# FACILITATING MENTAL HEALTH AWARENESS AND COMMUNITY ENGAGEMENT



# Community Mental Health Forums in Sierra Leone



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#### **EXECUTIVE SUMMARY**

Sierra Leone like many other low-income countries experiences poor mental health awareness and minimal engagement with any formal mental health services that are available. Globally, mental health is now being prioritised with its inclusion in agendas such as the Sustainable Development Goals (SDGs) and guidelines such as mhGAP, the urgent need to develop and implement interventions that improve access to effective, evidence-based mental health services is being recognised.

In order to increase service utilization and end the maltreatment of people with mental health problems in countries such as Sierra Leone, interventions that provide sensitisation and promote awareness and engagement in a culturally responsive way, are paramount. In an effort to make a contribution to this huge task, CBM International and other stakeholders developed and implemented a mental health awareness and community engagement programme. To create a dialogue and encourage shared learning between mental health stakeholders including clinicians, traditional healers and religious leaders the programme delivered three-day Community Forums in every district of Sierra Leone.

The aim of this study was to explore the outcomes of this programme and to establish the factors that act as barriers and facilitators to such interventions in low-income countries (Sierra Leone). Eight focus groups were held with stakeholders involved in the community forums and ten key informant interviews were held with mental health nurses from selected districts. The data was analysed using a qualitative method of deductive thematic analysis and qualitative coding techniques.

The study provides an insight into the numerous contextual and systematic barriers that influence the effective development and implementation of mental health interventions in Sierra Leone, such as; poor knowledge, traditional beliefs, programme planning, financial and material resources, infrastructure and political will. The data reveals the perceived outcomes associated with the programme, for example advocacy and community engagement activities, an established referral mechanism, increased service utilisation, collaborative relationships and a positive change in the way people with mental health problems are being treated. However it is evident that the positive outcomes of this intervention will not have a long-lasting effect or be sustained if this intervention is not systematically scaled-up and incorporated into a programme of longer duration.

In this context all socio-political levels from government to community must be included in long-term sensitisation and awareness raising activities, simultaneously, to achieve goals such as the reduction of stigma towards mental illness, a change in the way people with mental health problems are being treated and an increase in the number of people accessing evidence based mental health care. Such interventions need to be developed and implemented using a collaborative approach that guarantees cultural appropriateness. Future programmes and interventions would hugely benefit from using a community based participatory approach, that encourages engagement and ensures sustainability. There is a need for guidelines and a contextually adaptable framework which future programmes with similar objectives can utilise to maximise impact and overcome barriers.

#### INTRODUCTION

#### 1.1 Context

Located in West Africa, Sierra Leone is divided into four geographical areas totalling fourteen districts, with a population of over six million people it is home to various ethnic groups. Although the country is rich in natural resources, exporting large quantities of diamonds, gold, titanium and bauxite, it remains a low-income country. The majority of the population rely on subsistence farming and incomes from small trading, the average annual income is \$800 US dollars [1]. Sierra Leone is one of the lowest ranked countries on the Human Development Index (HDI) [2].

Sierra Leone is still reeling from a ten-year civil war that ended in 2002 and the recent Ebola outbreak (2014-15), which resulted in approximately 4,000 deaths and indirectly affected the entire population. During and after the war many people suffered severe long-term injuries, violence, trauma and death [3], following the war an increase in the prevalence of mental illness was observed [4]. According to Alemu et al. (2012), this increase was a result of the civil war, they suggested that approximately 442,000 people had suffered from a mental health disorder in the previous year, of those 102,000 were estimated to have been severe mental health problems. It is reported that only 2% (2,058) of those with severe mental health problems received care or treatment from government and non-government organisations, reflecting a 98% treatment gap [5].

The end of the war brought about increased political drive for health system investment and projects such as the Free Healthcare Initiative (FHCI) that followed showed minor improvements in health indicators [6], these improvements were primarily experienced by mothers and children as the FHCI only applies to pregnant women, lactating mothers and children under five. Then, in 2014, West Africa experienced the worst Ebola epidemic in history, with the virus crossing the Guinea and Liberian borders into Sierra Leone. Sierra Leone struggled to control the outbreak because of the ongoing inadequacies in health system capacity [7] such as drug stock outs and poor health awareness messaging. A poor cultural understanding is thought to be one of the reasons for the slow uptake of public health messaging. Any modest improvements made to restore the health infrastructure since the war, collapsed during the epidemic [6].

Impacting on the already heavy mental health burden of Sierra Leoneans, the epidemic introduced new sources of psychological distress, including stigma, quarantines and curfews [8], financial stress, economic turmoil and hunger [7]. In addition, strict burial and caring procedures imposed during the outbreak conflicted with the cultural belief system of many, traditional practices of caring and laying the dead to rest were not permitted, interference in the process of loss and mourning amplified the grief and trauma experienced by families and communities across the

country. This population-wide exposure to psychological distress and trauma are expected to result in a higher prevalence of mental health problems such as anxiety and post-traumatic stress while mental health outcomes in Sierra Leone remain poor [7].

#### 1.2 Healthcare in Sierra Leone

Healthcare in Sierra Leone is provided by a collaboration of government, non-government and faith based organisations as well as traditional and faith based healers. There are 22 government-run general hospitals in the country and only one mental health hospital (The Sierra Leone Psychiatric Hospital). Human resources for mental health are limited, the country count one retired psychiatrist<sup>1</sup> and only twenty-one<sup>2</sup> mental health nurses for the entire population. Mental health services are minimal and outdated [9], despite the great need for mental healthcare [10].



The Sierra Leone Psychiatric Hospital, Kissy, Freetown, Sierra Leone

The practice of seeking heath care from traditional healers predates the arrival of colonial rule in Sierra Leone and other West African countries, creating a parallel system of care. While this practice may in part be due to the lack of decentralised health services [3], it is primarily due to cultural beliefs and as a result of poor mental health knowledge and awareness [10]. It has been reported that as many as ninety percent of those with mental health problems in Sierra Leone

<sup>&</sup>lt;sup>1</sup> Following the conclusion of this research a newly trained army psychiatrist was appointed.

<sup>&</sup>lt;sup>2</sup> One of the 21 MHN's involved in the programme died as a result of Ebola in 2015, another two are currently not working due to Ebola related complications.

attend traditional healers for treatment [4] showing that this parallel system of care is highly utilized.

In 2010, the WHO identified Sierra Leone as a priority nation for the piloting of its Mental Health Gap Action Programme (mhGAP)[11, 12]. As a result, mental health activities within Sierra Leone increased [9]. Enabling Access to Mental Health in Sierra Leone (EAMH-SL) was a direct consequence of mhGAP incorporating the evidence base and guidance it set out, the project was designed to strengthen the national mental health system and to improve capacity [9]. EAMH-SL was implemented under the supervision of two international organizations: CBM International and Global Initiative on Psychiatry (GIP), funding was provided by the European Commission (EC). In line with mhGAP, EAMH-SL had three components, firstly to build capacity for service delivery at district and primary level by introducing a mental health nurse diploma course and the strengthening of systems including medication supply and clinical supervision. Secondly the development of a national mental health coalition to provide advocacy and peer support and thirdly, a national community engagement and mental health awareness programme which focused on informal and traditional providers of care such as traditional healers and religious leaders. Each component was implemented by a different in-country partner, the engagement and awareness programme was implemented by The Community Association for Psychosocial Support (CAPS). CAPS is a local NGO that provides community sensitisation through mental health screening and counselling.

#### 1.3 The Intervention

In 2014 and '15 under the supervision of EAMH-SL, CAPS delivered three-day Community Mental Health Forums across all fourteen districts in Sierra Leone. Through community engagement on mental health this intervention aimed to achieve the goals set out in Table 1.

# **Table 1. Goals of the Community Mental Health Forums**

- Engage with communities to share understandings of issues related to mental health.
- Strengthen the relationship between trained mental health nurses and the communities they serve including the facilitation of collaboration between both formal and informal care providers.
- Increase mental health awareness and sensitisation, particularly among informal care providers (traditional healers, traditional leaders and religious leaders).
- Strengthen a well-defined mental health referral mechanism to improve access to and utilisation of services.
- Encourage positive changes in the way people with mental health problems are treated within
  and by their communities by addressing negative myths and beliefs to reduce the stigma
  surrounding mental ill health.

Awareness raising interventions such as this which focus on knowledge, attitudes and practice are commonly used to address various issues such as stigma, human rights violations and service utilisation. Often these interventions are implemented using a 'top -down' approach that can be viewed as patronising and insensitive to the cultural context. Although culture is considered important it is rarely systematically addressed. The community forums were designed to facilitate a two-way approach that encouraged open dialogue, active listening, understanding and learning between all of the relevant stakeholders. It was hoped that this approach would provide an opportunity for a consensus to be reached on the relative merits of both systems of mental health care and not just the most dominant. In line with this, to ensure cultural responsiveness and lay the foundation for long-term relationship building the mental health nurses were involved throughout the implementation of this intervention and facilitated the forum in the district where they were based.

# 1.4 Research Aim and Objectives

While anecdotal evidence of the EAMH-SL awareness project demonstrated a positive response, the outcomes of the programme, as experienced by the stakeholders themselves, had yet to be systematically examined. This study aimed to explore the outcomes of the community engagement and awareness raising programme ran by the Enabling Access to Mental Health – Sierra Leone project. There were three study objectives:

- To explore the experiences and perceptions of programme stakeholders in order to determine programme outcomes.
- To identify the factors that facilitated and prohibited the desired outcomes of this programme.
- To ascertain what (if anything) needs to change for such programmes to be successful and any barriers to be overcome.

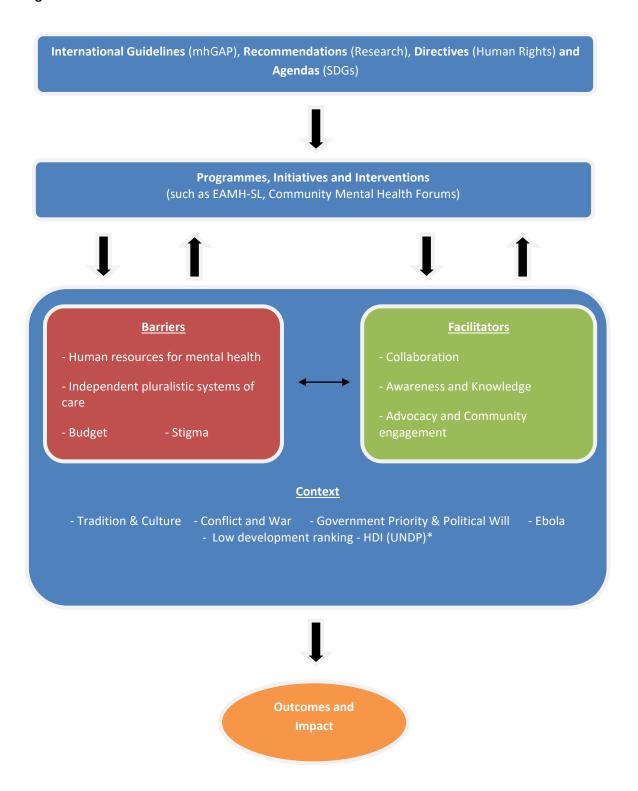
#### **METHODS**

# 2.1 Study Design

A qualitative approach was chosen for this study as it allowed for a more holistic, in-depth understanding of the experiences and perceptions shared by participants [13]. The foundations of this study were based on an interpretative phenomenological epistemology [14, 15], meaning that it aimed to offer insights and gain knowledge into how a given population, in a given context, make sense of a given phenomenon. This qualitative methodology offered context and methodological rigour whilst being considered an appropriate methodology for healthcare research [14]. As themes were hypothesised and developed on the basis of the existing literature, prior to the studies commencement, a deductive (theory driven) approach of qualitative thematic analysis (examining themes) was undertaken.

An exploratory literature review resulted in a Theoretical Framework (Diagram 1.) that informed the remainder of the research. A systematic search strategy was undertaken by utilizing electronic databases and using specific terms to gather literature. Searches were at times filtered to minimise the quantity and/or maximise the relevance of search results. Throughout the reviewed literature it became apparent that most of the relevant literature pertaining to mental healthcare in Sierra Leone or West Africa, directly or in-directly referred to barriers or facilitators of mental healthcare, service provision and utilization. A number of the themes that emerged are interlinked such as 'Stigma' and 'Awareness and Knowledge'. It was impossible to consider mental health in Sierra Leone without examining the context of which its population live and how this contributes to mental health, for example war and Ebola are frequent topics throughout the literature as previously discussed.

Diagram 1. Theoretical Framework



[11, 16]

<sup>\*</sup> The HDI is a composite metric of health (life expectancy), education and per capital income.

#### 2.2 Data Collection

#### 2.2.1 Methods

Semi-structured interviews with mental health nurses (MHNs) who facilitated the forum in their district and focus group discussions (FGDs) with forum attendees<sup>3</sup> were used for this study. Qualitative data collection took place over a three month period, between April-June 2016. The community engagement and awareness raising programme (community forums) had been carried out in all fourteen districts of the country throughout 2014 and 2015.

Purposive sampling was used with each district, forum facilitator and forum attendee being purposively selected for participation in the study [17]. Nine of the fourteen districts (Image 1.) were purposively selected in consultation with the EAMH-SL team due to the researchers limited time incountry and considering (i) rural – urban mix, (ii) the availability of the MHN in each district on dates that would allow a logical travel itinerary (reducing cost and time) and (iii) ensuring each geographical province (north, east, south and west) was included in the study.

Image 1. Map of Sierra Leones districts



When selecting forum attendees a maximum variation sampling strategy was employed, in an attempt to ensure a fair representation of all forum attendees and sample credibility [18] by

<sup>&</sup>lt;sup>3</sup> The word 'attendees' is being used to prevent confusion between this research studies 'participants', referred to as 'participants' and those who attended the Community Mental Health Forums, referred to as 'attendees'. MHNs who facilitated the forum(s) are referred to as MHNs or forum facilitators.

ensuring that stakeholders from each forum attendee 'group' (as in Table 2.) were included. The EAMH-SL team advised the researcher of the districts that had received the highest attendance rates to allow for successful recruitment and maximum variation sampling to take place. Table 2 shows the total number of facilitators and attendees involved in the forums and the number of those selected for recruitment.

Table 2. Forum attendees and number of those selected for recruitment

Facilitators & Attendees	Total No.	No. selected for recruitment
Forum facilitators:		
Mental Health Nurses	21	12
Forum attendees:		
Traditional healers		
Religious leaders i.e. Imams and Pastors		
Community Chiefs	1271	85
District Councillors		
Mammy Queens		
Community Chairladies		
Youth leaders		
Traditional birth attendants		

# 2.2.2 Instrument Development

As no validated interview guide fitting this study could be found, an interview guide was developed, using the theoretical framework, established indicators and the objectives of this study. The framework outlines the themes that emerged from the literature while the indicators are based solely on the goals (Table 1.) that EAMH-SL set out to achieve when implementing the programme.

A semi-structured interview guide which contained nine loosely structured and open ended questions, that allowed the researcher to pursue an idea or response in more depth when appropriate [19] was developed. The focus group guide consisted of twelve open ended questions and the facilitator was asked to encourage participants to explore the issues of importance to them. Both guides were comprised of questions to elicit stakeholders' views, posed in general terms to allow the respondents to explore issues from their own perspective. Interviewers probed and clarified as necessary to more fully understand the respondents' own point of view. Both guides were piloted and adjusted accordingly in Sierra Leone.

# 2.2.3 Participants

The purposively selected and eligible sample were contacted by the researcher or enumerator via phone (due to there being no postal system in Sierra Leone) and read the recruitment and participant information scripts, provisions for confidentiality were also discussed at this time. Most of those successfully contacted conveyed a desire to participate. Each person was given seven days to consider whether or not he or she agreed to participate in the study. All those who chose to participate and dates and times they were available were confirmed. Due to tragic<sup>4</sup> circumstances one semi-structured interview had to be cancelled.

The final sample of participants for semi-structured interviews included in this study consisted of MHNs from both rural and urban areas. A breakdown of the participants from semi-structured interviews and the eight FGDs is displayed in Table 3. The total number of participants from both semi-structured interviews (forum facilitators) and FGDs (forum attendees) was sixty two.

Table 3. Characteristics of research participants

Forum facilitators	No. Male	No. Female	TOTAL
Mental health nurses	5	5	10
Forum attendees			
Traditional healers	8	3	11
Imams	9	0	9
Pastors	9	0	9
Traditional birth attendants (TBA)	0	1	1
Community Chiefs	5	0	5
Youth leaders	2	3	5
District Councillors	3	0	3
Community Chairladies	0	5	5
Mammy Queens	0	4	4
TOTAL	41	21	62

Informed written consent was obtained from each participant on the day of their interview/FGD, they each received a copy of the consent form and a hard copy of the participant information leaflet. Some participants were read the consent form and asked to provide a thumb print instead of signature due to illiteracy. All interviews and FGDs took place in the main government ran hospital of each selected district or in the EAMH-SL office in Freetown. All FGDs were conducted by an enumerator from Sierra Leone who was fluent in the most common local

<sup>&</sup>lt;sup>4</sup> One of the remaining (20) MHN's died whilst undergoing a maternal procedure in a government hospital.

languages, Krio, Mende and Temne. The enumerator signed a non-disclosure agreement and received training from the researcher prior to the commencement of data collection.

#### 2.3 Data Analysis

Focus group discussions were transcribed by two transcribers with previous research experience, in order to ensure all data was captured correctly and within context. All FGDs were transcribed in their original language for example Mende before being translated into English, the transcribers both checked each other's work to prevent the loss of original meaning through the transcription process. Both transcribers signed non-disclosure agreements. The researcher transcribed all semi-structured interviews (conducted in English) personally to become familiar with the data in preparation for coding, all interviews were transcribed verbatim to maintain context with the inclusion of non-verbal cues.

Data analysis took place manually using a qualitative method of deductive thematic analysis [13, 20] as previously discussed. This approach allowed the phenomenological principles applicable to the subject to be central to the process of deductive analysis while at the same time allowing themes to emerge directly from the collected data [20].

The data collection and analysis stages of this research took place concurrently to ensure themes were grounded in the data [21]. Semi-structured interviews and FGDs were coded separately. Four rounds of data analysis (coding) took place. New themes and themes corresponding with the theoretical framework emerged. Finally, the data was then examined selectively in order to identify the most reoccurring themes, based on the data itself, the importance placed on them by participants and the theoretical framework. Numerous themes emerged, certain findings were corroborated and others contradicted, these findings are discussed in the sections that follow.

The collection, analysis and interpretation of data was carried out as systematically and transparently [22] as possible throughout this study to ensure rigour. A research schedule was established prior to data collection and all audio recording, transcribing and analysing was carried out through organised and vigilant methods. By using a research strategy that can address the research aim and objectives this study is defensive in design and offers reliable evidence [22].

In comparing the data from two different data sources (interviews and FGDs) as well as with the theoretical framework the researcher looked for patterns of convergence to corroborate emerging themes and to ensure the comprehensiveness of the analysis process. This method of triangulation has previously been reported to encourage reflexive analysis [19], eliminate bias and

increase truthfulness [23]. Defining the concept of triangulation in qualitative research Creswell & Miller (2000) describe the method used here as a validity procedure [24].

#### 2.4 Ethics

Ethical approval was granted by the Health Policy and Management and Centre for Global Health Research Ethics Committee from Trinity College Dublin (TCD). The Centre for Global Health at TCD also provided academic and ethical supervision throughout this study. Additionally ethical approval was granted by the Sierra Leone Ethics and Scientific Review Committee at The Ministry of Health and Sanitation (MoHS), Sierra Leone.

Informed consent was obtained from all participants as discussed, including their permission to record all interviews. Focus group participants were provided with a small travel allowance to cover the cost of transportation from their home to the study site. Each focus group participant received the same amount. MHNs were not provided with a travel allowance as interviews were conducted at their place of work during working hours. All participants were provided with refreshments. No other incentives or allowances were given to any participants at any time.

In order to protect the confidentiality of the participants all interview recordings and transcripts were anonymised using numerical descriptors. Only the researcher had access to identifying information such as consent forms which are now securely stored in TCD as per their ethics policy.

#### **RESULTS**

# 3.1 Introduction

Data analysis revealed the outcomes of the community mental health forums, additionally, and perhaps more importantly, factors (barriers and facilitators) that influenced programme success were also identified.

#### 3.2 Outcomes

Changes in awareness and beliefs including traditional practices were reported by both interviewees and focus group participants. Stakeholders shared their perceptions and experiences of the situation prior to the forums and the situation now. The traditional treatment of mental illness and beliefs surrounding mental health were discussed to establish exactly what this parallel system of care entails and what has and has not changed following the programme.

When coding the data various topics arose that related to a physical outcome or action, such as the receiving of referrals from forum attendees or witnessing a forum attendee relaying what they had learnt at the forum to their communities. These outcomes and actions were observed and corroborated by the majority of participants.

Table 4. Programme aims and corresponding outcomes

AIM	OUTCOME
Increase mental health awareness and sensitisation	A significant increase in awareness was perceived to have taken place by all stakeholders.
Address negative myths and beliefs	Beliefs and perceptions surrounding mental health causality and treatment was achieved with varying levels of confirmation and closely linked with an increase in awareness.
Reduce maltreatment/Promote human rights	A positive change in the treatment of people with mental health problems was self-reported although this only applies to those whom attended the forums/participated in the research.
Reduce stigma surrounding mental health	Negative myths and beliefs had changed however stigmatisation is ongoing.
Encourage community mental health engagement	Those whom attended the forums appeared to be actively engaging in mental health advocacy and other activities.
Relationship building/Collaboration	All stakeholders reported that due to the forums relationships had been developed, over 50% reported being eager and willing to work collaboratively with the mental health nurses if they were not already doing so.
To put in action a well-defined mental health referral mechanism/Increase service utilisation	A well defined referral mechanism is now in use. Each mental health nurse is now receiving referrals.

#### 3.2.1 Awareness

Many participants either reported an increased awareness surrounding mental health or portrayed it in their description of mental health:

"Good mental health relates to the health of the mind and body, having good senses and thoughts so that the body is well also. If you have poor mental health you will not be well in the body. The forum showed us that." (FGP32 - Religious leader)

The concept of encouragement appeared to replace fear, with some participants even recognising the need for empathy:

"Back then we used to be scared of them. Now we encourage them and speak nicely to them." (FGP27 - Mammy Queen)

"But now after the training, they said these people are not harmful they are not dangerous they understand they need to show empathy to them". (MHN2)

# 3.2.2 Stigmatisation and Social Exclusion

Despite moderate changes in participants' beliefs and awareness of mental illness, the continued stigmatisation of people with mental health problems and negative connotations surrounding mental illness were apparent throughout the data:

"To be honest, a mad person has no friend. None of us here would say that when a person with mental health problems that has reached the extreme level would be allowed to be in the same room as him. NO!" (FGP18 - Religious leader) (In response most of the participants of this FGD expressed their agreement)

"None of us would say even if the person were his son, they would like to share the same room with them once they had become completely mental." (FGP38 - Chief)

Some participants did discuss not being aware that their actions were stigmatising:

"...before this time we did not know we were in effect stigmatizing them." (FGP30 - Traditional healer)

# 3.2.3 Practices, Beliefs, Perceptions

It was overwhelmingly clear from the data that traditional systems of care are still the most predominant:

"...for the religious leader, most people it is based on their faith they take mental health condition as something demonic... even with a lot of sensitisation they think it's something very demonic... there is a big church here at (location), they have more than ten patients live there with mental condition." (MHN3) (At the time of interview this nurse had a case load of seven patients)

Some participants did report a change in traditional beliefs and perceptions of mental illness:

"...it was place where people were traditionally bound. But after the completion of this training (forum) it has changed, perception of them people has changed even with them the herbalist (a type of traditional healer)." (MHN1)

This varied among participants with aetiological views in some cases remaining unchanged:

"It is true that in spite of the rejection of the idea of spirits causing it, they are caused by spirits." (FGP40 - Religious leader)

"... We believe there are cases that God alone can cure and no amount of modern medicine can cure it." (FGP10 - Traditional healer)

Some of the forum attendees appeared open to bio-medical methods of treatment and had an increased knowledge of the causation of mental illness following the forums. Many had changed perceptions surrounding causality but not treatment or vice-versa:

"We always thought that only herbalist and traditional healers had the means to treat mental illness. It was from the training that we learned that there are people trained by the west that could treat mental illness." (FGP25 - Religious leader)

"There are benefits from the training we received. You see, poverty can cause mental health problems... smoking of drugs can cause mental illness." (FGP33 - Chief)

#### 3.2.4 Maltreatment and Human Rights

Many participants reported that traditional practices and the way people with mental health problems are now being treated has changed. Some traditional practices were often discussed in the past tense:

"When we came for the workshop, the son of one of my brothers was mentally ill. Each time the illness used to set in we would get him and beat him. But after the workshop (forum) I would not let the others or anyone beat him." (FGP39 - Religious leader)

"Formerly people used to tie them up and beat the mentally ill... But in the training we were taught that medicines are available... So the best we should do is bring them to the health centre instead of beating them or tying them up as if they were bad people." (FGP23 - Chief)

Changes in traditional treatment methods considered harmful were not corroborated by all participants. The maltreatment and human rights violations of people with mental health problems although changing as above is still occurring:

One nurse described a recent event in which they were called to assist a nurse whom was administering immunizations in a local community, "...hearing somebody screaming help, help, help in a room. And this guy was mentally disturbed so he was confined. Tied. Chained. A very big chain, that caused physical illness, the limbs got swollen they are sores around the limbs (pointing to ankles). Just like they tie an elephant somewhere. He has been tied in the room for months when I got there." (MHN5)

"If you are an aggressive person in my community (referring to people with mental health problems) and you threaten people we gather the youth and they collectively beat you till you leave the community." (FGP20 - Youth leader)

Some of the participants, especially the mental health nurses were acutely aware of the human rights violations that have and are still taking place, and the negative impact this has:

"...some of these strategies that they are using now, they are practicing is not humanly accepted... its above human rights, its human rights violation." (MHN2)

"It is like fuel and fire. With people with mental problems each time you hurt them, the problem become bigger." (FGP40 - Religious leader)

#### 3.2.5 Advocacy and Community Engagement

The promotion of self-advocacy and advocating for the rights of those with mental health problems was evident from the data with numerous MHNs stating they encouraged forum attendees to raise awareness and to advocate. Various participants shared examples of advocacy and community engagement activities taking place since the forums:

"If we have such people in our community, we as leaders have a responsibility to speak out on their behalf. We try now to sensitise the community and the family..." (FGP17 - Religious leader)

"...after the forum I see the people take the information even the churches, the pastors were using it like a sermon, even in the mosque they use it also like sermon." (MHN1)

Forum attendees frequently vocalised their frustration and suggestions of what they felt was needed to improve the current mental health situation in Sierra Leone. In the context of overall mental health system development and future programmes such as EAMH-SL. This is also considered evidence of advocacy and engagement and is demonstrated in the sections that follow as well as the recommendations.

## 3.2.6 An established Referral Mechanism

Four of the five MHNs interviewed reported receiving no referrals prior to the forums and how as a result they now do, numerous forum attendees also discussed the referring of community members:

"...there has been a lot of change (in reference to referrals) in this time... the chief and the head man in the community is referring to me frequently..." (MHN1)

"Before the training I did not send any cases but since then I send any case that I encounter." (FGP21 - Traditional birth attendant)

# 3.2.7 Collaboration and Relationships

Increased mental health awareness and the fact that the MHNs facilitated the forums in their own district/area reportedly led to the development of relationships between forum attendees and the MHNs:

"Before they think I call them (community leaders) to understand what they are doing (referring to testing them/taking their knowledge) but later (after the forum) they knew it's not something like that, we have a very good relationship (now)." (MHN5)

"Among the changes is that we have a lot of information sharing amongst one another since the training. The training helped us come closer to one another and to learn." (FGP2 - Traditional healer)

All of the mental health nurses explained how to varying degrees they now work in collaboration with forum attendees, this was corroborated by the majority of forum attendees:

"Before the forum we did not have good cordiality with the mental health nurse. We did not even know about their existence or the possibility of us working together with them to care for the mentally ill. We were collaborating with fellow traditional healers and we depended

almost entirely on herbs which is why many cases took so long with us. But since we came to know them and start the forum the nurse started visiting our communities and she commenced treatment with the cases we had it has been very different. The forum facilitated that." (FGP9 - Traditional healer)

"We work in collaboration since we came to know that is her job, when we see cases we know are relevant for her we contact her, there is good collaboration." (FGP31 - Religious leader)

Mental health nurses emphasised a need for a collaborative approach between them and forum attendees:

"...we know they can help us, you know it's not a one man show, one man's business.." (MHN3)

"...we can work together, they alone should not work, we ourselves could not work. We need to work together." (MHN5)

# 3.3 Factors affecting Programme Outcomes

Participants frequently discussed issues which they felt prohibited or affected the programme's success, including barriers to people with mental health problems receiving appropriate care and problems with the mental health system in general. These barriers were repeatedly reported as affecting the outcomes of any mental health initiative rolled out in Sierra Leone.

Although not discussed as frequently or as evident from the data, participants also discussed factors which they felt facilitated programme success such as their increased awareness and advocacy efforts following the forums. It was also reported that having the MHN from their district facilitating each forum was of huge influence to the successful achievement of goals such as a establishing a referral mechanism and working in collaboration.

#### 3.3.1 Tradition and Beliefs

Poor knowledge, 'myths' and beliefs were considered to prohibit programme success. Inferring that these beliefs are ingrained within Sierra Leonean culture and tradition, participants reported that this barrier will require a more long term approach to overcome:

"I think one of the major reasons is because of their knowledge about mental health problem. For us in Sierra Leone there are some beliefs that people have, we say in English 'myth'. They tell you this is devil and because of devil they thought the hospital cannot do

anything, it is no problem with health related issue, people think it's with tradition so the first people they can contact is the pastor or the traditional healers." (MHN1)

"Because the misconception, whenever someone has mental illness, you know with these things, the spirits. People believe in that, it is only when psycho-educate them, tell them, it will take time for them to believe you because it is started long time ago, it is not just one day you can teach them." (MHN3)

Traditional healers, religious leaders and chiefs were described as important and powerful people within their communities and the first point of contact for those with mental health problems. In addition to tradition and culture the practice of seeking advice, treatment and care from such figures was attributed to their continuous presence within the local community:

"And they are the first line because they are in the community living with them." (MHN1)

"In our culture and customs the traditional healers they are the ones at the forefront at community level. Whenever people face challenges with mental health condition they go to either traditional healers, they go to spiritual leaders and to tribal heads." (MHN5)

Most of the MHNs described that those in these positions of authority acted as gatekeepers to the community:

"In the community when they have problem they consult the chief so mostly when I get there I will go they will tell me the chief is over there, I will go to the chief. 'Cause like one or two case, the one case I can remember that I sent to Freetown (psychiatric hospital), it was the chief that sent the order for me to be taken to him and allowed me to send the case." (MHN1)

It was evident that alternative options to the traditional system of care were considered a last resort, with participants reporting prolonged attempts to 'cure' people with mental health problems before referring to a MHN:

"...we recently had a case that we tried for long time to treat with little success. So we transfer the case." (FGP7 - Traditional healer)

"The traditional healers always keep these people in their own places, for a long time to cure them, whenever they tired or they not able to cure them, they refer to us." (MHN4)

A loss of earnings for those whom have traditionally provided mental healthcare emerged as a barrier to forum attendees engaging with the MHNs and referring patients:

"The traditional people see it as a threat that will lose more patients if they refer to me."
(MHN1)

"As a traditional healer, many such cases are brought to me and in expectation that I would treat them as that used to be my trade. Since I attended the training, however, I no longer treat them and I no longer raise money from that source and it is therefore important that we be encouraged and supported to continue." (FGP48 - Traditional healer)

# 3.3.2 Programme planning and Implementation

Participants reported that the programmes planning and the distance participants had to travel to attend the forum in each district acted as a barrier to programme attendance and coverage:

"We have twelve chiefdom here, it was about five chiefdom that accessed the forum. So the remaining are left behind so we need to improve. So in total we have about seven areas that did not come. Which is very difficult for my work also. Because thinking of the culture the tradition I can't just get in community to work freely." (MHN1)

"...these people sometime don't even have time to come to the district headquarters. They have so much to do in their communities, it is far..." (MHN5)

Each of the ten MHNs reported that an issue with the incentivisation provided to forum attendees acted as a barrier to programme outcomes and could potentially affect their engagement with similar programmes in the future:

"There were issues with the forum, people were not ok with what was given to them... it was not very good to them because here in our culture or tradition you can't take the elders in the community, they are like the president in the local setting. You cannot move a chief far away from his chiefdom like to this town and then not give the chief something or not pay all the transport, so there are lots of problem regarding this." (MHN1)

"...the transportation they give them, some they come from far away. They ring me that the money was to small... if this money is not refund to them they will not come again next time." (MHN4)

# 3.3.3 The System

Issues with the current mental health system appeared frequently throughout the data, some of these criticisms were solely related to mental health service provision, whilst others were broader barriers to healthcare in general. Participants discussed these issues in the context of prohibiting mental healthcare/service utilisation and the success of any mental health intervention such as the community mental health forums:

"We need to talk about availability of services, accessibility of services and affordability of services. So these three is lacking... some do think there is no services for mental health, some do think, yes it's there but, how can I afford it. How can I access it? So we also need to think about this three things." (MHN5)

Political will and government priority towards mental health was considered lacking by many participants, with a reported need for investment both financial and political:

"The mental health situation in the country is not good. It is really not good. The ministries of social welfare and health have not invested enough in it. The problem though is that government has not supported mental health in the country." (FGP21 - Chief)

Interlinked with the perceived lack of political investment MHNs reported having no resources or support to assist them in providing mental health services. Their frustration and correspondent negative views surrounding the sustainability of the services they are attempting to offer was overwhelmingly apparent throughout the data:

"...as a professional I am saying I also need to have the support, running costs of offices, the unit, we don't have, there is nothing. So even if I sit in my office, I see patients coming who want services I can either close the door or go off, cause I just think I have nothing to offer for that person... so many other people have come trying to practice mental health but they lack support so what happened? They went off! It's not sustainable." (MHN5)

Some of the MHNs pointed out that they are limited in number and how this affects them personally and professionally. Other participants felt it important to point out that a barrier to mental healthcare in their area was the minimal human resources for mental health:

"It is the mental health nurse singular not plural, we only have one." (FGP24 - Councillor)

"We are just few in the country in mental health. I alone sometimes can get burdened, even if I decided to go and have a rest I could be there having calls, now because there is awareness, sometimes I feel angered but I say no because before then nobody calls me about mental health. I want calls, but not all of the time." (MHN5)

Worryingly but in-line with the aforementioned barriers forum attendees doubted the MHNs ability to provide mental healthcare, this was attributed to the absence of decentralised, local facilities and

resources to treat mental illness. Participants implied that the non-existence of local facilities and associated poor service quality prohibits the community from engaging with this system of care and acts as a barrier to programme success:

"...the mental health nurse but does not have a place to admit or keep mental health patients. How will people be convinced that the mental health nurse could deal with the situation." (FGP3 - Religious leader)

"If there is not a good place, how are the local people supposed to value this program? If the place is good you will not have to persuade people to send their loved ones there. Even recovery will be helped by the existence of a good place for keeping patients." (FGP25 - Religious leader)

"...there is also the interrelated issue of the effectiveness of the services available in the hospital for treating mental illness and the costs involved in getting the services. When people have a view that the services are not effective they are hardly going to put their money into seeking it." (FGP42 - Religious leader)

The countries poor infrastructure, specifically the transportation system and communication channels were also considered a barrier:

"...there are times the area where people live is not on a motorway road, most times it's not... it's hard for them to get this client to bring them to the hospital, it's big problem. The travel, those around this vicinity they can easily access. For those up the hills it's a big challenge." (MHN2)

"Our terrain is very bad and the current mental health nurse has a big challenge on her hands. She cannot transport patients on a motorbike, she needs a car." (FGP28 - Mammy Queen)

"Where there is better communication the situation is changing more." (FGP44 - Youth leader)

Poverty and the cost of mental health treatment were considered barriers to service utilisation:

"What prevents people from taking mentally ill persons to see the doctor is sometimes the issue of poverty." (FGP40 - Religious leader)

"Some of them it is money, if you have the medicines and you ask them to pay, he doesn't have money, he can't pay, he needs medicine." (MHN2)

All of the MHNs reported that the lack of access they have to medication is a major barrier to service provision. The current system of medication distribution requires many people with mental health problems or their families to travel to Freetown in order to purchase the medication from the government ran psychiatric hospital:

- "...it's far from them. It's in the capitol city and somebody living three hundred and something miles from the capitol, who does not have any good income, don't wish to go down to the capital." (MHN5)
- "...because we don't have medication the relatives came and snatch her away took her to the traditional healer... Unless you call (national person responsible for distribution of psychiatric medication to districts) tell him the case history, then he will maybe send medicine. People when something happens immediately want medicine." (MHN3)

#### **DISCUSSION**

#### 4.1 Introduction

Providing qualitative insights into the perspectives of mental health stakeholders this study has explored the outcomes of the mental health engagement and awareness raising programme ran by EAMH-SL through Community Forums. Some of the perceived successes and challenges have been identified in addition to the results uncovering obstacles for increasing mental health awareness, promoting community engagement and behavioural change in the specific cultural context of Sierra Leone.

#### 4.2 Outcomes

While traditional systems of care remain the most predominant in Sierra Leone, traditional beliefs were discussed and challenged through this programme and a change in stakeholders' perceptions of mental health took place. Although this varied among participants there was an significant increase in awareness and forum attendees are now open to other methods of treatment and care.

In contrast to the theoretical framework this increase in awareness does not appear to have had a significant impact on the stigmatisation of people with mental illness, the majority of forum attendees continue to use stigmatising terms and socially exclude those with mental health problems. Considered a cross-cutting issue [25] it is evident that in this context all socio-political levels from government to community must be included in long-term awareness raising activities, simultaneously, to reduce the stigmatisation of mental illness.

When analysing the data it became clear that the aforementioned changes in perceptions and awareness facilitated the achievement of other programme goals. These observable programme outcomes reflected in the results are advocacy and community engagement, the establishment of a referral mechanism (service utilisation), the creation of collaborative relationships and a change in the way people with mental health problems are being cared for. Hence this study provides an insight into how programmes such as this can achieve similar outcomes in similar contexts, demonstrating the mechanisms at play between inputs and outputs these findings would be of value in developing a theory and/or framework for such programmes going forward.

The result of increased awareness among forum attendees evidently resulted in a change in the way people with mental health problems are being cared for by their communities. The incidence of maltreatment and human rights violations towards people with mental health problems was reported to have reduced among forum attendees. This outcome although identified in the theoretical framework was much more apparent throughout the data than in the reviewed literature.

Advocacy and engagement activities were reported to be taking place at a local level as a result of the forums. This was corroborated by all participants, with MHNs having observed such activities taking place and forum attendees discussing sensitisation activities they undertook following the forum. Adding to this forum attendees eagerness to vocalise barriers to mental health care and make suggestions, demonstrates engagement and in itself is evidence of them advocating for mental health care. The promotion of advocacy and community engagement by the forums is considered a positive outcome with the potential to facilitate the scale-up of mental health services [26]. As reported by Petersen et al. (2012) when individuals and communities engage collectively in thinking, discussing, and helping one another with mental health and social problems, they are also more likely to develop collective agency to act on their problems and environment, hence developing greater efficiency to exercise control of mental health within their communities. As established in the theoretical framework community engagement and advocacy can also enhance social inclusion and reduce stigma by empowering individuals, families and communities, although the data from this study implies this is yet to take place in this context.

The reported and witnessed establishment of a referral mechanism provides evidence that another programme objective was achieved and how the programme has positively influenced service uptake (utilisation). Eighty percent of the MHNs reported that they had not received any referrals prior to the forums and welcomed the fact that following the forums a referral mechanism is now in place. The impact of forum attendees increased awareness and willingness to engage with formal care providers were obvious facilitators to the successful establishment of a referral mechanism. Additionally, advocacy and community engagement activities have reportedly led to laypersons<sup>5</sup> also being aware of how to refer and doing so. It is important to note that although inconclusive the available quantitative data (discussed further in limitations and recommendations) and the MHNs case loads demonstrate referral numbers have increased but are minimal and do not correspond with the estimated prevalence of mental illness in Sierra Leone.

Participants reported that relationships initiated throughout the forums had continued to develop following the forums. MHNs felt that these relationships have led to forum attendees being willing to work collaboratively and were keen for this to continue. One participant demonstrated how this has introduced the possibility of not only individuals working together but of both systems of care (informal and formal) working collaboratively.

<sup>&</sup>lt;sup>5</sup> Referring to general members of the community who were not present at the forums.

"Through the referral pathway we can explore a number of options, we can have the traditional option, the spiritual option and also invite the mental health nurse. So we have been using the two prong approach... spiritual leaders may combine with modern medicine." (FGP10 - Traditional healer)

As discussed in the literature by providing an educational intervention and dispelling myths and stereotypes within the community the forming of relationships and collaboration has been facilitated [27]. Collaboration as established in the theoretical framework could also assist in addressing numerous barriers identified throughout the data such as human resources for mental health shortages and forum attendees having control over the MHNs access to the community (gatekeepers).

# **4.3 Factors affecting Programme Outcomes**

Facilitators of programme success were never directly referred to throughout the data, studies elsewhere have shown similar community interventions to be useful in strengthening awareness among stakeholders. Numerous facilitators are considered responsible for the successful achievement of the outcomes presented; changes in awareness and perceptions, the programme contents emphasis on collaboration and the fact that local MHNs facilitated each forum, ensuring cultural competence and an understanding of local beliefs and practices [28], creating an opportunity for relationships to be developed.

Unsurprisingly considering the deductive nature of this study and the abundance of literature that focuses on barriers, obstacles to achieving programme goals and of the programme having a greater, sustainable impact emerged continuously throughout the data. It is important to note that although this mirrors the theoretical framework and could therefore be attributed to the deductive methodology, throughout the data participants continuously referred to barriers of mental healthcare and factors that prohibit programme success, voluntarily, and at times when the guide did not prompt them to do so.

The findings show that there are multiple factors prohibiting programme success and that participants identify barriers to overall mental healthcare as issues which have a negative effect on all mental health interventions and programmes. The historically ingrained nature of traditional beliefs and perceptions (those that may result in negative actions) is considered a barrier that to be overcome requires long-term and frequent input "...not just one day" (MHN3). Traditional and religious care providers are held in high esteem by their communities and therefore act as gatekeepers determining the MHNs access to the community. Due to the loss of earnings associated

with collaborating or engaging with the MHNs and the autonomous nature of their work some participants only use the formal system of care as a last resort.

Specific to the EAMH-SL/CAPS programme participants had criticisms of the programmes planning and implementation. Specifically in relation to an issue that occurred in every district where participants did not receive the incentivisation and travel reimbursement that had been agreed prior to the forums. All of the MHNs felt that not only did this jeopardise the future of such programmes but that in some cases it had a detrimental effect on their relationship with forum attendees, when an objective of the forum was to develop these relationships. Both sample groups corroborated this issue as did the EAMH-SL team and it is currently under investigation by CBM International. Additionally all of the MHNs and numerous forum attendees felt that the programme would have benefited from the inclusion of stakeholders in its planning and implementation specifically in relation to attendance, organisation/technicalities (such as location), community engagement and future sustainability.

Participants felt that several deeply rooted system issues were major barriers to mental health system scale-up. Barriers attributed to a lack of political will and government priority, minimal resources both human and material were frequently raised. Poor infrastructure, centralised services and the cost of and access to medication not only act as barriers but have reportedly created doubt in the community regarding the current systems (and the MHNs) capability of providing a mental health service. This also was considered by many participants as detrimental to the objectives of the forums and service utilisation. In contrast and corroborating with the literature, participants attributed the accessible, available and affordable nature of traditional and faith healers as factors contributing to their widespread use and greater patronage [28].

#### **LIMITATIONS**

#### 5.1 Potential Limitations and Bias

The absence of respondent validation is considered a methodological limitation of this study [19], methods such as triangulating the data and searching for negative evidence were used in an attempt to control this limitation [19]. Furthermore it was felt that some participants believed the researcher was working for CBM International. Due to CBM's continued financial assistance to on-going programmes involving some of these participants this may have influenced some of the participants responses. Every participant was informed that this was not the case, what the researcher's role was and his desire for truthful and open dialogue in order to produce objective results.

The researcher's background as a mental health professional was acknowledged as a potential bias from the beginning of this study therefore the researcher used a thematic framework based on the literature and took an iterative process to analysing the collected data.

Originally it was planned that this study would take a mixed-methods approach, using referral statistics from pre and post programme completion to quantitatively ascertain the programmes outcomes. Unfortunately this data was either non-existent or unreliable with vast amounts of missing data. Therefore this study had to rely solely on the researchers observations and stakeholders self reporting.

# 5.2 Transferability

Although this study may be transferable to similar contexts it is important to remember that Sierra Leone has a very particular contextual history (War and Ebola) and that this study was carried out to explore a specific programmes outcomes within that context.

However some findings specifically 'factors affecting programme outcomes' may be useful in the future development of community engagement and awareness programmes specific to mental health in countries with similar health systems and traditional care approaches of which there is many. As previously stated the findings presented here would also be useful in the development of a programme theory and/or framework.

#### **RECOMMENDATIONS**

#### 6.1 Recommendations for Furture Research

First and foremost a research component should be included in all future programmes of a similiar nature from the outset. With no pre-programme data to establish the situation as it was prior to the forums it was difficult to establish change; quantitative research to measure change, identify and measure variables would be useful.

Further qualitative research should explore the issues discussed including percieved changes following such programmes and barriers to mental health interventions in greater detail, including stakeholders from all levels, ranging from government officials to laypersons.

A mixed-method study to identify what impact programmes like this have on service user outcomes would provide much needed evidence and encourage the funding and commitment to scale-up such efforts.

Last but by no means least further research to identify what mechanisms are at play in achieving the objectives of similar programmes and the 'testing' of awareness and community engagement guidelines (informed by the literature, relevant stakeholders and research) would allow for the much needed development of a programme theory. Inclusive of an associated toolkit that would guide future intitiatives and activities to ensure they are successful, scalable and sustainable.

# **6.2 Recommendations for Future Programmes**

Exclusion in the planning and implementation phase of this programme was raised by participants throughout this study, both mental health nurses and forum attendees reported that this prohibitied programme success and did not encourage collaboration. In light of the cultural and contextual environment future programmes should include stakeholders selected by their community or stakeholder group to be involved in the planning and implementation of such programmes. Using a community based participatory approach from inception to completion would facilitate programme objectives by encouraging attendance, enagement and collaboration as well as ensuring cultural appropriateness [29] and future sustainability.

To negate issues such as that experienced with incentivization and travel reimbursement future programmes whose implementation involves a third party should include greater in-country supervision and more stringent reporting mechanisms.

The centralised location of the forum in each district was considered an issue due to the same system barriers identified in the results; infrastructure and the affordability of travel. Participants felt that future interventions need to be delivered in local communities and chiefdoms in order to extend there reach and have greater impact.

The programme segregated traditional healers, religious leaders and community chiefs into three sperate forums per district. MHNs felt this made achieving certain goals of the programme difficult (relationships, collaboration and changes in treatment), future programmes should avoid this to promote dialogue between stakeholders and promote collaborative relationships. Additionally future programmes should include other key representatives from the community such as teachers and law enforcement officials, again to increase the interventions reach and overall programme impact.

One-off awareness raising activities will not produce a long lasting impact due to stakeholders engrained beliefs and limited mental health knowledge. The implemented programme should be considered the first stage of an ongoing process. Going forward such activities should be of longer duration with more frequent interventions to ensure change is sustained i.e. the dose of such interventions needs to be increased and activities must be continued.

Future awareness raising campaigns need to take on a multifaceted approach as it is believed that stakeholders views are shaped and informed through various channels including the wider community, national socio-political and cultural contexts and international influences [25]. As previously mentioned stakeholders from all socio-political levels including high ranking government official and laypersons need to be included in these long-term awareness raising activities, simultaneously, to reduce the stigmatisation of mental illness and increase political will.

#### **CONCLUSION**

No previous literature or research could be found that explores the impact and outcomes of a programme like this in a West African context. This study attempted to address this gap in the literature whilst providing findings and recommendations for further research and how such programmes could be developed in the future. This report provides a snapshot of the outcomes and factors that influenced programme success. The evaluation of innovative programmes such as this can make an important contribution to this field and to the case for system development. Although contextually appropriate interventions differ, effective interventions are those shown to best achieve the relevant outcomes [10].

The data demonstrates that the programme has achieved the main goals it set out to (Table 4.) with varying levels of confirmation from study participants. It is evident that by promoting positive change in awareness, beliefs and perceptions a knock on effect took place resulting in tangible actions and the successful achievement of other goals. These changes in awareness, perceptions and beliefs are considered to be what facilitated and harnessed that success. However the programme has not accomplished all it set out to due to a multitude of barriers and contextual factors. Many of these barriers are not specific to the programme but represent broader national issues which evidently impact on all mental health inputs and outcomes.

Two major concerns emerged from this study, the system level barriers to mental healthcare especially the non-existence of resourced decentralised services at primary level and the ongoing maltreatment of people with mental health problems. The adoption of contemporary (formal) methods obviously does not go hand in hand with improved attitudes and treatment of people with mental health problems. A collaborative (formal and traditional/informal) rights based approach must be integral to health system reform as service quality is inherently linked to rights and doing no harm.

These findings draw attention to the need for both international and national input that facilitates political will and the urgent prioritisation of mental healthcare. There is an evident need for financial investment to develop a mental health system that is culturally appropriate and fitting to the mental health needs of the Sierra Leonean people. Continued efforts must be made to increase mental health awareness, reduce stigma and end the maltreatment of people with mental health problems.

The forums were useful for providing a dialogical space for engagement between traditional and formal health practitioners. In the future such programmes must broaden their audience to

include those both at the grass roots level and those in positions of power to ensure political support for programme activities and facilitate advocacy [26]. Traditional and formal health systems can both be promotive of health, damaging to health or have no direct impact on health. The ultimate goal of global mental health is to be able to harness and draw on the practices and interventions that promote mental wellness [28]. By developing a systematic, sensitive and practical way of meaningfully engaging with local culture in LMICs quality mental healthcare can be achieved whilst ensuring practices associated with negative outcomes are stopped.

#### **DISEMMINATION AND ENGAGEMENT**

The intended result of this study was to share identified lessons learnt in mental health awareness and community engagement through community forums with groups working in similar contexts in Sierra Leone and beyond, as well as feedback to those who participated in the programme itself, to build on their established success and involvement. It is intended to disseminate the research findings presented here through multiple channels with the hope of engaging stakeholders at all levels including the participants involved in this study.

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