, a prospective cohort study from Nigeria also indicated that involvement of families in treatment during psychiatric hospitalization predicted significantly improved post-discharge adherence to medication (91).

This review produced very limited evidence from LMICs in relation to service user and caregiver involvement in mental health service delivery and evaluation. More recently James et al completed a realist synthesis and systematic review of peer reviewed publications (n=37) and grey literature (n=20) about service user involvement (they used the term civic engagement) in LMICs (South East Asia). They reported that the majority of studies were based on Western models and had important cultural differences with their study settings. They developed a programme theory depicting the importance of context, mechanism and outcome configurations in LMICs. Their study illustrated that service user and caregiver involvement can be successfully implemented in LMICs (South East Asia) by adapting models that fit local cultures and values to promote successful implementation (12). Two previous systematic reviews in LMICs also reported that, although there are examples of studies on service user and caregiver involvement in service delivery and evaluation, only few studies included outcomes of service user involvement or actual involvement of service users in the monitoring of services (11, 88). Another study from a non-Western high-income setting (Hong Kong) conducted by Tang et al using a Photovoice approach showed that service user involvement changes gradually towards assuming the highest level of control through personal responsibility, connection with peers, collaboration with professionals, redefinition of boundaries and social inclusion (92). The authors reported that meaningful involvement gave rise to a sense of contribution, interpersonal

connection and self-worth and transformed identity. The Photovoice approach was found to open up new space for voicing expert knowledge.

In general, there is growing evidence about service user and caregiver involvement in service delivery and quality improvement; however, there is little evidence of this actually happening in LMICs. There are methodological issues, such as lack of agreed upon measures of outcomes, reports from a small number of countries, no report of the cost-effectiveness of interventions, a lack of clear strategies how best to involve service user and caregiver, and other methodological weaknesses in the research evidence that needs consideration.

### ***2.2.6.3. Service user and caregiver involvement in mental health research***

This review identified six primary studies, in addition to studies included within reviews, which examined service user and caregiver involvement in mental health research (APPENDIX 2C). More recently, Malterud and Elvbakken conducted systematic reviews of outcomes and experiences of service users involved as co-researchers throughout the research process (86). Their narrative synthesis of 17 qualitative studies (13 were related to mental health), all from four high income countries, found that a co-production approach represents the contemporary model of service user involvement. In this approach, shared experiences and strategy to expand understanding were the key outcomes in the studies. Their findings indicated that service user involvement was the primary focus (e.g. as collaborative process) or a means or strategy (e.g. to address some health issue) in the included studies. These reviewers had concerns over the prioritization of the process of collaboration at the expense of knowledge outcomes and scientific quality (86). In a scoping review and narrative synthesis of 32 studies (quantitative (n=5), qualitative (n=24) and mixed-methods (n=3) by Sangill et al., actual involvement of service user-researchers in research processes encompassed a complex set of precarious negotiation practices. In addition, the reviewers reported that collaborative research in mental health requires changes to traditional research practices to create and support genuine collaborative partnerships and thereby avoid tokenism and power inequalities (20).

Another systematic review carried out by Domecq et al (80) identified 142 studies (eight systematic reviews, seven randomized trials, 24 observational studies and 103 qualitative studies), where more than 20 studies were related to mental health service user involvement in research. The review addressed four key questions. The first question focused on the best ways or methods to select service user representatives to engage in research. In relation to this question their review indicated that very few studies randomly selected service user representatives and most of the studies described convenience sampling as the method to identify participants for engagement in research. For the second question, the best method of engaging service users in the design and conducting research, they reported various methods: focus groups, interviews, surveys, attending regular meetings with researchers, participatory research studies and community based participatory research. However, they did not find any comparative analytic studies to provide evidence supporting a particular method to select or best methods of engaging

service users in research. The authors identified a range of benefits of service user involvement as well as identifying many challenges to service user involvement (APPENDIX 2C). In general, the authors concluded that service user involvement in health care research is likely to be feasible in many settings; however research dedicated to identifying the best methods to achieve involvement is lacking and clearly needed (80). Similarly, Brett et al. conducted a systematic review and narrative synthesis of papers on the impact of service user and caregiver involvement on service users, researchers and the community involved in health and social research (81). They identified 65 papers (42 qualitative studies and 12 case studies, 3 case series, 3 cross-sectional, and 5 reviews) about the impacts of service user and caregiver involvement on health social care service users (e.g. having improved confidence, feeling empowered and valued). They also identified 35 papers (26 qualitative, 4 case studies, one case series, one cross-sectional, and 3 reviews) that reported impacts of service user and caregiver involvement for researchers (e.g. pertinent research objectives, improved participant documentation, better recruitment, service user-oriented analysis and enhanced dissemination, greater understanding of the research). Their review also identified 23 studies (17 qualitative studies, one cross-sectional, 4 case studies and one review) about the impact of service user and caregiver involvement on the community (e.g. improved knowledge about their local situation).

This review did not identify study of service user and caregiver involvement in mental health research from LMICs. Previous systematic reviews in the area also did not produce evidence on actual involvement or how best to involve service users and caregivers, instead finding that they are commonly involved as research participants for the evaluation of service rather than directly participating in the research process (11, 88).

In summary, the finding of the review showed that there is a growing recognition of the benefits of service user and caregiver involvement, along with other key stakeholders, in mental health systems research in various contexts globally. The involvement level covers a spectrum of engagement from the lowest level of information provision to the highest level of service user-controlled research where they have primary decision-making authority. Service user and caregiver involvement improves the relevance, appropriateness and usefulness of research to serve the interests and needs of service users. However, most of the theoretical and empirical

evidence was concentrated in a few high-income countries where service user involvement in research is a policy expectation and funding requirement. In LMICs there is a weak evidence base on the level of service user and caregiver involvement in mental health research, how best to involve them, the outcome of involvement and the barriers to involvement.

#### ***2.2.6.4. Service user involvement in mental health education and training***

Service users and caregivers have an important role to play in mental health education and training in various contexts, including higher education institutions. This review identified 12 publications (seven reviews and five primary studies) on service user and caregiver involvement in mental health professional training or in teaching and learning in higher education institutions (APPENDIX 2D). A comparative case study by Kaiser et al. included four cases that represented a range of contexts (including both high and low income countries) and examined how, why, and with what consequences recovery narratives are elicited in the context of global mental health (93). Their findings show the benefits of co-constructed narratives and potential negative impacts on service users in some contexts when narratives are used as a pre-requisite for accessing or being discharged from clinical care. They concluded that service users' recovery narratives can be used productively across purposes and contexts when there is adequate identification of, and response to, potential risks. More recently, Kang and Joung carried out a systematic review of studies in the last 10 years on the impact of service user involvement in education of mental health students. Their review identified 14 studies (10 qualitative and 4 quantitative), predominantly conducted in high income countries. The authors reported that service user involvement can bring positive changes in students' attitudes about service user involvement and people with mental health conditions, assessment of learning programme, and quality of nursing practice (85). Similarly, Soon et al conducted a systematic scoping review of studies over 24 years on service user involvement in university education programs in nursing, midwifery, and allied health professions, with specific focus on different strategies used to involve, recruit and retain service users (67). This review included 58 papers, including qualitative studies (n=25), quantitative (n=13), descriptive papers (n=15) and mixed methods (n=5), of which 32 studies were related to mental health practices. The review identified four areas of service user involvement and eight strategies to recruit and retain service users (APPENDIX 2D). The authors concluded that enriching tertiary education programmes with service users inputs enhances students learning, helps them to understand service users' perspectives and to develop empathy, ensures that they are well-prepared for the future workforce, and assists these professions to meet accreditation standards (67).

Arblaster et al identified 36 studies, including qualitative(n=23), quantitative(n=7), and mixed-methods(n=6) in a structured review that aimed to evaluate the available evidence for service user involvement in health professional education to inform occupational therapy educators (84). Their findings show that there was an emerging body of evidence in the area, but that studies lack quality, resulting in a low to medium level of evidence. In another study, Happell et al. (66) carried out a systematic review of 30 published studies on service user involvement in the education of health professionals(psychiatrists, nurses, psychologists, social workers and occupational therapists) and concluded that involvement in the education of mental health professionals is limited and variable across professions. The involvement of service users was reported to have benefits for the students, including: students gain insight about service users real life conditions, gain understanding about mental illness, the experience of admission and treatment, and how mental health service could be improved.

Perry et al. explored service user involvement in teaching interpersonal skills to mental health nursing students with the focus on improving their interpersonal communication skills (94). This review included 10 studies and concluded that involvement in teaching communication skills was valued and led to improved attitudes towards people with mental health conditions. However, the review also identified that some students were concerned whether service users' views were sufficiently objective. Similarly, Terry (95)conducted a comprehensive review of eight publications(four primary studies and four reviews)on service user involvement in pre-registration mental health nurse education, with specific focus on evaluation of classroom learning. The authors concluded that the articles reviewed offer promising reports, indicating that service user involvement can enable students to increase their awareness of service user perspectives. The authors also commented that the qualitative articles included in the review did not provide adequate detail of methods relating to credibility, transferability, dependability, and conformability to allow readers to make judgments. Hence, it was recommended that there should be further longitudinal research to establish the impact of classroom learning initiatives. The articles reported a range of teaching and learning strategies, ranging from exposure to users' personal stories, to students being required to demonstrate awareness of user perspectives in case study presentations, with others involving learning and assessment skills.

In LMICs there are growing examples of service user and caregiver involvement in mental health professional education/trainings or education institutions. Although a previous systematic review did not identify any research evidence from LMICs in this area (88), the review for this thesis showed that there are a few good examples of actual service user and caregiver involvement emerging within mental health research in LMICs. For example, more recently Tergesen et al conducted a three-arm RCT(8 minute didactic videos about a mental health condition; 8 minute videos with service users presenting recovery testimonials; and a no-video condition) to examine immediate explicit and implicit stigma attitudes after video viewing among medical students in Nepal (96). Paper 1 addressed depression, but Paper 2 addressed depression and psychosis. The findings show that in Study 1 both didactic and service user videos reduced stigma compared to the control condition. In Paper 2 there were no differences among the three arms. The comparison of the two studies shows that there was greater stigma reduction in the service user video arm with only depression versus service user videos describing depression and psychosis. The researchers reported that didactic and service user videos were associated with decreased stigma when content addressed only depression, but not for depression and psychosis.

Another promising study about service user and caregiver involvement from Nepal, was the REducing Stigma among HealthcAreProvidErs (RESHAPE) study, which is an initiative to engage service users and their caregivers to improve training of primary care workers in mental health services(43, 97). RESHAPE is developed based on stigma reduction theories from social psychology, social neuroscience, and medical anthropology using a ‘What Matters Most’ framework of motivation (43). The core methodology is photovoice, which is a participatory photographic narrative technique. In RESHAPE, trained service users and caregivers presented recovery narratives to primary care workers participating in Mental Health Gap Action Programme (mhGAP) trainings (WHO training programme for non-specialists), local community groups and policy makers. Proof-of-concept testing demonstrated feasibility and acceptability of the approach in Nepal, as well as suggestive benefits for reducing mental health stigma among primary care workers receiving mhGAP training (43).

In summary, the literature review indicated that the evidence base for service user and caregiver involvement in the teaching and education aspect of mental health systems is growing steadily in many countries and is well-developed in a few high-income countries (e.g. Australia and UK).

Service users are mainly involved in the teaching aspect, but also in course development and governance, assessment and student/educator recruitment. Service user involvement in education ensures that students strengthen their service user-focused practices before stepping into the workforce. There are some examples of incorporating service user and caregiver expertise into mental health training of health professionals/students, but these are rare in LMICs. Service user and caregiver involvement in this aspect of mental health systems strengthening is essential to ensure future mental health professionals value, know and deliver people-centered mental health practices through learning from service users' and caregivers' lived experiences.

### ***2.2.6.5. Informal service delivery and support groups***

There are others forms of service delivery and support groups for people with mental health conditions, which very often occur at some distance from, or outside, the formal structures of mental health systems. These services include peer support, family support, mutual support groups and networks/organizations of service users and caregivers (98). In many high-income countries, there is formal government support for, and promotion of, peer support for mental health and other health and social care areas. This review included nine relevant studies, including systematic reviews of randomised controlled trials (RCT), mainly from high income countries about service user or caregiver involvement in peer support activities (APPENDIX 2E). In a recent meta-analysis, White et al. identified 23 eligible publications reporting on 19 trials on the evidence about one-to-one peer support for eleven outcomes (APPENDIX 2E) (99). The authors concluded that one-to-one peer support in mental health services may impact positively on psychosocial outcomes, but is unlikely to improve clinical outcomes(99). Similarly, Ibrahim et al. identified 53 studies, including qualitative studies (n=38), RCTs (n=10), cohort studies (n=4) and controlled studies (n=1) in their systematic review carried out to identify factors that influence (barriers and facilitators) implementation of mental health peer support work. The following factors were identified as important influencing factors: organizational culture, peer role support, training, role clarity, resources, access to peer network, and professionals' attitudes (98).

Another systematic review of eleven randomized trials by Pitt et al. (100) compared mental health care services provided by service users and mental health professionals. The authors concluded that involving service users in mental health service provision led to a small reduction in emergency service use. The review indicated that services users can work in partnership with mental health professionals with roles including peer support, coaching, advocacy or peer interviewers, case management or outreach, crisis worker or assertive community treatment worker, and providing social support programmes. The authors highlighted the need for high quality studies that may also be applicable LMICs. Similarly, Fuhr et al.(101) conducted a systematic review and meta-analysis of fourteen randomized controlled trials (10 with people with severe mental illness and four for those with depression) that compared peer-delivered treatment and treatment delivered by health professionals. They found that peers have the

potential to deliver care to persons with severe mental illness and seem to positively influence clinical and psychosocial outcomes of service users because of their expertise by experience compared to lay health professionals. The authors also indicated many features of peer support that seem potentially advantageous to apply to LMICs, where specialist human resources are limited, including sharing socio-demographic characteristics with the service users they work with and potential to have a better match with the service user in terms of family background, community, age, gender or ethnicity. A related systematic review by Wright-Berryman, McGuire, and Salyers (102) included 16 studies (eight randomized controlled trials, five quasi-experimental, between group comparisons; and three pre-post designs) on service user-provider involvement in Assertive Community Treatment (ACT) and intensive case management teams. They concluded that involving service user-providers on ACT teams can help to bring service users to services and help with treatment engagement and therapeutic relationships over time.

In another study, Lloyd-Evans et al.(103) conducted a systematic review and meta-analysis of 18 studies (four trials of mutual support groups, 11 trials of peer support, and three trials of peer-delivered services) on peer support for people with severe mental illness in high income countries. Their review found a modest positive effect of peer-provided services on self-reported recovery and hope. They concluded that although there are some positive findings, there is little evidence from their reviews about the effectiveness of peer support for people with severe mental illness. However, another integrative review by Doughty et al. identified 29 publications(two systematic reviews, 17 randomized controlled trials, three quasi-randomized trials, and seven comparative studies) on service user involvement in mental health service delivery and reported beneficial outcomes of service users involvement (104). Service user-led mental health services had equally positive outcomes for their clients as professional-delivered services (See APPENDIX 2E).

This review identified a very limited number of studies evaluating the benefits of service user and caregiver involvement in peer support and mutual support groups in LMICs. Chen et al conducted a RCT to test effectiveness of nine-month family-led peer support group(n=35) for Chinese people with schizophrenia in Hong Kong over a three-year follow-up that compared outcomes with those receiving psychoeducation(n=35) and standard care(n=36). They measured multiple service user and family outcomes (e.g. service utilization, functioning, mental state, re-

hospitalisation rate) at different time points (at recruitment and one week, 18 months, and 36 months after completion of the interventions). The results showed that the families in the peer support group reported consistently greater improvements over the three years in overall functioning, and reduction in the duration and number of hospitalizations. A previous systematic review in LMICs also found a few studies (n=5) examining benefits of service user or caregiver involvement in service delivery through peer support groups. There are recommendations in the literature to learn from peer support activities in high-income countries and adapt for resource poor settings. For example, Charles et al. conducted a systematic review and narrative synthesis of 39 studies (qualitative studies (12), RCTs (13), pre-post (10) case control (3) and cohort (1) on peer support in mental health systems, whereby they identified about six areas for modification (role expectations, training, types of contact, role extensions, workplace support for peers workers, and recruitment) to address local contextual and cultural aspects for resource poor settings. They presented five rationales for modifications, including how best to provide possible peer support, meet services user needs, meet organizational needs , maximize role clarity, and to address social-economic issues (105).

In summary, this review identified that there is an extensive literature discussing the importance of, and evidence for (including RCTs), the benefits of mental health peer support. However, the evidence was mainly concentrated in a few high-income countries and little research evidence was accessed in LMICs. Peer support seems to be an under-utilized resource in LMICs. The highly localized nature of the evidence hinders general conclusions about effectiveness across diverse settings. Given the high mental health care gap and human resource shortage in LMICs, scale-up of peer support for people with mental health conditions through adaptation and making the necessary modification of these lessons seems viable and to have potential in LMICs.

### **2.2.7. Barriers and facilitators for involvement**

This review identified multilevel factors (both barriers and facilitators) that affect implementation of service user and caregiver involvement in various aspects of mental health systems strengthening.

#### ***2.2.7.1. Barriers to involvement***

In this review, many studies reported that significant gaps exist between what policies expect and what actually happens with regards to service user and caregiver involvement in different aspects of mental health systems strengthening. The lack of conceptual clarity, as well as the plurality and inconsistency of terms used to define involvement has been identified as one key barrier to the advancement and implementation of service user and caregiver involvement (2, 11, 20, 23, 50, 64-67, 80, 81, 83, 85, 86, 89, 93, 105). Another commonly reported factor that negatively impacts involvement was the lack of models/frameworks on how best to meaningfully implement service user and caregiver involvement, and how to evaluate the impact of involvement at the health system level (11, 12, 20, 23, 64, 65, 80). In particular in LMICs there is a lack of models(12, 23) that fit to local cultures and context (12, 68). Barriers to involvement were found to operate at multiple levels, including factors that relate to service users and caregivers, health professionals and healthcare organisations, wider society, and policy/political factors (2, 12, 19, 23, 65), Each of these will now be considered in turn.

#### **Service user and caregiver related barriers**

There are several service user and caregiver level factors that hinder involvement in mental health systems strengthening. Many studies reported lack of necessary knowledge and skills or low level of education as a key barrier to active service user and caregiver involvement in different aspects of the mental health system(2, 12, 23, 64, 66, 81, 106, 107). In spite of this, only a few studies reported pre-involvement preparation/training and supports provided to equip the stakeholders for their roles in involvement (12, 20, 43, 66, 83, 85, 90, 92, 93, 99, 105, 108). Service users and caregivers lack knowledge about how mental health systems work, which when compounded with the lack of preparation and training can lead them feel unable to contribute to the involvement activity and overburdened with the involvement work (64, 81).

Some studies reported that the effect of illness or unstable health conditions and associated lack of capacity to make decisions constitutes an obstacle towards meaningful service user involvement (2, 12, 23, 64, 107). Beyond this, the low socio-economic status of many service users and caregivers undermines their capacity to dedicate their resources to participate in important issues that affect their lives (2, 12, 23, 64, 109). The low economic status of service user and caregiver is the result of self-reinforcing cycles of poverty, stigma and discrimination, which deepen social, economic and political disadvantage that hinder their capacity for defense and self-representation (64, 109).

### **Professionals and organization-related factors**

Many studies reported organizational culture as a limiting factor for service user and caregiver involvement in mental health systems. Organization-related factors, including low leadership commitment, low priority and lack of supportive infrastructure (e.g. lack of/limited allocation of budget and resources, policy, strategies, legislations, training) are potent barriers to successful involvement (2, 11, 12, 23, 64, 65). Many studies commonly mentioned lack of resources in terms of funding, logistical costs, compensation for service users and lack of time (11, 20, 64, 65, 80, 81, 85, 89). Non-availability of these conditions leads to a lack of genuine involvement or only symbolic or false appearance of involvement(tokenism), which was the most commonly reported barrier to greater service user and caregiver involvement in various aspects of mental health systems(11, 12, 20, 23, 83, 89).

Meaningful service user and caregiver involvement practice can also be influenced by professionals' attitudes, training and competence. Many studies reported professionals' lack of training and skills on how to best conduct involvement and work collaboratively with service users and caregivers (11, 20, 50, 64, 65, 80). Professionals(service providers and researchers) lack of interest (11, 20, 65, 89), negative beliefs and attitudes about service user roles and inputs, and resistance to share power were the most consistently reported barriers to greater service user and caregiver involvement (11, 20, 65, 66, 68, 89, 110). Many studies mentioned that professionals' negative attitudes were related to a presumption of service users' incapacity, irrationality and dangerousness; which serve as key barrier for the service user involvement, and reinforce lack of empowerment and feelings of powerlessness (20, 64, 65, 96). Although some

scholars state that psychiatric conditions can affect service users' ability to be involved, due to deficits in understanding that would lead to irrational and poor decisions (2), many other scholars question these positions by stating that lack of capacity is an unverified assumption being made based on the dominant biomedical paradigm of disease and long-standing prejudiced beliefs regarding mental illness, which often consider people through a patient role (64, 109, 111).

Furthermore, health professionals and the scientific community seem to give more weight to scientific evidence than to the lived expertise of service users and caregivers, which puts knowledge production in the hands of professionals (20, 68). This challenges the legitimacy of service user and caregiver lived expertise and creates a knowledge disparity that leads to a power imbalance (resources, knowledge and skill, language) between professionals and service users/caregivers that invariably undermines the credibility of involvement (11, 20, 23, 64, 66, 68, 89, 106).

### **Wider societal level barriers**

The socio-cultural framework within which service users and caregivers reside may marginalize them so that their access to social, political and economic opportunities and influence is diminished due to mental illness (1, 64, 108-110, 112). The negative attitudes towards mental illness and people with mental health problems present in wider society are thought to be major influences in determining the extent to which service users can be involved in mental health systems and service strengthening (64, 89, 107). Studies have shown that prejudicial beliefs about service users' lack of capacity to make rational and informed decisions has led to infringements of the rights of service users to participate in political, legal, clinical and personal decisions which concern their lives (64, 89).

### **Policy/political related factors**

Many studies show that the broad structural factors, including low priority given to mental health in government policies, shortage of resources, budget, human resources and structural stigma, are crucial barriers to meaningful service user involvement in the strategic level of mental health systems particularly in LMICs (12, 22, 23, 64, 113). Many studies reported a lack of infrastructure at the strategic level, including policies, legislation and procedures related to service user involvement that hinders implementation of involvement (2, 12, 64, 65).

### ***2.2.7.2. Facilitators for involvement***

Many of the included studies mentioned, at least in their backgrounds, that there exist supportive local and international policies that promote service user and caregiver involvement at all levels of the mental health system (11, 20, 23, 64, 65, 80, 81, 83, 85, 86, 89, 93). In countries where government support is greater, in terms of strategic level involvement policy, legislation, structured working routines and procedures, funding and other supportive cultures for participation in decision-making, more actual involvement tended to take place (2, 12, 23, 64-66, 90).

There were also recommendations for human rights paradigm and multilevel and multi-system approaches to allow full social engagement, and ensure the sustainability of service user and caregiver involvement (2, 12, 19, 64). The involvement of key stakeholders, including top leadership support, and creating shared understanding of the value of service user and caregiver involvement, dedicated training and preparation of stakeholders are key success factors for involvement (67, 99). Institutional and community support, professionals' willingness to work with service users and caregivers, an organizational culture that is open to changes and provides a receptive context, and sufficient resources, allow service users to resume their personal, social, and community roles and increases the possibilities for greater participation (20, 64, 68, 83, 98, 109).

Many studies indicated the importance of strengthening capacity for involvement, through deploying education and training, and increasing access to information as important preconditions to involvement. In particular, clarifying the rationale, purpose, roles and expectations for service user and caregiver involvement, creating mutual understanding among stakeholders on the value of involving service users, providing support and supervision, and training service users and other key stakeholders for the roles had a positive effect on involvement (2, 20, 43, 50, 64-66, 68, 83, 90, 92, 93, 99, 108). Alongside these efforts, strengthening service user advocacy groups and empowering them to advocate for their rights has been identified as a condition for authentic involvement of service users in mental health systems strengthening (50, 86, 89).

In summary, the findings show that service user and caregiver involvement is a complex process affected by several multilevel factors, including strategic, organizational, community and service user and caregiver level factors. This implies that initiatives to involve service users and caregivers in mental health systems strengthening need to take into account broader systemic approaches, which consider these multilevel factors.

### **2.2.8. Models of involvement**

Various approaches, theories and frameworks have been identified in the literature in relation to service user and caregiver involvement, including social contact theory (96), medical anthropological models (43), recovery theory (84, 85, 93), participatory research such as photovoice, triologue, co-production, partnership or collaboration(20, 23, 50, 64, 68, 86, 87, 89, 90, 92, 93), and theory-driven approaches such as realist synthesis (12). However, only a few studies explicitly stated the basis for their work and were underpinned by conceptual models/frameworks(e.g. multidimensional framework (83)) or theoretical frameworks to guide the involvement process.

The most frequently cited model in the literature is Arnstein`s ladder of citizen participation, which displays different levels of involvement depicted in eight steps as rungs of ladder of power sharing arrangements in making decisions of public, The eight steps were categorized into three, including(i) non-participation (manipulation, therapy),which enables the power holders to educate or co-opt participants, (ii) tokenism (informing consultation, placation,), which are the middle rungs in which participants lack the power to influence decisions despites having a voice and being heard, and (iii) citizen power(partnership, delegated power and citizen control), which represents more authentic powers sharing and an increased extent of decision-making (77). Each step describes an increasing type of involvement people can have in decision making and the extent of involvement depends up on the power of influence. In this model, the redistribution of power to enable citizens excluded from different endeavors in the system is considered as a condition for involvement.

Arnstein`s model is criticised for being a linear and simplistic approach to involvement, which progresses from a state of complete powerlessness of the service user to absolute control, with little consideration given to the complexity of the situation, the evolution in the degree of user

participation and the service user's capacity for personal development and adaptation to an organization (114, 115). The model only displays the levels of involvement and lacks clear mechanisms on how to address the inherent power imbalances, inequalities in the process of involvement and factors that can constrain the assumed power redistribution to move to the higher levels of involvement (107, 115). In addition, the model did not consider other factors such as context; it simply indicates that the higher the level, the better the participation, while it may not always be practical to achieve the higher levels and in some situations the lower levels are more applicable and useful. Despite these criticisms, there are many frameworks of involvement derived from this model, which elucidate different levels of involvement including many of those discussed here.

Hickey and Kipping (107) described service user involvement using the consumerist and democratization approaches on a continuum comprised of four levels of participation: information/explanation, consultation, partnership and users control of transferring decision making power to the user. The consumerist approach strives to increase the choices of service users through commercial world techniques of protection or promotion of the rights of consumers, but they are not able to decide upon the contents of the services, only evaluate the output. The democratic approach emphasizes that the service users have decision power upon the content of the services which is governed by basic values and human rights, citizenship and empowerment. The approach focuses on the therapeutic value of involvement (2, 107).

Tambuyzer et al.(2) proposed a comprehensive model of involvement after analyzing 45 definitions generated from a comprehensive review of the global literature. They distinguished three levels of involvement in the mental healthcare system, including the micro, meso and macro levels. The model gives an overview of the determinants of service user involvement (communication and information, attitudes, resources, education and support, procedures, and legal framework), defining elements of service user involvement characteristics (definition, specificity of mental health care (e.g. inpatient), reasons for involvement, organisational levels, power dimensions, diversity issues, methods, formality, and related concepts); and a range of outcomes for service users (short-term and long-term). Even though the model may help to guide conceptual understandings about involvement, it has not been empirically tested. The listed determinants may not be comprehensive; at least from the

conceptual literature, many issues related to the conditions for involvement are not included, the role of family and local community especially in non-Western settings is not considered. The model is only based on evidence produced from a review of literature i.e., no input from involvement of other stakeholders in the real world to construct the model.

Another framework influenced by Arnstein's work was Carman et al.'s multidimensional model that describes various levels of involving service users and caregivers. This framework takes into account the complexity of involvement and considers involvement on a continuum as well as multilevel factors that influence involvement, including meso/patient factors (e.g. beliefs), organization (e.g. policies), and societal (e.g. social norms) (19). This model also still appears to suggest the greater levels of involvement are more desirable and did not show clearly the mechanisms for how to reach the higher levels.

In summary, the conceptual papers included show that service user involvement can occur at a number of levels, including micro/individual level (e.g. decisions about individual care plan), meso/organization level or service level (e.g. decisions about service planning), and macro/strategic/national level (e.g. decisions about national policy and strategy development). This review did not identify evidence about best models or strategies for service user and caregiver involvement across all aspects of mental health systems strengthening that was uniformly applied and recommended for wider use. However, there are many individual-centered involvement models that involve service users and caregivers in treatment and care and interaction of service users with health professionals, including patient-centered care, recovery model, and shared decision making models (116, 117). The models have arguably been too simplistic to adequately convey the complexity of involvement and less attention was given to a broader systemic approach to involvement, which considered multilevel factors related to micro-, meso- and macro-levels such as the wider social, political, contextual factors, and interventions at different levels. Previous systematic review in LMICs also reported lack of evidence on models of best practice for evaluation of capacity building activities for greater involvement of service users and caregivers in mental health system strengthening. A more recent theory-driven evidence synthesis from LMICs also reported that most models are oriented in the western – individualistic cultures which are different from the most collectivist societies in LMICs(12). This review suggests that complexity of service user and caregiver involvement and

mechanisms how to address the complex individual, healthcare organization and broader societal factors to service user and caregiver involvement as well as theory-driven approach to involvement were not well taken into consideration.

## **Chapter summary**

This chapter presented a scoping review of global evidence that illuminates the complex landscape of service user and caregiver involvement with emphasis on mental health systems strengthening. There is growing interest and recognition of the importance of service user and caregiver involvement in all aspects and levels of mental health systems among policy makers, researchers and service users globally. The review shows possibility of conducting involvement with benefits to individual participants, health professionals, health systems and broader society. However, lack of unifying definition/conceptualization of service user and caregiver involvement creates challenges to implementation of involvement.

The findings of the review show that the available evidence about service user and caregiver involvement is concentrated in a few high-income countries where there are enabling infrastructure and support mechanism (e.g. policy funding, involvement models), and there is great disparity between high income and low income countries in the performance of service user and caregiver inclusion in mental health systems. However, in LMICs, service user involvement has not been a policy priority and there is little strategic support to promote service user and caregiver involvement in mental health system strengthening. There is a scarcity of evidence in the literature on how to involve service user and caregiver in the mental health system, perspectives of different stakeholders on involvement and the barriers to involvement. In addition, to the limited number of published studies in LMICs, the scale and the quality of the studies hinder the possibility of drawing lessons.

The review showed that service user involvement is complex and multifaceted, affected by multilevel factors and challenging to define and measure its impact. A range of barriers to effective service user and caregiver involvement has been conceptualized, operating at different levels of the mental health system and beyond. Most of the reports included little description about the process of service user and caregiver involvement level. Information about the details

of the models may help to learn from and to apply to other settings. These review findings suggest that meaningful implementation of service user and caregiver involvement needs to be approached systemically, taking into consideration the complex multilevel factors.

The next chapters of the thesis describe the objectives (chapter 3) and methodology (chapter 4) of the study which aims to address the multiple, interdependent and multilevel factors by conceptualization of service user and caregiver involvement as a complex intervention using a socio-ecological approach.

## **Chapter 3: Objectives and research questions**

### **3.1. Objectives of the study**

#### **3.1.1. General objective**

To develop, pilot and evaluate a model of service user/caregiver involvement in mental health system strengthening in Ethiopia

#### **3.1.2. Specific objectives**

In a rural Ethiopian mental health system setting:

1. To explore the experiences, perceived barriers and facilitators regarding service user and caregiver involvement in mental health system strengthening.
2. To develop an acceptable, sustainable and feasible Theory of Change model of service user and caregiver involvement in the expanding mental health system.
3. To equip service users and health professionals for greater involvement in mental health system strengthening.
4. To pilot the feasibility and acceptability of a co-developed model of service user and caregiver involvement in mental health system strengthening.

### **3.2. Research questions**

1. What are the experiences, perceived barriers to, and facilitators of, service user/caregiver involvement in mental health system strengthening from perspectives of key informants in rural Ethiopia?
2. Using participatory planning, what is the theory of change model for how service users/caregivers can be involved in mental health system strengthening in rural Ethiopia?
3. How can service users, caregivers and health professionals be equipped to engage in processes leading towards greater involvement in mental health system functioning?
4. What is the feasibility and acceptability of a pilot model of service user and caregiver involvement nested within primary care based mental health services in a rural district?

## **Chapter 4: Research Methodology**

This chapter presents the theoretical and conceptual frameworks that informed the methodology of the study. First, the rationale for the choice of a participatory approach and the philosophical stance of the researcher are presented and justified with reference to ontological and epistemological perspectives. Then, the conceptual framework of the study is described. Following the conceptual discussion, a general summary of methods and materials, including research design, contexts and setting of the study, participants, recruitment, consent procedures, data collection, management and analysis, ethical considerations, and quality assurance procedures/rigor of the method is provided.

### **4.1. Theoretical frameworks of the study**

A researcher's understanding of the philosophical assumptions(paradigms) underpinning his/her research is valuable to determine explicit or implicit positions with respect to the nature of reality or the problem (ontology), the nature of knowledge and how knowledge is constructed (epistemology), the values underpinning the research (axiology) and the approaches used in the process (methodology) (118, 119).

Ontological perspectives exist on a spectrum from realism, whereby reality is conceptualized as existing entirely separately from human practices and understandings, to relativism, whereby reality is considered to be dependent on human knowledge and interpretation (120, 121). Ontology is also concerned with what constitutes reality, which includes the way that the individual(researcher) sees him/herself, which in turn can influence the way s/he sees others(participants) (119). Epistemology is concerned with the nature of knowledge and how it is created, acquired and communicated (119). Conceptualisations of knowledge range from positivism, a straightforward perception of the world and a human's perception of it, to constructionism or interpretivism where knowledge is seen as socially constructed (118, 121).

The positivist approach is the dominant paradigm in health sciences research. This paradigm strives to formulate general laws to predict behavior and assumes that the social world can be understood based on the objective measurements of phenomena. In positivism, the relationship between the researcher(s) and participants are expected to be neutral and objective, and the

impact of power relations, the values and ideologies of the researchers and participants, are not considered (118, 121). The standard model of research contends that science is a problem-solving task based on the empirical testing of hypotheses practiced by experts who are legitimized to conduct research, whereas ordinary people are the recipients (122). The positivist paradigm can be a useful theoretical framework, including the so called 'gold standards' of epidemiological and clinical, but may be inadequate to study some aspects of the social world (123).

In contrast, research paradigms such as interpretivism/constructivism and critical theory have relativist ontological and epistemological assumptions that there is no single reality, but multiple realities shaped by historical, political, societal, cultural values and disabilities. According to these perspectives, knowledge is embedded in the lives and experiences of individuals and that knowledge is developed through a cooperative process between researchers and experiencing individuals (118, 121, 124). These perspectives are embedded in the principles of participatory approaches, which emphasise working collaboratively, with inclusion of marginalised groups, and are well suited to study complex, unstable, non-linear social change (118, 119). Although both interpretivist and critical perspectives are based on a participatory paradigm, the former have been criticized for being uncritical, ignoring power relations, not changing the social situation of participants, and for not creating knowledge that gives voice to oppressed groups (118, 121, 124). The critical perspective is directed at interrogating values and assumptions, to expose hegemony and injustices, radically question/challenge conventional social structures and engage in social actions to address issues of social injustice (119, 125). The critical perspective adopts a human rights-based approach, and acknowledges that participants have meaningful insights into their own lived realities, their assets and challenges and emphasises the importance of actively involving them in the research process to promote epistemic justice (126).

In this thesis, my ontological position is more situated in a critical perspective and the belief that knowledge and meaning about service user involvement and actions to address barriers would be constructed by working with key stakeholders (125). I argue that, as there are multiple explanatory models of mental illness (127, 128), there are multiple representations of involvement and multiple ways of knowing about involvement, which are thus difficult to objectively measure in a way that leads to objective conclusions (125, 129). I believe that

participants are experts in their own conditions and can share this expertise with others; and that participants' lived experiences and narratives provide accurate information in explaining their lived realities of mental illness (125, 130). Hence, in this study participants are co-researchers, have rights to participate as anybody else and work together to address their problems (125). I believe that service users' useful experiential knowledge has been subjugated and their credibility as people with lived expertise has been devalued, resulting in epistemic injustice and oppression (24, 125). Service users and active involvement of other key stakeholders can create an opportunity to interactively engage and critically discuss these epistemic injustices and oppression, challenge, and collaboratively find possible solutions to identified barriers (125, 131). During the research process, as an academic researcher, I am not a detached neutral or objective observer; rather I am intimately involved with the participants in knowledge construction and taking actions (125).

As this thesis seeks to develop a model of service user and caregiver involvement with active involvement of key stakeholders, including service users and caregivers, the methodology chosen is therefore located within participatory paradigms and intentionally designed to be change oriented. There are many traditions of participatory research approaches, participatory rural appraisal (125). Although there are many participatory approaches, the common elements in these approaches include: (i) greater participation, collaboration/co-creation of knowledge that considers participants' realities and the influence of stakeholders, (ii) commitment to social change and problem solving extending beyond the generation of knowledge, grounding in participants' lived experiences in the local context, and reflexivity and, (iii) cyclical, rather than linear, processes (e.g., planning, action, observation and reflection) (132-134). The dominant methodology for this thesis, therefore, aligns with the epistemology of critical participatory action research (125, 135) and is informed by the social-ecological system framework. The next section describes the social-ecological framework and provides a justification its appropriateness to inform this thesis.

#### **4. 2. Conceptual framework of the study**

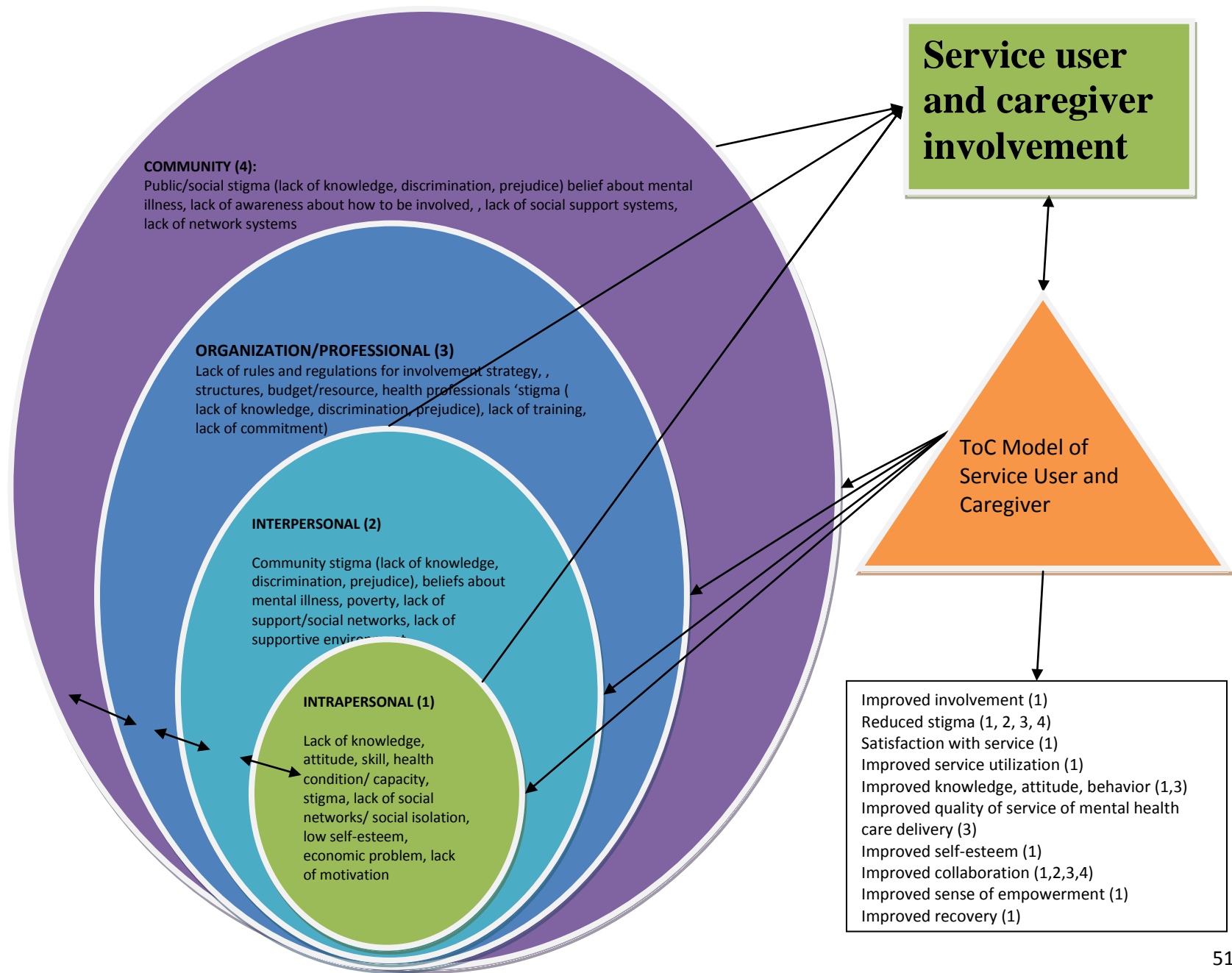
The reviewed literature shows that service user and caregiver involvement occurs at multiple levels, and is influenced by multiple factors, at individual, health professional, healthcare organization, community and broader strategic levels (2, 12, 19). From a theoretical perspective,

a socio-ecological system framework can offer a comprehensive conceptual understanding of multilevel factors for service user involvement, and can inform development of interventions to achieve this goal at multiple levels. The socio-ecological perspective gives due attention to the dynamic interactions within the social environment, extending beyond the individual level (interpersonal, organizational, community and policy) for effective positive change (136, 137). This framework assumes that the multiple levels of influence are interactive and reinforcing (136), and calls for a systemic worldview which allows for tackling different factors both vertically across and horizontally, within levels simultaneously, rather than piecemeal approaches that emphasize isolated targets of intervention (138, 139). This perspective helps to ensure that research recognizes the multiple components available at each level to select key stakeholders and the intersection of each stakeholders in the levels for desired change (140).

This socio-ecological approach has been applied in health promotion consisting of five levels:(i) intrapersonal factors related to the individual (e.g. service user and caregiver factors, including knowledge, attitudes, skills, and self-efficacy), (ii)interpersonal (family, friends, social networks, social support processes, primary groups, institutional factors),(iii) organizational factors (rules, regulations, policies, structures, challenges and opportunities), (iv) community factors (relationships among organizations/ institutions, community norms and regulations), and (v) public policy (local, state, national laws that regulate health actions) (136, 141).The socio-ecological theorists indicate that choosing the level with disproportionate influence on the specific health issue in question that needs intervention, and choosing among the intervention options, is the key in designing effective multilevel interventions (142). Hence as this thesis was conducted at the local level and mainly in relation to health systems, the levels are modified to include the local contexts of the study. Engaging service users, caregivers, service providers, and key stakeholders from the local area in collaborative work towards alleviating the potential modifiable factors at their respective level of influence is predicted to promote service user and caregiver involvement in mental health system strengthening with a range of expected outcomes. The nature of the barriers, facilitators and interventions at each level for a rural Ethiopian context were the focus for exploration in this thesis.

As indicated in figure 2, the conceptual framework comprises four essential parts illustrated by four interrelated concentric or nested circles, a rectangle, triangle, and a square. The four

concentric circles represent the levels of service user and caregiver involvement, key stakeholders who can play a role in service user and caregiver involvement, and where the potential barriers and facilitators to involvement are situated, including: (1) intrapersonal (service user and caregiver level) barriers, (2) interpersonal level (family, peers, neighborhood) factors, (3) healthcare organization/professional level factors, and (4) broader societal level factors. The concentric circles are connected by double arrows showing the interdependent influence of the level of involvement and factors influencing involvement. The green rectangle indicates the impact of the barriers at the different levels on service user and caregiver involvement. The triangle indicates the newly introduced ToC model of service user and caregiver involvement to influence the barriers to involvement. The final part of the conceptual framework is represented by the square which indicates the expected outcomes of service user and caregiver involvement at different levels.



*Figure 2. Conceptual Framework of the study*

### **4.3. Methods and materials**

#### **4.3.1. The Ethiopian health system context, mental healthcare and study setting**

##### ***4.3. 1.1. The health system in Ethiopia***

Ethiopia is located in the horn of Africa and covers an area of 1.1 million square kilometres with altitude ranging from as high as 4,620m above sea level to 110m below sea level at the Danakil depression in the northeast. The country is the second most populous next to Nigeria in sub-Saharan Africa with an estimated population of close to 109 million. The population is young, with 67% below 30 years of age (17). The total life expectancy (both sexes) for the country is 56.2 years (143). The national average literacy rate is 50%. Most of the population (79%) reside in rural areas and are heavily reliant on the agricultural sector(17).

Ethiopian health policy prioritises health promotion, which demands the involvement of all concerned stakeholders in the development of equitable and acceptable standards of essential health care services to reach all segments of the population (144). From 1997, the Federal Ministry of Health (MoH) implemented a 20 year comprehensive national Health Sector Development Program (HSDP), divided into four phases (HSDP I-IV), in order to meet health system challenges including the shortage of human resources for health service delivery and the lack of access to health services (144). Currently a new 20-year health sector vision has been developed for the country to achieve health outcomes that are appropriate to a lower middle income country by 2025, and an upper middle income country by 2035 (46). Within this vision, the MoH is now implementing the Health Sector Transformation Plan (HSTP) that emphasizes community empowerment as the means to attain the highest possible level of general health and quality of life for all citizens (46).

The current public health service delivery system of the country is organized in three tiers: primary, secondary, and tertiary level care (17, 46). The primary healthcare unit comprises five satellite health posts (each serving 3000-5000 people), primary health centers (serving 15000-25000 people) and a primary hospital and/or a health center in urban settings. A primary hospital provides services to about 60,000-100,000 people. The secondary level of healthcare comprises general hospitals that serve as referral centers for primary hospitals and training centers for

health officers and nurses and are expected to serve around 1-1,5 million people (17, 46). The tertiary level of healthcare comprises specialised referral and teaching hospitals to serve 3.5-5 million people. Governance of health service delivery is operated by the MoH and regional health bureaus. The MoH provides central direction with the national level health policy and plans. Each of the country's ten regions and the city administrations can exercise autonomy of governance that follows the political administrative structure and extends down to the district (*woreda*) level.

The Ethiopian health system has innovative community-based health service delivery mechanisms at the grass roots level through the implementation of the Health Extension Program (HEP) (144). The HEP operates to the lowest administrative structures (*kebele*) through community based Health Extension Workers (HEW)(144). Health extension workers are high-school graduates with one year of training in health promotion and illness prevention. They are all women, employed by the government and residing in the *kebele* where they deliver health education and basic interventions to the community either through house-to-house visits or based in a health post (145, 146).

#### ***4.3.1.2. The mental health context and expanding care in Ethiopia***

In Ethiopia there is a high treatment gap for mental healthcare (90%)(147). Mental health is the leading non-communicable disorder in terms of burden, which accounts for 11% of the total burden of disease in the country (148, 149). Although there is only for national level study for depression(150) to determine the prevalence of mental and neurological disorders in the country, the MoH estimates that problems related to schizophrenia, bipolar disorder, epilepsy and alcohol and substance dependence each affect 0.5 to 1.5 % of the population (149). Prevalence of common mental illnesses (depression and anxiety) has been found to be 22% and 36% in the general population and among service users with co-morbid conditions, respectively (17, 151). Several Ethiopia studies found that untreated mental health conditions lead to disability, create substantial personal burden for the people living with mental health conditions and their families, and are associated with poor quality of life, human rights abuses, stigma and discrimination, poverty, decreased productivity, poor physical health and premature mortality(152, 153). As with other LMICs, there are several health system challenges in the country, including a striking shortage of human resources (154), high level of poverty, low levels of education, lack of

infrastructure, low level of service development, lack of reliable health information systems, and a lack of models of collaborative working in relation to mental health (33, 34). Although Ethiopia is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), there is no officially approved mental health legislation (155), which could help to ensure adequate and appropriate care and treatment, protection of human rights of people with mental disorders and promotion of mental health of the population (9).

In response to these gaps, integration of mental healthcare into primary health care, through a model of task sharing with mental health specialists has been advocated as the best approach (34, 156). The Ethiopian government has long made it clear that mental health is one of the priority strategic issues. The Health Sector Development Program (HSPD) and the first National Mental health Strategy emphasised the importance of integration of mental health services into primary healthcare, with priority given to psychosis, epilepsy, depression and substance use disorders (149). The strategy aimed to make mental healthcare service accessible by scaling-up implementation of the World Health Organization's mental health Gap Action Programme (WHO mhGAP), which provided evidence-based clinical guidelines for non-specialist healthcare workers to deliver mental health care (17). In addition, the number of institutions providing mental health training has increased and helped to improve the mix and number of mental health professionals, as well as to increase the number of mental health facilities. Since 2014, the Ethiopian government began a programme to scale-up mental health care integration into primary health care throughout the country (100% of districts) by 2020 and to increase the number and range of routinely collected health management information system indicators for mental health (46). The national mental health programme is placed under the Disease Prevention Control directorate in the MoH, with similar structures in the regional health bureaus, and with focal persons at the district health office level. In 2015, mental health was included as one of the 18 health services packages to be delivered by health extension workers (157).

The second National Mental Health Strategy aims to empower individuals, families and the population at large to promote their mental health, help protect themselves from risk factors and create enabling conditions (legislative, regulatory, policy and taxation) that would support these target audiences to advance their mental health (17). Alongside government initiatives, various research-led partners have developed interventions, innovations and programmes for improving

access to mental healthcare and the quality of mental healthcare services. Notable among these are the Programme for Improving Mental health care (PRIME), the African Focus on Intervention Research for Mental Health (AFFIRM) and Emerald (Emerging mental health systems in low- and middle-income countries), all of which have sought to provide evidence on how integrated mental health care can work in practice (145).

#### **4.3.1.3. Study setting**

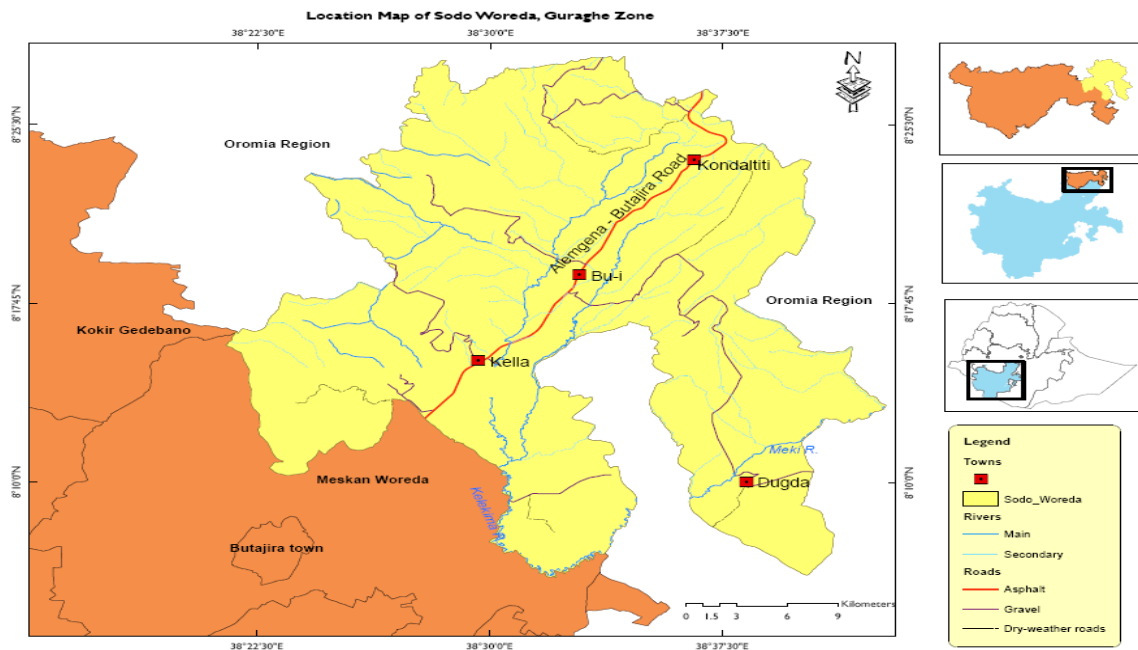
This study was conducted in Sodo district (Fig 3), Gurage Zone, Southern Nations Nationalities and People's Region (SNNPR) of Ethiopia. The capital town of Sodo district, Buei, is located about 100 kilometers south of the capital city of Ethiopia, Addis Ababa. The district had a population of 173,185 people (85,807 male, 87,378 female) as per population projection from 2014-2017 (158). The ethnic composition of the population of the district is *Gurage* (85.3%), *Oromo* (11.6%) and *Amhara* (1.5%). Most of the population in the district follows Orthodox Christianity (97%), followed by Islam (2.3%). The official language in the district is Amharic, which is the official language of the country (159). The district is characterized by both highland and lowland areas, and at the time of this study, the district was divided into 54 rural and four urban *kebeles* (the lowest administrative structure or sub-district in Ethiopia) (34). Around 90% of the district population resides in rural areas and most are reliant on subsistence farming (34). Published data indicates that literacy is around 22 % in the district (34).

There is one primary hospital with a psychiatric nurse-led outpatient service in the main town, and eight health centers (three urban and five rural). The primary hospital and all eight health centres have functioning mental health services, developed and implemented recently as part of PRIME (160). The health centres have general, non-physician health workers (health officers, nurses and midwives) trained in mental healthcare according to WHO's mhGAP (161). Every sub-district has a health-post staffed by two HEWs. In addition, there is a general hospital with a more established out-patient psychiatric facility located in the neighboring district (Butajira Hospital), 30 kilometer south of Buei (34).

Sodo district was selected for this study to build on previous work carried out by the PRIME (162) project, including (i) situational analysis and profile of the district (34), (ii) mapping of community resources, assets and needs (163), (iii) development and implementation of a

scalable district level plan for mental healthcare integration, including training of primary healthcare workers in mhGAP(154, 160, 164), and (iv) establishment of a multi-sectoral community health advisory board (CAB)(160) which has been involved in participatory collaborative work (160)and provided an enabling environment for service user and caregiver involvement. The CAB includes representation from key members of the district leadership (security, gender office, women and youth affairs, religious affairs and education), the community and service users and caregivers, and is chaired by the head of the district health office. The CAB meets twice a year to oversee and advise PRIME and support strengthening of the mental health system. However, there was no model for the involvement of service users and caregivers in the planning, development and monitoring of the new primary care-based service.

This PhD was the candidate’s independent work nested within Emerald (Emerging mental health systems in LMICs), which built upon and investigated the health system requirements for successful improvement of integrated mental healthcare in six LMICs(Ethiopia, India, Nepal, Nigeria, South Africa and Uganda), focusing on capacity building of researchers, policy makers, and planners and increasing service user and caregiver involvement in mental health systems strengthening (165).



**Figure 3. Map of study setting**

### **4.3.2. Research Design**

This study had a predominantly qualitative design, which was linked to the theoretical perspectives, conceptual framework and methods for the study. The study was conducted in three interdependent phases (Fig 4).

#### **Phase 1: Formative qualitative study**

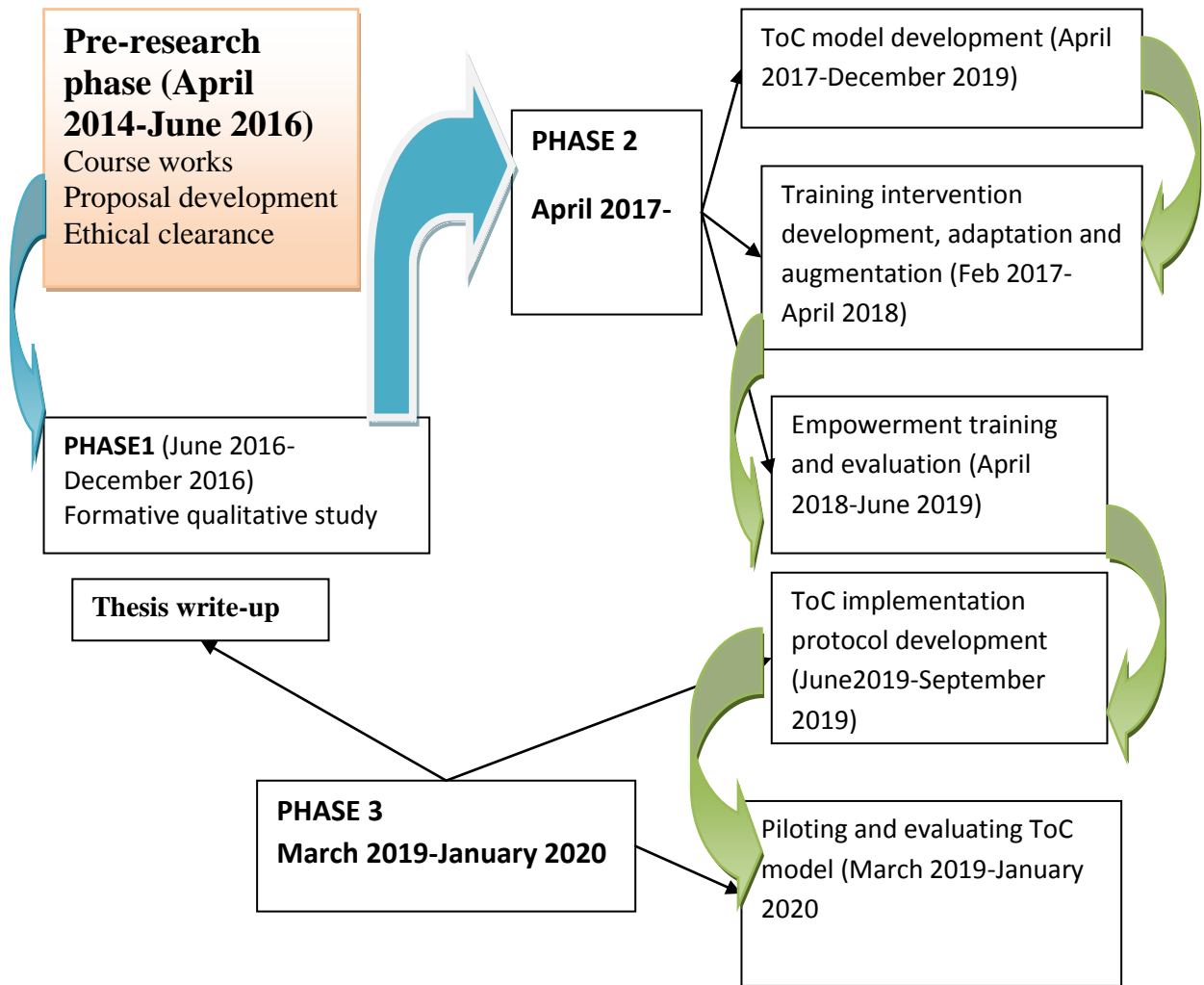
Phase one addressed objective one of the study. In this phase a qualitative formative study was conducted to explore the experiences, perceived barriers, facilitators and capacity building needs of key informants, which included service users, caregivers, health professionals, and policy-makers/planners/service developers in mental health system strengthening (chapter 5).

#### **Phase 2: Theory of change model development, and intervention design and piloting**

Phase two focused on three tasks (i) development of ToC model(objective 2), (ii) training intervention development and adaptation, and (iii) pilot empowerment training and evaluation(objective 3). The ToC model for service user and caregiver involvement was produced in ToC workshops conducted with psychiatrists and multidisciplinary researchers at Addis Ababa University, and community stakeholders at Sodo district (chapter 6). As part of the intervention to pilot the ToC model, a capacity building training curriculum was developed, adapted and augmented(166), and delivered to service users, caregivers and health professionals in Sodo district (chapter 7).

#### **Phase 3: Piloting the ToC model using participatory action research approach**

Phase3 consisted of two tasks (i) development of a protocol for piloting of the ToC model (study 4), and (ii) piloting the ToC model, and a case study of the processes, experiences and impact in Sodo district(chapter 8).



*Figure 4. Phases of the study*

#### 4.3.3. Sub-studies and methods

This thesis is based on information from five interconnected papers, which explored several thematic issues about service user and caregiver involvement in mental health system strengthening in rural Ethiopia. All papers focused on the topic of service user involvement and were interdependent (See Fig 4), which started from exploring the barriers and facilitators (Paper1), model development (Paper2), and piloting and exploring experiences (Papers 3-5). Details of methods, analysis, results, discussions and recommendations for each sub-study are presented under separate chapters (5-8) of this thesis. A brief summary is provided in Table 8.

**Table 3. Summary of methods of sub-studies included in the thesis**

<b>Studies</b>	<b>Paper 1</b>	<b>Paper2</b>	<b>Paper 3</b>	<b>Paper 4&amp;5</b>
Objective	To explore the experiences, perceived barriers and facilitators regarding service user and caregiver involvement in mental health system strengthening from the perspectives of key informants	To develop a Theory of Change map for an acceptable, sustainable and feasible model of service user and caregiver involvement in the expanding mental health system	To equip service users and health professionals for greater involvement in mental health system strengthening	To pilot the feasibility and acceptability of a model of service user and caregiver involvement in mental health system strengthening
Setting	National level and Sodo district	National level and Sodo district	Sodo district	Sodo district
Design	Qualitative phenomenological approach	Participatory theory of change workshops	Uncontrolled, convergent mixed-methods	Case study
Participants	39 stakeholders (policy makers from the Federal Ministry of Health and the WHO, psychiatrists involved in policy and service development, health administrators, primary care facility heads, service users and caregivers)	Seven clinicians/researchers, and 24 stakeholder groups, including service users, caregivers, clinicians, administrators and community leaders	12 service users, 12 caregivers and 18 health professionals	47 multi-sectoral community representatives (e.g. health administrators, religious leaders, community leaders); Research participant Groups: 6 service users, 4 caregivers, 2 health

				professionals.
Data collection methods	In-depth interviews	Process documentation including meetings minutes, audio-recordings, provisional ToC maps, stakeholder comments	Training process data, satisfaction questionnaires, retrospective pre-post-test surveys, exit and follow-up in-depth interviews	Process documentation, participatory observation, and in-depth interviews
Data analysis	Thematic analysis	ToC mapping and narrative analysis	Triangulated descriptive and thematic analysis	Descriptive and thematic analysis

#### 4.3.4. Data processing and management

Necessary measures were taken to ensure data quality. The in-depth interviews were conducted by experienced data collectors with a first or master's degrees and who had many years' experience of working in the study setting. All audio-recorded files (in-depth interviews, workshop meetings, and participatory sessions) were transcribed in Amharic and translated into English. The transcripts were exported to Opencode software program 4.02 to assist data management and analysis. The data collection, data entry, data auditing and data cleaning were handled by the researcher. All the audio records, interview transcripts and completed questionnaires were kept securely.

#### 4.3.5. Data quality assurance

This thesis was predominantly participatory qualitative approach. In participatory research, the researcher is not a neutral observer but is intimately involved with the construction of knowledge. This demands several mechanisms to maximize the scientific rigor and validity of the process and findings. Many scholars have reported challenges in ensuring rigour in PAR studies with the use of traditional validity/trustworthiness requirements alone because of its distinct ontological and epistemological stance (167-169). In this thesis, an integrative framework of quality criteria that took into account the nature of many variants of qualitative

study methods, including PAR, was used to enhance trustworthiness and reduce potential threats to validity(167, 169, 170). These quality criteria included: credibility, transferability, dependability, conformability, catalytic validity, outcome validity, democratic validity, dialogical validity, process validity, and ethical validity.

### **Credibility**

Credibility also called validity depends upon how closely the collection, presentation and interpretation of data matches the underpinning philosophy of the research methodology chosen to address the research question (171). Guba and Lincoln(172) provided five techniques for evaluating credibility: prolonged involvement, persistent observations, peer briefing, negative cases analysis, progressive subjectivity, member checks. In this thesis, this was achieved by several strategies. The research was implemented within pre-established community participatory structures (e.g. PRIME). In addition, the researcher had engaged for an extended period in the study area whereby he presented findings of formative research, facilitated all the workshops and PAR sessions with diverse stakeholders. This provided an opportunity to build an authentic, trusting rapport between the researcher and participants (169, 173).

During the extended period spent in the field, multiple sources and methods of data collection, including recordings of workshops and PAR sessions, minutes, flipcharts and oral presentations, participatory observation and in-depth interviews were utilized as described in the data collection section, which helped for triangulation (174). During data collection, the interviewers summarized the participants' responses throughout the interviews to confirm participants' viewpoints and the findings of each sub-study was presented and discussed with local stakeholders. Iterative reflection and reflexivity in a sustained dialogue with participants helped as member checking of the data (173, 175).

### **Transferability**

Transferability (related to generalisability) is about providing enough information in accessible language (176) to enable another to answer the question to transfer in other setting. The characteristics of the original study, including sample, setting and processes should be sufficiently described to enable a comparable study by another researcher (177). In this thesis, to enhance the transferability of the findings of the study, for each sub-study an in-depth, detailed

description of the study setting and activities of at all stages of the research process was provided. Furthermore, we provided in-depth, detailed and descriptive analysis of the data using the participants perspectives, proper documentation of data, activities, and thick descriptions by quoting participants responses to substantiate the findings as found in the results section and supporting with supplementary files (173, 174).

### **Dependability**

Dependability (related to reliability) can be described as making sure research questions are clear and appropriate to the study design, ensuring transparency of the researcher`s role and the use of appropriate data collection(177). In this study, the dependability of the study was ensured through thick/rich description of the study process through transcripts and field notes written by the researcher to record his reflections and experiences and consider any emerging issues in the data throughout the analysis (173). In addition, there was reflection with stakeholders during each PAR session and presentation of the preliminary process findings to community stakeholders in a consultative workshop. The data analysis and findings from the sub-studies were reviewed by the researcher`s supervisors and other senior co-authors (174). Furthermore, the interpretations of the researcher were challenged through discussion of the preliminary analysis in group meetings with patients, experts by experience and healthcare workers involved in the co-design trajectory

### **Conformability**

Conformability also called objectivity involves checking the extent to which the data and interpretations documented can be tracked to their sources and not fabricated (172), (173) and ensuring that there is an audit trail; enough information to follow what has happened in detail and sequentially, with the researcher making explicit their assumptions and biases(177). In this thesis, key stakeholder groups were involved in all stages of the PAR process whereby they maintained reflexivity and discussed on the summary of each session. Data analysis in each sub-study was crossed checked and the results were reviewed in relation to themes and subthemes with which their original data were linked by the investigator and at least one other researcher. Furthermore, the preliminary findings of the sub studies were presented to stakeholder groups for review and validation of the process findings. This was also ensured by audio recording of group

discussion. In addition, each emerging subtheme in the findings were substantiated with rich quotes extracted from the participants responses (173).

### **Catalytic validity**

Catalytic validity refers to how open participants and researchers are to changing their perspectives on the problem addressed by the action research (178). The stakeholder participants were provided with a detailed presentation about mental health services, the situation of service-users and the barriers and facilitators to service-user involvement in the local context. This helped the participants to become familiarized with the realities of service-users, prioritize action areas and generate action strategies, which is noble knowledge production with new possibilities for social action (169, 175). Health professionals, caregivers and service-users were trained to be involved in mental health system strengthening (169). The PAR process also helped participants' members to understand each other as well as reported feelings of empowerment (chapter 7&8).

### **Outcome validity**

Outcome validity refers to the extent to which actions taken during the research resolved the initial problem posed (169). The baseline study identified a range of barriers to service users' involvement including lack of models of involvement, lack of capacity building training interventions and knowledge and many others factors detailed in chapter 5 (179). Many of these problems were resolved with active involvement of stakeholders and outcome validity was achieved by a process of developing a ToC model for service user involvement(chapter 6) (180), developing and implementing capacity building training(chapter 7). In addition, the stakeholder groups identified top priorities for action, started an awareness raising intervention, mobilized community resource to empower service-user groups and agreed to mainstream service-user support in local statutory formal routines and community structures (chapter 8).

### **Democratic validity**

Democratic validity refers to the degree in which research is done in partnership with all stakeholders who are interested in the issue being studied; if it is a local project, it should produce solutions that are applicable to the service (169). This study included the views of a range of stakeholders who were interested in enhancing service user involvement by inviting

them to participate in a wide range of activities. Democratic validity is effectively addressed through active iterative involvement of key stakeholders throughout the study period. The findings of this study were co-produced in collaboration with stakeholders who were involved with their voluntary consent and thus identified locally relevant priorities and solutions (169, 175). Moreover, the voices of all who participated were accommodated using systematic approaches as detailed in our study protocol (125).

### **Dialogic validity**

Dialogic validity refers to an assessment of the “goodness of the research”(181), which is often achieved through peer review process (178). This study applied a participatory approach to the pilot study to enable equitable and inclusive participation of all stakeholders, including service-users. The study reported here was the outcome of multiple sources and methods of data collection(169). The iterative, cyclical PAR process and the critical and reflective dialogue with stakeholders helped to strength local stakeholder collaboration, enhanced working together and the development of understanding about the top priorities for action to empower service-user involvement in mental health system improvement (169).

### **Process validity**

Process validity refers to the framing and resolution of problems, essentially how deep does each action cycle go. It refers to the degree to which problems are outlined and solved in a way that encourages ongoing learning of the individual and organisation (169). Various triangulation mechanisms were used throughout the study, including participatory observation of group dynamics, accounts of each participants, challenges encountered and data generated in the three stages of the PAR process through a series of iterative reflections (169). The research was carried out in collaboration and active participation with community stakeholders and also with the author team who were able to act as auditors and critics of the process (169, 178). The findings of the study were agreed upon by the key stakeholders.

### **Ethical validity/fairness**

A range of perspectives from diverse stakeholders were considered. The participants entered the study fully informed, reflected through the PAR process that they were doing something helpful

to them and to improve the mental health system. They expressed satisfaction that all voices were heard and respected (173, 175).

#### **4.3.6. Ethical considerations**

##### ***4.3.6.1. Institutional Review Board (IRB)***

The study was started after obtaining written ethical approval from the Institutional Review Board (IRB) of Addis Ababa University College of Health Sciences (protocol number 027/16/Psy). Data collection commenced after obtaining permission from Sodo district health office.

##### ***4.3.6.2. Informed consent***

Each participant was informed about the voluntary nature of his/her involvement and was involved in the study voluntarily. The participant was also assured that he/she could withdraw from the study at any time without giving a reason. To ensure the participant's fully informed decision with regards to his/her participation, each participant was provided with detailed information about participation, including the aims of the study, methods, confidentiality, benefits, duration of the interview/questionnaire, and his/her rights to withdraw in advance of interview sessions both verbally and in writing. The potential risks and benefits of participating in the study were made explicit. Participants were also asked for agreement to audiotape and transcribe the interviews, to store and analyses data, and to include anonymised citations in report(s). Written informed consent was secured from each participant. A copy of informed consent and information sheet written in Amharic (official language of the district) was provided to each participant (Appendix2).

##### ***4.3.6.3. Confidentiality and anonymity***

The confidentiality protocol was explicitly explained in the information sheet. Confidentiality and anonymity of data was ensured throughout the study, and no identifiable information was made available outside authorised persons. Data collectors were well trained and experienced. All personal participant information was anonymised at the time of transcribing, by removing all identifiable information and replacing participants' names with specific codes on interviews and questionnaires. The personal identifiers of participants were kept separately from the responses

and all documents were kept securely and password protected. All audio files were stored on an encrypted with hard-drive and separate password-protected backups. Moreover, due to the small number of participants involved in the study, caution was taken when selecting accounts from the interviews to use in analysis by removing all potential identifiers.

#### ***4.3.6.4. Potential risks and benefits***

Service users are considered to be a vulnerable subpopulation because of their mental health conditions. Hence, all necessary care was applied to ensure the participants' eligibility for participation and to reduce potential harms. The recruitment process was performed with the assistance of their current healthcare professionals, and psychosocial support professionals because of their familiarity with the potential participants' functioning and mental health stability. Data collectors who had experiences of data collection from people with similar health conditions with a track record of research integrity and respect of service users' needs in the research setting were selected, trained and conducted in-depth interviews. All the participants took part in the research study only after providing informed consent. In addition, there were healthcare professionals in the established stakeholder groups who could avail mental health services in case of any unexpected harm or distress. The participants did not receive direct material benefits or financial gains, but they did receive financial compensation for their time and travel in relation to the study.

### **Chapter summary**

This chapter provided insight into the theoretical framework that underpins this study. In this chapter I have provided details of where the research is situated, the factors that influenced the ontological and epistemological position for the research and how this informed the research approach and methods. The chapter provides an argument for why a critical perspective and socio-ecological framework are necessary to understand the complexity of service user involvement, which is often described to be a multifaceted concept, affected by multilevel factors and that requires multilevel interventions. This chapter further provided a summary of the methods used in each sub-studies. The chapter also detailed how the data management, data quality assurance mechanisms and ethical considerations were addressed in the study. The next

sections will present the details of each sub-study including results and discussions under separate chapters (5-8).

## **Chapter 5: Service user involvement in mental health system strengthening in a rural African setting: qualitative study**

This chapter is a published paper describing the experiences, barriers, facilitators and capacity building needs of key stakeholders for greater involvement in mental health system strengthening in Ethiopia. This work was carried out as part of the formative work leading to development of a ToC model and a capacity building intervention to empower and equip service users. There was some modification to the introduction and references sections to fit into this thesis.

Current status: published in BMC Psychiatry:

*Abayneh S, Lempp H, Alem A, Alemayehu D, Eshetu T, Lund C, Semrau M, Thornicroft G, Hanlon C. Service user involvement in mental health system strengthening in a rural African setting: qualitative study. BMC Psychiatry. 2017;17(1):1-14.*

### **Abstract**

**Background:** It is essential to involve service users in efforts to expand access to mental health care in integrated primary care settings in low- and middle-income countries (LMICs). However, there is little evidence from LMICs to guide this process. The aim of this study was to explore barriers to, and facilitators of, service user/caregiver involvement in rural Ethiopia to inform the development of a scalable approach.

**Methods:** Thirty nine semi-structured interviews were carried out with purposively selected mental health service users (n = 13), caregivers (n = 10), heads of primary care facilities (n = 8) and policy makers/planners/service developers (n = 8). The interviews were audio-recorded and transcribed in Amharic and translated into English. Thematic analysis was applied.

**Results:** All groups of participants supported service user and caregiver involvement in mental health system strengthening. Potential benefits were identified as (i) improved appropriateness and quality of services, and (ii) greater protection against mistreatment and promotion of respect for service users. However, hardly any respondents had prior experience of service user involvement. Stigma was considered to be a pervasive barrier, operating within the health system, the local community and individuals. Competing priorities of service users included the need to obtain adequate individual care and to work for survival. Low recognition of the potential contribution of service users seemed linked to limited empowerment and mobilization

of service users. Potential health system facilitators included a culture of community oversight of primary care services. All groups of respondents identified a need for awareness-raising and training to equip service users, caregivers, service providers and local community for involvement. Empowerment at the level of individual service users (information about mental health conditions, care and rights) and the group level (for advocacy and representation) were considered essential, alongside improved, accessible mental health care and livelihood interventions.

**Conclusion:** As Ethiopia increases access to mental health care, a fundamental barrier to service user involvement is beginning to be addressed. Our study identified further barriers that need to be tackled, including a supportive political climate, and receptiveness amongst stakeholders. The findings will inform the development of a model of service user involvement, which will be piloted and evaluated.

## **5.1. Background**

In this paper, we focus on the active participation of local service users, caregivers, and its representatives in the mental health system components of policy making, service planning and deliver, advocacy, monitoring and evaluation, and research. Service user and caregiver participation has the potential to contribute to mental health system strengthening through increased acceptability, relevance, appropriateness and efficiency of care, improved service quality and more positive attitudes of service providers(3, 182, 183). In low- and -middle income countries (LMICs), service user and caregiver involvement has been proposed as an essential means of strengthening weak mental health care systems(184), to protect and promote service user rights and ensure successful scale up of quality mental health care(185-187). In LMICs, service user and caregiver contributions to the mental health system have received minimal attention. Service users are often excluded from their rights to full citizenship and from meaningful participation in decisions that have a direct impact on their lives (23, 109).

In Ethiopia, most people with mental health problems do not have access to mental health care, with an estimated treatment gap (the number of people with mental illness who need treatment but do not receive it) of over 90% for severe mental disorders(147). Lack of good quality care is associated with a high level of physical, emotional, economic and social suffering and

disability(188, 189), excess mortality (152) and experience of physical restraint or other forms of deprivations of liberty, discrimination and abuse(154). There is no mental health legislation to protect the rights of people with mental health problems (155) and there is limited representation for service users at the national level, with just one active advocacy group led by caregivers of people with mental health problems (46). Nonetheless, at the national level there is commitment to improve access to mental health care through integration into primary care(149).This provides an opportunity to increase engagement of service users and caregivers in service improvement as service development and expansion proceeds. However, there is a lack of evidence on the best models for successful involvement of service users and caregivers in LMIC settings (23).

This study was conducted as part of the ‘Emerging mental health systems in low- and middle-income countries’ (Emerald) project, which investigates the health system requirements for successful scale-up of integrated mental health care in six LMICs (Ethiopia, India, Nepal, Nigeria, South Africa and Uganda)(165). The aim of this study was twofold: to explore the experiences, perceived barriers and facilitators to service user and caregiver involvement in mental health system strengthening; and to inform development of a scalable model of involvement for Ethiopia.

## **5.2. Methods**

The authors approached the study from a phenomenological stand-point to explore service user and caregiver involvement from the perspectives of the participants. The study design was a qualitative study using in-depth interviews with key stakeholders.

### **5.2.1. Study setting**

This study was conducted at both the national level and in districts around Butajira town in the Gurage Zone, Southern Nations, Nationalities and Peoples Region of Ethiopia. Butajira has been a community-based mental health research site for over 20 years, including a large population-based study of people with severe mental disorders (147). Linked to mental health studies, a psychiatric nurse-led out-patient mental health service was established in 1997, located in Butajira Hospital (154). In the neighbouring district of Sodo, a district level plan for mental health care integration into primary care is being implemented and evaluated as part of the

PRogramme for Improving Mental health carE (PRIME)(160, 162). PRIME had not started to provide mental health care at the time of this study. More than 85% of people in the Gurage Zone reside in rural areas and are reliant on subsistence farming. Small-scale trading is common in the urban settings and cash crops (e.g. chilli peppers, khat and papaya) are sources of cash for the rural people in the area.

### **5.2.2. Participants**

Thirty–nine key stakeholders were selected purposively to participate in the study. At the national level, three planners/policy makers (PP) (two from the Federal Ministry of Health, one from the World Health Organisation) and four psychiatrists involved in policy, planning and/or service development were approached and interviewed by co-authors CH and AA. The national level participants were included because of their experience of working in mental health policy making and planning and/or intimate knowledge of the mental health system. At the district level, one district health administrator, eight primary care facility heads (HCH), service users (SU) with clinician-confirmed diagnoses of severe mental disorders (schizophrenia, schizoaffective disorder, bipolar disorder or major depressive disorder with psychotic features) (n = 13) and their caregivers (CG) (n = 10) participated. The district level professionals were included because of their familiarity with the health system at the local level and because of their involvement in managing primary care service delivery. Service user and their caregivers were included based on their gender, religion and duration of experience receiving biomedical mental health care. The service user and caregiver participants were approached initially by the district health service providers and asked if they would be willing to speak to project data collectors about possible participation in the study. In all cases, the service users were in remission or stable and able to give informed consent.

### **5.2.3. Data collection**

Data gathering was through a face-to-face in-depth interview with each participant. A topic guide was developed by last author (CH) for the Emerald cross-country study and adapted for the Ethiopian context on the basis of experiential knowledge of co-authors (CH and AA). The interview guide explored service user involvement in relation to aspects of the mental health system (policy making, mental health planning and service development, mental health research

and evaluation of mental health services) in terms of: (i) experience of service user/caregiver involvement, (ii) how service users/service user organizations might contribute, (iii) barriers to involvement and (iv) suggestions about interventions needed to facilitate service user and caregiver involvement. During data collection, probing and clarifications were used. The topic guide was developed iteratively as data collection proceeded, for example, expanding to ask respondents about service user involvement more generally in the health system as so few respondents had experience with respect to mental health care. The interviews with national informants were conducted in English by two co-authors (CH and AA). All of the district level interviews were conducted in Amharic, the official language of Ethiopia, by co-authors TE and DA. The interviews with service users and caregivers were carried out at Butajira mental health research office. The interviews with heads of health centres were conducted in a private facility. The interviews lasted an average of fifty five minutes. District level participants were remunerated for their time and transportation costs. The interviews were audio-recorded with prior written consent from all participants.

#### **5.2.4. Data analysis**

The interviews were transcribed verbatim in Amharic by experienced transcribers, and TE and DA translated into English, with the first author (SA) cross-checking selected audio files and transcripts for accuracy before coding. Data analysis was done using a thematic analysis approach(190). Open Code 4.02 (191), a qualitative software computer programme, was employed for the textual data analysis (192). SA familiarized himself with the data by repeatedly listening to the audiofiles and reading through the transcripts. Initially SA and CH coded four transcripts independently and compared the coding schemes and developed a draft coding framework. A further two transcripts were coded by SA and CH independently and consensus was reached. SA coded the remaining transcripts using the existing codes and adding further codes where relevant, with close supervision by CH. Sub-themes and themes were derived from the primary codes following further cross-checking by SA and CH and further comments of other co-authors (HL, CL). The final themes were developed deductively, based on the basic topic guide questions, and inductively by adding themes that emerged from the data (see Appendix 4). A comparative analysis was made between the categories of respondents.

### **5.2.5. Validity checks**

Single counting of the number of participants endorsing particular perspectives was used as a means to increase validity(193). However, given the potential positivist orientation of this approach, the analysis was not based on the frequencies of codes but on integrating all accounts into framework. Other validity checks included crosschecking emerging themes against the data and efforts to seek out deviant cases(194).

### **5.2.6. Reflexivity**

The interviewers of the policy makers and planner stakeholders were psychiatrists with PhDs in mental health epidemiology. The lead author trained in qualitative data analysis. The interviewers for the district level participants were Masters level research assistants from Addis Ababa University; one male and one female. When interviewing non-literate participants from the rural areas, some interviewees appeared to defer to the views of ‘experts’, as has been observed previously with a similar population(195). Efforts were made to communicate to participants that their views and perspectives were equally valid, that any information they disclosed would be confidential and that it would not have any bearing on their health care. Although care was taken to only interview people with severe mental disorders (SMD) who were not acutely unwell, some respondents were not able to tolerate lengthy interviews. The involvement of researchers with diverse educational backgrounds (psychiatry, psychology, sociology, demography and epidemiology) broadened the interpretation of the data.

## **5.3. Results**

### **Socio-demographic characteristics**

The national level respondents, district level health administrator and health centers heads were all male. The district level respondents were either health officers with degree level training, or nurse at degree or diploma level. The socio-demographic characteristics of the service user and caregiver participants are presented in Table 4. The analytical framework included four key themes related to involvement: (i) experience of involvement, (ii) barriers to involvement, (iii) potential benefits, and (iv) capacity building needs for greater involvement of service users and caregivers in the local mental health system.

**Table 4. Socio-demographic characteristics of service users and caregivers of the study**

<b>Characteristics</b>	<b>Service users</b>	<b>Caregivers</b>
Number of participants	13	10
<b>Gender</b>		
Male	8	4
Female	5	6
<b>Age (years)</b>		
≤ 25	0	2
25-34	2	3
35-44	6	0
45-59	4	3
60+	1	2
<b>Level of Education</b>		
Unable to read or write	5	2
Informal education	3	1
Primary education	4	5
Secondary education	1	0
Certificate and above	0	2
<b>Religion</b>		
Muslim	5	2
Orthodox Christian	8	3
Protestant Christian	0	5

### **Experience of involvement**

All groups of participants indicated that there was almost no involvement of service users and caregivers in mental health system domains. The national level participants noted that service user and caregiver involvement in policy making and planning was extremely limited. As one respondent commented:

*PP: There is only nominal participation, the ‘user ‘association is at best promotional and no meaningful attempt is being taken by the Ministry of Health to engage them.*

*Policy-maker/planner ID3*

At the primary health care level, people with mental health problems and their caregivers were not represented and their direct involvement in health service and system activities was non-existent.

*HCH. We invite for participate the “One to Five” community organization networks to report general health problems; we don't specifically enquire for mental health issues....*

### *Health Centre Head ID1*

The service user and caregiver participants also reported that they had no experience of involvement in mental health system domains. Some service user and caregiver participants reported experience of being the subjects of research. Most considered being approached and their involvement as a research respondent to be valuable for themselves as well as for the improvement of the mental health service.

*I: But do you think it is important in any way to involve people with mental health problems in research?*

*SU: I do think so. I am pleased you are here to listen to what I have to say because most of the time most people are not willing to listen to what we have to say because they believe we are mentally ill. ... But it blesses me to have people who listen to my ideas around.*

### *Service user ID*

Some service user and caregivers had concerns about the relevance of research to recipients of care. The current research approach appeared to be top-down with limited knowledge of how the findings would benefit them.

*CG: ...Yes, many students from universities made researches but nothing is obtained out of it.*

### *Caregiver ID5*

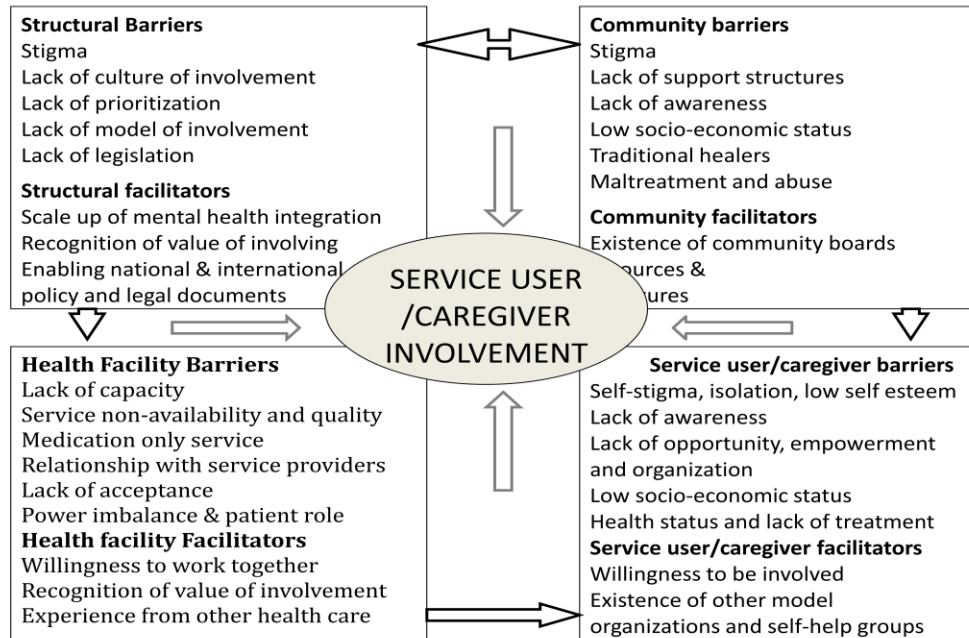
*They [researchers] came from Amanuel hospital [the only psychiatric hospital in Ethiopia]. Just like you [the interviewer]. Maybe, you came from the branches... Things move from the stem to the branches. Not from the branches to the stem. People from there will call me here or come to my house for the study. They [the researchers] will discuss many things, though it is not implemented.*

### *Service user ID5*

## **Barriers to involvement**

All the participants (39/39) in this study stated that there were many barriers to service user and caregiver involvement in the mental health system. The barriers to involvement are summarized in a multilevel conceptual framework encompassing the structural/system, community, health

facility and individual service user/caregiver levels, along with potential facilitators to involvement (see Fig. 5).



**Figure 5. Multilevel barriers and facilitators to involvement in mental health system strengthening**

**Involvement as an alien concept**

Most of the service users (11/13) and caregivers (6/10) were new to the concept of involvement, and repeatedly asked “what do you mean”, “what is that?” in response to questions exploring their experience of involvement in policy-making and planning, service development and quality monitoring. Commonly, they struggled to give examples of how they might contribute to mental health system strengthening, and many (10/23) instead focused on their role as a patient. Some service users (3/13) considered involvement as an assigned role, which they would be willing to embrace as a sense of duty, rather than as a right or benefit. They did not see involvement as the role of a service user and considered health system issues to be the responsibility of government workers.

*Service User (SU): Quality assurance kind of thing is done by higher bodies or by people assigned by the government for this purpose. ...*

*Interviewer (I): So, don't you think that your participation improves the service delivery?*

*SU: You [service user] will add nothing, since this [worker] is appointed by the government.*

*Service user ID5*

Some of policy-making/planning level participants reported that there was no culture of involvement of service users and caregivers at the mental health system level; as a consequence there was no structure or model for how involvement might work in practice. When asked about service user involvement, one planner replied:

*Policy/planner (PP): I think that's an excellent initiative. I see that it is very difficult to implement that in Ethiopia. I think there's not that type of culture in Ethiopia so I don't know how workable it is. Policy-maker/planner ID6.*

### **Stigma and mental health status**

Participants (18/39) spoke in many different ways about how stigma and discrimination serve as barriers to service user and caregiver involvement. Stigma and exclusion were noted to operate within the health system, in the community and even to affect the self-identity of the person with mental illness and their family. Half of policy/ planning level participants (4/8) perceived that service providers, policy makers and health system managers at all levels had negative attitudes towards mental health and people with mental health problems. Examples presented by some interviewees (14/39) to support this perspective included (i) the lack of prioritization of mental health in the policy agenda compared to other public health concerns, and (ii) the widespread assumption that service users would be unable to contribute anything of value to the mental health system because of the effects of mental illness. Some policy/planning level participants (3/8) articulated that system-level stigma would be an insurmountable barrier to service user involvement.

*PP: Yes, absolutely stigma is contributing.*

*I: Within policy-making and planning?*

*PP: I mean, for me, it is hard to separate anything you know. You are dealing with human beings who are doing the planning; you don't just put a new hat on when they come here. It is part and*

*parcel of the whole value system. Mental health, mental illness, has been neglected, stigmatized type of diseases and of course, it is the same person who is stigmatizing mental illness who is working in planning...*

*Policy-maker/planner ID1*

Some policy/planning level participants (2/8) doubted the possibility of service user and caregiver involvement at a higher strategic level, but recommended empowerment of service users and caregivers at the community level.

The low status of people with mental illness in society was considered to be an important barrier to involvement. The service user and caregiver participants (10/23) described repeated experiences of unsupportive, discriminatory behavior from the local community and a lack of acceptance of their right to take on social roles. As a consequence some interviewees (6/23) spoke of experiencing diminished opportunities for productive lives and exclusion from their civic rights (employment, participation in meetings, and voicing their say). Exclusion resulting from stigma was also reported to affect their access to treatment and thereby to impede recovery and limit their capacity to be involved in system strengthening. Two participants spoke passionately about this issue:

*Currently, there is no a good thing towards mental health patients in the society, once a person gets sick mentally, the society discriminates and takes that person as useless; they don't think mental health problem can be treated and the patient can be better and live a normal life again.*

*Health Centre Head ID8*

*Are you a fool? Only our families know what our problem is, but the others don't care. ... only you may want to help us or understand what our problem is; otherwise they wish us to disappear ...uhh...nobody wants us.*

*Service user ID10*

Many of the service users and caregivers (11/23) also had low expectations of their own capacity to contribute; some service users (3/13) preferred instead that their caregivers speak on their behalf. Other participants (6/39) also expressed the view that caregivers would be better placed to be involved in system strengthening due to their freedom from mental ill-health.

*To negotiate and to participate in planning, he [service user] should be healthy. How can a mentally ill person participate in management activities?*

*Disabled people can do this since they are physically disabled. But mentally ill person faces difficulty on the main part of thinking.*

*Service user ID5*

### **Lack of resources and empowerment**

Lack of resources and empowerment of service users/caregivers, and other stakeholders in the mental health system were also underlined (17/39) as barriers to involvement. A number of participants (14/39) spoke about the need to provide support (financial, space, organization, and training) and facilitate empowerment of service users and caregivers at the grassroots level. Some of the service users and caregivers (6/23) indicated that their low educational level, low socio-economic status and livelihood problems were major factors in their lack of involvement in mental health systems.

*It is because of our status...are educated and uneducated people equal?*

*Service user ID12*

During the interview process, both service users and caregivers (15/23) were noted to be reluctant to express their views, particularly in relation to their potential contribution to system strengthening for example, saying “*we agree with what you told us*”, “*everything you said is important*”, and that they were “*not the expert*”. Furthermore, participants (12/39) expressed the view that service users and caregivers are not mobilized for involvement, empowered, organized into groups or represented in strategic decision making. As a consequence, they lack power and support, and are reluctant to ask for their rights.

*We never speak for our rights, we have fears...Our fear is...it is difficult to speak about something which the society doesn't understand and nobody gave us strength to go forward other than giving a small amount of money and other things.*

*Service user ID9*

## **Poor access to mental health care**

Poor access to adequate mental health care was considered to be a major barrier to involvement of service users. The service user and caregiver participants (8/23) reported that they had to walk long distances, or incur high transport costs, and spend a lot of time seeking mental health care from the centralized, specialist service. Some caregivers (4/10) also noted the logistical challenge of conveying a person with mental illness (for example taking person to the health facility, medication use, and follow-up). As a consequence not all people could access treatment.

Service users and caregiver participants (9/23) noted problems in service delivery, including waiting time, medication provision, and service providers' lack of professional behavior and competence.

*They [service providers] don't treat mental health patients properly, the ill-treatment and abuse must be corrected, and the people at the health centre must be disciplined in case of mental health patients. They should be caring, should consider the mental health patients just like their children, and loving attitude.*

*Caregiver ID9*

Some service users and caregivers (5/23) spoke of feeling uncomfortable to express any form of criticism of the people providing them with mental health care, due to fears that this could jeopardize their access to a scarce and valued resource.

*SU. We have a fear.*

*I. What type of fear?*

*SU. They (health service officials) use to call us anything and they are trying to help us at least so it is difficult to talk about their deficiencies.*

*Service user ID10*

## **Potential benefits of involvement**

A number of potential benefits of involving service users and caregivers were reported, grouped into two subthemes: (i) advocacy, fighting exclusion and improving service quality, and (ii) awareness raising and service promotion.

## **Advocacy, fighting exclusion and improving service quality**

Most of the participants (21/39) across all stakeholders talked about various contributions that service users and caregivers could make, including (i) advocacy for better physical health services, (ii) suggestions of integration of non-medicinal interventions, (iii) help in reducing waiting times, (iv) assistance in service standards improvement by providing information about their experiences of the extent and adequacy of the service provided.

Many participants across the participants groups (14/39) also considered that service users and caregivers could strongly demand improved accessibility of mental health services, service expansion, budget allocation, service inclusiveness, efficient utilization of resources, and to bring their unique lived experiences to focus attention to mental health care during health system planning.

*We can oversee/push how the allocated budget is spent, whether they [health centre heads] are spending it properly for the intended purpose or not, because we can't be sure unless we participate there.*

*Caregiver ID6*

*It [involvement] has a significant impact on the improvement of the service quality and inclusivity, as you know in our country many strategic plans come from above ... if you base your planning... the low level, or the users, first of all there will not be any wastage and outflow of resources... if we [Health Centre Heads] involve the patients and their caregivers, in the planning, and even in the future research, then our plans would be very effective and problem solving.*

*Health Centre Head ID5*

Some participants from all groups (7/39) considered that improved participation would contribute to better understanding and support for service users. One service user (1/13) remarked “*the one who knows how comfortable the bed is, is not the person who made the bed but the person who slept on it*” (Service user ID10) to illustrate the importance of sharing their experiential knowledge with service providers. Many of the service user and caregiver participants (10/23) also suggested that service users and caregiver involvement can help to

protect patients from maltreatment, voice the rights of service users and improve service providers' behaviors.

*Well, I think it [involvement] will be important because it will help people with mental health problems to have control about the quality of service they receive and manoeuvre the way their problem is addressed. It [involvement] can also help protect people with mental health problem from any abuse and maltreatment. Their [service users and caregivers] participation could also mean that the professional can get needed information from them about their need and situation.*

*Service user ID3*

### **Awareness raising and service promotion**

Study participants (11/39) underlined the important role that service users and caregivers could play in raising awareness and mental health service promotion through experience sharing, including providing testimonials about mental health care and how they are living with mental health problems productively. About half of the service users and caregivers reported (12/23) their willingness to share their own experience of mental illness and living with the illness, about the medicine and treatment, the improvement in their health following treatment, and to create awareness about mental health services in the local community.

*Our[caregiver]contribution will be...we will tell other patients and caregivers to go to hospital...I use to tell everyone to go there and get treatment...there are many people with this problem on the streets and who are walking around...*

*Caregiver ID8*

Some participants (8/39) spoke of how service users and caregivers can communicate first hand with the wider local community to raise awareness more effectively than health workers, who tend to talk about mental health in the abstract. For example three health centre heads (3/8) expressed:

*... if that patient is treated well he will be witness and will publicize positively and propagate the good result of the program to the community, the treated-patients would spread out where they took the medicine and what type of program helped them restore their health. In addition the*

*participation of the patients or their caregivers will be a good source of constructive comments, on the both strength and weakness of the program.*

*Health Centre Head ID8*

### **Need for capacity building**

Participants (23/39) highlighted the following as essential capacity building strategies to support greater service user involvement: (i) enabling community structures and past experience, (ii) mental health advocacy and (iii) the need for service use/caregiver mobilization and empowerment.

### **Enabling community structures and past experience**

Many participants (20/39) emphasized the importance of giving recognition for developing the mental health system, particularly planning, at the lower district level. This was informed by the needs of service users to improve service quality, to make the service inclusive, to plan health service resources more efficiently and to receive feedback and correct mistakes at a higher system level.

*I: But if that [involving service users and caregivers] were possible, do you think that could be constructive?*

*PP: Not could be, it should be. Unless you involve the users, unless you involve the beneficiaries, how do you know? For me, it is very, very critical. And some day it is going to come, but it requires awareness, organization and stuff like that. I think it is very important.*

*Policy-maker/planner ID1*

The service users and caregiver participants (5/23) identified existing structures which could be leveraged to promote involvement, including availability of health workers at the grassroots level, opportunities from frequent social gatherings, and structures for awareness creation and mechanisms for selection of a representative who could voice their interest in involvement. An opportunity for learning from experiences in other aspects of health care (e.g. reproductive health) and HIV was noted.

*...About HIV, they are doing many things in different organizations, in health facilities and also on media; so, they need to do better than HIV, you know mental illness can be treated like HIV; therefore, it needs everyone's participation.*

*Service user ID11*

### **Mental health advocacy**

Across the different groups of participants (16/39) the need for mental health advocacy to overcome stigma and discrimination was emphasized.

The participants noted the lack of knowledge about mental health and mental health services and linked this to abusive practices. One caregiver (1/10) commented the following:

*We need to educate the families, the caregivers and the community altogether, not to physically and psychologically attack mental health patients. People used to insult, condemn, despise mental health patients, they may be even severely attacked to death, if they leave their village, they cannot participate in normal social relations, and this will aggravate their anger and touches their emotion...*

*Caregiver ID10*

Some service users (3/13) underlined the need for empowerment in their livelihoods and support from non-governmental organizations, pointing at the success of this strategy in the field of HIV/AIDS. The different groups of participants (17/39) expressed a need to be equipped with training in different areas including: how to work with others, communication skills, social aspects of mental health, and how to care for patients. The health centre head participants (6/8) emphasized the need for training and one of the health centre heads (1/8) recommended the following areas:

*To work with them [service users and caregivers] you have to have better knowledge. This is because they may raise their real experience since they are living with the problem. They may ask you actual issues which they face when they took the medicines. If you can clarify them [what they need] they will build confidence to work with you. You need to know more. The kind of training that helps you [healthcare providers] to work with people and help you to convince others are the important ones.*

*Health Centre Head ID8*

Some service user and caregiver participants (5/23) also indicated the importance of training for service providers in the areas of care-giving and treatment for patients.

### **Service user and caregiver mobilization and empowerment**

Interviewees across all groups (12/39) expressed that service users' mobilization and empowerment are the appropriate area for greater involvement in the mental health system and other domains of life, such as social roles. The participants outlined various benefits of having a representative organization, but also raised practical concerns about the need for space for meeting and representation in the formal structure of the health system for involvement, a relevant strategy and guidance to support different stakeholders to work together:

*To bring change, we [service users] should get together and discuss about solutions and things which are helpful for us...We should be together, we need to stay together as we couldn't stand problems related to our sickness, so, we need to organize or we should establish our own unity; we want our health..., they [health service managers] should tell us the rules and regulation from the government and also things we should do not only to oppose their work.*

*Service user ID10*

*...In that case my first recommendation even before giving them [service users] financial and any material support is [to] establish a kind of club, where they can discuss together ... then education can be conducted on different subject matters ... and in this way we[caregivers] can provoke them[service users]to stand for their right and the rights of patients. In this way we can also reduce the problems...Yes! We need training. We need to know what we have to do, at all level, so that we will have acceptance by the people [community] whom we are going to work together. ... We must know the extent and the limits of our rights and what duties we have to carry out.*

*Caregiver ID10*

A need for support with transport and financing of a representative organization was also raised by some service users (5/13).

## **5.4. Discussion**

In this qualitative study from Ethiopia, we examined systematically the perspectives of a range of stakeholders about the possibilities for service user and caregiver involvement in policy making, planning, service delivery, mental health research, monitoring, and scale-up of mental health care. Only a few previous studies from LMICs have focused on service user involvement in policy development, and most focused on involvement in self-help groups, individual care plans or as ‘subjects’ of research rather than system level involvement (23, 109, 196).

Although starting from a low baseline, most stakeholders in this study considered mental health service user involvement to be an important and achievable goal of the health system. Participants identified a range of potential benefits from service user involvement. Service user and caregiver respondents also anticipated individual benefits of being more closely involved in system issues, including access to basic information about mental health conditions and treatments, advice on the best way for them to provide care and a feeling of recognition. These potential benefits of involvement have also been identified within the limited existing publications from LMICs(109, 113)

Despite the recognition of benefits, few respondents had personal experience of service user involvement in any aspects of mental health system strengthening. Low levels of involvement have been reported even from better-resourced LMICs with more empowered and mobilized service user groups (23). In our study, a number of barriers to achieving service user involvement were identified, as well as potential facilitators (see Fig. 5).The barriers to service user/caregiver involvement will now be discussed in relation to potential strategies to promote service user involvement: (i) creating an enabling environment, (ii) multi-system approach to mental health advocacy and fighting stigma, (iii) comprehensive mental health service in primary health care, (iv) ensuring human rights for greater involvement, and (v) service users/caregiver mobilization: organization and empowerment.

### **Creating an enabling environment**

The study participants noted that there was no specific strategy or model to guide how best to involve service users and caregivers, and a lack of clarity about the roles and responsibilities of

the different parties. There are similar results from LMICs as well as high income countries (23, 197). In a systematic review of studies from LMICs (23), there was almost no evidence and no conceptual framework to inform effective involvement of service users and caregivers. Similarly, in a recent narrative review from high income country studies (1969–2016), most attempts at involvement were criticized for exclusivity and for being tokenistic, with little evidence on how to support involvement of a diversity of service users and members of the public, rather than a few selected individuals (197).

Many high-income countries where service user involvement is embedded have clear policy provisions and legislative requirements about service user/caregiver and public involvement (183, 197, 198). The Ethiopian national constitution (199) clearly guarantees the rights of people with disabilities; and the country has ratified the United Nations Convention on the Rights of Persons with Disabilities (200). However, the Health Policy (201), National Mental Health Strategy (149) and the Health Sector Transformation Plan (46) do not include explicit provisions articulating how service users and caregivers should be involved at the level of the mental health system.

There is no separate national human rights review body with authority to oversee mental health facilities and to ensure service user rights; there is also no legislation to protect persons with mental health problems against discrimination (155). These enabling frameworks need to be put in place in the future revisions of the Health Policy, National Mental Health Strategy and Health Sector Transformation Plan to institutionalize and guide service user involvement.

### **Multi-system approach to mental health advocacy and fighting stigma**

In our study, negative attitudes towards people with mental health problems were reported to be pervasive and a significant barrier to service user/caregiver involvement. Within the mental health system, despite high level political commitment, a lack of (i) prioritization of mental health, (ii) access to mental health services, and (iii) representation and support for the empowerment of service users, was identified. At the health facility level, service users and caregivers are poorly informed about their rights, the nature of their illness, available treatments and services, and may experience negative attitudes and abusive behaviour. At the societal level, people with mental health problems often experience discrimination and maltreatment;

individually mental health problems may affect their sense of identity and self-worth, exacerbating disempowerment and impeding realization of their rights.

These findings are similar to reports from studies conducted in LMICs and globally. In a recent narrative review, Semrau et al. (202), concluded that *“Stigma and discrimination have been identified as major negative forces against full citizenship and social participation everywhere that they have been assessed”*. Similarly, in a qualitative study from South Africa (109), stigmatization and low prioritization of mental health, poverty, and incomplete recovery and community support were identified as major barriers to involvement. A study from India (203) also showed various impacts of stigma, including social exclusion, restricted opportunities in civic rights, impaired quality of life and avoidance of mental health services due to fear of labelling. Such structural stigma undermines access to mental health care, civic rights such as education and employment, and affects all aspects of daily living, contributing to disempowerment, and feelings of hopelessness, helplessness and guilt about being a burden to others(204, 205).

International narrative and conceptual reviews have identified a lack of evidence on anti-stigma interventions to support service user involvement, particularly in LMICs(202, 206, 207). Nonetheless, service user and caregiver involvement in anti-stigma interventions is considered to be an important principle for mental health system development (206). Studies also recommended lessons about the important roles of service users and caregivers in (i) advocacy to mental health and services, (ii) informing policies and research, (iii) giving testimony about their mental problems and services with a lasting effect on reducing stigma (208, 209). Despite this strong evidence, there seems to be little commitment to promoting and supporting service user and caregiver involvement, particularly in LMICs (202, 206, 209).

### **Comprehensive mental health services in primary health care**

The service user/caregiver participants in this study spoke of accessible and adequate mental healthcare as being a priority for them, and recommended expansion of care to include psychosocial support and rehabilitation services. All three groups who participated in the study articulated the need for capacity building, promotion of awareness-raising and facilitation of

structures for service user and caregiver involvement. A situational analysis study on the challenges and opportunities for integrating mental health conducted in Sodo district(34) identified various difficulties, including financial constraints, high level of poverty, low literacy, social deprivation, limited level of community awareness, high level of stigma and abuse, absence of health system structures and support systems for mental health care, and a lack of reliable supplies of medications among others. However, concerted efforts are now made to implement multi-faceted mental health care plans in Ethiopia, which in turn provides an opportunity to integrate service user involvement (160).

The Ethiopian National Mental Health Strategy states that the single most important factor to improve the situation of people with mental health illness and caregivers who are experiencing stigma, discrimination and human rights abuses is to increase the availability of mental health services (149). The integration of mental health services into primary health care needs to consider the social, economic and educational status of service users, as well as the stigmatizing and discriminatory practices that tend to disempower and marginalize service user and caregiver involvement (187, 210). There is emerging evidence that interventions to improve access to mental health care combined with promoting livelihoods and peer support (e.g. the BasicNeeds model of mental health and development) can lead to empowered service users and caregivers who are able to take on active roles within society, and regain social capital and influence (187, 210). For example, Raja et al. (187)in their case study of the BasicNeeds model implemented in Nepal found considerable evidence of service user and caregiver involvement in income generation activities and productive work. In rural Kenya, Lund et al. (210)evaluated the effects of participating in the BasicNeeds program on the outcomes of mental health including social support, and poverty alleviation of a cohort of people living with severe mental disorders. Their results showed substantial and statistically significant improvements in mental health, quality of life, social functioning and economic activity after two years.

### **Ensuring human rights for greater involvement**

There is a need to address the stigmatizing and discriminatory practices that hinder the involvement of service users and caregivers in the mental health system, as well as in their full participation in social life and realization of their civic rights(211, 212). This approach is focused on redressing the unfair distribution of power and discriminatory practices, with an emphasis on

empowering service users and caregivers to know and claim their rights, and building the capacity and accountability of individuals, organizations and professionals to promote respect, protection and fulfillment of responsibilities (113, 211, 212). The human right-based approach is guided by core values and principles of participation, accountability, non-discrimination, empowerment and legality and requires health facilities, goods and services to be available, accessible and acceptable services that help service users and caregivers to exercise their rights to health (211, 212).

### **Service users/caregiver mobilization: Organization and empowerment**

Participants of this study recommended organization and empowerment of service users and caregivers, particularly at the grassroots level, referring to what has been achieved by the government and non-governmental organizations to empower and support similarly stigmatized service users with other long-term health conditions (e.g. HIV/AIDS associations). Other studies also found that mental health service users are invisible, poor, voiceless and comprise a fragmented movement that may result in weak mental health advocacy, particularly in LMICs (31, 212, 213).

Addressing the multi-level barriers to greater involvement of service users and caregivers in the mental health system and other domains of life requires inputs of various stakeholders (national to local level service providers in all government structures, development agencies, non-governmental organizations and self-help organizations). These stakeholders can create opportunities to access resources, training and skill development, health and psychosocial support and provide space and structures (strategies, rules, legislations) (31, 38, 209). In addition, ensuring national and international human rights instruments for the protection of the rights of service users; enacting comprehensive anti-discrimination legislation with robust enforcement mechanisms are also key areas that need attention (31, 214). Empowering service users to self-organize and advocate for their interests and needs promotes their recognition and develops their confidence, strengths, resources and skills (31, 38). Empowerment of service users also ensures a collective voice to influence and lobby for policy and legislative reforms (212).

In a study of seven African countries, networks of service users were found to play a range of important and influential roles, including serving as alternatives to traditional mental health

services that deliver only medical treatment, development of income generation opportunities and building service users' work skills, provide psychosocial support, active participation in advocacy, lobby for improved government services and support to build self-esteem in resource poor settings (38).

## **5.5. Strengths and limitations**

The strength of the current study lies in its use of qualitative research methods with a wide range of participants who brought broad perspectives on service user and caregiver involvement across the mental health system. Our findings should be considered within the limitations of the study. As a qualitative study, the findings may not be transferable to broad populations of service users and caregivers because our study focused on the views of people with severe mental disorders. In addition, the low level of education, empowerment and lack of involvement experiences of participants can limit to elicit service user views. The purposeful selection of participants can create selection bias.

The professionals who facilitated service users and caregiver recruitment may have been selective in recruiting participants and participants who were not contacted may have different perspectives.

## **5.6. Conclusions and research implications**

Service user and caregiver involvement is almost nonexistent in the Ethiopian mental health system. Multilevel stigmatizing attitudes, discriminatory practices and lack of capacity impede service user and caregiver involvement in mental health system strengthening, civic rights and social roles. The planned mental health care scale-up through integration into primary health care will address one of the fundamental barriers to service user involvement and provides a critical opportunity to institutionalize involvement. The findings of this study will inform the participatory development and piloting of a model of service user and caregiver involvement in the new integrated primary mental health services in Ethiopia.

## **Chapter 6: Developing a Theory of Change model of service user and caregiver involvement in mental health system strengthening in primary health care in rural Ethiopia**

This chapter presents a published paper describing a ToC model co-produced with key stakeholders for service user and caregiver involvement in mental health system strengthening in Ethiopia. This work was carried out as part of the formative work leading to the actual implementation of service users and caregivers in strengthening mental health system in rural Ethiopia and develops pertinent interventions to equip key stakeholders for the involvement role. There was some modification to the introduction and references sections to fit into this thesis.

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### **Abstract**

**Background:** The involvement of service users and caregivers is recommended as a strategy to strengthen health systems and scale up quality mental healthcare equitably, particularly in low- and middle-income countries. Service user and caregiver involvement is complex, and its meaningful implementation seems to be a worldwide challenge. Theory of Change (ToC) has been recommended to guide the development, implementation and evaluation of such complex interventions. This paper aims to describe a ToC model for service user and caregiver involvement in a primary mental health care in rural Ethiopia.

**Methods:** The ToC was developed in two workshops conducted in (i) Addis Ababa with purposively selected psychiatrists (n = 4) and multidisciplinary researchers (n = 3), and (ii) a rural district in south-central Ethiopia (Sodo), with community stakeholders (n = 24). Information from the workshops (provisional ToC maps, minutes, audio recordings), and inputs from a previous qualitative study were triangulated to develop the detailed ToC map. This ToC map was further refined with written feedback and further consultative meetings with the research team (n = 6) and community stakeholders (n = 35).

**Results:** The experiential knowledge and professional expertise of ToC participants combined to produce a ToC map that incorporated key components (community, health organisation, service user and caregiver), necessary interventions, preconditions, assumptions and indicators towards the long-term outcomes. The participatory nature of ToC by itself raised awareness of the possibilities for service user and caregiver involvement, promoted co-working and stimulated immediate commitments to mobilise support for a grass roots service user organization.

**Conclusions:** The ToC workshops provided an opportunity to co-produce a ToC for service user and caregiver involvement in mental health system strengthening linked to the planned model for scale-up of mental health care in Ethiopia. The next steps will be to pilot a multi-faceted intervention based on the ToC and link locally generated evidence to published evidence and theories to refine the ToC for broader transferability to other mental health settings.

**Keywords:** Theory of Change, Service user involvement, Caregiver involvement, Mental health system, Rural, Ethiopia

## 6.1. Introduction

In low-and-middle income countries (LMICs), service user and caregiver involvement has been widely recommended as an essential ingredient of strengthening weak mental health systems(213),(215), which has potential to increase the likelihood of scale-up of appropriate and quality mental healthcare(44),(216), and reduce the treatment gap for quality care, (217),(218). However, in LMICs, there is less prioritization and government support for either mental healthcare provision or involvement of service users (219),(26). Furthermore, there are often no policies and laws to direct mental health programs and/or the policies and laws are not fully in line with human rights recommendations (e.g., service user participation) or are poorly implemented (219),(26). Service users and caregivers are still exposed to stigma and discrimination(202),(220) and have multiple unmet needs (220), including symptoms of illness and disability (221), premature mortality(152),(222), and human rights abuses (e.g., being chained or kept in isolation) (202), (31), (223).

While the importance of service user and caregiver involvement in the mental health system is clear, the question of how to implement participation in practice remains a global challenge. The involvement of services and caregivers is a complex process that (1) has been variously defined

(2), (1); (2) is characterized by multiple and often inequitable interactions at the micro-level, the meso-level, and at the macro-level [(2), (107), (19)]; and (3) requires resources and actions of actors at multiple levels to build a supportive environment [(2), (110), (224)]. This complexity can be a barrier to developing consensus in relation to (i) the meaning of involvement, (ii) understanding the goals, (iii) identifying the appropriate model and (iv), the expectations, roles and responsibilities of stakeholders for service user and caregiver involvement [(2), (3), (23), (225)]. Recommended approaches to complex intervention development and implementation (226) have not been applied to articulate what the complex nature of service user involvement might look like in practice [(2), (107), (19)].

A growing body of development and health actors recommends Theory of Change (ToC) for dealing with complex health interventions(227),(228),(229). ToC has been adopted in some LMICs, including Ethiopia, to develop, implement and evaluate interventions in mental healthcare [(228), (230), (231)]. ToC is a participatory approach to explore processes for change; “a theory of how and why an initiative works” (232), which both develops an intervention using the experience and expertise of the participants, and documents key indicators that allow systematic evaluation of processes and outcomes of the intervention (e.g., service user and caregiver involvement) for expected steps on the hypothesized causal pathway to impact (229). Furthermore, several scholars suggested that ToC gives insights not only into intended change, but also the model of action or practice and unforeseen consequences(233),(234),(235).

However, there is little published evidence of the application of ToC to the involvement of service user and caregivers in mental health system strengthening. The main objective of this study was, therefore, to describe our experiences of bringing together service users, caregivers, and other key stakeholders to use a ToC approach to develop a model of how best to involve service user and caregivers in mental health system strengthening in primary healthcare in rural Ethiopia.

## **6.2. Methods**

### **6.2.1. Setting**

This study was conducted as part of the ‘Emerging mental health systems in low- and middle-income countries’(Emerald) project, which investigated the health system requirements for successful improvement of integrated mental health care in six LMICs(Ethiopia, India, Nepal, Nigeria, South Africa and Uganda)(165). Emerald built upon the PRogramme for Improving Mental health carE (PRIME), an implementation research project which developed, implemented and evaluated an integrated district mental health care plan in collaboration with local stakeholders(162),(160).

This study was undertaken at both the national level in the capital city, Addis Ababa, and the district level in Sodo district, Gurage Zone, located about 100 km south of Addis Ababa( See details in section 4.3.1.3)

### **6.2.2. ToC workshop participants**

Two ToC workshops were held in 2017 to engage stakeholders in tackling the challenge of how best to embed service user and caregiver involvement in mental health system strengthening. The first ToC workshop was carried out with seven participants (three male, four female) from Addis Ababa University, Department of Psychiatry, who had extensive experience working to expand mental health care in the study site, as well as experience working with service users and advising the Federal Ministry of Health on policy and service planning. The participants had diverse professional backgrounds (psychiatry, psychology, social work, pharmacology, epidemiology, public health).

The second ToC workshop took place in Sodo, and involved 24 participants selected purposively on the basis of being key stakeholders in mental healthcare or possessing expertise in service planning. The participants included: (i) district level government office representatives(managers of the district health administration, focal person for mental health, women and children’s office, youth and sport office, social affairs office), (ii) community-based organizations and leaders (religious and faith-based leaders, non-governmental organization representatives), (iii) representatives of service providers, service users and caregivers, and (iv) five senior mental

health researchers from Addis Ababa University who had also participated in the first ToC workshop to provide cross-learning and link local perspectives with national scale-up plans.

### **6.2.3. Procedures**

The ToC development underwent five iterative activities in three stages (See Fig. 6 for a schematic depiction of the process).

The first stage involved provisional ToC development using workshops. The first ToC workshop was conducted at Addis Ababa University in April 2017. The second ToC workshop was conducted in Sodo district in July 2017. The ToC workshops were co-facilitated by senior psychiatrists and researchers (AF and CH). Both authors are trained in the use of ToC and had experience of facilitating ToC workshops with diverse stakeholders, including the PRIME project that involved most of the participants who participated in this study. As mental health professionals, both AF and CH were mindful of how they would be perceived by the participants and sought to emphasise that the focus of involvement went beyond narrow biomedical concerns. Power differentials between the facilitators and the Sodo participants were reduced by building on existing collaborative relationships where trust has been build up and participants are comfortable expressing opinions. In both workshops, the facilitators introduced and stated the objectives of the workshop, provided a brief description of the ToC approach and moderated discussions. The processes used to create the ToCs started by defining the desired impact and long-term outcomes, and then worked backwards iteratively to map out preconditions, interventions, assumptions and indicators to generate desired change (227). The process was assisted by writing down the preconditions, interventions, assumptions, and indicators suggested by the participants on sticky notes on a wall. The two workshops led to two provisional ToC roadmaps.

Second stage, SA drafted the ToC by combining the provisional ToC road maps, minutes of the workshops and inputs from a formative qualitative study detailed elsewhere (179). In that qualitative study, in-depth interviews were conducted with policy makers/planners, health professionals/facility heads, service users and caregivers from the current study setting and at the national. We found that all groups of participants supported service user and caregiver involvement in mental health system strengthening; however, hardly any respondents had prior

experience of service user involvement. Key barriers to involvement identified included limited knowledge of stakeholders about how to work together, service user/caregiver lack of experience and opportunities to be involved, lack of service user networks/associations, and lack of systemic collaboration among stakeholders to support service user involvement. Pervasive stigmatizing attitudes and discrimination operating at multilevel (the health system, the local community and individuals) tended to disqualify service user and caregiver involvement from full social acceptance, marginalize them and hinder their active involvement. All groups of respondents identified a need for awareness-raising and training to equip service users, caregivers, service providers and local community for effective involvement. The findings of the study informed the development of the ToC, particularly to triangulate components of the interventions, barriers, facilitators, and capacity building needs for participation.

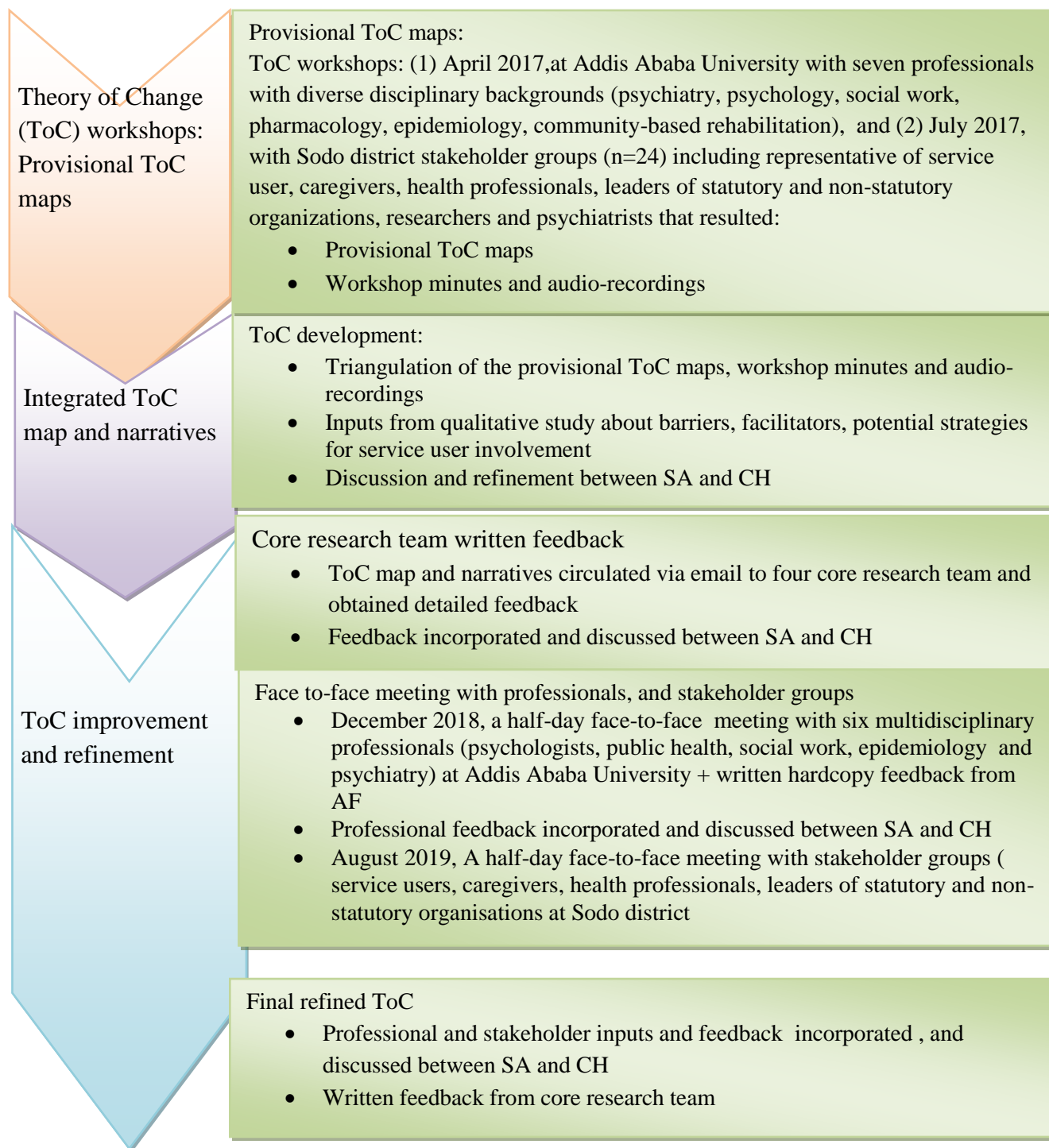
The third stage of the ToC development process involved further stakeholder consultation to refine the ToC, comprising: (1) core research team written feedback, (2) consultation meeting with professionals (n= 6, e.g. psychology, social work, public health, psychiatry, epidemiology backgrounds), and (3) Community stakeholder group meeting.

The revised ToC was then discussed and validated in a half-day face-to-face meeting with stakeholder groups including service users (n = 7), caregivers (n = 5), health professionals (n = 8), leaders of statutory and non-statutory organisations (n = 15). The workshop was convened at Sodo district and held in August 2019. After a brief presentation to recap the ToC process and existing ToC map, the group was encouraged to refine and validate the draft ToC against the practical problems encountered in the local district and their knowledge, e.g. of what may work in this context.

#### **6.2.4. Data collection**

The data for this study came mainly from the workshops and meeting minutes, and the provisional ToC maps developed during the workshops. The first ToC workshop was audio-recorded and notes were taken by the first author. These formed the basis for a detailed report of the ToC, which was checked against the audio files for completeness. In the second ToC workshop, minutes were taken. The first (national level) workshop lasted 3:30 h, and the ToC in Sodo district lasted 2:10 h. Data from the formal process documentation of ToC workshops, the

two draft ToC maps and consultation meetings were reviewed and combined to develop the final ToC map. We included in the result some illustrative quotes from the minutes cross-checked with notes made by the first author and audio-recordings.



**Figure 6. ToC development process**

### 6.3. Results

The details of the ToC workshop participants are presented in Table 5.

**Table 5. Theory of change workshop participants' demographic data**

Stakeholder Group	N	Female	Literate
ToC 1- National			
Psychiatrists	4	2	4
Researchers	3	2	3
ToC 2 –Sodo district			
Service users	1	1	1
Caregivers	1	0	1
Local government administrators	5	2	5
Health workers	4	1	4
Community representatives	4	0	4
Senior psychiatrists and researchers	9	4	9

The following sections will describe details of (i) the finally agreed ToC map (Fig. 7) and (ii) narratives of the process of ToC development to highlight the programme levels, preconditions, assumptions [1–8], indicators (i–iv), and interventions (a–e).

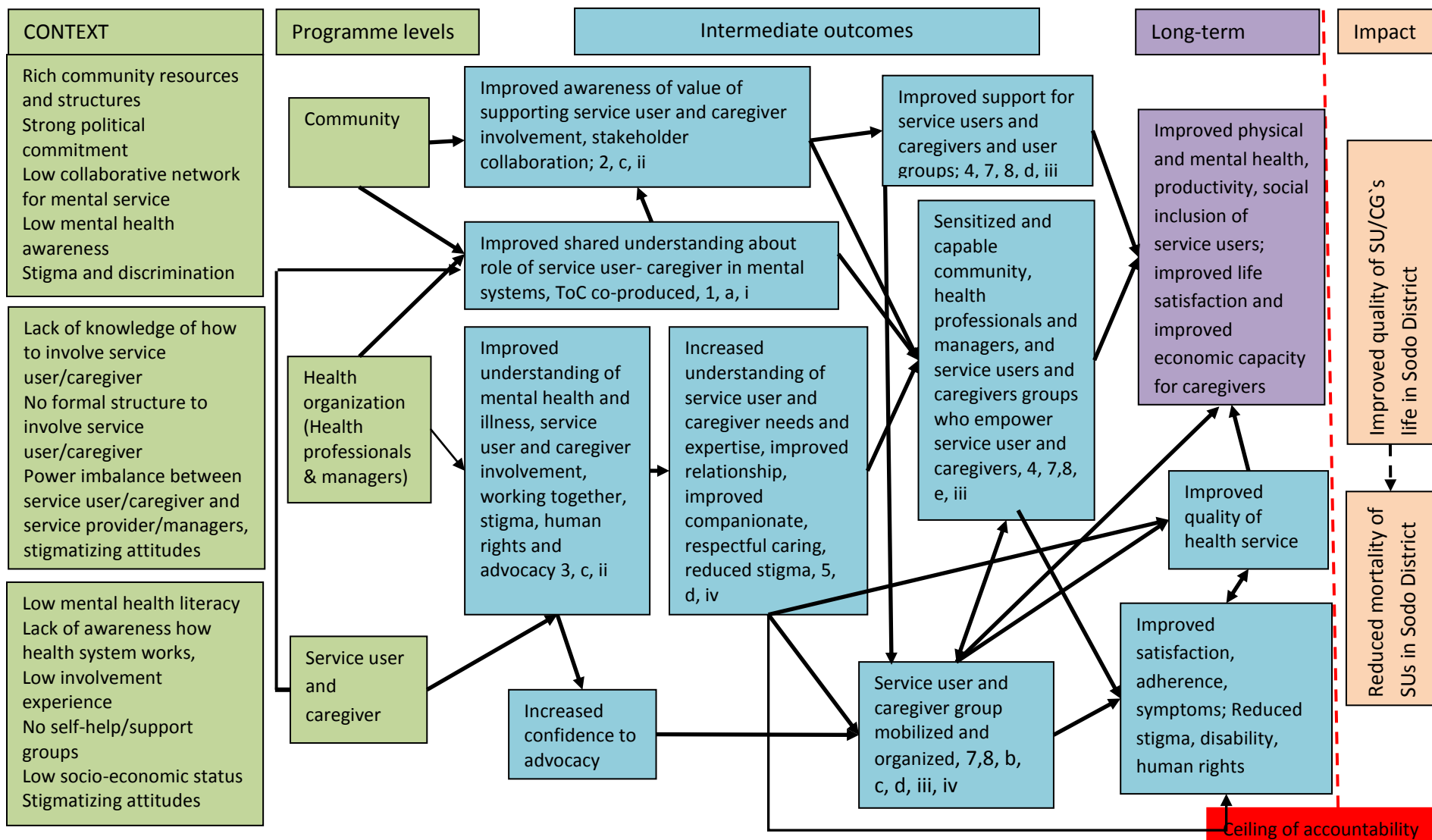
#### **Consensus on outcomes and impact**

In the first ToC workshop, the participants suggested (i) improved quality of mental healthcare as the long-term outcome and (ii) better quality of life for service users and caregivers as the ultimate impact of the study. In contrast, members of the second ToC workshop advocated for enhanced (i) physical and mental health, (ii) work productivity, (iii) social inclusion for service users (e.g. Community activities);(iv) improved life satisfaction and (v) economic capacity for caregivers as long-term outcomes. Furthermore, reduced (vi) homelessness and (vii) mortality of service users was identified as a desired impact that went beyond the ceiling of accountability of the project. During the follow-up consultation meetings, the participants came to a consensus on the long-term outcomes, leading to minor modifications to the impact (improved quality of life and reduced mortality of service users in the district). During meetings with health professionals

and researchers, concern was expressed about the feasibility of some aspects of the long-term outcome (e.g., work productivity and economic capacity). This concern was presented to stakeholder groups at the meeting at Sodo district and stimulated a heated discussion, with the group expressing their firm belief in the necessity and feasibility of the outcomes. Some participants justified the ambitious long-term outcomes, recounting that they, at the beginning of the PRIME project, had been pessimistic about the viability of integration of mental health care within primary care in the district, but that their perspectives had changed in a very relatively short time after seeing what could be achieved. For example, one participant from the health professional stakeholder group stated:

*“When PRIME project conducted its project sensitization workshop, I and many of my acquaintances who attended that meeting considered many of the project objectives as impossible dreams and mere wishes....but now in a very short time all became true...we have mental health service integrated at primary healthcare delivered with professionals working there, which reduced enormous problems families used to struggled with... maybe this is the best experience that others can take ... now we have many experiences....no doubt if we collaboratively work and tap our rich social capital of supporting each another and effectively use our community resources..... we can achieve.” (Health professional at Sodo district)*

The positive changes observed in service users with severe mental health conditions after accessing the new service, now productively working, attending school, farming, and carrying out their daily home routines, were given as evidence of the achievability of the outcomes. In addition, the district government commitment and action to cover costs of medication, combined with an emerging government focus on community-based care and economic empowerment of people under difficult circumstances were considered conducive to success.



**Figure 7. ToC map for developing service user and caregiver involvement in mental health system strengthening in rural Ethiopia**

**Example assumptions:** Willingness to (1) involve in ToC workshop, (2) undergo consultative workshop on service user and caregiver mobilization and support, (3) undergo participatory capacity building training (4) form collaborative community (5) involve in participatory action plan development, implementation and evaluating the ToC for service user and caregiver involvement; (6) Availability of reliable medication supply; (7) CAB's willingness to mobilize resources to service user and caregiver; (8) Non-governmental organization support to service user and caregiver. **Example indicators:** i. Number of people participated in ToC workshop, consultative workshop, capacity building training and involvement plan. ii. Changes in knowledge and perception pre and post training, experiences gained developing and evaluating the plan for service user and caregiver involvement. iii. Service user and caregiver groups established, and support generated. iv. Experience of involvement in participatory action plan development, implementation and evaluation. **Example interventions** a. Conduct (a) ToC workshop, (b) consultative workshop (c) capacity building participatory training, (d) facilitate participatory involvement in mental health system, (e) Assist service user and caregiver and their group

**Figure 7. ToC Map**

The participants identified the necessary interventions and preconditions to be in place to achieve the outcomes (See Table 6).

## **Interventions**

In the first ToC workshop, participants emphasized three programme levels (service users, caregivers, and district health organisation) where interventions would be necessary. The participants from the second workshop added ‘local community’ as an important additional level. During the meeting with researchers and particularly stakeholder groups, the participants spent much time unpacking the changes and inputs needed from different actors at different layers of the community (e.g., leaders of social organizations, faith-based organizations) and interventions at the community programme level. The final ToC roadmap included four programme levels: i) local community, ii) district health organisation (service providers and health service managers), iii) service users, and iv) caregivers. For each level, various interventions and distinct preconditions (see Table 6) were identified by the participants as necessary steps towards achieving the long-term outcomes.

## **Community level**

The participants of the ToC workshops reflected on the challenges of the service users and caregivers in the local setting, because they tended to be excluded from social participation in the community, and tended to be of lower socio-economic status or unemployed and at risk of lack secure housing, food, clothing and abuse of their rights.

There was no organized community support for service users and caregivers, except the ad hoc contributions of individuals who were supporting some service users on a voluntary basis. The participants identified various barriers (e.g., low awareness about mental illness in the community, lack of service user and caregiver organizations) that needed to be addressed in their local settings.

During the two workshops and meetings, the need for community mobilization was prioritized to overcome the socio-economic challenges of service users and caregivers and to empower them to contribute to the strengthening of the mental health system. At the subsequent consultation

meetings, several actors, preconditions and interventions were added to the community programme level. For example, participants recommended expanding the composition of the CAB to include more faith-based organizations, traditional healers, social association leaders (e.g., *Idir*; burial societies), HEWs, development agents, and health development army leaders (community health volunteers). The participants emphasised the need to identify and work with these actors as champions at the community level for the following reasons: to facilitate community awareness raising about mental health/illness, to promote roles of service users and caregivers, to help to mobilise community resources, and to expand community-based psychosocial care for mental health. The CAB was assumed to serve as a vital platform for information sharing, community dialogue, strengthening collaborations and involvement of local statutory bodies (e.g., district health office, justice, social and labor affairs) and non-statutory organizations (e.g., social associations, religious and faith-based organization, non-governmental organizations) to organize and support self-help groups (e.g., orphan support group, caregiver organization, service user organization), as well as to overcome the barriers to involvement and facilitate the recovery of service users. HEWs were identified as the key actors for awareness raising activities and stigma reduction in the wider community, due to their links with community leaders, and close relationships to the community and health facility. The recognition of mental health as a key package in the health extension programme was raised in support of the proposal.

The participants made strong verbal commitments to work together, although working plans for specific outcomes still needed to be drawn up (e.g., processes or procedures for awareness raising, packages of training at community level). Participants' verbal feedback indicated that the ToC process helped to clarify how programme level actors saw their roles and how they could work together. For example, one participant from the stakeholder leaders group explained how the process of ToC development had been helpful:

*'The discussion was really a learning forum, really forces us to put our thoughts and experiences that we have been doing the last five or so years... discussion helped us critically reflect what we have done so far; the reflection in the process stood out in what we have discussed during the previous ToC workshop; this also pointed to what we are going to work as in a government*

*strategic direction, to strengthen what we have done in PRIME, also showed what we have not done well and where we need to improve particularly strengthening collaboration and CAB....it has been great. (District official)*

As shown on the ToC map and Table 11, at the community level, the participants articulated key preconditions to achieve the intended long-term outcome. In particular, the need for strengthening service user and caregiver associations to function as an important partner in healthcare service improvement was stressed at all levels of the ToC development process. The participants recommended working with the CAB of the PRIME project. During the meeting with stakeholders in Sodo district, priority was given to the need for capacity building training for CAB members and key community leaders to enable them to promote community level awareness raising about mental health/illness, to reduce the impact of stigma and discrimination associated with mental illness and promote the human rights of service users and caregivers. Some participants advised that mental health promotion should be linked to schools.

#### **Health organization (service providers/managers) level**

The workshop participants appreciated the initiative by the government and PRIME to integrate mental health services into primary healthcare, and thus to provide accessible mental healthcare in Sodo district. In order to ensure ongoing sustainability of mental health services, participants identified the following as crucial: to equip healthcare centres with adequate medication supplies, and ensure continued availability of competent, compassionate, respectful and caring service providers. Unreliable medication supplies were raised by both service providers and users as a source of dissatisfaction. During the stakeholder meeting, the officials described several efforts to improve the conditions of service users and practical measures taken since the first ToC workshop (e.g., housing, community-based initiatives to support service users). All the stakeholder groups appreciated these efforts, particularly the commitment of the district health office to improve medication affordability through alternative solutions to cover the costs for those who cannot afford to pay. However, the lack of a consistent supply of psychotropic medications remained a severe problem. The root cause of the problem was a point of heated discussion, with accusations of discrimination against mental health care when compared to

physical health service delivery. For example, one health professional currently working in the district administration stated:

*“We have enough money to cover the psychotropic medication, but the problem is unavailability of the medication at stock even sometimes in Emmanuel Hospital...is not in the essential medicines list in their procurement processes. This is lack of attention to mental health and service users within the health systems...human rights violation...we can do or perfectly capable of doing this, but negligence... for example, after PRIME we started doing many things by ourselves.” (District health official)*

The participants discussed the need to advocate and create pressure at federal level about the medication supply problem. The importance of empowering service user associations to advocate for their rights was underlined. Communication problems between recipients and providers of care, lack of relevant evidence-based information for service users and caregivers about mental health treatment options, including medication types and side effects, were also highlighted as a barrier to better involvement. Staff expressed the need for training about how best to collaborate and involve service users and caregivers within the healthcare system. Several preconditions were articulated, together with necessary interventions (see Table 6) at the health organization level to achieve the intended long-term outcome.

### **Service user and caregiver level**

The participants voiced their concerns about the lack of service user and caregiver involvement in the mental healthcare system in Sodo district. In the qualitative formative study [40], several barriers to involvement were identified, including severity of mental health condition and lack of a service user and caregiver organization and empowerment. The qualitative study and ToC workshops participants demanded the establishment of an effective service users-caregivers association. The ToC workshop participants listed several tasks that service users-caregivers and their organizations could accomplish to support health system strengthening (e.g., serve as pathways to enhance advocacy for mental health, peer support; see Table 6). The ToC workshop participants debated about the best focus for a new service user and caregiver organization. In the first ToC workshop it was proposed to cover the entire Sodo district, but in the second workshop

the participants agreed to start in the capital town (Buie) of the district and gradually scale up because of topographical, logistical and other perceived challenges.

The workshop participants agreed that the district health office needed to take responsibility to facilitate the establishment of representative service user and caregiver organizations, with technical support, e.g. draft charter, to be provided from researchers and professionals in the area of developing policy/charters. The district health office made a public commitment to support establishment of a service user and caregiver association in the district, including the process of certification to become a legal entity. Stakeholders drew on their experience and recommended adopting the model used for HIV/AIDS associations.

At the service users-caregivers programme level, several interventions were identified (See Table 11), including the need for capacity building training for service users caregivers and to promote the role of non-governmental organizations (e.g. the recently established Mental Service Users Association at Addis Ababa, the Mental Health Society of Ethiopia), and professionals and researchers to empower service user and caregiver for meaningful involvement. The ToC workshops participants also articulated pre-conditions (see Table 6) to be achieved at this level to reach the intended long-term outcome.

**Table 6. Summary of programme levels, key tasks, interventions and preconditions of the ToC**

<b>Levels of intervention</b>	<b>Key tasks</b>	<b>Intervention</b>	<b>Preconditions</b>
Local community level	<p>Mobilize resources</p> <p>Raise awareness about mental illness, roles of service user and caregivers</p> <p>Establish and empower service user and caregiver groups</p> <p>Support rehabilitation/livelihood support and social inclusion of service user and caregivers</p> <p>Promote human rights protection</p> <p>Support mobilization and organization of service user/caregiver organizations</p>	<p>Working with the Community Advisory Board (CAB), leaders of social associations, faith based and religious organizations, Health Development Army, Development agents and health extension workers</p> <p>Building capacities (e.g., training) local statutory and non-statutory leaders in service user involvement and empowerment</p> <p>Conducting CAB consultative meetings</p> <p>Awareness raising to the local community about service user and caregiver involvement</p> <p>Strengthening collaboration and involvement of community stakeholders</p>	<p>Improved community awareness about mental health/illness, and service user and caregiver involvement</p> <p>Non-stigmatizing support</p> <p>Improved collaboration of community stakeholders</p> <p>Improved support, inclusion, human rights protections, and rehabilitation/livelihood support of service user and caregivers</p>
Health organization (Service provider/managers)	<p>Provide mental health services within primary healthcare</p> <p>Avail adequate and reliable treatment (medication and basic psychosocial care)</p> <p>Ensure competent, compassionate and respectful care services</p> <p>Provide relevant and evidence-based information and treatment choices</p> <p>Ensure services are accountable and responsive</p> <p>Mobilize and organize service user</p>	<p>Capacity building training about how best to involve and work with service user and caregivers</p> <p>Facilitate involvement to develop and evaluate a plan for service user and caregiver involvement, focused to ensure availability and quality of mental health care</p>	<p>District health office continues to support availability of integrated mental health care in the study site</p> <p>Improved information and treatment choices for accountable and responsive mental health care</p> <p>Improved knowledge of participatory care provision involving service user and caregiver</p> <p>Non-stigmatizing (inclusive) care</p> <p>Availability of competent, compassionate, respectful and caring service providers</p>

	and caregiver groups Encourage social inclusion		
Service users	Establish service user groups Advocate for prioritization of mental health service delivery, sustainable medication supplies, and human rights protection for service users Provide peer support, awareness raising about mental illness for the local community Establish collaborations with various stakeholders to empower service users and address unmet social needs	Capacity building training about basics of mental health and illness, understanding service user involvement, mental health related stigma and discrimination, human rights issues and mental health advocacy Facilitation of service user organization and empowerment Facilitation of involvement to develop and evaluate a plan for service user involvement	Improved service user awareness about mental health and mental health services Improved communication between service users, caregivers and service providers Non-stigmatizing attitudes Improved treatment adherence of service users Improved care(pharmacological and basic psychosocial) for service users Improved influence of service user voices and perspectives
Caregiver	Collaborate with service user groups Enhance advocacy for mental health service and protection of service user`s rights Provision of peer support Provision of awareness raising about mental health for the local community Encourage social inclusion Establish collaborations with various stakeholders	Capacity building training about basics of mental health and illness, understanding caregiver involvement, mental health related stigma and discrimination, human rights issues and mental health advocacy Facilitation of caregiver organization and empowerment Facilitation involvement to develop and evaluate the plan for caregiver involvement	Improved caregivers awareness about mental health and mental health services Non-stigmatizing attitudes Improved communication between service user and caregiver Reduced caregiver burden of care, costs Increased economic productivity Improved influence of caregiver voices and perspectives

## **Key assumptions, evidence and indicators**

Our ToC identified several assumptions (e.g. willingness of actors to work collaboratively) deemed necessary to be in place for the outcomes to be achieved. The ToC also outlined indicators of success (e.g., comprehensiveness of mental healthcare at primary health, stakeholder satisfaction), as well as the key rationale for the programme along the ToC causal pathway to the intended long-term outcome. A summary of the key assumptions, evidence/experience base and indicators to reach the long-term outcome and intermediate outcomes at the four levels is presented in Table 7.

**Table 7. Key assumptions, evidence and indicators of the ToC**

Outcomes levels	Assumptions	Evidence/ experience base	Indicators
Long-term outcome	Preconditions at the community, health organization, service user and caregiver level met Improved community organizations and inter-sector collaboration	Stated during the workshop by the participants that represented diverse stakeholder groups	Health care system inclusive of service user and caregiver needs(service user and caregiver satisfaction, affordable medication, holistic care, including medication and psychosocial, involvement structure and strategies) Comprehensives and reliability mental healthcare service (pharmacological and basic psychosocial interventions) Established service user and caregiver involvement structures within healthcare systems(e.g. peer support, board/committee members)
Community intermediate outcomes	Willingness of community stakeholders to work collaboratively to mobilize, support and empower service user and caregivers and their organization Willingness of social organizations to promote mental health for their members	Stated during the ToC workshops and meetings by the participants that represented diverse stakeholder groups Research evidence in the local context showed the need (236)	Number of stakeholders involved in ToC workshops Number of stakeholders involved in service user and caregiver support meeting ToC map and narratives Community stakeholders collaborate to empower service user and caregiver groups Number and types of community support generated to empower service users
Health organization	Willingness of health professionals and managers to undergo capacity building training; engage in participatory action research with service user and caregiver`s Commitment to create enabling environment service user and caregiver involvement	Stated during the ToC workshops by the participants Assessed need in the qualitative study Several research findings from HICs [(110, 237) and international study (209)	Number of participants attendance at the capacity building training Changes in knowledge and attitudes compared in pre-and-post training Number of members involved in participatory action research activities Reported personal experiences related to ToC model introduction
Service users and caregivers	Willingness by service user and caregiver to undergo capacity building training Willingness to work with health professionals, managers and community Time and resources to engage in involvement activities	Stated during the ToC workshops by the participants Identified needs in the qualitative study Recommended by several studies from HICs (110, 237), LMICs(23, 36, 38, 165) and international study (209)	Number of participants attended capacity building training Changes in knowledge and attitude compared in pre-and-post training Number of participants involved in participatory action research activities Reported personal experiences related to ToC model introduction Service user and caregiver groups organized

## 6.4. Discussion

In this study, we report about the development of a Theory of Change (ToC) which aimed to integrate service user and caregiver involvement in mental health system strengthening in a primary healthcare setting in a low-income country. The ToC describes service user and caregiver involvement as a complex intervention and makes explicit the hypothesized pathways through which the intervention components interact to achieve the intended long-term goals of (i) improved physical and mental health, work productivity and social inclusion for service users, and (ii) improved life satisfaction and economic capacity for caregivers. The achievement of these long-term outcomes may ultimately lead to improved quality of life and reduced mortality of service users in the Sodo district. The current study drew upon findings from rigorous formative work with key stakeholders and involved diverse representation of service users, researchers and community groups in the co-produced ToC.

The final ToC consists of four programme levels (community, health organization, service user, and caregiver). This is in line with the well documented evidence that determinants of mental health and illness are multi-layered (238) and require intervention packages beyond a health facility (e.g., health system, and community levels) (239, 240) to address service users' and caregivers' multidimensional needs (e.g., health costs, employment, education, housing, social inclusion). Clear articulation and understanding of how different programme levels fit together is essential to guide the coordinated working of multiple actors and agencies and provide a clear picture of what needs to change and how, to achieve sustainable change (241, 242). For example, district stakeholders identified the availability of rich community resources (also reported in previous study in the district (163)) and multiple actors, particularly at community programme level (e.g., social organizations like Idir) with viable potential to address the psychosocial needs of service users-caregivers locally, with less external support and in a sustainable manner.

In our study, the ToC development process created a forum for knowledge exchange and dialogue among stakeholders about the value of service user involvement, needs, and how to work together to implement this in the local context. The critical reflective discussion with stakeholder groups at Sodo district applied participatory action research (PAR), where

participants brainstormed possible solutions to several barriers for effective service user involvement, including the urgency for local solutions (e.g., medication supply challenges, supporting establishment of a service user association). For example, in our separate ToC with professionals (psychiatrists and researchers) and community stakeholders we observed that professionals emphasized long-term outcomes that were more health system focused compared to the community stakeholder groups that tended to emphasize more holistic goals. In the subsequent meeting, the participants discussed this difference of perspective and reached consensus on outcomes that accommodated the perspectives of all participants. Much research evidence indicates that active involvement of stakeholders, including service-users and caregivers, in research ensures that the research evidence is relevant, useful and trusted by all, including the end user (service users) (243, 244).

More importantly, the process created heightened stakeholder buy-in (245), particularly among the political leaders and the community representatives. The ToC process also stimulated collaborative working of stakeholders to empower mental service users-caregivers, which was identified to be starting from a 'low base' in the district (34). ToC approach offers a key contribution to enhance equity and reach of key stakeholders (246), and to incorporate the expertise and knowledge of diverse stakeholder groups` values, needs and preferences. Hence, the ToC development process by itself can be capacity building (247), helping to foster learning and reflection (248), and can facilitate contextualised solutions through a sense of stakeholder ownership of the programme (249-251). Particularly when ToC employs the techniques of participatory action research, it can serve as a catalyst for learning and promote informed action by supporting stakeholders to achieve sustained positive changes in the local context (229, 252).

In our previous qualitative study (179), several structural barriers (e.g., lack of access to care) was identified that serve to disempower people with lived experience of mental health conditions and undermine involvement within healthcare systems. Recently, the Ethiopian government has made a national level commitment to improve the situation of people with mental health conditions through increasing the availability of mental healthcare services at primary healthcare level (46, 149).

Based on our ToC findings, this initiative needs to ensure good quality of care and interventions to address the high levels of physical, emotional and social suffering and disability (189), excess mortality (152), lack of reliable supplies of medication, and low socio-economic status of service users and caregivers (lack of basic needs, shelter, education) (34, 179). Many studies from LMICs (187, 210) and high-income countries (110, 237) similarly recommend to address and overcome these structural problems, including opportunities to ensure social inclusion and protection of basic human rights (including healthcare) as required conditions to enable mental health service user involvement and recovery to occur.

In many high-income countries, enabling organisational level conditions (e.g., policy directives, legislation, strategies/guidelines, education and support) are available to support meaningful service user and caregiver involvement in mental health systems (2, 19, 115). In this regard, the promotion of and effective implementation of national and international instruments for the protection of the human rights of service users; and enacting comprehensive mental health legislation with robust enforcement mechanisms are key areas that need attention in LMICs (155), including Ethiopia. The Ethiopian national constitution (199) clearly guarantees the rights of people with disabilities. The country has ratified the United Nations Convention on the Rights of Persons with Disabilities, which includes both physical and mental disabilities (200); and employment rights (253). The Health Policy (201), the revision of the National Mental Health Strategy (149) and the Health Sector Transformation Plan (46) also need provisions to explicitly state how service user and caregivers need to be involved within the mental health system.

In our ToC, we identified strengthening local community collaboration to support service user and caregivers as a major intervention component. Previous studies from Sodo district have indicated that there are potentially rich local resources and capabilities (e.g., diverse community based organizations, community based health workers, assets, micro-finance institutions, social capital, community self-support organisations (34, 163).

These resources are not currently mobilized to support mental health service users and caregivers, and there is still limited inter-sectoral collaboration and community awareness about mental illness (34) that may contribute to marginalisation of service users in society. The community level problems require the participation of a range of societal actors (251); and the

need for community collaboration in the provision of comprehensive community mental health services is well recognized, including in LMICs (185, 254). The current direction of global mental health care emphasizes strengthening community resources, greater focus to address local priorities and developing local assets to solve local problems(10, 255, 256). One of the mechanisms of community involvement that has been of high policy interest, and is increasingly supported by research evidence, such as engaging local community stakeholders through Health Committees/Community Advisory Boards (CAB)(257-259). CABs mediate between communities and health services in many health systems(257) and can be effective to improve the quality and coverage of healthcare, as well as impacting on health outcomes(186, 209, 258).

A healthcare organization programme level was included in our ToC as a key intervention pathway to empower service users and caregivers to play a role to improve the mental healthcare system. A qualitative study of nine service user and caregiver organizations in seven African countries found that one of the important success factors is strategic government level and health organization support that promotes self-determination and service users' and caregivers' control over agenda setting (260). There are various ways in which healthcare organizations can create an enabling environment for involvement, including development of a culture of acceptance(non-stigmatizing attitudes and eliminating discriminatory practices); allocation of financial, human and material resources, and recognition of experiential knowledge to strengthen the mental health system (110, 237). At the health facility level, available up-to-date information about service user rights, the nature of their condition, available evidence-based treatment options and services, and provides infrastructure for involvement can enhance meaningful involvement of service users and caregivers (110, 237, 260).

The service user and caregiver programme level was a key intervention pathway in our ToC to mobilize and empower service users and caregivers for mental health system strengthening. Various barriers hinder service user involvement (e.g., severity of mental and physical illness, lack of decision making skills, poor information and insufficient opportunities for choice) (11, 110, 237, 260). The pervasive stigma operating within the health system, the local community and individuals, and limited empowerment and mobilization of service users can have disempowering effects on active involvement (179). Moreover, resource limitations, practical

and logistical challenges are important barriers to mental health service user involvement in LMICs which must be addressed (261).

The importance of empowerment of service users and caregivers (at individual and group level) has been recognized widely in mental health system strengthening (11, 110, 237, 260). At the individual level, empowerment involves addressing both knowledge (e.g. training about effective communication, advocacy, working collaboratively)(110, 212, 225, 237) and health challenges (e.g., medication supply) (110, 237). Training can improve self-esteem and self-advocacy, assertiveness, confidence and hopefulness of service users and promotes recovery (110, 212, 237). At the group level, empowerment can be achieved through organization of service users-caregivers. Several studies identified a range of benefits of service user and caregiver organizations to service users and caregivers, health professionals and health systems.

Empowering service users to self-organize and advocate for their interests can promote their recognition of a sense of belonging, and develop their confidence, strengths, resources and skills (31, 260). This also ensures a collective voice to influence and lobby for policy and legislative reforms (11, 260, 262). Service user and caregiver associations operate at different levels to protect the rights of service users (210, 260, 263) and there are reports that participation in self-help groups is an independent predictor of improved functioning in areas like voting, marriage, attending festivals, treatment adherence (264), fostering greater acceptance of service users by their family members and by the community, consistent treatment and better outcomes (265); income generation and quality of life (210). Self-help groups are important platforms for exchange of individual experiences and mutual support that can lead to better quality of life and insight about how best to cope with their situations (260). However, there are few service user and caregiver associations in LMICs; for example, in Ethiopia the Mental Service User Association was established in Addis Ababa in 2018, and there is only one association of caregivers at the national level (34).

The ToC workshop and qualitative study participants (179)underlined the importance of capacity building training for service providers/managers and service users-caregivers to enable service user and caregiver involvement. Our finding aligns with Carman et al. (225) who identified the

importance of technical support, strong leadership, preparation of service users, health professional and other stakeholders, and partnerships as key facilitators in implementation of multilevel frameworks for service user and caregiver involvement. Various studies also recommend addressing the knowledge, attitudes and skills needed for service providers, health administrators at all levels of the healthcare system and service user and caregivers to implement models of service user and caregiver involvement (110, 212, 237). Participatory action research oriented approaches, such as photovoice, can create longer and repeated opportunities for social contact between service user and caregivers and care providers (266-268) and lead to attitudinal change. Photovoice is a multistep participatory action research methodology whereby service users are equipped to represent their stories, including their perceived health and work reality, using photographs, with the goal of impacting an aspect of the system and/or policy (92, 269, 270).

## **6.5. Strengths and limitations**

The participatory ToC development and refinement process brought together diverse stakeholder groups including service users and caregivers to work collaboratively to strengthen service user and caregiver involvement in mental health system, which is a novel approach in LMICs. Their involvement in the ToC development created a sense of ownership and stakeholder buy-in, which is important from the point of view of follow-through on implementation. The overarching goal of this study was to develop active service user and caregiver involvement in mental health system strengthening. We did not attempt to stratify the ToC process as a mechanism to overcome power imbalance among the multi-stakeholder groups; because the process of bringing diverse stakeholder groups through facilitated interaction can offer better social contact opportunities. Such an approach has been recommended as an effective mechanism to improve attitudes and reduce stigma(195, 271). Nonetheless, we drew upon the rich experience of the facilitators and their awareness of the potential power difference to intentionally encourage service users, caregiver and other less vocal participants to engage more. The principal facilitator (AF) started the process with a simple and concrete example to explain about ToC to make it understandable for all participants, and to ensure the process achieved its intended goal with the highest possible buy-in from the participants.

Despite this, even with encouragement from the facilitator, the service user participants were not as active as other participants in voicing their views during the ToC workshop. Similar observations have been made previously when developing a participatory mental health care plan in a neighbouring rural Ethiopian district (195). We were able to draw upon findings from in-depth interviews conducted in the formative phase, which may have helped to mitigate this problem (179). We don't think there is a 'one-size-fits all' recommendation to make the ToC process more inclusive and overcome the inherent power differentials that could exist in multi-stakeholder discussions. However, we believe that, in addition to the key role of trained and experienced facilitators' efforts to make the process more inclusive, it is helpful to train/ equip the participants to engage in discussions and to provide clear initial orientation about the ToC process using local metaphors. The ToC is mainly based on the views of stakeholders from a limited geographical area of Ethiopia (Sodo district) and may not be transferable to other settings.

## **6.6. Conclusions**

The development of ToC and the involvement of diverse community representatives in the process were critical in terms of understanding the context of the programme intervention, to identify components of interventions, and articulate preconditions and underlying assumptions. The participatory approach, systematically applied, gives structure to the identification and articulation of programme theory, an important step of service user involvement in mental health systems strengthening initiatives. This study adds to the limited empirical data on best practices to develop service user and caregiver involvement, particularly in LMICs. The next step will be to pilot and evaluate the model using participatory action research methodology in this rural Ethiopian setting.

## **Chapter 7: Empowerment training to support service user involvement in mental health system strengthening in rural Ethiopia: a mixed-methods pilot study**

This chapter presents empowerment capacity building training developed and conducted for greater involvement of service users and caregivers in mental health system strengthening,

Current status: Manuscript prepared for publication:

*Abayneh S, Heidi H, Brandon A. Kohrt BA, Girma E, Getachew M, Alem A, Hanlon C. Empowerment training to support service user involvement in mental health system strengthening in rural Ethiopia: a mixed-methods pilot study.*

A protocol for participatory action research to implement the ToC programme, including the empowerment training component (the focus of this chapter) has been published:

*Abayneh S, Lempp H, Hanlon C. Participatory action research to pilot a model of mental health service user involvement in an Ethiopian rural primary healthcare setting: study protocol. Research Involvement and Engagement. 2020;6(1):1-14.*

### **Abstract**

**Background:** Increased service user involvement is recommended to improve weak mental health systems in low-and middle-income countries (LMICs). However, involvement is rarely implemented and interventions to support involvement are sparse. In this study we evaluated the acceptability, feasibility and perceived outcomes of an empowerment and training program for service users and health professionals to facilitate service user involvement in mental health system strengthening in rural Ethiopia.

**Methods:** REducing Stigma among HealthcAreProvidErs (RESHAPE) is a training curriculum for service users, their caregivers, and aspirational health workers, which uses PhotoVoice methodology, to prepare them for participation in mental health systems strengthening in LMICs. We delivered the RESHAPE training augmented with empowerment content developed in

Ethiopia. The interactive face-to-face training was delivered to service users and caregivers (over 10 days), and health professionals (one day) separately. The study was an uncontrolled, convergent mixed-methods design. The quantitative data consisted of process data, satisfaction questionnaire, and a retrospective pre-test survey. Qualitative data included exit and follow-up in-depth interviews with the service users. Descriptive statistics were performed for quantitative data, and qualitative data were thematically analysed. The findings were integrated through triangulation for convergent themes following analysis.

**Results:** 12 service users, 12 caregivers and 18 health professionals were enrolled, and completed the training. Participants valued the content, delivery process; the standard of the training program met their expectations, improved positive gains in understanding about mental illness, stigma, service-user involvement, and human rights. The qualitative findings indicated that the training had positive impacts for service users, including increased self-confidence and sense of empowerment, as well as reported social and therapeutic benefits.

**Conclusions:** We found that the RESHAPE training with added content for Ethiopia, delivered using the PhotoVoice methodology, is feasible, acceptable and of value to develop and implement training programmes which can empower service users to be involved in mental health system strengthening in a primary healthcare setting in Ethiopia. Further study to assess the impact on health systems strengthening is warranted.

**Key terms:** Training, PhotoVoice, service-users, Ethiopia, convergent mixed method research.

## 7.1. Background

Empowering service users and caregivers (hereafter service users unless otherwise specified) to be involved at all levels of the mental healthcare system (advocacy, policy, planning, service provision, monitoring, research and education) is at the centre of the international mental health policy agenda (10). Involvement has been increasingly acknowledged as fundamental to the scale-up of quality mental health services in low-and middle-income countries (LMICs)(11, 12, 272). However, actual involvement remains largely aspirational, with little guidance on how to achieve involvement in practice (11, 12, 23). In many LMICs, service users are still largely excluded from involvement in mental health systems (12, 23, 36). Multiple factors hinder service user involvement, including the limited attention given to empowerment and mobilization of

service users, and the lack of preparation of other stakeholders to work with service users (12, 36, 37).

There is a strong argument for interventions to build the capacity of service users and health professionals (including service managers) to facilitate active participation and to overcome stigma and exclusion (12, 273, 274). Studies from high-income countries indicate that empowerment and training of key stakeholders is helpful or can lead to successful working partnerships (275-277). However, the evidence base for effective models of capacity-building is weak, limited to descriptions of training initiatives, and there are no programmes to equip key stakeholders to work together within LMICs mental health systems (41-43).

In Ethiopia, there have been no training programs designed to equip service users and health professionals for collaborative working in mental health system strengthening. Indeed the key stakeholders themselves reported being ill-equipped and expressed a strong need for training on how to work together to effect change(179, 180). As a part of an intervention to pilot a new model of service user involvement in mental health system strengthening in Ethiopia, the authors developed and delivered interactive training to service users and health professionals in the Sodo district of southern Ethiopia. In this paper, we describe the development, and evaluate the feasibility, acceptability, and perceived outcomes of the pilot training program.

## **7.2. Methods**

### **7.2.1. Study design**

We used an uncontrolled, convergent mixed-method study design to assess feasibility, acceptability, and preliminary evidence of impact of a pilot training program for service users and health professionals. This study formed part of a larger research project aiming to develop service-user involvement in mental health system strengthening in Ethiopia. This was initiated as part of the ‘Emerging mental health systems in low-and-middle-income countries’ (Emerald) project including six LMICs (Ethiopia, India, Nepal, Nigeria, South Africa and Uganda)(278). In addition, this specific study is also linked with OPAL(Optimizing Provider Attitudes and competence in Learning mental health systems) project(97), and was one component of an intervention to pilot a Theory of Change model for service user involvement in mental health system strengthening in rural Ethiopia, described elsewhere (180).

### 7.2.2. Setting

The study was conducted in the Sodo District of the Gurage Zone of the Southern Nations, Nationalities and Peoples' Region, Ethiopia (See details in section 4.3.1.3).

### 7.2.3. Participants

The participants of the study were 12 service users, 12 caregivers, and 18 general health professionals, purposively selected based on pre-set inclusion criteria (See Table 8). The service users had confirmed diagnoses of schizophrenia or epilepsy or alcohol use disorder or depression; and they all had accessed integrated mental healthcare in primary healthcare as part of a previous study (279). The clinician involved in their care (a psychiatric nurse based in Buei Primary Hospital) and a project psychiatric nurse ensured their capacity to participate. The health professionals were recruited from the Sodo district health office (the administrative office coordinating all non-hospital health care in the district), and three health facilities (Buie Hospital, Kela and Tiya primary health centres) in the district.

**Table 8. Study 3 participant inclusion criteria**

Inclusion criteria	Stakeholder groups		
	Service users	Caregivers	Health professionals
Health professional who directly provide healthcare to service-users			X
Have a psychiatrist confirmed diagnosis of the priority mhGAP mental health conditions: Schizophrenia or Epilepsy or Alcohol use disorder or Depression	X		
Immediate caregiver to the service-users and need be closely related with service-users		X	
Adults(18 <sup>+</sup> years)	X	X	X
Considered by themselves, by healthcare providers, and by the family to have improved in capacity to participate/functioning and with stable mental health conditions	X		
Working or receiving/have received healthcare services from primary healthcare at the Sodo district at least for six months	X	X	X
Participant has time available and is willing to be involved in the training, or share their own recovery stories	X	X	X

## 7.2.4. Overview of the training program

### 7.2.4.1. Theoretical lens

The training program design and interactive delivery was informed by principles of participatory action research (PAR) (125) and experiential learning theories (280, 281), suitable for adult learning and for people with low literacy. These approaches: (i) pay attention to empowerment, building on strengths and resources inherent in participants, and are defined by mutual trust, co-learning, active participation, and respect to promote social action; (ii) places value on life experiences as a central and necessary part of the learning process, and (iii) acknowledge that participants bring a wealth of experiential knowledge on the topics discussed and are well-positioned to speak about their experiences(125, 280, 281).

The REducing Stigma among HealthcAreProvidErs (RESHAPE) program is an initiative to engage service users and their caregivers to improve training of primary care workers in mental health services (43, 97). RESHAPE is developed based on stigma reduction theories from social psychology, social neuroscience, and medical anthropology using a ‘What Matters Most’ framework of motivation(43). The core methodology is PhotoVoice, which is a participatory photographic narrative technique. PhotoVoice is a PAR methodology, involving creation of a visual reality of a person’s lived experiences with a particular topic and their reflections. The PhotoVoice approach is rooted in participatory empowerment education/critical consciousness theory and other participatory approaches (282, 283). These theoretical underpinnings promote power sharing, understanding of lived experiences and encourage the participants to construct and share their reality to take collective action for positive change. PAR PhotoVoice has been employed within the field of mental health to: (i) explore and understand service user experiences of treatment of mental illness and the recovery process, (ii) engage in psycho-education programmes, (iii) dispel issues such as shame, social exclusion and stigma associated with mental illnesses, and (iv) advocate for more inclusive, co-produced and participant-centric ways of uncovering and discovering the lived experiences of service users (282, 283). photovoice combines photography, interviews, and group discussions mainly guided by SHOWED questioning techniques to elicit discussion about participants’ photographs (282, 283), as follows: (i) What do you See here? (ii)What is really **H**appening here? (iii) How does this relate to **O**ur lives? (iv) Why does this condition **E**xist? And(v) What can we **D**o about it? For

RESHAPE, PhotoVoice is used to help health workers understand the experience of mental illness through the eyes of persons with lived experience of the conditions. RESHAPE was developed in Nepal, where service users and caregivers were trained in PhotoVoice. The trained service users and caregivers then presented the photography narratives to primary care workers participating in mhGAP trainings, local community groups and policy makers. Proof-of-concept testing has demonstrated feasibility and acceptability of the approach in Nepal, as well as suggestive benefits for reducing stigma among primary care workers in mhGAP training (43). The current study in Ethiopia is the first test of the RESHAPE approach outside of Nepal.

#### **7.2.4.2. Development of the training program**

The development of the training program was informed by (i) needs identified through in-depth qualitative interviews with service users, health professionals, planners and policy makers (179); (ii) mapping out existing materials and consulting with experienced researchers in LMICs, particularly informed by a training manual developed by a Nepal research team (43), and (iii) by international literature on similar initiatives(275, 276).

Based on these inputs, co-authors (SA, CH, and HL) developed two training manuals for: (i) service users, and (ii) health professionals. The appropriateness, contextual relevance, basic delivery and assessment modalities for the translated manuals (Amharic) were reviewed by six professionals who were either university faculty staff members or researchers from diverse disciplines (psychiatry, health education, clinical psychology, public health, and mental health epidemiology). The core content of the training manual was similar for both target groups, but the service users training included additional content on basic knowledge about mental health and illness, treatment options and their rights to receive care. The training manuals are freely available (166).

The training program for service users had additional content on the development of recovery narratives using PAR photovoice techniques. The approach was adapted from similar work carried out in Nepal (42, 43, 97). SA and MG in Ethiopia reviewed the content, flow, interactive delivery modes, assessment techniques, and augmented the content of the photovoice training manual with the training programs developed for service users that supplement each other on contents, avoid duplications of efforts and resources, and are contextualized to Ethiopia

background (See Appendix 4). The Ethiopian team had close dialogue with the OPAL Nepal team who had firsthand practical experiences of providing training and applying photovoice techniques.

#### **7.2.4.3. Training delivery**

The interactive training was delivered face-to-face separately for (i) health professionals, and (ii) service users. The training for health professionals was conducted for a full day, which was divided into seven sessions. The training for service-users consisted of two parts, including an initial three day training course that focused on core topics, and eight PAR photovoice sessions, each of 3-4 hours duration conducted two times per week (See Appendix 5). The photovoice training had two components. First, field activities whereby service-users were supplied with digital cameras, a notebook and pen to take photographs of people, places or objectives/mementos that depicted their own recovery journey, followed by preparation of service user narratives closely linked to the taken and self-selected photos. Participants were first trained in the use of the digital cameras, including about the ethical aspects to consider when taking photographs of people. The participants then took photos for each session on three themes about the time: before receipt of professional treatment, during- and after treatment ongoing treatment.

Second, there were interactive classroom learning and reflection sessions. During the classroom sessions participants were asked to choose photographs that were most relevant to the theme and that they felt comfortable discussing in a group. The photographs were transferred onto laptops to display the photos for discussion with all participants. Accordingly, every service user presented and was involved in discussions about the photographs, using the SHOWED techniques. A range of facilitated discussions were conducted on several topics, including identifying strengths and resources, combating stigma and myths about mental illness, advocacy, communication skills, understanding and managing crisis (See Appendix 5).

In line with principles of PAR and experiential learning theories, the learning goals, content, and activities for both target groups were designed and delivered consisting of interactive techniques, including didactic, small group discussions and presentations, case scenarios analysis, audio-

visual material showing the recovery narratives from lived experiences in the local area, and own recovery narratives using PAR photovoice, and action plan development exercises.

The training for both groups was held in a private setting in Buie town in Amharic. The first author (SA) with two research assistants led the training for health professionals. The training for service users was facilitated by SA and MG. A senior professor of psychiatry from Addis Ababa University (AA) taught the mental health related topics for service users. The trainers were assisted by three psychosocial service providers with people with mental health conditions and residing in the study area. SA and the OPAL field coordinator had received five days of intensive face-to-face training by three professionals from Nepal to equip them to facilitate the planned photovoice sessions. The OPAL Nepal team also provided ongoing supervision and support throughout the training.

#### **7.2.4.4. Evaluation of the training program**

We evaluated the training program using a triangulated mixed-methods approach which involved multiple sources of quantitative and qualitative data (284).

##### ***Quantitative assessment***

The quantitative data collection consisted of self-reported or interviewer-administered (for those with no or low literacy) rating scales and process data; which included demographic data, program feasibility and acceptability, and changes in understandings.

##### **Demographic data**

Socio-demographic data including gender, age, education, and experiences (work/caregiving or living with mental health condition) were gathered at the beginning of the first session.

##### **Feasibility and acceptability of the training program**

To assess the feasibility of the training program, we collected process information that consisted of the number of participants who enrolled, attended, and completed each training session. Acceptability of the program was operationalized to include participants' satisfaction with the training sessions, standard of the training and fulfilment of their expectations. This was assessed immediately after completion of the training using a questionnaire comprising both structured

and unstructured questions (274). Aspects of the training sessions were rated on a 4-point Likert scale from 1(excellent) to 4(poor), and questions about the standard of training and fulfillment of expectations were rated from 1(strongly agree) to 4(disagree).

### **Evaluation of understanding**

We employed a retrospective pre-post-test questionnaire to investigate whether the training produced changes in participants' self-reported understanding related to the objectives of the training program. The concept of service user involvement is relatively new within the Ethiopian mental health system, and prior to the training participants had no experience of involvement and working collaboratively in this area (179). We anticipated that in most cases participants lacked sufficient knowledge to provide pre-training ratings, as has been reported previously (285). With the retrospective pre-post-test approach, participants estimate their pre-intervention levels of understanding after receiving the training and can therefore situate themselves in relation to what they have since learned. This avoids response-shift bias, which occurs when participants may not fully understand how to assess the target understandings before the training, therefore leading to inaccuracies in pre-test ratings(285, 286).

We employed a bespoke questionnaire developed for Emerald (See <https://www.emerald-project.e/ome/>) in line with the training goals. The instrument consisted of 17 items for health professionals and 15 items for service-users, with 13 items common to both groups. Participants reported their response to the questions via five point scale of 'not very well' (1), 'somewhat well' (2), 'don't know' (3), 'moderately well' (4), or 'very well' (5). The participants completed the questionnaire immediately at the end of the first day (health professionals) and after the three-day training (service users). For each item participants provided two ratings (i) their current level after the training, and (ii) retrospective estimate of their level before the training. Five interviewers wrote the responses for participants who had low literacy (n=15) with their agreement.

### ***Qualitative assessment***

#### **Exit interviews**

Face-to-face in-depth interviews were conducted individually with the service users and caregivers (n=24) immediately at the end of the last photovoice session. The interviews explored

why participants attended the training, the aspects of the program that they found most helpful and enjoyed, aspects that made them feel uncomfortable, and how the program could be improved and perceived benefits/impacts of the training. The interviews were conducted by five (2female and 3 male) project field research assistants and the SA was not involved in the interview to avoid social desirability bias. The interviews were audio-recorded and lasted between 6-46 minutes (with an average of 13minutes).In addition, qualitative responses to open-ended questions nested in the quantitative survey related to the perceived challenges or comforts about the training process were collected.

### **Follow-up in-depth interviews**

Individual in-depth interviews were conducted with subsets of service user (n=4) and caregivers (n=4) approximately six months after the end of the training sessions. In between the training and the interviews each of the participants had gained practical experience of giving testimonies to health professionals on a five-day training programme (each participant had attended at least two training sessions). The topic guides were adapted from similar research used by the OPAL team. In addition to the exit interview questions, the topic guide aimed to explore participants' impressions of the training, knowledge and skill they had acquired, and how they had applied the knowledge and the skills since the past training sessions. All interviews were conducted by a single experienced interviewer (female), who had not been engaged in the training programme. The interviews were conducted in Amharic and were audio-recorded. Interviews lasted between 16 -58 minutes (with an average of 30minutes).

### **7.2.5. Rigor**

To enhance trustworthiness of the results we employed different strategies, including data and methods triangulation, use of field observation notes, and prolonged engagement with participants (173). We applied triangulation of multiple data sources that helped to include various points of data in the analysis. Through prolonged engagement in the field with participants, SA took observational field notes throughout the study period that helped to enrich data from the interview transcripts and compare personal experiences during the subsequently bracketing (287)and data analysis. Information for the photovoice narratives were participants' own observations and interpretation included, which is considered as member checking (288).

### 7.3. Results

The results of the training are presented in three sections, including participant characteristics, training program feasibility and acceptability, and perceived impacts.

#### Participant characteristics

12 service users, 12 caregivers and 18 health professionals attended and completed the training, and provided responses to the program assessments. Socio-demographic data for participants is presented in Table 9. To maintain anonymity, the participants were represented with identification numbers to describe their qualitative accounts in the results, for example service user (e.g. SU1, SU2), caregiver (e.g. CG1, CG2), and health professionals (HP1, HP2).

**Table 9. Study 3 participant socio-demographic information**

Characteristics	Service users	Caregivers	Health professionals
<b>Gender</b>			
Male	6	5	15
Female	6	7	3
<b>Age</b>			
20-25	2	0	2
26-30	0	3	4
31-35	3	2	6
36-40	1	2	4
41+	6	5	2
<b>Educational attainment</b>			
Non-literate	4	7	0
Informal Education	2	2	0
Primary School	6	1	0
Secondary School	0	2	0
Diploma	0	0	5
First degree	0	0	13
<b>Years of work experience or caring or living with mental health condition</b>			
1-5years	5	5	3
6-10years	3	3	8
11-15years	1	0	1
16 <sup>+</sup> years	3	4	6

## Training program feasibility and acceptability

### Feasibility

Feasibility of the training program was supported by high enrolment, training completion and response to the training assessment by all eligible service users (12/12), caregivers (12/12) and health professionals (18/20)(See Table 10). Moreover, all participants who enrolled attended all sessions except one who missed one session because of a social obligation.

**Table 10. Training programme feasibility and acceptability indicators**

Indicators	Service uses	Caregivers	Health professionals
<b>Indicators of feasibility</b>			
Participants invited to participate in the training	12	12	20
Participants enrolled in training	12	12	18
Participants attended all the sessions	12	11	18
Participants completed the sessions	12	12	18
<b>Indicators of acceptability</b>			
Number of participants who reported that their expectations had been fulfilled:			
Strongly agree	10	11	12
Agree	2	1	6
Number of participants who reported that the training of high standard:			
Strongly agree	9	11	11
Agree	3	1	7

The analysis of the qualitative datasets (open-ended questions, interviews: exit and follow-up) strongly supported the feasibility of the training programme. The participants reported only a few challenges to attending the training program. These logistical issues included challenges with transportation, accommodation, overlap with their regular duties, and health challenges.

*I attended all the training attentively with interest. The time schedule was good and it did not waste our time. (SU20, Exit interview)*

*I attended all the ten days, previously I used to feel health problems all the days, but there was no problem during the training. I saw changes [health] in this regard. (SU3, Exit interview)*

Only one participant (coming from rural area) reported challenges related to transportation and weather conditions that affected attendance.

*Sometimes I was delayed getting transportation and when there was rain we did not get transport, but there was nothing else. (CG20, follow-up interview)*

Some participants coming from rural area reported challenges related to accessing a power supply to charge the digital cameras. Notwithstanding the affirmative feedback about the training content and values, almost all health professionals indicated areas where the training programme could be improved in terms of time and supplementary reading materials.

*The training was very nice, but the time was very short. If the time was longer we could have discussed many points. The trainer covered a lot of key points in [a] very short time. (HP13, Response to open-ended questions)*

### **Acceptability**

The quantitative analysis indicated that the majority of participants reported strong agreement (31/42) or agreement (11/42) that the training was of a high standard and that their expectations had been fulfilled (strongly agree=33/42; agree=9/42) (See Table15). This positive feedback was captured in the qualitative data in participants' accounts about the adequacy of the training content, recommendations about how the training could be improved, and the most useful aspects of the training.

Almost all the participants mentioned that the training included many useful topics, and their expectations were largely met. They described the training program using words and phrases like 'interesting', 'very nice', 'very relevant', 'very useful/helpful', 'very happy', and one participant said "This lesson cannot be gained even by paying for it," (CG12-Follow-up interview). Many of

the participants recommended no change or additional topics to the training program, except three participants who wanted to get training about income generation (SU11, SU21,CG4).

*I am very happy about the training; the issues discussed were very important. The recommendations and solutions raised during the training should be changed into practice involving all stakeholders (HP6, Response to open-ended questions)*

*The training contained many useful topics. It helps to learn how to properly use medication, and how to teach other people. It helps to clearly learn from others' stories, for example about how to avoid alcohol use and factors that worsen mental illness. (CG 22, Exit interview)*

Almost all participants recommended the need for expansion of the training programme to reach more people, including involving more people with lived experiences and engaging community stakeholders. The service users also expressed their readiness to share what they had gained from the training and their lived experiences.

*This training was provided for 12 service users and 12 caregivers. They should share the knowledge to many people. The training program should be supported by governmental and non-government organizations to reach many people. For example, if teachers participate in the training, the lesson can reach many people. (CG12. Follow-up interviews)*

The participants appreciated the different activities and interactive training techniques, including case scenarios analysis and PAR photovoice recovery narratives, which were considered to encourage collaborative learning, share experiences, and made training understandable.

*The service users actively participated by capturing and describing photos and this made the training very clear to understand. This training included many things and was unusual. There were photographs, videos, and people with the mental health conditions shared their experiences throughout the training. I liked it very much. (CG 24, Exit interview)*

*The PhotoVoice was helpful to express idea easily. It nicely helped me to express my ideas. I am very happy talking about my experiences to others. (SU21, Exit interview)*

## Perceived impacts of the training programme

### Improved understanding/knowledge

The descriptive analysis of the retrospective pre-test responses showed that increased numbers of participants reported higher understanding levels after the training than before (see Appendix 6 and Table 11).

**Table 11. Descriptive statistics of participants' training programme understanding after and before the training**

	I understood:	Phases	N	Mean	St.d
1	why service users and caregivers wanted to be involved in mental health system	After	18	4.9	0.32
		Before		3.3	0.97
2	the value of service users and caregivers' involvement in mental health system	After	18	4.9	0.32
		Before		3.3	1.09
3	how to involve service user and caregivers in the different aspects of mental health system	After	18	4.7	0.49
		Before		2.8	1.06
4	how to collaborate with service users and caregivers for mental health system strengthening	After	18	4.8	0.43
		Before		3.3	1.09
5	what kinds of contributions service users and their caregivers can make to improve mental care in my district (Sodo district)	After	42	4.6	0.59
		Before		3.0	1.08
6	about the international protections (and protections within Ethiopia) for the rights of people with mental health problems	After	42	4.3	0.67
		Before		2.9	1.30
7	the experiences of people with mental health conditions in Sodo district	After	42	4.3	0.75
		Before		2.7	1.27
8	the levels of service users and caregivers involvement in mental health system strengthening	After	42	4.3	0.75
		Before		2.8	1.17
9	myths and facts about mental illness	After	42	4.6	0.59
		Before		3.4	1.23
10	types of mental health related stigma and discriminations	After	42	4.6	0.55
		Before		3.3	1.05
11	the impacts of mental health related stigma and discrimination	After	42	4.6	0.54
		Before		3.4	1.08
12	about strategies to reduce mental health related stigma and discrimination	After	42	4.6	0.58
		Before		3.0	1.19
13	about types of mental health problems	After	42	4.7	0.47
		Before		3.6	1.08
14	about the treatments that can help people with mental health problems	After	42	4.6	0.54
		Before		3.6	1.15
15	about definition of service user	After	42	4.7	0.48

		Before		3.2	1.09
16	about the definition of caregiver	After	42	4.6	0.50
		Before		3.5	1.17
17	about definition of involvement in mental health system	After	42	4.6	0.55
		Before		3.3	1.13
18	how I can contribute to improve mental care in my district (Sodo district)	After	24	4.1	0.68
		Before		2.9	1.04
19	how I can contribute to the development of mental health policy and law development in Ethiopia	After	24	4.2	0.66
		Before		2.9	1.19

Consistent with the quantitative findings, the qualitative data supported that participants perceived this training improved their understanding. The participants appreciated the interactive learning activities and the PAR photovoice enhanced their active involvement and understanding of the training. The participants reported learning new skills that they could use or are using at various areas.

*The training gave us sufficient knowledge about mental illness, medication use and stigma and discrimination. I got good knowledge when I heard their advice (participants sharing lived experiences) and the way they talk. (SU16, Exit interview)*

*The training had a lot of benefit. When participants presented their experiences of living with mental illness, this becomes a good experience and advice for us [participants]. When they [service users] talk we [participants] were happy. Just when they speak about their past experiences and how well they are doing now it gives hope [to the] service user. (CG15, Follow-up interviews)*

Besides the improved understanding and skills, the qualitative data highlighted numerous perceived outcomes/benefits of the training programme, including feelings of empowerment, social benefits, and perceived therapeutic benefits.

### **Sense of empowerment**

The participants mentioned the valuable contribution of their participation in the interactive PAR photovoice group activities and having the opportunity to give testimonies to health professionals. For many participants, the social space for sharing their recovery journey, having their views heard, valued and acknowledged by health professionals had led to improved self-confidence, a sense of valued contribution and increased self-worth.

*...they (health professionals) were very happy, clapped their hands for us, and they told us to help us [service users and caregivers] if we faced any problem even at night. (CG20, Follow-up interview)*

*I am very happy having a freedom to discuss with others and sharing my experience about my previous situation. I feel like I rebirth and feel like my age is just like a child. Previously I have suffered a lot... when that time passes and I become to this stage, this is rebirth for me. I am happy. (SU 17, Exit interview)*

### **Perceived social benefits**

Almost all participants valued the social benefits of the training programme in terms of improved social acceptance. The participants mentioned the PAR photovoice process helped them to be valued and acknowledged for their lived experiences in the family and community.

*We were stigmatized and discriminated by community, no one used to visit us, including our neighbours, and we did not go to other peoples' homes. After we started participation in this training many people started greeting us. My relatives who used to reject me are now accepting me. People started treating us as human beings. We have hope. God knows the future. (CG7, Exit interview)*

*In my family no one was looking for me because of my illness. They were wishing my death; no one used to give me even free rain water and considered me as useless. My husband is very nice person and he encouraged me and after my involvement in the training my family started visiting me. (SU11, Exit interview)*

*The training showed us many good things. I am communicating with my family very well now and they are also asking me to share my ideas with them. They are also accepting my ideas. (SU1, Exit interview)*

Although there was improved acceptance of service users in the community, the participants mentioned that more work needed to be done in the community and institutions through awareness creation and involving service-users.

*There are many people who stigmatise and discriminate against people with mental illness. They lack understanding about mental illness and people with mental illness. We should provide awareness to all people. (SU 11, Exit interview)*

At beginning of the training process, we observed that some participants felt uneasy to share their own recovery stories because of being upset due to past unpleasant experiences of discrimination. This problem was anticipated by the trainers before the training started and managed by probing participants to share their personal strengths rather than focus on their personal mental illness. The participants liked the opportunity to meet, spend time and interact with people with similar mental health conditions. The participants welcomed the opportunity to have the time and space to exchange their lived experiences and learn with or from each other. They reported that this created a sense of belonging, strengthened their relationships and stimulated action to establish long-term relationships through getting organized into a grass roots service user association. The participants reported that being organized into an association would support their collective efforts to tackle problems facing people with mental health conditions.

*The training process brings people to deeply connect with each other. Our (service users) coming and discussing together enabled us to establish a service users association, and hope that it [association] will be the best association in the Sodo district and the entire country. (CG12, Exit interview)*

### **Perceived therapeutic benefits**

Many of the participants reported making changes in their lifestyles and behaviour with perceived therapeutic value because of the knowledge and skills gained from the training. Some reported making changes to unhealthy aspects of their lives, including reducing/stopping alcohol drinking, improved medication use, attending health facilities, improvements in the way they experienced their family relationships and the wider community.

*The man (service user) used to be in bed and feeling pain all day; and I was not able to attend meeting even at my neighbourhood. I am very happy for attending this training. The man is effectively taking his medication. The man was a difficult person, but after the training [he] has showed improvement. He started meeting people and participation in social activities. He is started looking for and feeding cattle. The training gives hope. (CG2, Exit interview)*

*This training was more than taking medication, helpful to change the mind and giving hope about the future. Thanks to God we are here to get involved here. We used to chain her all the days just like a sheep and goat. I remember many people visited and took her photo while she was chained. (CG7, Exit interview)*

Many of the service users mentioned involvement in peer support, advocating for own human-rights and supportive relationships with health service providers that could help to improve health service quality.

*When both of us (service user and caregiver) go to health facility, we don't feel shameful and [can] freely talk about her (service user) mental health condition without fear. I ask for timely service without waiting for long. They (health professionals) are also serving us with good manner and respect. (CG10, Exit interview)*

#### **7.4. Discussion**

In this paper we have described the development, delivery and evaluation of the feasibility, acceptability, and preliminary outcomes of a participatory training and empowerment programme for mental health service users and health professionals. This was one component of an intervention to support service user involvement in mental health system strengthening in Ethiopia (180). There was high participant enrolment, completion, response to assessments, and few challenges or discomforts during the training process. The training program content, delivery process, standard, and relevance were well received. The participants recommended continuing and expanding the training program to reach many people. The training had positive impacts, including improved understanding of issues related to service user involvement, mental illness, increased confidence, social impacts and perceived therapeutic benefits. Our program showed that training service users and health professionals for greater involvement in mental health system strengthening is feasible, acceptable, and can have several benefits at small scale in rural Ethiopia.

The preliminary findings of feasibility and acceptability of the training programme indicate that this is a promising approach to equip key stakeholders to support greater service user involvement (179, 180). This step was identified as a necessary precondition to service user

involvement in our Theory of Change model for mental health system strengthening in Ethiopia(180).This study also contributes to the small evidence base on training programs designed to empower mental health service users in LMICs(23, 41, 273, 274).

Our findings indicated that participants valued the wide range of interactive training strategies utilized during the training (e.g., group exercises and reflections, photovoice recovery narratives). The findings reinforce studies from high-income countries that reported similar active involvement of service-users(276, 277). These activities are key strengths of PAR and experiential learning approaches that we applied, which integrate participation, promote supportive relationships, and recognise knowledge and lived experiences as vital to the knowledge generation process(20, 280, 281). Many publications report that the PAR photovoice method values the expertise of participants and their direct involvement in all aspects of research is positive, including the visual data analysis about the meaning and importance of self-selected of photos and their narratives (131, 282, 283). PhotoVoice is inclusive and particularly suitable for those with low literacy, because this method does not presuppose any working knowledge of traditional research methods; and participants mainly use photography as the medium through which they communicate their lived experiences (282, 283). Combined use of visual data(photos) together with individual and group reflective sessions(voice) can facilitate an authentic, active participation, co-creating/co-production of knowledge, and provides a powerful means for marginalized groups to communicate their experiences (131, 283).

Our findings show that the training program positively improved participants' understandings related to service user involvement, and mental health recovery journeys. This is in line with evidence that show that PhotoVoice approaches support participants to take an active role and improve understanding by conveying the why, how, and what of living with mental illness, the complexities of their recovery process, and their experiences of dealing with mental health challenges in the private and public domains (283, 289). In addition, the active involvement of participants in the PhotoVoice process and learning of new skills (e.g. photography, collaborative group working) can promote increased self-confidence, self-worth, and sense of contribution (283, 289).

Moreover, we identified that service users reported the adoption of more healthy lifestyles in a number of ways, for example, reduced alcohol consumption, effective use of medication, and improved social interaction and healthcare attendance. These outcomes are in line with evidence that greater participation in PhotoVoice can have therapeutic benefits for participants to improve self-understanding, a sense of empowerment, self-esteem, and assistance to overcome stigma (283, 290). Similarly, case studies from diverse countries reported that programmes that engage service users to share their recovery narratives can reduce stigma, facilitate healing, and promote engagement in mental healthcare, while also assuring that service users have autonomy in the content and form of the narratives (93).

Our results show that the participants reported improved social acceptance in their community. This is consistent with the evidence that active participation and reflection during photovoice can achieve social acceptance through addressing multi-level stereotypes, stigma and feeling of shame and isolation that is often associated with mental illness (131, 283). This aspect of PhotoVoice in challenging stigma is likely to be crucial in overcoming the main barrier that service users face to meaningful civic participation and steers away from the past systemic disadvantages in most facets of their daily lives in LMICs (202, 291).

The training process had social benefits, including opportunities to meet and engage with people with similar experiences, share experiences and learn from each other, and building social networks. Other studies also reported that such sharing of stories can instill a sense of connectedness, and participants benefit from group support due to the shared experiences (283, 289, 292). In our study, service users who participated in the training decided to establish a service user association in Sodo district. The association comprised of 24 founding members (12 service users and 12 caregivers) to support each other to expand their networks in an organized way for involvement in mental health systems strengthening and to advocate for their human rights.

We also identified areas of the training programme that need further attention. Health professionals suggested future training might be improved by extending the one-day program to facilitate in-depth coverage of the training content. Our training process observations show that some service users were highly emotional when narrating their recovery journey. This implies the importance of taking necessary precautions and preparation of participants for strategic

disclosure of recovery narrative during the PAR photovoice process. Other studies also recommended the need for preparatory training (e.g. “Coming Out Proud”) to support participants to affirm their own readiness to disclose their mental illness and combat self-stigma and reframe the meaning of mental illness (293).

## **7.5. Strengths and limitations**

The program development and delivery were informed by participatory action research and an experiential learning approach that promotes active involvement of participants. We employed prospective convergent mixed methods design, which utilized multiple data sources and allowed us to triangulate findings.

There were several limitations of this pilot study that warrant consideration. (i) The study sample was small, (ii) there was no control group and (iii) participants were selected purposively, with the potential for selection bias that may limit generalizability of the findings. There was also concern that an (iv) interviewer administered assessment could lead to social desirability bias. The quantitative measures used in this study, although based on other studies of a similar nature, have undergone limited psychometric testing or were unstandardized measures with unknown psychometric properties. We have employed a PAR real-time engagement approach and several triangulation techniques to obtain in-depth assessment of the perceived understanding changes, however, use of validated measures in future evaluation of this training will be useful in benchmarking improvements against other training approaches. Moreover, this study did not evaluate the impact on health workers attitudes and behaviors, which are the end targets of the RESHAPE intervention.

## **7.6. Conclusions**

Our study has provided preliminary evidence of the acceptability, feasibility and perceived benefits of a training programme to empower and equip service users and health workers to collaborate to strengthen mental health systems in rural Ethiopia. Future work need to focus on evaluation of the programme at a larger scale and to further investigate the ongoing support required to achieve sustainable service user involvement.

## **Chapter 8: Using Participatory Action Research to pilot a model of service user and caregiver involvement in mental health system strengthening in Ethiopian primary healthcare: A case study**

This chapter described the case study of the pilot implementation of the ToC model using a participatory action research approach, which was conducted to determine the acceptability and feasibility of the ToC model in practice.

Current status: Manuscript prepared for publication:

*Abayneh S, Heidi H, Kohrt BA, Alem A, Hanlon C. Using Participatory Action Research to pilot a model of service user and caregiver involvement in mental health system strengthening in Ethiopian primary healthcare: A case study.*

The findings presented in this chapter followed a published protocol for implementation and participatory evaluation of a ToC-informed model of service user involvement in mental health system strengthening:

*Abayneh S, Lempp H, Hanlon C. Participatory action research to pilot a model of mental health service user involvement in an Ethiopian rural primary healthcare setting: study protocol. Research Involvement and Engagement. 2020;6(1):1-14.*

### **Abstract**

**Background:** Little is known about actual involvement or how to achieve service user and caregiver in mental health systems strengthening in low-and middle-income countries. This study describes the processes and explores involvement experiences of participants in a pilot study of a new model of service user involvement in mental health system strengthening in a rural district in southern Ethiopia.

**Methods:** We applied a case study design using participatory action research (PAR). The PAR process comprised of three stages, each with iterative activities of plan, act, observe and reflect. Two stakeholder groups, a Research Advisory Group (RAG) and Research Participant Group (RPG), were established and collaborated in all stages of PAR. Data collection involved process documentation of meetings and activities: attendances, workshop minutes, discussion outputs, reflective notes, participatory observation of sessions, and in-depth interviews with 12 RPG

members. We analyzed the process data descriptively. Thematic analysis was used for qualitative data. Triangulation and synthesis of findings was carried out to develop the case study.

**Results:** The stakeholder groups identified their top research priorities, developed an intervention and action plan and made a public presentation of preliminary findings. Key mechanisms used for inclusive participation included capacity building and bringing together diverse stakeholders, anchoring the study in established strong community involvement structures, and making use of participatory strategies and activities during the PAR process. Our thematic analysis generated four themes about experiences of involvement in PAR: (i) expectations and motivation, (ii) experiences of the dynamics of the PAR process, (iii) perceived impacts of involvement in the PAR process, and (iv) implementation challenges and future directions.

**Conclusion:** This case study demonstrated the feasibility and acceptability of implementing a complex model of service-user involvement in mental health system strengthening in a resource constrained setting. More needs to be done to embed service-user involvement into routines of the primary healthcare system in relation to systemic support and strengthening multi-stakeholder collaboration at multiple levels.

Key terms: Theory of Change, Participatory action research, Ethiopia, service-user involvement

## 8.1. Background

In the Ethiopian mental health system, service-user involvement is a new concept, and is influenced by complex intersecting factors within and beyond the healthcare system, operating at the individual, healthcare organization, community and strategic levels. There is limited experience and awareness of how to address that complexity and achieve a workable model of involvement (179). To fill this gap, a generic Theory of Change (ToC) model for service-user involvement in mental health system strengthening has been developed (180). The model development process enhanced stakeholder buy-in and agreement upon the key components and interventions needed at the community, health organisation, service user and caregiver levels, as well as identifying preconditions, assumptions, indicators towards the long-term outcome, and stimulating stakeholder ownership (180). However, the model depicts service-user involvement in mental health system strengthening in a general way and leaves the potential focus areas (e.g.,

advocacy, service delivery, research, education) to be specified. The ToC also lacks an appropriate methodological approach to foster active and inclusive involvement of all stakeholders, especially to overcome power dynamics that typically exclude service-users onset(18, 294).

In order to address these gaps and provide a more inclusive participatory and contextually useful ToC, we choose to use a Participatory Action Research (PAR) approach as a heuristic to support implementation of the ToC as detailed elsewhere (125). This is in line with theory of action, which advocates for the need to insert action mechanisms into programs to activate ToCs (295). The iterative cyclical activities of PAR (plan, act, observe, and reflect) are promising strategies to facilitate learning about what, how and why change is unfolding (295). PAR offers possibilities for equitable active participation of diverse stakeholders, and has been recommended as a suitable approach to explore, understand, and provide solutions to emerging, complex, contextual issues, including system needs in public health(296, 297).

In this study, we describe the PAR process and explore participants' experiences of involvement in PAR as a case study to evaluate the pilot of a model of service-user involvement in mental health system strengthening in rural primary healthcare in southern Ethiopia.

## **8.2. Methods**

### **8.2.1. Setting**

Previously, we conducted formative qualitative exploration of the experiences, perceived barriers and facilitators to service-user involvement in mental health system strengthening (179) and a ToC was developed (180).The current study is part of the pilot implementation of the model.

This work was conducted in Sodo district of the Gurage Zone of the Southern Nations, Nationalities and Peoples' region, southern Ethiopia (See details in Section 4.3.1.3). This pilot was linked to the primary hospital, situated in Buie town. Service-users from eight primary healthcare clinics had been referred to the psychiatric nurse-led clinic at Buei for mental health care. The hospital was selected for pilot implementation together with local stakeholders considering accessibility (walking distance) and the higher service-user caseloads compared to primary health centers.

### 8.2.2. Design

The pilot implementation process was guided by a PAR approach situated in critical social theory; details of the theoretical background have been described in the study protocol (125), briefly described here. Given the identified gaps in the ToC (180), we devised ways to make the pilot implementation process theory-informed and to enhance collaborative working of diverse stakeholders. PAR was selected as a suitable approach, previously applied to this area and providing practical strategies for involvement of service-users in numerous domains of mental health systems (e.g., planning, research, service quality improvement, and advocacy) (125). Critical social theory-informed PAR, which positions PAR within a critical onto-epistemology (Critical Participatory Action Research; hereafter, CPAR), provides a theory-informed basis for the kinds of relationship that need to be developed among individuals, institutions and other key stakeholders in a particular initiative (125). CPAR acknowledges the marginalization of service-users and seeks to create a communicative space for ethical relationships. An approach such as CPAR is required to examine, expose and alter the unacknowledged social inequalities, structural and power injustices that are experienced by service users towards empowerment and partnership (125).

We used a qualitative case study approach to describe the process and to explore the experiences of participants in an ongoing pilot of service-user involvement in mental health system strengthening in rural Ethiopian primary healthcare (the unit of analysis for this study) (298, 299). Case studies can directly inform assessments of where, when, how and for whom interventions might be successfully implemented, and to consolidate learning on how interdependencies, emergence and unpredictability can be managed to achieve and sustain desired effects (298, 299). Moreover, a case study offers a flexible approach that enables holistic, in-depth, multiple perspectives to examine and understand a complex phenomenon within a natural setting from the perspective of those involved (298). A case study can offer considerable potential for strengthening faith in both external and internal validity (299). The study was undertaken between March 2018 and January 2020.

### 8.2.3. Participants

At the beginning of the PAR process, we established two stakeholder groups: a Research Advisory Group (RAG) and a Research Participant Group (RPG). The RAG played and could play several roles in during the study, including: (i) oversee and advise on priority problems for improving mental health care from their local community perspectives, (ii) provide a conduit between the Research Participant Group(RPG) and the community to ensure that the research findings are put into action and disseminated in their local context; (iii) create a strategy to enable an empowering environment(e.g., through resource mobilization) for service user involvement,(iv) facilitate further consultation and community involvement for service user mobilization and empowerment, and (v) advocate for the protections of rights of service users. Recruitment of members was using a purposive maximum-variation sampling strategy to ensure adequate representation from a broad range of stakeholders and most of RAG members were recruited from an existing PRIME Community Advisory Board (CAB) (160). The RPG participated throughout the research process in (i) identification and prioritization of priority problem areas, (ii) identification of specific areas of concern at the health facility level; development, implementation and evaluation of an action plan, and (iii) validation of the research process and local dissemination of the findings of the study.

Table12 presents a summary of the composition of the stakeholder groups; more details about inclusion criteria and roles of the stakeholder groups have been described previously (125). During the study period, the RAG and RPG met about four times.

**Table 12.Composition of stakeholder groups participated in study 5**

Composition Research Advisory Group	No	Composition of Research Participant Group	No
Health sector	5	Service users	6
Justice sector	3	Caregivers	4
District administration	2	Health professionals	2
Education	1		
Labor and social affairs	1		
Gender, youth and children affairs	1		

Community organizations(Religion, Idir)	2		
Volunteer activists	2		
Service users	5		
Caregivers	4		

#### 8.2.4. Data collection

We gathered data through various sources and methods, including process documentation, participatory observations and in-depth interviews (See Table13)

**Table 13. Summary of data collection methods of the study**

Methods of data collection	Description
Process documentation	<ul style="list-style-type: none"> <li>• Workshop participant attendance(n=3) and PAR sessions(n=11)</li> <li>• Workshop minutes(n=3) and audio-recordings(n=11)</li> <li>• Summary of prioritization exercise outputs, review of flipchart notes, and photographs</li> <li>• Facilitator reflection notes</li> </ul>
Participatory observation	<ul style="list-style-type: none"> <li>• Participatory observation of workshops (n=3) and PAR sessions (n=11). Data collection focused on: interaction between participants/group dynamics, role of participants, agenda items discussed</li> </ul>
In-depth interviews	<ul style="list-style-type: none"> <li>• Conducted face-to-face interview with 12 members of RPG to explore experiences of involvement in the PAR process using a topic guide.</li> <li>• Participants were fully informed about the study and gave informed written consent (finger print if non-literate)</li> <li>• All interviews were conducted by a single interviewer (female) with a master's degree, who had not been engaged in the research process</li> <li>• All interviews were audio-recorded</li> <li>• Interviews lasted between 23 and 49 minutes (with an average of 32minutes)</li> </ul>

#### 8.2.5. Data analysis

A descriptive analysis was used for the processes of the PAR, and thematic analysis for RPG experiences of involvement (See Table 14). The PAR data analysis process was ongoing throughout the study in an iterative process. PAR offers several methods and techniques (e.g. charts and diagrams), which function as a powerful mechanism to facilitate active engagement of

participants (e.g. in the case of literacy and/or numeracy challenges) in data generation, analysis and synthesis (300).

**Table 14. Summary of data analysis methods**

PAR process description	Experiences of involvement
<p>Data analysis was participatory that engaged participants:</p> <ul style="list-style-type: none"> <li>• Members of RPG and RAG identified, categorized and summarized top priorities using nominal group techniques (125)</li> <li>• Members of RPG generated long lists of data in small groups in a two-times per weekly PAR sessions using Venn diagrams and flipcharts</li> <li>• SA conducted preliminary thematic analysis of from meeting minutes, flipchart notes and facilitators reflective notes</li> <li>• Then shared with RPG by displaying on the wall to demystify the PAR process, enable collective sense-making of the data, encourage their active participation, ensure an accurate representation of their views and critically reflect on any gaps</li> <li>• Finally, the summary of the prioritization exercise and flipchart presentations at each session was triangulated with audio-recordings of sessions, minutes of the workshops and the SA's reflective notes; and presented descriptively for the three stages of PAR( See Figures 3-5)</li> </ul>	<p>RPG experience of involvement data was analyzed using inductive and deductive approach using six steps thematic analysis procedures described by Braun and Clarke (190)</p> <ul style="list-style-type: none"> <li>• All interviews were transcribed verbatim into Amharic by independent transcribers</li> <li>• SA checked transcripts for accuracy, and translated into English</li> <li>• De-identified transcripts were then uploaded to Opencode 4.03 software, to assist data management and analysis</li> <li>• SA and a colleague independently carried out initial coding of two randomly selected transcripts inductively</li> <li>• Following discussion and consensus about the coding, SA coded all the transcripts and collated the codes into sub-themes and themes</li> <li>• The coding trees developed from the in-depth interviews data were used to link the content and common elements from supporting datasets (field notes, workshop minutes and reflective notes, observation) through a deductive thematic analysis approach (190) using a process of describe-compare-relate (301).</li> </ul>

### 8.2.6. Rigour

To enhance trustworthiness of data, we used several strategies. Many scholars have reported challenges in ensuring rigour in PAR because of the diversity in approaches and types of PAR. PAR cannot ignore the traditional validity requirements (e.g., validity, reliability, trustworthiness), but these alone are inadequate to judge the quality of PAR because of its distinct ontological and epistemological stance (167). Within the cyclical collaborative decision-

making process in PAR, the participants drive processes that make the content of interventions unpredictable. Hence, the mainstream notions of fidelity need to be reframed to respond to the complexity, culturally situated, and constantly changing (emergent nature rather than predetermined intervention protocol) circumstances of PAR interventions (302). According to Trickett et al. three main factors pose challenges in using traditional fidelity conceptualizations in PAR: (i) the goal is not only scientific but also social action on local issues, (ii) engagement of various stakeholders/partners by itself is part of intervention, which affect both processes and outcomes, and (iii) goals include community level as well as individual level changes (303). In this study, we utilized quality criteria adopted from several studies which consisted of elements of qualitative study, case study and PAR approaches (167, 170). These quality criteria included: credibility, transferability, dependability, conformability, consistency/construct validity, outcome validity, process validity, democratic validity, dialogical validity, and catalytic validity (See methods section for details).

### **8.2.7. Reflexivity and positionality**

The co-authors have previous experiences of participatory research, are mental health researchers, and have multi-disciplinary backgrounds (psychiatry, psychology, sociology, and epidemiology), which facilitated critical reflection and contextualized interpretation of the data. AA facilitated the workshops and SA facilitated the field PAR activities.

Being aware of the obvious differences in position between participants and SA (coming from university, educated, and research experience), SA made a deliberate attempt to equalize power with participants through making participants aware that each of them had lived experiences and roles to play in knowledge production, SA used non-technical language so that all participants would understand the PAR process; encouraged participants to share experiences and express opinions non-judgmentally (positive or negative) and gave persistent affirmation to participants' ideas. As sessions progressed, participants were encouraged to take on more active roles, including leading the sessions, presenting findings, and facilitating workshops. SA acted as a mediator to create mutual understanding and agreement where consensus was absent and to create opportunities for critical dialogue among participants to enhance their understanding through questioning and help participants to challenge long-held myths about mental illness that tend to be sustained (304).

### 8.3. Results

The results are presented in two sections. In the first section, we describe the key activities involved in the three stages of PAR to pilot the model. In the second section, we present the analysis of the experiences of participants involved in the PAR process.

#### Description of the PAR process

The PAR process case description covers activities in the three stages of PAR, each with cyclical activities of plan, act, observe and reflect (See Appendix 7):i) Establishing partnership, capacity building, and prioritization exercise, ii) program development and action planning, iii) Implementation and process evaluation.

#### Stage 1: Establishing a partnership, capacity building and prioritization exercise (March-2018-August 2019)

During this first stage, we established the RPG and RAG. In our ToC, building capacity of stakeholders was a key intervention to facilitate involvement (180). Accordingly, prior to involvement and during the PAR process, the stakeholder groups were equipped and empowered through participatory training and consultative workshops. The trained service users and caregivers established a service user association with 24 members (12 service users and 12 caregivers), the first grassroots association in Ethiopia. We also convened three consultative workshops and capacity building sessions to create a receptive community environment, involving engagement with diverse stakeholder groups in addition to the RPG and RAG (n=47); See Table 15 for stakeholder characteristics. The objectives of the training courses, consultative workshops and activities are briefly summarized in Appendix 8. The stakeholders collaborated with the researchers throughout the PAR process and actively contributed to the success of the study as insiders, being members of the community (See figures 8-10).

**Table 15. Characteristics of stakeholders participated in study 5**

Types of Participants	Characteristics						
	Number of participants			Gender		Age range	Highest formal education
	Worksh op 1	Worksh op 2	Worksh op 3	Male	Female	18-29, 30-49, 50+	None, Primary,

							Secondary, Tertiary
Government sector office leaders	8	16	18	13	5	18-30(3), 30-49(13), 50+(2)	BSC/BA(11) , Diploma(6), MSC(1)
Community institution leaders(Idir leaders, Religious and faith-based)	6	-	3	7	-	50+(7)	Non-formal (4), BA (2), Diploma (1)
Health professionals	5	6	6	3	3	18-29(3),30-49(3)	Diploma(1), BSc(5)
Service-users	14	9	11	5	9	18-29(5), 30-49(5), 50+(4)	No literacy(4),N-formal one(3), primary(7)
Caregivers	14	6	8	7	7	18-29(3),30-49(9), 50+(2)	No literacy(7), None(1), primary(5), secondary(1)
Total	47	37	46	35			

To identify which specific aspect of mental health system strengthening was a priority for action, we convened a two day prioritization exercise with the stakeholders (n=37) using principles of PAR based on Nominal Group Techniques, as detailed elsewhere (300) and summarized in Figure 8. Participants identified their top ten concerns; which included multilevel lack of awareness about mental illness, and stigma and discrimination at the top of list (See Appendix 8).

Stages	Description
Brainstorming	<ul style="list-style-type: none"> <li>Stakeholders divided into homogenous groups: service user, caregivers, health professionals and organization leaders</li> <li>Each group generated (individually and then collated within group through discussion and consensus) a list of 10-12 priority topics</li> <li>In addition, SA distributed pre-generated lists of potential topic/problems to be considered for relevance by group members</li> <li>Each group presented in a plenary session and group discussion</li> </ul>
Theme development	<ul style="list-style-type: none"> <li>SA and a research assistant reduced the list to ten unique themes for voting and ranking through grouping ideas into categories and reducing redundancy.</li> <li>Themes, along with specific lists, presented to stakeholders, discussed, refined and consensus established.</li> </ul>
Mid/Interim Prioritization	<ul style="list-style-type: none"> <li>Themes distributed back to small stakeholder groups</li> <li>Within each theme, specific priority selected, collated within the group through discussion and consensus</li> <li>Group priorities identified through consensus, presented in a plenary session.</li> <li>Listed 10 priorities considered most important by all stakeholder</li> </ul>
Final voting and Ranking	<ul style="list-style-type: none"> <li>Participants prioritise areas using pre-set criteria: relevance, feasible and practically actionable with the local stakeholder capacity</li> <li>Priorities listed by group facilitator, open group discussion to allow participants to discuss, clarify, dispute and discard or add or modify a priority</li> <li>Presentation of final priority lists in a plenary session, grouping of priorities and whole group discussion to ensure that all participants understand and approve.</li> <li>Each participant provided with combined consensus priorities, individually and anonymously, to select and rank the five priorities in order of importance between 1 (lowest) and 5 (highest)</li> <li>Stakeholders reorganized into small groups for further ranking between 1 (lowest) and 10 (highest) of priorities</li> <li>Mean priority scores calculated</li> <li>Maximum possible ranking score for a given priority calculated by multiplying the number of participants who considered the priority by 10 (maximum rank)</li> </ul>

**Figure 8. Steps of Nominal Group Technique**

**STAGE 2. Programme development and Action planning, September -December 2019**

The purpose of this stage was to develop interventions and action plans based on the priorities identified in stage 1. Members of the RPG, SA and a research assistant worked together over

eleven biweekly sessions, each approximately two hours long, to explore the priorities in more depth, selected a priority, develop an intervention and action plan (See Figure 9).

Sessions and activities	Descriptions
Session 5. Setting background	<p>Re-introduced to each other</p> <p>Discussion about objectives of stage 2</p> <p>Brainstorming about expectations and motivation for involvement</p> <p>Collective decision on date, time, duration and place of meetings</p> <p>Setting ground rules</p>
Session 6. Review priorities, select focus and define problem	<p>Lack of awareness-raising about mental health selected as a priority because assumed to be foundational for addressing other priorities</p> <p>Brainstorming in small groups about how lack of awareness was expressed, explained and ways people view mental illness and people with mental health conditions; used Venn diagram to identify, classify and map out.</p>
Sessions 7. Design intervention strategies	<p>Small group brainstorming, discussion and plenary sessions to identify effective and sustainable strategies to increase public awareness about mental illness and role of service-user:</p> <p>Multi-level public awareness raising approach</p> <p>Strengthening multi-stakeholder partnership</p> <p>Empowering service user association to advocate for mental health and their rights</p>
Sessions 8. Map out available community resources and assets	<p>Small group brainstorming, mapping using Venn diagrams, plenary reflection, charting and categorization methods used to identify and map out local capabilities and resources: a range of services, available resources, social institutions, e.g. schools, religious and faith-based organizations, traditional associations (e.g. Idir-often funeral association, Iqub-traditional micro finance, Mahiber-religious based usually monthly gathering together)</p>
Session 9. Map out partners and target groups	<p>Discussed applicability of community level and government support for other health conditions (e.g. HIV/AIDS)</p> <p>Small group brainstorming, mapping of contribution/role analysis to inform the selection of stakeholders with high potential to have impact: community leaders, religious and faith leaders, justice (police, courts and judges), school directors, health professionals/managers, social organization leaders, service-users, caregivers, activists and volunteers, NGOs.</p>
Session 10-11. Reflective meeting and detail action planning	<p>Reflected and drew together previous discussions</p> <p>Decided next activities, including sustainability mechanisms</p> <p>Developed detailed action plan that included objectives/activities, resources required, actors/person responsible, and timeframe/timelines.</p> <p>Designed mechanisms of how to collaborate with stakeholders</p>

**Figure 9. Summary of stage 2 activities**

### **Stage 3. Implementation and process evaluation, December 2019-January 2020**

In stage3, the RPG conducted reflective and implementation strategy development sessions on how to apply the plan into doable action and reconvened a one-day consultative workshop (December 2019) with a broad range of stakeholders (See Table16, workshop 3). An overview of stage 3 PAR processes is summarized in Figure 10.

Activities	Descriptions
<p>Session12. Implementation planning</p>	<p>Reflected on stage 2 sessions Identified four immediate action areas: public dissemination of preliminary findings, awareness creation about mental illness amongst key stakeholders, service-user experience sharing and testimonies, and putting the way forward for collaborative working Developed plans for consultative workshop and implementation schedule</p>
<p>Session 13: Public dissemination of preliminary findings</p>	<p>Convened consultative and awareness-raising workshop Four members of RPG presented preliminary findings including highlights of ToC development, prioritization exercise and details of stage 2 activities and findings including action plans for ways forward Workshop facilitated by one caregiver member of RPG.</p>
<p>Session 14: Awareness creation about mental illness to key stakeholders</p>	<p>Implemented awareness-raising for stakeholder groups Content based on formative qualitative study, ToC and key areas identified by RPG: basics of mental illness (definitions, types, prevalence, risk factors, associated myths and facts), treatments (including plurality of treatment modalities), opportunities and challenges of alternative mental health treatment modalities, stigma and discrimination, roles of mental health service-users/association in mental health system, and health policy and future directions in Ethiopia. Workshop facilitated by senior psychiatrist (AA)</p>
<p>Session15: Service-users experience sharing and testimonies</p>	<p>Two executives of national level Mental Health User Association of Ethiopia (MUAE) shared their personal experiences about living with mental illness, treatments and sources of treatment , and also explained about the importance of service user association in mental health and their organization`s achievements. They also expressed their willingness to support grassroots service user associations. Executive from service user association of people living with HIV/AIDS from Sodo district shared experiences, mainly emphasizing the experience of community support in empowering service user association</p>
<p>Session 16: Putting the way forward for collaborative working</p>	<p>RPG convened discussion session for stakeholders to reflect on the presentation, and develop collective views on action plans for next steps. The stakeholders discussed, promised and took several practical actions (e.g. generated money, established community advisory boards) to: empower service user association and solve several barriers to involvement, including concerns about availability of medication.</p>

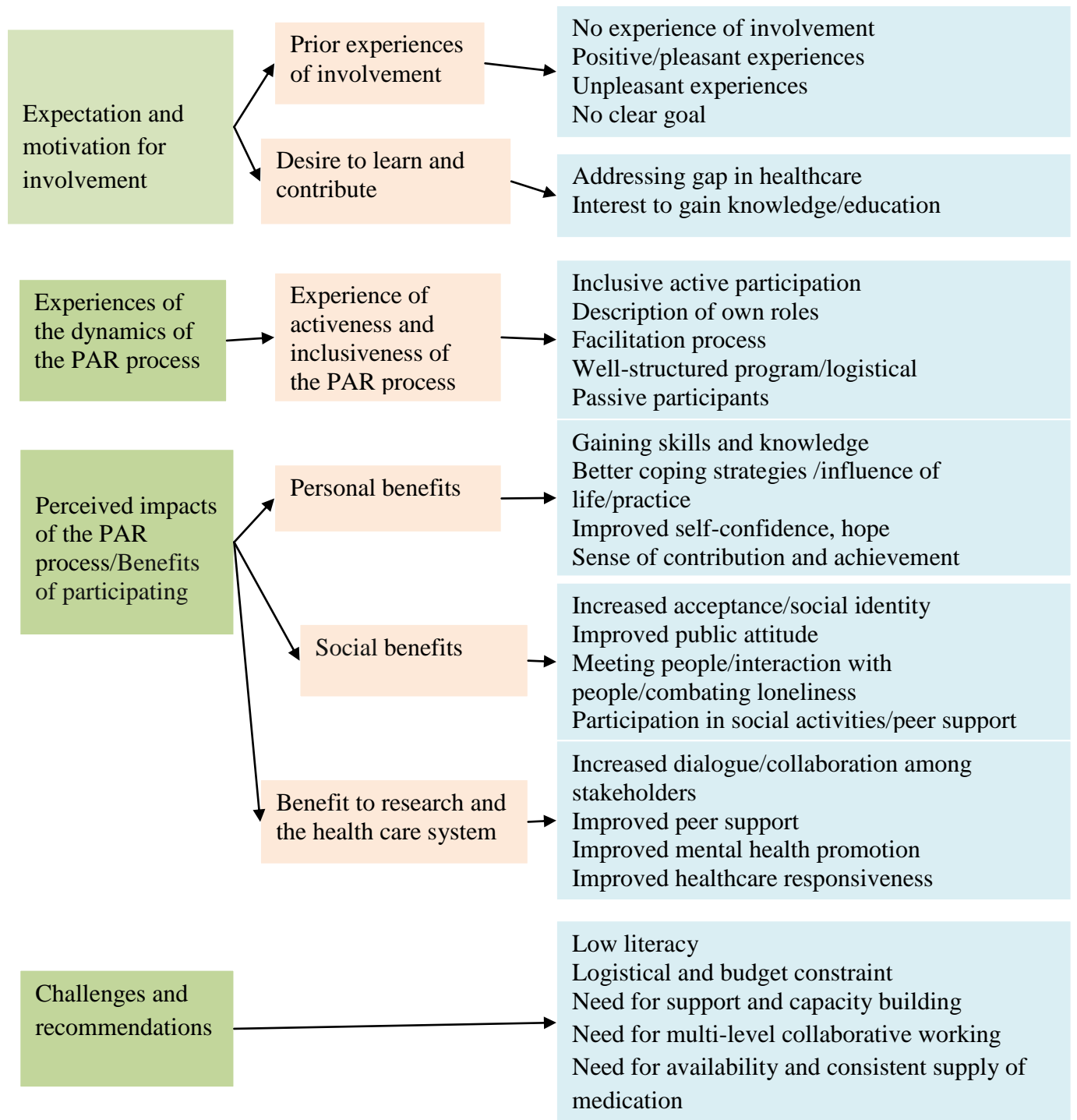
*Figure 10. Stage 3 activities*

## Experiences of involvement in PAR process

In this section, we present the findings of the case study about the experiences of members of RPG involved in the pilot model. All service-user participants had a confirmed diagnosis of psychosis/bipolar, epilepsy, or alcohol use disorder (See Table 16 for demographic characteristics). The thematic analysis resulted in four main themes, illustrated with sub-themes and key codes in Figure 11.

**Table 16. Demographic Characteristics of RPG members involved in the study**

Characteristics	Frequency
Gender	
Male	6
Female	6
Age range	
23-30	4
31-39	3
40-49	3
50+	2
Highest formal educational attained	
Non-literate	4
Primary school	4
Secondary school	1
University	3
<b>Diagnosis</b>	
Depression	1
Schizophrenia	2
Bipolar disorder	1
Alcohol user disorder	1
Epilepsy	1
Length living with mental health condition/service	
3-5	5
6-10	5
11+	2



**Figure 11. Thematic map of data analysis**

## **Participants' expectation and motivation for involvement**

The various reasons for participants' motivations and expectations were captured using two subthemes: prior experiences, and desire to learn and contribute.

### *Prior experiences of involvement*

Prior to this study, none of the participants had experiences of active involvement in research. Many of the participants mentioned their experiences of involvement in the capacity building training delivered to prepare them for the current role or the ToC model development/refinement processes leading to this study (P1, P2, P3, P5, P6) as a favorable experience that motivated them to join the current study.

*I have never been engaged ...except participation in interviews. I had experience of participation only related to this study...to Addis Ababa two times where I shared my experienced on large meeting at big hotel...When coming to this group I was expecting that they have planned to expand that more (previous capacity building training) ...I expected that they might have planned to organize service user more so as to achieve our goal... (P2)*

At the beginning, some participants had low motivation and were skeptical about value of being involved, which was explained in relation to lack of prior experiences of active involvement or unpleasant experiences of involvement. However, their motivation gradually improved after getting clarification about the objective, making sense of the relevance of the activities to improve their life and opportunities for active participation. For example, two participants described:

*...at the beginning I was not that much motivated and expected something good. I appeared only to sit and see what would happen ... I had some concerns in the previous training, which was too long (whole day), very intense and was a bit boring. ...[But] as sessions progressed, I realized that the PAR is actually doing about my own problems, we [the group] discussed and worked together something important for people with mental illness...Finally I said to myself "I should actively participate". (P1)*

*"I was expecting them (researchers) to ask me questions as they usual do. But this [work] was very different from the previous, we developed a roadmap, established user organization and*

*developed action plans. I am very happy. Totally different, I get what I did not expect; very interesting thing". (P6)*

### ***Desire to learn and contribute something valuable***

The common thread among many of the participants regarding their key motivation to get involved was wishing to gain more (personal or professional) knowledge and skills that could help them to address issues related to mental health conditions, help others, and address deficits within the healthcare system. Many of the participants expressed emphatically a desire to engage in advocacy and to improve multifaceted injustices, experienced by people with mental health conditions (e.g. stigma and discrimination, chaining). Particularly, some participants' motivation was rooted in their own painful lived experiences and observations of how badly people with mental health conditions have been treated at home, within healthcare systems and the community (P2, P3, P6, P7, P9).

*...I felt pain when observing many service-users suffering just like I used to. I felt a sort of like the same bad experience. I have been in the same situation for 10 years. Now thanks to God I have passed that bad stage. So I want to contribute. I want to make things better for those suffering with mental illness (P2).*

### **Experiences of the social dynamics in the PAR process**

This theme illustrates how participants experienced and described the active participation, inclusiveness, and respectfulness of the team atmosphere in the PAR process.

#### ***Experience of activeness and inclusiveness of the PAR process***

When asked about personal experiences of and others active participation, and inclusiveness of the PAR process, many participants narrated details of activities they had engaged during the training and ToC development process in previous years(P1, P3, P4, P6). Many of the participants described the process gradually progressed from passive participation at the earlier sessions to more active, and inclusive participatory process overtime as described in the following four accounts.

*“...In my group (caregivers), the participation of all individuals was not the same. But we used to let everyone to express idea to his/her level of understanding. Everybody contributed to his/her level of understanding. There was no situation where anyone was passive observer and other individual dominate the discussion...everyone contributed his/her opinion. That was how we used to run the group discussion”... (P1)*

Many of the participants appreciated the techniques used to enhance interactive involvement (e.g., small group discussion, reflection sessions) as well as the facilitation process to accommodate all viewpoints by encouraging all participants to share ideas, find solutions, freely interact with each other and make decisions during the PAR process. For example, participants described the process as follows:

*“The facilitator... ‘operated’ very well to bring all together and discussed in a way that made all open to discuss idea. So my feelings were generally very positive about it [group technique]. I used to anticipate the next session eagerly”.*(P3)

*“I appreciated... used to encourage high level of involvement of all participants in the PAR process... accommodated everyone to have chance to express opinion. I think everybody got a time to reflect opinions. That is one of the reasons I committed and stay engaged in the PAR process”.* (P5).

Many participants spoke about the logistical practicalities, including the convenience of the time and place of the PAR sessions, and financial compensation for their time (P1, P2, P10, P3, P11) as key factors for their active participation.

*“... We utilized our time efficiently; because we come on time, engage in the discussion effectively and complete on time...because we scheduled it [the meetings]during public holidays (out of our working time). We used to meet two days per week for two to three hours, which was very easy contribution of time”.* (P1).

The experience of active inclusiveness of the PAR process was not homogeneously reported by all participants. For example, one participant noted that: *“there was one participant who did not say anything”* P3, and expressed concern that potentially articulate participants were not recruited. Some participants expressed some challenges encountered in group activities that involved writing and reading because of their low literacy (P2, P6, P7, P10). However, they

appreciated the oral reflection and use of various techniques that helped them to get adequately involved.

*...our involvement is very active...although that was challenging to me when that required doing it in writing...although we cannot write we effectively contributed in the discussion and generating ideas (P7).*

### **Perceived outcomes/benefits of the PAR process**

Linked to their involvement in the PAR process, the participants described experiences of positive outcomes/benefits at personal, social, research and healthcare service levels.

#### ***Personal benefits***

All the participants made positive comments and reported personally gaining from being part of the PAR process in terms of improved knowledge and skills, self-confidence, health, and feeling of achievement and contribution.

Almost all participants spoke of gaining knowledge about mental illness, treatment, and about managing mental illness during PAR sessions from each other, and education delivered by professionals. Some participants particularly appreciated the discussions with RPG members outside of the clinical context. The value of critical reflection instilled into the PAR process enabled them to uncover issues which had received inadequate attention and gain a deeper understanding of service users` expectations, unmet needs and the gaps in the healthcare service and their own gaps (e.g. inadequacy of information about medication use, lack of focus on physical health).

*“There was a lot of education in the group...we discussed ideas, freely exchanged ideas in small groups. We exchanged education from the facilitators and our presentations...The education works for service users... We can identify people chained at home through education....I got additional knowledge.... Now I can teach my neighbors during coffee ceremony and at work place. I advised them to go to healthcare service and take medicine and medicine can help for recovery. Now I am teaching how to safely use medicine”. (P10).*

Some participants spoke about improved communication skills (writing and public speaking) through the writing and reflection during the group sessions, public dissemination and public

speaking, and developing research skills that could be immediately applied in their daily lives or professional development.

*The PAR process taught me a lot. First, I noticed that I can generate useful ideas from beginning to the end of all sessions; there were several thought provoking ideas discussed during the research process that creates 'Ha!' here am correct and I have created sense of being of value. Second, I have gained knowledge about how to develop action plan; how to start planning, with whom to work, about sources of support...HA! ... This is not only for the study, but it is very important for personal life. I have learned how to live planned in my personal life. (P3)*

Some participants described health related benefits such as improvements in their mental health or healthcare habits/coping mechanisms, and improved social life. For example, some participants reported increased medication adherence and visiting healthcare service more often (P2, P9), reducing (P1, P9) or totally stopping (P4) alcohol consumption, observed others stopped drinking alcohol while taking medication (P1), improved self-and others care (P2,P7, P10), reduced family (P4) or neighbors disturbance (P7). Some participants mentioned that participation in PAR process offered them a platform to exchange experiences with people who have similar mental health conditions, which helped them in terms of reduced feelings of depressed, worries or anxiety (P2,P6), combating loneliness (P6,P7, P8,P9), improved satisfaction with life and hope (P2, P6,P7, P9), being able to comfortably talk about mental illness (P2,P6, P9).

*I have developed the confidence to take medication without fear of side effects. I am taking advice from health professionals about all side effects...I have great improvement after getting this experience in many aspects of my life. I have improvement. I am happy. I have hope. Thanks to God now I am health. I have recovered in health... I am relaxed... Thanks to God...I have passed that difficult/crisis time, that dark time; now I am in light... (P2).*

The participants reported that involvement in the PAR processes positively influenced them in terms of improved self-confidence, which was evident in some participant comments about the personal changes in their capacity to communicate in situations outside of the group sessions:

*...That helped her very much. She had no training before and lacked knowledge; after the training and involvement in the research she gets improved much more. For example, before she*

*did not speak more in public, now she started expressing herself very well in group discussion; ... I saw her asking and speaking in social association(Idir)....during coffee ceremony at home and neighborhoods she started teaching about the causes and problems of mental illness. ... (P1)*

All participants reported that the PAR process was a valuable investment of their time working together to address issues of relevance to themselves and that directly impacted on mental health service improvement. The participants mentioned the action plan developed to raise public awareness, the establishment of service user association, and to empower the association as their valuable contribution, which they expressed as sense of achievement, contribution, and agency:

*“...We become united... because of the participation in the research group we have got freedom, now we are organized as service user association...we started saving money in bank...we started saving that can strengthen our relationship. I am very happy”. (P2)*

*“...One of the hopeful gains is the established service user association. More than what we put in our stomach (eat) and pocket, better to support this hopeful organization. We are expecting the licensing of the service user association”. (P7)*

### ***Social benefits***

The participants mentioned the opportunity to meet other people, combating loneliness and engagement in important activities and improved social acceptance as key social benefits of their involvement in the PAR process. Some participants expressed their experiences of living alone or having very limited opportunity to get out of home to interact with other people outside of their family circles (P2, P7, P8,P9). Some placed high value on spending time together and the positive experiences of the informal interaction and laughing(energizer in-between sessions), sharing ideas and experiences during the PAR sessions. Some participants explained the value of the PAR process looking back to the painful experiences of feeling ignored by people who were close acquaintances, including family members.

*“...I consider participation in this group as my rebirth. This is the chance I missed in my entire life. ... I have been a person discriminated and neglected for a life time...Now other people started appreciating the improvements observed in myself; they are saying to me “you are really getting young”. They say “she becomes new person... improved” talking at my back. When I hear this, I feel deep satisfaction... I keep my hygiene, dress very well and enjoy with my*

*children. I dress my hair well and just I am free. Thanks to God...This is new beginning of my life...” (P2)*

*“...This helped me to improve my relation and communication with people; the value people give has improved. This makes me happy... I developed skills of participation with people, sitting with others and working with others. I used to pass time locked up at home; passing time here is very interesting. This is leisure time and recreational...there was no such opportunity...this helped me not to remain hidden or neglected. Here I have freedom to share my ideas. I have nice times here...” (P8)*

Some participants (P2, P3, P4,P6, P7) spoke about social acceptance and improvement in public attitude towards them.

*“...I have received feedback from different people. I have presented the finding of the research to representatives of different community and government offices. Our findings touch every sector, gender office, health office, psychiatry and others. People appreciated my presentation and commented that I was unnecessarily quiet for too long. There were good things”. (P3)*

### ***Benefit to research and the health care system***

When asked about what their involvement in PAR benefit or potentially contribute to the healthcare improvement, the participants mentioned many examples of activities during and after the PAR process that could improve mental health services. For example, some participates reported volunteering in various activities, including support to people with mental health conditions(peer support), e.g., finding cases and supporting them to access healthcare (P1,P2, P7), and giving education and advice (P1,P3,P7,P10).

*“...In addition to the lesson I get here, I shared a lot from my lived experience to change and motivate people to take their medication properly. In my neighborhood I have supported many people to take medication properly and told them that they could recover through proper use of medicine. Even if the patients resist taking the medicine, caregivers need to help with the medication [of a family member] through negotiation. For many people, I personally, gave education. I have tried all my best”. (P10)*

When asked about any improvements in the hospital or healthcare centers after their involvement in the PAR process, some participants who had chances to visit the health facilities expressed their observation in improved receptiveness and healthcare service delivery.

*“...We have clearly discussed with health professionals about their problem in patient care, receptiveness, medication availability and ...we discussed many issues. After I got involved in the research I had visits to the hospital for another individual and for my child, and I noticed that they are doing well...There is some improvement that can be appreciated”. (P6)*

The health professional participants also spoke about readiness to apply the knowledge and skills they gained from the PAR process to improve the healthcare service delivery (e.g., the way they diagnose and treat patients, provision of sufficient information).

*“...Before involvement in the research, health professionals had self-distancing or pushing behavior towards mental health service users. We (health professionals) used to say the psychiatric nurse`s (...named) people came (mental service users)... consider only the psychiatric nurse in charge of the mental health service. More recently we are working with him at the psychiatric unit. This collaborative work needs to be strengthened”. (P5)*

Some participants (P1, P3, P5) mentioned that the increased involvement and collaboration of the diverse local stakeholders’, political officials’ willingness to undertake empowering actions for service-user involvement, and promises to solve problem of availability of medication could be an important initiative towards improving the mental health service.

*“... If we are able to work sustainably with these stakeholders including religious institutions, schools teachers and students we can bring change. The community stakeholders who participated in the workshop can support and build capacity. The hospital management body, including the medical director and CEO participated in the final stakeholder consultative meeting and discussion on research participant group findings’ dissemination. They have agreed to integrate the research participant group in the health education mainstream routine of the hospital”. (P5)*

*“...There is some change; now a roadmap has been developed with stakeholders. A range of stakeholders that included religious leaders, education sectors, community associations (Idir), health professionals and all others received some training. Now, there is good beginning. (P1)*

## **Implementation challenges and recommendations**

When asked about challenges experienced during the PAR process, most participants gave neutral responses, e.g. ‘no problem ‘or ‘everything is ok, or no need for modification’ and only few participants (P1, P3, P5, P6, P7) made comments about ways to improve the study, which focused on the need to cover wider healthcare areas and involve more participants, and enhance support for service user association at follow up.

However, when asked about what support they would need for strengthening service-user involvement, the participants mentioned various logistics, funding, systemic and organizational constraints to be resolved. As an immediate challenge, the participants mentioned logistical problem (meeting places/office). The participants also stated the need for financial support to cover engagement related costs, including time compensation and transport costs for members who could be involved in next PAR activities; need for more capacity building and training materials for community awareness-raising to pursue their next action plans.

All participants had deep concern regarding the long time taken by district officials to reach decision in licensing/registration of service user association. Some participants also noted that mental healthcare was not effectively integrated within the healthcare/hospital settings, where there are general health workers trained in first line mental health care.

*“I repeatedly visited the relevant administration office in the district to facilitate the registration of the association. But it is still challenging and took a lot of time for them [administrators] to respond and endorse the registration of the service user association. There was little practical support and I have completely giving up hope. I find that they are not moving as they promised during the workshop”. (P4)*

*“There is a tendency to push the healthcare service for people with mental health conditions to the psychiatric nurse alone. There are trained professionals in mhGAP, but are not appointed to the psychiatric service unit...the system has been working as it was for years... (P5).*

The participants (P1, P4, P6, P7) suggested for expanding the scope of the study, more collaborative working at different levels within the healthcare system, enhance stakeholder

collaboration, community mobilization and addressing mental health medication problems to support the initiative sustainably.

*“The current study was a bit narrow. First, it seems it had limited budget to involve more people over longer time. This is one important area that needs improvement. Secondly, the political leader should make mental illness a mainstream routine activity. Unless mental illness was supported with political leaders and government, this research group alone with external assistance... may not last long ...and be able to bring sustainable change...Government has to put their hand in this initiative... Therefore, as ownership to these initiatives our local government needs to give attention, allocate budget, take it as mainstream agenda, otherwise I do not think this would be sustainable...the involvement of political leaders in this initiative need to improve”...(P1)*

## **8.4. Discussion**

In this study, we described the process and experiences of involvement in a pilot model of service-user involvement using PAR in rural Ethiopia. This study is one of only a few empirical studies of service-user involvement in mental health systems in LMICs. PAR was a promising approach to achieving equitable and diverse stakeholder involvement, establishing a partnership, and recognizing the value of service-user contributions. The findings highlighted the importance of multiple consultative meetings, building capacity and collaborative working with diverse stakeholders in empowering service-user involvement. Participants valued the process of PAR and identified a range of benefits, particularly feeling equipped with knowledge and included within society. This study identified some structural challenges to embedding service-user involvement in the mental health system in Ethiopia.

### **Creating an inclusive participatory space**

The pilot process created a communicative space—a platform in time and space where diverse stakeholder groups could come together and enter into constructive dialogue to share, understand and change key points of common concern to them (125, 305). We employed various strategies to create the communicative space. First, our study was built on existing community strengths, collaborative working experiences, and infrastructure, which was evidenced by diverse stakeholder involvement experiences during our formative studies (179, 180) and studies in

relation to the PRIME project (160). In line with existing evidence, building on pre-existing conditions provided valuable opportunities to build trust and optimize engagement (306).

Second, in line with our proposed key interventions during ToC, towards strengthening service-user involvement through community collaborative engagement (125, 180), we set up two multi-stakeholder groups (RPG and RAG), conducted capacity building through training and workshops to enhance formal community participation, collaborative structures, and equip them for active partnership. Existing evidence supports the importance of capacity building for key stakeholders, forming trusting relationships and alliances with them as a key mechanism for active involvement, challenging the barriers that marginalize service-user involvement, and promoting shared understanding of service-user engagement activities (12, 37, 306, 307).

Third, our findings show that application of participatory techniques, e.g. small group discussions and critical reflection, and prioritization exercises can enhance creation of an active inclusive participatory space. These techniques can provide all stakeholders equitable opportunities, uniquely provide opportunities for those marginalized (in our case service-users) as equals to voice their views, and reduce risk of tokenism (20). Particularly the critical aspect of PAR enabled us to prompt a variety of direct and indirect questions to initiate critical dialogue among stakeholder groups, clarify key gaps in the health system and set out priorities for action. For example, the stakeholders were openly critical of the healthcare system for failings related to mental health care (e.g. inconsistent supply/lack of psychotropic drugs, low budget, and lack of trained mental health professionals). This finding accords with several PAR studies that advocate to provoke participants to surface their values, beliefs, and purposefully employ strategies to interrupt and challenge social, cultural and political structures and practices, which marginalize service-users roles, which results in new forms of relationships and more informed ways to deal with problems (20, 305).

### **PAR process outcomes**

Our findings indicated examples of the added value of PAR towards intermediate outcomes that were articulated within the ToC model (180), including enhanced inclusive participation, improved stakeholder collaboration, a range of personal and social benefits for RPG and lessons

that could help to refine the ToC model to increase impact. Specific examples of these outcomes in our study are discussed here.

Our findings show that the active involvement of diverse stakeholder groups in PAR enhanced willingness to work in collaboration, commitment to mobilize resources and prompted several course of actions to overcome some challenges to service-user involvement using their local capacities e.g. started financial contributions, promised to create mechanisms that help to generate income, established community advisory committee to support the service user association movements in awareness creation, advocacy and lobbying for resource mobilization. Our finding also shows the feasibility and acceptability of what has been considered imperative and anticipated early during our ToC development about the need to establish multi-stakeholder response and collaborative working as crucial contact points for increasing service-user involvement (180).

The participants (RPG) described numerous personal benefits from being involved in the PAR process, including experience to gain knowledge and skills that helped them to take action to improve their living conditions and situation at home/work, improved confidence and more positive sense of self, improved communication skills (public speaking). Many of them also mentioned experiences of social benefits in terms of space for collaborative meeting and working with others, building friendship and trusting relationships. These experiences and benefits were in line with what have been expected as short and medium term outcomes in our ToC model (180). Evidence form small scale, largely retrospective accounts of engagement in PAR studies, predominantly in high-income countries, found similar multi-dimensional impacts of involvement in PAR, e.g. meaningful social support, sense of empowerment because of the critical dialogue and reflection in PAR process that improves critical consciousness about sources of oppression and capabilities to deal with a problem that is identified by the participants themselves (20, 86). The service-user participants also reported experiences of improved public acceptance, attitude and engagement in social activities in their local community. This is in line with the evidence showing that close, targeted, and continuous positive social contact between service-users, health professional and other key health system stakeholder are effective strategies to foster mutual understanding, social inclusion and reduce stigmatizing attitudes (43, 270).

Another important outcome of this study is establishment of service user association in Sodo district for the first time. The need to organize and empower the association has been a priority in the study area (179), and was also one of key intermediate outcome expected in the ToC model (180). Evidence show that service user associations can provide a variety of services to healthcare system improvement, which included education and advocacy for raising the public health priority of mental health (37), pooling of funds for medication, peer support, social inclusion, promote recovery and personal agency, and promote the protection of service-users rights (38, 308).

The application of the PAR approach contributed to the pilot implementation of ToC in many ways. First, the PAR approach created opportunity for inclusive active involvement and collaboration of diverse stakeholder groups expected as intermediate outcome in our ToC (180). Second, in line with previous studies, the prioritization exercise ensured a shared understanding of local priorities and target areas that has the greatest potential benefits to local context (309) as well as enabled us to specify the mental health system component in the generic ToC (180). In the same vein, the PAR process showed the availability and the importance of tapping the rich community resources and assets such as social institutions, e.g. religious and faith-based organizations and schools as key partners in awareness-raising and improvement of mental health service. Evidence in our study setting (163, 310) and many LMICs show the abundant availability and considerable (79%) population (service-users) rely on traditional and religious/faith-based healers as their pathways to mental healthcare (311). This is in line with the strength-based principle of PAR (312), which emphasis the need to work and bring together multiple perspectives, resources, skills, shared leadership to address intersecting factors(e.g. social, environmental, economic, political) greater emphasis on institutional/political and social responsibilities for removing barriers to disadvantaged groups to use their capabilities and address social injustices (313).

Third, our study also showed that the micro- and meso-levels interventions alone were not enough to implement service-user involvement at primary healthcare system, rather intervention pathways need to extend to strategic level so that the model could take into account involvement challenges at strategic level (see next section). Scholars in the area also recommended the need to include broader focus on ToC, even if problems are systemic and distal (e.g., poverty, social

inequality) in nature, because doing so is helpful for promoting recognition of the multi-factorial nature of social or health needs and to recognize the intervention in its systemic context and to see it as one part of wider picture of impetus for change (294, 314, 315).

### **Challenges to embed service-user involvement in primary healthcare**

Our findings show key structural issues that demand attention for service-user involvement to become a routine, normalized way of working in the primary mental healthcare system. Many of these barriers fall somewhat outside the scope of the current study, but negatively affected our attempt to legitimately embed service-user involvement. Some of the key barriers that need future attention are discussed here. The service user association reported logistical (e.g. meeting place/office) and financial constraints in moving towards collective action. Some of these challenges could be addressed with available resources and drawing on the readiness of the local stakeholders, but putting this into action is still in its infancy and needs more follow up and support for resource mobilization. These challenges have been well documented in the literature as key factors that need to be addressed for effective implementation of service-user involvement (11, 12).

Our study was conducted in a context with intersecting health system challenges such as budget limitations, inconsistent supply of medication, low socio-economic status of service-user (e.g., unemployment, poverty, low education), and pervasive stigma and discrimination (34, 162). More importantly, there is no national regulatory mechanism to enforce planners and healthcare workers to involve service-users in mental health system strengthening in Ethiopia and involvement has not been explicitly stated in strategic health policy documents (179). There is no officially approved mental health legislation (155), which is an important mechanism for protection of human rights of the disadvantaged, marginalized, and vulnerable peoples, ensure appropriate, adequate, timely, and humane health-care services (31). These deficits had negative impact on efforts to embed service-user involvement at primary healthcare level. In our case for example, while the district officials were of interest to empower service user association, actively involved and facilitated the PAR process; later we noticed that they tend to be challenged in the formalization of the association. Effective integration of service-user involvement in mental health system demands creating national structures (e.g. policy contexts), cultures (governance

and organization context) and practices, as well as local level structures to ensure accountability (12, 316).

We believe that mobilizing and empowering service user associations at grassroots to advocate for themselves can create social movements that compel strategic level decision-makers to acknowledge the reality of service-users and achieve structural changes( e.g. influence policies) and protect the rights of service-users (38, 317). In addition, a holistic approach to service-user involvement in line with rights-based approach that emphasizes redressing the unfair distribution of power, economic, social, and cultural rights, discriminatory practices that hinder service-users realization of rights is needed (8).

## **8.5. Strengths and limitations**

Our study adds to the growing need and is one of only a few studies that applied actual inclusive participatory approach to involve local stakeholders with diverse experiences/expertise in all levels of PAR to implement complex model of service-user within primary healthcare setting in LMICs. This active involvement of stakeholders at all stages of the study increases the authenticity and trustworthiness of the findings. In addition, our study drew on multiple methods and sources of data that provided greater depth to capture comprehensive accounts of the processes and experiences of involvement. The prospective nature of the study enabled to include observational data on the implementation process is key strength, which is an important part of case study (318). The researcher(s) prolonged involvement with stakeholders allowed the participants to be more open and honest that can make the accounts more reflective of their true feelings towards their participation.

However, the findings of this study need to be interpreted within the context of its limitations. Influence of power dynamics on service-user involvement was observed to be a challenge. We tried to minimize this by including proportional or majority of service-users in all collective meetings. The facilitation process was conducted in a way that service-users would feel comfortable in expressing their views. It was very difficult to involve the participants in interview data analysis, due to the participants being either illiterate or having low literacy. Due to time and resource constraints, our study did not include more strategic level stakeholders that

might have been able to create enabling environment to service-user involvement integration in mental health system. This study was small scale based on a single case study with no comparative case or control group thus limiting representativeness of all experiences of service-user involvement or generalization that can be made from it in Ethiopia. Hence, a study of wider scope might be needed that could enrich future service-user involvement models. However, we believe that our findings can provide valuable insights to build a comparable database and about what is needed to support successful collaborative working with stakeholders into service-user involvement in primary healthcare mental health system strengthening in rural Ethiopia.

PAR needs time, however, we were constrained to a short implementation time that limited our ability to achieve implementation of action plans. Hence, the findings need to be considered preliminary; we recommend additional follow-up commitment to take action on the priorities identified. Further refinement of the model with broader evidence synthesis and testing in wider contexts would ensure usefulness of the model to replicate in wider areas.

## **8.6. Conclusion**

Our case study shows that the application of the PAR approach can offer a useful, feasible, and acceptable mechanism to implement a complex model of service-user involvement in resource constrained setting. Building trusting relationships with community stakeholders, the willingness of leaders, and existing structures and community networks were crucial for the success of this study. Given the multilevel discrimination and stigma against people with mental health conditions, we believed that a further critical dialogue is needed to challenge the status quo and achieve action at higher policy levels to further enable the involvement of people with lived experiences within the mental health system.

## **Chapter 9: General discussion, implications and conclusions**

This thesis is comprised of published (Papers 1, 2 and 4) and ready to be published (Papers 3 & 5) journal articles. In the previous chapters, I have detailed the major findings of each sub-study independently. In this concluding chapter, I provide an integrated interpretation of the findings of the sub-studies. In the first section, I give a summary of the main findings of the preceding chapters in relation to the objectives and research questions (Section 9.1). Then, I present a discussion of overarching factors about service user and caregiver involvement in the context of mental health system strengthening and relevant literature (Section 9.2). Following this, the strengths and limitations will be addressed (Section 9.3). Then, implications and recommendations relating to policy, theory, practice and future research directions will be presented (Section 9.4). The chapter ends with overall conclusions (Section 9.5).

### **9.1. Summary of main findings**

The main aim of the thesis was to develop, pilot and evaluate a model of service user and caregiver involvement in mental health system strengthening in Ethiopia. The specific objectives of the study were to:

1. explore the experiences, perceived barriers and facilitators regarding service user and caregiver involvement in mental health system strengthening (paper 1).
2. develop an acceptable, sustainable and feasible Theory of Change model of service user and caregiver involvement in the expanding mental health system (Paper 2).
3. equip service users and health professionals for greater involvement in mental health system strengthening (Paper 3).
4. pilot the feasibility and acceptability of a co-developed model of service user and caregiver involvement in mental health system strengthening (Papers 4 and 5).

#### ***9.1.1. Objective 1. To explore experiences, barriers, facilitators and capacity building needs for greater involvement in mental health system strengthening (Paper 1)***

In Paper 1, we aimed to answer the research question:

*What are the experiences, perceived barriers, facilitators, and capacity building needs for greater service user and caregiver involvement in mental health system strengthening?*

In response to this question, we conducted a formative qualitative study, which involved thirty nine multilevel key stakeholders. The findings show that service user and caregiver involvement is a new concept. Service users and caregivers had little experience of direct involvement in different activities relating to the mental health system; rather they were more commonly involved in research through responding to interviews or filling questionnaire. The findings of the study illustrated the complexities and multifaceted nature of service user and caregiver involvement, which is shaped by multiple and multilevel interacting factors (service user and caregiver, health organisation, society and strategic).The participants reported various unmet capacity building needs for greater involvement in mental health system strengthening. This study highlighted the essential capacity building strategies needed to support greater service user and caregiver involvement, including enabling community structures and drawing on available community experience, promoting mental health advocacy, and mobilizing and empowering service user and caregiver groups. This study helped to inform the development of the ToC model and the empowerment intervention detailed in the subsequent sub-studies. Moreover, we presented the findings of this study to key community stakeholders, which stimulated discussions about the value of service user and caregiver involvement in the study setting.

***9.1.2. Objective 2: To develop an acceptable, sustainable and feasible Theory of Change model of service user and caregiver involvement in the expanding mental health system***

Paper 2 brings the focus on the development of the ToC change model to guide the initiative for the actual involvement of service users and caregivers in mental health system strengthening, which aimed to answer the question:

*Using participatory planning, what is the theory of change model for how service users and caregivers can be involved in mental health system strengthening in rural Ethiopia?*

The process of ToC model development was informed by the findings of Paper 1 and involved a series of iterative ToC workshops with key stakeholders that produced a ToC map to support service user and caregiver involvement in mental health system strengthening in an Ethiopian primary healthcare setting. This study involved diverse representations of key stakeholders including service users, caregivers, researchers and other community groups in the co-production of the ToC model. The ToC describes service user and caregiver involvement as a complex

intervention and make explicit the contextual factors, components of interventions, intermediate and long-term outcomes, assumptions and indicators of success. The ToC development process also identified new problems to be addressed, including lack of inclusiveness and meaningful involvement of service users and caregivers in equitable ways, which led to further development of mechanisms to make the involvement process active and interactive as reported in Paper 4.

***9.1.3. Objective 3: To equip service users, caregivers and health professionals for greater involvement in mental health system strengthening***

In Paper 3, we intended to answer the question:

*How can service users, caregivers and health professionals be equipped to engage in processes leading towards greater involvement in mental health system functioning?*

Based on the capacity building needs identified (Paper 1/chapter5) and as a component of the ToC intervention to support greater service user and caregiver involvement in mental health system strengthening (Paper 2/chapter 6), an empowerment training programme was developed and empirically tested to equip service users, caregivers and health professionals for their roles. In Paper3, we have described the development, delivery and evaluation of the feasibility, acceptability, and preliminary outcomes of a participatory training programme. The findings show that there was high participant enrolment, completion, response to assessments, and few challenges or discomforts during the training process. The training program content, delivery process, standard, and relevance were well received. The participants recommended continuing and expanding the training program to reach many people. The training had positive impacts, including improved understanding of issues related to service user involvement, mental illness, increased confidence, social impacts and perceived therapeutic benefits. Our program showed that training service users and health professionals for greater involvement in mental health system strengthening is feasible, acceptable, and can have several benefits at small scale in rural Ethiopia.

***9.1.4. Objective 4: To pilot the feasibility and acceptability of a co-developed model of service user and caregiver involvement in mental health system strengthening.***

In Papers 4 &5, the following basic research question was addressed:

*What is the feasibility and acceptability of a pilot model of service user and caregiver involvement nested within primary care based mental health services in a rural district?*

As part of implementation of the ToC model and participatory evaluation of the process, I developed a protocol about the utility of the PAR approach to pilot the ToC model (Paper 3). Utilizing the PAR principles in three stages, the ToC model was piloted in a rural Ethiopian primary healthcare setting. Key stakeholders, including service users, caregivers, health professionals, and key community stakeholders were involved, identified problems, and prioritised and generated solutions based on their contextual realities and experiences. Then, a case study of the piloting process and participants' experiences of being involved in the PAR was conducted (Paper 5/chapter 8). The results show that service user and caregiver involvement in mental health system strengthening is feasible, acceptable and can have several perceived impacts. The PAR approach was promising to achieve equitable and diverse stakeholder involvement, establishing a partnership, and recognizing the value of service-user contributions. The findings highlighted the importance of multiple consultative meetings, building capacity and collaborative working with diverse stakeholders in empowering service-user involvement. Participants valued the process of PAR and identified a range of benefits, particularly feeling equipped with knowledge and included within society. But more work is needed in order to overcome structural barriers and embed service user and caregiver involvement into the formal routine of the primary healthcare system. The study also identified a number of potential factors that would enable the successful implementation of service user and caregiver involvement. The facilitators include establishing collaborative working relationships with stakeholders, supporting community structures, supporting involvement with resources, increasing people's awareness about the value of service user and caregiver involvement, and encouraging service users and caregivers to advocate for their rights.

## **9.2. General discussion**

In this section, I bring together the overarching findings from the sub-studies and discuss the implications in relation to relevant involvement literature. The sub-studies discussed multiple and multilevel factors that affect involvement, and strategies for meaningful involvement, including development of an involvement model, creating enabling conditions through

institutional and community support, empowerment and capacity building for key stakeholders at multi-system level.

### **9.2.1. Factors that affect service user and caregiver involvement in mental health system strengthening**

The findings of this thesis show that multiple and multilevel factors (barriers and facilitators) operating at structural/strategic, health organisation and health professional, community and individual levels affect involvement of service users and caregivers in mental health system strengthening. Many studies have previously reported similar factors that influence service user and caregiver involvement at multiple levels across the health system (2, 12, 19, 319). These studies show that involvement at a mental health systems level can be hampered by many factors, including lack of prioritisation of mental health, access to mental health services, policy and legislation, resources, representation and empowerment of service users. In this thesis, stigma and discrimination (structural, health professional, community and self-stigma) were pervasive contributors to the exclusion and disempowerment of service users and caregivers from involvement. Several previous studies have reported stigma and discrimination as major barriers that limit participation, reduce access to health care, lead to social exclusion, restrict civic rights such as education and employment, result in unequal access to resources, and lead to impaired quality of life (109, 202, 203).

In Ethiopia, there is a lack of explicit organizational and policy support; and the strategic health policy documents do not include provisions articulating how mental health service users and caregivers need to be involved at the mental health system level (46, 149). In addition, there is no separate national human rights review body with authority to oversee mental health facilities and to ensure service user rights; there is also no legislation to protect persons with mental health conditions against discrimination (155). This is contrary to many high-income countries where service user and caregiver involvement is embedded within their mental health and social care systems with systemic enabling conditions (e.g., policy directives, legislation, strategies/guidelines, education and support) to support meaningful service user and caregiver involvement in mental health systems (2, 12, 19, 197, 320). The piloting process of the ToC model (Chapter 8), showed that this lack of macro-level regulatory support for involvement was a barrier to institutionalisation of ongoing service user and caregiver involvement initiatives in

primary healthcare services. This implies the macro-level policy contexts can shape the broad context of involvement in mental health systems, even at the grass roots(321). At the health facility level, service users and caregivers are poorly informed about their rights, the nature of their illness, available treatments and services, and experience negative attitudes and abusive behaviour. At the individual level, various barriers hinder service user involvement (e.g., severity of mental and physical illness, undermined decision making skills, poor access to information and insufficient opportunities to exercise choice) (110, 237, 260). Moreover, resource limitations, practical and logistical challenges are important barriers to mental health service user involvement in LMICs, which must be addressed (11). In this regard, the promotion of, and effective implementation of, national and international instruments for the protection of the human rights of service users; and enacting comprehensive mental health legislation with robust enforcement mechanisms are key areas that need attention in LMICs (31, 155), including Ethiopia.

These multiple and multilevel factors make interventions to support service user and caregiver involvement complex (2, 19, 107), however, there are few existing frameworks or models that provide insights into this complexity and the multilevel determinants of outcomes to guide successful involvement of service users and caregivers in mental health systems (2, 12, 23, 197). Although numerous involvement frameworks have been developed, mainly in high-income countries, they are generic ones that have not been developed for people with mental health conditions and have been critiqued for being too broad and ignoring the contextual and situational nature of involvement (115, 322). Many attempts at involvement have also been criticised for exclusivity and for being tokenistic globally (197). There is little in the way of guidance or models of involvement in LMICs (12, 18, 23), and existing models have been criticised for being Western-culture oriented and needing adaptation or re-invention (12). Moreover, there has been little focus on what techniques of service user and caregiver involvement work, in what circumstances, how, and why and where, which is necessary to be able to make recommendations for policy and practice improvements (12, 18). Most models have been developed from either literature reviews or by professionals without service user and caregiver involvement (2). This thesis study has added knowledge of how the complexity of service user and caregiver involvement may be addressed in the efforts of strengthening the mental health system in a rural, low-income country setting (See section 9.2.2.)

### **9.2.2. Strategies to promote service user and caregiver involvement**

In this study, several strategies to develop and promote greater service user and caregiver involvement in mental health system strengthening were identified, including development of a participatory ToC model, promoting institutional and community support, empowerment and capacity building.

#### **Participatory ToC model of involvement**

One of the key objectives of this thesis was to develop a ToC model of how best to involve service users and caregiver in mental health system strengthening. The co-produced ToC model hypothesises that effective involvement of service user and caregiver will not be met by a narrow individual level intervention, but needs a multi-sectoral response, multilevel interventions, and various preconditions for achieving the ultimate goal of more active involvement of service users, caregivers and other key stakeholders. The ToC model (Fig7) depicts multilevel participatory stakeholder engagement beyond mental healthcare service settings, including those within health systems/organisations, community, and service users and caregivers. The ToC model was mapped encompassing broader social contexts and determinants of involvement and multi-stakeholder collaborative work towards the removal of the multilevel barriers that hinder service user and caregiver involvement initiatives (180).

This thesis recognised the barriers, facilitators and capacity building needs (Chapter 5), and through the ToC model (Chapter 6) and pilot study (Chapters 7&8) took account of this complexity. For example, the ToC model consists of four programme levels (community, health organization, service user, and caregiver) with specific intervention and preconditions at each level (Fig7). This is in line with studies that suggested that initiatives to involve service users and caregivers are dependent on taking a whole system approach that addresses imbalances of power experienced by different groups (19, 107, 319). In addition, our finding is also in line with the well documented evidence that determinants of mental health and illness are multi-layered (238) and require intervention packages beyond a health facility (e.g., health system, and community levels) (306) to address service users' and caregivers' multidimensional needs (e.g., health costs, employment, education, housing, social inclusion).

There are few frameworks that have provided insights into the determinants and essential elements of successful service user and caregiver involvement in mental health systems (2, 12). This thesis study uniquely adds to the research in the area through approaching service user and caregiver involvement at multiple levels and designing intervention across levels (180). In addition, our ToC model intentionally attempted to make the implementation process more inclusive and participatory using the PAR approach to guide this process (125) wherein multi-stakeholder groups were actively involved in the co-production and implementation process, which formed the basis of the development of an acceptable and feasible intervention for the study setting (See chapters 6-8) (180). This study can also address the criticism of Western-culture based biomedical models being uncritically transferred to non-Western cultural contexts in LMICs (12). This approach can contribute to overcome some of the limitations of traditional ToC processes (e.g. addressing power imbalance and exclusiveness of diversity) (125), and criticism of other involvement efforts, including inattentiveness to complexity, tokenism and professional centrism (197).

### **Institutional and community support**

The ToC model, and the piloting process identified strengthening institutional support at health organisation level as a core intervention component of the ToC model to support service user involvement (180) (See Chapter 8). Institutional managers were involved in this thesis research process. In line with this, a previous study from a LMIC showed that strategic government level and health organization support helps to promote self-determination and service users' and caregivers' control over agenda setting (38). There are various ways in which healthcare organizations can create an enabling environment for involvement, including development of a culture of acceptance (non-stigmatizing attitudes and eliminating discriminatory practices); allocation of financial, human and material resources, and recognition of experiential knowledge to strengthen the mental health system (12, 22, 110, 237). At the health facility level, available up-to-date information about service user rights, the nature of their condition, available evidence-based treatment options and services, and provision of infrastructure for involvement can enhance meaningful involvement of service users and caregivers (12, 22, 110). Moreover, addressing the multi-level barriers to greater involvement of service users and caregivers in the mental health system and other domains of life requires inputs of various stakeholders (12). These stakeholders can create opportunities to access resources, training and skill development, health and

psychosocial support and provide space and structures (strategies, rules, legislations) (12, 31, 38, 209).

The findings of the thesis also identified strengthening community collaboration as a core intervention component of the ToC model, and the initiatives that were undertaken during the piloting of the model also indicated the feasibility and acceptability of the assumptions around community mobilisation (180)(See Chapter 8). Our formative study(179)(Chapter 6), as well as a previous situational analysis on the challenges and opportunities for integration of mental health conducted in this thesis study setting (34) identified various difficulties including financial constraints, high levels of poverty, low literacy, social deprivation, limited levels of community awareness, high levels of stigma and abuse, absence of health system structures and support systems for mental health care, and a lack of reliable supplies of medications among others. Evidence shows that the integration of mental health services into primary health care needs to consider the social, economic and educational status of service users, as well as the stigmatizing and discriminatory practices that tend to disempower and marginalize service user and caregiver involvement (187, 210). There is emerging evidence that interventions to improve access to mental health care combined with promoting livelihoods and peer support (e.g. the BasicNeeds model of mental health and development) can lead to empowered service users and caregivers who are able to take on active roles within society, and regain social capital and influence (187, 210).

Addressing structural and community level barriers to involvement require wider platforms outside the healthcare system and the participation of a range of actors, tapping into stakeholders capabilities for provision of comprehensive mental health services, particularly in LMICs (12, 251, 254, 323). This is also in line with the current direction of global mental health care, which emphasizes strengthening community resources, greater focus on addressing local priorities and developing local assets to solve local problems (255, 323) by engaging community stakeholders, e.g. through Health Committees or Community Advisory Boards (CAB)(160, 257, 258). CABs can mediate between communities and health services in many health systems(160, 257) and can be effective in improving the quality and coverage of healthcare, as well as impacting on health outcomes (160, 209, 258). This thesis study provided an opportunity for collaborative working of key stakeholders and involved multi-stakeholder groups in the ToC model co-production,

prioritization of specific interventions targets, action strategy development and interventions (Chapter 8). For example, district stakeholders identified the availability of rich community resources, particularly at community programme level (e.g., social organizations like Idir) with viable potential to address the psychosocial needs of service users-caregivers locally, with less external support and in a sustainable manner. There are rich community resources and capabilities(e.g., diverse community based organizations, community based health workers, assets, micro-finance institutions, social capital, community self-support organisations) (34, 163), which were not previously effectively mobilised to support mental health service users and caregiver involvement.

### **Empowerment and capacity building**

The findings of this thesis show that building the capacity of key stakeholders was an important and necessary precondition to enhance service user and caregiver involvement in mental health system strengthening. The empowerment training programme conducted to equip service users, caregivers and health professionals for involvement was found to be feasible and acceptable(See Chapter7) (179, 180). These findings align with previous studies that emphasized the need to address the knowledge, attitudes and skills of health care providers and managers as well as service users and caregivers to implement models of service user and caregiver involvement (261). Our findings also support Carman et al. (225) who identified the importance of technical support, preparation of service users, health professionals and other stakeholders, and partnerships as key facilitators in implementation of multilevel frameworks for service user and caregiver involvement. This study also contributes to the small evidence base on training programmes designed to empower service users in LMICs (23, 41, 273, 274).

Empowering service users and caregivers for involvement can take place at individual or collective levels. At the individual level, empowerment involves addressing both knowledge (e.g. training about effective communication, advocacy, working collaboratively) (225, 261)and health challenges (e.g., medication supply) [12, 13]. Training can improve self-esteem and self-advocacy, assertiveness, confidence and hopefulness of service users and promote recovery (261, 324). Training also enhances the credibility of experts by experience, decreasing the pressure on them to gain acceptance (325).

The findings of this thesis show that service users and caregivers have limited organized representation within the mental health care system in Ethiopia. There is only one service user association, the Mental Health Service User Association of Ethiopia, which was established in Addis Ababa in 2018, and there is only one association of caregivers at the national level (34). The study identified mobilisation and empowerment of service users and caregivers to self-organise and advocate for their rights as a key intervention area. In our study, service users who participated in the training established a service user association in Sodo district, to support each other to expand their networks in an organized way for involvement in mental health systems strengthening and to advocate for their human rights. Several studies identified a range of benefits of organized service user and caregiver groups, including that organisation promotes their collective recognition and develops their individual confidence, strengths, resources and skills (31, 38). Empowerment of service users also ensures a collective voice to influence and lobby for policy and legislative reforms (38, 212). Self-help groups are important platforms for exchange of individual experiences and mutual support that can lead to better quality of life and insight about how best to cope with their situations (38).

### **9.3. Strengths and limitations**

This thesis has several strengths. This study addressed development of service user and caregiver involvement in mental health strengthening and provided examples of actual involvement experiences, which is a noble contribution in an under-researched area in many LMICs. The thesis combined traditions of qualitative and critical participatory research approaches (critical social theory), which allowed for a more comprehensive understanding of the complexity of service user and caregiver involvement. This study is one of a few studies that applied inclusive participatory approach to involve diverse stakeholders, including service users, caregivers, health professionals, and other community groups in co-production and implementation of aToC model of service user and caregiver involvement in mental health system strengthening in LMICs. The key stakeholders were involved in ToC development and piloting of the model using cycles of PAR, including problem identification, prioritisation, action planning and dissemination of findings. Prospective accounts of participants involvement could therefore be obtained throughout the study process using various data collection methods (e.g. reflective dialogue, field notes, participatory observation, in-depth interviews, and quantitative surveys), which have not

been widely adopted in the service user and caregiver involvement field in LMICs. This also increases the authenticity and trustworthiness of the findings. This study also took into account the complex nature of involvement and designed model of involvement at multiple levels and piloted and evaluated actual involvement of service users and caregivers. In LMICs there are very limited studies where such involvement has actually taken place and there are limited models of involvement, which is the unique contribution of this study to service user and caregiver involvement literature of LMICs.

There are also a number of limitations that should be considered. The predominantly qualitative and small-scale nature of the study and the small number of participants involved can limit wider transferability of findings to other Ethiopian contexts. The purposive sampling strategy used and the use of district health professionals/PRIME field coordinators for recruitment of participants can introduce selection bias into the study. Nevertheless, the qualitative approach provided a suitable platform for informants to share useful information about the study and to develop deep understanding of the complexity of service user and caregiver involvement. The piloting of the study took place at one health facility. The final action plan was not fully piloted due to insufficient time to complete the doctoral thesis, and partly because of lack of resources. Lack of participants' involvement starting from the formative qualitative study directly could be perceived as a limitation, particularly in light of the PAR stance.

## **9.4. Implications and recommendations**

In this section, the implications of the findings and recommendations for policy, practice, knowledge and research will be addressed.

### **9.4.1. Policy implications and recommendations**

Service user and caregiver involvement in all aspects of mental health system strengthening activities is advocated as a global health policy agenda; and also there are strong arguments that service user and caregiver involvement enhances scale up of quality mental health services in LMICs. The Ethiopian MoH is planning to empower key stakeholders including service users and caregivers to ensure effective collaboration between various stakeholders to implement the

mental health strategy. Given this political interest in service user and caregiver involvement, this study could make a worthwhile contribution to an area where there has been relatively little research in the country. The contextual findings about barriers, facilitators, capacity building needs, the ToC model and the lessons gained from the development and implementation of capacity building interventions could help to guide how best to develop wider involvement of service user and caregivers and other key stakeholders along with the integration of mental health services into primary healthcare.

There is no explicit policy/strategic direction about inclusion of service user and caregiver involvement within the Ethiopian mental health system. This study recommends the need for recognition of the roles that service users and caregivers could play in strengthening mental health systems, and commitment of key health system stakeholders, particularly those at strategic level to ensure that service user rights to health and participation are considered as effective mechanisms for mental health system strengthening. These commitments are expected to fill the current gap between willingness and practical implementation, lack of involvement enabling infrastructures, including explicit strategic level policies for the integration of and legislations to promote and protect the rights of service user and caregiver involvement within mental health system and beyond. Policy makers, planners, health organisation and health facility managers need to ensure that service user and caregiver involvement is included as an integral part of policy making, service planning and delivery, research, education and training programmes at all levels. In addition, there is a need to support service user and caregiver associations, advocacy groups and promote peer support within the mental health care system.

Key mental health system stakeholders, including local community groups were identified as important partners in the research processes to be mobilised at grassroots to support service user and caregiver involvement. The current study showed the possibilities of achieving this and improved on the previous lack of local community involvement and collaborative working with regard to mental service user empowerment and support activities. Therefore, there is a need to examine ways of establishing a multi-stakeholder response to the complex barriers to empowering service users and caregivers for greater involvement.

#### **9.4.2. Theoretical implication and recommendations**

The findings from this thesis have a number of important theoretical implications for the research on service user and caregiver involvement in mental health system strengthening in resource constrained setting. The findings from this thesis can contribute to an improved theoretical understanding of service user and caregiver involvement in the mental health system strengthening field by drawing on participatory research approaches to explore the pathways through which the involvement of service user and caregiver could be initiated. The participatory ToC model co-production, and piloting using principles of PAR approach intended to move research process from theory to practice, which contributes to knowledge on how best to apply PAR for active, inclusive service user involvement. The study contributes to an improved understanding of the role of the multilevel collaborative approach in co-producing change models for involving service user and caregiver. This study demonstrates the value of PAR as one type of model for development of meaningful service user and caregiver involvement, which is a relatively neglected area in Ethiopian and many LMICs. By taking a critical perspective to examining the basis for developing an evidence base, the study finds that knowledge and the agenda for user involvement in health research could be significantly strengthened. These findings also provide an example of application of social contact theory to reduce stigma and discrimination associated with mental health conditions. These findings also lay foundation for development of theory-driven approaches, which offer a more evidence based understanding of how, why, where, and when service user and caregiver involvement works or not, the mechanisms and outcomes of involvement.

#### **9.4.3. Practice implications and recommendations**

The findings from this thesis have important implications for those designing interventions to improve service user and caregiver involvement in mental health service improvement in primary healthcare. There is no current best practice for intervention to promote mental health service user involvement at health system level in LMICs. This study could help professionals towards involvement of service users and caregivers in health service quality improvement and ensuring that the services are tailored to the service user's needs. The collaborative working of service users, caregivers and health professionals during the piloting of the ToC model indicates the possibilities for integration of service user and caregiver involvement as part of the on-going

mental health service scale up within primary healthcare in Ethiopia. However, if service user and caregiver involvement in mental health improvement is to be fully realized, the findings of this thesis needs to be taken up and applied in a sustainable way. In addition, appropriate education and training opportunities incorporating service user and caregiver involvement is recommended as an integral component of the continuous professional development programmes for healthcare professionals.

#### **9.4.4. Research implications and recommendations**

The findings of this thesis lay the ground for future research regarding development of service user and caregiver involvement in mental health system strengthening in Ethiopia.

- This research has contributed to the body of knowledge regarding the feasibility and acceptability of service user and caregiver involvement in rural Ethiopia. However, more research is needed how best to address key barriers to embed service user and caregiver involvement, including the policy context within which service user and caregiver involvement initiatives are implemented, lack of funds and resources, which impede sustainability of active involvement.
- This study did not include more strategic level stakeholders that could have relevance to creation of an enabling environment to service-user involvement. Further research is required to replicate the present research in wider areas and expand to different levels of the health system (e.g. strategic levels) and other health care settings in different regions of the country; which would allow for making comparisons between different levels and settings, enhance the ability to generalize findings and explore different contexts for service user and caregiver involvement in mental health system strengthening in Ethiopia.
- The participants were purposefully recruited and volunteered to participate, which raises questions about the motivation and representativeness of the participants. Future research might look to address this potential selection bias, and how to select a mix of participants so that diverse perspectives are included.
- A more theory-driven involvement model could be developed to better understand multilevel factors affecting involvement, to create more transferable/generalisable evidence

to inform policy and practice models of service user and caregiver involvement in mental health system strengthening.

- Further evaluations are needed over time to examine the enduring impacts of service user and caregiver involvement in PAR that were seen in the case study of the process and experiences of involvement (Chapter 6 and 8). In addition, further research is required that could evaluate effectiveness of the training interventions and involvement in PAR at larger scale.
- Further study could be undertaken to more comprehensively explore the effectiveness of PAR as a methodology through all stages, including longer-term implementation of the action stages.
- Service users, caregivers, and health professionals involved in the PAR process emphasised the need and interest to create awareness about mental illness at different levels in the local context; however they also described the difficulty of getting awareness creation packages suitable for the purpose, which is recommended as an area of future research focus.
- There is a need for further research on how measures of success for service user and caregiver involvement can be identified.

## **9.5. General conclusions**

This thesis is the first to provide empirical evidence on the development, piloting and evaluation of a ToC model of service user and caregiver involvement in mental health system strengthening in Ethiopia. The findings indicated that service user and caregiver involvement is useful and possible, but there is little actual involvement experience. Service user and caregiver involvement is a complex process affected by multiple and multilevel interacting factors. Meaningful involvement needs to consider broader socio-ecological systemic approaches that take into account the complexity of involvement. Key community stakeholders provided considerable expertise in co-producing a ToC model of service user and caregiver involvement, which was acceptable and feasible. The flexible nature of PAR approaches can offer communicative space for diverse stakeholders to learn and work together, set realistic goals/priorities and formulate action plans that their expectations, capabilities and the local context. The participants identified various unmet needs, including lack of awareness, stigma and

discrimination at the top priority that need addressing. Implementing service user and caregiver involvement requires time and willingness for participation from all stakeholders, including managers, health professionals, service users and caregivers. However, actual embedding of service user and caregiver into formal routines needs practical support in terms of policy, legislation, and other regulatory mechanisms to ensure accountability, resource and capacity building of key stakeholders.

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## **APPENDICES**

## Appendix 1. Literature search terms and strategies (Sample for used in Medline database)

1	exp patient participation/
2	((((patient participation or patient outcome assessment or patient-centered care or community participation or patient engagement or patient involvement or patient empowerment or patient collaboration or public) and patient involvement) or service user engagement or service user involvement or service user participation or user engagement or user participation or consumer participation or consumer involvement or consumer engagement or family engagement or family involvement or family participation or caregiver participation or caregiver involvement or caregiver engagement or carer involvement or carer participation or consumer organization or self-help).ti. or (((patient participation or patient outcome assessment or patient-centered care or community participation or patient engagement or patient involvement or patient empowerment or patient collaboration or public) and patient involvement) or service user engagement or service user involvement or service user participation or user engagement or user participation or consumer participation or consumer involvement or consumer engagement or family engagement or family involvement or family participation or caregiver participation or caregiver involvement or caregiver engagement or carer involvement or carer participation or consumer organization or self-help).ab. or (((patient participation or patient outcome assessment or patient-centered care or community participation or patient engagement or patient involvement or patient empowerment or patient collaboration or public) and patient involvement) or service user engagement or service user involvement or service user participation or user engagement or user participation or consumer participation or consumer involvement or consumer engagement or family engagement or family involvement or family participation or caregiver participation or caregiver involvement or caregiver engagement or carer involvement or carer participation or consumer organization or self-help).sh.
3	1 or 2
4	exp mental disease/
5	(Mental health or mental problems or serious mental illness or psychiatric illness or Schizophrenic or schizoaffective or mental disorders or mentally ill persons or Psychoses or major depressive disorder or schizophrenia or psychotic disorders or bipolar disorder or mood disorder or affective disorders or people with mental disorders or psychiatric survivors or mental illness or mental health challenge or psychiatric disabilities).ti. or (Mental health or mental problems or serious mental illness or psychiatric illness or Schizophrenic or schizoaffective or mental disorders or mentally ill persons or Psychoses or major depressive disorder or schizophrenia or psychotic disorders or bipolar disorder or mood disorder or affective disorders or people with mental disorders or psychiatric survivors or mental illness or mental health challenge or psychiatric disabilities).ab. or (Mental health or mental problems or serious mental illness or psychiatric illness or Schizophrenic or schizoaffective or mental disorders or mentally ill persons or Psychoses or major depressive disorder or schizophrenia or psychotic disorders or bipolar disorder or mood disorder or affective disorders or people with mental disorders or psychiatric survivors or mental illness or mental health challenge or psychiatric disabilities).sh.
6	4 or 5
7	exp health care policy/
8	exp health service/
9	exp health services research/
10	exp health care quality/
11	exp health care system/ or exp health care policy/ or exp health care delivery/
12	(Delivery of health care or Health policy or policy making or health care reform or Health services or Mental health services or community mental health services or community health planning or health planning or health services research or public health systems research or outcome assessment or quality control or quality assurance or quality of health care or self-help groups or peer group or consumer organizations or decision making or patient advocacy or consumer advocacy or Community mental health planning or mental healthcare delivery or Health system strengthening or Mental health policy or Mental health system or mental health research or action research or participatory research or community -based participatory research or community mental health or peer services or development of services or training of health workers or education of health workers or monitoring or evaluation or peer support or mental healthcare planning or Delivery or Policymaking or Policy formulation or Program formulation).ti. or (Delivery of health care or Health policy or policy making or health care reform or Health services or Mental health services or community mental health services or community health planning or health planning or health services research or public health systems research or outcome assessment or quality control or quality assurance or quality of health care or self-help groups or peer group or consumer organizations or decision making or patient advocacy or consumer advocacy or Community mental health planning or mental healthcare delivery or Health system strengthening or Mental health policy or Mental health system or mental health research or action research or participatory research or community -based participatory research or community mental health or peer services or development of services or training of health workers or education of health workers or monitoring or evaluation or peer support or mental healthcare planning or Delivery or Policymaking or Policy formulation or Program formulation).ab. or (Delivery of health care or Health policy or policy making or health care reform or Health services or Mental health services or community mental health services or community health planning or health planning or health services research or public health systems research or outcome assessment or quality control or quality assurance or quality of health care or self-help groups or peer group or consumer organizations or decision making or patient advocacy or consumer advocacy or Community mental health planning or mental healthcare delivery or Health system strengthening or Mental health policy or Mental health system or mental health research or action research or participatory research or community -based participatory research or community mental health or peer services or development of services or training of health workers or education of health workers or monitoring or evaluation or peer support or mental healthcare planning or Delivery or Policymaking or Policy formulation or Program formulation).sh.

	advocacy or consumer advocacy or Community mental health planning or mental healthcare delivery or Health system strengthening or Mental health policy or Mental health system or mental health research or action research or participatory research or community -based participatory research or community mental health or peer services or development of services or training of health workers or education of health workers or monitoring or evaluation or peer support or mental healthcare planning or Delivery or Policymaking or Policy formulation or Program formulation).sh.
13	7 or 8 or 9 or 10 or 11 or 12
14	exp "Interaction Model of Client Health Behavior"/ or exp model/ or exp Health Promotion Model/ or exp process model/ or exp model based iterative reconstruction/ or exp theoretical model/
15	exp conceptual framework/
16	(Model or Framework or Strategies or Guideline or Roadmap or Intervention or Theory or Theories or Capacity Building or Training or Education or Systems or Mechanisms or Structures).ti. or (Model or Framework or Strategies or Guideline or Roadmap or Intervention or Theory or Theories or Capacity Building or Training or Education or Systems or Mechanisms or Structures).ab. or (Model or Framework or Strategies or Guideline or Roadmap or Intervention or Theory or Theories or Capacity Building or Training or Education or Systems or Mechanisms or Structures).sh.
17	14 or 15 or 16
18	3 and 6 and 13 and 17

## Appendix 2: Summary of studies about service user and caregiver involvement in different activities of mental health system

### Appendix 2A. Overview of studies about service user and caregiver involvement in mental health policy, service planning and development

<i>Study</i>	<i>Country/location</i>	<i>Study type/design</i>	<i>Participant and sample group involved</i>	<i>Sample size</i>	<i>Health system level of involvement</i>	<i>Outcomes/problems measured</i>	<i>Findings</i>	<i>Comment on the quality</i>
(50)	Eight high income countries	Scoping review	Not reported including in the primary studies	Partially reported for eight studies (2591)	Health service development	Impact of the participatory process and the participatory research on service user, health professionals and the health organization	<p>Involvement had impact on:</p> <p><b>Service users</b>, e.g. enhanced collaboration skills, fostered personal growth, felt empowered, and feeling a sense of well-being, expanded social networks</p> <p><b>Health professionals</b>, e.g. improved attitude toward involvement, gave insight into patients needs, developed empathy and a better understanding of patients situation, increased motivation for organizational change, improved collaboration competency, lessened concerns of tokenism</p> <p><b>Health organizations</b>, e.g., improved integrated patient perspectives in the service development, mutual understanding among participants, expanded patient participation within the origination, increased informal communication between health professionals and patients,</p>	<p>The studies are concentrated in only few high income countries. The design of the studies are predominantly qualitative studies which give context specific information that limits potential to generate wider lessons</p> <p>There are risks of publication bias because of focusing on published evidence</p>

							<i>improved power balance among participants</i>	
(64)	<i>Multi – sites, including Canada, UK, USA, Belgium, South Africa and Brazil</i>	<i>Integrative review</i>	<i>Heterogeneous groups of health conditions</i>	<i>Not reported</i>	<i>Mental health policy</i>	<i>Status of research on participation of service user in policy formulation</i>	<i>Identified seven relevant studies There is a growing legislative and government recognition of service user involvement in public policies of mental health There is persistent challenge to service users related to negative attitude towards service users with presumed lack of capacity Identified several barriers and strategies to overcome the barriers</i>	<i>The search time period was narrow The quality of reporting of the studies was not assessed There was no search beyond the electronic databases</i>
(23)	<i>14 upper-LMICS</i>	<i>Systematic review</i>	<i>Heterogeneous health conditions</i>	<i>Pooled information was not reported</i>	<i>Mental health system aspects</i>	<i>Evidence and experiences of involvement Models of best practice for evaluation of capacity building activities</i>	<i>There are examples of service user and caregiver involvement There was a lack of high-quality research and weak evidence base There was lack of model how best to implement involvement</i>	<i>Given the review is about service user and caregiver involvement, what counts as high quality study is not clear It was difficult to ascertain how degrees of involvement were assessed There was clearly known evidence of service users and caregiver involvement in LMICS before this review. The heterogeneous nature of data sources and synthesis makes the justification for a systematic review unclear.</i>
(79)	<i>High income</i>	<i>Systematic review</i>	<i>Professional conducted report</i>	<i>Not-meta-analyzed</i>	<i>Range of levels: Planning Advocacy</i>	<i>Effect of service users involvement in health care planning and</i>	<i>Range of effects including: Improved engagement with service users and staff awareness Improved self esteem of service</i>	<i>Most studies (31) are case studies hence generalization is difficult Varied types of health conditions</i>

					<i>Forums Monitoring Research</i>	<i>development</i>	<i>users Improved design of new services Improved information of service users and service providers Culture shift in service delivery Reduced dependency of service users Improved organizational attitude towards service users involvement</i>	<i>are included hence comparison of effects is difficult Evidence included is restricted to a few studies from high income countries, hence difficult to generalize to other areas The roles of service users are not described The health condition or severity level of the illness is not reported</i>
(87)	<i>High income (Canada)</i>	<i>PAR</i>	<i>Service users, caregivers, health professionals</i>	<i>146 service users with severe mental illness</i>	<i>Mental health service development</i>	<i>Feasibility and acceptability of patient partnership and patient-oriented research approaches</i>	<i>Established service user and caregiver friendly Interactive Guide for Medical Appointment Ensured acceptability and feasibility of partnership; service users produced a series of 33 short videos showing signs and symptoms of common chronic diseases</i>	<i>The use of PAR approach is relevant for the nature of the study. However, it is not clear how level of participation is measured and reported. The PAR process activities are not clear and the specific PAR approach is not explained. The process of ensuring trustworthiness, including the positionality and reflexivity issues were not detailed</i>
(11)	<i>Low income</i>	<i>Rapid review</i>	<i>Professional conducted</i>	<i>Not reported</i>	<i>Mental health systems : policy, service development</i>	<i>Improvements of service user involvement in mental health as of prior review</i>	<i>The number of publications has been increasing but reported few improvements and more remains to be done.</i>	<i>Based only on published academic work, hence publication bias is high Focused only on database searching and likely to miss non-database resources</i>
(68)	<i>LMICs (China)</i>	<i>Cross-sectional</i>	<i>Mental health service users, caregiver and service providers</i>	<i>300</i>	<i>Service planning and management</i>	<i>Service user and service provider beliefs about partnership  Scope of service users involvement Extent of agreement on service users involvement</i>	<i>Reported positive belief about partnership  Participants supported involvement of service users in service planning and monitoring</i>	<i>Preferences and values need qualitative design  Sampling did not allow generalization to others</i>

## Appendix 2B. Overview of studies about service users and caregivers involvement in service delivery, evaluation and quality improvement

<i>Study</i>	<i>Country/ location</i>	<i>Study type/ design</i>	<i>Participant group involved</i>	<i>Sample size</i>	<i>Health service/ system level of involvement</i>	<i>Outcomes/ problems measured and findings</i>	<i>Findings</i>	<i>Comment on the quality</i>
(12)	Ten LMICs	Systematic and realist review	Service users Caregivers Community members	Not reported	Many aspects, mostly in service delivery	Development of program theory to involve service users, caregivers and health professionals with specific context, mechanism and outcomes	Identified barriers and facilitators operating at multiple levels, including individual, health system and community, and strategic/policy level factors. Identified four mechanisms, contextual barriers and facilitators, and associated outcomes	The study was very informative and included diverse evidence including from grey literature. Involved the participants at different stages of the study Gave high value to the importance of context , mechanisms, outcomes and the complexity of service user and caregiver involvement The findings can give insights for policy and practice recommendations However, the way the authors wanted to prove outcome seems oriented to the positivist approach. This also underpinned their recommendation for more RCTs.
(89)	High income countries	Qualitative -meta-synthesis	Professional focused	662(service users(320), public representatives(16), health professionals(220), and	Mental health care	Essential processes that enable service user participation in mental health care	Exercising influence, tokenism, sharing knowledge, lacking capacity, respect, and empathy	Studies are predominantly from a small number of high-income countries and all qualitative, which restricts to context specific evidence. Search was conducted only in databases, hence leads to missing non-indexed

				<i>unspecified (106)</i>				<i>literature that leads to publication bias</i>
(83)	<i>Predominately high-income countries: UK, USA, Norway, Sweden, Mexico, Ireland, Australia, Canada and Netherlands</i>	<i>Systematic review</i>	<i>Service user(35% mental health service users), caregivers, health professional, board members, healthcare manages, administrators, and decision-makers</i>	<i>Ranges from 3 to 372 including service users, caregivers, healthcare providers, board members healthcare managers and decision makers</i>	<i>Health service design, delivery and evaluation/quality improvement</i>	<i>Strategies and contextual factors that enable optimal engagement and patients experiences of engagement</i>	<i>Educational tool development, informed policy or planning documents, enhanced care processes or service delivery and governance Level of involvement influence outcomes, which indicate the active the involvement the higher the impact at highest level. Few studies evaluated experiences of involvement Most participants experienced increased self-esteem, feeling empowered, or independent Identified strategies and contextual factors that enabled service user involvement including techniques to enhance design, recruitment, involvement and leadership action and those aimed at creating receptive context.</i>	<i>Utilized different involvement models and also reported levels of involvement in each study Concentrated in few high-income countries Publication bias is highly probable due to focus on published studies Did not evaluate quality of reporting of each study The terminologies used were very confusing, e.g. patient, service user, user, caregiver, family etc.</i>
(78)	<i>High income</i>	<i>Systematic review of controlled trials and comparative studies</i>	<i>Severe mental illness</i>	<i>Not meta-analyzed</i>	<i>Various mental health service e.g., Health care Training research</i>	<i>Range of outcomes</i>	<i>Clients of the service had improved quality of life, improved social functioning, less burden to the family Improved attitude to mental illness and mentally ill</i>	<i>Studies confined to few high income countries and case management model No comparative study to confirm whether the outcome is the result of involvement Heterogeneous outcomes make generalization difficult</i>

(65)	Mainly high income	Systematic review	Professional conducted	1185	Service delivery	<p>Several barriers:  <i>Practical needs associated with family work: managing workload, practical burdens and balancing responsibilities</i>  <i>Poor allowance of time from service</i>  <i>Lack of structures and standardized systems to support family work</i>  <i>Logistical issues</i>  <i>Personal and training needs: problems with access to supervision, lack of skills or confidence</i>  <i>System-wide approaches and attitudes to family work: organizational culture and paradigms.</i>  <i>Unsupportive attitudes of managers, lacking shared team commitment to family work, negative staff attitude</i></p>	<p><i>Service provider training gap on how to involve family</i>  <i>Lack of clear structure how to involve family</i>  <i>Gap of relationship between service providers and family</i></p>	<p><i>Specific areas of family involvement and approaches, models and specific challenges are not reported</i>  <i>Most studies reviewed are qualitative studies but quality criteria such as credibility, transferability, dependability, and conformability were not reported</i></p>
(90)	High income-UK	Mixed-methods	Caregiver, service users, and clinicians	Caregivers (n=30), service user(n=30) and clinicians( 6)	Inpatient care	<p><i>Feasibility of caregiver delivered care and experiences of participants</i></p>	<p><i>Seemed feasible in about half of the wards</i>  <i>Facilitating a three-way collaboration between service user, caregiver and health professionals is mandatory</i>  <i>The mental health status of the service user can be facilitator or barrier to the intervention being implemented</i>  <i>Simple structure approach can facilitate dialogue; service users, clinicians and</i></p>	<p><i>The study is small scale and from one health facility in high-income country context, hence, its applicability LMICs setting needs attention.</i>  <i>The finding is the pilot feasibility study and evidence from wider testing may give lessons that can be tested in other contexts with necessary adaptation</i></p>

							<i>caregivers appreciate this approach to care Implementation requires the wider organizational support</i>	
(92)	<i>LMICs-China/Hong Kong</i>	<i>Participatory qualitative inquiry</i>	<i>Researchers and service users with diagnosis of schizophrenia</i>	<i>Two researchers and three participants</i>	<i>Health service</i>	<i>Impacts and experiences of involvement</i>	<i>Service user involvement is a gradual change process of assuming responsibility, connection with peers, collaboration with staff, redefinition of boundaries and social inclusion Impacts included improved sense of contribution, interpersonal connection and self-worth and transformed one's identity Photovoice opens up new space for unfolding expert knowledge</i>	<i>The study did not report the challenges encountered during the photovoice sessions and how they managed the risk of relapse. It was conducted on a small scale in a non-Western high income setting, hence, transferability to LMICs needs careful adaptation</i>
(108)	<i>LMICs-Iran</i>	<i>Non-randomized interventional trial/quasi-experimental</i>	<i>Service users family members and mental health workers</i>	<i>129 service users with schizophrenia</i>	<i>Community based health service</i>	<i>Burden, knowledge, quality of life and general health conditions of caregivers, positive and negative symptoms and social skills of service users Hospital admission rate</i>	<i>Most clinical variables improved without significant difference between groups and hospitalization rate reduced</i>	<i>The groups are educationally homogeneous; generalization to others is difficult Patients' health literacy level, adherence, family support and socio-economic variables are not clearly addressed Did not indicate the acceptability to service users of having family as case managers</i>
(91)	<i>LMICs-Nigeria</i>	<i>Prospective observational cohort study</i>	<i>Caregivers</i>	<i>81</i>	<i>Care delivery</i>	<i>Association of family involvement with post-discharge appointment and medication adherence</i>	<i>Significantly improved adherence to appointment</i>	<i>The role of the family in the treatment is not clearly stated The nature of family is not considered Level of involvement and reasons for non-involvement</i>

								<i>is not assessed</i>
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## Appendix 2C. Overview of studies about service users and caregivers involvement in mental health research

Study	Country/location	Study type/design	Participant group involved	Sample size	Health system level of involvement	Outcomes measured /problems assessed	Findings	Comment on the quality
(86)	<i>High-income countries: UK, Canada, Norway and Australia</i>	<i>Systematic review</i>	<i>Service with diverse health conditions( e.g. mental health occupational injuries, cancer) caregivers and researchers</i>	<i>Not reported</i>	<i>Research</i>	<i>Scope and types of studies Outcomes and experiences of involvement</i>	<i>Included 17 studies that involved service users and caregivers There are several studies that focus service user involvement as an outcome and considered collaboration and allocation of resources Many studies considered patient involvement as strategy to achieve other outcomes including improvement in health and systems</i>	<i>The studies are concentrated in a few high-income countries and external validity is questionable. Level of involvement and quality of reporting of the papers was not explicitly and formally stated</i>
(20)	<i>High income: UK, Canada, Norway, Australia, Ireland, Korea, Sweden, and USA</i>	<i>Scoping review</i>	<i>Diverse groups of people with mental health conditions and key health system stakeholders including health professionals, managers, and researchers</i>	<i>Not polled together</i>	<i>Mental health research</i>	<i>Actual involvement of service users in mental health research  Unmet expectations, part of the research process where participants involved, contributions to the research process and gains from the research process in terms of training and learning</i>	<i>Identified 32 studies Actual involvement of service users is a complex process that included expectations about the research process, contribution to the research process, availability of capacity building and gains from the research. Changing tradition of research from professional centered approach to collaboration, avoiding tokenism and power imbalance are key factors for success</i>	<i>The level of service user and caregiver involvement was not formally assessed  The reporting and quality of the studies was not explicitly stated and evaluated  Only based on published findings and from high-income setting, hence bias is high</i>

(80)	High income country	Systematic review	Professional conducted	Not – polled together	Health research	Methods of service users selection Method of service users involvement Benefits of service users involvement , Challenges and harms of service users involvement	Not possible to recruit best methods of service users selection and engagement Improved enrolment of rate, aided research found , choice of relevant outcome, Logistic problems, tokenism	Included diverse types of health conditions that make it difficult to unpick condition-specific issues. The methods, target population, measured outcomes are heterogeneous, which might limit identification of common barriers and generalizable benefits
(81)	<i>High income countries: UK, USA, Canada, Australia, Sweden and Netherlands</i>	<i>Systematic review</i>	<i>Health professionals and service users</i>	<i>Not reported</i>	<i>Health service research</i>	<i>Impact of service user and caregiver involvement on the participants, researchers and community</i>	<i>Service users reported feeling empowered and valued , gain confidence and life skills Researchers developed a greater understanding and insights into their research are, gaining respect and a good rapport with the community The community involve become more aware and knowledgeable about their condition</i>	<i>Included service users in the advisory groups of the study which is good example of doing such types of study Include both grey literature and peer-reviewed papers Concentrated in a few high-income countries, hence transferability/generalisability to low income settings is questionable Level of involvement and quality of reported of the individual papers was not formally assessed It is not clear how many papers were finally included in the study The health condition/ specific diagnosis of participants was not clear</i>
(92)	China(Hong Kong)	Participatory qualitative research	Researchers, peer researchers and three other participants	Five service users with schizophrenia	Health service research	Experiences and impact of service user participation and effect of photovoice on service user involvement	Participants gradually assumed control through personal responsibility, connection with peers, collaboration with professionals, redefinition of boundaries and social inclusion Participation gave a sense of contribution, interpersonal connection, self-worth and transformed identity Participants enjoyed the mutual interaction and derived benefit from the photovoice process	The preparation of the participants was not clear  Mechanisms to avoid potential risks of the photovoice narration were not clear

## Appendix 2D. Overview of studies about service users and caregiver involvement in training and education

<i>Study</i>	<i>Country/ location</i>	<i>Study type/ design</i>	<i>Participant group involved</i>	<i>Sample size</i>	<i>Health system level of involvement</i>	<i>Outcomes measured /problems assessed</i>	<i>Findings</i>	<i>Comment on the quality</i>
(96)	LMICs- Nepal	RCT	Medical students	Study1 (n=94) Study2(n=213)	Teaching medical students	Impact of didactic videos and service user testimonial videos on mental illness stigma among medical students	Didactic and service user videos were associated with decreased stigma when content addressed only depression, but no stigma reduction was seen when included both depression and psychosis	There was no power analysis for the first study Small sample size It was not clear why they used service user video testimonies instead of live testimonies. The cost effectiveness justification was not substantiated with rights-based issues There was no pre-post comparison or follow up of the assessments
(326)	LMICs- Nepal, India, High income- Urban Australia ,Rural USA	Case study	Mental health service users , caregivers, health professionals	Not clearly stated	Health professional s education	Recovery narrative variations(context), purpose, content and implications	There is different intention of recovery based on audiences and this intention had types of service users included, narrative contents, and training provided for service users Service users recovery narrative significantly reduced stigma of health professionals compared to non-service user groups Recovery narratives have the potential to be used in different contexts	The contexts are very diverse and represents different social structures Fragile areas in terms in LMICs had different contexts in other relatively stable LMICs Not clear why these cases were selected The type of case study design and its rationale was not clear The cases were outside the formal health system structure

(43)	LMICs(Nepal)	Mixed-methods repeated measure design	Service users and health professionals	41(26 female and 15 male )	Training/education	Stigmatizing attitudes and role play-based clinical competency, assessed with the ENhancing Assessment of Common Therapeutic factors tool (ENACT), were evaluated pre-training and followed-up at four and 16 months. Key informant interviews with 25 participants and Focus group discussion	Qualitative interviews show change in perception of violence of survival threat, and ability to treat mental illness or professional threat Improved willingness to interact with patients (54% to 81%) Improved observed clinical competence (49% to 93%)	No controlled comparison group to claim changes reported  High lost to follow-up
(67)	High-income countries , including UK, Australia , and Canada	Systematic scoping review	Not clearly specified	Not reported	Service user involvement in university education	Consolidated strategies for service users to be involved, recruited and retained	Identified 58 papers Four main areas for service user involvement types: teaching, course development and governance, assessment and recruitment panel Eight strategies for recruitment(collaboration with external agencies, direct invitation, networking with/between service users, social media invitation) and retention(service users as staff, funding provision, incentive provision, support provision prior/during involvement)	The diverse nature of the disciplines and strategies used, the evidence synthesis used may not allow generation of evidence that could be recommended for practice and policy, because lacks focus on what, who, how, where and when. The review findings were from few high-income countries and transferability/generalisability to other settings is questionable
(85)	High-income countries	Integrative review	Divers conditions	Ranges from 12-112	Education of nursing students	Attributes of service user involvement in education Outcomes of service user involvement in education	Identified positive changes I studies perception of education using service user involvement, people with mental health conditions and mental health nursing education	Focused only on published studies, hence publication bias. The studies are concentrated in few countries and generating transferable/generalisable findings difficult Impacts on the service user and the educational institution and service deliver were not specified

								<p><i>Level of involvement of service user was not formally assessed</i></p> <p><i>The quality of reporting of the studies was not presented</i></p>
(95)	High income country UK	Systematic review	Students in different health disciplines, service users, professionals	Polled total is not – reported and also difficult to put ranges	Mental health education	Nature of service users involvement Prerequisites and processes for involvement Reported outcomes from students Ethical challenges	Range of methods used The prerequisite and processes included : linking with existing user groups, preparation and support with users	<p><i>Instruments used for measurement were not reported</i></p> <p><i>The review included only a few studies from only one country</i></p> <p><i>The nature of the health conditions and literacy level of service users were not reported</i></p>
(66)	High income country:	Systematic review	Mental health nursing students, postgraduate psychiatric nursing students, undergraduate nursing students, doctoral level trainees and staff,	Ranges form 12-189	Education of nursing students and staff	Not clearly indicated or the research question or objective was not clearly stated	Service user involvement across professions was limited and varies across professions Evaluation of involvement focus only on students perception Reported a range of benefits: students gained insight into service users perspectives in relation to their life, mental illness, experiences of health service use and service improvement	<p><i>The outcomes to be measured and how measured is not clear; severity of illness and literacy level of service users is not reported</i></p> <p><i>Only focused on published peer-reviewed work</i></p> <p><i>Level of involvement and reporting qualities of the studies was not clearly evaluated and indicated</i></p>
(84)	High-income countries :Australia	Structured review	Service users, caregivers, students, educators, mental health staff,	Range from 3-244	Education for occupational therapy students	Evidence of involvement Stage of educational process Recovery oriented practice capabilities	Students involved at different stages including planning, delivery, and evaluation of education Students perceptions of service user participation in the classroom were mostly positive Reduced stigma and improved attitudes Service users personal value of feeling contribution and feeling empowered improved	<p><i>The search strategy was very focused and not comprehensive</i></p> <p><i>Concentrated in few high-income countries</i></p> <p><i>The level of involvement is not formally assessed with existing frameworks</i></p>

							<i>Improvements in different levels of recovery domains based on the recovery framework used</i>	
<i>(94)</i>	<i>High-income</i>	<i>Systematic review</i>	<i>Mental health nurses, medical education, social work, multidisciplinary, service users and students</i>	<i>Pooled sample was not reported</i>	<i>Interpersonal communication training</i>	<i>Quality of evidence and effect on students communication skill</i>	<i>Identified ten studies, but the quality of the evidence is poor The approach was acceptable to students Improved attitude of students towards people with mental health conditions There concern about representativeness of service users Improved professionals deep reflective communication</i>	<i>Used broad databases for search The study was only from one country and generalization/transferability was questionable The studies were small scale from diverse healthcare settings needs complex evidence synthesis approach to show what for whom , how and where</i>

## Appendix 2E. Overview of studies about service users and caregiver involvement in mental health peer support activities

Study	Country/location	Study type/design	Participant group involved	Sample size	Health system level of involvement	Outcomes/problems measured	Findings	Comment on the quality
(105)	Predominantly high-income countries: USA, UK, Canada, Australia, Ireland, and Libya	Systematic review	Not specified	Not reported	Peer support in mental health services	Typology of modifications to peer support work for adults with mental health problems	Six modification areas: role expectations, training, types of contact, role extensions, workplace support for peers workers, and recruitment Five rationales : how best to provide possible peer support, meet services user needs, meet organizational needs, maximize role clarity, and to address social-economic issues	Use multi-language The importance of culture and context emphasized Given the heterogeneous categories of mental health peer support, it was difficult to understand the focus of the target of modification Very limited studies from LMICs Not clear how much modification addressed based on the based only literature evidence
(99)	Six high-income countries: USA, UK, Canada, Australia, Germany and Japan	Systematic review and meta-analysis	People with diagnosis of psychosis, depression, mood, personality, anxiety	Ranges from 21 to 468 in the studies with total sample being 3329	Peer support in mental health service	Effectiveness of the service Heterogeneity of peer support	The meta-analysis of eleven outcomes (hospitalization, emergency service user, employment, overall psychiatric symptoms, symptoms of psychosis, depression and anxiety, quality of life, recovery, hope empowerment, satisfaction with services, social functioning, social network support, working alliance)	Concentrated in few high income countries and contexts making generalization challenging

							<i>(clinician rated/ patient rated), self-stigma, experienced stigma, engagement with services, and wellbeing show that one-to-one peer support may have a modest positive impact on self-reported recovery and empowerment. But there was no impact on clinical symptoms or service user. Peer support can improve social network support</i>	
<i>(98)</i>	<i>High-income countries: USA, UK, Australia, Canada, Ireland, Belgium, Germany, Hong Kong, Japan, Netherlands, Israel</i>	<i>Systematic review</i>	<i>Professional focused</i>	<i>Not reported</i>	<i>Peer support work</i>	<i>Barriers and facilitators for peer support work</i>	<i>Identified various implementation influences: Organizational culture, training for service workers role definitions, staff willingness and ability to work with service users, resource availability, financial arrangements, support for service users well-being, access to a peer network</i>	<i>The authors utilized different languages, many databases and search approaches to access relevant studies</i>
<i>(101)</i>	<i>High income</i>	<i>Systematic review and meta analysis of randomized controlled trials</i>	<i>Severe mental health /depression service users, and mental health professional</i>	<i>Ranges from 20 to 352</i>	<i>Mental health service</i>	<i>Clinical (change in psychiatric symptoms) and psychosocial outcomes(quality of life, social functioning, and hope)</i>	<i>Small positive changes for peer providers in clinical (change in psychiatric symptoms) and psychosocial outcomes(quality of life, social functioning, and hope) Peer delivered service may be equivalent to</i>	<i>Acceptability is not reported The aim is to show global experiences but included only three high income countries Small number of studies Level of peer support Involvement is not well reported</i>

							<i>professional delivered services</i>	
(104)	<i>High income</i>	<i>Integrative review</i>	<i>Professional supported and service users –run partnership and service users as staff members</i>	<i>Heterogeneous</i>	<i>Range of health service activities</i>	<i>Service user recovery(emotional mental wellbeing, symptoms ,social) service users practical needs(employment, housing, financial)</i>	<i>Equally positive outcomes in the areas of employment or living arrangements, reduced hospitalization and cost of service</i>	<i>Comparison of recovery is difficult as the reviewed articles included varied outcome measures Did not indicate the level of involvement of service users, severity level of service user illness</i>
(100)	<i>High income</i>	<i>Systematic review of randomized controlled trials</i>	<i>Service users and mental health professionals</i>	2976	<i>Mental health service delivery</i>	<i>Client psychosocial outcomes :quality of life, functioning, social relations General mental health symptoms Client satisfaction with treatment Client –managers relationships Use of mental health services Hospital admission and length of stay</i>	<i>There is no significant difference between service users provided and health professional provided services There are equally positive outcomes particularly for practical outcomes: employment, income, education, living arrangements, and in reducing hospitalizations and the cost of services.</i>	<i>The studies are from a small number of countries Did not compare service user-reported outcomes with service provider reported outcomes The benefit of service provision for the service users providing the service is not reported The cost of involving the service users is not reported The capacity and competence level of service users was not reported</i>
(103)	<i>High income countries</i>	<i>Systematic review and meta analysis of randomized controlled trials</i>	<i>Professional conducted on severe mental illness</i>	<i>Ranges from 33to 333 and the aggregate was 5597</i>	<i>Not clearly defined on health system structures</i>	<i>Hospitalization Employment Overall psychiatric symptoms , depression and anxiety, quality of life, recovery, hope, empowerment , satisfaction with service</i>	<i>Incomplete outcome reporting and high risk of bias was identified Little or no evidence of effect on: hospitalization, overall symptoms, satisfaction with service Positive effect on: hope, recovery and empowerment</i>	<i>Measure of success is not analyzed in stratified by outcome parameters Peer support system is not explicitly specified Social network and others cultural issues are not included</i>
(102)	<i>High income countries</i>	<i>Systematic review</i>	<i>Service users providers on ACT and case management</i>	<i>Not pooled, but ranges from 14 to 260</i>	<i>Community Mental health service</i>	<i>Level of engagement Symptoms Hospitalization Quality of life</i>	<i>Improved engagement in treatment Limited support for reduced hospitalization Lack of evidence for symptom reduction or</i>	<i>Outcomes measured are not clearly stated Specific role and mechanisms used to engage service users is not clear The severity level of illness ,</i>

							<i>improved quality of life</i>	<i>health literacy level of service user is not clear</i>
(327)	<i>China</i>	<i>Randomized controlled trials with a three group repeated measure</i>	<i>Family-led peer support</i>	<i>106</i>	<i>Outpatient care</i>	<i>Family support service utilization Functioning Patients functioning mental state, hospitalization rate Family care giving burden Patient functioning</i>	<i>Overall improvement in functioning Reduction in duration and number of hospitalization</i>	<i>The participants are more homogeneous on socio-demographic variables generalizing to others is very difficult Some variables which affect outcome such as culture, severity level, health literacy need consideration</i>

### Appendix3. Information sheet, consent forms and interview guides

#### Study I: Information sheet and consent form for service users – English version



#### INFORMATION SHEET FOR PARTICIPANTS

*KCL REC reference number: PNM-1314-4*

*Local reference number: XXXX*

#### **YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET**

#### **EMERALD: Assessment of capacity-building needs of service users with respect to mental health system strengthening**

We would like to invite you to participate in this original research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

#### **What are the study's aims?**

This study is looking at how patients can be involved to make mental health care systems and services better.

#### **Who are we recruiting for the study?**

We are including people with psychosis, depression or alcohol use disorder, as well as their families or main caregivers, and representatives from patient or caregiver organisations.

#### **What will happen if you agree to take part?**

You will be invited to take part in an interview. The interview will last one hour at the most. We will ask you questions about your personal experiences and opinions of mental health services. We will particularly ask you about your experiences and opinions of how to involve patients better when developing, monitoring and assessing mental health services. We will also ask you for your opinion about the kind of training or support patients may need in order to help them take part more actively in their mental health care.

#### **Are there any risks or disadvantages associated with taking part in the study?**

We do not think that the interview will cause you any problems. However, on rare occasions, somebody might be upset by the questions that they are being asked. If you are upset by the questions, then you do not have to answer the question; the interview can also be stopped at any time.

#### **Are there any benefits of taking part in the study?**

There is no direct benefit to you or your family or caregiver by taking part in the study. However, we hope that the information we collect will help to improve mental health services in Ethiopia and other similar countries.

#### **What will we do with your information?**

Interviews may be tape-recorded, if you agree to this. If you take part in a tape-recorded interview, we will make sure that the tapes do not include your name or any information from which you can be identified. If notes are taken instead of tape-recordings, these notes will also not include your name or information from which you can be identified. The tapes and notes will be kept in a locked cupboard. Once the interview tapes have been written down, and the data has been analysed, the tapes will be cleared.

Nobody except the project co-ordinators and project data managers will know that the information belongs to you. We will keep the questionnaires in a locked cupboard.

After the end of this study, the information you give us may be stored and used by other researchers, but they will not be able to identify you in any way.

If we come across any harmful activity during the research, we do not have a legal obligation to tell anyone about this. However, if we think that you or anybody else is at risk of being harmed, we may ask a support team to do something about this, or we can try to help you contact a relevant support person if you wish.

**What will we do with the results of the study?**

Once the overall study is completed, we will let you know what we have found out, either by inviting you to a meeting, by giving you a leaflet, or publishing our findings in the district.

We plan to publish the findings in scholarly journals and at conferences. We will also tell our findings to policy makers within the Ministry of Health in Ethiopia and other similar countries.

**Do I have to take part in the study?**

It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw from the study at any time and without giving a reason.

You may also withdraw any information you have already provided up until 01 March 2014. A decision to withdraw at any time, or a decision to take part, will not affect the standard of care you receive, or disadvantage you in any way.

If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

**Who is funding the study?**

This study is being funded by the European Union.

**Who is carrying out the study?**

The study is part of the EMERALD (Emerging mental health systems in low- and middle-income countries) project, which is being carried out in Ethiopia, India, Nepal, Nigeria, South Africa and Uganda. The project is led by Professor Graham Thornicroft from the Institute of Psychiatry, King's College London. The study in Ethiopia is being carried out by Addis Ababa University.

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Prof. Atalay Alem and Dr Charlotte Hanlon. Contactable through the Butajira project office on telephone number 046 151595, from Monday to Friday during working hours.

If this study has harmed you in any way, you can contact the Institutional Review Board, Addis Ababa University, using the details below for further advice and information:

- Institutional Review Board, School of Medicine, Addis Ababa University  
Telephone number: 0115-5538734

## Study1. Consent Form for Participants in Research Studies



Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Study:

**EMERALD: Assessment of capacity-building needs of service users with respect to mental health system strengthening**

King's College Research Ethics Committee Ref: PNM-1314-4

Local Research Ethics Committee Ref: XXXX

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Please tick or initial  
to show agreement

- I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw   
from it immediately without giving any reason. Furthermore, I understand that  
I will be able to withdraw my data up until 01 March 2014.
- I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in   
accordance with the local data protection rules and the rules of the UK Data  
Protection Act 1998.
- I understand that the information I have submitted will be published as a report. I note that confidentiality and anonymity will be maintained and it will not be   
possible to identify me from any publications.
- I agree that the research team may use my data for future research and understand that any such use of identifiable data would be reviewed and   
approved by a research ethics committee. (In such cases, as with this project,

data would not be identifiable in any report).

- I agree that my data will be archived in anonymised form, so that other researchers may use my data for future research. I understand that any such use of identifiable data would be reviewed and approved by a research ethics committee. (In such cases, as with this project, data would not be identifiable in any report).

- I agree for the interview to be audio-recorded.

**Participant's Statement:**

I \_\_\_\_\_  
agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed \_\_\_\_\_ Date \_\_\_\_\_

**Witness Statement (in event that participant is not literate):**

I \_\_\_\_\_  
agree that the research project named above has been explained to \_\_\_\_\_ (participant) to his/her satisfaction and that s/he agrees to take part in the study. Both the notes written above and the Information Sheet about the project have been read to him/her, and s/he understands what the research study involves.

Signed \_\_\_\_\_ Date \_\_\_\_\_

**Investigator's Statement:**

I \_\_\_\_\_  
confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

Signed \_\_\_\_\_

Date \_\_\_\_\_



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The quality and appropriateness of mental health care can be improved by involving patients and caregivers in designing, monitoring and evaluation of mental health services. There is not much experience with this approach in low- and middle-income countries, like [Ethiopia]. The aim of this interview is to hear about any experiences you have of being involved in mental health service development, monitoring and evaluation. We are also interested to hear about your opinions on this approach and the barriers that might exist to trying this in [Ethiopia]. We will also ask you about the kind of training or support you might need in order to get more involved. There are no right or wrong answers, we are particularly interested in your personal experiences and views. I have four main questions for you with additional questions. If you prefer some of the information you provide not to be audio-recorded please let me know, and I can stop the tape recorder and start the recording again only with your verbal agreement.

*Socio-demographic information*

1.	Gender	Female Male
2.	Age	[ ] [ ] years
3.	Educational level	Non-literate Literate, no formal schooling Literate, formal schooling – completed grade [ ] [ ]
4.	Ethnicity	Amhara Oromo Tigray Other
5.	Religion	Orthodox Christian Muslim Protestant Christian Other
6.	Mental health condition	Schizophrenia Bipolar Disorder Depression Epilepsy Alcohol use disorder Any other/combination of the above
7.	Length of time in contact with services	[ ] [ ] months/years

*Interview schedule*

**A. Mental health policy-making**

First I would like to ask you about mental health policy-making. For example, the national Strategy developed by the Ministry of Health for Ethiopia that sets out the priorities and overall approach to mental health care.

- (1) Were you / your organisation involved at all in the development of the mental health policy in [Ethiopia]?
  - a. Can you tell me about that experience? What was your contribution? Why were you selected? Was it a positive experience? What could have improved the experience? Would training in mental health policy-making be useful to facilitate your contribution?

- (2) How do you think patients / patient organisations can contribute to mental health policy-making?
  - a. What could be their specific contribution?
  - b. How would patients be selected to participate?
  - c. What type of training would be helpful?
  - d. What kind of support in your view is required?
- (3) What kind of barriers do you know about that would hinder patient involvement in policy-making? (from the service user perspective, from the policy maker perspective)

## **B. Mental health planning and service development**

Now I am going to ask you about the planning and development of mental health services. For example, the decisions that are made about what type of service is going to be delivered, where it will be delivered, who will deliver it and how they will deliver it.

- (4) Have you / your organisation ever been involved in any aspects of the design and development of mental health services?
  - a. If so, can you tell me about that experience?
    - i. Which mental health service?
    - ii. What was your level of involvement?
    - iii. What contribution do you think you made?
    - iv. Can you tell me about positive parts of the experience?
    - v. What kind of difficulties did you encounter in the process?
    - vi. Is there anything about the process that could be improved?
    - vii. How can training be helpful to you to contribute? What kind of training?
  - b. If not, what do you think about the idea of patients getting involved in service development in that way?
    - i. Given your experiences living with a mental health condition for a while how can you contribute?
    - ii. What do you think could be of benefit to you?
    - iii. From your perspective what kind of problems or challenges would you anticipate and why? From the side of the service planners?
    - iv. What else might help to facilitate greater involvement of patients in this process?

## **C. Monitoring mental health services**

Now I am going to ask you about patient involvement in monitoring the quality of mental health services.

- (5) Have you / your organisation ever been involved in monitoring the quality of a mental health service delivered in your area?
  - a. If so, can you tell me about the experience?
    - i. Which mental health service?
    - ii. Can you describe to me your level of involvement?
    - iii. Can you give me examples what kind of contribution(s) you made?
    - iv. In your view, can you describe to me what positive experience(s) there were or what kind of difficulties you encountered?
    - v. How were you able to help improve the quality of the service?
    - vi. Is there anything about the process that could be improved?
    - vii. How can training be helpful to you to contribute? What kind of training?

- b. If not, what do you think about the idea of involving patients in improving the quality of mental health services?
  - i. Given your experiences living with a mental health condition for a while how can you contribute?
  - ii. What do you think could be a benefit of your involvement?
  - iii. In your view, what kinds of problems or challenges could there be to getting involved? From your side? From the side of the service providers?
  - iv. How can training be helpful to you to contribute? What kind of training?
  - v. What else might help to facilitate greater involvement of patients in this process?

**D. Mental health research and evaluation of mental health services**

Lastly I am going to ask you about patient involvement in research projects to improve mental health services.

- (6) Have you / your organisation ever been involved in a research project related to mental health services?

- a. If so, can you tell me about the experience?
  - i. Which mental health service?
  - ii. What was your level of involvement?
  - iii. What contribution do you think you made?
  - iv. Was it a positive experience or were there any difficulties? Did you feel that people listened to your contribution?
  - v. Is there anything about the process that could be improved?
  - vi. Would training be helpful to help you contribute more? If so, what kind of training?
- b. If not, what do you think about the idea of involving patients in research projects about mental health services?
  - i. Given your experiences living with a mental health condition for a while how can you contribute?
  - ii. What do you think could be a benefit of your involvement?
  - iii. In your view, what kinds of problems or challenges could there be to getting involved? From your side? From the side of the researchers?
  - iv. How can training be helpful to you to contribute? What kind of training?
  - v. What else might help to facilitate greater involvement of patients in this process?

**Study 1: Interview schedule -- Amharic version**  
**ጥቅል የሥራ ግብአት 2 - እዝል ለ፡ የ ቃለ መጠይቅ ማረጋገጫ**

**የ በሽተኞችን የ አቅም ግንባታ ፍላጎት ከአዕምሮ ጠፍ አጠባበቅ ስርአት ማጠናከሪያ አንጻር ዳሰሳ/ፍተሻ ማድረግ**

1. ለ በሽተኛው ወይም ለተንከባካቢው/አስታምቧቸው ለሆነ ውድር ጅት

**የ ቃለ መጠይቅ አላማ**

በሽተኞችን፣ ተንከባካቢዎቻቸውን/አስታምቧቸውን እና የእነርሱ ተጠሪ የሆነውን አካል በጠፍ አገልግሎት ንድፍ(ቀረጻ)፣ ቁጥጥርና ግምገማላይ በማሳተፍ የአዕምሮ ጠፍ ህክምና አገልግሎትን ጥራትና አግባብነት ማሻሻል፡፡ ይህን አይነት አቀራረብ እንደ ኢትዮጵያ ባሉ ዝቅተኛና ማከለኛ ገቢ ባላቸው ሀገሮች ብዙ ተግባር የለም ስለሆነ ምንም እንኳን ቃለ መጠይቅ አላማ እርሰዎ ወይም የእርሰዎ ድርጅት በማንኛውም የጠፍ አገልግሎት ልማት፣ ቁጥጥር፣ ምርምርና ግምገማላይ ተሳትፎ ወይም ልምድ ካላችሁ ለማወቅ ነው፡፡ ከዚህ ጋር ተያያዘ ስለሆነ አቀራረብ/ዘዴ ያለዎትን የግል አስተያየት እና ይህንን አቀራረብ ኢትዮጵያ ውስጥ ተግባራዊ ለማድረግ ምን አይነት እንቅፋቶች ሊያጋጥሙ እንደሚችሉ ከእርሰዎ ለመሰማት ፍላጎት አለን፡፡ በተጨማሪም እርሰዎ ወይም በእርሰዎ ድርጅት ውስጥ የሚገኙ ሰዎች ንቁ ተሳታፊ እንዲሆኑ ምን አይነት ስልጠናና ድጋፍ እንደሚሰጡ ለሌሎችህ የምንጠይቀዎት ይሆናል፡፡

ስለ መላሹ ወይም ስለ ድርጅቱ ዋና ዋና ሚዛኞች

1	ድርጅቱ የ ማዘጋጀት ወይም ሌላ ማንኛውን ነው	በሀገር አቀፍ ደረጃ ላሉ ታምቧቸው በክልል አቀፍ ወይም ከሀገር ላሉ ታምቧቸው በሀገር አቀፍ ደረጃ ላሉ ተንከባካቢዎች/አስታምቧቸው በክልል አቀፍ ወይም ከሀገር ላሉ ተንከባካቢዎች/አስታምቧቸው
2	የድርጅቱ ተዋጊዎች የ ማዘጋጀት ወይም ሌላ ማንኛውን ስህተት ህመም ያለባቸውን ሰዎች ነው	ስኬታዊነት ባይደረግ ዲስኬት/ሽቅለት ድብደባ የ ማዘጋጀት በአልኮል ማጠገን ያያት የ ማዘጋጀት አዕምሮ ህመም ማንኛውም የ አዕምሮ በሽታ ሌላ ካለ ይጥቀሱ -----
3	የ መላሹ ያታ	ሴት ወንድ
4	በድርጅቱ ውስጥ ያለዎት የሥራ ድርሻ	

የ ቃለ መጠይቅ ማረጋገጫ

2. ለ በሽተኞች/አስታምቧቸው

**የ ቃለ መጠይቅ አላማ**

በሽተኞችንና ተንከባካቢዎቻቸውን/አስታምቧቸውን በጠፍ አገልግሎት ንድፍ(ቀረጻ)፣ ቁጥጥርና ግምገማላይ በማሳተፍ የአዕምሮ ጠፍ ህክምና አገልግሎትን ጥራትና አግባብነት ማሻሻል፡፡ ይህን አይነት አቀራረብ እንደ ኢትዮጵያ ባሉ ዝቅተኛና ማከለኛ ገቢ ባላቸው ሀገሮች ብዙ ተግባር የለም ስለሆነ ምንም እንኳን ቃለ መጠይቅ አላማ እርሰዎ ወይም የእርሰዎ ድርጅት በማንኛውም የጠፍ አገልግሎት ልማት፣ ቁጥጥር፣ ምርምርና ግምገማላይ ተሳትፎ ወይም ልምድ ካላችሁ ለማወቅ ነው፡፡ ከዚህ ጋር ተያያዘ ስለሆነ አቀራረብ/ዘዴ ያለዎትን የግል አስተያየት እና ይህንን አቀራረብ ኢትዮጵያ ውስጥ ተግባራዊ ለማድረግ ምን አይነት እንቅፋቶች ሊያጋጥሙ እንደሚችሉ ከእርሰዎ ለመሰማት ፍላጎት አለን፡፡ በተጨማሪም

እርስዎ ወይም በእርስዎ ድርጅት ውስጥ የሚገኙት ሰዎች ንቁ ተሳታፊ እንዲሆኑ ምን አይነት ስልጠናና ድጋፍ እንደሚሰጡዎትሁ የምንጠይቀዎት ይሆናል፡፡

ስለግለሰቡ አጠቃላይ መረጃ (ማህበራዊና ስነ-ህዝባዊ መረጃዎች)

1	የጾታ	ሴት ወንድ
2	እድሜ	( ) ( ) ዓመት
3	የትምህርት ደረጃ	ያልተማረ የተማለ ነገር ግን ማደብኛ ትምህርት የሌለው ማደብኛ ትምህርት የተማረ ( ) ( ) ክፍል ያጠናቀቀ
4	ብሔር	አማራ አሮሞ ትግሬ ሌሎች
5	ሐይማኖት	አርቶዶክስ ክርስቲያን ሜሃሊም ፕሮቴስታንት ክርስቲያን ሌሎች
6	የአዕምሮ ጠፍ ሁኔታ	ስኪዥኒዥን ባይፖላር ዲስኦርደር/ሽቅለት ድብርት የሚጠፍ በሽታ በአልኮል ማጠጥ ምክንያት የሚመጣ የአዕምሮ ህመም ሌላ ካለ ይጥቀሱ/ ከላይ ከተጠቀሱት ሁለቱ ወይም ከዚያ በላይ በአንድ ላይ ካለበት
7	አገልግሎቱን በማጠቃለያ ቆይቶበት ጊዜ	( ) ( ) ወሮች ዓመታት

የቃለ መጠይቅ መርሃግብር

**ሀ. የአዕምሮ ጠፍ ፖሊሲ አቀራረጽ**

በመጀመሪያ ስለአዕምሮ ጠፍ ፖሊሲ አዎጣጥ/አቀራረጽ ልጠይቀዎት እወዳለሁ፤ ለምሳሌ ያክል፤ በፌዴራል ጠፍ ጥበቃ ሜሪትቴር የተቀረጸው ሀገር አቀፍ ስትራቴጅ የአዕምሮ ጠፍ ህክምናን በተመለከተ ቅድመ ሊሰጣቸው ስለሚገቡ አንገብጋቢ ጉዳዮችንና ጥቅል አቀራረቦችን አስቀምጧል፡፡

- እርስዎም ወይም ድርጅታዎ በማንኛውም ሀገሪቱ የአዕምሮ ጠፍ ፖሊሲ አዎጣጥ/አቀራረጽ ላይ ተሳትፈው ይወቃሉ?
  - ሀ. አላይ በተጠቀሰው ጉዳይ ላይ ያገኙትን ተግባር ሊነግሩኝ ይችላሉ? ያበረከቱት አስተዋጽኦ ምን ነበር? እርስዎ ለምን ተመረጡ? አዎነታዊ ልምድ ምን ነበር? ልምድ ምን ለወጥ ወይም መሻሻል አመጣ? እርስዎ ያለዎትን ተሳትፎ ለማዘጋጀት በአዕምሮ ጠፍ ፖሊሲ አዎጣጥ/አቀራረጽ ላይ ስልጠና ጠቃሚ ሊሆን ይችላል?
- በሽተኞች/ የእነርሱ ድርጅቶች ለአዕምሮ ጠፍ ፖሊሲ አዎጣጥ/አቀራረጽ አስተዋጽኦ ማድረግ ይችላሉ ብለው ያስባሉ?
  - ሀ. ግልጽ አስተዋጽኦቸው ለምን ይችላሉ?
  - ለ. በሽተኞች እንዴት ሊሚጠቅሙ ይችላሉ?
  - ሐ. ምን አይነት ስልጠና ቢሰጥ ጠቃሚ ይሆናል?
  - መ. በእርስዎ አስተያየት ምን አይነት ድጋፍ የሚሰጥ ስልጠና ይመስለዎታል?

3. ከበሽተኞችም ይሁን ከፖሊሲ አወጫቸው በኩል በሽተኞችን በፖሊሲ አወጣጡላይ እንዳይሳተፉ ምን ምን መሳተፍ ክስቶች ሊገጥሟቸው እንደሚችሉ ያውቃሉ?

**ለ. የአዕምሮ ጠፍ እቅድ እና የአገልግሎት ልማት**

አሁን ስለአዕምሮ ጠፍ አገልግሎት እቅድ እና ልማት እጠይቀዎታለሁ፤ ለምሳሌ ያክል፣ ምን ዓይነት አገልግሎት እንደሚሰጥ ስለሚወሰን ወውሳኔ፣ የት እንደሚሰጥ፣ እነ ማን እንደሚሰጡትና እንዴት እንደሚሰጡ፡፡

4. እርስዎ ወይም ድርጅታዎ በማንኛውም የአዕምሮ ጠፍ አገልግሎት ቀረጻ/ንድፍና ልማት ላይ ተሳትፋችሁ ታቃላችሁ?

ሀ. ተሳትፈው የሚያወቁ ከሆነ፣ ስለአገልግሎት ልምድ ሊነግሩኝ ይችላሉ?

- i. የትኛው የአዕምሮ ጠፍ አገልግሎት?
- ii. ተሳትፎዎት በምን ያህል ደረጃ ነበር?
- iii. ምን ያህል አስተዋጽኦ አበርክቻለሁ ብለው ያስባሉ?
- iv. ያገኙትን አዎንታዊ ልምድ ሊነግሩኝ ይችላሉ?
- v. በሂደቱ ወስጥ ምን ዓይነት ችግሮች ገጥመዎት ነበር?
- vi. በሂደቱ ወስጥ መሻሻል የነበረበት ነገር ነበር?
- vii. ስልጠና ለእርስዎ ተሳትፎ ምን ያህል አስፈላጊ/ጠቃሚ ነው? እንዴት ያደገዎት ያስልጠኑ?

ለ. ተሳትፈው የሚያወቁ ከሆነ፣ የበሽተኞች በአዕምሮ ጠፍ አገልግሎት ልማት ላይ በዚህ መልክ መሳተፍ ስለሚላው አስተሳሰብ ምን ያስባሉ?

- i. ስለአዕምሮ ጠፍ ችግር ባለዎት ልምድ ምን ዓይነት አስተዋጽኦ ሊኖረዎት ይችላል?
- ii. ስለአዕምሮ ጠፍ ችግር ልምድ ቢያገኙ ምን ጠቀሜታ ሊያገኙ ይችላሉ ነበር?
- iii. በእርስዎ እይታ ምን ዓይነት ችግሮችና ተግዳሮቶች ያጋጥሟሉ ብለው ይጠበቃሉ? ለምን? ከአገልግሎት እቅድ አወጫቸው በኩልስ?
- iv. በሽተኞች በሂደቱ ንቁ/የበለጠ ተሳትፎ እንዲኖራቸው ለማድረግ ምን ተጨማሪ ነገር በደረግ ይጠቅማል ይላሉ?

**ሐ. የአዕምሮ ጠፍ አገልግሎት ቁጥጥር/ክትትል**

አሁን በሽተኞች በአዕምሮ ጠፍ አገልግሎት ጥራት ቁጥጥር/ክትትል ስላላቸው ተሳትፎ እጠይቀዎታለሁ፡፡

5. እርስዎ ወይም ድርጅታዎ በማንኛውም የአዕምሮ ጠፍ አገልግሎት ጥራት ቁጥጥር/ክትትል ላይ ተሳትፋችሁ ታውቃላችሁ?

ሀ. ተሳትፈው የሚያወቁ ከሆነ፣ ስለአገልግሎት ልምድ ሊነግሩኝ ይችላሉ?

- i. የትኛው የአዕምሮ ጠፍ አገልግሎት?
- ii. ተሳትፎዎት በምን ያህል ደረጃ ነበር?
- iii. ካደረጓቸው አስተዋጽኦዎች ምሳሌ ሊነግሩኝ ይችላሉ?
- iv. በእርስዎ እይታ፣ ያገኙትን አዎንታዊ ልምድ ወይም ምን ዓይነት ችግሮች እንዳጋጠሙት ሊያብራሩልኝ ይችላሉ?
- v. ለአገልግሎት ጥራት መሻሻል ምን ያህል አስተዋጽኦ ለማድረግ ችለው ነበር?
- vi. በሂደቱ ወስጥ መሻሻል የነበረበት ነገር ነበር?
- vii. ስልጠና ለእርስዎ ተሳትፎ ምን ያህል አስፈላጊ ነው? እንዴት ያደገዎት ያስልጠኑ?

ለ. ተሳትፈው የሚያወቁ ከሆነ፣ የበሽተኞች የአዕምሮ ጠፍ አገልግሎት ጥራት ቁጥጥር/ክትትል ላይ መሳተፍ ስለሚላው አስተሳሰብ ምን ያስባሉ?

- i. ስለአዕምሮ ጠፍ ችግር ባለዎት ልምድ ምን ዓይነት አስተዋጽኦ ሊኖረዎት ይችላሉ?
- ii. ስለአዕምሮ ጠፍ ችግር ልምድ ቢያገኙ ምን ጠቀሜታ ሊያገኙ ይችላሉ ነበር?
- iii. ከእርስዎ ወይም ከአገልግሎት ሰጪዎቹ በኩል ምን ዓይነት ችግሮችና ተግዳሮቶች ያጋጥሟሉ ብለው ይጠበቃሉ? ለምን?
- iv. ስልጠና ለእርስዎ ተሳትፎ ምን ያህል አስፈላጊ ነው? እንዴት ያደገዎት ያስልጠኑ?
- v. በሽተኞች በሂደቱ ንቁ ተሳትፎ እንዲኖራቸው ለማድረግ ምን ተጨማሪ ነገር በደረግ ይጠቅማል ይላሉ?

**መ. የአዕምሮ ጠፍ አገልግሎት ምርምርና ግምገማ**

በመጨረሻም በሽተኞች የአዕምሮ ጠፍ አገልግሎትን ለማሻሻል ከሚሰጡ የምርምር ፕሮጀክቶች ላይ ስላላቸው ተሳትፎ እጠይቀውታለሁ፡፡

6. እርስዎ ወይም ድርጅቱም በማንኛውም የአዕምሮ ጠፍ አገልግሎት ጋር የተያያዘ የምርምር ፕሮጀክት ላይ ተሳትፏችሁ ታወቃላችሁ?

ሀ. ተሳትፏው የሚያወቁ ከሆነ፣ ስለአገራችን ልምድ ሊነግሩኝ ይችላሉ?

- i. የትኛው የአዕምሮ ጠፍ አገልግሎት?
- ii. ተሳትፎዎት በምን ያህል ደረጃ ነበር?
- iii. ምን ያህል ተሳትፎ ነበረኝ ብለው ያስባሉ?
- iv. ልምድ አዎንታዊ ነበር ወይም ስሜት አይነት ችግሮች ነበሩ? የእርስዎን ተሳትፎ ሰዎች ተገንዝበውታል ብለው ያስባሉ?
- v. በሂደቱ ወስጥ ማሻሻል የነበረበት ነገር ነበር?
- vi. ስልጠና ለእርስዎ የበለጠ ተሳትፎ ምን ያህል አስፈላጊ ነው? እንዴት አይነት ስልጠና?

ለ. ተሳትፏው የሚያወቁ ከሆነ፣ የበሽተኞች የአዕምሮ ጠፍ አገልግሎት ላይ የሚሰጡ የምርምር ፕሮጀክቶች ላይ መሳተፍ ስለሚችሉት ስሜት ስለተሰጠ ምን ያስባሉ?

- i. ስለአዕምሮ ጠፍ ችግር ባለዎት ልምድ ምን አይነት አስተዋጽኦ ሊኖረዎት ይችላሉ?
- ii. ስለአዕምሮ ጠፍ ችግር ልምድ ቢያገኙ ምን ጠቀሜታ ሊያገኙ ይችላሉ ነበር?
- iii. ከእርስዎ ወይም ከአገልግሎት ሰጪዎቹ በኩል ምን አይነት ችግሮችና ተግዳሮቶች ያጋጥሟሉ ብለው ይጠብቃሉ? ለምን?
- iv. ስልጠና ለእርስዎ ተሳትፎ ምን ያህል አስፈላጊ ነው? እንዴት አይነት ስልጠና?
- v. በሽተኞች በሂደቱ ጋር ተሳትፎ እንዲኖራቸው ለማድረግ ምን ተጨማሪ ነገር ቢደረግ ይጠቅማል ይላሉ?

## Study 1: Interview Schedule for District Level Managers/PHC Co-ordinators

### Aim of the interview

The new National Mental Health Strategy of Ethiopia (Federal Ministry of Health) stipulates that mental health care should be integrated into primary health care. While a number of low- and middle-income countries have policies and legislation which support the integration of mental health care into primary health care to varying degrees, these are not sufficient to ensure transformation of the health care system towards integrated primary mental health care. In addition to the integration of packages of care for mental disorders using a task sharing (or task-shifting) approach, health systems strengthening is needed to support these integrated services.

The aim of this interview is to get your opinions on health system factors at the level of the district that you think might be barriers to or facilitate the implementation of Ethiopia's mental health service integration plans.

### Research Question

**What district health system level processes are likely to aid or impede the implementation of mental health service integration plans in Ethiopia?**

#### 1. AWARENESS OF THE IMPORTANCE OF MENTAL HEALTH AND REDUCED STIGMA

1.1 How much of a burden do you think mental health problems are amongst people attending health centres? What about in the community?

1.2 In a setting like Ethiopia, how important do you think it is to have integration of mental health care into primary health care services?

a) Probe for possible advantages and disadvantages of integration.

1.3 How important do you think it is that primary health care staff are trained to deliver mental health care?

- a) Probe for possible advantages and disadvantages of this training.
- 1.4 Are you aware of any anti-stigma programmes for mental health?
  - a) Probe for whether they have been involved/would like to be involved.
  - b) Probe for whether they think patients and/or caregivers should be involved in these activities.
  - c) Probe for whether they think health professionals should be involved in these activities

## 2. HUMAN RESOURCE ISSUES

2.1. Is there a co-ordinator appointed to oversee the integration of mental health care in this district?

Probe for how much of a role this person has (or will have) in the following activities:

- a) Ensuring ongoing training and supervision of primary care staff in mental health care
- b) Monitoring the quality of services
- c) Ensuring reliable and timely supply of adequate medication.
- d) Ensuring the timely appointment of specialist mental health professionals to support the primary care workers.
- e) Any other roles?

2.2. What are the possible barriers/facilitating factors to having maximum coverage of staff trained in mental health guidelines?

Probe for how the following affect coverage:

- a) Staff turn-over. Is there high staff turn-over? If so why? What measures can be taken to improve retention of staff?
- b) Recruitment procedures. Are these procedures efficient (e.g., how long does it take to recruit and appoint new staff?). If not, what problems exist with recruitment procedures? What measures can be taken to improve these procedures?
- c) Training procedures. Are there procedures in place that would ensure that new staff are quickly trained in mental health care. If not, how can these procedures be put in place? Are there procedures for refresher training? What measures can be taken to improve these procedures?

2.3. What are the possible barriers/facilitating factors for using **health extension workers** to help identify and/or provide psychosocial interventions?

Probe for the following:

- a) Whether the role of **health extension workers** in mental health care would have official recognition.
- b) Whether they would have time? Or sufficient skills?
- c) What kind of support would they need? Are there systems in place to provide this support?

2.4. What are the possible barriers/facilitating factors for using the **health development army** to help identify and/or provide psychosocial interventions (e.g. basic counselling)?

Probe for the following:

- a) The sustainability of relying on health volunteers
- b) Whether they would have sufficient skills?
- c) What kind of support would they need? Are there systems in place to provide this support?

2.5. What are the possible barriers/facilitating factors to having sufficient **specialist mental health professionals** to provide support (e.g. in terms of ongoing/refresher training, supervision, support and a referral service for more complex/treatment resistant cases)?

Probe for:

- a) Staff turn-over. Is there high staff turn-over of specialist staff? If so why? What measures can be taken to improve retention of specialist staff?
- b) Recruitment procedures. How much of a role does the district health office have in recruitment of specialist mental health professionals?

- c) Training procedures. Are there procedures in place that would ensure that new specialist staff are retrained to provide appropriate supervision and support? If not, how can these procedures be put in place? Who is responsible for ensuring this happens?
- d) Attitudes of specialist staff towards task sharing. Are specialist staff supportive of diversifying their roles to provide training, supervision and support to non-specialist staff in mental health care?

### **3. EQUIPMENT AND INFRASTRUCTURE FOR MHC**

3.1. How adequate is the supply of drugs/medications for mental health care at the district health facilities?

If not adequate, probe for how the following may affect drug supply

- a) Drug policies. How do these impact on availability of drugs? Are psychotropic medications part of an essential drug list? Are these drugs made available free of charge to patients? What measures can be taken to improve drug policies?
  - b) Supply systems. How are drugs distributed to PHC clinics? What are the problems with the supply system? Are there buffer supplies/emergency stocks? What can be done to improve it?
- 3.2. What difficulties could there be with the supply of guidelines to treat mental disorders (and retaining these materials) in the clinics?  
Probe for reasons for problems and possible procedures that can be put into place to overcome them.
- 3.3. To what extent do you think people with mental disorders will be able to speak privately to the health worker?  
Probe:  
Are there enough consultation rooms for people to be seen individually?  
What issues could there be regarding confidentiality?
- 3.4. How could the health centre know which people with mental illness need regular follow-up and identify people who drop out of care? Are there mechanisms to support this activity?

### **4. SYSTEMS FOR PLANNING AND MANAGEMENT**

- 4.1. How do systems for planning and management operate? Probe for:
- a) Where does healthcare planning take place? Zonal level? District level? Regional level? Is this the same for mental health care? Are decisions about different aspects of health care taken at different levels?
  - b) How can planning procedures for mental health care that are successful in the PRIME district be transferred to other districts?
- 4.2. Given that mental health care is a multi-sectoral endeavour, at a district level, how does the district health office collaborate with other sectors to tackle mental health problems and its determinants? Probe for
- a) Mechanisms/structures that facilitate this. If there aren't existing mechanisms, probe for measures that can be put in place to facilitate this.

### **5. PATIENT PARTICIPATION**

5.1. What is the extent of patient or caregiver participation in the planning and delivery of mental health services?

5.2. How could patient or caregiver participation improve how mental health care is implemented in your district through the PRIME project?

Probe for:

- a) How might patients and caregivers contribute to making the service development / implementation a success?
- b) How could patients and caregivers be involved in monitoring quality / improving services?
- c) How would you feel about working with patients and caregivers in this way?
- d) What type of training might help you to work with patients and caregivers in this way?

## 6. Monitoring and evaluation

- 6.1 How can delivery of mental health care in primary care be monitored in a feasible and sustainable way?  
Probe:  
What kind of HMIS indicators would be useful?
- 6.2 Are there processes in place to give feedback to individual health centres about how well they are doing in terms of mental health care delivery?  
Probe:  
What could be done to improve this?

## 7. Capacity Building

7.1. We have been discussing many aspects of health system strengthening, especially focusing on mental health systems. Are there any parts of health system strengthening where you [or other people in the district health office] would value (additional) training?

*[Document spontaneous response]*

7.2. Then probe with the following for the capacity-building priorities within their organisation

### **PRIORITIES FOR CAPACITY-BUILDING AT THE DISTRICT LEVEL**

	<i>How important is it for your institution to build capacity in each of the following areas?</i>				
	<i>1 = irrelevant</i>	<i>2 = not a priority now</i>	<i>3 = important but not a priority</i>	<i>4 = a priority need</i>	<i>5 = an essential need</i>
	1	2	3	4	5
<b><i>Mental health policy, planning and programme development</i></b>					
<i>Mental health policy development or policy review and re-formulation</i>					
<i>Evidence-based mental health care planning</i>					
<i>Mental health programme development</i>					
<i>Planning for a system of mental health in primary care</i>					
<i>Developing partnerships with patients for policy-making and service development</i>					
<i>Human resources projection and cost calculation</i>					
<b><i>Mental health systems</i></b>					
<i>Governance of mental health systems</i>					
<i>Mental health system leadership</i>					
<i>Mental health information systems</i>					
<i>Mental health system communication</i>					
<i>Mental health system advocacy strategies</i>					
<b><i>Mental health service implementation</i></b>					
<i>Training for mental health workforce</i>					
<i>Antistigma campaigns</i>					
<i>Monitoring and evaluation of mental health services</i>					

<i>Developing partnerships with patients to involve in quality control</i>					
<i>Implementation of mental health services in post-conflict settings</i>					
<i>Community-based approaches to mental health care</i>					
<b><i>Mental health research</i></b>					
<i>Priority setting in mental health systems research</i>					
<i>Conducting mental health needs assessments</i>					

## **Study 2-4: service users/caregiver information sheet - English version**

### **Addis Ababa University Research Ethics Committee Ref No:**

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

#### **Study title: Developing Service User/Caregiver Involvement in Mental Health System Strengthening In Ethiopia**

We would like to invite you to participate in this post graduate research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

#### **Aim of the study?**

This study is looking at how service user/caregiver can be involved to make mental health care systems and services better.

#### **Who are we recruiting for the study?**

We are including people with psychosis (schizophrenia /Bipolar disorder) well as their families or main caregivers, and representatives from service user or caregiver organizations.

#### **What will happen if you agree to take part?**

You will be invited to take part in research. We also invite you to trainings. Before the training and after the training you will be invited to interview. The interview will last one hour at the most. We will ask you questions about your own understanding on types of mental health problems, treatments for mental health problems, the protections for people with mental health problems, kind of contribution you and your caregiver/family can make to improve mental health system, your understanding about other people with mental health problems. We will also ask you about your experiences and opinions of how to involve service users/caregivers better in mental health system when developing, monitoring and assessing mental health services and mental health research. We will also ask you after the training for your opinion about the capacity building training, your level of satisfaction with the training and your comments how to improve the capacity building in the future. Furthermore, we will invite you individually or in group to participate in participatory action research.

**Are there any risks or disadvantages associated with taking part in the study?**

We do not think that the interview will cause you any problems. However, on rare occasions, somebody might be upset by the questions that they are being asked. If you are upset by the questions, then you do not have to answer the question; the interview can also be stopped at any time.

**Are there any benefits of taking part in the study?**

There is no direct benefit to you or your family or caregiver by taking part in the study. However, we hope that the information we collect will help to improve mental health services in your district *and* other similar areas in Ethiopia.

**What will we do with your information?**

Interviews may be tape-recorded, if you agree to this. If you take part in a tape-recorded interview, we will make sure that the tapes do not include your name or any information from which you can be identified. If notes are taken instead of tape-recordings, these notes will also not include your name or information from which you can be identified. The tapes and notes will be kept in a locked cupboard. Once the interview tapes have been written down, and the data has been analysed, the tapes will be cleared.

Nobody except the researcher and co-ordinators (research assistants in data collection and processing) and data managers will know that the information belongs to you. We will keep the questionnaires in a locked cupboard.

After the end of this study, the information you give us may be stored and used by other researchers, but they will not be able to identify you in any way.

If we come across any harmful activity during the research, we do not have a legal obligation to tell anyone about this. However, if we think that you or anybody else is at risk of being harmed, we may ask a support team to do something about this, or we can try to help you contact a relevant support person if you wish.

**What will we do with the results of the study?**

Once the overall study is completed, we will let you know what we have found out, either by inviting you to a meeting, by giving you a leaflet, or publishing our findings.

We plan to publish the findings in scholarly journals and at conferences. We will also tell our findings to policy makers within the Ministry of Health in Ethiopia.

**Do I have to take part in the study?**

It is up to you to decide whether to take part or not. If you decide to take part you are still free to withdraw from the study at any time and without giving a reason. A decision to withdraw at any time, or a decision to take part, will not affect the standard of care you receive, or disadvantage you in any way.

If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form.

**Who is funding the study?**

This study is being funded by Emerald project and Addis Ababa University.

**Principal investigator**

Sisay Abayneh, Mobile: 0910399053. Primary supervisor *Dr Charlotte Hanlon*

If you have any questions or require more information about this study, please contact the research team using the following contact details:

Prof. Atalay Alem and Dr Charlotte Hanlon. Contactable through the Butajira project office on telephone number 046 151595, from Monday to Friday during working hours.

If this study has harmed you in any way, you can contact the Institutional Review Board, Addis Ababa University, using the details below for further advice and information:

- Institutional Review Board, School of Medicine, Addis Ababa University  
Telephone number: 0115-553873

### **Study 2-4: service users/caregiver information sheet – English version**

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

#### **Title of Study: Developing service user/caregiver involvement in mental health system strengthening in Ethiopia**

Addis Ababa University Research Ethics Committee Ref No:

**Thank you for considering taking part in this research. The person organizing the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.**

**Please tick or initial  
to show agreement**

- **I understand that if I decide at any time during the research that I no longer wish to participate in this project, I can notify the researchers involved and withdraw**

**from it immediately without giving any reason. Furthermore, I understand that**

**I will be able to withdraw my data up until they are published.**

- **I consent to the processing of my personal information for the purposes explained to me. I understand that such information will be handled in**

**accordance with the Ethiopian data protection rules**

**I understand that the information I have submitted will be published as a report.**

**I note that confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.**

- I agree that the research team may use my data for future research .
- I agree that my data will be archived in anonymised form, so that other researchers may use my data for future research

I agree for the interview to be audio-recorded.

**Participant’s Statement:**

I \_\_\_\_\_  
 agree that the research project named above has been explained to me to my satisfaction and I agree to take part in the study. I have read /listened to both the notes written above and the Information Sheet about the project, and understand what the research study involves.

Signed \_\_\_\_\_ Date \_\_\_\_\_

**Witness Statement (in event that participant is not literate):**

I \_\_\_\_\_  
 agree that the research project named above has been explained to \_\_\_\_\_ (participant) to his/her satisfaction and that s/he agrees to take part in the study. Both the notes written above and the Information Sheet about the project have been read to him/her, and s/he understands what the research study involves.

Signed \_\_\_\_\_ Date \_\_\_\_\_

**Investigator’s Statement:**

I \_\_\_\_\_

confirm that I have carefully explained the nature, demands and any foreseeable risks (where applicable) of the proposed research to the participant.

Signed \_\_\_\_\_ Date \_\_\_\_\_

**Study 2-4: Information sheet form for service users/caregiver – Amharic version**

አዲስ አበባ ዩኒቨርሲቲ የምርምር ስነ-ምግባር ኮሚቴ ማሳያ ቁጥር :

3/42=I S[Í Ñê pĪ ÃcÖ-ታM::

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**Study2-4 Consent Form for Participants in Research Studies- Amharic version**

ኃይሉ ለሰው ጥናት ተጠቃሚዎች/ች ማህተም

እነዚህን ማህተም ለማንበብ እና ለመግባባት ይህን ማህተም ለማንበብ ይገባል፡፡

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ሁሉም ጥናቶች ለሰው ጥናት ለማሳካት የሚያስፈልገውን ጥናት ለማሳካት ይህን ማህተም ለማንበብ ይገባል፡፡

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**Form 1: Satisfaction of participants with capacity-building activity**

<i>Capacity Building Workshop Feedback Form</i>	
<i>Date</i> ___ ___ / ___ ___ ___ / ___ ___ ___ ___	<i>Background of participants</i> Service user <input type="checkbox"/> Caregiver <input type="checkbox"/> Service provider <input type="checkbox"/> Health center heads <input type="checkbox"/> District health office heads <input type="checkbox"/> Other (specify) _____
<i>Day 1 Session1</i>	Excellent <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor <input type="checkbox"/>
<i>Comment /how could the session be improved?</i>	
<i>Day1 Session2</i>	Excellent <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor <input type="checkbox"/>
<i>Comment /how could the session be improved?</i>	
<b>Overall Feedback</b>	
<i>Standard of the training on this workshop was high</i>	Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree or disagree <input type="checkbox"/> disagree <input type="checkbox"/>
<i>My expectations of the course have been fulfilled</i>	Strongly agree <input type="checkbox"/> Agree <input type="checkbox"/> Neither agree or disagree <input type="checkbox"/> disagree <input type="checkbox"/>
<i>Comments on the short course overall/how it could be improved?</i>	

*Date* \_\_\_ \_\_\_ / \_\_\_ \_\_\_ / \_\_\_ \_\_\_

**Form2.Evaluation of Capacity Building Workshop for Service User/Caregiver Involvement (Pre-and Post Structured Questions)**

For completed by service user  caregiver  project worker

Please circle the appropriate number to indicate your degree of understanding of the listed topics AFTER and BEFORE the training

	<b>Strongly disagree</b>	<b>Disagree</b>	<b>Don't know</b>	<b>Agree</b>	<b>Strongly agree</b>
<i>1) I understand about types of mental health problems</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>3</i>	<i>4</i>
<i>2) I understand about the treatments that can help people with mental health problems</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>3</i>	<i>4</i>
<i>3) I understand about the international protections (and protections within Ethiopia) for the rights of people with mental health problems</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>3</i>	<i>4</i>
<i>4) I understand what kinds of contributions service users and their caregivers can make to improve mental care in my district (Sodo district)</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>3</i>	<i>4</i>
<i>5) I understand how I can contribute to improving mental health care in my district (Sodo district)</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>3</i>	<i>4</i>
<i>6) I understand how I can contribute to the development of national mental health policies and laws in Ethiopia</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>3</i>	<i>4</i>
<i>7) I understand about the experiences of other people with mental health problems in our district.</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>3</i>	<i>4</i>
<i>8) I can understand levels of service user/caregiver involvement in mental health system</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>3</i>	<i>4</i>

#### Study 4: interview topic guide for service user/caregiver –English version

Thank you very much for being voluntary to participate in this interview. There are some questions I will ask. Please feel free to say anything you want. The interview will last one hour maximum. We can stop anytime you want.

#### 1. Socio-Demographic Background

<i>Now we will ask you general information about your corrent conditions</i>				
		<i>Category</i>	<i>Label</i>	<i>Code</i>
1	Age		[ ] [ ]	Age
2	Gender	Female	0	Gender
		male	1	
3	Marital status	Single	1	MARST
		Married	2	
		Divorced	3	
		Widowed	4	
4	Place of residence (urban or rural?)	Rural	0	Residen
		Urban	1	
5	Education level (what grade level you attained in your formal education?)		[ ] [ ]	Educ
6	Ethnicity	Gurage	1	Ethn
		Amhara	2	
		Oromo	3	
		Tigray	4	
		Other specify-----	5	
	Religion	Orthodox Christian	1	
		Muslim	2	
		Protestant Christian	3	
		Others specify	4	
	Length of contact with health service		[ ] [ ]	

#### 1. Experiences of group dynamics

- a. How long have you been coming to this Research Participant Group?
- b. Had you taken part in any involvement activities in like this before you started coming to Research Participant Groups?
- c. How do you see yourself in the role of service user/caregiver involving in mental health system strengthening?
- d. Do you think all group members participated well?
- e. How do you think other participants see you in the group?
- f. Could you want to participate in similar activity yourself or advise others to participate in the future?
- g. Can you tell me how was relationship with group members and their relationship with you?
- h. Was it of value to participate in groups like this to you and to the others?

**2. Perception of value in participation in mental health system strengthening**

- a. Do you think that your involvement in this mental health system strengthening has value?
- b. How do you feel about the time you have spent in the mental health system strengthening research?
- c. What do you like most about the involvement process?
- d. Is there anything about the involvement process that you disliked or would be changed?
- e. Do you think you have got something useful from participating in this mental health system/research? **If yes probe:**
  - Can you give me some examples?
  - Is it your involvement in mental health system/research here that you experience these benefits or are there other areas of your life changed to contribute for these benefits?

**3. Feeling of achievement**

- a. Some people feel that participation in mental health system (research) gives them sense of achievement, do you feel that? **If yes probe:**
  - In what ways?
  - What makes you feel like that?
  - Are there other ways this feeling affected your life areas outside your involvement in this research? **If yes probe:**  
Can you give me some examples?  
Is that participation in this research that makes you feel like that or is there other things in your life that have made you feel achievement?
- b. Did you have any goals in mind or things that you wanted to achieve, when you started participation? **If yes probe**
  - What are they?
  - Have you achieved them?
  - Can you give some examples?
- c. Do you think that any improvement in the health services in the health center you participated in after your and others participation in this mental health system strengthening research? **If yes probe:** Can you tell me some examples?

**4. Feeling of confidence**

Feelings of confidence were talked about when people were asked about participation in mental health system strengthening. Do you think your confidence affected the same? **If yes probe:**

- In what ways?
- What makes you feel like that?
- Can you give some examples?

**5. Perception of social benefit**

- a. Some people said they enjoy social benefits of participating in occasions like your participation in mental health system strengthening; for example meeting people, friends and others. Does that apply to you? **If yes probe:**
  - In what ways?
  - What makes you feel like that?
  - Can you give me some examples?

- Are there other ways having the social benefits of involvement in Research Participant Group / mental health system strengthening had an effect on your life in general outside of your involvement here? **If yes probe:** can you give some examples?

**6. Feeling of acceptances**

- People also talked about feelings of being accepted in participation in mental health system strengthening. Is this applied to you? **If yes probe:**
  - In what ways?
  - What makes you feel that?
  - Can you give me some examples of how this affects you?
- Do you think that those feelings of acceptance had effect on your life outside involvement here? **If yes probe:**
  - In what ways?
  - Has anything changed in your life since you have involved in this mental health system strengthening research? **If yes probe:**  
Can you give for example, in what areas?  
What do you think for changes, is it because of your involvement here or other changes in your life?  
How do you describe yourself before and after the involvement?
- Do you think that other community members accepted you more after your participation here?

**7. Future plan.** Some people now seem to have future plans for their involvement in mental health systems. Do you have any goals in mind in relation to your involvement in mental health systems? **If yes probe:** Can you give me some examples of your future goals?

**Study 4: Service user/caregiver interview schedule –Amharic version**

ለዚህ ቃለ መጠይቅ ፈቃደኛ ስለሆነ ክ(ሽ) በጣም አመሰግናሁ፡፡ ቀጥሎ የተወሰኑ ጥያቄዎች አሉኝ፡፡ የሚጠየቁት (ሽ) ለመናገር ሙሉ ነጻነት ማጠናቀቅ/ሽ ቃለ መጠይቁ ቢበዛ አንድ ሰዓት ይፈጃል፡፡ ማቆም ከፈለግህ/ሽ በማንኛውም ጊዜ ማቆም እንችላለን፡፡

1. ስለግለሰቡ አጠቃላይ መረጃ (ሚስት/ሰውና ስነ-ህዝባዊ መረጃዎች)

በቅድሚያ ስለ አሁን ስላሉበት ሁኔታ ጠቅላላ መረጃ እንጠይቅህ/ሻለን.				
		Category	Label	Code
1	እድሜ	( )() ዓመት	[ ] [ ]	Age
2	ፆታ	ሴት	0	Gender
		ወንድ	1	
3	የጋብቻ ሁኔታ (በአሁኑ ወቅት የትዳር ሁኔታ እንዴት ነ ወ?)	ያላገባ	1	MARST
		ባለትዳር	2	
		በፍቺ የተለያየ	3	
		በጥንቅቅ የተለየ	4	

4	የሚኖሩበት ቦታ (ከተማ ወይስ ገጠር?)	ከተማ	0	Residen
		ገጠር	1	
5	የትምህርት ደረጃ (በሙሉ ትምህርት እስከ ስንት ተምረዎል?)		[ ] [ ]	Educ
6	ብሔር	ጉራጌ	1	Ethn
		አማራ	2	
		አሮሞ	3	
		ትግሬ	4	
		ሌላ ካለ ይጠቁሱ	5	
	ሐይማኖት	ኦርቶዶክስ ክርስቲያን	1	
		ሙስሊም	2	
		ፕሮቴስታንት ክርስቲያን	3	
		ሌሎች	4	
	አገልግሎቱን በመጠቀም የቆዩበት ጊዜ	( ) ( ) ወሮች ዓመታት		

**1. በጥናት ቡድን ውስጥ ስለነበረ ተሳታፊ ተሞክሮ**

- ሀ/ በዚህ የጥናት ተሳታፊ ቡድን ውስጥ መሳተፍ ከጀመርኩ/ሽ ምን ያህል ጊዜ ሆነ ህ/ሽ?
- ለ/ እዚህ ቡድን ከመጣኩ/ሽ (ሽ) በፊት ሌላ ተመሳሳይ ቡድን ተሳታፊ ህ/ሽ ታወቃለህ/ታወቁልሽ?
- ሐ/ እንደ አገልግሎት ተጠቃሚ ተንከባከቢ በዚህ የአእምሮ ጠፍ አገልግሎት ማሻሻያ ጥናት ውስጥ የአንተን/አንቺን ማዘጋጀት ታዩዋለህ/ታይዋለሽ?
- መ/ ሁሉም የቡድን አባላት በጥሩ ሁኔታ ተሳታፊዎል ብለህ/ሽ ታስባለህ/ታስብዋለሽ?
- ሠ/ ለአንተ/ቺ ሌሎች የቡድን አባላት ያላቸው አመለካከት ምን ይመስልህ/ይመስልሻል?
- ረ/ ወደፊት በተመሳሳይ ጥናት መሳተፍ ትፈልጋለህ/ትፈልገለሃለህ? ሌሎችንስ እንዲሳተፉ ትመከራለህ/ሪያለሽ?
- ሰ/ የእርስ በእርስ ግንኙነታችሁ ምን እንደሚመስል ትነግረኛለህ/ሽ?
- ሸ/ በቡድኑ ውስጥ መሳተፍ ለአንተ/ቺ እና ለሌሎች ዋጋ ነበረዎታል/ሽ ታስባለህ/ሽ?

**2. የአእምሮ ጠፍ ስርዓት ለማሻሻል የሚደረግ ተሳታፊ በተመለከተ ያለአመለካከት**

- ሀ/ የአንተ እና የሌሎች የአእምሮ ጠፍ ስርዓት ለማሻሻል መሳተፍ ዋጋ ነበረው ብለህ/ሽ ታስባለህ/ቢያለሽ?
- ለ/ በዚህ ጥናት ያሳለፍኩ/ሽዉን ጊዜ እንዴት ታዩዋለህ/ታይዋለሽ?
- ሐ/ በዚህ ጥናት ተሳታፊ ህ/ሽ ውስጥ የወደድኩ/ሽ/ ነገር ምን ነበር?
- መ/ በተሳታፊ ህ/ሽ ውስጥ ያልወደድኩ/ሽ ወይም ማሻሻል አለበት የምትለው/የምትይው ነገር ምንድን ነው?
- ሠ/ በዚህ ጥናት በመሳተፍ ህ/ሽ ያገኘው/ያገኘሽው ጠቃሚ ነገር አለ ብለህ/ሽ ታስባለህ/ሽ? ማለት አዎ ከሆነ ..... ጠይቁ
- የተወሰኑ ምሳሌዎች ልትጠቅሱ/ልትጠቅሽላችኋል ትችላለህ/ሽ?
- እዚህ መሳተፍ ህ/ሽ/ ነው ወይስ ሌላ ነገር ነው እነዚህ ጥቅሞችን/ ወጠቶች ያስገኘህ/ሽ?

**3. የወጠታ ማካት ስሜትን የተመለከተ**

- ሀ/ እንደንድስዎች እንዲዘህ ባለጥናት ውስጥ መሳተፍ ወጠታ ምን እንደሆነ እንዳደረጋቸው ይሰማቸዋል: :
- አንተስ/ቺስ ይህ ስሜት ተፈጥሮ ብህል/ሻል?
- አዎ ከሆነ ማለት**
- በምን ማለት ገልጸዋለህ/ሽ?
- እንደዚህ እንዲሰማህ/ሽ ያደረገህ/ሽ ምንድን ነው?
- ይህ የወጠታ ማካት ስሜት ህ/ሽ ከዚህ ጥናት ወጭብሌላ ህይወት ህ/ሽ ውስጥ ያሳረፈው ተጽዕኖ አለ? አዎ ከሆነ ማለት

ጥቂት ምሳሌዎች ልትነግረኝ/ልትነግሪኝ ትችላለህ/ሽ?

ይህ የወጠሜክ ትስማኝ/ሽ/ከዚህ መሳተፍህ/ሽ ነው ወይንስ በሌላ ነገር የመጣ ይመስልህ/ሻል?

ለ/ ወደዚህ ጥናት ስትመጣ/ጩግብ ነበረህ/ሽ? **አዎ ከሆነ መልሱ**

- ግብህ/ሽ ምን ነበር?
- ተሳክተዋልህ/ሻል?
- የተሳክተህ/ሽን ጥቂት ምሳሌዎች ልትነግረኝ/ሪኝ ትችላለህ/ትችያለሽ?

ሐ/ አንተ/ቺ እዚህ መሳተፍ ከጀመርክ/ሽ ወዲህ የክሊኒኩ የአገልግሎት አሰጣጠ ለወጥ ያሳየ ይመስልህ/ሻል? **አዎ ከሆነ መልሱ** ጥቂት ምሳሌዎችን ብትነግረኝ/ሪኝ?

**4. በራስ የመታማመን ስሜት**

አንዳንድ ሰዎች በአንዲዘህ አይነት ጥናት ወስጥ መሳተፋቸው በራስ የመታማመን ስሜት እንደፈጠባቸው ይናገራሉ፡፡ የአንተ/ቺ ስሜት እንደሂያ ይመስልህ/ሽ?

**አዎ ከሆነ መልሱ**

- ምን ሁኔታ ተፈጠረብህ/ሽ?
- እንደዚህ እንዲሰማህ/ሽ ያደረገህ/ሽ ምንድነው?
- ለዚህ ስሜትህ/ሽ ምሳሌዎችን ትነግረኛለህ/ትነግረኛለሽ?

**5. የተሳታፊ ማህበራዊ ጠቀሜታን በተመለከተ ያለ አመለካከት**

ሀ. አንዳንድ ሰዎች በዚህ አይነት ጥናት ወስጥ መሳተፍ ማህበራዊ ጠቀሜታዎች እንዳለው ለምሳሌ ከሰዎች ለመገናኘት ጓደኛ ለጭጠር እና ሌሎች ይሰማቸዋል፡፡ ይህ ስሜት በአንተ/ቺ አለ? **አዎ ከሆነ መልሱ** የበለጠ ጠይቁ

- ስሜትህ/ሽ በምን መልኩ ይገለጻል?
- እንደዚያ እንዳታሰብ/ቢ ያደረገሽ/ሽ ምንድነው?
- ላገኘህ/ላገጠህ ማህበራዊ ጥቅም ምሳሌዎች ብትጠቅሰልኝ/ብትጠቅሽልኝ?
- በዚህ የጥናት ቡድን ወስጥ ካገኘሽ/ሽው ማህበራዊ ጠቀሜታ ሌላ በበህብረሰቡ ወስጥ ያገኘሽ/ሽው ጠቀሜታ አለ? **መልሱ አዎ ከሆነ** ጥቂት ምሳሌዎችን ብትጠቅሰልኝ/ሽልኝ

**6. የተፈላጊነት/ተቀባይነት ስሜት**

ሀ/ አንዳንድ ሰዎች በዚህ ዓይነት ጥናት እና ቡድን ወስጥ መሳተፋቸው የተፈላጊነት/ተቀባይነት ስሜት እደፈጠረላቸው ይናገራሉ፡፡ ይህ ስሜት በአንተ/ቺ ተፈጥሯል? **መልሱ አዎ ከሆነ**

- በምን መልኩ?
- እንደዚያ እንዲሰማህ/ሽ ያደረገው ምንድነው?
- ይህ ያሳደረብህ/ሽን /ሽን ተዕፅኖ ምሳሌዎች ብትገልጽልኝ/ጩኝ?

ለ/ ይህ የተፈጠረብህ/ሽ የተፈላጊነት ስሜት ከዚህ የጥናት ተሳትፎ ወጭበሌላ ህይወትህ/ሽ የፈረጠው ወጠኛ አለ? **መልሱ አዎ ከሆነ**

- በምን ሁኔታ?
- ከዚህ መሳተፍ ከጀመርክ/ሽ በኋላ በህይወትህ/ሽ የተፈጠረ ነገር አለ?

**መልሱ አዎ ከሆነ**

- ጥቂት ምሳሌዎችን ልትነግረኝ/ሪኝ ትችላለህ/ሽ?
- ከዚህ መሳተፍ ከመጀመሪያህ/ሽ በፊት እና በኋላ ያለውን ተፈላጊነትህ/ሽን እንዴት ታነጻጽረዋለህ/ሪዋለሽ?

ሐ/ ከዚህ መሳተፍ ከመጀመሪያህ/ሽ ወዲህ ሌሎች የህብረተሰብ ክፍሎች ዘንድ ተፈላጊነትህ/ሽ ምን ይመስላል?

**7. የወደፊት እዕድ**

ሀ/ አንዳንድ ሰዎች በአለምጭ ጠፍ ስርዓት ማሻሻል ወስጥ ለመሳተፍ እቅድ አላቸው፡፡ አንተ/ቺስ ለመሳተፍ ታስባለህ/ሽ? **መልሱ አዎ ከሆነ**

የተወሰኑ እንቅዶችህ/ሽን ብትነግረኝ/ሪኝ

አመላካች ስም :

**Study 4: interview topic guide for service providers –English version**

Thank you very much for being voluntary to participate in this interview. There are some questions I will ask. The interview will last one hour maximum.

Socio-demographic background of participants				
S.	Variable	Category	Label	Code
1	Age (how old are you?)		[] []	Age
2	Gender	Female	0	Gender
		Male	1	
3	Marital status	Single	1	MARST
		Married	2	
		Divorced	3	
		Widowed	4	
4	<b>Discipline of training</b>	Health Officer	1	TRAIN
		BSc nurse	2	
		Diploma nurse	3	
		Other (specify) _____	4	
5	Number of service in the profession( no years of service)		[] []	EXPER
6	Current work health center location	Rural	1	RESID
		Urban	2	
7	Religion	Orthodox Christian	1	RELIG
		Muslim		
		Protestant Christian		
		Others specify----		

II. Interview topic guide (Service provider)

1. Can you tell me about the experience you had with service user/caregiver you have participated with in the mental health system strengthening in this district? **Probe: can you tell me more about**
  - Your relationship with them and their relationship with you
  - What did you liked most in the process of the course of your involvement
  - Is there anything about the involvement process that you disliked or would be changed?
  - Was it of value to you and to the others?
  - How do you see the change in attitude of service providers
  - Could you involve in similar study if you get the chance in the future? Do you encourage other to participate as you did?

2. How do you describe your role as service provider working with service users/caregivers for mental health system strengthening?
3. What is your attitude of service user/caregiver involvement in mental health system before you involve with them and after involved?
4. Do you think that service user/caregiver involvement in mental health system strengthening has contributed something? **If yes probe:** Can you give me some examples?
5. Do you think any improvement in the service of health center after service user/caregiver involvement in mental health system strengthening? If yes probe: can you give some examples?
6. Do you think that service user/caregiver involvement for mental health system strengthening has contributed for service user/caregivers? **If yes probe:** in what ways? Can you give me some examples?
7. In your experience could more be done to support service user/caregivers within the health system settings and wider community? **If yes probe:** Can you give some examples?

Thank you very much

#### Study 4: interview topic guide for service providers –Amharic version

ለዚህ ቃለ መጠይቅ ፈቃደኛ ስለሆነ ክ(ሽ) በጣም አመሰግናሁ፡፡ ቀጥሎ የተወሰኑ ጥያቄዎች አሉኝ፡፡ የሚሰጡን(ሽ) ለመናገር ሙሉ ነጻነት ማሰጠት/ሽ ቃለ መጠይቁ ቢበዛ አንድ ሰዓት ይፈጃል፡፡

1. ስለግለሰቡ አጠቃላይ መረጃ (ሚስብራዊና ስነ-ህዝባዊ መረጃዎች)				
	Variable	Category	Label	Code
1	እድሜ	( ) ( ) ዓመት	[ ] [ ]	እድሜ
2	ፆታ	ሴት	0	Gender
		ወንድ	1	
3	የጋብቻ ሁኔታ (በአሁኑ ወቅት የትዳር ሁኔታ እንዴት ነው?)	ያላገባ	1	MARST
		ባለትዳር	2	
		በፍቺ የተለያየ	3	
		በሞት የተለየ	4	
4	የሰልጠና ማከክ	ጤ ማከንን	1	TRAIN
		BSc ነገር	2	
		ዲፕሎማ ነገር	3	
		ሌላ (ይጥቀሱ) _____	4	
5	በሙያ ወይም ገለገለበት ዓመት ባዛት		[ ] [ ]	EXPER
6	አሁን ማስሪያ ቤቱ (ከተማ ወይስ ነገር?)	ከተማ	0	RESID
		ነገር	1	
7	ሐይማኖት	ኦርቶዶክስ ክርስቲያን	1	RELIG
		ሚስሊም	2	
		ፕሮቴስታንት ክርስቲያን	3	
		ሌሎች	4	

1. በዚህ ወረዳ ወስጥ የአእምሮ ጠፍ ስርዓትን ለማሻሻል ከአገልግሎት ተጠቃሚዎች እና ከተንከባካቢዎች ጋር ባደረገው/ሽውተሳትፎ ሰለነ በረሀ/ሽ ተጥክሮ በትነ ግረኝ/ሪኝ? **የበለጠጠይቅ**
  - የእርስ በእርስ ግንኙነታችሁ ምን እንደሚቆይ ትነ ግረኛለህ/ሽ?
  - በዚህ ጥናት ተሳትፎህ/ሽ ወስጥ የወደድከው/ሽ/ ነገር ምን ነበር?
  - በተሳትፎህ/ሽ ወስጥ ያልወደድከው/ሽ ወይም ማሻሻል አለበት የምትለው/የምትይውነገር ምንድን ነው?
  - በቡድኑ ወስጥ መሳተፍ ለአንተ/ቼ እና ለሌሎቹ ዋጋ ነበረዉበለህ/ሽ ታስባለህ/ሽ?
  - በአገልግሎት ሰጪዎች ላይ ያለውን የአመለካከት ለውጥ እንዴት ታዩዋለህ/ሽ?
  - ወደፊት በተመሳሳይ ጥናት መሳተፍ ትፈልጋለህ/ትፈልጋለህ? ሌሎችንስ እንዲሳተፉ ትመክራለህ/ሪያለሽ?
1. እንደ አገልግሎት ሰጪ በዚህ የአእምሮ ጠፍ አገልግሎት ማሻሻያ ጥናት ወስጥ የአንተን/አንቺን ምክንያት ታዩዋለህ /ታይዋለሽ?
2. በዚህ ጥናት ወስጥ ከአገልግሎት ተጠቃሚዎች እና ከተንከባካቢዎች ጋር ከመሳተፍህ/ሽ በፊት እና ከተሳተፍክ/ሽ በኋላ ያለህ/ሽ ስለእነ ሱ ያለህ/ሽ አመለካከት ምን ይመስላል?
3. አገልግሎት ተጠቃሚዎች እና ተንከባካቢዎች የአእምሮ ጠፍ ስርዓት ለማሻሻል መሳተፍ ጠቀሜታ ነበረው ብለህ/ሽ ታስባለህ/ቢያለሽ? **አዎ ከሆነ ማልሱ**  
የተወሰኑ ምሳሌዎች ልትጠቅሱኝ/ልትጠቅሽልኝ ትችላለህ/ሽ?
4. አገልግሎት ተጠቃሚዎች እና ተንከባካቢዎች እዚህ መሳተፍ ከጀመሩ ወዲህ የክሊኒኩ የአገልግሎት አሰጣጥ ለውጥ ያሳዩ ይመስልሃል/ሻል? **አዎ ከሆነ ማልሱ** ጥቂት ምሳሌዎችን ብትነ ግረኝ/ኒ?
5. በዚህ ጥናት መሳተፍ ለአገልግሎት ተጠቃሚዎች እና ተንከባካቢዎች ያገኘው ጠቃሚነገር አለ ብለህ/ሽ ታስባለህ/ሽ? **ማልሱ አዎ ከሆነ** ..... ምሳሌዎች ልትጠቅሱኝ/ልትጠቅሽልኝ ትችላለህ/ሽ?
6. በአንተ/ቼ ተጥክሮ የአገልግሎት ተጠቃሚዎች እና ተንከባካቢዎችን ተሳትፎ በጠፍ ስርዓት እና በሚበረሰቡ ወስጥ የበለጠ ድጋፍ መደረግ አለበት ትላለህ/ሽ? **ማልሱ አዎ ከሆነ** ምሳሌዎች ልትጠቅሱኝ/ልትጠቅሽልኝ ትችላለህ/ሽ?

አመላግና ሱ: :

### Appendix 4: Themes, Sub-Themes and Codes

Themes	Sub-themes	Codes
Experience of involvement in mental health System	No involvement in mental health system	No experience of involvement Understood at individual level

	Limited involvement in mental health system	Limited involvement Concern about value of research Concern about research procedure
Barriers to involvement in mental health system	Alien to the involvement concept	Difficulty conceptualizing concepts of involvement New about involvement Lack of /no expectation of involvement Involvement as assigned role Lack of model /structure of involvement Lack of participatory approach
	Stigma and mental health status	Ascribed patient role Health status Doubt about service user involvement Lack of prioritization Lack of acceptance Lack of community support Lack of opportunity Paternalistic caregivers Perceived lack of capacity Perceived negative effect Stigma(attitude) Stigma(discrimination) Stigma(knowledge problem) Stigma(self) Stigma(structural)
	Lack of resource and empowerment	Lack of ability to articulate Lack of association/organization Lack of SU/CG representation/say Lack of empowerment Lack of resource Lack of opportunity Low education/knowledge/awareness Low self-esteem/capacity
	Poor access to mental health care	Lack /Unavailability of accessible service Power imbalance Reluctant to criticize Issues about medicine Issues to be improved in service Concern about competence /behavior of service providers Medicine only services and concern about asking more Time off work
Potential benefits of involvement	Advocacy , fighting exclusion and improving service quality	Advocacy role Budget allocation and control Demand creation Demand for right to be involved Make service accessible /service expansion Demand for services more than medicine Experiential support Unique lived experience Fighting stigma Patient protection Improve service Knowledge/information source Improve providers behavior
	Awareness raising and service promotion	Awareness creation Case finding Mental health promotion
Need for capacity building	Mental health advocacy and stakeholder empowerment	Advocacy to overcome mental health stigma Empowering stakeholders to involve Need to equip with training
	Need for SU/CG mobilization and empowerment	Need for SU/CG organization and representations Space and structure for involvement Treatment and more services in addition to medicine
	Enabling community structures and past experience	Existing social structure for awareness raising Experience from other health care user Experience from other healthcare user associations Experience of public involvement in health system Right to be involved

		Value SU/CG lived /experiential knowledge Valuing SU/CG involvement
	Mental health advocacy	Advocacy to overcome mental health stigma Empowering stakeholder to involve Need to equip with training
	Service user and caregiver mobilization and empowerment	Challenges to organize and select representative Criteria to select representative Space and structure for involvement SU/CG Organization and representation Treatment & more service in addition to medicine

## Appendix 5: Empowerment training contents and sessions

Table 1. Empowerment training contents and sessions for service providers/ health service managers training

No	Topics	Time
<b>1</b>	<b>Getting started</b>	<b>8:30-9:25</b>
1.1	Participant registration, getting to know each other	8:30-8:45
1.2	Participants expectation review and training objectives presentation	8:45-9:00
1.3	Setting training ground rules	9:00-9:10
1.4	Conducting pre-training questions	9:10-9:25
<b>2</b>	<b>Understanding the concept of service user and caregiver involvement in mental health system</b>	<b>9:25-10:30</b>
2.1	Brainstorming- the concept of service user and caregiver involvement	9:25-9:35
2.2	Group discussion and reflection- level, methods and benefits of service user and caregiver involvement in mental health system	9:35-9:55
2.3	Group discussion and reflection-barriers to service user and caregiver involvement	9:55-10:15
2.4	Group activity-deigning strategies how to overcome barriers to service user and caregiver involvement	10:15-10:30
	<b>Tea break</b>	<b>10:30-11:00</b>
<b>3</b>	<b>Understanding knowledge, attitudes and behaviors that influence service user and caregiver involvement in mental health system: stigma</b>	<b>11:00-12:30</b>
3.1	Discuss case scenarios, define stigma and identify various forms/types of stigma	11:00-11:20
3.2	Brainstorm and analyze the various level impacts of mental health related stigma	11:20-11:40
3.3	Design strategies to overcome mental health related stigma in the local setting	11:40-12:30
	<b>Lunch break</b>	<b>12:30-13:30</b>
<b>4</b>	<b>Human rights -based approach to service user/caregiver greater involvement in mental health system strengthening</b>	<b>13:30-14:30</b>
4.1	Brainstorm basic concepts - human rights, human rights-based approach and characteristics of human rights	13:30-13:45
4.2	Group discussion and reflection: major human rights issues related to mental health service users and caregivers	13:45-14:10
4.3	Discussion-national and international human rights instruments in relation to	14:10-14:30

	mental health	
<b>5</b>	<b>Understanding meaning, processes and strategies for advocacy in mental health, mental service user/caregiver involvement and a way forward</b>	<b>14:30-15:45</b>
5.1	Brainstorm the concept of advocacy, processes and roles of different stakeholders in relation to mental health and service user/caregiver involvement	14:30-14:50
5.2	Group discussion and reflection: advocacy campaign , steps and characteristics of successful advocacy	14:50-15:15
5.3	Group activity: problem identification and outline an action plan that enables service user and caregiver in their local areas	15: 15-15:45
	<b>Tea break</b>	<b>15:45-16:15</b>
<b>6</b>	<b>Close up</b>	<b>16:15-16:45</b>
6.1	Gathering feedback and comments on the training	16:15-16:30
6.2	Conduct post-training questions	16:30-16:40
6.3	Closing remark	16:40-16:45

Table 2. Empowerment training contents and timetable for service user and caregiver participants

<b>DAY ONE</b>		
No	Topics	Time
<b>1</b>	<b>Getting started</b>	<b>9:00-4:30</b>
1.1	Participant registration, getting to know each other	9:00-9:10
1.2	Participants expectation review and training objectives presentation	9:10-9:25
1.3	Setting training ground rules	9:25-9:35
1.4	Distribute pre-training questions	9:35-10:05
	<b>Tea break</b>	<b>10:05-10:30</b>
<b>2</b>	<b>Raising awareness about mental health and mental illness</b>	<b>10:30-12:30</b>
2.1	Defining mental health and mental illness	10:30-11:00
2.2	Describe types of mental illness, causes and symptoms	11:00-11:30
2.3	Discuss the various treatments for mental illness	11:30-12:00
2.4	Introduce the mental health situation in Ethiopia	12:00-12:30
	<b>Lunch break</b>	<b>12:30-13:30</b>
<b>3</b>	<b>Understanding the concept of service user and caregiver involvement in mental health system</b>	<b>13:30-15:10</b>
3.1	Describe the concept of service user and caregiver involvement in the mental health system	13:30-13:50
3.2	Describe service user and caregiver involvement in mental health system: level, stages, methods, and benefits/outcomes	13:50-14:20
3.3	Discussion on perceived barriers to service user and caregiver involvement	14:20-14:55
3.4	Group activity-design strategies how to overcome barriers to service user and caregiver involvement	14:55-15:10
	<b>Tea break</b>	<b>15:10-15:40</b>
<b>4</b>	<b>Understanding knowledge, attitudes and behaviors that influence service user and caregiver involvement in mental health system: stigma</b>	<b>15:40-16:50</b>
4.1	Discuss case scenarios, define stigma and identify various forms/types of stigma	15:40-16:05

4.2	Brainstorm and analyze the various level impacts of mental health related stigma	16:05-16:30
4.3	Design strategies to overcome mental health related stigma in the local setting	16:30-17:00
<b>DAY TWO</b>		
<b>5</b>	<b>Human rights-based approach to service user/caregiver greater involvement in mental health system strengthening</b>	<b>9:00-10:30</b>
5.1	Describe major human rights issues related to mental health service users and caregivers	9:00-9:55
5.2	Discussion-national and international human rights instruments in relation to mental health	9:55-10:30
<b>Tea break</b>		<b>10:30-11:00</b>
<b>6.</b>	<b>Understanding meaning, processes and strategies for advocacy in mental health, mental service user/caregiver involvement and a way forward</b>	<b>11:00-12:30</b>
6.1	Familiarize with roles of various stakeholders in advocacy for mental health and service users and caregivers involvement	11:-11:40
6.2	Group activity : problem identification and crafting action plan for enabling service user and caregiver in their local areas	11: 40-12:30
<b>Lunch break</b>		<b>12:30-13:30</b>
<b>7</b>	<b>Close up</b>	<b>13:30-14:10</b>
7.1	Gather feedback and comments on the training	13:30-13:50
7.2	Distribute post-training questions	13:50-14:20
7.3	Closing remark	14:20-14:25
<b>DAY THREE</b>		
<b>1</b>	Creating a recovery story	1:45 – 2:30
<b>2</b>	How do we tell a story – PART 1 (documentary if the video in the Ethiopian context is there)	2:30 – 2:45
<b>3</b>	Introduction to camera (Practice during evening session)	3:05 – 4:30)
<b>4</b>	Confidentiality	4:30 – 5:00
<b>DAY FOUR</b>		
<b>1</b>	Public speaking	9:00-9:30
<b>2</b>	Practice taking pictures outside	9:30 – 10:30
<b>3</b>	Practice describing the photos taken	10:45 – 12:00
<b>4</b>	Describing homework assignment	1:00 - 1:30
<b>5</b>	Wrap up and information for the training, collect feedback and comments	1:30-2:00
<b>DAY FIVE</b>		
<b>1</b>	Re-introduction and review of previous training contents	9:30 – 10:00
<b>2</b>	Review of what is stigma and 8 myths	10:00 – 10:30
<b>3</b>	Recognizing our strength	10:30 – 11:00
<b>4</b>	SHOWED Method	11:00 – 11:45
<b>5</b>	Lunch break	11:45 – 12:30
<b>6</b>	Photo presentation based on SHOWED	12:30 – 1:45
<b>7</b>	Next photo theme: Any photos that shows the SU's struggle during the mental illness period; and fix time for next session	1:45 – 2:00
<b>DAY SIX</b>		
<b>1</b>	Re-introduction and review of previous sessions	9:30 – 10:00
<b>2</b>	Review of what is stigma and 8 myths	10:00 – 10:20
<b>3</b>	Understanding distress: What is distress and how to cope with it?	10:20 – 10:40
<b>4</b>	What helps are available for distress during and after training?	10:40 – 11:00

	Lunch break	11:00 – 11:45
5	Review of SHOWED Method	11:45 – 12:00
6	Photo presentation based on SHOWED	12:00 – 2:00
7	Discussion on challenges faced coming to the training, understanding training contents and taking photographs	2:00 – 2:30
8	Next photo theme: Any photos that shows the SU's life during the treatment phase. Inform date and time for next session	2:30 – 2:45
<b>DAY SEVEN</b>		
1	Re-introduction and review of previous session	9:30 – 10:00
2	Tackling challenges	10:00 – 10:30
3	Mental health stigma	10:30 – 11:00
4	Mapping mental health stigma	11:00 – 12:00
<b>LUNCH BREAK</b>		
5	Photo presentation based on SHOWED	12:45 – 2:30
6	Next photo theme: Photos that shows the SU's life after recovery	2:30 – 2:45
<b>DAY EIGHT</b>		
1	Re-introduction and review of previous session	9:30 – 10:00
2	Photo Presentation based on SHOWED	10:30 – 12:30
<b>LUNCH BREAK</b>		
3	Summary and Review of what was covered	1:30 – 2:30
4	Recovery Narratives (phase One)	2:30 – 5:00
<b>DAY NINE</b>		
1	Recovery Narratives (phase Two)	9:00 – 10:30
<b>TEA BREAK</b>		
2	Review Of the recovery narratives phases	11:00 – 12:00
<b>LUNCH BREAK</b>		
3	Tackling Difficult questions	1:00 – 1:30
4	Recovery Narratives and tackling difficult questions	1:30 – 5:00
<b>DAY TEN</b>		
1	Recovery Narratives and tackling difficult questions Review of last sessions and continuing final phase	9:00-10:30
<b>TEA BREAK</b>		
2	Review of entire photovoice sessions	10:30 – 10:45
	Myth Busting	11:15 – 12:00
<b>LUNCH BREAK</b>		
3	Recovery Narratives and filming of service user videos	1:00-4:00
4	Final reflections and farewell	4:00-5:00

## Appendix 6. Frequencies of participants' response to the topic after the training and before the training

Not very well (N) 2. Somewhat well (S) 3. Don't know (D) 4. Moderately well (M) 5. Very well (V)

	I understood:	Phases	Service users					Caregivers					Health professionals				
			N	S	D	M	V	N	S	D	M	V	N	S	D	M	V
1	why service users and caregivers wanted to be involved in mental health system	After											0	0	0	2	16
		Before	-	-	-	-	-	-	-	-	-	-	5	3	9	1	0
2	the value of service users and caregivers' involvement in mental health system	After											0	0	0	2	16
		Before	-	-	-	-	-	-	-	-	-	-	6	2	8	2	0
3	how to involve service user and caregivers in the different aspects of mental health system	After											0	0	0	2	16
		Before	-	-	-	-	-	-	-	-	-	-	1	9	1	7	0
4	how to collaborate with service users and caregivers for mental health system strengthening	After											0	0	0	6	12
		Before	-	-	-	-	-	-	-	-	-	-	2	2	2	12	0
5	what kinds of contributions service users and their caregivers can make to improve mental care in my district (Sodo district)	After	0	0	1	5	6	0	0	0	6	6	0	0	1	4	13
		Before	3	2	5	2	0	1	1	6	4	0	1	6	1	9	1
6	about the international protections (and protections within Ethiopia) for the rights of people with mental health problems	After	0	0	1	8	3	0	0	0	8	4	0	1	1	7	9
		Before	3	4	3	1	1	2	0	4	6	0	4	3	1	8	2
7	the experiences of people with mental health conditions in Sodo district	After	0	0	2	6	4	0	0	1	8	3	0	1	1	4	12
		Before	4	2	3	3	0	2	4	1	5	0	3	5	2	6	2
8	the levels of service users and caregivers involvement in mental health system strengthening	After	0	0	3	5	4	0	0	3	4	5	0	0	1	5	12
		Before	2	5	4	1	0	2	3	3	3	1	2	6	1	8	1
9	myths and facts about mental illness	After	0	0	2	6	4	0	0	0	6	6	0	0	0	2	16
		Before	2	4	2	4	0	1	1	3	7	0	0	4	0	7	7
10	types of mental health related stigma and discriminations	After	0	0	0	8	4	0	0	1	4	7	0	0	0	5	13
		Before	1	2	4	5	0	1	1	3	7	0	0	6	0	9	3
11	the impacts of mental health related stigma and discrimination	After	0	0	1	5	6	0	0	0	5	7	0	0	0	4	14
		Before	1	5	2	4	0	0	2	3	6	1	0	4	2	8	4
12	about strategies to reduce mental health related stigma and discrimination	After	0	0	2	5	5	0	0	0	4	8	0	0	0	3	15
		Before	4	3	2	3	0	0	4	1	7	0	1	5	2	8	2
13	about types of mental health problems	After	0	0	0	6	6	0	0	0	3	9	0	0	0	4	14
		Before	1	1	5	5	0	1	0	1	9	1	1	2	1	8	6
14	about the treatments that can help people with mental health problems	After	0	0	1	5	6	0	0	0	6	6	0	0	0	4	14
		Before	1	3	3	5	0	1	1	1	7	2	1	2	1	9	5
15	about definition of service user	After	0	0	0	6	6	0	0	0	5	7	0	0	0	3	15
		Before	1	6	2	3	0	0	3	3	5	1	0	5	1	9	3
16	about the definition of caregiver	After	0	0	0	8	4	0	0	0	7	5	0	0	0	2	16
		Before	1	4	1	5	1	1	3	1	6	1	0	3	0	10	5
17	about definition of involvement in mental health system	After	0	0	1	7	4	0	0	0	7	5	0	0	0	2	16
		Before	1	6	1	3	1	1	2	3	6	0	0	4	1	10	3
18	how I can contribute to improve mental care in my district (Sodo district)	After	0	0	3	6	3	0	0	1	7	4	-	-	-	-	-
		Before	2	3	5	2	0	1	2	3	6	0	-	-	-	-	-
19	how I can contribute to the development of mental health policy and law development in Ethiopia	After	0	0	2	8	2	0	0	1	5	6	-	-	-	-	-
		Before	3	2	4	3	0	1	3	2	5	1	-	-	-	-	-

## Appendix 7. Summary of stages, activities, and session plans for the PAR process.

Stages	Cyclical activities	Descriptions	Time periods
<b>Stage1: Establish stakeholders groups, capacity building training /consultative Workshop and prioritization exercise</b>	Plan	Identify and establish cross-stakeholder groups that services as a reference group, and working group together with Sodo district health office Getting stakeholder groups and agree on time and place for regular sessions Develop summary of findings from foundational studies Identify and prioritize top thematic concerns	Between March 2018-August 2019
	Act	Conduct capacity building training and consultative workshops, present and discuss on foundational studies in a consultative workshop with stakeholder groups Systematically identified priority areas through small homogenous groups and heterogeneous group discussions, prioritize top areas using Nominal Group Techniques	Between March 2018-August 2019
	Observe	Conducted pre-post training survey about perception of training, knowledge and attitude as well as exist and follow up in-depth interviews, Collected key priorities generated in small group and plenary sessions, through audio-recording, captured minutes, field notes Principal investigator/a research assistant recorded field notes on group dynamics and interactions and on the context surrounding the discussion.	Between March 2018-August 2019
	Reflect	Discussed on and reached consensus on ways forward and priority areas Reflected within homogeneous groups, heterogeneous; compare the reports of each group The stakeholder groups make sense of what has happened through thinking about how it fits with their experiences and local contexts using criteria	Between March 2018-August 2019
<b>Stage2: Development of program and action plan</b>	Plan	Reached common understanding between RPG and the researchers and assistants what the research involves and ensure consent to participate RPG agreed on time, place, number of sessions per week and duration of the sessions at primary health facility level(Buie Primary Hospital) Reviewed the thematic priorities identified in Stage 1, discussed, selected and prioritized one priority for action as trial of proof of concepts Generated set of solutions and design intervention strategies	Between August 2019-December 2019
	Act	The RPG identified gaps in lack of awareness, available community resources and assets, target partners, and developed implementation strategies and action plans	Between August 2019-December 2019
	Observing	SA conducted participatory observation and documented the process through notes, and audio-recordings, summaries of discussions on flipcharts and photographs Evaluate participation and representation	Between August 2019-December 2019
	Reflection	RPG conducted continuous reflection throughout the action planning stages on data from observation, field notes and reflect on the action options	Between August 2019-December 2019

		Examined whether the proposed improvement methods was feasible in terms, time, additional resources availability, and local experiences	
<b>Stage3:Preliminary implementation and evaluation</b>	Plan	RPG reviewed the developed program and action plans and reach agreement about the way strategies would be put into operation and how to document observations RPG designed implementation and action strategies	December 2019
	Act	Conducted consultative workshop with multi-stakeholders Disseminated preliminary process findings from Stages 1-2 Conducted awareness-raising education and experiences sharing for stakeholders Established community advisory committee to support service user association Reached consensus with stakeholders to sustain the activities of the research in their local contexts on their own	December 2019
	Observe	SA documented the consultative workshop process through taking detailed field notes, observation and discussion with RPG and community stakeholders Preliminary analysis and findings of the process will be collected Conducted in-depth interviews with RPG to ascertain their perceptions and experiences of the process of PAR	December 2019- January 2020
	Reflect	Conducted evaluation meeting with RPG and community stakeholders and collect feedback about the process of the PAR process, and reflected on the process of implementation RPG members identified options to sustain the PAR and action with minimal or without academic researchers	December 2019- January 2020

### Appendix 8. Summary of consultative workshop aims and activities

Training/ Workshop	Aims	Activities
March 2018	To ensure service users, and health professionals/managers have the necessary knowledge and skills for active participation and working	Two training manuals were produced and provided to 12 service users, 12 caregivers and 18 health professionals  The training for health professionals/managers

	collaboratively within mental health systems	(n=18) was conducted for a full day (7 hours).The initial training for service users and caregivers (n=24) was three full days, followed by seven biweekly photovoice sessions of 3-4 hours duration.
Workshop 1(August 2018)	<p>Generally to learn the situation of service user involvement in mental health systems strengthening in the study site in relation to the global situation, specifically to:</p> <p>Create awareness about international experiences of stakeholders' roles in relation to mobilization and empowerment of service user association, and the roles of service user associations in mental health systems strengthening</p> <p>Create mechanisms to gauge stakeholder groups' interest, collaboration, and sense of ownership of service user involvement in mental health systems strengthening in their local context;</p> <p>Discuss, and seek stakeholders feedback about the draft bylaws of the service user association; and</p> <p>Establish mechanisms for formalization of the certification of the service user association and link with the local community.</p>	<p>Two co-authors (AA and SA) with the facilitation of the then district administration head, presented on discussed on:</p> <p>Existing experiences on the role of service user organizations in mental health system</p> <p>Role of stakeholders in empowering and spotting windows of opportunity in the local setting service user involvement</p> <p>Draft bylaws for service-user organization</p>
Workshop 2(August 2019)	<p>To create awareness about what is known about the facilitators and barriers to service-user involvement in the local context,</p> <p>Discuss on ways to tap local community resources and assets to empower service-user involvement in mental health system strengthening</p> <p>To reflect on the ToC map and identify top priorities for action to effectively involve service-user in mental health system strengthening</p>	<p>First author (SA) and research assistant (a PhD student) with facilitation of the then district administration health office head presented and discussed on formative studies in the area on:</p> <p>(i)Involvement experience, barriers, facilitator and capacity building for service-user involvement, (ii) components of the co-produced ToCmodel, systematic review about the application of PAR for service-user involvement in mental health system(unpublished), (iv) two relevant studies about local community resources and assets with potential for use to empower service-user for involvement in mental health strengthening</p>

Workshop3 (December 2019)	To foster stakeholder collaboration and support through dissemination of preliminary findings of the PAR process, and awareness creation to diverse stakeholder groups	<p>Four key activities were accomplished: Members of RPG presented highlights of ToC, prioritization exercise outcomes and details of the process findings of the Stage to PAR processes on program and action plan to a broader range stakeholder groups</p> <p>Conducted awareness-raising education to enhance stakeholders' awareness about mental illness and roles of service users within mental health system strengthening (By a senior professor of psychiatry (AA) from Addis Ababa University)</p> <p>Three people from two service-user associations (Mental Health Users Association in Ethiopia-from Addis Ababa, and Sodo district Association of People Living with HIV/AIDS) shared their lived experiences, association, and how to collaboratively work in empowering service user association.</p> <p>RPG convened discussion session for stakeholders to reflect on the presentation, and develop collective views on action plans for next steps and ways forward</p>
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### Appendix 9. List of top ten priorities by stakeholder groups

No	Topic	Maximum value assigned by stakeholder groups				
		Service user	Caregivers	Health professionals	Leaders	Mean value
1	Stigma and discrimination	7	10	7	8	8
2	Low service user and caregiver involvement	5	4	6	3	4.5
3	Socio-economic problems	6	6	4	6	5.5
4	Lack of stakeholders collaboration	2	2	8	5	4.25
5	Inadequate and inconsistent supply, problem of use of Psychotropic	10	8	5	9	8
6	Multilevel lack of awareness about mental illness	9	9	10	10	9.5
7	Communication problem(at home and with health problems)	4	5	2	1	3
8	Lack of organization of service users	8	7	1	7	5.75
9	Lack of rehabilitation center	3	3	3	2	2.75
10	Risk factors for mental illness(Khat and alcohol use)	1	1	9	4	3.75

## Appendix 10. Studies

### Paper1

Abayneh S, Lempp H, Alem A, Alemayehu D, Eshetu T, Lund C, et al. Service user involvement in mental health system strengthening in a rural African setting: qualitative study. *BMC psychiatry*. 2017;17(1):1-14.

### Paper2

Abayneh S, Lempp H, Alem A, Kohrt BA, Fekadu A, Hanlon C. Developing a Theory of Change model of service user and caregiver involvement in mental health system strengthening in primary health care in rural Ethiopia. *International Journal of Mental Health Systems*. 2020;14(1):1-1

### Paper3

Abayneh S, Heidi H, Brandon A. Kohrt BA, Girma E, Getachew M, Alem A, Hanlon C. Empowerment training to support service user involvement in mental health system strengthening in rural Ethiopia: a mixed-methods pilot study

### Paper 4

*Abayneh S, Lempp H, Hanlon C. Participatory action research to pilot a model of mental health service user involvement in an Ethiopian rural primary healthcare setting: study protocol. Research Involvement and Engagement. 2020;6(1):1-14.*

## Abstract

**Background:** Involvement of service-users at all levels of the mental health system is a policy imperative in many countries internationally. However, putting policy into practice seems complex; little is known about how best to involve service users and efforts are often criticized for being tokenistic. In low-and-middle income countries, less attention has been given to the roles of service users within mental health systems. The proposed study is part of a larger project intended to develop service-user involvement in mental health system strengthening in Ethiopia. A Theory of Change (ToC) model has already been developed through a participatory approach. This study protocol aims to describe the theoretical background and methods to pilot this model using participatory action research (PAR) and explore participants' experience of involvement.

**Methods:** The proposed study will apply a PAR approach situated in critical social theory and conduct a phenomenological case study to find out participants' experience of involvement. This will be conducted in three stages. The focus of Stage 1 will be to (i) establish a Research Advisory Group (RAG), and Research Participant Group (RPG) at district and primary healthcare facility levels, respectively, and (ii) identify and prioritize potential areas of concern for involvement in the domains of advocacy, service planning and development, monitoring and improving service quality. In Stage 2, we will work with the RPG to develop a plan of action for the selected area. Stage 3 will aim to assist the RPG to implement and evaluate the plan of action. Process indicators and observation will be combined with in-depth interviews with participants to elicit their experiences of involvement. Thematic content analysis will be used.

**Discussion:** The participatory approach to mental health service user involvement in health system strengthening employed by this study will support the implementation of solutions through locally relevant and contextualized actions. Findings from this study will contribute to the body of knowledge towards understanding the complexity of implementation of service user involvement and refine the ToC model for transferability to similar settings.

**Keywords:** Participatory research, service user involvement, action research, Sub-Saharan Africa, Mental health, Patient and public involvement

### **Plain English summary**

In order to improve mental health care, it is vital that service planners, managers and health professionals work closely with service users. Service users are experts by experience. They can help to hold services to account and make sure that services reach the people who need them in a fair way. In developing countries, the voices of mental health service users are doubly important to make sure that care is respectful, appropriate and of good quality. But in most developing countries, service user voices are not heard. The aim of this paper is to describe our plans to try out a model of service users and health professionals working together to improve mental health care. The setting will be primary care services in a rural district of Ethiopia. We will set up two groups. Group 1 is called the 'Research Advisory Group'. The members of this group will be mental health service users, health professionals, officials and community representatives from the district. Group 1 will decide on which problems are most important. Group 2 is called the 'Research Participant Group'. This group includes service users, their caregivers, health

professionals and health managers at a primary care facility. Group 2 will work out how to address the top priority problems. They will then put the plan into action. Together the groups will help to improve mental health care. At the end of the study we will understand more about how services users can be at the heart of improving mental health care in a low-resource African country.

## **Background**

The importance of involvement of service users and their caregivers (hereafter referred to as ‘service-users’) at all levels of the mental health system has been recognised globally [1, 2]. The concept of involvement (alternatively referred to as participation or engagement) [3–5] is defined as “a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change” [6]. There is explicit international policy direction from the World Health Organization for national mental health systems to empower and involve service-users in mental health advocacy, policy, planning, legislation, service provision, monitoring, research and evaluation [7, 8]. The same directive has become a policy imperative and is therefore firmly embedded in policy documents of many high income countries [1, 9].

In low-and-middle income countries (LMICs), where more than 80% of service-users are living [10], there is less prioritization and government support for either mental health care provision or involvement of service users [10, 11]. In many of these countries, there are no policies and laws to direct mental health programs and/ or the policies and laws are not aligned with human rights recommendations (e.g., social care, participation) or are poorly implemented [10, 11]. Service-users are exposed to stigma and discrimination [12, 13] and have several unmet needs [13], exemplified by suffering of illness and disability [14], impoverishment [15], premature mortality [16, 17], and human rights abuses(e.g., being chained or kept in isolation) [12, 18]. Studies suggest that service-user involvement can also protect and promote human rights [19, 20]. In LMICs, service-user involvement has been widely recommended as an essential ingredient to strengthen weak mental health systems [21, 22], increasing the likelihood of scale-up of appropriate, quality mental healthcare [23, 24] and thereby reducing the treatment gap [8, 25].

However, little is known about how best to optimize and lasting involvement of service-users [5, 26]. Service-users are often excluded (rendered invisible and voiceless) from their rights to meaningful participation in decisions that have direct impact on their lives [18, 26, 27]; and are at risk of being left behind during efforts to expand universal health coverage [28].

Methods for service-user involvement have been criticized for the lack of a participatory approach/inclusivity, and being unable to move beyond a tokenistic mode of participation [1, 2, 26, 29]. One promising approach to address these criticisms is Participatory Action Research (PAR). The PAR approach is highly conducive to enable marginalized people (in this case people with lived experience of mental illness) to be meaningfully involved in areas of concern to them through developing their capacities and address more holistically the complex factors that hinder their involvement [30–32]. Our recent systematic review (Abayneh et al., in progress) found that PAR is a well-established approach to involve service-users within mental health systems in high income countries; however, there are few similar studies from LMICs.

## **Objectives**

The proposed study is informed by a larger project, ongoing since 2014, intended to develop service-user involvement in mental health systems strengthening in Ethiopia. The aim of this paper is to describe the theoretical foundations and methods for a PAR case study of piloting a Theory of Change model for service-user involvement in mental healthcare in a primary health care setting in rural Ethiopia. The specific objectives are to:

- Identify, prioritise and select an area of concern with respect to the integration of mental health into primary healthcare as a focus for involvement of service-users, from the perspectives of service-users, caregivers, health professionals/managers and other key community stakeholders.
- Develop plans for action for the selected area of concern.
- Assist service-users, caregivers, health professionals and managers in the implementation of the plan of action.
- Evaluate the process of, and explore the experience of, involvement of service-users, caregivers, health professionals and managers in the PAR activity.

## **Theoretical Foundation**

Historically, mental health service-users have been excluded from participation in many mainstream social structures, disqualified as knowers and in knowledge production, because they are construed as irrational, unreasonable, incoherent, lacking in insight, deviant from standards of normalcy, unpredictable, unsafe to themselves and others, victims or deficient of mental capacity [33–35], and considered to have a flawed or spoiled identity [33, 36]. Within the mental health system, knowledge gained through formal education is often more highly valued than the experiential knowledge of service-users gained through lived experiences [33, 37, 38]. Although health professionals and researchers have important perspectives on science and practice, service-users can contribute their unique expertise as individuals with lived experiences of their condition and as a recipient of the healthcare services.

When service-users do have contact with mental health services, the system can hinder [39] or deprive them of any real chance to participate, or their input may be devalued in decision-making with respect to aspects affecting their lives [29, 33, 40]. Health systems value and legitimize service providers to act in the “best interest” of service-users [36, 41]. Service-users may have little control over either the nature of the services they receive or the evidence base that legitimizes these services [33, 37, 42]. They have described the exclusion and neglect of lived experiences from knowledge production as ‘false and potentially dangerous views of the world’ [43] and have highlighted the crucial contribution that their ‘experiential knowledge’ has to bring to the ‘evidence table’ [38, 44, 45], including constructing alternative narratives of experiences and new forms of knowledge [46, 47].

There are also a range of international studies supporting the desirability of lived experience and knowledge for health systems strengthening [48, 49]. However, pervasive stigmatizing attitudes and discrimination [12, 50, 51] at multilevel tend to disqualify service-users from full social acceptance, marginalize them and hinder their active involvement [33, 36, 52]. Furthermore, because of these negative attitudes and practices, service users may experience powerlessness, consider themselves as ‘lesser citizens’ or feel unable to act, worthless and incompetent [53, 54], commonly described as “internalized oppression”[55].

Given these factors, the authors argue that service user involvement needs to be approached within a critical paradigm [56, 57]. More specifically, we choose to ground the proposed study in critical social theory (CST) [58] with focus on Habermas's theory of communicative space and action [59]. The choice of CST has significance in several ways for the proposed study. First, CST can offer a 'communicative space' required to create fora for service-users and other stakeholders to engage in dialogue to reach inter-subjective agreement, mutual understanding, and consensus to guide deliberate, and collaborative social action [60–62]. Communicative space, as employed in this protocol, refers to the spaces in time and place where service-users, caregivers, health professionals/managers and other key stakeholders come together in the PAR process [62, 63], and within created social arenas (e.g., mutual recognition, trusting relationship, reciprocal perspective taking, a shared willingness to consider one's own conditions, learning from each other, reaching common ground for action, sense of agency) [64, 65].

Second, CST guides towards recognizing the social, economic, political, and historical contexts that shape human thought and action, and the social structures that have historically served to oppress certain groups in society (e.g., persons with lived experience of mental health conditions) [66–68]. CST can give clues about how to transform social relations of power and enable service-users through (a) expose injustice (through critical analysis and questioning of longstanding established rules, beliefs and practices and conceptualizations about service-users); (b) challenging relationships of domination that exist within the lives of service-users, and allowing them to engage on an equal footing by bringing service-users, health professionals and health administrators to collaborate on a common issue [60–62], and (c) creating opportunities for service users to gain experiences of emancipator knowledge and greater awareness about their situation, break attitudes of silence, gain confidence and abilities, open themselves up to new ways of understanding, take effective action to alter unjust conditions and structures [69], to formulate alternative stories that are empowering [65, 70], and gain more control over their situation [68, 71, 72]. Third, CST is based on a capability/strength-based approach of participation [69], engages directly with service--users [73] and acknowledges service-user knowledge as valid, encouraging mutual recognition and sharing of perspectives [59, 73].

## Methods

### Setting

The proposed study is part of a larger project that was instigated as part of the ‘Emerging mental health systems in low- and middle-income countries’(Emerald) project, which investigated the health system requirements for successful implementation of integrated mental health care in six LMICs(Ethiopia, India, Nepal, Nigeria, South Africa and Uganda) [74, 75]. The study will take place in Sodo district, a rural district located in the Gurage Zone of the Southern Nations, Nationalities and Peoples’ region, about 100 km south of Addis Ababa. The district had a population of 161,952 people in 2007 [76]. Around 90% of the district population reside in rural areas and are reliant on subsistence farming [77]. The district population is predominantly composed of the Gurage ethnic group and followers of Orthodox Christianity. The official language of the district is Amharic [76]. There are 58 sub-districts or kebeles (the smallest administrative units with 2000 to 5000 people each), which are both geographically and climatically diverse. There is one primary hospital with an outpatient psychiatric service (run by a psychiatric nurse) in the main town and eight health centres, four of which are located within the three towns of the district. The primary hospital and all eight health centres have functioning mental health services using a task-shared model of care. Each health centre serves about five sub-districts, comprising a population of about 25,000–40,000 people [78]. Each sub-district has a health post (lowest statutory healthcare facility). The health posts are staffed by a pair of community health workers called health extension workers (HEWs). The HEWs are high school graduates with one year of training in sixteen packages of care which cover four main areas: disease prevention and control, family health, hygiene and environmental sanitation, and health education and communication [79]. A minority of HEWs have received training in mental health as part of their upgrading to level IV.

Sodo district is the research and implementation site for the PRogramme for Improving Mental health care (PRIME) [80, 81]. As part of PRIME, primary care staff in Sodo district have been trained to deliver packages of care for people with mental health conditions, including prescription of antipsychotic medication, follow-up, limited adherence support, basic psycho-education and community awareness-raising of mental illness [82]. PRIME established a multi-sectoral community health advisory board with representatives from key members of the district

leadership (security, gender office, women and youth affairs, religious affairs and education), the community and service users and caregivers, and was chaired by the head of the district health office [82]. The CAB met twice a year to oversee and advise PRIME [83].

## **Design**

This section describes the research design, rationale and stages of the proposed study. We propose to use a PAR approach [84] and a phenomenological case study [85] to explore participants' experiences of involvement. In this study, drawing on work by Rouleau et al. [86], and Nelson et al. [87], PAR is defined as the: (i) valuation, mobilization and legitimization of service user experiential knowledge of living with a particular health condition( e.g., mental illness); (ii) conduct of research that focuses on service users' concerns, participation, and outcomes; and (iii) active partnership among a variety of stakeholders/actors(e.g., researchers, health professionals, decision makers, organizations, service-users) [86], for the purpose of taking action and making change [87]. PAR is the approach of choice for the proposed study for several reasons.

First, PAR has a collection of research methods (epistemological pluralism) [88] that is uniquely suitable to address complex problems (such as service-user involvement [3, 89]), build evidence in areas that lack an empirical evidence base and find practical solutions in the areas of health systems strengthening, implementation research, various health and social care settings [88, 90, 91]. PAR has been increasingly said to be more robust than other approaches because the process (a) simultaneously generates knowledge and initiates actions informed by that knowledge [73, 92, 93], (b) makes knowledge accessible and relevant to stakeholders to underpin change [93, 94], (c) relies on a commitment to bring together theoretical and methodological expertise and the practical knowledge of non-academic participants ('creates self-critical communities' [95, 96]), (d) shares leadership and resources to address issues in specific systems [67, 97], and (e) enables co-design of culturally appropriate and effective interventions, their implementation and collaborative evaluation of impact [60, 95].

Second, although many programme theories articulate intended changes [98], engage with the complexity of interventions and provide a framework to guide action, monitoring and evaluation [99], there is little empirical evidence of how theories can be applied in practice [100–102]. Hence, there have been calls for PAR in theory-based implementation and evaluations [103–

105]. Early integration of Theory of Change (ToC) and PAR during planning and implementation is recommended [103, 106, 107]. To the best of our knowledge, no one has yet offered a description of how to combine ToC and PAR to apply service-user involvement in mental health systems. We attempted to address this gap by taking cues from the evidence base on combining ToC and PAR from other disciplines (e.g., agriculture [100, 108], education [102], development studies [109], programme evaluation [110, 111] and implementation sciences [112]).

For our proposed study, combining ToC along with PAR is a promising approach for several reasons:

- A) At the core of both ToC and PAR is a concern with how and why change takes place. Both anticipate a range of positive changes/outcomes [96, 100] including: individual level outcomes (e.g., advancing participants' personal and collective sense of agency, social networks) and community level outcomes (awareness raising, stigma reduction, and strengthening community capacity, collaboration) [54, 56, 113]. ToC provides a strong heuristic device for deeper understanding of the implementation context [100, 112, 114], guides the direction of change and how to achieve the intended transformation, defines collaborative outcomes and surfaces the various layers of interventions with underlying assumptions, and ensures that different perspectives of participants are reflected in the design [111, 115, 116]. However, that alone may not be sufficient to support the actions required to achieve implementation [102, 107, 108]. This gap can be balanced when ToC is combined with PAR, because the cyclical nature of PAR (iterative cycles of reflection, planning and acting), facilitates learning about what, how and why change is unfolding [103, 108, 111].
- B) In practice, ToC and other programme theories may have a problem of reach, i.e., they do not explicitly consider issues of inclusivity and there is little acknowledgement of the way in which power operates to affect the building of collaborative capacity or how this notion needs to be addressed to enable stakeholder participation [106, 107, 117]. Without such explicit consideration of power dynamics, ToC approaches may inadvertently reinforce a hierarchical relationship between stakeholders and privilege the perspectives of those in power (e.g., policy makers, professionals) and downplay or even disregard entirely the views of others (e.g., service-users) [116, 118, 119].

These drawbacks may be minimized through the emancipatory and critical theoretical foundation of PAR that seeks to explicitly and intentionally work with a range of stakeholders, including those historically oppressed, disempowered, vulnerable and marginalized groups (e.g., service-users) [62, 107, 112]. The participatory commitment of PAR provides space for diverse forms of expertise and promotes understanding of the different life-worlds of participants [32, 87, 120]. Working in a collaborative and non-hierarchical manner may facilitate deeper understanding of how implementation can be achieved [56, 84, 100, 112, 121]. Furthermore, the dialogue and critical reflection incorporated within PAR enables participants to challenge the status quo of professional-dominated health systems, dismantle unequal power relations between service users/caregivers and those within health systems and society and create fruitful communication [121–123].

C) PAR also rejects objectivist assumptions that distance the researcher and the participants from one another [121, 123]. The close proximity of working can promote inclusion and confront engrained stigma and prejudices [32, 120, 124]. In line with the contact hypothesis [125] and social contact theory [125, 126], positive contact between service-users, health professionals and others within the health system, e.g. by giving them equal status in pursuing common goals, can foster mutual understanding and reduce stigmatizing attitudes [127, 128].

### **Sessions and stages of the proposed study**

The study procedure will take place in three stages, with cyclical recurring activities involving planning, acting, observing and reflecting, informed by the model proposed by Kemmis and McTaggart [129] (See Table 2 for proposed sessions plans, stages and activities). The three stages are: i) Establishing of groups, identification and prioritization of thematic concerns, ii) Planning of action, and iii) implementation (See Fig. 1, for summary of stages). We anticipate that the participants will need to meet for at least seven weekly sessions for two to three hours. The first two sessions will take place at district level at Buie town, the capital of Sodo district, and the other five sessions within the primary health care facility and will be conducted in Amharic language.

## **STAGE 1: establishment of groups, discussion of foundational studies, identification and prioritization of concerns**

### *Formation of cross-stakeholder groups (planning)*

For the proposed study, we aim to maximize participation of diverse representatives of the local community through establishing two multi-stakeholder groups that will collaborate and be involved within the research process: (i) a Research Advisory Group (RAG), and (ii) a Research Participant Group (RPG).

### **Research Advisory Group**

The importance of involving a Research Advisory Group (RAG) was recognized early during the larger study. Although our plan was to establish a new RAG, after our discussion with Sodo district health officials, we agreed to work with the existing community advisory board (CAB) that had been established to oversee efforts to expand access to mental health care in the district (working with PRIME) [82]. As part of the larger study, the Sodo district CAB has participated in the coproduction of the ToC for mental health service-user involvement and contributed to a community stakeholder consultative meeting. To ensure a feasible working group size, for the RAG we will purposively select 20 participants from the larger CAB. Decisions on who to select will be made collectively with district officials involved in the mental health care programme, based on pre-specified criteria (See Additional file 1 for inclusion criteria). In addition we will ensure gender representativeness of participants.

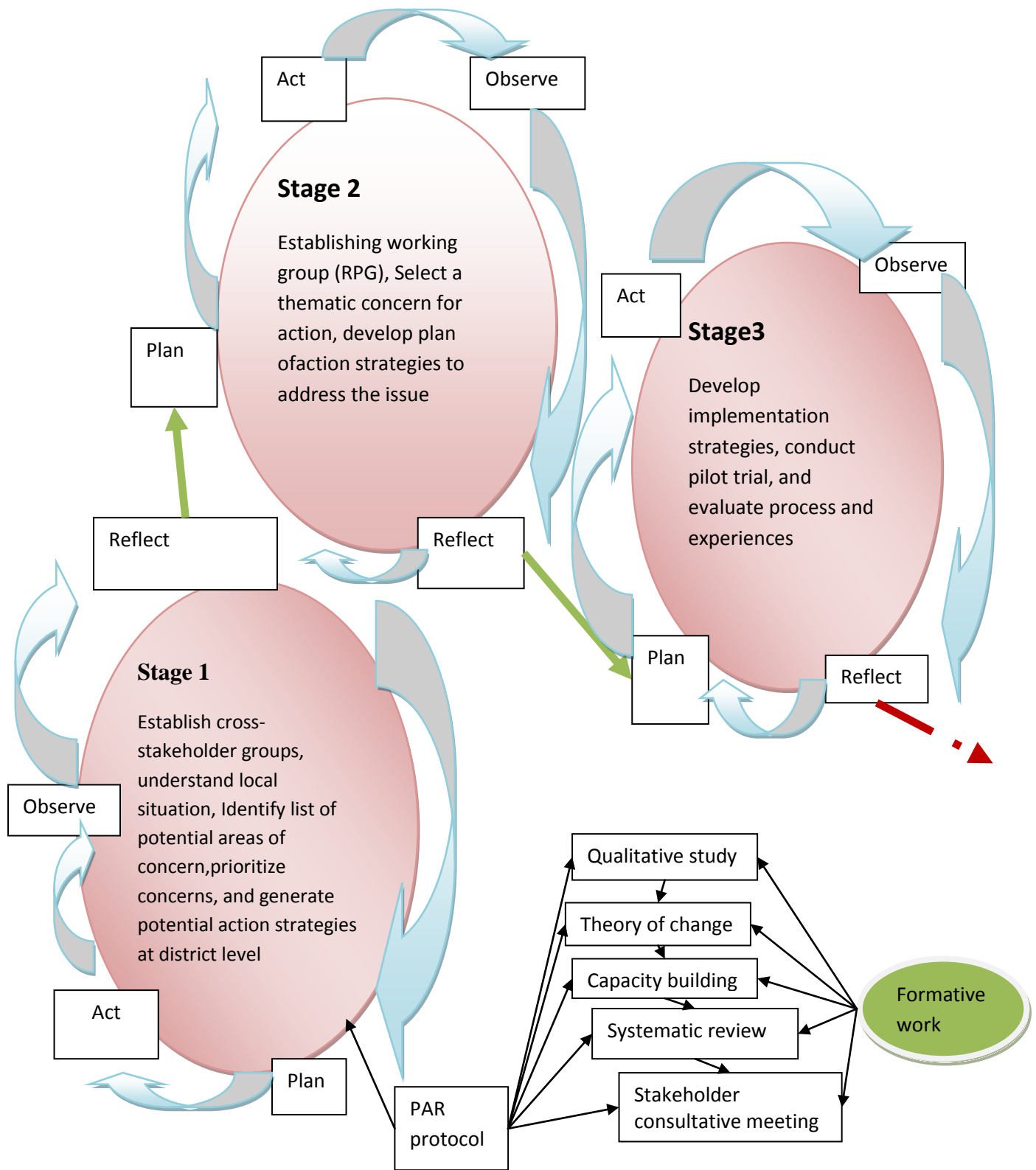


Figure 12. Formative works and stages of the Proposed Study

improving mental health care from their local community perspectives, (ii) provide a conduit between the Research

Participant Group(RPG) and the community to ensure that the research findings are put into action and disseminated in their local context; (iii) create a strategy to enable an empowering environment(e.g., through resource mobilization) for service user involvement,(iv) facilitate further consultation and community involvement for service user mobilization and empowerment, and (v) advocate for the protections of rights of service users. The RAG will meet three times during the course of the research in Sodo district: two half-day meetings during Stage 1 and once in Stage 3.

### **Research Participant Group**

A Research Participant Group (RPG), comprising of up to 12 participants (mental health service-users-n = 4, caregivers-n = 4, and health professionals and health facility managers-n = 4), will be convened at a health facility in Sodo district (See Additional file 1for inclusion criteria to guide purposive selection of participants). As our research objective is not specific to certain mental health conditions, and to increase the social validation of the study objectives, procedures and outcomes [130], we will included service users with psychosis, depression, epilepsy, and alcohol use disorder. We also try to balance gender representation of participants. The RPG will participate throughout the research process in (i) identification and prioritization of priority problem areas, (ii) identification of specific areas of concern at the health facility level; development, implementation and evaluation of an action plan, and (iii) validation of the research process and local dissemination of the findings of the study. The principal investigator and a research assistant will act as facilitators of the process of prioritization, design, conduct and dissemination of activities of the research study with a view to empowering the RPG at each stage in the PAR cycles.

### ***Discussion of foundational studies, identification and prioritization of potential areas of concern (action)***

This session will include two sets of activities including [1] presentations and discussion about foundational studies, and [2] identification and prioritization of potential areas of concerns as briefly detailed below.

### **Presentation and discussion about formative works**

The development of this protocol was informed by formative work: (i) a qualitative study, (ii) development of a Theory of Change model for service-user involvement, (iii) capacity building training, (iv) a systematic review, and (v) a community stakeholder consultative meeting (See Fig. 1) in a larger project intended to develop service-user involvement in mental health system strengthening in Ethiopia. In Stage 1 of the proposed study, based on the findings of the formative works, a half-day consultative workshop with representatives from stakeholder groups will be conducted to ascertain the situation of service user involvement in mental health system strengthening in the study site in relation to the global situation. The intention of this protocol is not to report the details of the foundational studies; rather we present a brief overview of the ToC to inform readers about how that informed the development of this protocol.

### **Theory of Change**

As part of the larger study, a generic ToC for service user and caregiver involvement in mental health system strengthening in Ethiopia was co-produced with stakeholder groups, including service users, caregivers, psychiatrists, researchers, and statutory and non-statutory community representatives. The ToC helped to make explicit the hypothesized pathways to achieve the long term outcome (derived by consensus) of “improved physical and mental health, economic productivity and social inclusion for service users, and improved life satisfaction, including economic capacity for caregivers”. The ToC also allowed identification of necessary preconditions for success, programme levels for an intervention (service user/caregivers, health facility and community), indicators of success, assumptions underpinning the pathway and the types of interventions needed. In the ToC, capacity building training for service users, caregivers, and health professionals/managers, PAR with stakeholder groups, inter-sectoral collaboration, and service-user mobilization were identified as programme interventions to enable service user involvement to achieve the long-term outcome.

The co-production of the ToC with diverse stakeholder groups and the embedded PAR in both the design and implementation of the interventions will enable the ToC to be responsive to local needs [131–133]. However, in the same way that most ToCs are comprehensive road maps for the implementation of a programme [102, 103, 107], our one was also generic and cannot show the specific target of action for service user and caregiver involvement. Service users can potentially be involved in each domain of the mental health system (service planning, service

development and delivery, service quality improvement, education/training, service promotion and advocacy); however, there is no evidence-based algorithm to determine how to prioritize the domains. The embedded PAR as an intervention component in our ToC can help to identify and prioritize problems, the specific targets of action as well as the domains of mental health systems, and develop a plan of action based on unique local contexts and strengths by involving service users and other key stakeholders [102, 107, 134]. Therefore, to specify the ToC interventions for a primary healthcare setting, we will conduct a half-day participatory interactive workshop involving stakeholder groups (See prioritization section).

### ***Identification and Prioritization of Thematic Concerns (Action, Observation and Reflection)***

In the proposed study, we will use PAR to initiate a one day priority setting exercise by bringing together service users, caregivers, health professionals/managers, and CAB members (including RPG and RAG) to generate a list of their top priority problems for research in involving service users in mental health system strengthening in Sodo district. The study will be informed by guidance from the James Lind Alliance (JLA) [135] to ensure a balanced, inclusive and transparent process for priority problems identification, and the Nominal Group Technique (NGT) to establish consensus, prioritize and rank the thematic concerns [136–138]. The JLA approach enables us to create an environment that encourages open discussion, respect for diversity and clarity of thought, and also has been used to identify research priorities in several areas including mental health [135, 139].

For the proposed study, potential priority problems for involvement of service users in mental health systems improvement will be identified and short listed by stakeholder groups in a 1-day workshop in Sodo district using the five step JLA process [135](see Table 1 for details of the steps). Given the complex nature of service user involvement within the mental health system [3, 5, 89], and low levels of experience of service users, caregivers and other community stakeholders working together within mental health systems in Ethiopia [140], the principal investigator will provide a list of potential priority problems (questions) extracted from the foundational studies and evidence review (See Additional file 2) to prompt discussion and enable participants to choose problems of relevance to their local context. To reduce the possibility of bias and influence by the potential priority problems/questions, the principal investigator and facilitators will encourage participants to reflect upon the sample priority areas, to modify or

drop the potential thematic concerns provided and add their own thematic areas that are most important for themselves.

Although JLA enables the identification of potential priority problems of interest to stakeholders; there is a need to move beyond a focus on uncertainties to the generation of shared priorities, ranking and achieve consensus on the priorities. For this, group decision making processes such as NGT are helpful, because of a well established, multistep facilitated group interactive process through increased engagement of relevant stakeholders( including those otherwise excluded groups)on concerns that are important and matter to them [136, 137]. The processes of silent generation of responses, round-robin listening and independent voting ensures the participation of all individuals. The structure of voting and discussion allows the person to express a view, influence decisions, avoid conformity or social pressure, and individual judgments can be aggregated into group conclusions whereby anonymous individual rank-orderings are aggregated across members to determine the relative importance of all responses [136, 137]. For the proposed study, we integrated NGT with stage 5 in JLA which seems ideally suited for PAR and consistent with the critical social theory, NGT will give all participants a voice, and produce priorities and practical change [137, 138]. Following the NGT, the participants will generate, revise, vote on and rank priority problems of importance to their local context (See Table 1 for details). Participants will rate the importance of the thematic concerns on a 5-point Likert scale (very high priority to very low priority).The priority list that is created will be grouped into broad thematic areas of domains of mental health systems (e.g., research, quality improvement, advocacy) by consensus and using an inductive approach.

## **STAGE 2. Plan of action development**

In stage 2, the key themes generated and prioritized from Stage 1 will be presented back to the RPG and reviewed at a healthcare facility in Sodo district. The RPG will discuss the prioritized areas of concern and choose one concrete theme/problem to be addressed in their specific health facility/setting, identify lists of strategies to solve the problem and develop a plan of action for that specific health facility/local setting. During this stage, the cycles of PAR (including planning, acting, observing and reflecting) will be undertaken (See Table 2).

### Stage 3: implementation and evaluation

The focus of this stage is actual field implementation of the proposed strategies and action priorities in Stage2, and evaluation of the process. In partnership with the RPG, assessment of the local context of the health facility will be conducted by the principal investigator, including identification of potential opportunities and barriers to implementing the agreed actions. The entire implementation process will be underpinned by the cyclical PAR activities of planning, acting, observing and reflection (See Table 2). However, as this study is also of interest for academic purposes (principal investigator), the authors anticipate time pressure may hinder the full involvement of the principal investigator in the final cycles. Hence, some key strategies and actions that can be implemented within the time frame of the study and will be identified during the initial discussions with RPG, implemented and evaluated(See Table 2) as a proof of concept. As the action stages evolve, the RPG will be empowered to become autonomous to take actions and effectively implement their action plan in their areas of priority, and the role of the principal investigator will become advisory and consultative [141].

### Data collection and analysis

Multiple sources and methods will be used to collect data. All participants (RAG and RPG) will fill out socio-demographic questionnaires at the beginning of the first session. The following types of data will be collected: meeting minutes, written documentation of prioritization and consensus processes, reflective field notes(reflective journal) of obstacles and successes of the research process, participant observation during all group discussions, and anonymous feedback from the participants about the process, and audio recordings of all sessions. After the last session of PAR, in depth interviews will be conducted with the RPG members to explore their experiences of involvement in the PAR processes.

**Table1. Procedures to thematic concern identification and prioritization**

Stages	Description
<b>Step 1. Establishing the priority setting Partnership and defining scope</b>	A cross-stakeholder groups(n=20-25)including RPG and RAG will be selected with maximum variation comprising of relevant statutory and non-statutory organization representatives and individuals that can reach and advocate for, mobilizing resource, empower and support service users for involvement in mental health systems strengthening. The stakeholder groups will be invited to a half-day consultative meeting and discuss on the findings of foundational studies in Phases 1&2 about service user involvement so as to raise awareness, create the need for collaboration, and define the scope of the study for future action.

<p><b>Step 2. Gathering and identifying questions</b></p>	<p>The cross-stakeholder groups will be invited in a 1-day thematic concern identification and prioritization exercise at Sodo district.</p> <p>The participants will be divided into four homogeneous groups (service user, caregivers, and health professionals, community stakeholders) so that the participants are comfortable voicing their opinions.</p> <p>Each group separately will be asked to list as many priority questions from their own perspectives perceived as the most important challenges to be addressed for service user and caregiver involvement in mental health system improvement.</p> <p>Facilitators will gather the list of questions/thematic concerns in each group and record in a flip chart</p> <p>In addition, each group will be provided with the pre-generated lists of potential priority areas (Additional files 2) to discuss on, augment their priorities, and identify additional priorities</p>
<p><b>Step 3. Reducing the questions and processing uncertainties</b></p>	<p>Each group will present their list of thematic concerns in a plenary session.</p> <p>Facilitators will create a list of unique themes by merging duplicates and overlapping questions (issues) on a flip chart.</p> <p>The identified themes will be grouped into key themes with list of specific concerns/issues.</p>
<p><b>Step 4. Interim Prioritization</b></p>	<p>The consolidated lists of priorities will be distributed to the homogenous groups to identify their top 10 research priorities in the order of perceived importance that they think need be the focus of research involving service users within Sodo district using pre-set criteria (e.g., relevance local primary health care and community, public health significance, magnitude of the problem, severity, feasibility/amenability to change with local context). Accordingly, each participant will select his/her top ten priorities and ranks them by giving each priority a score between 1(lowest) and 10(highest). The top list of each participant within the homogeneous groups will be combined by consensus and presented in a plenary session for listing the 10 priorities considered most important by all stakeholders group and reach consensus.</p>
<p>Step 5. Final Priority setting</p>	<p>The participants will be organized into nominal groups, and generate their top five priorities and rank them in orders of importance. This will follow the following five steps.</p> <ol style="list-style-type: none"> <li>a. The participants will be divided into four groups with balance of service user, caregivers, health professionals and community stakeholders and each participant within each group will be asked to silently generate top five priorities from the top 10 lists generated.</li> <li>b. A round robin approach of recording of priorities will be used to collate priorities, that is, each participant in turn will be asked to read one priority off the list within each group. This priority will be written on flip chart by a facilitator of each group.</li> <li>c. Once all the priorities are written on the flip chart an open discussion will be conducted to allow all participants within each group to discuss, clarify, dispute and discarded or add or modify a priority within their groups.</li> <li>d. The final lists of priorities from each group will be presented in a plenary session, bring similar priorities together on a flip chart, and will be discussed with the whole group in order to ensure that all participants understand and approve of the congregated priorities.</li> <li>e. Finally, each participants will be provided with the combined consensus priorities and asked individually and anonymously, to rank all the five most important priorities in the order of importance by giving five to the highest valued priority, the next most important, a value of four and so on progressively down to the least important which will be assigned a value of 1. A mean priority score for each priority across all groups will be calculated by summarising ranking scores and dividing this by the maximum possible ranking score of that priority. The maximum possible ranking score for a given priority will be calculated by multiplying the number of participants who considered the priority by 5(the maximum rank)</li> </ol> <p>Similar NGT will be conducted with RPG at a health facility level to identify and establish two top priorities for action trial.</p>

Thematic analysis of the data will be conducted [142]. The data analysis method will be based on Interpretative Phenomenological approach, which places the participants’ experiences at the core

[143]. We expect that it will be challenging to involve service user in the data analysis, in the true sense of the word, hence the principal investigator will lead the data analysis, and the results of the analysis will be fed back to the participants for member checking.

**Table 2. Summary of stages, activities, and session plans for the proposed study.**

Stages	Cyclical activities	Descriptions	Sessions
<b>Stage 1: Formation of stakeholders Groups, and Consultative Workshop</b>	Planning	Identify and establish cross-stakeholder groups that services as a reference group, and working group together with Sodo district health office Getting stakeholder groups and agree on time and place for regular sessions Develop summary of findings from foundational studies Identify and prioritize top thematic concerns	1
	Action	Present and discuss on foundational studies in a consultative workshop with stakeholder groups Systematically identify thematic concerns through small homogenous groups and heterogeneous group discussions, prioritize thematic concerns using Nominal Group Techniques	2
	Observing	Collect key thematic concerns and priorities generated in small group and plenary sessions, through audio-recording, capture minutes, field notes A research assistant will record field notes on group dynamics and interactions and on the context surrounding the discussion.	1-2
	Reflection	Discuss on and reach consensus on priority areas Reflect within homogeneous groups, heterogeneous; compare the reports of each group The stakeholder groups make sense of what has happened through thinking about how it fits with their experiences and local contexts using criteria	2
<b>Stage2: Planning of action</b>	Planning	Reach common understanding between RPG and the researchers and assistants what the research involves and ensure consent to participate RPG agree on time, place, number of sessions per week and duration of the sessions at primary health facility level Review the thematic priorities identified in Stage 1, discuss, select and prioritize two thematic concerns for action as trial of proof of concepts Generate set of solutions and design intervention strategies	3
	Action	Work with RPG and develop viable and realistic change strategies taking into account their local realities; set evaluation strategies for actions	4
	Observing	Observe and document the process through notes, and audio-recordings Evaluate participation and representation	3-4
	Reflection	Continuous reflection throughout the action planning phases on data from observation, field notes and reflect on the action options Examine whether the proposed improvement methods is feasible in terms, time, additional resources availability, and local experiences	3-4
<b>Stage3: Implementation and evaluation</b>	Planning	Review of the plan action with RPG and reach agreement about the way strategies would be put into operation and how to document observations	5

		Designing implementation strategies and action Discuss about and set implementation indicators Discuss and research consensus how the RPG will continue with the PAR processes on own	
	Action	Implementation meeting with RPG Reach agreement about the way the program would be put into operation and how to document observations Select few interventions and commence as trial of proof of concept Discuss and research consensus how the RPG will continue with the PAR processes on their own	6
	Observing	Document the trial process through taking detailed field notes, observation and discussion with RPG Preliminary analysis and findings of the process will be collected Conducted in-depth interviews with RPG to ascertain their perceptions and experiences of the process of PAR	6
	Reflection	Conduct evaluation meeting with RPG and collect feedback about the process of the PAR process, and reflect on the process of implementation Identify options for further PAR and action with or without academic researchers	7

## Rigour

Several measures will be employed to increase the rigour, authenticity, and trustworthiness of the proposed data collection and analysis. Bias in data collection and coding by the principal investigator and research assistant will be reduced through regular discussions (to maintain reflexivity) with the RPG [144, 145]. In addition, the principal investigator will acknowledge and record sources of potential personal bias that may influence the process of data collection and analysis as a result of existing networks and connections. The process will provide an audit trail of the reflective process; compliance with the criteria of confirmability data will be ensured by audio recording of discussion groups [144, 145]. Increased credibility will be achieved through prolonged engagement of the principal investigator within the setting, triangulation of multiple data sources and methods( e.g., written minutes, observations, field notes, and in-depth interviews), and regular member checking of raw data, and reports, which will support sustained dialogue with participants, and development of authentic, trusting rapport between the researcher and participants [144, 145]. Transferability of the study will be increased through sufficient and rich contextual description of the study setting, thick contextual data and activities details, and proper data documentation to allow others to analyze the situation and research outcomes based on setting and context [145].

## **Strengths and limitations**

The use of PAR to pilot the model for service user involvement within the health systems is a new experience, and to our knowledge, there have not been any studies that have piloted and evaluated ToC in conjunction with PAR for service users and caregiver involvement in mental health systems strengthening in Ethiopia or other LMICs. The PAR approach will enable us to improve the model to fit the needs of service users and improve its relevance; the co-design of the model also ensures its local applicability and sufficient adaptability to be transferable to other health facilities in LMICs. The use of PAR that embedded within critical social theory provides a strong theoretical foundation, which bring stakeholders together to define for themselves their needs and experiences, identify any areas of concern, develop a plan of action, and support the implementation of solutions.

The findings of the study are likely to result in an increased understanding of complex phenomena of service user involvement; can contribute in refining the ToC model for better transferability, and may provide future researchers with useful insights and foresights in the development and implementation of more stakeholder inclusive initiatives for service user involvement in mental health systems strengthening in Ethiopia and other similar LMICs. There are several limitations to the proposed study. The proposed pilot study is a small-scale exploratory study and there is no comparison group. A comparative study of larger scale of the proposed study is justified for interested researchers for more rigorous evaluation to provide further support to the impact of the implementation of service user/caregiver involvement experiences. The selection of the participants and pilot site is purposive and so this limits the transferability of the study findings. However, the aim of our pilot study was not to be representative of the whole landscape of primary care clinics and service-users, but to co-design a model with service-user, caregivers, primary health care professionals and health facility managers. The low literacy levels of service users and caregivers may be a barrier to involvement in all stages of the PAR process.

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### **Paper 5**

Abayneh S, Heidi H, Kohrt BA, Alem A, Hanlon C. Using Participatory Action Research to pilot a model of service user and caregiver involvement in mental health system strengthening in Ethiopian primary healthcare: A case study