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#### Master's Thesis

# The dynamics of community participation in the context of the HIV/AIDS epidemic in Zambia –

A case study with the Mboole Rural Development Initiative

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#### **Abbreviations**

ADP Area Development Programme

AIDS Acquired Immune Deficiency Syndrome

CBO(s) Community-Based Organization(s)

CDD Community-Driven Development

CSO(s) Civil Society Organization(s)

CSS Community Systems Strengthening

FAO Food and Agriculture Organization

FBO(s) Faith-Based Organization(s)

FGD(s) Focus Group Discussion(s)

GIZ "Deutsche Gesellschaft für Internationale Zusammenarbeit"

HIV Human Immunodeficiency Virus

IRDP Integrated Rural Development Programme

LCDD Local and Community-Driven Development

LUMID Lund University Master in International Development and Management

M&E Monitoring and Evaluation

MoGE Ministry of General Education

MRDI Mboole Rural Development Initiative

NAC National HIV/AIDS/STI/TB Council

NGO(s) Non-Governmental Organization(s)

OVC Orphans and Vulnerable Children

PLHIV People Living with HIV

PRA Participatory Rural Appraisal

R-NASF Revised National AIDS Strategic Framework

SADC Southern Africa Development Community

SRHR Sexual and Reproductive Health and Rights

STI Sexually Transmitted Infection

TB Tuberculosis

UNAIDS Joint United Nations Programme on HIV/AIDS

UNDP United Nations Development Programme

USAID United States Agency for International Development

USD United States Dollar

VMMC Voluntary Medical Male Circumcision

WHO World Health Organization

ZDHS Zambia Demographic and Health Survey

ZMW Zambian Kwacha

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#### **Abstract**

This thesis uses a mixed-method strategy to scrutinize the dynamics of community participation and how it can contribute to improve HIV/AIDS-related knowledge, attitudes and behaviors, paying particular attention to aspects of power and gender. In a case-study design, this thesis analyzes participation in the Mboole Rural Development Initiative and its projects with international donors utilizing an analytical framework developed for the purpose of this study. Furthermore, it examines the implications of community participation for the fight against HIV/AIDS and the performance of Mboole in addressing the epidemic.

The findings suggest that the approach to community participation matters with implications on project effectiveness and sustainability. The analytical framework developed in this study provides a useful tool to analyze differing approaches to participation. Additionally, the results highlight the role of traditional hierarchies, role modeling and gender in participatory processes in Mboole. Traditional elites influence participation and are key for conveying positive health messages — as are "community champions". Furthermore, gender roles can substantially hamper female participation. Lastly, this thesis stresses the importance of community participation for the acceptance of health messages and its relevance for the fight against HIV/AIDS, with Mboole showing successes in addressing the epidemic, but also areas for further improvements.

#### Introduction

"Community participation", "community-based development" or "community-driven development" (CDD) ... – there is a multitude of concepts that describe related ideas, in which the active involvement of communities in development efforts takes center-stage (Mohan & Stokke 2000). Participatory approaches refer to a shift of thinking in development cooperation. Instead of top-down approaches from the Global North, communities are supposed to participate in the projects affecting them. The basic rationale behind this is that involving communities in development projects to identify their own needs and issues of concern as well as to take action, will not only create ownership and thus contribute to sustainability <sup>1</sup>, but "social involvement and participation can themselves be significant factors in improving perceived control, empowerment [and] individual coping capacity" (Minkler, Wallerstein & Wilson 2008:288). While some perceive participation as a value in itself encouraging empowerment, in development practice it has often been applied following a neoliberal tradition focusing on cost- and project-effectiveness (White 1996:7 ff.; Pretty 1995:1251).

There is a vast debate around participatory approaches, which highlights the complexity of the topic, but also points at a very value-laden context to the discussion. Therefore, when discussing community participation, it is not only important to identify what role participation plays for communities and project outcomes, but also to very clearly outline the understanding of – and specific approach to – participation.

In the area of health, community participation is on the one hand seen as a way of improving health service delivery and coverage, especially in remote areas and for key population groups. On the other hand, it is perceived as an opportunity for enhancing acceptance of and adherence to health messages.

In Zambia, one of the major health challenges is the HIV/AIDS epidemic, which is the main reason for premature death in the country (Institute for Health Metrics and Evaluation 2010:1). The burden of disease is high and Zambia is experiencing a generalized epidemic, with a prevalence rate of around 12.9% - the seventh highest

<sup>&</sup>lt;sup>1</sup> See appendix A for key definitions of concepts like ownership, sustainability, development or empowerment.

worldwide (UNAIDS 2017). Against this background, the Zambian National HIV/AIDS/STI/TB Council (NAC) has highlighted the importance of community participation for a successful HIV/AIDS response (NAC 2014b).

However, there are limited structured studies about community participation in the response to the HIV/AIDS epidemic in Zambia, which provide a clear understanding of the concept of participation or the specific approach to participation in development projects and which outline the dynamics of community participation. This study provides a comprehensive analytical framework for examining community participation and applies it in a case-study design to the Mboole Rural Development Initiative (MRDI) – a community initiative par excellence in the rural areas of the Southern Province of Zambia. Consequently, the aim of this thesis is to scrutinize the dynamics of community participation in Mboole and how a participatory approach can contribute to improve HIV/AIDS-related knowledge, attitudes and behaviors. Against this background and paying particular attention to aspects of power and gender, this study seeks to answer the following three research questions:

- 1. What are the approaches to community participation in donor-funded projects with MRDI and what implications can be identified resulting from those approaches?
- 2. How do the power relations and social norms within the community affect participation?
- 3. What role can community participation play for enhancing efforts to address the HIV/AIDS epidemic?

#### Thesis outline:

Setting out to answer these questions, this thesis firstly provides the relevant theoretical background in chapter one by introducing the concept of community in section 1.1 and moves on by discussing two dimensions of participation in sections 1.2 and 1.3, respectively, which revolve around the questions of "how do people participate?" and "who participates?". Chapter one concludes by developing a new analytical framework in section 1.4, which will be utilized to analyze the approaches to community participation in the case of MRDI.

In light of the theoretical background, chapter two provides a short summary of the debate around participatory approaches in section 2.1. Afterwards, empirical findings on participation, its practical applications and implications are discussed in section 2.2 and section 2.3 moves on to review studies on participation specifically in the context of health and HIV/AIDS.

Subsequently, chapter three contextualizes this study by providing information on the socioeconomic development in Zambia as well as by presenting relevant policies addressing participation and HIV/AIDS in section 3.1. MRDI and the Mboole community are introduced in section 3.2.

Chapter four clarifies the philosophical worldview underlying this study in section 4.1 and continues by explaining the research strategy and study design in section 4.2. Thereafter, section 4.3 provides details about the applied methods and sampling strategies and section 4.4 outlines how the relevant data have been collected and handled. The chapter concludes by discussing ethical considerations and aspects of reflexivity in section 4.5.

In chapter five the available data are analyzed and the resulting findings discussed, whereas each research question is devoted one section within this chapter.

Lastly, this thesis concludes by presenting a summary of the key findings as well as by providing some suggestions resulting from this study.

# 1. Theoretical background

There is a multifaceted discourse on community participation and one needs to consider many complexities around that topic. This chapter will set off by providing a brief discussion of the term "community" before introducing different typologies of participation suggested by various authors. These are embedded into the wider conceptual debate on participation. Based on this, the chapter will develop an analytical framework, which will be used for the purpose of this study.

# 1.1. Community

In the area of development cooperation, the term "community" is often used in a geographical sense, as a group of people living together in a village or chiefdom becoming the subject of field research or a development project. However, the concept of "community" goes beyond this spatial dimension. According to Hunter

(1975:538), there are three different dimensions that can constitute a community: (1) space, (2) social relations, or (3) identity<sup>2</sup>. In terms of social relations, Etzioni (1996:5) argues that in a "community" these are more than "one-on-one relations". Rather, the multitude of interconnections between individual relations forms a social network that transcends the mere sum of the individual relations.

While it is possible to focus on each of these dimensions individually, communities are usually constituted by an interplay of two or more of them. Therefore, the term "community" in this study will be understood as a multidimensional concept as suggested by Hunter (1975). However, as will be discussed later in further detail, it is important to not perceive a community as a homogenous group. Individuals can be part of several communities at the same time, translating into a number of identities, roles and interests, which can be conflicting.

#### 1.2. How are people participating?

One of the most well known typologies of participation is Arnstein's (1969) "ladder of citizen participation". She identifies eight different forms of participation, which are subsumed under three broader categories: (1) non-participation, (2) degrees of tokenism and (3) degrees of citizen power (Arnstein 1969:217). In the first two forms of "manipulation" and "therapy" there is literally no community participation, characterized by hierarchy and significant power imbalances between project professionals and community members. The next three forms of "information", "consultation and "placation" include the community to various "degrees of tokenism" as they are informed about the project objectives or their opinions are heard. However, there are still power inequalities, since the community has no means of ensuring that their perspective is actually integrated and acted upon. The last three forms of "partnership", "delegated power" and "citizen control" refer to a situation, where power is shared with or handed over to the community. Their voices are not only heard, but they have actual decision-making power (ibid.).

Essentially, Arnstein's typology answers the question of "How are people participating?", which relates to the degree of their involvement and whether or not

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<sup>&</sup>lt;sup>2</sup> End and Parker (1994:199) as well as Heller (1989:3-4) use a similar definition as Hunter (1975), but instead of identity, they are referring to a political dimension – one where people organize around a common problem, goal or agenda for social action.

they have actual decision-making power<sup>3</sup>. Figure 1 presents an adaptation of Arnstein's original "ladder". The categories are placed along a continuum, where the far ends are either "manipulation" or "citizen control" and consequently ranging from no community participation to situations, where the power to make decisions is with the fully involved community. The author's choice to visualize this along a continuum instead of using Arnstein's "ladder" highlights that "real cases" might not necessarily fit into one category, but rather be located between two categories entailing aspects of both (Arnstein 1969:217-218).

Figure 1: Form of participation and influence of participants based on Arnstein's (1969) ladder of citizen participation.

# Influence Form of Participating: Citizen Control Delegated Power Partnership Placation Consultation No decision-making power Information Therapy Manipulation

# How are people participating?

Source: Own visualization based on and adapted from Arnstein (1969:217).

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<sup>&</sup>lt;sup>3</sup> In Arnstein's (1969:217) words, decision-making power is "the extent of citizens' power in determining the end product".

Within the participatory discourse community participation seems often to be perceived as something that is externally encouraged. "Community groups are helped to identify" (Minkler, Wallerstein & Wilson 2008:287, own emphasis in italics) their goals by external actors, which are "hand[ing] over the stick" of authority" (Chambers 1994:1255, own emphasis in italics). This raises the question of agency. Where is the power to control projects in the first place? And who has the power to share it or pass it on? This kind of rhetoric neglects the possibility that communities are empowering themselves enabling them to approach external actors on eye-level — an idea that is captured under Arnstein's eighth category of "citizen control". Lennie (1999) points out that the question of agency is vital to the concept of empowerment, which otherwise can be an expression of "a hidden paternalism within the support agency" (Sanger 1994:200 cited in Lennie 1999:103).

Related to the question of "How are people participating?", are also the questions of "Why to involve?" or "Why to get involved?". Owusu (2014:2-3) differentiates between "participation as a means" and "participation as an end". According to him, "participation as a means" refers to a situation where external agents pre-set the objectives of a project. The community becomes merely an implementing partner, whose knowledge, skills and resources are utilized for increased efficiency of development projects. Participation in this instrumental sense can become a tool for legitimizing the external intervention. "Participation as an end", on the other hand, follows a more transformative line of thought to promote self-reliance. Sharing or handing over the power of issue selection, project design and implementation to the community strengthens its capacity (WHO 1991:5-6). This is an empowering process that enables the community "to identify what they need, make decisions and develop the means of attaining such desires" (Owusu 2014:2).

In line with these ideas, White (1996) has suggested another typology, focusing on the motivations for participation. She differentiates between four forms of participation: "nominal", "instrumental", "representative" and "transformative" (White 1996:7-9). These relate back to Arnstein's (1969) broader categories, where a nominal interest in participation can be seen as "non-participation", an instrumental or representative motive speaks to Arnstein's "degree of tokenism" and a transformative interest to the "degrees of citizen power". This highlights that the "how?" and "why?"-questions are strongly intertwined. However, they set different

foci. While the "how?"-question has strong practical implications, the "why?"-question is situated more on a meta-level. Indeed, White (1996:7) proposes this typology to draw attention to the politics of participation, which according to her can be obscured by an all too technical understanding of the concept. There is certainly an analytical value in asking questions about the motives for participation. However, the author of this study also argues that the question of "why?" is to a certain degree reflected in the "how?": If one wants to see empowerment through a transformative approach to participation, the choice would most certainly not fall onto a manipulative or consultative form of participation. The motivation for participation will thus be reflected in the form of participation.

#### 1.3. Who participates?

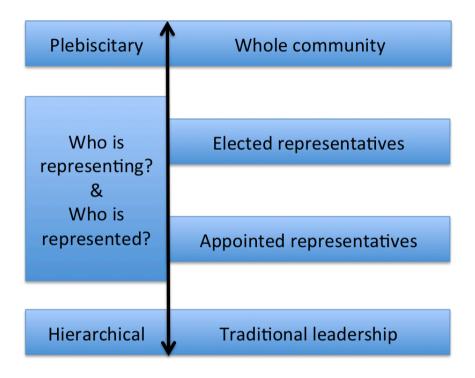
Another approach to categorizing participation is by Farrington and Bebbington (1993). While their underlying rationale follows similar ideas as suggested by the previous authors, they introduce a two-dimensional conceptualization where various forms of participation can be located along the axes of scope and depth (Farrington & Bebbington 1993:106). The depth axis refers to the level of participation following the same line of thought as Arnstein (1969). The scope axis, on the other hand, refers to how wide the subject inclusion is, where the authors see subject inclusion mainly on a thematic level (e.g. change in a broader context versus focusing on a narrow subject matter). However, Cornwall (2008:276) transfers this to the scope of involvement of participants (e.g. from a narrow group of elites to a broad group of participants). The question of "who participates?" is considered relevant for this study and a number of authors have criticized the misleading narrative around "community" as a homogenous group (Momsen 2006:50; Akerkar 2001:7). Cornwall (2003:1331) stresses that failing to acknowledge intra-community power struggles and inequalities basically leads to maintaining a social status quo that might infringe on the voices of marginalized groups and their ability to participate, ultimately hindering a transformative process. Instead, there is a need to allow for diverging opinions to be raised following cleavages along characteristics like gender, age or economic status (Akerkar 2001:1). Therefore, the questions of "who participates?" and on "what" or "whose terms?" become central (Cornwall 2008:275 ff.). In fact, it has been argued that gendered aspects of power relations are all too often obscured by catch-all terms like "community", hiding a "male bias" in decisionmaking (Akerkar 2001:4; Cornwall 2003:1329). The mere participation of women might be abused to legitimize decisions that are made by established (male) elites (Cornwall 2003:1330). Furthermore, Cornwall (2008:277) argues that the questions of voice and representation are vital and need to be considered. This means that even if the term "community" is broken down into different gender groups, one needs to acknowledge that individuals are characterized by a multitude of socioeconomic and cultural aspects, where a financially "better-off" woman might not necessarily be able to represent the voices of women within a given community. Ultimately, this is a question of legitimacy as the inclusion of everyone might sometimes not be feasible (or wanted) and representation thus necessary. Against this backdrop, it matters how individuals get to represent others. Are they elected or appointed? Who is involved in the decision and how is the exchange between the represented and the representative?

Lastly, Cornwall (2008:278) points out that while it might be analytically useful to divide "the community" into social or economic subgroups, the situatedness of people within a larger context makes it also difficult to isolate subgroups and their interests from their wider social networks.

Figure 2 visualizes the discussion on who participates with the far ends of the continuum describing situations, where either the whole community participates or the traditional elite, whose right to represent is based on kinship rather than merit or election. In-between are various forms of representation, where the questions of "Who represents?" and "Who is represented?" are central.

Figure 2: Representation and voice in participation.

# Who is participating?



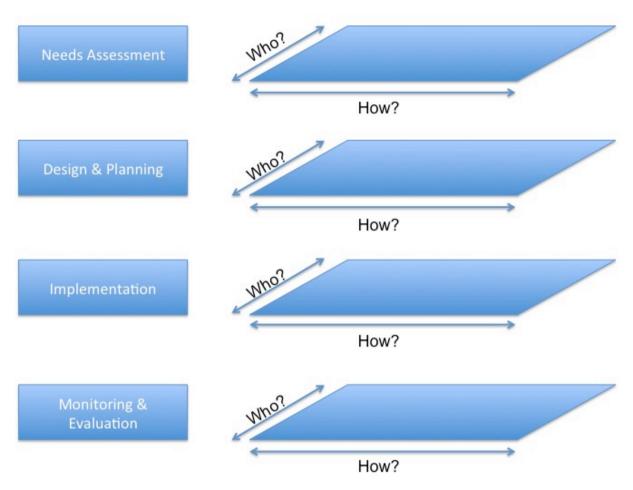
Source: Own visualization based on Cornwall (2008:276) and Farrington & Bebbington (1993:106)

## 1.4. Analytical framework

As this study is concerned with a specific community initiative in the context of development projects – specifically in the area of public health and HIV/AIDS – the author argues that it matters, on which level(s) of development projects participation takes place. Embedding the ideas presented so far, the author has therefore created a new analytical framework (see figure 3) including four major project stages: (1) needs assessment, (2) design and planning, (3) implementation and (4) monitoring and evolution (M&E) (see also Rudqvist and Woodford-Berger 1996:13). It is of relevance whether, for example, the community is only involved in project implementation or also in the needs assessment, design and/or M&E of projects. This brings the analysis closer to development practice making it potentially more useful for analyzing actual development projects and also offering a tool for practitioners to guide conceptualization or evaluation of participatory projects.

Figure 3 presents the analytical framework for this thesis. It includes the dimensions of "how?" and "who?" at the all four project stages.

Figure 3: Conceptualization of participation along the dimensions of "how?" and "who?" on the four project stages.



Source: Own analytical framework inspired by the work of Arnstein (1996), Cornwall (2008) and Farrington & Bebbington (1993).

The framework is a contribution to the analytical debate around participation. Distinguishing between the "how?", "who?" and the project stages offers a structured way of conceptualizing the multiple dimensions of participation. This allows differentiating between, for example, projects that include a large group of people ("who?") in a consultative manner ("how?") for the needs assessment, but only small group of people ("who?") in a manner of partnership ("how?) for the other project stages — or any other combination along the two axes and four project stages. This provides analytical clarity and promotes a nuanced understanding of participation.

#### 2. Literature review

This chapter discusses the historical background to the participatory debate and presents empirical findings concerning the practical realization of participatory approaches, encountered challenges as well as how the empirics relate to the theoretical arguments surrounding the participatory ideology. Lastly, this chapter presents some findings on the application of participatory approaches in the areas of health and HIV/AIDS.

#### 2.1. Historical overview

The idea of community participation in development has a long history dating back to the 1950s, when concepts of participatory development started emerging in a number of countries in conjunction with the debate around decentralized approaches (Binswanger-Mkhize et al. 2010:27 ff.; Rudqvist & Woodford-Berger 1996:10). In the context of public health, the Declaration of Alma-Ata (1978) has brought the topic of community participation in primary healthcare onto the high-level agenda of the international community. In the general debate, one of the leading scholars has arguably been Robert Chambers, with seminal work like "Rural Development: Putting the Last First" (1984) or "Whose Reality Counts? Putting the First Last" (1997). Chambers laid much of the groundwork and has been a driving force behind the conceptualization of the "participatory rural appraisal" (PRA) method, which remains prominent within the wider pool of participatory methods (Parnwell 2006:73 ff.).

Chambers' work has been influential for the shifts of development ideology, policies and practices around that time and has been actively involved in the "Consultations with the Poor" project by the World Bank Poverty Group informing the World Development Report 2000/1, which had a strong focus on the subject's perspective on poverty. This paradigm-shift led to an increase of participatory programs by the World Bank at the turn of the millennium (Mansuri & Rao 2003:7).

Figure 4: Evolution of participatory approaches for community involvement.

Indicator	1950s	1960s	1970s-80s	1990s	2000	2005
Development approach	Centralized, decentralized	Sectoral, technology-led, green revolution, irrigation development	Special area or target group, ADP and IRDP, NGOs and private sector	CBD, social funds	CDD	LCDD
Community involvement		Consultation $\longrightarrow$	Participation —	$\longrightarrow$ E	Empowe	erment

Source: Binswanger-Mkhize et al. (2010:28)

Note: ADP: Area Development Program; IRDP: Integrated Rural Development Program; NGO: Non-Governmental Organization; LCDD: Local and Community-Driven Development.

Figure 4 shows the evolution of participatory approaches since the 1950s up to 2005 as suggested by Binswanger-Mkhize et al. (2010:28). While this gives a useful overview, it is mainly focused on approaches used by the World Bank. However, it also acknowledges different levels of community involvement starting from consultation, moving to active participation and finally empowerment. This must be understood more as a retrospective realization by the World Bank that on an implementation level many projects did not meet the quality of community involvement set out by the participatory ideology (Binswanger-Mkhize et al. 2010:14-15, 32-33; Lamb, Varettoni & Shen 2005:174).

# 2.2. Empirical findings on participation

The participatory development agenda is criticized for being too much rhetoric and lacking meaningful operationalization and implementation on the ground as well as sufficient empirical evidence (Rudqvist & Woodford-Berger 1996:1). International institutions are accused of paying lip-service to the concept as a way of co-opting communities for their own interest and legitimacy (Akerkar 2001:1,2; Arnstein 1969:216; Cornwall 2003:1326-1327; Morgan 2001:222). Mosse (2001:19 ff.) concludes that participatory processes hide external agendas, which tend to determine the outcomes of those processes.

An interesting argument made by Cornwall (2003) is that in as much as the participatory discourse might be about empowerment and inclusion of marginalized

groups into projects affecting their lives, the practical realization remains within the contemporary narrative of development cooperation. It thus continues to lend itself "to congruence with neoliberal development agendas in which fundamental questions of structural, intersubjective and personal power remain unaddressed" (Cornwall 2003:1326). Power is a central aspect and participation must always be seen in light of power relations (Rifkin 1986:243). On intra-community level, Adam and Oshima (2014:25) highlight that marginalized groups like youths have been historically excluded from decision-making power and they caution to carefully consider the possible impacts of participation on consolidated power dynamics. Community elites usually dominate participatory processes, not only because of established traditional roles, but also as "they tend to be better educated" and "have fewer opportunity costs on their time" (Mansuri & Rao 2003:42).

Concerning external institutions, Merzel and D'Afflitti (2003:566) assert that there are often conflicting interests in participatory projects, where power relations are negotiated on unequal terms as control over resources and issue selection usually rest with the external agency. This relates to the issue that communities in participatory projects tend to be mainly involved at the implementation stage of projects and much less so in the areas of needs assessment/ issue selection or project design (Merzel & D'Afflitti 2003:559 ff.). A survey in Zambia showed that only 22 percent of the respondents felt that the social funds of the 1990s, which were envisioned to include levels of community consultation and participation, addressed the key problems identified by the communities themselves (Binswanger-Mkhize et al. 2010:45). Against this background other authors highlighted that the instrumental approach to participation with a focus on results and effectiveness is much more widespread than the more transformative approach (Walsh et al. 2012:10; Harman 2009:300).

However, it has been pointed out that there is little empirical evidence supporting the claims of increased efficiency or effectiveness of participatory approaches (van Kempen 2014:201). Some even argue that participation decreases cost-effectiveness of projects and the rhetoric fuels hopes that cannot be met in practice (Lamb et al. 2005:185; Walsh et al. 2012:2). In opposition to this, Rudqvist and Woodford-Berger (1996:16) contend that participatory projects tend to have higher

costs at the beginning, but that these investments pay off in the long-run as sustainability and efficiency increase.

Mansuri and Rao (2003) reviewed studies on participatory projects by the World Bank, finding very mixed and context-specific results. While overall a larger number of studies found a positive impact of participation on project effectiveness, the authors criticize that they often fail to establish a causal link between participatory elements and improved project outcomes (Mansuri & Rao 2003:41). Calling for a cautious assessment of the determinants for successful programs, the authors highlight that the success of participatory approaches is dependent on the degree of community organization – it's capacity and existing structures (Mansuri & Rao 2003:22).

Furthermore, the instrumental approach, where communities are involved as a means of increasing legitimacy, efficiency or, in fact, control, as "[i]ncorporation, rather than exclusion, is often the best means of control" (White 1996:7), has been condemned as superficial and undermining the transformative potential of participatory approaches (WHO 1991:1,6; Cornwall 2003:1326; White 1996:7).

However, one needs to acknowledge a dilemma that comes with the transformative approach to participation, which values local knowledge and the local "way of doing things" without imposing an outsider's agenda (Mohan & Stokke 2000:252). Encouraging a change of the status-quo in intra-community power relations, as usually advocated by neo-Marxist or feminist scholars, also runs the risk of being perceived as imposing a "Western agenda" of empowerment and it actually has led in practice to harm: "Women had been beaten as a direct result of spending their time in PRA meetings rather than on domestic work. The divorce rate was up as a consequence" (Cornwall 2003:1334, see also Rifkin 1986:244). This needs to be considered carefully within participatory projects.

# 2.3. Empirical findings on participation and health

In terms of health and HIV/AIDS, Merzel and D'Afflitti (2003:557) in their review of 24 participatory health programs found that these had only a relatively small impact on health promotion and disease prevention (see also Rifkin 1986:242), with the exception of HIV/AIDS programs. Community-level approaches to increase people's awareness of HIV and its consequences seem to have been quite effective (Breslin

& Sawyer 1999:474). Several studies attributed this to a deep understanding of the local context and norms, where culturally sensitive approaches are used to address the needs of the community and to effectively reach vulnerable groups (Walsh et al. 2012:2; Rodriguez-García et al. 2011:8,13; Harman 2009:300). Especially in rural areas, reaching communities and vulnerable groups is often beyond the ability of governments and international agencies (Rodriguez-García et al. 2011:10).

Indeed, Janz et al. (1996:90) found that community participation at all project stages increases the credibility of HIV/AIDS-related health messages contributing to positive behavior-change. Furthermore, Riehman et al. (2013:67, 75) report that community-based HIV prevention efforts in Kenya were related to an increased use of condoms, better knowledge of HIV transmission and prevention methods, higher uptake of HIV counseling and testing, better treatment compliance, a reduction of HIV/AIDS-related stigma and of service delivery costs.

Local volunteerism and peer education have been identified as major drivers behind the success of community participation and community-based HIV prevention efforts. There seems to be a higher level of acceptance of local peer educators, "whose life circumstances and characteristics closely [resemble] those of the target population", where aspects like trust and credibility play a major role and with positive implications for the project effectiveness (Janz et al. 1996:93; see also Walsh et al. 2012:8).

#### 3. Context and the case

This chapter provides firstly, an overview about the country context with regards to developmental indicators as well as specifically concerning the HIV/AIDS epidemic. Furthermore, it outlines some key policy documents addressing community participation in the fight against HIV/AIDS. Secondly, this chapter locates the Mboole community within the context of the Southern Province of Zambia and the local chiefdom and provides background information about MRDI, its history and successes.

#### 3.1. Contextualization

In 2015, Zambia had an estimated total population of 16.21 million, of which around 60% were living in rural areas and 46% were below the age of 15 (World Bank

2017). Poverty levels in Zambia remain high, with the last official estimate counting ca. 65% of the total population living in extreme poverty<sup>4</sup> - the vast majority of which lives in rural areas (ibid.). Zambia's Human Development Index is at 0.59 in 2014, ranking 139<sup>th</sup> of 188 countries (UNDP 2016:32).

Concerning HIV/AIDS, Zambia had approximately 60,000 new infections in 2015, of which around 43% occurred among young people below the age of 24. Furthermore, UNAIDS (2017) estimates that there are around 380,000 orphans and vulnerable children (OVC)<sup>5</sup> in the country.

In terms of financing, Zambia's HIV response is strongly dependent on external donors. In 2012, 92% of the total ZMW 1.46 billion<sup>6</sup> spent on HIV prevention, care and treatment came from external sources (NAC 2014a:8). Considering the budgetary allocations to community engagement, Zambia has spent 1.5% of its HIV prevention budget on community mobilization, 0.1% of its overall OVC budget on OVC community support and 2.4% of the HIV services were provided by civil society organizations (CSOs)<sup>7</sup> (NAC 2014a:40, 43, 51).

The Zambian government lacks both the capacity as well as the financial resources to address the HIV/AIDS epidemic centrally. Therefore, one of the core priorities is "to strengthen the capacity for a well coordinated and sustainably managed HIV and AIDS multi-sectoral response" that builds on a decentralization process (NAC 2010:xi; xiv). As part of this process, the role of local communities and community-based organizations (CBOs) has become more prominent in the fight against HIV/AIDS.

The "Revised National AIDS Strategic Framework 2014-2016" (R-NASF) (NAC 2014b) stresses "Community Systems Strengthening" (CSS) as one of the major enabling factors for a successful HIV/AIDS response. The R-NASF highlights the important role of communities to raise awareness about HIV/AIDS amongst its members and to provide services and support to those living with or affected by HIV

<sup>&</sup>lt;sup>4</sup> Less than USD 1.90 per day.

<sup>&</sup>lt;sup>5</sup> See appendix A for definition.

<sup>&</sup>lt;sup>6</sup> USD 283 million.

<sup>&</sup>lt;sup>7</sup> Including NGOs, faith-based organizations (FBOs) and CBOs.

(NAC 2014b:49). Specifically, and in strong relevance for this study, NAC pledges that:

"[a] broad-range of community actors will be engaged to participate in HIV responses as equal partners. CSS recognises the role of key populations and communities and of community-based organisations in the design, delivery, monitoring and evaluation of services and activities" (NAC 2014b:50).

Therefore, the Zambian government not only commits to a participatory approach in its response to the HIV epidemic engaging the communities as "equal partners", but also recognizes the importance of involving the community and CBOs at different stages of interventions, which relates well to the analytical framework suggested in this study.

# 3.2. Mboole community and the Mboole Rural Development Initiative

Mboole is a rural community situated in the district of Choma, Southern Province of Zambia. It consists of around 20 villages and is part of the Cooma Chieftainship. Figure 5 depicts the governance structures in Cooma Chiefdom and where the Mboole community is located therein.

His Royal Highness Chief Cooma Cooma Royal Cooma Chiefdom Cooma Chiefdom Family Royal Council **Development Trust** Government of the Republic of Zambia and other Zones developmental Level of Mboole (Headed by Senior stakeholders community Headmen) 20 Villages are part Village of Mboole (Headed by Village Headmen) community

Figure 5: Governance structures in Cooma Chiefdom.

Source: Own visualization based on and adapted from Cooma Royal Establishment (2013:13).

Mboole is affected by high poverty levels and livelihoods are dependent on subsistence farming. As of early 2017, the community had one government school up to grade nine and two community schools up to grade seven (all primary schools). Both, the nearest secondary school and the nearest health clinic are around ten kilometers away in Sikalongo. According to one of the village headmen, there are on average around 200 children enrolled in primary school each year, of which only one to three manage to ever reach tertiary education. Most pupils drop out of school early or finish their education after primary school.

Youths started MRDI in 2002 and introduced it to the overall community one year later. MRDI was officially registered in 2009. Originally, as they had no money, the youths set out to create an income opportunity for themselves by tailoring clothes and selling them within the community. It was a business idea. However, OVC households, which were affected by HIV/AIDS and poverty, started approaching the group to ask for cheaper or free school uniforms, as they couldn't afford them.

Against this backdrop, MRDI set out to support those OVC and youths as a community initiative.

MRDI started without external interference to address the needs of the community within its own capacities and resources. Although since then, MRDI has received donor support through project-based funds or capacity-building, the initiative managed to remain operational independently from these additional resources. Despite being internationally recognized as a SADC best practice initiative (SADC 2008) and winning the Red Ribbon Award at the 2006 Toronto AIDS Conference for community action, MRDI struggles to mobilize continues donor support. After relying on local resources for a longer period of time, MRDI recently managed to enter into projects with the Food and Agriculture Organization (FAO) and the "Deutsche Gesellschaft für Internationale Zusammenarbeit" (GIZ)<sup>8</sup>, respectively.

Against this background, district officials highlighted that community initiatives usually have challenges to sustain themselves over long periods of time, because they lack the resources and connections to donors that CSOs in urban areas usually have. MRDI's work does not rely on huge financial assets, which enables them to continue their work even with low funds or without additional donor support. To cover their basic running-costs, the organization manages to mobilize a small amount of resources within the community and by engaging in small incomegenerating activities, like tailoring or carpentry. This does not only provide funds to MRDI, but a portion of the revenue goes to the youths themselves, who have been trained in tailoring, etc. – this way the organization provides an income for young people affected by poverty.

MRDI is based on volunteerism of local community members. The organization has around 65 volunteers, who are engaged in different activities and capacities, e.g. as peer educators, caregivers, in the management or board.

The organization's mission statement is:

"The Mboole Rural Development Initiative is committed to addressing the spread and impact of HIV and AIDS through youth empowerment and education of the orphans and vulnerable children" (internal MRDI project document).

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<sup>&</sup>lt;sup>8</sup> German Development Cooperation.

Consequently, MRDI caregivers support an estimated 287 OVC with counseling as well as by providing uniforms, school material and subsidizing school fees whenever funds are available. Furthermore, the organization reaches out to the youths and the general community to raise awareness and sensitize about HIV/AIDS, its risks, ways of transmissions and prevention – mainly through peer education.

# 4. Design, methodology and methods

This chapter sets off by clarifying the philosophical worldview underlying this study. It continues by outlining the research strategy and design, the applied methods and sampling strategies as well as by describing the process of data collection and how the data have been handled and analyzed. Finally, this chapter discusses aspects of reflexivity and ethical considerations.

#### 4.1. Ontological and epistemological position

In this study, the author takes an ontological and epistemological position based on critical realism. This means acknowledging that there is a "real world" – however, covered in "[...] many layers of truth, and [...] filled with complexity, [...]" (Moses & Knutsen 2012:13). For example, HIV is a real virus (natural world) that has an empirically identified impact on human health (AIDS). However, this cannot be separated from the social context, in which a myriad of experiences and narratives provide different meanings to social phenomena around HIV/AIDS, including stigma, discrimination or taboos – all of which have real impacts on health outcomes. Also, participation is an approach that has been applied in various contexts and with different understandings of what it entails. These differences, however, have a real impact on project outcomes or the health of the community in question.

For critical realists, contexts matter and they are thus wary of "universal laws" (Bryman 2012:29; Moses & Knutsen 2012:13). However, they are concerned with structures and mechanisms (which can be and very often are socially determined) and the conditions under which they unfold (Bryman 2012:29). While social constructivism provides convincing arguments around the interpretive nature of research as concepts like "participation", "power" or "community" entail "subjective

meanings [that] are negotiated socially and historically" (Creswell 2009:8), critical realists do not object this notion – rather, they provide a useful approach that aligns socially situated meaning and interpretations with their real impact on humans. Something that seems particularly relevant in the context of health.

#### 4.2. Research strategy and design

This thesis applies a mixed methods research strategy<sup>9</sup> – however, with a strong priority given to qualitative methods (Bryman 2012:631-632). Qualitative methods focus on contextual information and highlight the point of view of the research participants in order to understand the complexities of the social world in a holistic way. Therefore, they make use of "thick descriptions" to contextualize social behavior and the varying meanings that individuals attribute towards social phenomena (Bryman 2012:175-176; Mayoux 2006:116; Brockington & Sullivan 2003:72).

Quantitative methods, on the other hand, will be primarily used to triangulate some of the findings in this study (Bryman 2012:633 ff.). This is particularly relevant for the third research question that considers the role of community participation for aspects like HIV/AIDS-related knowledge, attitudes and behavior.

A mixed methods research strategy serves the purpose of this study, as it allows to analyze the dynamics of "community participation" in the specific context set by the case and to include a variety of perspectives from different participants on participation and power relations as well as how they influence health and project outcomes. This strategy also allows juxtaposing the qualitative and quantitative data to support or challenge the respective findings.

The research design is based on a (single-)case study design, which facilitates an in-depth analysis stressing the complexity of a case in a particular context (Bryman 2012: 66 ff.).

case study designs.

<sup>&</sup>lt;sup>9</sup> The terms "research strategy" and "research design" are sometimes used incoherently. This study follows the terminology suggested by Bryman (2012), who uses the term "research strategy" in order to differentiate between quantitative, qualitative and mixed methods research strategies. "Research design", on the other hand, distinguishes experimental, cross- sectional, longitudinal, comparative and

Furthermore, following the discussions in the theoretical chapter, this study intends to "open the box 'community'" in order to explore the intra-community power relations that unfold in participatory processes. Therefore, the approach is an "embedded" case study design (Yin 2003:43-45).

As discussed previously, MRDI was initiated within Mboole and is run by community volunteers. This context provides a "unique case" in which this study wants to explore the concept of community participation and how it contributes to positive health behaviors, knowledge and attitudes in the area of HIV/AIDS (Yin 2003:41 f.). However, as Bryman (2012:71) argues, individual cases can combine elements of various types of cases<sup>10</sup>. In this sense, the dynamics that unfold in participatory processes on community level also constitute an "exemplifying case" in this study, which "allow[s] the researcher to examine key social processes" (Bryman 2012:70).

#### 4.3. Methods and sampling

The data were collected by utilizing both qualitative and quantitative methods, including semi-structured interviews, focus group discussions (FGDs) and a survey.

The semi-structured interviews ensure a level of flexibility and "openness", which is required to create an environment, where the interviewee can express his or her views as well as to enable the interviewer to follow up on new themes raised throughout the interview. However, they provide enough structure to ensure a level of comparability and that the aspects relevant for this study are raised throughout all interviews (Bryman 2012:403, 470-472).

FGDs, on the other hand, are particularly useful for extracting a "joint construction" of meaning". Interviewees are confronted with other perspectives and can challenge each other's opinions (Bryman 2012:502-503). In this study, FGDs have been very valuable to discuss, for example, aspects of gender and participation or to observe power relations within group discussions.

However, quantitative data are also relevant to contextualize and triangulate some of the findings. This includes primary data from a survey, which has been

<sup>&</sup>lt;sup>10</sup> Based on Yin (2003), Bryman (2012:70-71) differentiates between five types of cases: "critical case", "extreme/unique case", "representative/typical/exemplifying case", "revelatory case" and "longitudinal case".

conducted on-site, as well as data from secondary sources like the Zambia Demographic and Health Survey 2013-14 (ZDHS) (Central Statistical Office 2015) or statistical bulletins. Furthermore, information from other secondary sources, like reports from the Zambian government or international institutions, project documentation as well as journal articles or relevant studies, were also used where suitable.

Concerning the sampling strategy, several approaches were applied, depending on the purpose and who or what needed to be sampled.

#### (1) Sampling of context:

As discussed previously, the circumstances and processes that led to the establishment of MRDI as well as the way it has been run for over 14 years, provide a "unique case" for studying community participation in the context of the HIV/AIDS epidemic in Zambia (Yin 2003:41 f.). Mboole community and MRDI were thus purposively sampled guided by the research questions ("sampling of context" (Bryman 2012:417)).

#### (2) Selection of donor-projects with MRDI:

To answer the first research question, MRDI's two currently running projects with FAO and GIZ were selected. Furthermore, a finalized project by USAID was chosen, which involved the whole chiefdom including Mboole. All three projects included aspects of community participation or involvement of community-based initiatives, either throughout the whole project or in specific project components. While they were against this background purposefully sampled, the limited number of available donors, who cooperate(d) with MRDI make it also a case of convenience sampling.

#### (3) Sampling of respondents for qualitative data:

With regards to the "sampling of participants" for the collection of qualitative data, a mixture of criterion, opportunistic and snowball sampling approaches has been applied (Bryman 2012:417-419). In reality, those sampling strategies are difficult to neatly separate. For example, criteria like demographic characteristics or roles and responsibilities held by respondents (see table 1) guided the selection. Furthermore, the director of MRDI was a central contact point. While being a key

informant himself, he helped identifying other research participants, who then facilitated the contact to further interviewees following a snowball-sampling technique (Bryman 2012:424). But also "opportunistic encounters", for example with regional government officials and experts, were utilized to gain further perspectives and insights to the questions posed by this study.

#### (4) Sampling of survey respondents:

In terms of the sampling strategy applied for the survey, some considerations had to be made. Because of logistical and financial constrains, it was impossible to get a representative random sample for the whole population of Mboole. So the decision was made to focus on one of the primary target groups of MRDI – youth in the age group 15-24<sup>11</sup>. Again, however, there are difficulties in getting a representative random sample for this whole age group: there are in- and out-of-school youths, there are three different primary schools in Mboole and the secondary schools are altogether outside of the community. So it was decided to take a complete sample of the respective age group in the largest of the three primary schools in Mboole, translating into all students from classes 8-9 in the age 15-24. Furthermore, all interviewees in the respective age group from the qualitative research were also included. It can be assumed that choosing a complete sample of one of the three primary schools, gives a good representation of the in-school youths in the respective age group. However, it does not capture the out-of-school youth and leads to a bias towards the age group 15-19, as most of the 20-24 youths were either attending the secondary schools located outside of Mboole or are out of school. These sampling choices, which had to be made, unquestionably bias the survey sample. The findings from the survey can therefore only be considered as indicative.

# 4.4. Collection and handling of data

Preparations for data collection started at the end of November 2016, including a first site-visit to Mboole from the 28th until the 30th of November. This visit was intended to explain the research aims to key informants at MRDI, to meet the local chief for obtaining official permission for conducting research with Mboole as well as

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<sup>&</sup>lt;sup>11</sup> This age cohort is also in accordance with the definition of youth by the United Nations (United Nations 2010:10).

to discuss relevant logistics. Primary data collection was conducted from the 12<sup>th</sup> of January until the 3<sup>rd</sup> of February 2017, which included a field visit to Mboole of around two weeks as well as individual meetings with development experts both in the provincial capital Choma and the national capital Lusaka.

In order to collect the required quantitative data, the author prepared a survey form with a total of 38 questions covering demographic information as well as topics around HIV/AIDS and sexual and reproductive health and rights (SRHR)<sup>12</sup>. Table 1 presents some basic information about the survey and its participants. It shows that the data have a balanced representation of males and females, but are skewed towards the lower end of the total age-range, with implications for the later analysis of the survey.

Table 1: Basic survey information.

Basic survey info	Basic survey information		
Total number of	Total number of participants:		
Valid questionna	Valid questionnaires:		
Number of partic	Number of participants in the age group 15-19:		
Number of partic	100		
	Mode:	16	
Age	Median:	16	
	Mean:	17	
Number of fema	51		
Number of male	49		

Source: Primary data collected for this study.

For the collection of qualitative data, the author has carried out 27 semi-structured interviews (see table 2)<sup>13</sup>. The interviews ranged in length from about 15 minutes to as long as 90 minutes. Furthermore, two FGDs were conducted with five peer educators and six beneficiaries, lasting 60 and 120 minutes, respectively. Both, the interviews and FGDs, took place in separate rooms to create an enabling

<sup>13</sup> See appendix C for a sample interview guide.

<sup>&</sup>lt;sup>12</sup> See appendix B for the survey questionnaire.

environment that ensures confidentiality and reduces external distractions or interferences. Interviewees were given the choice to answer either in English or their mother tongue Tonga. Although the majority used English, a local interpreter was available for those who chose Tonga. Two problems arose when working together with a local interpreter:

- (1) The potential impact of the interpreter being male and from within the community on the answers of participants (Hammett et al. 2014:52). Working with a local interpreter has its pros and cons (Leslie & Storey 2003:132; Bujra 2006) knowing the interpreter instead of talking to yet another stranger can be perceived as both, a barrier and a benefit. Furthermore, employing someone from within the community was thought to be a way of "giving back" (Creswell 2009:90). However, having two males (interpreter and author) sitting in a room with a female participant for an interview would most likely affect the answers given.
- (2) Working with an interpreter adds another layer to the interpretation process in research. The "double hermeneutics", where the meaning an interviewee attributes to a certain statement is re-interpreted by the researcher, who is influenced by his or her own background and experiences, are further complicated through the interpretation process (Ginev 1998; Leslie & Storey 2003:133; Bujra 2006).

While the final impact of gender (both with regards to the researcher as well as the interpreter) on the data can hardly be assessed, it is important to be aware of the dynamics at play. Furthermore, gender played a major role for this study on additional levels. Not only was it difficult for a number of reasons to identify female participants<sup>14</sup>, but also those who did join, were usually more shy than men, struggled more in terms of language or in FGDs female participants would rarely challenge the opinions of their male counterparts<sup>15</sup> (Scheyvens & Leslie 2000:120, Chambers 2008:36).

<sup>&</sup>lt;sup>14</sup> This will be discussed in more depth in section 5.2 of this study, as similar issues were relevant for both, participation in the research project and overall participation processes in the community in terms of girls and women.

<sup>&</sup>lt;sup>15</sup> In the case of the FGD with peer educators, a female-only FGD has been considered. However, this was simply not feasible as only one female peer educator was available.

Table 2: Overview of interviews and FGDs.

Туре	Role	Number		
Semi-structured	MRDI management and staff	7**		
Interviews*	Beneficiaries	8		
	MRDI peer educators	5		
	Experts (provincial officials and donor- project representatives)	5		
	Others (non-assignable to above categories)	2		
Total		27		
Focus Group Discussions	MRDI peer educators	1		
	Beneficiaries	1		
Total		2		
* A detailed list of interviews can be found in appendix D.  ** Includes one follow-up interview with the same person				

A number of project documents from the three donor-funded projects that were selected for this study were also reviewed. Again, the information gathered in this process were used to triangulate or contextualize the findings from the interviews

The data collected through interviews and FGDs were audiotaped <sup>16</sup> and transcribed <sup>17</sup>. The transcripts were coded using *NVivo*® and analyzed through a thematic approach (Bryman 2012:578-581; Creswell 2009:184).

Lastly, some quality criteria were considered for this thesis in line with academic practice to ensure a rigorous research process. In order to safeguard "reliability" (or "dependability"), all raw material including audio-records, transcripts, survey forms, etc. are stored safely. Additionally, an auditing approach was applied with critical

and FGDs.

<sup>17</sup> Transcripts are kept by the author and are not attached to safeguard anonymity of participants and confidentiality. However, upon request, anonymized transcripts can be shared with individuals who explain a justified interest in the material (e.g. for transparency purposes) and formally agree to safeguard the information and rights of the research participants.

<sup>&</sup>lt;sup>16</sup> Audio-records were only taken upon approval of each participant.

peer reviews at several stages throughout the research process (Bryman 2012:390,392; Creswell 2009:190 f.). In terms of "internal validity" (or "credibility"), the findings through interviews and FGDs were triangulated with the primary data collected in the survey as well as information from other sources. Furthermore, to reduce the aforementioned challenges with translating responses in Tonga through an interpreter, a former Zambian student from Lund University verified the translations in the process of transcribing those interviews that were in Tonga.

The quality criterion of "external validity" ("generalizability" or "transferability") is problematic, as the findings are very context-specific and cannot be generalized to a larger population (Bryman 2012:390-392; Creswell 2009:191-193). However, Yin (2003:37) suggests that instead of "statistical generalizations", case studies allow for "analytical generalizations", where "the investigator is striving to generalize a particular set of results to some broader theory". Consequently, this study aims to contribute analytically to the broader discussion around community participation, in this case in the particular context of HIV/AIDS and SRHR, both in terms of theoretical perspectives as well as the practical sphere of development cooperation.

#### 4.5. Ethics and reflexivity

This study abides by the ethical guidelines set by Lund University<sup>18</sup> and the LUMID program. The "LUMID Ethical Guidelines for Fieldwork" (2013) identify four main requirements for ethical research: (1) the information requirement, (2) consent requirement, (3) confidentiality requirement and (4) the use requirement.

In terms of the "information requirement", the research participants and the Mboole community overall were duly informed about the study. This included a courtesy visit to the local chief to obtain official permission for the research following the traditional norms in Cooma Chiefdom. From the outset, community leaders were informed about the research, its aim, the author's relationships with any third parties, as well as the usage of the findings and final dissemination (Scheyvens et al. 2003:174 f.). Before commencing any research activity, it was highlighted that

The ethical guidelines of Lund University are available under: http://www.kom.lu.se/fileadmin/user\_upload/kom/Filer/PDF/MKV/Ethical\_issues\_atLundUniversity\_Not es\_for\_guidance\_01.pdf

participation is voluntary and that participants can choose to withdraw at any time. Furthermore, they were informed about the study both orally as well as by providing a hand-out detailing the study aim as well as answering a number of questions, e.g. on confidentiality or usage of material<sup>19</sup>. In cases where participants were not in good command of English, an interpreter went through the hand-out step by step explaining the meaning in Tonga. Opportunities for questions were provided before and after each interview.

Concerning the "consent requirement", after informing all participants in detail about the study and their rights, they signed an informed consent form (Creswell 2009:89). In those cases where the participants were illiterate in English, the interpreter also signed in confirmation of a duly exercised information and consent process. Additionally, before audiotaping conversations or taking pictures, the participants were asked for permission. With regards to the "confidentiality requirement", research material has been anonymized and stored safely (Bryman 2012:137).

Lastly, in light of the "use requirement", the collected information and data will not be used for any other purpose but the one explained to the participants. This also relates to the issue of "reciprocity", as the study should not only benefit the researcher, but also the participants (Scheyvens et al. 2003:155-158). Therefore, the author has pro-actively discussed with community representatives how this study could be useful for them and it was agreed that the final thesis would be provided to MRDI and other participants. Furthermore, since the research took valuable time of the participants just right during the rainy/farming season, impact needed to be minimized and compensated for. Local key informants advised to not provide monetary compensation, but instead to offer snacks and drinks during the interviews/FGDs. Furthermore, an informal "get-together" was organized with the community at the end of the research as a sign of appreciation where anyone was free to join whether they participated in the research or not. Lastly, all interviews and FGDs were scheduled according to participants' availability.

Throughout the field research, the impact of the author's own background on the interaction with interviewees and on the research process needed to be considered

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<sup>&</sup>lt;sup>19</sup> See appendix E for the informed consent form.

(Scheyvens et al. 2003:150-151). Being a white, European, middle-class male certainly influenced how participants perceived the researcher. Although dressing informally, as aspects of personal appearance could increase awareness of status and power imbalances, informal conversations with community participants revealed misperceptions, like about the author's age, which could have affected the research, since generational hierarchies matter in traditional communities like Mboole (ibid.).

# 5. Analysis and discussion

This chapter presents and discusses the findings from analyzing the collected qualitative and quantitative primary data as well as further secondary sources in light of the three research questions posed by this study.

## 5.1. Approaches to community participation and its implications

In terms of projects with external stakeholders, the approaches to community participation differ considerably. Table 3 presents a summary of the three donor-funded projects with MRDI using the analytical framework developed in the theoretical chapter of this study. While some background information about the three donor projects are provided in the table and the relevant subsections, the author abstains from providing detailed descriptions, as this is not a project evaluation. All of the three projects are larger donor programs involving a wide range of stakeholders at micro-, meso- and macro-levels. However, since this study focuses on the dynamics of community participation, only those components of the respective donor projects were considered, which involved MRDI and the Mboole community.

Table 3: Assessment of participation in three donor projects cooperating with MRDI.

Droject stage	Dimension of	GIZ	FAO	USAID
Project stage	participation	(2015-2018)	(2016-2017)	(2010-2015)
Needs	Who?	N/A	Driven by MRDI, community	Representatives of various sub-
assessment			representatives	groups
	How?	·		Delegated power
Design &	Who?	N/A	Driven by MRDI, community representatives	Representatives of various sub- groups
1 laming	How?		Partnership	Delegated power
Implementation	Who?	MRDI staff, peer educators	Driven by MRDI, community volunteers	N/A
	How?	Consultation	Partnership	N/A
M&E	Who?	MRDI staff	Unclear	N/A
IVIQL	How?	Consultation	Unclear	N/A

## (a) GIZ:

This project did not do any direct needs assessment in the community and consequently did also not involve the community when identifying the focal concern as well as designing the project activities. This was done solely by the donor agency based on national priorities. However, segments of the overall project are to be implemented by local partner organizations — one of them being MRDI. Considering the "who"-dimension of participation, the project involves primarily the management of MRDI for coordination as well as local peer educators for implementation of the planned activities. While a representative of MRDI was invited to national steering meetings, there is no decision-making power of MRDI at that level whatsoever. On the community level, on the other hand, MRDI was granted decision-making power with regards to the selection of the peer educators. When talking to a project representative, it became clear that while there is an appreciation of community participation, this was primarily in an instrumental understanding of the concept. This is in terms of "localizing" messages to ensure acceptance, or in terms of cost-effectiveness, as the community contributes

resources. There were also lessons-learned from previous project-phases, where the peer educators were selected by the project, which caused challenges. Now, when the community is in charge, the situation changes: "If there is something wrong, definitely it falls onto that community or that CBO in the selection. [...] And they will find a solution on how to go about that" (donor-project representative 1, 13.01.2017). In terms of M&E, there is no structured participation of MRDI envisioned in the project conceptualization. M&E is primarily done by donor staff. Nonetheless, the MRDI management was consulted to provide information relevant for the monitoring of the project. However, as project implementation has not fully commenced at the time of data collection, a final assessment of participation in M&E was not yet possible.

Overall, the project is strongly pre-defined, where issue-selection, design, implementation activities and M&E systems are given by the donor agency. Furthermore, there is little structured capacity-building or systematic local integration accompanying the implementation of this project casting doubt on the long-term sustainability. MRDI is primarily involved in the implementation of this project and has limited to no substantial decision-making power, which consequently could be categorized as showing a primarily consultative approach to participation.

### (b) FAO:

This project used an open call for proposals for small community grants, which set the thematic frame, but the community was allowed to therein identify their own core problem as well as to design and suggest activities to address it. While this project is not directly HIV/AIDS-related, it is still worth mentioning here, firstly, because of its participatory approach and secondly, because MRDI is using it to engage their youth and OVC and to create income sources for them, linking it back to HIV/AIDS and AIDS-induced poverty. Indeed, this is an interesting fact in itself, as MRDI managed to connect a different thematic area with its core concern to address the HIV/AIDS epidemic in the community.

When considering the different project stages, the flexible structure opened the project up for ideas coming from the community itself. While providing accompanying trainings and capacity-building measures, the process was very

community-driven resulting in a high level of ownership. This was highlighted during the interviews held with community members, who specifically referred to their participation in this particular project. A representative from the MRDI management commended the project for its openness towards community ideas. Looking in detail at who has participated in the process, the needs assessment and project design were steered by MRDI and inputs from the community gained in meetings involving both women and youth. Some of the youth interviewed reported that they have contributed ideas for specific activities, which were included in the proposal for the project. This assessment is the same for the implementation of the project, where a considerable number of community volunteers were involved. The feedback from the community in terms of participation is in line with the project's participatory approach and its objective to encourage the inclusion of youth and women as one of their priority areas<sup>20</sup>.

Regarding the "how?"-dimension, the approach can be seen as one of "*partnership*" between MRDI and the donor. While the overall process of needs assessment, design and implementation of project activities was handed over to the community, the donor retained the final decision-making power "in line with the program objectives" (donor-project representative 2, 27.01.2017)<sup>21</sup>.

#### (c) USAID:

In this project, the whole chiefdom was engaged in a strategic planning exercise, where the inherent idea was that central problems and needs are identified locally (needs assessment) and suitable solutions developed by the community members of the chiefdom (design and planning). The project was funded to conduct an intervention addressing the HIV/AIDS epidemic in Zambia and while the strategic planning exercise covered around twelve different socioeconomic sectors, "HIV/AIDS [was] mainstreamed in every economic and social sector in the community [...]" (donor-project representative 3, 03.02.2017). Both the assessment and the strategic planning were led by the traditional leadership, but involved a wide

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<sup>&</sup>lt;sup>20</sup> This objective is also reflected in project indicators on inclusion of diverse community groups (FAO 2017:77).

<sup>&</sup>lt;sup>21</sup> With regards to M&E, no specific information were obtained about whether and to what extent MRDI is engaging in M&E of its project funded by FAO. However, the M&E of this project would be independent from the M&E of the overall FAO program, in which MRDI is not involved.

range of community representatives (who-dimension) including women and youth (Cooma Royal Establishment 2013:3-4). This process was guided by the donor, which provided localized tools as well as participatory methodologies and ensured that various groups within the chiefdom were involved. However, as the donor took the role of a facilitator and handed over a considerable amount of agenda-setting and decision-making power to the chiefdom, it can be categorized at the level of "delegated power" (how-dimension). With regards to the other two project stages of implementation and M&E, the objective of this particular project component was to develop a strategic plan, which is owned by the chiefdom – the implementation and monitoring of the plan is outside the project scope and intended to be carried out by the chiefdom and its communities, where the final document is "defining the roadmap for achieving these [the chiefdom's] aspirations, and outlining a monitoring process to periodically assess progress [...]" (Cooma Royal Establishment 2013:4).

Both of the later projects came with an understanding that structures and capacities are already in place at the community level. The donors assumed a role as facilitators and provided a number of capacity-building and training measures to accompany the process. This relates to the findings of Mansuri and Rao (2003:22) presented in the literature review, who assert that successful community participation is dependent on existing structures and capacities within the community. Interestingly, all projects, regardless of the specific approach to participation, involved the community in isolated sub-projects or components of a larger overall program, which is nonetheless pre-determined by the donor agencies. It is in these specific components of the program, which target the community-level, where participatory approaches are being considered. But the approaches differ. The two projects that involved a wider group of community representatives and handing over some level of decision-making power to them, had designed these components of their overall program in a flexible way that allowed community ideas and preferences to influence the aim and outcome of these components as long as they are in line with the overall program goals.

This reflects the realities of development cooperation, where it seems difficult to integrate community participation right from the program's inception – especially with large programs targeting different levels. This speaks to Cornwell's (2003:1326) assertion discussed in section 2.2 that the practical implementation of

participatory approaches remains within the contemporary narrative of development cooperation without addressing structural issues of power.

Relating back to the findings presented in the literature review, which indicated that communities seem to be much less involved at the project stages of needs assessment and project design, the interviews revealed similar assessments by the community members<sup>22</sup>, but also highlighted that there are considerable differences between individual projects – an assessment, which is also in line with the findings discussed above:

"There are different organizations. Some organizations, they already have an idea, written up activities. [...] And some they are open. They say that they have got this money and want someone, who can do maybe HIV/AIDS activities. But it depends on the community, what ways or strategies they are going to use to address that problem" (MRDI management 3, 25.01.2017).

Another community member raised an issue in terms of ownership and sustainability. The participant highlighted that some donors would come with their pre-defined projects, which do not respond to the needs considered important by the community at that time – however, the community would not refuse this money or project. One of the local experts expressed similar concerns and sees the danger that consequently "the community tries to justify a problem that didn't really exist and then they sideline the problem that is the main problem, because they just want to access the money" (SRHR professional, 21.01.2017).

The observation that some donors come with pre-defined projects is an issue that was raised by all the experts and government officials interviewed. Everyone highlighted that there is still a number of projects (not just referring to Mboole, but to Zambia in general), which do not involve the communities at the early project stages of needs assessment, design and planning and often do not address the topics deemed central by the community. The interviewees reported that those projects are lacking ownership and tend to fail or do not manage to sustain themselves after the project phases out. While some interviewees see improvements in community participation in donor-funded projects, others identified a level of what one termed "donor fatigue". This basically refers to a realization that:

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<sup>&</sup>lt;sup>22</sup> Referring to all donor projects they have witnessed, not just the ones presented here.

"[...] the approaches some donors took may not bear a lot of fruit right now, and unfortunately they could have gotten tired right now. But the problem is, perhaps our starting was not very strong" and "[...] if we had started by making people become more responsible to their own communities for instance, taking ownership, and so forth, I think we would have actually gone far by now" (donor-project representative 3, 03.02.2017).

The reoccurring perceptions of all expert interviewees are in line with some of the findings from other studies presented in the literature review and therefore suggest patterns that might go beyond the case of this study calling for further empirical investigations on a larger scale.

## 5.2. Power relations, social norms and participation

As discussed in the theoretical chapter of this study, it is important to not treat the community as a homogenous group. To understand the dynamics of community participation, it is therefore relevant to consider the power relations and social norms within the community.

Before analyzing the power dynamics in participatory processes on an intracommunity level, it is interesting to consider what community members understand under the word "participation". Commonly, this has been defined as "taking part" in something where one is gaining from but also contributing towards. With regards to the aspect of gaining something from participation, this was often mentioned in the context of gaining knowledge. Another participant raised the aspect of "willingness" to participate – meaning that the mere inclusion is not enough and can be very passive. Therefore, one also needs to be willing to actively participate for it to work. When probing further on the rationale for participation, participants highlighted that MRDI could not succeed without involving the community. One was referring to a pluralism of ideas, making the project progress, and another one was in essence referring to the issue of accountability in terms of how donor-money is put to use and who in the community is benefitting from it.

On an intra-community level, the scope of community involvement and who gets to participate vary considerably, where differences occur depending on the project stage as well as the specific approach taken by the donor. The widest group of people seems to be involved in the area of needs assessments – for example in the FAO project described above, where MRDI gets to self-organize the needs

assessment process inviting the input and ideas of a wider group of community members. The chosen modality for this is usually in the form of community meetings and while it is never the whole community participating in those meetings, they are described as open and various community groups are represented – including community leaders as well as key population groups like people living with HIV (PLHIV), women and youths. Several interviewees reported that when MRDI calls for meetings, people come in "large numbers". This was attributed by some interviewees to the community-based nature of MRDI – attendance is easy as meetings take place within the community locality (spatial dimension), they are scheduled at convenient times for community members and there is a level of ownership of and identification with MRDI, as the initiative is by the community and for the community resulting in strong commitment among the community members.

While in terms of numbers, participation in those meetings seems to be quite wide, it is essential to discuss how power dynamics as well as social norms influence the decision-making process. There are several aspects, which need to be considered.

Firstly, leadership and traditional hierarchies are very important. In Southern Province and specifically in the rural areas, the role of traditional leaders remains influential. Many interviewees see it as one of the main success factors for MRDI going through the traditional leadership system from the very beginning involving key figures in the chiefdom, including the chief himself as well as senior village headmen. Gaining and maintaining the support from the traditional leaders seems to have been vital for the sustainability of the organization. Especially, with regards to the goodwill of the local chief, who continues to exercise considerable influence. Several key informants have stressed the importance of having an open-minded chief, who advocates and pushes for change and development. It seems therefore inevitable in a rural community like Mboole to involve the traditional leaders.

However, this also has implications for the participation process:

- a) Calls for community meetings often happen through the traditional leaders, which might affect the scope of participation.
- b) The established role of traditional leaders makes their voices very influential.

This is in line with findings of Mansuri and Rao (2003:42) discussed in the literature review, who stress that participatory processes are usually dominated by

community elites. However, this is not to say that those points are necessarily negative. For example in terms of messages around HIV, it can go both ways. Many interviewees highlighted that traditional leaders have a strong influence on the community. If this is used to encourage behavior-change, it can have positive impacts on health outcomes. However, if community leaders promote traditional beliefs like witchcraft or traditional practices like sexual cleansing<sup>23</sup>, it can also become a serious problem. In Cooma Chiefdom the circumstances were very enabling with a chief that was described as comparatively progressive and supportive of HIV-related initiatives in the chiefdom.

Another point that needs to be mentioned under the topic of leadership is the role of the director of MRDI, who is at the same time village headman and secretary to Chief Cooma and therefore holding several influential positions simultaneously. Most of the expert interviewees see him as the driving force behind MRDI, who is relatively successful and creative in resource mobilization, well networked and who has personally grown with MRDI. This has made him a leadership figure, who is accepted by the community to lead and represent MRDI and Mboole at large. Again, while strong leadership was one of the key success factors for MRDI, some of the experts also see a need to share responsibilities with a larger group of people and to build confidence in them towards their abilities to represent and speak out for MRDI and Mboole. This process seems to be slowly under way – while the director is still primarily the one attending various stakeholder meetings at district, provincial and national levels, other members of MRDI start to step in.

What the discussion so far has shown is that structures in MRDI and in the community are – and traditionally so – quite hierarchical. Leaders, either appointed or elected, represent the organization and the community's interests. In the case of MRDI strong leadership has been a major determinant for the organization's achievements and their drive for community involvement has resulted in high levels of acceptance and ownership amongst the community. However, the interviewed

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<sup>&</sup>lt;sup>23</sup> A community member described this practice as follows: "After someone had died, for instance if my wife dies. Traditionally, they get me another woman so that I sleep with her without a condom" (MRDI staff 2, 17.01.2017). However, usually sexual cleansing refers to the practice of a male relative (e.g. brother) of a deceased husband to sleep with the widow without using a condom.

experts encourage MRDI to devolve power and responsibilities as to ensure long-term sustainability.

The second aspect that needs further discussion concerns the topic of gender. Donor representatives highlighted that Southern Province and particularly the rural areas are characterized by patriarchal structures with established gender roles, which inevitably have an impact on participatory processes. While the donor-projects discussed in this study as well as observations during the data collection show that females do participate in MRDI and the donor-projects, it is difficult to accurately assess the quality of involvement (e.g. how often do they speak and are their ideas considered?). A donor representative acknowledged that it is important to question who participated and represented the women of the community. As it was logistically impossible to involve everyone, the interviewee recognized that those who participated could have been "more confident by nature of the roles they have been playing in the community even before" (donor-project representative 3, 03.02.2017). This relates back to the discussion in the theory-section on voices and representation.

In terms of quantitative numbers, around half (30-35) of the approximately 65 volunteers at MRDI are women according to staff estimates. Many of them are involved in the area of caregiving, considerably less so in management or peer education, which matches with established gender roles. In terms of their qualitative contributions, it was observable during a meeting that it was mainly men discussing and women raised their voices much less so. This was also confirmed during the FGDs held for this study. There were not only fewer females, but they were also very shy to speak, often only saying something when directly addressed by the researcher and they rarely challenged male opinions.

When further probed on the reasons behind the difficulties in female participation, a complex network of causal relations emerged leading back to women's role within society. One example of these causal chains described by the participants revolves around the problem of early marriages and teenage pregnancies, resulting in early school dropout. These observations are well supported by macro-level data: in Southern Province of Zambia, 36.0% of women in the age group of 15-19 years old have already had a live birth or are pregnant with their first child – this is well above the national average of 28.5% (Central Statistical Office 2015:77). Also, females in

Southern Province in the grades 8 to 12 are almost four-times more likely than males to drop out of school (MoGE 2016:36). In terms of marriage the data show that in the age of 15-19, 16.5% of girls are already married compared to only 1% of men in the same age group. In the age group of 20-24, already 55.4% of women are married (compared to 21.9% of men) (Central Statistical Office 2015:55-56).

The data and the accounts from the interviewees indicate that girls often get married to older men. The reasons, which the participants stated for early marriage (with older men), are the need for financial support and pressure from the family in order to receive a family income through the tradition of "Lobola" <sup>24</sup>. The consequences of early marriage, teenage pregnancies and the resulting high dropout rates of females are lower educational attainments as well as, in fact, lower levels of knowledge (e.g. around HIV/AIDS). This, in turn, leads to less confidence and more shyness amongst women affecting their ability to actively participate: "It is because of fear. Because males have more knowledge. They don't feel shy" (beneficiary 2, female, FGD, 20.01.2017). Another issue that impedes female participation is the high burden of responsibilities that also come with early marriage and teenage pregnancies – women need to care for the children, need to do the household chores and help on the field<sup>25</sup>. Furthermore, participants reported that there might be issues in terms of females getting permission by their parents or husbands to participate:

"Girls here in the rural work a lot at home. So you would find that parents do not allow them to attend such meetings" (peer educator 5, male, 19.01.2017).

"Some are married. So we don't know what happened at their homes. Maybe their husbands don't allow them to come" (peer educator 4, male, 19.01.2017).

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around 1500-2000 ZMW per cow.

<sup>&</sup>lt;sup>24</sup> "Lobola" or "bride wealth" is a customary law requiring the prospective groom to pay cash or in kind to the bride's family. According to a village headman, in Mboole the "Lobola" is two cows, worth

<sup>&</sup>lt;sup>25</sup> This relates to the "double" or "triple day" of women (see, for example, Chant 2007:304).

## 5.3. Community participation and the HIV/AIDS epidemic

As discussed in the literature review, community participation plays an important role in the fight against HIV/AIDS. In this regards the idea of "localizing messages" has already been brought up. This revolves around two aspects, which were described by the participants as:

- a) The acceptance of messages; and
- b) The trust towards or comfort with the messenger.

Against this background, traditional leaders and local role models – often referred to as "community champions" by the interviewees – play a major role.

In terms of a), the acceptance of messages, participants highlighted that local people stand a better chance of conveying messages to the community than outsiders. With community leaders, this has to do with respect and traditional authority. Community leaders have been leading "their people" and successfully conveying messages to them for a long time. The community respects them. Indeed, all of the experts highlighted that these are existing and functioning systems external actors would be well-advised to tap into:

"So really, [...] they do stand a better chance of successfully transmitting messages within their communities than the most educated professor from any University globally" (donor-project representative 3, 03.02.2017).

However, the involvement of community leaders rests on the assumption that they are willing and prepared to communicate messages around HIV and promote behavior-change. Another important aspect to the involvement of traditional leaders concerns their active engagement as positive role models. In MRDI, community leaders were taking the lead in driving for change – including cases where a headman took the lead in voluntary medical male circumcision (VMMC) to promote this HIV prevention method or set an example in terms of monogamy by committing to one wife. This carries weight in a traditional set-up like in Mboole.

But acceptance does not only come with the authority of traditional leaders. The involvement of role models amongst the community or "community champions" can be equally important. Examples that were given by the research participants are PLHIV, giving their testimonials to the community to bring the issue of HIV into the

public discourse fighting taboo and stigma. In an enabling environment, these people become respected and encourage other people to seek support. Also the role of peer educators was highlighted, who are from within the community and comfortable to speak about sensitive issues like SRHR and HIV/AIDS. Them involving large groups of their fellow youths in discussions about these topics again brings it into the public sphere and takes away the taboo - a prerequisite for tackling risk behavior and discriminatory attitudes. This supports the findings of Walsh et al. (2012:8) as well as Janz et al. (1996:93), who identified local community peer educators as one of the most important drivers for successfully conveying HIV/AIDS-related health messages at the community-level. Against this background, all interviewees in this study self-reported that they are feeling generally comfortable talking about SRHR and HIV/AIDS - however, level of comfort tends to increase with the majority of the interviewees the closer the characteristics of the person they talk to resemble their own background. Furthermore, some of the older interviewees reported a change over time in how comfortably and openly people would engage in discussions around those topics as well as in people's behavior. Reportedly, the community discourages traditions like sexual cleansing and the practice is in decline, the chief is condemning child marriage, the issues of polygamy and multiple sex partners are being discussed and more people go for VMMC. In fact, data collected on-site suggest that the ratio of circumcised young men is considerably higher in Mboole compared to the national average (see table 4)<sup>26</sup>.

Table 4: Percentage of young men, who have undergone VMMC, Zambia (2013-14) and Mboole (2017).

Question		Men (15-24)	Men (15-19)
Undergone VMMC (4)	Zambia	24.7%	22.7%
(1)	Mboole	32.7%	31.7%

Sources: Own compilation based on the ZDHS (Central Statistical Office 2015) for national data (representative for Zambia) and own data collection for Mboole (not representative for whole community).

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<sup>&</sup>lt;sup>26</sup> These data are only indicative and in support of the qualitative accounts from research participants since the data for Zambia and Mboole are from different reference years.

Another interesting aspect that was brought up in terms of acceptance is credibility. Some interviewees mentioned that the community would not really perceive messages as credible, if "outsiders" deliver them, who are (believed to) getting paid for it:

"People would be seeing that this person has been given money to come and teach us. You create a barrier. People are even blocked, they will not listen" (provincial official 1, 20.01.2017).

"Even if I am HIV/AIDS positive, people won't believe. They would say: '[...] he has just been paid to tell a false story'. But from within the community, the people are able to receive the message" (MRDI management 3, 25.01.2017).

This also relates to point b), the trust towards or comfort with the messenger. However, this goes beyond mere credibility. The majority of young people interviewed reported that they prefer talking to someone who is local, of same gender and similar age, as they would feel comfortable and free to cover topics around SRHR and HIV/AIDS. Again, the aspect of shyness came up where many youths mentioned that they would feel shy talking to someone they don't know (from outside the community). However, there were also a few who answered in contrast to that — one of the peer educators, for example, said that he feels that the community knows how he behaved in the past and thus would not take him serious. He therefore stated to feel more comfortable talking to someone from outside the community. This relates to the idea of role modeling and came up again in a FGD, where other peers felt that "positive" behavior-change is something valuable for being a role model in the community.

Following the discussion so far, study participants from the community as well as experts perceive community participation to deliver SRHR- and HIV/AIDS-related messages as well as to encourage behavior-change as vital in terms of acceptance and credibility. And this, in turn, will have an impact on development projects and efforts in HIV prevention, as it relates to issues like project effectiveness and sustainability. However, considering the participatory and community-based approach taken in Mboole, how does the community perform on indicators of HIV/AIDS-related knowledge and attitudes compared to the national average based on the ZDHS 2013-14? Table 5 and 6 summarize the findings from the survey conducted for this study juxtaposed to the ZDHS data. The data show that the issue

of gender inequality discussed under research question two, is strongly supported by the survey findings. On all but one indicator, females perform worse than males – in some cases considerably so. The differences are also much more pronounced in the data for Mboole than in the national data. The only indicator where females are achieving better results than males is the one assessing their willingness to care for a family member who got sick due to AIDS, which again speaks to the established gender roles and that the majority of female volunteers at MRDI are caregivers to OVC.

## Knowledge:

In terms of knowledge (see table 5), young women in both age groups are performing worse than the national average on three out of five indicators as well as on the aggregated indicator. Young men in both age groups, on the other hand, are performing better than the national average on three out of five indicators. Looking at the aggregated indicator, males in the age group 15-19 perform slightly better than the national average. Interestingly, when comparing the age group 15-24 (male) in Mboole to the national average of the rural population in Zambia for the same age group, Mboole performs much better. This is relevant, as most of the ZDHS data do not disaggregate for the rural-urban dichotomy for the age groups assessed in this study<sup>27</sup>. However, for the total age range 15-49, the ZDHS indicates on all but one indicator a better scoring of the urban population compared to the rural population. This means that Mboole could still perform much better if compared only to the rural population of the respective age groups.

Overall, the data suggest some success in imparting HIV/AIDS-related knowledge in Mboole's youths compared to the national average with an observable gender-bias towards the performance of young males.

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<sup>&</sup>lt;sup>27</sup> Except for the aggregated indicator presented in table 5 in the age group 15-24.

Table 5: Knowledge about HIV/AIDS, Zambia (2013-14) and Mboole (2017).

Question		15-24		15-19	
Question		Male	Female	Male	Female
A healthy-looking person	Zambia	85.1%	79.5%	81.9%	76.9%
can be HIV+ (2.1)	Mboole	59.2%	38.0%	61.0%	37.5%
Cannot get HIV by sharing	Zambia	84.3%	82.8%	82.6%	80.9%
food with HIV+ person (2.5)	Mboole	95.9%	90.9%	95.1%	89.6%
Cannot get HIV/AIDS	Zambia	83.6%	80.1%	81.2%	78.4%
through witchcraft (2.6)	Mboole	89.8%	82.0%	87.8%	81.3%
One uninfected partner who	Zambia	93.6%	90.3%	92.2%	88.7%
has no other partner (2.9)	Mboole	87.8%	87.8%	87.8%	87.2%
Cannot get HIV from	Zambia	70.4%	70.6%	67.7%	70.1%
Mosquito bites (2.10)	Mboole	74.5%	62.5%	71.8%	63.0%
	Mboole	44.7%	28.3%	42.5%	27.3%
Comprehensive Knowledge	Zambia,	46.7%	41.5%	42.3%	38.9%
$(2.6 + 2.9 + 2.10)^*$	total	40.770	71.570	72.070	30.970
(2.5 * 2.5 * 2.15)	Zambia,	37.4%	33.5%	_	_
	rural	37.170	33.570		

Sources: Own compilation based on the ZDHS (Central Statistical Office 2015) for national data (representative for Zambia) and own data collection for Mboole (not representative for whole community).

## Attitudes:

Looking at the indicators on attitudes towards PLHIV, young men and women in both age groups are performing worse than the national average on all but one indicator (see table 6). Only when asked whether a HIV-positive teacher should be allowed to continue teaching, more respondents in Mboole supported that than in the national average. On some of the indicators Mboole scores strikingly worse than the Zambian average, suggesting that stigma and discrimination still play a major role in Mboole (at least in the age groups included in the survey) – this is in strong contradiction to the findings from the qualitative data.

<sup>\*</sup> Percentage of respondents who gave the correct answer on all indicators.

Table 6: Attitudes towards PLHIV, Zambia (2013-14) and Mboole (2017).

Question		15-24		15-19	
Quodion		Male	Female	Male	Female
Willing to buy vegetables from	Zambia	79.6%	76.5%	76.3%	72.0%
HIV+ person (3.1)	Mboole	28.6%	13.7%	19.5%	10.2%
Would not want to keep HIV+	Zambia	35.8%	28.2%	35.6%	29.8%
family member a secret (3.3)	Mboole	16.3%	7.8%	14.6%	4.1%
Would care for family member	Zambia	93.1%	92.7%	91.8%	91.4%
who got sick from AIDS (3.4)	Mboole	73.5%	80.4%	70.7%	79.6%
HIV+ teacher should be	Zambia	83.0%	83.4%	80.1%	81.1%
allowed teaching (3.5)	Mboole	95.9%	90.2%	95.1%	89.8%
Accepting attitudes on all four	Zambia	23.0%	17.3%	21.1%	16.2%
indicators	Mboole	16.8%	8.3%	8.3%	2.9%

Sources: Own compilation based on the ZDHS (Central Statistical Office 2015) for national data (representative for Zambia) and own data collection for Mboole (not representative for whole community).

However, it needs to be mentioned that indicator 3.1 is flawed. There has been a mistake in the exact wording of this question compared to the ZDHS question. making it prone to misinterpretation<sup>28</sup>. This is supported by comparing questions 2.5 and 3.1 – it does not make sense that people know they cannot get HIV by sharing food with an HIV-positive person (all survey groups performed better than the national average), but are not willing to buy vegetables from an HIV-positive person. However, this does not explain the performance on the other two indicators, where Mboole achieves worse results than the national average. Here, the considerable difference between Mboole and the national average on indicator 3.3 is especially puzzling, asking whether the participant would want it to remain a secret, if a family member got HIV. One possible explanation for these results is that the survey is skewed towards the lower end of the age range, where SRHR topics have just started to be addressed. In Mboole SRHR topics are treated with a lot of cultural sensitivity, where youths, for example, are encouraged to abstain rather than to use

<sup>&</sup>lt;sup>28</sup> The question in the survey used the wording "would you hesitate to buy" rather than "would you buy". This change of wording has caused the question to be open for interpretation rather than a simple yes- or no-question.

condoms despite national data showing that youths are engaging in sexual activities nonetheless and not waiting for marriage (Central Statistical Office 2015:60 ff.). Interestingly, the median age at first sexual intercourse is much lower in rural areas than in the urban areas. This relates to another possible explanation for the contradicting findings of the survey. As mentioned above, the relative performance might improve, if disaggregated data would be available to only compare Mboole to the rural population of Zambia.

These findings are essentially about the issue of stigma and not so much about taboos. Indeed, additional survey questions<sup>29</sup> unrelated to the ZDHS suggest that youths feel comfortable talking about SRHR- and HIV/AIDS-related topics – something that is strongly supported by the qualitative data in this study. In fact, in an FGD with peer educators, participants mentioned that they do not think that talking about SRHR and HIV/AIDS is still a taboo in Mboole. However, they went on to add that stigma, on the other hand, continues to be an issue in the community. Consequently, these qualitative accounts match very well with the findings from the survey.

At this stage, it is important to highlight what the survey can indicate and what not. Keeping in mind the aforementioned limitations to the survey, the results can locate the performance of the respective age groups in Mboole within the wider context of Zambia when compared to the ZDHS data. However, the survey data cannot provide any information about changes within the Mboole community itself over time. That would require sequential data. However, as discussed above, the qualitative accounts from research participants do in fact suggest changes in behaviors and norms in Mboole.

# 6. Conclusions and further suggestions

Based on the analysis, there are three main conclusions that can be drawn from this study.

Firstly, and in response to the first research question, approaches to participation vary considerably in donor-funded projects with MRDI and the Mboole community, where the question of how community-members are involved ranges from

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<sup>&</sup>lt;sup>29</sup> See appendix F.

"consultation" to "delegated power". This, in turn, translates into a strong instrumental understanding of participation in the first project with little to no decision-making power of the community and more transformative approaches in the other two where the community has actual decision-making power in the project to various degrees. Concerning the question of who participates, the findings suggest that (1) the scope of community involvement in Mboole seems to be related to the "how"-question with wider engagement of community members in projects, where the form of participation translates into more power and responsibility for the community; and (2) the scope of participation seems broader at early project stages (e.g. needs assessment) and becomes more narrow at later stages. However, interviewees also indicated that participation is most common at the implementation stages of a project and much less so, for example, at the stage of needs assessment, which is supported by findings of other studies presented in the literature review. Furthermore, this study suggested that the reality of (large) donor programs seems not to facilitate community participation at all levels and from early program inception. Rather, the donors designed the programs with individual components targeting the communitylevel, where then different approaches to community participation were considered.

While the analyzed projects can only be indicative for the case of Mboole, the accounts of experts interviewed for this study strongly support these patterns, which is in line with the findings of other studies presented in the literature review. Therefore, the findings suggest that not only participation per se matters, but that the approach to participation matters with implications on aspects like ownership, acceptance and sustainability of projects.

Furthermore, the analysis showed that the framework presented in this study offers a very structured way of assessing the approaches to participation taken in specific projects. This not only offers conceptual clarity, but could also provide a useful tool for practitioners conducting project evaluations. Moreover, it can improve project-design encouraging practitioners to purposefully consider not only who to involve, but also how and at which stages of the project. However, it must also be mentioned that this framework is too detailed for application in large-scale (e.g. large-N) studies. The more projects to be analyzed, the less focus can be given to the details on all three dimensions of the framework. Nevertheless, this framework could prove useful for studies that might want to analyze participatory approaches in a large number of

projects by allowing it to clearly isolate which dimension of participation is being considered and which is not. A study might, for example, want to further investigate the finding suggesting that donors tend to involve communities more at the implementation stages rather than needs assessment, design or M&E of projects. Against this background, such a study could clearly highlight that it does not seek to answer the questions of who is participating and how, while acknowledging that these questions matter. Again, this allows for conceptual clarity.

A second major conclusion, and answering the second research question, is that participation and the question of who participates is strongly affected by hierarchies and gender norms in the Mboole community. While involving traditional leaders was not only necessary for MRDI's success, but also beneficial as leaders committed to a relatively progressive agenda, experts cautioned that this is very context specific. Furthermore, the strong role of MRDI's director also seems to have been a major success factor for MRDI, but here experts are encouraging a devolvement of responsibilities to a wider group of people. One might say that strong leadership seems important from an organizational perspective, but it also has further implications for participatory processes at the community level.

With regards to gender, the findings show that traditional gender norms play a major role in Mboole with noticeable effects not only on female participation but also on women's general position within the community. The study highlighted some causal chains, where female participation seems to be determined by phenomena like early marriage, teenage pregnancies, early school dropouts and lower educational attainments. While MRDI addresses female participation, the broader norms around gender roles seem to be particularly difficult to challenge considering the patriarchal context. These findings are also reflected by a strong gender-bias in the data and discussions covered under research question three.

The third conclusion drawn from this study and answering the third research question is that community participation seems to be vital for the acceptance of SRHR messages and also the messenger and consequently relevant for efforts addressing the HIV/AIDS epidemic. Having community leaders as well as local peer educators and role models conveying messages around SRHR and HIV/AIDS seems to matter for the interviewees in Mboole and was highlighted as a successful method by the experts interviewed for this study. From the perspective of the research participants it

is of relevance if youths are addressed by their local peers, where not only age is of relevance but also gender. The qualitative data suggest MRDI's community-based approach and community involvement has changed SRHR- and HIV/AIDS-related norms and behaviors. There is strong evidence that the taboos around these topics have been lifted. Also, traditional norms and practices (e.g. sexual cleansing, child marriage or polygamy) are being challenged and reportedly in decline. When comparing the performance of youths in Mboole on indicators concerning HIV prevention methods, knowledge and attitudes with national data, the results are mixed. Mboole performs better in VMMC (HIV prevention method), has moderate successes in imparting HIV/AIDS-related knowledge amongst their youths compared to the national averages, but performs much worse when it comes to attitudes towards PLHIV (stigma). These findings are supported by the qualitative assessments of research participants.

With these three major conclusions in mind, a number of suggestions can be made. These have two addressees: (1) MRDI and the Mboole community; and (2) a wider group of development practitioners and researchers.

## (1) MRDI:

- a) Further devolvement of power and responsibilities in the MRDI management structure could encourage wider participation of community members in roles of decision-making power and contribute to long-term sustainability. This could also strengthen and build the capabilities and leadership skills amongst other community members taking over roles of responsibility within MRDI.
- b) Additional efforts are needed to address gender inequalities in Mboole, especially through male sensitization and by targeting girls and young women with activities to increase their participation as well as to improve their opportunities.
- c) More attention should be paid to the issue of stigma, especially amongst young people, where discriminatory attitudes towards PLHIV seem to persist.

#### (2) Practitioners and researchers:

a) The study findings suggest that projects could benefit if they acknowledge existing structures and systems and tap into them.

- b) Community participation and the specific approach to participation seem to matter. Involving the community has implications on project acceptance, ownership and consequently long-term sustainability. The author therefore suggests to carefully consider who participates, how and at what project stages.
- c) The analytical framework developed in this thesis can be applied to provide more conceptual clarity around participation and to further investigate the impact of differing approaches to participation on aspects like project effectiveness or sustainability.

## References

Adam, Sarah G. & Oshima, Kaori (2014): Engaging Youth through Community-Driven Development Operations - Experiences, Findings, and Opportunities, Global Stocktake Synthesis Paper, World Bank, Washington.

Akerkar, Supriya (2001): Gender and Participation – Overview Report, Institute of Development Studies, Brighton.

Arnstein, Sherry R. (1969): The Ladder of Citizen Participation, in: The Journal of the Royal Town Planning Institute, Vol. 35, No. 4, pp. 216-224.

Binswanger-Mkhize, Hans P.; Aiyar, Swaminathan S. Anklesaria; de Regt, Jacomina P.; Serrano-Berthet, Rodrigo; Helling, Louis; Van Domelen, Julie; Warren, David & Spector, Stephen (2010): Historical Roots and Evolution of Community Driven Development, in: Binswanger-Mkhize, Hans P.; de Regt, Jacomina P. & Spector, Stephen (eds.) (2010): Local and Community Driven Development - Moving to Scale in Theory and Practice, The World Bank, Washington, D.C.

Breslin, Edward D. & Sawyer, Ron (1999): A Participatory Approach to Community-Based HIV/AIDS Awareness, in: Development in Practice, Vol. 9, No. 4, pp. 473-479.

Brockington, Dan & Sullivan, Sian (2003): Qualitative Research, in: Scheyvens, Regina & Storey, Donovan (eds.) (2003): Development Fieldwork: A Practical Guide, Sage Puplications, Los Angeles, pp. 57-74.

Bryman, Alan (2012): Social Research Methods, 4th ed., Oxford University Press, Oxford.

Bujra, Janet (2006): Lost in Translation? the Use of Interpreters in Fieldwork, in: Desai, Vandana & Potter, Robert B. (eds.) (2006): Doing Development Research, SAGE Publications, London, pp. 172-179.

Central Statistical Office (2015): Zambia Demographic and Health Survey 2013-14, Lusaka.

Chambers, Robert (1983): Rural Development: Putting the Last First, Longman, London, Lagos and New York.

Chambers, Robert (1994): Participatory rural appraisal (PRA): Analysis of experience, in: World Development, Vol. 22, No. 9, pp. 1253-1268.

Chambers, Robert (1997): Whose Reality Counts? Putting the First Last, Intermediate Technology Publications, London.

Chambers, Robert (2008): Revolutions in development inquiry, Earth Scan, London.

Chant, Sylvia (2007): Gender, Generation and Poverty: Exploring the 'Feminisation of Poverty' in Africa, Asia and Latin America, Edward Elgar, Cheltenham and Northampton.

Cooma Royal Establishment (2013): Cooma Chiefdom Development Strategic Plan 2013-201, Choma.

Cornwall, Andrea (2003): Whose Voices? Whose Choices? Reflections on Gender and Participatory Development, in: World Development, Vol. 31, No. 8, pp. 1325-1342.

Cornwall, Andrea (2008) Unpacking 'Participation': models, meanings and practices, in: Community Development Journal, Vol. 43, No. 3, pp. 269-283.

Creswell, John W. (2009): Research Design: Qualitative, Quantitative, and Mixed Methods Approaches, 3rd ed., Sage Puplications, Los Angeles.

Datta, Dipankar (2009): Addressing the needs of orphans and vulnerable children: Strengthening ongoing community actions in Nyanza province, Kenya, draft paper presented at the Community Development Journal International Symposium, 3rd – 5th September, Glasgow.

Eng, Eugenia & Parker, Edith (1994): Measuring Community Competence in the Mississippi Delta: The Interface between Program Evaluation and Empowerment, in: Health Education Quarterly, Vol. 21, No. 2, pp. 199-220.

Etzioni, Amitai (1996): The Responsive Community: A Communitarian Perspective, 1995 Presidential Address, in: American Sociological Review, Vol. 61, pp. 1-11.

FAO (2017): Filling the Gaps in Rural Development, Annual Report 2016, FAO, Rome.

Ginev, Dimitri (1998): Rhetoric and Double Hermeneutics in the Human Sciences, in: Human Studies, Vol. 21, pp. 259-271.

Hammett, Daniel; Twyman, Chasca & Graham, Mark (2014): Research and Fieldwork in Development, Routledge, Oxford.

Harman, Sophie (2009): Bottlenecks and Benevolence: How the World Bank is Helping Communities to 'Cope' with HIV/AIDS, in: Journal of Health Management, Vol. 11, No. 2, pp. 297-313.

Heller, Kenneth (1989): The Return to Community, in: American Journal of Community Psychology, Vol. 17, No. 1, pp. 1-15.

Hunter, Albert (1975): The Loss of Community: An Empirical test Through Replication, in: American Sociological Review, Vol. 40, No. 5, pp. 537-552.

Institute for Health Metrics and Evaluation (2010): Global Burden of Disease (GBD) Profile: Zambia, Seattle.

Janz, Nancy K.; Zimmerman, Marc. A.; Wren, Patricia A.; Israel, Barbara A.; Freudenberg, Nicholas & Carter, Rosalind J. (1996): Evaluation of 37 AIDS Prevention Projects: Successful Approaches and Barriers to Program Effectiveness, in: Health Education Quarterly, Vol. 23, No. 1, pp. 80-97.

Lamb, Robert D.; Varettoni, Bill & Shen, Chunli (2005): Participatory Development and the World Bank, in: International Affairs Review, Vol. 14, No. 2, pp. 171-194.

Lennie, June (1999): Deconstructing Gendered Power Relations in Participatory Planning: Towards and Empowering Feminist Framework of Participation and Action, in: Women's Studies International Forum, Vol. 22, No. 1, pp. 97-112.

Leslie, Helen & Storey, Donovan (2003): Entering the Field, in: Scheyvens, Regina & Storey, Donovan (eds.) (2003): Development Fieldwork: A Practical Guide, Sage Puplications, Los Angeles, pp. 119-138.

Mansuri, Ghazala & Rao, Vijayendra (2003): Evaluating Community-Based and Community-Driven Development: A Critical Review of the Evidence, Development Research Group, the World Bank, Washington.

Mayoux, Linda (2006): Quantitative, Qualitative or Participatory? Which Method, for What and When?, in: Desai, Vandana & Potter, Robert B. (eds.) (2006): Doing Development Research, SAGE Publications, London, pp. 115-129.

Merzel, Cheryl & D'Afflitti, Joanna (2003): Reconsidering Community-Based Health Promotion: Promise, Performance, and Potential, in: American Journal of Public Health, Vol. 93, No. 4, pp. 557-574.

Ministry of General Education (MoGE) (2016): 2015 Educational Statistical Bulletin, Republic of Zambia.

Minkler, Meredith; Wallerstein, Nina & Wilson, Nance (2008): Improving Health Through Community Organization and Community Building, in: Glanz, Karen; Rimer, Barbara K. & Viswanath K. (eds.) (2008): Health Behavior and Health Education – Theory, Research, and Practice, 4<sup>th</sup> edition, Jossey-Bass, San Francisco.

Mohan, Giles & Stokke, Kristian (2000): Participatory development and empowerment: the dangers of localism, in: Third World Quarterly, Vol. 21, No. 2, pp. 247-268).

Momsen, Janet H. (2006): Women, Men and Fieldwork: Gender Relations and Power Structures, in: Desai, Vandana & Potter, Robert B. (eds.) (2006): Doing Development Research, SAGE Publications, London, pp. 44-51.

Morgan, Lynn M. (2001): Community participation in health: perpetual allure, persistent challenge, in: Health Policy and Planning, Vol. 16, No. 3, pp. 221-230.

Moses, Jonathon W. & Knutsen, Torbjørn L. (2012): Ways of Knowing: Competing Methodologies in Social and Political Research, 2nd ed., Palgrave Macmillan, New York.

Mosse, David (2001): 'People's Knowledge,' Participation and Patronage: Operations and Representations in Rural Development, Chapter 2 in: Cooke, Bill & Kothari, Uma (eds.) (2001): Participation: The New Tyranny?, Zed Books, London and New York.

National HIV/AIDS/STD/TB Council (NAC) (2010): National HIV and AIDS Strategic Framework 2011-2015: Towards Improving the Quality of life of the Zambian People, Lusaka.

National HIV/AIDS/STD/TB Council (NAC) (2014a): Zambia's National AIDS Spending Assessment 2010-2012, Draft 3, Lusaka.

National HIV/AIDS/STD/TB Council (NAC) (2014b): National HIV and AIDS Strategic Framework 2014 – 2016, A Nation Free from the Threat of HIV and AIDS, Lusaka.

Owusu, Nicodemus O. (2014): Community participation in malaria control strategy of intersect oral collaboration in Ghana: Myth or reality?, in: African Journal of Primary Health Care & Family Medicine, Vol. 6, No. 1, pp. 1-8.

Parnwell, Michael (2006): Robert Chambers, in: Simon, David (ed.) (2006): Fifty Key Thinkers on Development, Routledge, London and New York, pp. 73-78.

Riehman, Kara S.; Kakietek, Jakub; Manteuffel, Brigitte A.; Rodriguez-García, Rosalía; Bonnel, Rene; N'Jie, N'Della; Godoy-Garraza, Lucas; Orago, Alloys; Murithi, Patrick & Fruh, Joseph (2013): Evaluating the effects of community-based organization engagement on HIV and AIDS-related risk behavior in Kenya, in: AIDS Care, Vol. 25, No. 1, pp. 67-77.

Rifkin, Susan B. (1986): Lessons from community participation in health programmes, in: Health Policy and Planning, Vol. 1, No. 3, pp. 240-249.

Rodriguez-García, Rosalía; Bonnel, Réne; N'Jie; N'Della; Olivier, Jill; Pascual, F. Brian & Wodon, Quentin (2011): Analyzing Community Responses to HIV and AIDS: Operational Framework and Typology, Policy Research Working Paper 5532, The World Bank.

Rudqvist, Anders & Woodford-Berger, Prudence (1996): Evaluation and Participation – some lessons, Sida Studies in Evaluation 96/1, Department for Evaluation and Internal Audit, Stockholm.

SADC (2008): Mboole Rural Development Initiative (MRDI) in Zambia, SADC HIV and AIDS Best Practice Series.

Scheyvens, Regina & Leslie, Helen (2000): Gender, ethics and empowerment: dilemmas of development fieldwork, in: Women's Studies International Forum, Vol. 23, No. 1, pp. 119-130.

Scheyvens, Regina; Nowak, Barbara & Scheyvens, Henry (2003): Ethical Issues, in: Scheyvens, Regina & Storey, Donovan (eds.) (2003): Development Fieldwork: A Practical Guide, Sage Puplications, Los Angeles, pp. 139-166.

Sen, Amartya (1999): Development as Freedom, Oxford University Press, Oxford.

UNAIDS (2011): UNAIDS Terminology Guidelines, revised version, Geneva.

UNAIDS (2017): AIDSinfo databank, available at: http://aidsinfo.unaids.org, last accessed: 30.03.2017.

UNAIDS, UNICEF & USAID (2004): Children on the Brink 2004: A Joint Report of New Orphan Estimates and a Framework for Action, New York.

UNDP (2016): Zambia Human Development Report 2016 – Industrialisation and Human Development, Poverty Reduction Through Wealth and Employment Creation, Lusaka.

UNHCR (2008): A Community-based Approach in UNHCR Operations, Geneva.

UNICEF (2005): Guide to Monitoring and Evaluation of the National Response for Children Orphaned and made Vulnerable by HIV/AIDS, New York.

United Nations (2010): World Programme of Action for Youth, Economic and Social Affairs, United Nations, New York.

Van Kempen, L. (2014): Mansuri, Ghazala and Rao, Vijayendra: Localizing development. Does participation work?, Book Review, in: Journal of Economics, Vol. 112, No. 2, pp. 201-205.

Walsh, Aisling; Mulambia, Chishimba; Brugha, Ruairi & Hanefeld, Johanna (2012): "The problem is ours, it is not CRAIDS'". Evaluating sustainability of Community Based Organisations for HIV/AIDS in a rural district in Zambia, in: Globalization and Health, Vol. 8, No. 40, pp. 1-16.

White, Sarah C. (1996): Depoliticising development, The uses and abuses of participation, in: Development in Practice, Vol. 6, No. 1, pp. 6-15.

World Bank (2001): World Development Report 2000/2001 – Attacking Poverty, published for the World Bank by Oxford University Press, New York.

World Bank (2017): DataBank – World Development Indicators, available at: http://databank.worldbank.org/data/, last accessed: 30.03.2017.

World Health Organization (1978): Declaration of Alma-Ata, International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978.

World Health Organization (1991): Community Involvement in Health Development: Challenging Health Services – Report of a WHO Study Group, in: WHO Technical Report Series, 809, WHO, Geneva.

Yin, Robert K. (2003): Case Study Research: Design and Methods, 3rd ed., Sage Puplications, Thousand Oaks.

# **Appendices**

## Appendix A: Key definitions

### Development:

In *Development as Freedom* (2000), Amartya Sen encourages a broad understanding of the concept of "development". He understands it as the "removal of various types of unfreedoms that leave people with little choice and little opportunity of exercising their reasoned agency" (Sen 2000:xii). The expansion of individual freedoms as development encompasses several areas including "economic opportunities, political freedoms, social facilities, transparency guarantees, and protective security" (ibid.).

### Empowerment and Power:

"Power can be defined as the capacity to make informed choices and have the freedom to take action. Empowerment is not something that is "done" to people; it is the process by which individuals in the community analyze their situation, enhance their knowledge and resources, strengthen their capacity to claim their rights, and take action to achieve their goals. At the same time, their capacities and skills are recognized by others. Empowerment requires change at the individual and structural levels" (UNHCR 2008:20).

#### Orphans and Vulnerable Children (OVC):

In the context HIV/AIDS, UNAIDS (2011:22) defines "orphans" as children who have lost one or both parents due to AIDS. However, there is no agreed-upon definition for other children made vulnerable by HIV/AIDS. They can include those who or whose parents or guardians are living with HIV, are ill or dying due to AIDS, who live in child- or grandparents-headed households or who live in poor households that have taken in orphans (UNAIDS, UNICEF & USAID 2004:3; UNICEF 2005:17; Datta 2009:2)

## Ownership:

"Ownership is achieved when persons of concern assume full responsibility [...] and manage the activities and services that they consider priorities. It is the natural

outcome of a process that has respected the principles of meaningful participation and empowerment" (UNHCR 2008:21).

## Sustainability:

"Sustainability is the possibility of maintaining the achievements of any support provided to the community [...]. Sustainability is about community development: building on the capacities and skills of community members to manage representative and fair structures that can respond to both immediate and long-term [...] needs, and to develop solutions while upholding individual rights. Maximum ownership and sustainability are achieved when interventions are responses to community-driven demands" (UNHCR 2008:22-23).

# Appendix B: Survey questionnaire

## Questionnaire

Study title: "The dynamics of community participation in the context of the HIV/AIDS epidemic in Zambia – A case study with the Mboole Rural Development Initiative"

<u>Researcher</u>: Rico Bergemann, MSc Candidate in International Development and Management, LUMID Programme, Lund University, Sweden

Contact: rico.bergemann@gmx.de

Section	Section A. Demographic Characteristics				
A1	How old are you?				
A2	What is your gender?	Male Female			
A3	In which grade are you? (grade 1 to 12; or out of school)				
A4.1	Are you currently in a relationship?	Yes No			
A4.2	Are you married?	Yes No			
A5.1	Are you currently pregnant?	Yes No			
A5.2	Do you have children?	Yes No			
A5.3	If so, how many children do you have?				
Section	n B. Knowledge about HIV/AIDS and attitudes				
B1	Do you know about HIV/AIDS?	Yes No			

B2	Please indicate whether you think the statement about HIV/AIDS is true, or false, or whether you don't know.				
		True	False	I don't know	
B2.1	You can see whether a person has HIV.				
B2.2	It is possible to cure AIDS.				
B2.3	Sleeping with a virgin can cure AIDS.				
B2.4	A mother can transmit HIV to her child when she is pregnant.				
B2.5	You can get AIDS by sharing food with a person who has AIDS.				
B2.6	You can get AIDS because of witchcraft.				
B2.7	You cannot get HIV the first time you have sex.				
B2.8	You can get HIV through kissing.				
B2.9	People can reduce their chance of getting the AIDS virus by having just one uninfected sex partner who has no other sex partners.				
B2.10	People can get the AIDS virus from mosquito bites.				
В3	Please answer the following questions with either "yes",	"no" or "I do	on't know".		
		Yes	No	I don't know	
B3.1	Would you hesitate to buy fresh vegetables from a				

	vendor if you knew that this person had HIV?			
B3.2	Would you still hang out/ play with a friend if you knew that this friend is HIV positive?			
B3.3	If a member of your family got infected with HIV, would you want it to remain a secret?			
B3.4	Would you be prepared to care for a family member that got sick due to AIDS?			
B3.5	In your opinion, if a teacher is HIV positive but not sick, should she/he be allowed to continue teaching?			
B3.6	Would you ever date someone, if you knew that this person is HIV positive?			
B3.7	Do you talk with your parents about HIV/AIDS?			
B3.8	Do you talk amongst your friends about HIV/AIDS?			
Section	n C. Sexual behavior and HIV/ AIDS			
C1.1	Have you ever been tested for HIV?	Yes	No	
C1.2	If "Yes", have you been tested in the past 12 months?	Yes	No	
C1.3	Do you know your HIV status? ( <u>Don't mention your status</u> , just tick "yes" if you know your status or "no" if you don't know)	Yes	No	
C2.1	Have you ever had sexual intercourse?	Yes	No _	
C2.2	If "yes", how many sexual partners have you had in the last 12 months?			

C2.3	If "no", what is the main reason? (just tick one)	I am too young  No opportunity yet  No sex before marriage  Concerned of getting pregnant  Afraid of getting diseases  I want to be abstinent  Don't know
C3.1	Do you have free access to condoms (male/ female condom)?	
C3.2	Did you use a male or female condom at your last sexual intercourse?	Yes No
C3.3	Do you use condoms consistently?	Yes No
C4	(males only) Have you gone for male circumcision?	Yes No

## Appendix C: Sample interview guide

## Interview Guide (MRDI staff)

## Research project with the Mboole Rural Development Initiative

Rico Bergemann Lund University

E-Mail: rico.bergemann@gmx.de

## **General Questions:**

- Age? Male/Female?
- What is the aim/ purpose of MRDI?
- What was the process of getting MRDI started?
- What is/are the target group(s)?
- How many villages are services by MRDI?
- How many people are reached by MRDI? (# of OVC reached, # number of youth groups?)
- How many people are in the core management team of MRDI? (How many are female? Age of the youngest? Age of the oldest?)
- Can you please describe the work of MRDI?
- What are the challenges MRDI is facing?
- What do you think is the most unique aspect of MRDI?

## **Community Participation and Ownership:**

- How are the priorities of MRDI identified? (e.g. community involvement, needs assessment, etc.)
- Please describe the relationship between MRDI and:
  - o a) community members in general?
  - o b) youth?
  - o c) community leaders?
  - o d) religious leaders?
- How does the community perceive MRDI? Is there any difference between today and when MRDI was started?
- In what ways does the community contribute to achievement of the goals of MRDI?
- How do community members become active in MRDI?
- Please describe specific platforms and procedures at MRDI for involving the community.
- How many women and how many young people are among the 65 volunteers?
- How are young people engaged in MRDI specifically?
- How do you make decisions at MRDI? Who is involved? What are the procedures?
- Please list the services MRDI is providing.
- What determines who has access to these services?

## Power Relations with external donors:

- Has MRDI ever received funds from external donors?
- In the past, which were the largest donors of MRDI?
- With what donors is MRDI currently cooperating?
- Please describe the process of entering the cooperation with each respective donor.
- How were the needs of the community assessed for each respective project with external donors?
- Please describe the involvement of MRDI in:
  - o The planning and design of the project.
  - The decision-making about project objectives and activities.
  - o The implementation of the project.
- Were the experiences and the local knowledge of MRDI staff and the community a large considered? If so, in what ways?
- Where any of the projects funded by external donors specifically framed as community-based projects?
- Have you ever experienced challenges when working with external donors? What were these challenges?
- Is MRDI invited to stakeholder and planning meetings of donors? If so, please describe your role in those meetings.
- Do you feel free to express concerns to external donors?

## Sustainability:

- How do you mobilize support? From whom?
- How has the MRDI project managed to sustain itself?
- Do you cooperate with other/ similar community initiatives?
- What are the key success factors of MRDI?

## **HIV/AIDS** related questions:

- What is MRDI's approach to HIV prevention?
- What specific activities do you run to raise knowledge and awareness about HIV/AIDS in your community?
- How do people react when you approach them with these topics? Has this changed over time?
- What kind of strategies does MRDI use to approach community members on these topics? Are there different strategies for different target groups?
- Do you think there has been a noticeable change in sexual risk behavior amongst the community and young people?
- If so, what do you think are the key success factors of achieving this change in sexual risk behavior?

# **Appendix D: Detailed list of interviewees**

Table 7: Detailed list of all interviewees.

Role	Age group	Gender
MRDI management and staff		
MRDI management 1	25-35	Male
MRDI management 2	25-35	Female
MRDI management 3	25-35	Male
MRDI management 4	25-35	Male
MRDI staff 1	25-35	Female
MRDI staff 2	36+	Male
Beneficiaries		
Beneficiary 1	15-24	Male
Beneficiary 2	15-24	Female
Beneficiary 3	15-24	Male
Beneficiary 4	15-24	Male
Beneficiary 5	15-24	Male
Beneficiary 6	15-24	Male
Beneficiary 7	15-24	Male
Beneficiary 8	15-24	Male
MRDI peer educators		
Peer educator 1	15-24	Male
Peer educator 2	15-24	Female
Peer educator 3	15-24	Male
Peer educator 4	25-35	Male
Peer educator 5	15-24	Male
Experts (provincial officials and dor	or representat	ives)
Donor-project representative 1	36+	Male
Donor-project representative 2	36+	Male
Donor-project representative 3	36+	Male
Provincial official 1	36+	Male
Provincial official 2	36+	Male
Others		
Senior village headman	36+	Male
SRHR professional	25-35	Male

## **Appendix E: Informed consent form**

## **Informed Consent Form for Research Participants**

For the Research Project titled:

"The dynamics of community participation in the context of the HIV/AIDS epidemic in Zambia – A case study with the Mboole Rural Development Initiative"

Researcher: Rico Bergemann, MSc Candidate in International Development and Management, LUMID Programme, Lund University, Sweden

Contact: rico.bergemann@gmx.de

#### 1. What is the purpose of this study?

This study aims to analyze the role and dynamics of community participation in the context of HIV/AIDS epidemic in Zambia. For this purpose, the processes and structures behind community initiatives like the "Mboole Rural Development Initiative", participation processes within the community as well as the involvement of the community in projects with external stakeholders will be studied. Furthermore, it is in the interest of this research to understand how health topics like HIV/AIDS are addressed within the community and what role peer education and community-based approaches play for successful communication of HIV prevention messages.

#### 2. What will happen if you take part in the study?

If you decide to participate in this research, it would be in one or several of the following activities:

- Individual interview (last between 60 and 90 minutes)
- Focus Group Discussion (lasting around 90 minutes)
- Individual questionnaire for survey (lasting around 30 minutes)

Either way, you will be asked questions about yourself and to share and discuss your opinion, knowledge and perceptions on the topics related to this study (see 1<sup>st</sup> question). To join the study is voluntary. You can also decide to stop participating in the study at any time, or stop answering questions without any explanation or consequences.

#### 3. What are the possible benefits from being in this study?

Research is designed to benefit society by gaining new knowledge. You will not receive any personal benefit by participating in this study. However, the study results will be shared with the Mboole community for their interest.

### 4. Will you receive anything for being in this study?

Research participants will not be paid for taking part in the study. However, refreshments and a little snack will be provided during the interviews and focus group discussions.

#### 5. What happens if you choose not to take part in this study?

It's OK if you don't want to participate. There is neither a penalty nor a consequence of any kind. You should also feel free to not respond to questions that make you feel uncomfortable. You can stop participating at any time without the need for explanation.

#### 6. Will it cost anything to be in this study?

There will be no monetary cost involved for participating in the study. However, you would need to commit some time (see 2<sup>nd</sup> question).

#### 7. How will the information you are sharing be protected?

If you agree to participate in this study, the answers and information you are sharing will be kept confidential. The results of the study may be published for scientific purposes, but the results will be anonymous and neither your name nor anything that could potentially help to identify you will ever be published. Also, no one but the researcher will have access to the original information you are providing (e.g. interview records or filled-out survey form). If at any point in time before final dissemination of the study (1<sup>st</sup> of May 2017) you want the information you have shared to not be used, you can contact the researcher (see contact details above), who will immediately exclude your data and information from the study and delete them.

## 8. What if you have questions about this study, or about your rights?

If you have any questions or concerns about this study, you may contact either the researcher himself (see contact details above) or your community leader.

document.	egai rights by signing this informed consent
Signatures for Participation:	
The above document describing the benefits, rig read and explained to me, the participant. I have voluntary and that I can withdraw at any time. I ha any question that I don't want to answer. I ha questions about the activity and my questions have	e been told that participation in this study is ave been told that I do not have to answer to ave been given an opportunity to ask any
Printed Name of Participant giving consent	
Signature or Thumb Print	Date
Witness (only if participant is illiterate):	
I was present throughout the entire informed corresearch participant. All questions from voluntee to take part in the study.	·
Printed Name of Witness	
Signature or Thumb Print	 Date

# Appendix F: Survey results

Table 8: Survey results for question groups B2 and B3, disaggregated by age groups (15-24,15-19) and gender (male, female).

Overtions	15-24		15-19	
Questions	Male	Female	Male	Female
Knowle	edge	•		
A healthy-looking person can be HIV+ (B2.1)	59.2%	38.0%	61.0%	37.5%
It is possible to cure AIDS (B2.2)	63.3%	58.0%	65.9%	58.3%
Sleeping with a virgin can cure AIDS (B2.3)	87.8%	88.0%	87.8%	87.5%
Mother can transmit HIV to child when	61.2%	46.9%	58.5%	46.8%
pregnant (B2.4)	01.270	40.570	30.570	40.070
Cannot get HIV by sharing food with HIV+	95.9%	90.0%	95.1%	89.6%
person (B2.5)	33.370	30.070	33.170	03.070
Cannot get HIV/AIDS through witchcraft (2.6)	89.8%	82.0%	87.8%	81.3%
Cannot get HIV at first sexual intercourse	69.4%	66.0%	73.2%	66.7%
(B2.7)	03.470	00.070	7 3.2 70	00.7 70
Can get HIV through kissing (B2.8)	59.2%	60.0%	63.4%	60.4%
One uninfected partner who has no other	87.8%	87.8%	87.8%	87.2%
partner (2.9)	07.070	07.070	07.070	07.270
Cannot get HIV from Mosquito bites (2.10)	74.5%	62.5%	71.8%	63.0%
Attitu	des			
Willing to buy vegetables from HIV+ person	28.6%	13.7%	19.5%	10.2%
(B3.1)	20.070	10.7 70	10.070	10.270
Willing to hang out/ play with HIV+ friend	69.4%	60.8%	68.3%	61.2%
(B3.2)	00.170	00.070	00.070	01.270
Would not want it to remain a secret, if family	16.3%	7.8%	14.6%	4.1%
member got HIV (B3.3)				,.
Would care for family member who got sick	73.5%	80.4%	70.7%	79.6%
from AIDS (B3.4)				
HIV+ teacher should be allowed to continue	95.9%	90.2%	95.1%	89.8%
teaching (B3.5)				2.2
Talking with parents about HIV/AIDS (B3.7)	87.8%	86.3%	85.4%	85.7%
Talking with friends about HIV/AIDS (B3.8)	89.8%	86.3%	87.8%	85.7%

Source: Own primary data.