COMMUNITY PARTICIPATION IN MASS DRUG ADMINISTRTATION FOR LYMPHATIC FILARIASIS IN LUANGWA DISTRICT, LUSAKA PROVINCE

By

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DECLARATION

I, Adam Silumbwe, hereby declare that this research work being presented for the Master of Public Health in Health Policy and Management with Implementation Research degree, has not been previously submitted either wholly or in part for the same purpose, at this or any other University nor is it being currently submitted for any other degree.

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CERTIFICATE OF APPROVAL

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ABSTRACT

The World Health Organisation recommends implementation of mass drug administration (MDA) programmes in areas at high risk of infection with lymphatic filariasis (LF), as a principle strategy for elimination of the disease. However, these programmes are faced with numerous challenges some of which include: establishing accurate monitoring and evaluation systems by the communities, increasing involvement of the local communities and engaging in effective advocacy for continued MDA for LF support. This study sought to explore how the various engagement approaches used in MDA for LF shaped community participation in the programme in Luangwa district of Lusaka province.

A qualitative grounded theory approach was employed in answering the research question at hand. Aided by the theoretical sampling approach, FGDs (n=9), in-depth (n-5*)* and key (n=7) informant interviews were conducted with various participants that included programme managers, district programme coordinators, health workers, community leaders, community members, community drug distributors and other key stakeholders.

The results showed that engagement strategies to promote community support and stakeholder by-in included the use of community health structures, non-governmental organisations (NGOs) and the district development committee. Awareness creation strategies comprised of IEC materials, drama, public-address system, community meetings and the door-to-door approach. Overall, the engagement and awareness creation strategies were effective as most of the community members had a good understanding of LF, the essence of MDA for LF and its benefits. Although, the engagement and awareness creation processes were effective, a number of barriers to implementation such as the short MDA for LF implementation period, mobile populations, large and distant catchment areas, shortage of drugs, and refusal to take the drugs hampered community participation. Some strategies such as providing appropriate and timely incentives, innovative awareness creation and morbidity management were suggested as ways enhance both community participation and programme implementation.

A theoretical model explaining how community engagement can be made more effective in facilitating community participation was developed. Three core categories that should be priority for all programme planners and implementers were identified, namely; well-motivated community health structures, appropriate and adequate health education and partnership approaches to MDA for LF implementation, as essential elements in developing an effective community engagement strategy.

Key words: Community participation, community engagement, lymphatic filariasis, mass drug administration and implementation.

DEDICATION

I dedicate this dissertation to my family, who have consistently provided me with the much-needed support to undertake my studies. I am eternally grateful to them for the values and ideas I have come to cherish during my pursuit for academic excellence. To my late aunty, Margret Namukoko, I wish say to thank you for your encouragement and love during the course this journey. I also dedicate this dissertation to the many lymphatic filariasis patients in Zambia and across the globe. I hope this work will contribute towards better community engagement, as well as improved implementation of the mass drug administration programme for lymphatic filariasis elimination.

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LIST OF ABBREVIATIONS

CFA	Circulating Filarial Antigen
CDTI	Community Directed Treatment with Ivermectin
CDT	Community Directed Treatment
CP	Community Participation
DOT	Directly Observed Treatment
GPELF	Global Programmes to Eliminate Lymphatic Filariasis
IEC	Information Education and Communication materials
IDI	In-depth Interviews
KII	Key Informant Interviews
LF	Lymphatic Filariasis
LMIC	Low and Middle-Income Countries
MDA	Mass Drug Administration
NTDs	Neglected Tropical diseases of poverty
PH	Public Health
WHO	World Health organization

CHAPTER 1: INTRODUCTION

1.1 Background

Lymphatic filariasis (LF) is one of the neglected tropical diseases (NTDs). Neglected tropical diseases are a group of 17 major disabling chronic conditions that are most common among the poorest people in the world (Feasey et al., 2009). These diseases have been neglected for decades, primarily as part of a general neglect in the developing world, and more recently due to the intensity of focus on HIV/AIDS, tuberculosis and malaria-the big three (Bhutta et al., 2014). Lymphatic filariasis is caused by infection with nematodes worms transmitted by the different species of mosquitoes. In Sub-Saharan Africa, the major vectors that transmit these worms are the Culex mosquitoes in urban and semi-urban area (Arensburger et al., 2010). It attacks the lymphatic system, developing after some time into chronic conditions of lymphedema (swelled tissue), elephantiasis (thick skin) of limbs and hydrocele (swelled scrotum) (Kumaraswami, 2000).

1.1.1 Prevalence

Globally, over 947 million people are at risk of infection with LF (WHO, 2015), and estimated 67.88 million are infected, with as much as 36 million people disfigured and incapacitated by its resultant chronic conditions (Ramaiah and Ottesen, 2014). According to the WHO, LF accounts for 2.8 million disabilities adjusted years (DALYs) not including the significant co-morbidity of mental illness commonly experienced by patients and their caregivers (Ton et al., 2015, WHO, 2015). This disease affects the poorest populations in society, particularly those living in areas with poor water, sanitation and housing, causing permanent disfigurement, reduced productivity and social stigma (Perera et al., 2007). South East Asia and sub-Saharan Africa (SSA) account for about 94 % of the LF global disease burden (WHO, 2015). The SSA region is estimated to have 409.7 million people from 35 endemic countries at risk of infection (Bockarie and Rebollo, 2016), which is about 32% of the LF global disease burden. LF is associated with massive economic losses in SSA, impairing economic activity of up to 88% in infected people and causes up to US$1billion in annual productivity losses, mostly resulting from disability linked to hydrocele in men (Hotez and Kamath, 2009, Conteh et al., 2010).

In Zambia, an estimated that 10 million people are at risk of infection with LF, and according to Mwase et al., LF is surprisingly widespread (Mwase et al., 2014). The mapping of the

Circulating filarial antigen (CFA) estimated a prevalence ranging from 1% to 54% in some parts of the country. The highest mean CFA prevalence were seen in Western (19.0%) and Lusaka (18.8%) provinces, whereas the lowest were in Copperbelt (3.4%) and North-western provinces (2.5%). It was also reported that most of the provinces had prevalence below 15%. However, six of the mapped cites had prevalence of above 15%. Named by district of location, these were Kalabo and Senanga (both in Western Province), Luangwa and Kafue (both in Lusaka Province), Serenje (Central Province) and Lundazi (Eastern Province). The first four of these sites had a particularly high prevalence of above 25%, and among these, Kalabo had more than 50% prevalence. Similar studies conducted in other areas, for example, in Luangwa district have confirmed the existence of the disease (Shawa et al., 2013).

1.1.3 Intervention

In response to the global burden of LF, the WHO formed the Global Programme to Eliminate Lymphatic Filariasis (GPLF) in 2000 (Ottesen, 2000). The GPLF strategy has been to promote large scale mass drug administration (MDA) in endemic countries with annual doses of Albendazole and Ivermectin or Diethylcarbamazine (DEC) (Gyapong et al., 2005). The core objective of MDA is to reduce the parasite levels in the human populations so as to interrupt the LF transmission cycle between the mosquito (vectors) and humans (Molyneux et al., 2003). A minimum annual MDA coverage of >65% of the population at risk is recommended by the WHO for 4-6 years (Ranganath, 2010). However, this is usually dependent on the baseline prevalence in the population at risk and other factors determining transmission (Kyelem et al., 2008). Additionally, community adherence to drug regimen determines effective programme coverage, and hence the maximum rounds of MDA (Molyneux et al., 2003). The GPLF also encourages provision of minimum care to every person with LF associated chronic manifestations (Gyapong et al., 2005). The figure below provides detailed information on key stages in MDA for LF implementation.

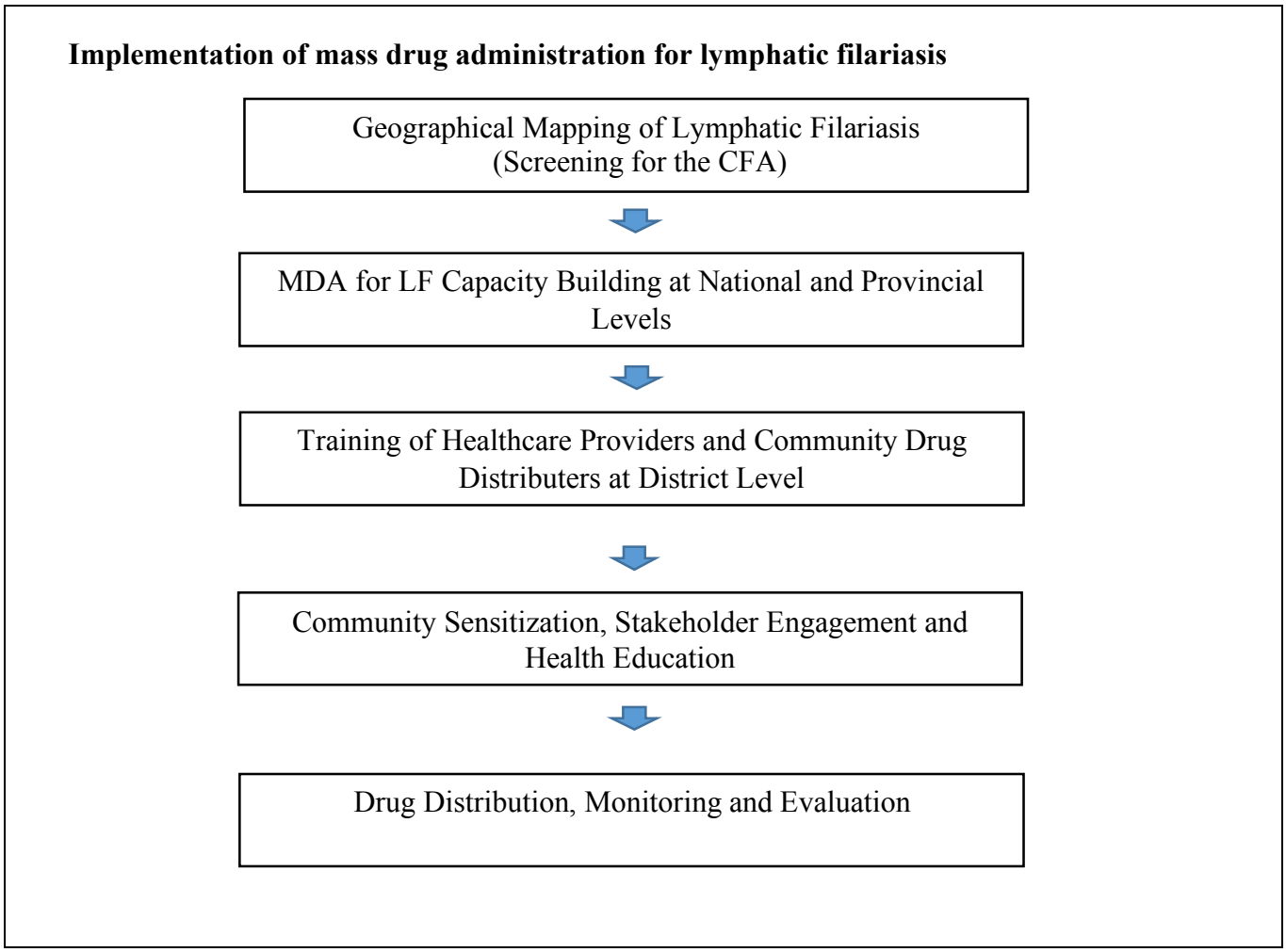

Figure 1: Implementation stages of MDA for LF

Since the formation of the GPLF in 2000, several countries that have implemented MDA for LF report numerous implementation challenges that result in low treatment coverage levels and non-compliance to treatment by the communities (Babu and Kar, 2004, Gunawardena et al., 2007, Partono et al., 1989, Vanamail et al., 2005, Bockarie et al., 2013, Cantey et al., 2010, Mathieu et al., 2004). This poses a great risk on the capacity to eliminate the disease. Other programmatic challenges include; sustaining timely distributions of drugs, establishing accurate monitoring and evaluation systems by the communities, increasing involvement of the local communities and engaging in effective advocacy for continued MDA for LF support (Bockarie et al., 2013).

To address these implementation challenges Manderson, Allotey, Bardosh and Atkinson et al., have suggested that community engagement approaches that facilitate participation in MDA for LF should be at the center of all national programme implementation efforts to achieve

programme sustainability and probable LF elimination (Manderson et al., 2009, Allotey et al., 2008, Bardosh, 2014, Atkinson et al., 2011). They further argue that attaining high levels of community participation is critical to achieving WHO required levels of MDA for LF treatment coverage of between 65%-80%, acceptability and compliance. Krentel et al., also echoes these assertions in his systematic review of factors that affect individual compliance to MDAs for LF, by stating that the success of the GPLF will be very dependent on the capacity of national programmes to motivate populations risk to participate in all rounds of MDAs for LF (Krentel et al., 2013).

Despite the evidence suggesting the role played by community participation in MDA for LF implementation success, they are very few or limited studies on this topic in Zambia and other SSA countries (Silumbwe et al., 2017). This study therefore sought to address this implementation research gap.

1.2 Statement of the Problem

The high prevalence levels of LF in many parts of Zambia have dictated the implementation of MDA as recommended by the WHO (from 2015-2019). The period falls a year short of the international target to have LF eliminated as public health problem by the year 2020 (Ottesen, 2000). This entails that Zambia has a relatively constrained period to implement the MDA for LF programme, which therefore requires an accelerated implementation plan that consistently meets the WHO set annual coverage threshold of 65-80% of the population at risk. It also demands the putting in place of effective engagement strategies that encourage high levels of community participation.

Successful undertaking of MDA for LF requires that communities are actively engaged. Individuals may be wary of participating during the first round of MDA, so it is essential that they receive adequate health education. One way of providing information to the community is to educate community leaders and influential community members. These individuals should be engaged in awareness creation efforts and determining the best time to conduct the MDA for LF campaigns. Their leadership and cooperation during Implementation is critical to the success of the programme.

Community engagement processes that promote participation are essential to achieving sustainable and successful implementation of MDA for LF. They provide an opportunity for improved awareness creation, community empowerment and facilitate programme ownership

by the communities. Consequently, it is important that much attention be dedicated to the processes by which communities are engaged in MDA for LF campaigns as it has huge implications on their ability to participate.

Despite the wide documentation of the pertinent role engagement processes play in shaping community participation in MDA for LF campaigns, Literature from Zambia and several other sub-Saharan African Countries (SSAs) has shown that there is limited knowledge on understanding the specific community engagement processes. This was a key highlight of the systematic review conducted by the author on factors that shape implementation of MDA for LF in sub-Saharan Africa (Silumbwe et al., 2017). In this regard, there indeed remains much scope to explore how MDA for LF programmes are engaging communities, where implementation research can help address barriers and propose new strategies preferably as part of a long-term engagement strategy.

1.3 Significance of the study

Community engagement processes have long been highlighted in most studies as key to shaping community participation in infectious diseases control programmes, including MDA for LF (Manderson et al., 2004, Woelk, 1992, Botes and Van Rensburg, 2000). Being the first time that Zambia has undertaken a large-scale MDA for LF programme, this research will be critical in identifying some of the gaps and success areas in the current community engagement processes and how they influence community participation. Indeed, this study will help generate knowledge that will contribute to the sustainability of the MDA for LF programmes in Zambia and other Low and middle-income countries (LMICs). Additionally, this research may serve to document some of the lessons learnt in as regards to the current community engagement processes, hence provide evidence to influence policy or recommend future programme adjustments for meeting the global set target of LF elimination by the year 2020.

1.4 Research Question

i. What community engagement processes are used in MDA for LF and how do they shape community participation in MDA for LF?

1.5 Objectives

1.5.1 General Objective.

To explore the community engagement processes and how they shape community participation in mass drug administration for lymphatic filariasis in Luangwa District of Lusaka Province, Zambia.

1.5.2 Specific Objectives

1. To identify and explore key community stakeholders' roles in the planning and implementation of MDA for LF in Luangwa District, Lusaka.

2. To explore the current community engagement processes/strategies used during implementation of MDA for LF.

3. To document stakeholders (both community and the implementers) perspectives regarding the current awareness creation strategies in MDAs for LF and how they influence community participation.

CHAPTER 2: LITERATURE REVIEW

Nakibinge et al., defines community engagement as the processes of collaborative work with relevant partners who share common goals and interests (Nakibinge et al., 2009). Tindana et al., adds that it involves "building authentic partnerships, including mutual respect and active, inclusive participation; power sharing and equity; mutual benefit" in a health programmes so as to achieve the best possible health outcomes (Tindana et al., 2007). It usually has three main levels involving (i) information sharing and provision, (ii) consultation and (iii) decision-making. This study explored features of all the levels of engagement to determine how they shaped participation in MDA for LF.

To organise the literature review, we used Atkinson et al's systematic review of the architecture of community participation in communicable diseases control programmes (Atkinson et al., 2011). This review identifies six essential community engagement processes/strategies that facilitate community participation. These are: (i.) Engagement of Key Community Stakeholders, (ii.) Promotion of a partnership approaches, (iii.) Participation in problem Identification and Priority Setting, (iv.) Participation in programme design, (v.) Participation in programme implementation, (vi.) Participation in monitoring and evaluation (Atkinson et al., 2011).

It is however important to note that most community engagement processes are often limited to implementation of externally determined programme activities. Literature also suggests that effective community participation can be achieved without engaging communities in all the above stated engagement processes; but rather, community participation is additionally influenced by factors including community characteristics, health and disease priorities, political system, integration of programme into primary healthcare, level of decentralization, inter-sectoral collaboration and administrative structures of the programme (Bermejo and Bekui, 1993).

2.1 Engagement of key community stakeholders

Community engagement processes involving key stakeholders like the traditional and opinion leaders provide an opportunity or platform for dialogue, interaction and partnership building with the community representatives and members themselves hence fostering community participation in disease control programme activities like MDA for LF (Bracht and Tsouros, 1990). In addition, they help to take into account particular community interests and ensure that various categories of members are represented. Engagement of key stakeholders can

further strengthen community participation through dissemination of MDA for LF information on goals, risks and benefits by incorporating local views into the development of informational aspects of MDA for LF health promotion materials, like health education campaigns (Cornwall et al., 2000, Murry and Brody, 2004). The following studies highlight the role of key community stakeholder engagement in shaping community participation in MDA for LF.

A mixed method study from Nigeria, reported that prior to launching MDA for LF, conduction of workshops and meetings with various key community stakeholders enabled the programme to develop IEC materials that were target specific and responsive to community needs, which subsequently facilitated community members to lead the information dissemination process (Hopkins et al., 2002). This consequently contributed to the high levels of MDA for LF treatment coverage in the later years. This study however did not evaluate the role of various context specific engagement strategies used and their influence on participation in the MDA for LF. A focus on engagement processes could have greatly aided the understanding of the key drivers to community participation.

Similarly, Krentel et al., also reported that engaging key community stakeholders in designing health education materials, informed by a knowledge attitudes and practices (KAP) survey, prior to launching a pilot MDA for LF in Indonesia had resulted in high compliance to treatment. In this study, baseline measurements reviewed low levels of compliance at 21%. After conducting a KAP survey and engaging key community stakeholders in developing health education messages, and implementing an intervention package targeting behaviour change, it was reported that compliance had risen to 88% in the subsequent MDA for LF campaigns (Krentel et al., 2006). Though this cross-sectional study reported community involvement in designing the intervention package, it did not however evaluate community engagement processes during the implementation phase, but rather sought to determine baseline and end-line measurement differences due to the intervention.

2.2 Promotion of partnership approaches

During the implementation of community health programmes, partnerships approaches with community groups/structures, other related governmental units and NGOs have been found to facilitate community empowerment and participation (Heenan, 2004). Identifying of the key Local partners within the community structures such as the churches, the mosques, community radio stations and above all the local traditional, government and health systems leadership

have been shown to be critical to achieving high community participation in MDA for LF programmes (Dembele et al., 2012, King et al., 2011).

Some authors have reported that in rural areas, the use of traditional leadership and local structures in MDA for LF campaigns facilitates community participation (Gyapong et al., 2001, Hodges et al., 2010, Njomo et al., 2012b, Njomo et al., 2014). Collaborating with the community and local government structures provides a platform to build respectful relationships, engender trust, awareness creation for the campaigns, and take into account community perspectives. Partnerships may also offer an opportunity for enhanced accountability and improved responsiveness to MDA for LF (Cornwall et al., 2000).

A mixed methods study that employed inclusive partnerships and community participation approaches in urban India MDA for LF programme reviewed that significantly higher coverage and compliance was recorded in the urban setting where these approaches had been implemented than in similar urban settings where there had not been such interventions (Babu et al., 2006). This was because the creation of partnerships enabled the identification and bringing on board of otherwise marginalised and usually unrepresented groups, which intern facilitated community participation. It also enabled the at-risk communities to be more aware of the risks posed by LF and the benefits of MDA. The innovation aimed at making MDA for LF more effective in urban settings through inclusive partnership and community participation. However, this study only aimed at establishing the effectiveness of participatory and partnership approaches in enhancing treatment coverage in urban MDA for LF campaigns, but did not explore how these particular engagement strategies shaped community participation.

Another mixed methods study conducted in the American Island of Samoa by King et al., identified the creation of Partnerships with local community institutions such as the churches, mosques and use of various community media channels for health promotion as key to successful MDA for LF implementation. The institutions played a critical role in drug distribution activities and information dissemination during a particular MDA for LF campaign. King highlights that they were the key reason for increased treatment coverage after a period of low treatment coverage in Samoa (King et al., 2011). Baseline indicators reported 24-52% coverage levels and after implementations of these partnership approaches, coverage levels rose to 65-71%. Though partnership approaches were identified as critical components of programme success, the study did not however explore the role various engagement strategies played in influencing community participation.

A cross section survey by Moala-Silatolu et al., established that engagement of communities through traditional village forums in Fiji was associated with adherence to drug regimens and participation MDA for LF community activities. Greater adherence to mass drug administration was achieved through using these village health forums to disseminate information and by individuals taking roles in community LF activities regardless of their educational attainment (Moala-Silatolu et al., 2012). The study uses quantitative methods, but does not explore in how some of the underlined engagement process influenced community participation.

Similarly, various other studies conducted in India, Togo and Zanzibar demonstrated that establishment of community-based lymphedema management programmes had independently enhanced participation in MDA for LF (Cantey et al., 2010, Sodahlon et al., 2013, Mohammed et al., 2006). This was because these community led programmes included both a community-driven health education component for the entire populace about MDA for LF and a patient self-care component focused on foot and leg hygiene for affected individuals and their families.

2.3 Community Participation in problem Identification & Priority Setting

According to literature, there is increasing interest, in involving the community in health care priority setting and problem identification. At the same time, however, there is evidence of lack of clarity about the objectives of some priority setting in health programmes and also about the role of community involvement (Mullen, 1999). Further, this principle seems not to be very applicable to most MDA for LF programmes due to the fact they are usually planned at central level and then implemented at community level. Basically, the principle involves engaging the community in identifying key health problems and prioritizing health actions and resource allocation towards particular interventions (Kapiriri et al., 2003).

2.4 Community participation in programme design

Community participation in MDA for LF programme design is central to the Community Directed Treatment (CDT) model of drug distribution. In this model, the selection of CDDs is conducted by the community members, who set a minimum number of standards that should be fulfilled by those who are recruited. An individual's standing in the community, should originate from the same community where they are assigned to do drug the distribution and possess a reasonable level of education are but some of the standards set forth for selection of CDDs by the community members (Dembele et al., 2012, Gyapong et al., 2001, Njomo et al., 2014, Richards et al., 2011). The selected CCDs participate in designing and providing health

education in MDA for LF programmes. They also participate in designing the best drug delivery strategies, especially for hard to reach populations. Furthermore, communities decide on appropriate modes of incentives to provide the CDDs, ranging from moral support to material items to help them conduct MDA for LF (Krentel et al., 2013).

2.5 Community participation in programme implementation

Various studies have reported better successes when there is greater participation of the community in programme implementation (Gyapong et al., 2001, Mohammed et al., 2006, Sodahlon et al., 2013, Wamae et al., 2006). The Community Directed Treatment (CDT) programmes for Onchocerciasis and LF are typical examples of community participation in the implementation of MDAs (Coffeng et al., 2013). In these programmes, the communities played an active role in the selection of the community drug distributors (CDDs), designing their preferred delivery strategies and deciding the best time to distribute the drugs.

Two similar mixed method studies conducted by Wamae and Gyapong et al., in Kenya and Ghana, respectively found that implementation of MDA for LF through CDT achieved higher levels of treatment coverage than programmes delivered exclusively through the formal health systems, and that they were particularly effective in remote and distant areas (Gyapong et al., 2001, Wamae et al., 2006). In Kenya, coverage achieved by the regular health systems was 46.5%, whilst that of the CDTs was 88%%. Ghana on the other hand reported 43.5% coverage for the regular health systems and 74.5% when implemented with CDTs. In both studies, CDTs models allowed community members to organize, lead the implementation and engagement processes of other community members. The success in this approach was attributed to the fact that community involvement would most likely foster ownership and hence boost community participation. Though treatment coverage, a summative quantitative health outcome was reported, the study however fell short of evaluating the engagement processes and what influence they had on participation in the programme.

2.6 Community participation in monitoring and evaluation

Community involvement in monitoring and evaluation through the collection of information regarding the treatment coverage of every campaign plays a critical role in facilitating participation. This is conducted through the CDDs who record the information on the tally sheets. The information is then used to calculate treatment coverage and to provide information to the district medical office for planning of supplies in the following campaigns. The CDDs have indicated in the Kenyan study conducted by Njomo et al., that they are better motivated

with the provision of sufficient supplies needed to conduct these treatment coverage surveys like the registers, tally books, pens bicycles for easy movements etc. (Njomo et al., 2012a).

A qualitative research case study carried out in Tanzania, 2011; found that providing mobile phones to Volunteer Health Workers (VHW) helped to increase the efficiency of routine monitoring work, and boosted their motivation and self-esteem. This study aimed at testing the feasibility of using frontline health workers to capture and report data at point of source, through piloting a mobile phone-based Management Information System (MIS) for the control of neglected tropical diseases (NTDs) where village health workers (VHWs) were given mobile phones with web-based software. Though the community were involved in capturing the data, they were not necessarily engaged about the use and dissemination of this information at district level (Madon et al., 2014). Although the study highlights the fact that empowerment approaches improve VHW's capacity in monitoring, it does not however explore the engagement processes and their influence on participation in NTD control activities.

CHAPTER 3: METHODOLOGY

3.1 Study Design

A systematic grounded theory approach by (Strauss & Corbin, 1990) was employed to answer the research question at hand. This is because we sought to gather information, generate theory, to explain practices regarding the processes used to engage communities in MDA for LF and how they interact together to influence community participation in Luangwa district of Lusaka province.

The use of grounded theory in this study helped to move beyond general descriptions and lead to generation of unified theoretical explanation of various stake holders' views regarding engagement processes in MDA for LF and how they shaped community participation (Corbin and Strauss, 2014). The developed theory was grounded in the qualitative data.

3.2 Study setting

The study was conducted in Luangwa District of Lusaka province, South-East Zambia. The district is located in the Rift Valley, at the confluence of the Zambezi and Luangwa rivers at altitudes below 600 m above sea level. There are three main seasons: a cold season from May to August (temperature range 6-26°C), a hot season from September to October (17-35°C) and a rainy season from November to April (14-30°C). The main source of livelihood in the district is fishing on the rivers, production of reed mats and subsistence farming. The study site was identified based on findings from an LF mapping survey carried out in the area in 2011, when it recorded a CFA prevalence of 33.3%, the highest in the province.

3.3 Study population

The study population consisted of people that had participated in at least one MDA for LF campaign. Also, they had to be resident of MDA for LF target area, and were at least above the age of 18yrs. The healthcare providers and other key community stakeholders involved in the programme were sampled.

3.4 Sampling

Theoretical sampling was used in order to collect data and generate theory relating to various engagement processes and how they shaped community participation. This sampling technique is defined as "the process of data collection for generating theory whereby the researcher jointly collects, codes and analyses the data and decides what data to collect next and where to find them in order to develop the theory as it emerges"(Glaser and Strauss, 2009). Specific sampling decisions were made during the research process itself. Theoretical sampling translates in

practical terms into two sampling events; an initial case is selected, and based on the data analysis pertaining to that case, and hence the emerging theory, additional cases are selected. This sampling procedure is closely associated with grounded theory methodology. An illustration of the data coding process is provided in the data analysis section. Table 1 provides details of how theoretical sampling approach was employed. The categories were selected based on the literature review, and initial cases identified to provide information pertaining to a particular category. Analysis of this information allowed for identification of other cases until theoretical saturation.

The sample comprised of stakeholders such as the district health office, programme coordinators, facility health workers, community leaders, community members and community drug distributors. The sample size was subject to change depending upon reaching of theoretical saturation. Further details of the sample composition are provided in the following sections.

Table 1: Application of theoretical sampling approach

Categories	Sampled participants
Engagement of key stakeholders	Traditional and religious leaders, district development committee, healthcare providers
Community participation in programme implementation	CDDs, healthcare providers, programme person
Community participation in information dissemination	CDDs, traditional and religious leadership,
Promotion of partnership approaches	Community development, Child fund, DHO, DEBs, ZANIS
Community participation in programme design	Community members, traditional leadership
Participation in monitoring and evaluation	CDDs, healthcare providers
Participation in programme identification and priority setting	Healthcare providers, community members and traditional leadership

3.5 Data collection

Qualitative data was collected using In-depth (IDIs) as well as Key-informant interviews (KIIs) together with focus group discussions (FGDs). The interviews were steered by an interview guide, recorded and transcribed verbatim. Some field notes were also taken. The data was collected over a period of four weeks. Using the health workers at the health facilities and the local network of community health workers, community members that met the inclusion criteria were identified and interviewed, after consenting. Interviews were conducted in

different locations based on the advice from district health office. Luangwa was subdivided into three main zonal areas, consisting of; Luangwa BOMA clinic to present urban community, Chitope and Mpuka health centres catered for the rural communities. The FDGs were conducted with community members, KIIs with programme implementers and IDIs with key stakeholders.

3.5.1 In-depth Interviews

In-depth interviews or unstructured interviews are some of the main methods used in qualitative research. IDIs were conducted with various key stakeholders who according both the community members and healthcare providers had a role in MDA for LF implementation. These individuals were sampled as per theoretical sampling approach, where data collection was guided to target particular individuals after preliminary analysis of data provided by earlier respondents.

Table 2: In-depth interviews

Participants	**Number of Interviews**
Religious leadership	1
Traditional leadership	1
Community development	1
Child fund	1
School health and nutrition coordinator (SHIN)	1
Zambia information services (ZANIS)	1
Total number of interviews	**5**

3.5.2 Key-informant interviews-KIIs

Key informant interviews are the other forms of unstructured interviews used to collect qualitative information. These kind of interviews are used to collect information from people who are experts in this area of research (Kumar, 1989). We conducted KIIs in each of the three facilities, with the facility In-charge and the programme coordinators. We also interviewed the head of the program at the district health office. In total, they were seven KIIs (table 3).

Table 3: Key informant interviews

Participants	**Number of Interviews**
Facility In-Charges	3
Program Coordinators	3
District Health Office	1
Total number of KIIs	**7**

3.5.3 Focus group discussions (FGDs)

Focus group discussions were held with the community members to collect information regarding their views on engagement processes that they thought fostered community participation in MDA for LF. In each of the facilities, we conducted three FGDs consisting a range of 7-10 members per group. We had two groups for the community members (youths and adults) and another one for the community drug distributors (CDDs). In total, nine FGDs, with 69 participants were conducted as shown in table 4. The age ranges were comprised of; Adolescents 18-19 years, and adults >19 years.

Table 4: Focus group discussions

Sites	Focus Group Discussions	Participants
Luangwa BOMA Clinic (Urban)	Adolescents (18-19 years)	7
	Adults (>19 years)	10
	Community distributors	8
Mpuka Health Centre	Adolescents (18-19 years)	8
	Adults (>19 years)	8
	Community distributors	7
Chitope Health Centre	Adolescents (18-19 years)	7
	Adults (>19 years)	7
	Community distributors	7
Total FGD participants		**69**

3.6 Data management and analysis

Data were analysed using grounded theory approach, which requires data collection and analysis to be done simultaneously. This is critical for identification of categories and themes for theory development. According to Corbin and Strauss, grounded theory approach has three main stages of coding that aided the theory building process (Corbin and Strauss, 2014). These are:

Firstly, open coding, which involved coding the data for its major categories of information, which in this study was identification of broader categories of information regarding specific engagement strategies and how they shaped community participation in MDA for LF. This process identified major concepts around the engagement strategies and compared them to come up with other subcategories.

Secondly, Axial coding occurred in which we identified one category from the open coding stage (called the "core" phenomenon), and through further analysis created emergent categories around this core phenomenon. Straus and Corbin prescribe that these categories can be referred to as strategies, Contextual and intervening conditions and consequences (Corbin and Strauss, 2014). These identified categories relate to the core phenomenon in a visual model called the axial coding paradigm (Fig 2).

Thirdly, selective coding, in which we took the model created above and developed hypotheses that interrelated the categories in the model (Fig 2).

Once the theory was developed, we compared it to previous work as well as other literature to validate current understandings of on community engagement processes and how they shape participation.

3.7 Use of software

To facilitate the process illustrated above, NVIVO 10 software by QSR international was used to manage and analyse the data. This software facilitated identification of categories by running theory-building queries. These included text mining queries such; as text search, word frequency, coding, coding comparison and matrix coding. Below, we present the code-list, iteratively developed from the field notes and more detailed reading of the transcribed data. The code-list provided the basis for structured data analysis and theory building process.

Table 5: Qualitative data analysis code-list

Broader categories	Analytical node 1	Analytical node 2	Analytical node 3
Community engagement	Awareness creation	Sources of information	
		Information and education materials (IECs)	Shortage of IECs
			Translation of IECs
	participation in implementation	Community health workers	Transportation
			Long distances
			Training
			Remuneration
	Partnership approaches	Stakeholder engagement	District development committee
			Non-governmental organisations
			Traditional leadership
			Stakeholder roles

Community participation	Decision to participate		
	Information dissemination		
	Drug distribution		
	Rejection of drugs		
	Participation of LF patients	LF patient challenges	
		Assistance for LF patients	
Knowledge	Lymphatic filariasis	Definition	
		Disease source	
		Symptoms or manifestation	
	MDA for LF	Purpose	
		Benefits	
		Fears	
MDA for LF implementation	Implementation period		
	Drug supply		
	Health education		
	Coverage		
	Challenges	Mobile populations	
Effectiveness of strategies	Awareness creation		
	Engagement		
Practices	Health seeking behaviour		
Recommendations to improve MDA for LF	Mosquito net provision		
	Management of side effects		
	Morbidity management		
	Fixed annual MDA day		
	Continued health education		
	Innovative awareness creation		

The software further facilitated the process triangulating the qualitative data from various sources through cross-case comparison queries. This helped to bring out the differences between mere opinions and facts. Key among these cross-case comparisons were between the healthcare providers and community members. This triangulation helped to increase the credibility and validity of the results by crosschecking data from the various sources, highlighting the differences and similarities.

3.8 Dissemination Plan

The findings of the study will be published in a peer-reviewed journal. A copy will be made available to the UNZA School of Public Health Library. The finding of this research will also be availed to district health of Luangwa. Some copies of the dissertation will be provided to the health facilities where the study was conducted.

3.9 Ethical Considerations

The University of Zambia biomedical research ethics committee (UNZABREC) and the Zambia national health research authority (ZNHRA) provided ethical approval for this study. During data collection, participants were provided with sufficient information about the study for them to make informed decisions on whether to participate or not, and consent was sought from them. In all the three health facilities, participants were gathered in securely private places, and then provided with transport refunds after interviews. All the participants were de-identified by providing them with participant IDIs as opposed to using their actual names during both data collection and analysis. Data collected were treated with outmost privacy and securely stored on a password-protected computer.

CHAPTER 4: RESULTS

This section is structured to respond to the general and specific objectives of this study. Firstly, we report on the stakeholder roles in planning and implementation of MDA for LF. Secondly, we explore the engagement and awareness creation strategies, and their effectivity, respectively. Thirdly, we describe some of the factors that shape community participation in MDA for LF. Lastly, we present a theoretical model that guides development and implementation of effective and context specific community engagement strategies that facilitate community participation in MDA for LF.

4.1 Stakeholder roles in planning and implementation of MDA for LF

Table 5 provides details of the key stakeholders and their roles in planning and implementation of MDA for LF. These key stakeholders are categorised into community structures, non-governmental organisations (NGOs) and the district development committee. Below we report the views from the sampled participants.

Table 6: Stakeholders roles in MDA for LF implementation

Stakeholders	Role in planning and implementation
Church leaders	Information generation and dissemination
Traditional leaders	
CDDs, School health coordinators	Information dissemination and drug distribution
District commissioner office	Generation of political support
Ministry community development	Provided their established community structures
Child fund and other prominent non-governmental organisations	Resource leveraging (transport) and provided their established community structures
District development committee	Facilitating stakeholder buying-in all government departments within Luangwa

4.1.1 Role of community health structures

Local network of community health workers (CHWs)

Both the community members and the healthcare providers reported that community health structures were a starting point in realising community participation in MDA for LF. They indicated that these structures always played a critical role even in other programmes implemented by the district health office. In MDA for LF, the local network of CHWs was said to be responsible for conducting health education and drug distribution, respectively. The community members however, emphasised the importance of CHWs having to originate from the same community where they were assigned to do the health education and drug distribution, so that people could trust and still refer to them even after the distribution exercise.

> *"…We have people that volunteer to be part of a health facility, to help in extending services to the community. When it comes to MDA for LF, we use them to distribute the drugs and conduct health education. The main reason is that they are known to the community as representing the health facility, so they can be trusted…" [KIIB2_ Healthcare provider]*

> *"…It's important that those who are selected for drug distribution come from the same community so that people can still refer to them after the exercise..." [FGDC2_adult]*

Traditional leadership

Community structures like the traditional and religious leadership were reported to play an important role in facilitating community participation. Churches for example, were said to command huge followings in most of the communities, and were therefore engaged in the provision of health education. The healthcare providers recounted that they sent letters to the local churches explaining the essence of MDA for LF and requested that they encourage their members to participate. Some community members further reported that they had gotten information about MDA for LF from the churches.

> *"…We usually talk to the churches. We realised that traditional leaders have a bigger voice, and maybe even bigger than us. As you are aware, people will usually believe a pastor or an elder than a health worker. So, we thought one of the ways we are going to engage the community is to use the religious leaders…" [KII1_ Healthcare provider]*

4.1.2 Non-governmental organisations

Some NGOs were stated to be essential partners in the implementation of MDA for LF. They played various roles that aided community participation. For example, NGOs with already established community structures like the child fund were reported to avail these structures to the district health office to assist in social mobilisation activities. Additionally, they also provided resources such motorbikes to help with transportation in certain instances.

> *"...Here where we are the child fund has community groups known as the communication agents, who hold meetings with parents and their children. These were also used to deliver information to the community..." [FGDM5_CDDs]*

4.1.3 Luangwa development committee

Other government departments were also reported to play a vital role in enhancing community participation in MDA for LF. The Luangwa district development committee provided a platform for linkages between the district health office and other departments. It allowed for the coordination of development efforts from all key stakeholders in the district including the department of health, education, agriculture and fisheries and community development. With regards to MDA for LF implementation, the committee was fundamental in fostering local support from the onset.

> *"...Before administration of the drug, stakeholder meetings through the district development committee were held with traditional and civic leader, district heads of departments and the community to explain what MDA for LF entails..." [IDI1_Key stakeholder]*

4.2 Engagement and awareness creation strategies in MDA for LF

4.2.1 Engaging of key stakeholders

Engaging of key stakeholders such as civic leaders was used to promote stakeholder buy-in and generation of political-will for the programme. These influential people played an important role in motivating the community members to participate in MDA for LF. In the local schools for example, the district education board (DEBs) was engaged to facilitate for the process of allowing teachers to participate in conducting health education and drug distribution in their institutions. This was critical in facilitating participation of students in the schools.

"…We engage those influential people. For example, the civic leaders such as the counsellors and council chairperson. Then we have the senior people in the government who are the DC, council secretary and the DEBs. So, we usually have what we call the stakeholders' meetings with them where we present what lymphatic filariasis is, the background and then the benefits to the community. So, from the onset we build the foundation where they understand why it's necessary…" [KII1_Healthcare provider]

4.2.2 Awareness creation strategies

Awareness creation strategies included the use of the door-to-door approach to conduct health education. This is where the CDDs moved from one house to another educating people about MDA for LF. Drama was also used in instances when they were sufficient financial resources to hire performers. Community members were made to gather in a particular location, where key LF diseases aspects were dramatized. Furthermore, Information education materials (IEC) such as posters and leaflets were used for health education. These were stack in selected places such as the health facility, and some were given to the CDDs as references when conducting health education.

"…Through the drama groups, people were informed. When they performed, they educated the people because the drama was based on the disease. Drama tends to bring a lot of people together, and after that they provide them with health education and people do learn…" [FGDB6_ CDDs]

"…We only knew about elephantiasis after we were shown pictures, which showed swelling of one breast, legs and deformation of body parts. I heard that a specific mosquito causes elephantiasis and one has to take the drugs before they acquire the disease and that is how we took the drugs…" [FGDC4_ Adolescent]

Community meetings called by community leaders such as the headmen, neighbourhood health committees and primary health centres were also used to create awareness. In these meetings, community members were informed about MDA for LF and its benefits, and encouraged to participate. The public-address system was also used in certain areas to inform communities about the programme.

"…They are community meetings called by influential leaders like the headmen where people are informed about MDA for LF. There is also a public-address system used to sensitize people. When they are sufficient funds, they do also drama. They also go door–to-door educating the households…" [KII3_Healthcare provider]

4.3 Effectiveness of engagement and awareness creation strategies

4.3.1 Knowledge about MDA for LF

Most of the community members had a good understanding of what LF is. They defined LF as the abnormal swelling of body parts such as the limbs and genital organs. They were also able to explain the cause of the disease together with its symptoms. Similarly, community members were knowledgeable of the essence of MDA for LF and its benefits. However, they stated that it was difficult to ascertain how helpful the drugs were given that infected people could not be cured after taking the drugs.

"…Elephantiasis causes swelling of legs and hands and is transmitted through a mosquito. One may not know that they have the disease unless after years…" [FGDM6_ Adolescent]

"…Elephantiasis is a disease whereby one part of the body enlarges more than the other, take for example, the hand; one side may become extremely larger than the other. Even the breast, you find breast may be larger than the other…" [FGDC3_Adult]

"…To say the truth, it's very difficult to know whether these drugs are helpful because we have old cases of people with swollen body parts and they have not necessarily reduced even after taking the drugs…" [FGDB7_ Adult]

4.3.2 Practices of LF patients

The community members explained that before the implementation of MDA for LF, most LF patients did not seek medical help. This was because they believed that they were bewitched, hence they resorted to visiting witchdoctors with the hope of being cured. Others also stated some LF patients used to think that it was a family disease passed on from one generation to another. However, after the introduction of MDA for LF, most LF patients had gotten more knowledge about the disease and had begun seeking medical assistance at the local health facility.

"…Long ago, LF patients did not know the source of the disease so they often time tattooed themselves, but without any improvements in their conditions…" [FGDB9_ Adult]

"…In the community, we the CDDs provide help to LF patients when distributing these drugs. We encourage them to visit the hospital and provide them with some helpful information on how they should live with the disease..." [FGDM6_ CDDs]

"…In the olden days LF patients would sit at home without medical care. They visited witchdoctors who eventually tattooed the swollen body parts with the intention to reduce the swellings. For a swollen leg, they tattooed the entire back and similarly for the hydrocele. But nowadays people are going to the hospital…" [FGDC4_Adult]

4.3.3 Decision to take the drugs

Pictures of LF patients were influential in convincing people to take the drugs. Community members narrated that they were motivated to take the drugs after seeing pictures of LF patients during the health education campaigns. They indicated that they were scared of acquiring the disease so they had to take the drugs despite of the side effects. Others reported that they took the drugs because they were scared the disease would cause a lot of suffering in their family if one of their members had acquired it.

"…When you see the picture of the disease itself, it's so scary. That's what motivates them to take the drug. Though they are side effects…" [FGDB1_Adolescent]

"…. When the CDDs were distributing, they showed us pictures and brochures of LF patients with swollen breast and hydroceles, which was scary and made us to ensure that all our family members took the drugs…" [FGDC5_ Adult]

"…We were scared that the disease would cause a lot of suffering in our families if on the members had acquired it…" [FGDM3_ Adult]

4.4 Factors that shape community participation in MDA for LF

4.4.1 Period for MDA for LF Implementation

The period dedicated to implementing MDA for LF was reported to be short by both the healthcare providers and CDDs. They indicated that usually, national orders to implement MDA for LF came at a short notice. Because of this, the CDDs recounted that they had to overwork themselves in order to meet the set targets within a short period. The short period of implementation was also said not to accord adequate time for health education campaigns before the actual distribution of drugs. Health education was in most instances conducted simultaneously with the drug distribution.

> *"…The period for the drug distribution is very little for us to be able to make follow-ups. We have to panic for us to reach the set targets or percentages. As a result, we are overwhelmed by the work. If the period can be increased so that we can reach the set MDA for LF targets very well…" [FGDB6_CDDs]*

> *"…In the time frame that we had it was not enough I can say to adequately give information. You resort to just saying that people from the facility are coming to your place, but not spend much time with community members because you want to cover everyone…" [KII4_Healthcare provider]*

4.4.2 Mobile populations

A good number of community members were reported to be fishermen and women, who spent most their times camping and doing business in the neighbouring countries of Zimbabwe and Mozambique. As a result, they would miss the actual drug distribution days; hence, they would not participate in MDA for LF. This was due to the fact they spent quiet a long time away from their homes, and they would not be aware of the programme, only to return when it had already been implemented.

> *"…You find that for those who might have gone to Mozambique like in this area we are bordering Mozambique and Zimbabwe and most of our people here that's where they do their businesses. They go and buy fish, maybe some other things, meaning that those who are absents during that week, like those selling fish, maybe missed during the five-day period given for drug distribution…" [KII6_Healthcare provider]*

4.4.3 Large and distant catchment areas allocated for drug distribution

The CDDs explained that long distances covered in reaching all village households during the drug distribution exercise was a hindrance to MDA for LF implementation. This affected their capacity to track and provide drugs to populations that otherwise may not have been present during the distribution days. Furthermore, the lack of transportation also affected their capacity to efficiently manage and monitor drug distribution within large catchment areas.

> *"…The challenges faced by us the community health workers were that: we were covering long distance on foot and sometimes we would find that some people where at the garden. Therefore, we did not go back because we were too exhausted to do so…." [FGDM5_ CDDs]*

> *"…The main challenge is hunger. Some communities are very large for one to do the distribution alone without eating from morning. It was very challenging, as some people where in far places and so it was difficult to walk with hunger…" [FGDC4_ CDDs]*

4.4.4 Shortage of drugs

Both the HCPs and CDDs reported that drugs had run out before completion of the distribution exercise. In some facilities, it was reported that they had run out drugs by the third day and they had to wait for more consignment from the district health office. For houses that were skipped during the distribution day, some CDDs conveyed that in cases where drugs had run out, those houses would not be covered in that MDA for LF round. Similarly, the mobile populations who returned home after the distribution exercise would find that the drugs were run out; as a result, they would also not be covered.

> *"…Another challenge we found was that the LF drugs were insufficient. The houses that we skipped saying we would come back later, we found that there was no medication left for them...." [FGDM3_CDDs]*

> *"…The challenges apart from transport itself, I can say the main challenge we had was the late supply of drugs. Okay we had drugs from start but they were not enough. You find that you receive one bottle and then you start sharing just for each area to have some, you give a few to each area before you could receive some supplies. So, that lag in time was basically time wasted…" [KII7_Healthcare provider]*

4.4.5 Refusal to take the drugs

Possible refusal by certain communities to take the drugs was another challenge to MDA for LF. Various reasons were reported, but mostly it was due fear of side effects, personal beliefs and general lack of information about LF treatment in few instances. Some people were afraid that the drugs would make them drowsy, hungry and vomit. Whilst for other common diseases people were much more knowledgeable, it was not the same for LF. In some instances, it was due to lack of health education in certain areas. The failure of the public-address system to reach all communities meant that people only found out about the drugs on the actual day, hence increasing the chances of refusal.

> *"…The other challenge was that some people refused to take the drugs. Even if they were to be in far places, we had to make an effort to follow and convince them to take the medication. They said the drugs made them hungry, sleepy, or it made them to vomit. There is need to educate people so that they can get used…" [FGDB4_ CDDs]*

> *"…They are some communities that are difficult; they have got their own beliefs. I wouldn't mention names here, but there is a certain community in one chiefdom, they always refuse when they are such programs to say us as our religion does not condone such things..." [IDI5_Key stakeholder]*

4.4.6 Appropriate incentives for the CDDs

Both the HCPs and community members reported that there was need to provide appropriate incentives to the CDDs for them to work efficiently. The current financial incentives were thought to be inadequate for the large amount of work that they did. In both of the previous two rounds of MDA for LF, the CDDs conveyed that the money was paid months after they had finished the distribution exercise. This, they said, was demotivating, because they had invested a lot of time that they could have used on other things to benefit their families. Furthermore, incentives such as bicycles to help ease transport challenges were suggested. There was also suggestion to provide bags for the CDDs for carrying the drugs.

"…These volunteers offer their energy and resources in capturing information needed by the district. We need some incentives that can help to appreciate their hard work. When we promise them an allowance at the end of each MDA, I think it would be better to give them immediately they are done. That helps to encourage them to do the work better next time, but where we delay to give our dues, it demotivates them…" [KII4_Healthcare provider]

"…It's only that we incentive is quite small, thirty kwachas, but looking that the amount of work which is there, it's too much work. If we can increase the amount to fifty kwachas. Looking at these volunteers they do a lot of work…" [IDI4_Key stakeholder]

4.5 Strategies to enhance community participation MDA for LF

4.5.1 Innovative awareness creation approaches

Community members suggested the need to use innovative awareness creation approaches in order to inform everyone. They proposed use of mobile phones to send text messages about MDA for LF in areas with network. In addition, they suggested that use of neighbouring countries' community radio stations would help inform people who conducted business outside the district. Once such people were made aware of the program, they could easily plan their activities and avoid missing the drug distribution days. It was further suggested that engaging LF experts to discuss with community members on radio programs would assist in creating awareness and combating any negative beliefs regarding the drugs.

"…Another way for those who have no radio or TVs, we can use the mobile phones like the way receive health tips. They can arrange with the network providers and send the text messages about MDA for LF to everyone…" [FGDM4_ Adolescent]

"…One of the ways is to bring us experts in this field to talk to the community members through the headmen and volunteers, who can now do the teaching their communities. Since they are from the same communities, it's easy even for people to follow them at their houses and consult…" [FGDC7_ Adult]

4.5.2 Extension of implementation period

Both the healthcare providers and CDDs reported that there was need to extend the period of MDA for LF, to enable allocation of adequate time to implementation and social mobilization activities. It would provide ample time for conduction of health education campaigns before the actual drug distribution days. This would also allow for capturing of community members that may otherwise have missed the distribution days for one reason or another. It was further suggested that as opposed to the five days, extending it to 2 weeks or 10 days would suffice to cover every area in the district.

> *"…Even the drug distribution time will require a week and some days, because this enables to capture even those that did not get the MDA for LF message. The days should be extended…" Community member [FGDC7_ CDDs]*

> *"…I would also recommend that the timeframe be extended from a one week program to two weeks program or maybe to 10 days, at least it can help to cover quiet a large population…" [KII6_Healthcare provider]*

> *"…In my opinion, I think it is better if people are given enough time to be sensitized so that even they are taking the drugs, they are able to understand why and they can share the information with another person…" [IDI2_Key stakeholder]*

4.5.3 Establishment of a morbidity management programme

Most of the participants recounted the suffering that LF patient had to go through in their daily lives within the communities. They suggested that whilst MDA was for prevention, there was need to have another programme specifically to help identify those infected with LF and link them to healthcare. Furthermore, both the CDDs and healthcare providers reported that during the drug distribution exercise LF patients would question the essence of taking the drugs given that they would not be cured.

> *"…LF patients suffer a lot. We all tend to think they are just swollen body parts, but when you hear the patient talk, they say it's painful. I experienced that from a close friend who told me that it's painful sometimes…" [FGDC6_ Adult]*

"…We are hoping that as we continue doing it we can even do better. Maybe also try to see how we can help even those who are infected, because sometimes we collect figures, but we don't provide any help to the people who are infected. So, if we can try to provide assistance to those who are infected wit will be better…." [KII1_Healthcare provider]

"…We have people that have these conditions in this area like lymphedema, they ask to say we continue getting this medication, but what are we getting out of it?" [KII3_Healthcare provider]

4.5.4 Provision of mosquito nets

Most community members reported that they were taught that LF was transmitted through a mosquito bite, and that there was need to keep their environments clean to avoid breeding of mosquitoes. However, they indicated that mosquito nets were not provided during MDA for LF. They stated that mosquito nets were only provided to expecting mothers at the health facility. There was therefore need for the program to consider distributing mosquito nets to the community members as way of encouraging community participation in MDA for LF.

"…After educating the people about LF, a lot request for mosquito nets, since it's caused by mosquitoes. Even as they are told to use these mosquito nets, they do not have. The program people should consider that. The previous mosquito nets I head of were only given to the breast-feeding mothers and they were not a lot…" [KII5_Healthcare provider]

4.6 Theory development

The underlying principles in the development of the theoretical model were guided by Straus and Corbin's systematic approach to grounded theory building (Corbin and Strauss, 2014). The theoretical model depicts an interrelationship between various categories of factors and their interaction with the core phenomenon. It describes some fundamentals approaches to community engagement required to facilitate community participation in MDA for LF.

Through the various stages of coding stipulated by Straus and Corbin, we identified the core phenomenon as comprising effective community engagement that is context specific. Around the core phenomenon, we identified some other subcategories that were found to be essential in facilitating community participation. These subcategories consisted of appropriate and adequate health education, strong community health structures and partnership approaches (Fig 2).

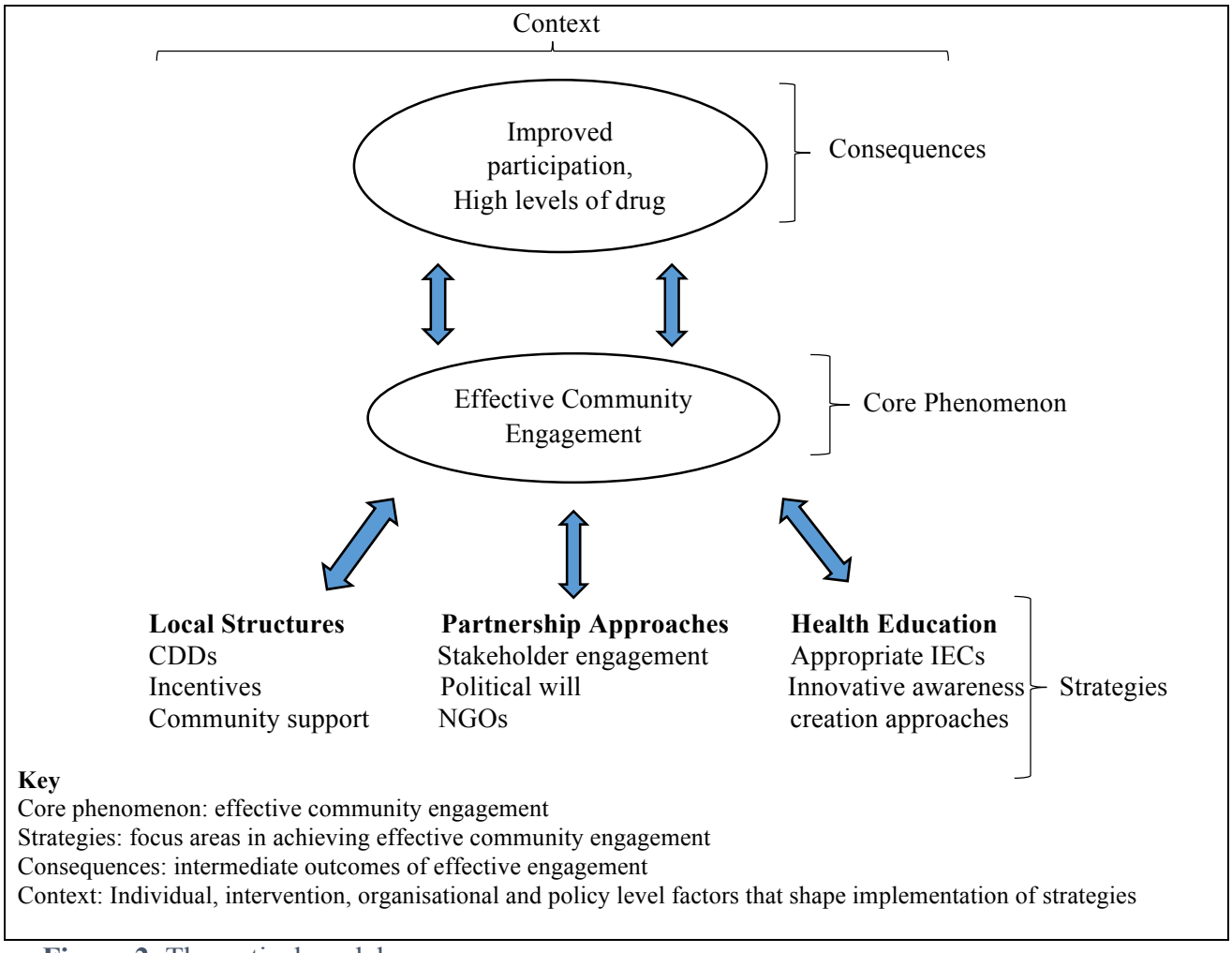

Figure 2: Theoretical model

The theoretical model underscores that for community participation in MDA for LF to occur, there is need to employ context specific and effective community engagement strategies. Three key elements were identified to be essential for developing and deploying effective community engagement strategies. These elements include; appropriate and adequate health education, strong and well-motivated community health structures and partnership approaches to MDA for LF implementation.

Appropriate and adequate health education

All the participants underlined the importance of health education (H.E) in people's choices to participate in MDA for LF. They indicated the need to dedicate sufficient time to H.E campaigns for effective and meaningful participation. Furthermore, some of the English worded IEC materials used for H.E needed to be interpreted into local languages if communities were to fully understand the key messages. Additionally, approaches to awareness creation had to be enhanced to capture also the mobile populations (community members that were mostly out of the district for business or other commitments). To do this, use of mobile phones in areas with network and radio stations for the neighbouring countries was suggested.

Motivated community health structures

The research participants identified the local network of community health workers as having a crucial role to play in MDA for LF implementation. The CDDs, selected from the community, were the frontline personnel and epitome of community participation in MDA for LF. Their participation was however shaped by number of factors: such as MDA for LF implementation period, training, distances covered and incentives for the work done. According to both the community members and healthcare providers, maximising their participation and motivation required provision of appropriate incentives and sufficient time to conduct the work. Some of the suggested incentives included better and timely financial remuneration, bicycles for transport and adequate training.

Partnership approaches

The healthcare providers and key stakeholders highlighted the role of partnership approaches in enhancing community participation in MDA for LF. Stakeholder engagement through the district health committee, which brought together various government departments, facilitated generation of political will from government heads of department and NGOs. These partnerships provided the much-needed constrained resources to the programme like transportation and structures to conduct social mobilisation. For example, the DEBs under the

ministry of education allowed teachers to do the drug distribution within the school as way of enhancing student participation.

CHAPTER 5: DISCUSSION

The study findings suggest that in order to attain high levels of community participation in MDA for LF, there is need to design and implement effective community engagement strategies. The engagement strategies must aim to address three core issues if they are to be effective in facilitating community participation, which include appropriate and adequate health education, motivated community health structures and partnership approaches to implementation.

The first core category, health education, plays an important role in facilitating community participation in MDA for LF. It helps to transform the mindset of the community through empowering them with information about the relevance of MDA. For such transformation to occur, it is imperative that sufficient time is allocated to health education, IEC materials are translated into local languages and innovative approaches are employed when creating awareness. These findings are consistent with similar studies conducted in other parts of sub-Saharan Africa (Dembele et al., 2012, Richards et al., 2011).

A study from Sierra Leone showed that use of innovative and more "modern" sensitization approaches, enabled the reaching of individuals and institutions that had otherwise been unaware of MDA for LF (Hodges et al., 2010). Two Nigerian studies further reported that conducting knowledge attitude and practices (KAP) surveys enabled the MDA for LF programme to design target specific, responsive and widely accepted IEC materials (Hopkins et al., 2002, Richards et al., 2011). These approaches to health education were vital as they encouraged active community participation and sustainability of MDA strategies by facilitating better understanding of community concerns, beliefs and potential challenges during the campaigns.

The second core category, partnership approaches to MDA for LF implementation is crucial to facilitating community participation as it provides a basis for sustained political commitment and support for the programme from government heads of departments and NGOs at both national and district levels. Community partnerships further shape community participation and implementation by providing a platform to build social capital, respectful relationships, engender trust and sustain community support towards the MDA for LF programme (Liese et al., 2010). Though these findings underscore the importance of local partnerships, strategic international collaborations equally contribute to facilitating community participation in MDA

for LF as reported in studies conducted in Togo, Mali and Nigeria (Dembele et al., 2012, Hopkins et al., 2002, Sodahlon et al., 2013)

The third core category, empowering and motivating community health structures is another essential component to facilitating community participation in MDA for LF. These structures include local actors like the traditional and religious leaders, neighborhood health committees and the network of community health workers. For example, to ensure that local actors such as the CDDs who are key to MDA for LF programme success are motivated, there is need to provide appropriate and timely incentives. The intricate nature of their work in MDAs for LF demands for consistent motivation. Several motivating factors have been suggested by Njomo et al., that include provision of transportation, capacitation and training, proper supervision, trust and familiarity with community and recognition (Njomo et al., 2012a). A Tanzanian study further reported that the CDDs had better capacity to provide real-time data for the MDA for LF programme after being provided with mobile phones (Madon et al., 2014).

Enhancing community participation and the functioning of local health structures in MDA for LF, will require establishment of formal morbidity management programmes that identify LF patients and link them to care. Whilst the MDA for LF programme's main focus is disease prevention, there is need for programmes that address the plight of people who are already infected with this long-term debilitating condition. Studies from Togo and the island of Zanzibar have shown that Lymphedema management programmes help to maintain community support for MDA for LF through addressing the needs of the individuals in the community with the most visible LF manifestations and providing information about the disease to the family members (Malecela et al., 2009, Sodahlon et al., 2013).

Implementing public health interventions such as MDA for LF remains a complicated process, because of limited evidence on how to accurately select and tailor implementation strategies to address the local contextual needs (Powell et al., 2017). Existing systematic reviews have provided limited guidance regarding the types of strategies that may be effective in particular circumstances. This research addresses this gap in implementation research by proposing a theoretical model that highlights three critical focus areas when selecting, designing, planning and implementing of effective community engagement strategies that maximise community participation in MDA for LF.

Community participation in MDA for LF does not only influence health outcomes, but also has a considerable impact on implementation outcomes and processes. Implementation outcomes such as acceptability, sustainability, appropriateness of the MDA for LF interventions are highly associated with community participation. A systematic review of the Influence of implementation on programme outcomes found that one of the most important organizational practice supporting implementation processes was community participation (Durlak and DuPre, 2008). Another study by Hahn et al (Hahn et al., 2002) found community participation to be one of the key predictor of programme sustainability.

Given the importance of community participation in facilitating implementation success, the study findings are of great relevance to MDA for Implementation teams. It is important that before the design and actual programme implementation, emphasis is placed on developing effective engagement strategies that maximise community participation, as this will be crucial in reaching the WHO set target of effective coverage of >75% in all 4-6 rounds of MDA for LF, and ultimately LF elimination.

MDA for LF implementation teams should systematically consider the factors affecting community participation such as the implementation period, mobile populations, incentives, drugs shortages and drug rejection, determine their relevance to the local context and develop a plan to specifically address them in advance of implementation efforts. For example, the facilitating factors and barriers could be assigned to specific team members to assess, determine and record how they will be addressed prior to implementation.

With only a few more years to the WHO set target LF elimination in 2020, there is need for Zambia to double her efforts to ensure that she is not left behind. Reaching the global target for LF elimination will also require multi-sectoral approaches and integration of the already effective control strategies. This will mean not only focusing our attention on MDA for LF, but also strengthening vector control strategies and compliance to mosquito net use in endemic areas. These strategies will similarly require high levels of community participation to achieve their intended outcomes.

5.1 Study Strengths

This was a qualitative study that empolyed a grounded theory approach, which facilitated for collecting of rich and deailed data regarding exissting engangement strategies in MDA for LF. The study also tried to collect data from a wide variety of sources, which enabled for cross-

case comparisons so as to separate facts from mere opinions, hence increasing the valididity of findings. Furthermore, the qualitative team was composed of a student and two supervisors with vast experience in conducting similar qualitaive work, including programme evaluations.

5.2 Study limitations

The study was conducted in a single settinge, with a fairly small sample of respondents as well as using only qualitative approaches to collect data which limits the extent to which the findings can be generalized.

CHAPTER 6: CONCLUSION

This research has highlighted various factors that shape community participation in MDA for LF. Facilitating community participation in MDA for LF will require designing and implementing effective community engagement plans. In order for this to happen, this study identifies three focus areas which are appropriate and adequate health education, well-motivated community health structures and partnership approaches to MDA for LF implementation. MDA for LF implementation teams should systematically consider these key factors, determine their relevance to the local context and develop a plan to address them in advance of the implementation efforts.

The need to understand context specific factors shaping community participation in MDA for LF is not only important for Zambia, but also for other countries at risk of LF infection. This understanding will form the basis for all planning, organization and implementation of MDA for LF, if we are to reach the WHO 2020 target of elimination. We therefore recommend that research on MDA for LF not only focuses on drug delivery and uptake, but also more so on the main implementation issues as identified by this study.

6.1 Recommendations

i. There is need to employ innovative awareness creation strategies such as; mobile phone text messaging in network-connected areas and use of community radio stations from the neighboring countries of Mozambique and Zimbabwe to inform people that may be out of the district during MDA for LF.

ii. Community drug distributors should be provided with appropriate and timely incentives given that they are the frontline personnel in MDA for LF implementation. It was recommended that at least a K50/day during the five-day distribution exercise would suffice as opposed to the K25/day.

iii. There is need to establish morbidity management programmes, which can help to identify and link LF patients to various forms of healthcare, including surgery and psychosocial counseling.

iv. MDA for LF programme implementation period should be extended to a period of at least 14 to 10 days, so as to allocate sufficient time for conduction of health education and putting in place of logistics.

v. Set an annual date for MDA for LF implementation, so as to enable local implementation teams to plan implementation efforts much in advance.

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APPENDICES

Appendix A: Information Sheet

Community participation in mass drug administration for lymphatic Filariasis Luangwa district.

Greetings. My name is Adam Silumbwe, a student at the University of Zambia, School of Medicine, and Department of Public Health. I will read you a form that explains the research study you are being asked to join. This study aims at documenting the processes by which you the community are engaged to participate in MDA for LF and how these processes shape community participation itself.

You have been asked to join this study because you have been identified as the ones that will give correct information regarding this topic. Additionally, you may be called for a subsequent interview if there is need, but this is very unlikely.

There are no physical no psychological risks involved in this study but if you feel uncomfortable answering some of the questions, you may refuse to answer any questions and stop the interview session at any time.

Your responses or participation in this study will not affect you in any way. However, this study will generate information regarding community engagement processes and their effect on community participation. The idea is to hear from you what and how you think these processes of engagement can be done better to encourage participation.

You can either choose to be in the study or not. If you choose to participate, you do not have to stay in the study until it ends and this will not affect you or any other privileges that you may enjoy now.

For confidentiality, your identity has been kept secret with numbers, your name will not be revealed at any time of the study and after. Only the people who are involved in this study will have access to this information and it will be properly secured.

There shall be no financial re-imbursement of any sort, but we are providing transport refunds for your participation in the study.

If you need more information about the study, you can contact the Principal Investigator, Adam Silumbwe at +2609776085894, or you can call the Chairperson of the University of Zambia Biomedical Research Ethics Committee at +260211256067.

Appendix B: Consent Form

By signing below, I _____, agree to take part in this study willingly. I understand the purpose of the study as well as the usefulness of the findings. I know my rights as a participant and I know the risks and benefits of this research.

Participant's signature/ thumbprint: _____

Witness signature/ thumbprint: _____

Date: _____

*If you want to talk to anyone about this study, you can contact me, the Principal Investigator, Adam Silumbwe at +260976085894, or you can call the Chairperson of the University of Zambia Biomedical Research Ethics Committee at +260211256067.

Appendix D: Guide for community focus group discussions (female)

Purpose of the research

To help us understand better how the community would like to be engaged in mass drug administration for Lymphatic Filariasis to attain higher levels of community participation. We are interested in knowing your experiences, views, submissions, and recommendations. This may help to inform the programme implementers of the need to take into account the needs of the community in the planning of future MDAs.

Discussion ground rules

In this discussion, we have no right or wrong answer; we are all free to express our views. People are encouraged to speak through the facilitator. We can only talk after one person has finished talking so as not to interrupt them. No side discussions will be allowed. Kindly be informed that whatever we discuss here today will remain confidential and protected. All cell phones should be turned off to avoid any disturbances.

We would like to inform you that you are not obliged to answer all the questions in the guide, you free not to answer any question you may consider risky to your own goals.

[Turn on the recorders]

I am the facilitator……. interviewing FGD……...Date……..Start time…….End time……..

	Main question	Probe
Lymphatic Filariasis Knowledge, attitudes and practices		
i.	Kindly describe to your understanding of lymphatic Filariasis and MDA.	• Kindly describe anything you know about lymphatic Filariasis? • Describe how someone would acquire lymphatic Filariasis? What causes the disease? • What are the common manifestations of lymphatic Filariasis? • Describe any experiences you may have with Lymphatic Filariasis patients? • What kind of treatment/help do Lymphatic Filariasis patients seek? / Where do they seek treatment?
Treatment of Lymphatic Filariasis with mass drug administration		
ii.	Kindly explain your understanding of mass drug administration for Lymphatic Filariasis.	• Describe your understanding of mass drug administration? • In your own opinion, what do you think is the purpose of mass drug administration? • Have you participated in mass drug administration for lymphatic Filariasis before? Explain how you participated and what motivated you to do so? • Do you think the drugs are beneficial to the people in the community? • Who do you think should receive MDA for LF treatment? Explain why you think so
Health education and awareness creation for mass drug administration to promote community participation		
iii.	Could please explain how you came to know about mass drug administration for lymphatic Filariasis	• Explain how you got to know about mass drug administration for Lymphatic Filariasis? • Explain who are the major sources of information about mass drug administration for Lymphatic Filariasis in this community? • Implementers/sources of information (the CDDs and Healthcare providers) use various ways to create awareness in your community. Describe how this process is done • Explain your views on the effectiveness of the awareness creation strategies, are effective in encouraging community participation? • Do you have any recommendations of how the implementers can best engage the community in creating awareness about mass drug administration for Lymphatic Filariasis?
Community participation in mass drug administration for lymphatic Filariasis		
iv.	Kindly explain you understanding of community participation. How has it been used in mass drug administration. Give	• Describe how the approaches mentioned affect how communities participate or accept mass drug administration. • Explain how you think certain community participation approaches can be used to encourage participation in Mass drug administration?

	examples of what it constitutes…the approaches	• Who are the most influential people, institutions within the community that can motivate communities to participate in mass drug administration? How can they be engaged? Explain. What kind of influence they have in the community? • Suggestions of how you think community participation can be achieved in mass drug administration for lymphatic Filariasis.

Appendix D: Guide for community focus group discussions (male)

Purpose of the research

To help us understand better how the community would like to be engaged in mass drug administration for Lymphatic Filariasis to attain higher levels of community participation. We are interested in knowing your experiences, views, submissions, and recommendations. This may help to inform the programme implementers of the need to take into account the needs of the community in the planning of future MDAs.

Discussion ground rules

In this discussion, we have no right or wrong answer; we are all free to express our views. People are encouraged to speak through the facilitator. We can only talk after one person has finished talking so as not to interrupt them. No side discussions will be allowed. Kindly be informed that whatever we discuss here today will remain confidential and protected. All cell phones should be turned off to avoid any disturbances.

We would like to inform you that you are not obliged to answer all the questions in the guide, you free to not answer any question you may consider to be risky to your own goals.

[Turn on the recorder]

I am the facilitator……. interviewing FGD……...Date……...Start time…….End time……..

	Main question	Probe
Lymphatic Filariasis Knowledge, attitudes and practices		
i.	Kindly describe to your understanding of Lymphatic Filariasis and MDA.	• Kindly describe anything you know about Lymphatic Filariasis? • Describe how someone would acquire lymphatic Filariasis? • What common manifestations of lymphatic Filariasis do you know? • Describe any experiences you may have with Lymphatic Filariasis patients? • What kind of treatment do Lymphatic Filariasis patients seek? / Where do they seek the treatment?
Treatment of Lymphatic Filariasis with mass drug administration		
ii.	Kindly explain your understanding of mass drug administration for Lymphatic Filariasis.	• Describe your understanding of mass drug administration? • In your own opinion what do you think is the purpose of mass drug administration? • Have you participated in mass drug administration for lymphatic Filariasis before? Explain how you participated. • Who do you think should receive MDA for LF treatment? Explain why you think so.
Health education and awareness creation for mass drug administration to promote community participation		
iii.	Could please explain how you came to know about mass drug administration for lymphatic Filariasis	• Explain how you got to know about mass drug administration for lymphatic Filariasis? • Explain who are the major sources of information about mass drug administration for Lymphatic Filariasis in this community? • Implementers/sources of information (the CDDs and Healthcare providers) use various ways to create awareness in your community. Describe how this process is done? • Explain your views on the effectiveness of the awareness creation strategies, are effective in encouraging community participation? • Do you have any recommendations of how the implementers can best engage the community in creating awareness about mass drug administration for lymphatic Filariasis?
Community participation in mass drug administration for lymphatic Filariasis		
iv.	Kindly explain you understanding of community participation. How has it been used in mass drug administration. Give examples of what it constitutes…the approaches	• Describe how the approaches mentioned affect how communities participate or accept mass drug administration. • Explain how you think certain community participation approaches can be used to encourage participation in Mass drug administration? • Who are the most influential people, institutions within the community that can motivate communities to participate in mass drug administration? How can they be engaged? Explain. What kind of influence they have in the community? • Suggestions of how you think community participation can be achieved in mass drug administration for Lymphatic Filariasis.

Appendix F: In-depth interview guide (key community stakeholders)

Purpose of the research

To understand the community engagement processes and how they shape community participation in mass drug administration for Lymphatic Filariasis. To help do that, we are interested in knowing your experiences, views, submissions and recommendations on the current practices as key community stakeholders. This may help to inform the programme implementers of the need to take into account community needs during the planning of future MDAs.

Discussion ground rules

After the completion of the consent process that explains the study in detail and gives us permission to discuss with you, you are requested to provide answers to all the questions, if uncomfortable you may move to other questions.

Have you any questions prior to the interview?

[Turn on the recorders]

I am the interviewer……...……, interviewing IDI
……Date……...Start time……...……End time

Background Information (kindly fill in the information below**)**

Sex: Male…….
Female……

Occupation and
Sector……
……

Experience/years in executing current
duty……

Age at last
birthday……
…….

	Main question	Probe
Lymphatic Filariasis Knowledge, attitudes and practices		
i.	Kindly describe to your understanding of lymphatic Filariasis and MDA.	• Kindly describe anything you know about Lymphatic Filariasis? • Describe how someone would acquire lymphatic Filariasis? What causes the disease? • What are the common manifestations of Lymphatic Filariasis? • Describe any experiences you may have with Lymphatic Filariasis patients? What challenges do they face? • What kind of treatment do Lymphatic Filariasis patients seek? / Where do they seek treatment in the community? • Is there any form of assistance that is provided by your structures/office/committee as key stakeholders to help these kinds of people?
Treatment of Lymphatic Filariasis with mass drug administration		
ii.	Kindly explain your understanding of mass drug administration for Lymphatic Filariasis.	• Describe your understanding of mass drug administration? • In your own opinion what do you think is the purpose of mass drug administration? • Have you been involved mass drug administration for lymphatic Filariasis before? Explain how you participated • Do you think that mass drug administrations is beneficial to the community? explain • Who do you think should receive MDA for LF treatment? Explain why you think so • Describe what your role as key stakeholder in mass drug administration is with regards to encouraging community participation. Kindly explain how the programme implementers have engaged your services.
Health education and awareness creation for mass drug administration to promote community participation		
v.	Could please explain how you came to know about mass drug administration for lymphatic Filariasis	• Explain who are the major sources of information about mass drug administration for Lymphatic Filariasis in this community? • Implementers/sources of information (the CDDs and Healthcare providers) use various ways to create awareness in your community. Describe how these processes are done? • Do you think these strategies are effective in encouraging community participation? Do they reach everybody in the community? If so how effective, are they? Explain • Do you have any recommendations of how the implementers can best engage the community in creating awareness about mass drug administration for lymphatic Filariasis? • Have there been any partnerships created with your institution? If so what has been its role in creating awareness about the programme?

		• Do you think there would be need to for partnerships during the implementation of mass drug administration? Explain why your thoughts.
Community participation in mass drug administration for lymphatic Filariasis		
vi.	Kindly explain you understanding of community participation. How has it been used in mass drug administration. Give examples of what it constitutes…the approaches	• Describe how the approaches mentioned affect how communities participate or accept mass drug administration. • Explain how you think certain community participation approaches can be used to encourage participation in Mass drug administration? • Who are the most influential people, institutions within the community that can motivate communities to participate in mass drug administration and what kind of influence do they have? • Suggestions of how you think community participation can be achieved in mass drug administration for Lymphatic Filariasis? • How do you think community leadership can be engaged to foster community participation? What strategies would you recommend to be effective for your area? • What forms of partnership with the community leadership would you suggest for future mass drug administration campaigns?

Appendix G: key informant interview guide

Purpose of the research

Thank you for agreeing to do this interview. My name is……. This study seeks to understand the community engagement processes and how they shape community participation in mass drug administration for Lymphatic Filariasis. To help do that, we seek would like to know your experiences, views, submissions and recommendations on the current practices as key community stakeholders. This may help to inform the programme implementers of the need to take into account community needs during the planning of future MDAs.

Discussion ground rules

After the completion of the consent process, which explains the study in detail and gives us permission to discuss with you, you are requested to provide answers to all the questions, if uncomfortable you may move to other questions. The interview will last an hour. Please note that we shall be recording the information for our analysis. The interview will be confidential and the information will be secured from any external parties. For privacy, we will identify you as participant KII1.

Have you any questions prior to the interview?

[Turn on the recorders]

I am the interviewer……..……, interviewing IDI
……Date…….Start time……..……End time

Background Information (kindly fill in the information below**)**

Sex: Male…….
Female……

Occupation and
Sector……
……

Experience/years in executing current
duty……

Age at last
birthday……
…….

	Main question	probe
Community engagement processes and community participation in mass drug administration for lymphatic Filariasis		
i.	I would like to get your opinion on the two concepts of community engagement and community participation.	• Describe your understanding of community engagement processes/activities. • What engagement processes/activities is the programmes using in conducting MDA for LF in Zambia? • Do you think these activities/processes are very affective? Do the community respond? • What is your opinion on the current levels of coverage in the programme?
Health Education and awareness creation about MDA		
ii.	Could you kindly explain any health education and awareness creation programme that you have for the sensitization of communities about mass drug administration?	a. Please describe any awareness creation strategies the programme uses to educate the people about Mass drug administration? b. Does the programme use any IEC materials for health education, if so what are they and what role does the community play in their design? c. In your opinion are these strategies effective, if not what would you recommend? d. In your opinion who are the key stakeholders at community level that the programme engages/involves in planning and implementation of the all programme.
Implementation of mass drug administration		
iii.	Please describe in detail how the implementation of mass drug administration for lymphatic Filariasis is conducted in Zambia?	a. How would you describe the role of the community in these implementation processes? Are they involved if not how do you think they should they be involved? b. What Community institutions/ structures/partners do you involve when conducting mass drug administration? Describe their roles? c. Are there any community participation approaches that you promote to encourage participation in mass drug administration? If they are, describe how effective they are? d. What would you recommend to be the best way to engage the community in mass drug administration?