

**Community Participation Practices in Health-related NGOs in the Western Cape: A Focus  
on Stakeholders' Perspectives**

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## **DECLARATION**

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## ABSTRACT

Community participation has been of interest to health planners, policymakers and activists on a global scale for over thirty years. It was first introduced in 1978 at the Alma-Ata conference and is seen as an essential tool for promoting health and general well-being within different health systems. This study sought to understand the manner in which community participation is practiced and implemented in health-related non-governmental organisations (NGOs), in and around Stellenbosch in the Western Cape. The main purpose was to examine whether community participation policies were implemented as intended by the policymakers. Stakeholders in different health-related NGOs in Stellenbosch participated in this study giving their accounts of community participation policies and practices in their organisations, as well as their direct or indirect involvement in the process of policymaking and implementation. As a result themes developed from participants responses. The participants gave their perspectives on community participation practices within their health-related NGOs. These themes indicated how all NGOs employed the top-down approach and admitted to altering and amending policies to meet the needs of the community they aimed to serve. While NGO stakeholders liaised information about community participation policies from the top-down to community participants they also communicated needs and concerns directly from the community to the policymakers, from the bottom-up. Community participation policies are thus only used as a point of reference and altered to best suit the needs of each unique NGO.

## OPSOMMING

Gemeenskapsdeelname is van belang vir die gesondheid beplanners, beleidmakers en aktiviste op 'n globale skaal vir meer as dertig jaar . Dit was die eerste keer in 1978 by die Alma-Ata konferensie bekendgestel en word gesien as 'n noodsaaklike hulpmiddel vir die bevordering van gesondheid en algemene welstand binne verskillende gesondheid stelsels . Hierdie studie probeer om die wyse waarop die gemeenskap deelname beoefen is te verstaan en in gesondheid- verwante nieregeringsorganisasie (NROs), in en rondom Stellenbosch in die Wes-Kaap geïmplementeer word. Die hoofdoel was om te ondersoek of deelname van die gemeenskap beleid geïmplementeer was soos bedoel deur die beleidmakers. Belanghebbendes in verskillende gesondheid- verwante NRO's in Stellenbosch het aan hierdie studie deelgeneem het hul rekeninge van gemeenskapsdeelname en -praktyke in hul organisasies gegee , sowel as hul direkte of indirekte betrokkenheid in die proses van beleidmaking en implementering. As gevolg hiervan het temas ontwikkel uit die deelnemers se antwoorde. Die deelnemers het hul perspektiewe op gemeenskapsdeelname praktyke binne hul gesondheidsverwante NROs gedeel. Terwyl belanghebbendes inligting oor gemeenskapsdeelname beleide oorgedra het van beleidmakers na gemeenskap deelnemers, het hulle ook die behoeftes en bekommernisse direk uit die gemeenskap aan die beleidmakers gekommunikeer. Gemeenskapsdeelname beleide is slegs gebruik as 'n verwysingspunt en word verander om die die behoeftes van elke unieke NGO te pas.

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## CHAPTER 1

### Introduction

Ideas about community participation emerged at the Alma-Ata conference in 1978. The conference focused on the “need for governments, health and development workers to protect and promote the health” (p. 1) of all people (Declaration of Alma-Ata, 1978). According to WHO (1986, 2001) primary health care (PHC) is a concept that was re-introduced and particularised at the Declaration of Alma-Ata in 1978, based on principles of equity, community participation, intersectoral action to promote health and the availability of appropriate technology. Primary health care is the most basic level of health care comprising of programmes aimed at health promotion which operates within the health system (WHO, 2001). As a major milestone in the twentieth century field of public health, the Alma-Ata conference marked the inclusion of participation of community members in health promotion programmes, as an essential starting point for proactive approaches to community participation (Morgan, 2001). These proactive approaches assist in eradicating potential barriers within communities; i.e., navigating complex health care systems, language barriers and the lack of health care providers, by involving members from the community to assist in the provision of services (Raco, 2000). Community participation is a key component in health promotion and aims to enable “local people in assessing their own needs and organising strategies to meet those needs” (Preston, Waugh, Taylor & Larkins, 2009, p. 1).

The growing interest in community participation, from health planners, policymakers and activists, resulted in the initial ideas and approaches to community participation (Minkler, 2005; Murray, 2004). These ideas and approaches focused on efficient primary health care services and

further health promotion (Minkler, 2005; Murray, 2004). Community participation in health services is primarily based on the notion that community health and sustainability are at risk if health services are not available (Pollett, 2007; Preston et al., 2009). According to Preston et al. (2009) the aforementioned form of community participation is largely driven by lay community members. Thus, resulting in the rare occurrence of community participation practices reported in academic literature (Preston et al., 2009). A body of literature describing community participation practices is important to keep track of which methods and strategies work best for the most desired positive health promotion outcomes. The aforementioned guidance and tools to community participation therefore promote health outcomes (Nkwake, Trandafili & Hughey, 2013; Preston et al., 2009). Community participation can make a difference in health promotion and health care services by using one (or both) of the two key perspectives in policy implementation; i.e. the top-down or the bottom-up approach. Each perspective focuses on approaching health promotion at different levels in the health care system (Matland, 1995; Preston et al., 2009).

In health promotion programmes, community participation is strongly linked to the bottom-up approach. This approach is more focused on the grassroots level, which involves lay people from the community, beneficiaries to programmes promoting health and well-being. The bottom-up approach also involves those who receive assistance from programmes designed by health-related NGOs, much like the health-related NGOs that participated in the current study (Matland, 1995). The bottom-up approach is essential for stakeholders who want to do a needs-assessment or evaluate direct feedback from the communities and beneficiaries on efficient service delivery and community participation practices (Bhyuan, 2004). In the current study the bottom-up approach helped to understand how beneficiaries provided feedback to stakeholders

regarding community participation practices in health care services and the policy implementation procedures related to the aforementioned services (Panda, 2007). According to Girdwood (2013) the bottom-up approach highlights the notion that community participation policy will inevitably fail if it does not take into account the expertise of the people impacted by the policy. With the bottom-up approach, everyone might not be able to implement policies as intended due to the different types of health services provided by different NGOs and in using their own discretion stakeholders who implement community participation policies can activate more useful practices or ignore policy that will hinder the goal of the health programme (Matland, 1995).

However, in contrast to the bottom-up approach, the top-down approach to community participation is the more conventional method to approaching policy and implementation. For this approach lay community members and beneficiaries to community participation programmes are merely subjected to policies set for them by authoritative figures, government and formal policymakers instead of partaking in the drafting and evaluating of such policies (Girdwood, 2013).

The top-down approach traditionally perceives community members and community participation beneficiaries as passive recipients to programmes designed for them by stakeholders i.e., government officials and health professionals. The top-down approach is very important in assessing how policies are set and how effective those policies work, without directly involving community participants in the policymaking process (Matland, 1995). Thus, there is a need to document community participation practices in health-related NGOs in order to evaluate whether or not community participation policies work as intended. Extensive documentation can only be kept on record if community participation policies clearly state that a

paper trail needs to be kept while prescribing how to document and evaluate community participation in health-related NGOs (Girdwood, 2013; Matland, 1995). This can only be achieved when the bottom-up and top-down approaches are used collaboratively. By involving and including the grassroots level during the policymaking process by looking at the challenges faced during implementation, policymakers could realistically set up attainable goals for effective community participation implementation.

Hence, it is essential to focus on both, top-down and bottom-up approaches used by health-related NGOs in the current study. The top-down approach focuses on stakeholders who formally set the policies and how they prescribe for policies to be implemented. Compared to the bottom-up approach regarding how policies are implemented by community participants in reality, without step-by-step guidance from stakeholders. For the purpose of the current study the top-down approach strongly takes on the perspective of NGO stakeholders, i.e., policy makers, health professionals, government officials and NGO Managing staff. The purpose for using both bottom-up and top-down approaches is to better understand the policy making process from policy design by stakeholders to policy implementation by community participants (Girdwood, 2013).

The World Health Organization (2001) highlights an increase in interest by community members to “participate in policies” (p. 4) and become sources of change in their communities. Community participation practices are catalysed and supported by non-governmental organizations (NGOs) and strengthened through partnerships between health professionals and lay community members (Klarenberg, Masondo, David, & Harris, 2005). Community participation is a tool often used by NGOs from a non-profit approach by involving individuals from the community to assist in service delivery by being a part of processes affecting their lives

(Klarenberg et al.,2005). The benefits of community participation are that the community becomes empowered to take responsibility for their own health, health awareness and health practices. Thus, assisting in sustainability as knowledge about health behaviour is advocated by community members themselves. In the current study, some of the community participation activities and practices are, counselling for voluntary counselling and testing of HIV/AIDS campaigns, counselling youth on risk behaviour in peer education programmes, frail and child care training and, nutritional and dietary knowledge and guidance assisting teachers and community members in and around the local communities in Stellenbosch. . Through directly involving the community to participate in health promotion, prevention and sustainability projects; community participation is viewed as a tool of empowerment giving local communities the ability to diagnose and solve their own health-related problems (Claridge, 2004)

## CHAPTER 2

### Literature Review

#### 2. Introduction

Community participation practices have always largely been endorsed by the World Health Organisation (WHO) and other large funding organisations (Rifkin, 2001). The concept of community participation continues to be of interest of health policymakers more than thirty years after it was initially introduced as a developmental tool (Morgan, 2001; Rifkin, 2014).

Community participation is a tool that enables people to be responsible for their own health outcomes. It aims to create empowerment, awareness and sustainability about health issues affecting community members (Sarkissian, Walsh, & Cook, 1997). Community participation in health care is largely driven by NGOs, since NGOs are assumed by funders, to be the best equipped organisations to identify and realistically represent the actual needs of communities (Van Driel & Van Haren, 2003).

Policies about community participation in practice are primarily formulated using top-down approaches; these policies are formulated on a national level and are implemented by different NGOs (Kelly, Yutthaphonphinit, Seubsman & Sleight, 2012). However, more effective and more practical policy implementation is often done using the bottom-up approach to community participation policies (Girdwood, 2013). The bottom-up approach takes into consideration the challenges faced by community participants at the grassroots level, during the community participation implementation process. Directly gaining insight from community participants on the policies that can be effectively implemented compared to policies proving to be more challenging to implement as intended. Even though community participation is largely

driven and used by organisations that are fundamentally non-governmental (NGOs), community participation policies are still asserted and formulated by key stakeholders, i.e., government officials and policymakers (Zakus & Lysack, 1998). Thus NGO stakeholders, i.e. staff members, managers and directors, attempt to apply community participation policies as prescribed by key stakeholders (Girdwood, 2016).

The implementation of community participation is the responsibility of local health programme planners and facilitators (Girdwood, 2016). However, community participation is a complex concept having an array of different meanings and definitions. Thus a variety of definitions and forms of community participation exist, making it difficult identify and apply the method of community participation that will ensure the most effective health promotion outcomes (Zakus & Lysack, 1998). Multiple meanings may create confusion during the implementation of community participation if the expectations and aims are not clearly defined and community participation practices are not later evaluated by policymakers. Hence, Matland (1995) proposes that how community participation is implemented be left to the discretion of NGO community participants because they would be most knowledgeable regarding the health needs of the particular community they are serving.

According to Matland (1995) the bottom-up approach contends that if local organisations, i.e., health-related NGOs are not allowed discretion in adjusting community participation implementation to suit their local communities, failure is inevitable. Despite the popularity of community participation amongst analyst and policymakers, there is still a considerable lack of evidence that links community participation directly to improved health outcomes because community participation is not adequately documented from policy conception to implementation (Rifkin 2014). A lack of documentation is partly due to the small scale and weak

resource base of NGOs attributed to time consuming administrative training and filing which NGOs often cannot invest in due to a shortage of funds and staff (DeJong, 1991). The lack of vital information i.e., records of community participation practices, implementation methods, which methods worked effectively and which methods proved ineffective; creates a gap between the implementation and formal documentation of community participation in NGOs (DeJong, 1991). However, funding organisations i.e., WHO and UNICEF invest in community participation primarily based on the critical assumptions that: communities want to be more involved in the promotion of their own health; that community participation is encouraged by attracting community participants with incentives to participate (Rifkin, 2011); providing people with information about health will automatically change their behaviour (Ottawa Charter, 1986); community participation will create capacity building, empowerment and sustainability (Rifkin, 1986, 2011, 2014). Funding is imperative for effective community participation. Rifkin (2014) believes that community participation can contribute significantly to health promotion, if adequate resources i.e., money, time and support is provided by influential people within the community (Rifkin, 2011).

This review will highlight the ways in which community participation is practiced in the health-related NGOs; and how policies are formulated and implemented. It will also focus on bottom-up and top-down approaches of policy implementation and community participation practices and how the use of these approaches affects the health outcomes and well-being of community participants. The key concepts will be defined followed by the contextual meanings of the core constructs which formed the basis of this study. Furthermore, a theoretical framework based on the community health psychology from an ecological multi-level perspective, will

follow this review to better understand community participation within the community health psychology paradigm.

## **2.1 Definitions of key concepts**

### **2.1.1 Community members, participants and participation outcomes**

According to Cohen (1985) people co-existing in close proximity define a community. Sharing and living in the same geographical space. For the purpose of this study, people living in and around Stellenbosch are defined as the community members. Community members can therefore form part of different NGOs as community participants, participating in certain NGO related projects and programmes often run by the NGO and local government offices. Therefore a community participant is a community member who engages in an activity within their community, in order to assist others and themselves in different activities enhancing their lifestyles in terms of health and well-being. In this study a community participant is defined as a community member from Stellenbosch, participating in health-related NGO activities and programmes (Boyce & Lysack, 2000).

The outcomes of community participation can be defined as the results attributed to community participation practices in health systems. All aspects of community participation from positive, neutral to negative which possibly indicates that community participation practices are key factors in service delivery (Preston et al., 2009). Respectively; positive, neutral and negative community participation outcomes refers to, increased health services contributing towards increased health outcomes, zero impact or change attributed to community participation in health care service provision and also less desired health outcomes due to the involvement of

community participation in health programmes. Health outcomes include whether the state of health has improved or declined in the presence (and sometimes absence) of intervention. Health outcomes refer to positive, neutral and negative results in individual, group and population health status after planned intervention (Berenson et al., 2013). In the context of the current study intervention is taken in the form of community participants involved in health-related NGO programmes focused on health promotion.

### **2.1.2 Health promotion and health care**

According to the World Health Organisation (2001) health promotion is a process that allows community members to have control over and improve their own health, focusing on interventions that go beyond individual behaviour by taking into account social and environmental factors. Health promotion is not to be confused with health care. Health care encompasses improvement and the maintenance of both physical and mental health, especially through the availability of adequate medical services. According to Belcon, Ahmed, Younis, & Bongyu (2009) health care also serves to prevent illness, while maintaining mental and physical health, and is therefore more than medical care. Thus health care is not limited to the accessibility of medical care but also the continuous maintenance of holistic health (Belcon et al., 2009).

### **2.1.3 Stakeholders and key stakeholders**

There are three forms of stakeholders, primary, secondary and key stakeholders. Primary and secondary stakeholders are people in organisations like NGOs who may positively or negatively,

affect or be affected by, policies and objectives of an organisation, i.e. staff, directors, government, owners and in some cases the community in which the organisation operates (Patterson, 1999). Primary stakeholders are beneficiaries and targets of effort. Beneficiaries are people who are eligible to receive certain benefits under a given policy. In health-related NGOs, beneficiaries are referred to people who receive certain benefits from participating health promoting NGO activities (Boyce & Lysack, 2000)

Secondary stakeholders are people who are primarily responsible for beneficiaries and targets of effort. Key stakeholders are defined as government officials and policymakers who formally plan policies and enforce laws and legislation pertaining to these policies (Rabinowitz, 2013). For the purpose of this study primary stakeholders refer to community members benefitting from tasks and health programmes, also known as beneficiaries. Secondary stakeholders are the NGO directors, staff and managements working directly with beneficiaries and the community. Lastly, Key stakeholders will refer to government officials and policymakers, specifically those in charge of designing community participation policies. Only secondary stakeholders perspectives are accounted for in this study however, reference is made to primary and key stakeholders throughout the current study.

#### **2.1.4 Stakeholder perspectives**

Stakeholder perspectives refer to different views taken by stakeholders depending on the degree of their involvement in an organisation. Stakeholder perspectives can be categorised in different ways, two of these perspectives applicable to this study are the ethical and integrated perspectives (Kouwenhoven, 2009). The ethical perspective is the perspective concerned with making sure all members of the organisation are treated fairly, while all opinions, preferences

and interests are taken into account in order to ensure the maximum positive outcomes (Heath & Norman, 2004). This ethical approach in stakeholder perspectives focuses on fairly assessing the needs of the community by directly involving influential people representing the community in the decision-making process (Laplume, Sonpar & Litz, 2008). This approach is achieved when NGO stakeholders interpret the feedback from the community members and incorporate it into the organisational policymaking process and then applies it in terms of implementation of those policies. The other stakeholder perspective is known as the integrated perspective (Laplume, Sonpar & Litz, 2008). The integrated perspective suggests that an organisation cannot function or adequately operate within a given community or society if it does not take into consideration the views of all stakeholders (Laplume, Sonpar & Litz, 2008). This perspective holds that decisions and actions are interlinked between multiple stakeholder interests including; primary, secondary and key stakeholder perspectives. Thus, for the purposes of this study, health-related NGO stakeholders who make decisions in isolation of the multitude of stakeholders may overlook potential threats. These potential threats could be prevented and treated by directly involving other stakeholders, i.e., community members before, during and after implementing community participation policies to health promotion (Roberts & Mahoney, 2004).

It should be noted that the ethical view of stakeholders focuses on fairness emphasising a right and wrong way to act or react. Over-emphasising this perspective within an organisation could result in the loss of attaining the initial aims of the NGO by focusing too much attention on what everyone needs, as opposed to what the NGO can provide and what the initial health-related and health promotion goals were (Heath & Norman, 2004; Roberts & Mahoney, 2004 ).

## **2.2 Community Participation Defined**

Community participation is a tool used by different sectors i.e, health, international rural development, governance and environment, in order to increase sustainability and empowerment of community members within a given community working towards providing more adequate services in their own communities. For the purposes of this study community participation in health or more specifically health-related NGOs was the main focus. Community participation in practice is believed to assist in health promotion due to the participation of lay community members. Community participation has become a valued strategy founded on efficiency, equity and social cohesiveness it contributes to different health promoting programmes (Sarkissian, Walsh, & Cook, 1997). However, community participation is a complex and loaded concept, which can be defined in various ways across various contexts (Zakus & Lysack, 1998)

In order to better understand community participation and its complexities, it will broadly be defined in the following section by firstly defining community and participation separately before defining it as a concept. A contextual definition of community participation as a concept in health care and health promotion will follow the aforementioned definitions.

### **2.2.1 Defining community**

A community can be defined in two ways, either through affinity or geography. The primary idea that constitutes a community is based on a relationship that exists between two or more parties. In community groups based on affinity, shared human characteristics which they cannot change, such as ethnicity, age, gender, disablement, and sexual orientation is what makes them a community (Glisson, Dulmus & Sowers, 2012). However the more conventional definition of community is based on people living in the same geographical location or co-existing in close proximity of each other, sharing the same goals and ideals (Boyce & Lysack,

2000). It is also important to note that communities serve as key mediators between individual and social levels (Campbell & Murray, 2004)

Moreover, when it comes to defining the concept of community it is essential to recognise that most communities are heterogeneous and not homogenous (Claridge, 2004; Mompati & Prinsen, 2000). In heterogeneous communities, people come from different backgrounds, i.e., income, race and ethnicity and more often homogeneous groups exist within heterogeneous communities (Alesina & Ferrara, 2000). It is thus important to understand that a community consists of multiple interests and actors, influencing decision-making that affects the people in the community (Agrawal & Gibson, 1999; Claridge, 2004).

### **2.2.2 Defining Participation**

The concepts of participation and community participation are often used interchangeably within the literature (Claridge, 2004; White, 1981). Many definitions of participation refer to a continuum of participation at different levels of community involvement. Hence, participation is primarily defined as the involvement of community members and stakeholders in, decision-making regarding development projects or the implementation of development projects. Thus creating an opportunity for information to be passed from the community to stakeholders to ensure decisions are based on input from the community in which it is applied (Devas & Grant, 2003). According to Sarkissian et al. (1997), when participants are able to assist in determining the outcomes, participation is perceived to be genuine. Participation is therefore important, in order to involve the community in decisions and actions that impact their lives (Claridge, 2004).

However without a proper context, i.e., health promotion, development projects, urban renewal, etc., the concept of participation will be lost or misinterpreted. Furthermore, the participation of community members in health-related projects forms the basis of this study. The next section serves to look at community participation as it is defined in the literature as well as in the context of health care, health promotion and prevention projects.

### **2.2.3 Defining community participation in context**

The World Health Organization (2001) defines community participation as a collaborative process in which people voluntarily agree to collaborate with an externally determined project. Community participation is thus also viewed as an empowerment tool through which local communities take responsibility for diagnosing and working to solve their own health and development problems (Morgan, 2001). The conceptual development of community participation is predominantly attributed to the World Health Organisation and other similar large multinational institutions, which causes a disconnection between the conceptualisation of community participation and the implementation of community participation (Zakus & Lysack, 1998). According to Rifkin (2014) in spite of three decades of interest in community participation by key stakeholders, there is not enough concrete evidence linking community participation directly to improved health outcomes.

Ultimately community participation, in health care, strives to prevent illness and promote health and well-being of community members by allowing community members to identify their needs, assist in decision-making to establish mechanisms to meet the needs they identified (Ndekha et al, 2003). The common element defining community participation is the emphasis on a partnership that exists between the community and respective stakeholders. This partnership

creates empowerment within the community and a sense of responsibility from both parties regarding health-related issues in their community. Community participation indicates an active role of the community which ultimately leads to significant control over decision making (Claridge, 2004). These aforementioned, key aspects of community participation, namely prevention, promotion and empowerment are the building blocks and the guide to community participation practice and also results in the provision of services that benefit both stakeholders and beneficiaries. Community participation relies on having a good understanding about communities and group dynamics, within those communities. Interventions are most effective when the community itself supports the identified health needs, priorities, capacities and barriers to action (McLeroy, 2003). According to Arnestein (1969) in order for health promotion to work well, health programmes must be implemented by or with the people as opposed to on the people. This means that those involved in community participation are partners in health promotion and not subjects merely benefiting from community participation programmes (McLeroy, 2003).

The establishment of meaningful partnerships between community participants and stakeholders are the building blocks and the guide to effective community participation and also results in the provision of services that benefit both stakeholders and beneficiaries. Community participation relies on having a good understanding to the communities and group dynamics within those communities (Campbell & Murray, 2004).). Interventions work most effectively when the community itself supports the identified health needs, priorities, capacities and barriers to action (WHO, 2007). For health promotion to work well, it must be carried out by and with the people as opposed on or to the people. This means that those involved in community participation are partners in health promotion and not subjects merely benefiting from community participation programmes (McLeroy 2003).

According to Rifkin (1996) community participation has been a critical part of health programmes, since the acceptance of primary health care as the health policy of the member states of the World Health Organisation. However, it has rarely met the expectations of health planners and key stakeholders. Rifkin (1996) argues that the reason for this failure is attributed to unrealistic expectations by planners that community participation can alleviate community problems yet issues are embedded in rigid systems, i.e. policy in health care systems, limited resources, etc. In addition, Cuero (2004), states that the reason for this failure is because programme designers assume that: people will automatically be supportive of health services if they are allowed to make decisions about the way services are delivered; people are willing to invest time and effort into improving the health conditions in their community; people will alter their health behaviours when they are involved in decisions promoting healthy behavior; Lastly, that people will feel a sense of empowerment by acquiring knowledge, confidence and skills while being involved in community health promotion programmes.

Community participation is beneficial in assisting the structuring and planning of NGOs and more specifically, health-related NGOs (Báez & Barron, 2006). In order for the planning of participation practices to work in full effect, stakeholders and policy makers need to be made aware of the challenges in the health sector when setting certain goals (Báez & Barron, 2006). Goals may be set out by various stakeholders but not all of these goals can be achieved in reality as stated by policymakers. The goals include empowering the community and building capacities by enabling them to sustain health promoting behaviour (WHO, 2001).

#### **2.2.4 The purpose of community participation**

The Alma-Ata (1978) states that individuals and groups have the right to directly participate in the implementation and planning of their own health and the health care of others in their community. Collaboration efforts in the implementation and planning of health care and health promotion is encouraged among community participants and stakeholders (i.e., health professionals, NGO staff, etc.) alike (Nkwake, Trandafili & Hughey, 2013). This approach of collaboration between the community members and stakeholders creates an opportunity for community participants to get directly involved in improving the conditions health and well-being within their community by the means of community participation (Khan & Van Den Heuvel, 2007). Thus the main purpose of community participation is to promote the health and well-being of communities through collaboration between community members and secondary stakeholders.

In order to ensure that community participation works optimally and efficiently to promote health, there is a need for, consistent commitment to the primary principle of health for all and consistent policy and action that is not disintegrated (Lawn et al., 2008). Thus, there is a need to bridge the gap between existing policies and the implementation of community participation policies (Rifkin, 2014). The purpose of community participation is primarily based on health promotion through collaboration and partnerships between community members and health professionals.

#### **2.3 Non-governmental Organisation (NGO) and Health-related NGOs**

Non-governmental organisations known as NGOs are defined as privately run, not-for-profit organisations aiming to serve specific societal needs and interests (Kouwenhoven, 2009). These organisations are largely staffed by altruistic workers and volunteers working towards achieving ideological goals rather than gaining financial compensation (Werker & Ahmed, 2008). NGOs are primarily concerned with advocating for social, political and economic goals to be met. These goals include equity, health and human rights (Kouwenhoven, 2009).

These NGOs are professionally staffed non-profit groups run by ordinary citizens, functioning independent of government (Streeten, 1997). Health-related NGOs are organisations participating in supplementary health related programmes by providing health care and assisting the health promotion of the community it is based in (Morgan, 2001). NGOs provide extra health services when the local government may not have the resources to do so. Health-related NGOs provide services in addition to, or paired with, primary health services provided by government. These services are provided with the help of community members participation in health promotion programmes by assisting in service provision.

#### **2.4 Community participation in NGOs**

After a range of successful health projects were run by NGOs embedded in the community and responding to health needs that were identified by the community, community participation was acknowledged as an essential tool for enhancing health care (Lawn et al., 2008). Thus the potential for health promotion using community members was identified. Community participants are the driving force of NGOs in providing efficient service delivery (Lang, 2000; Trickett, 2013).

Health-related NGOs assist in providing sufficient health care service delivery with the use of community participation (DeJong, 1991). Health-related NGOs thus aim to promote the health and well-being of community members through collaboration of stakeholders and the empowerment of the community, through their involvement in planned community projects. It is difficult to measure how these goals are attained and how much of the policy and planning can be implemented and executed (Morgan, 2001). The success of primary health care depends on the interactions of families and communities with health care workers (Lawn et al, 2008). Although the strength of community action and low level trained workers is well proven, they must not be exploited as this happened all too often in the past. Another pitfall is the lack of systematic planning and investment in supervision and on the job training. Many of these principles are lessons learned by trial and error decades since Alma-Ata, despite limited attention to systematic evaluation (Lawn et al., 2008).

According to Fischer (1993) there is a lack of documentation related to the practice of community participation in health-related NGOs. Community participation for health was a central tenet of the comprehensive primary health care approach although more difficult to implement (Lawn et al., 2008). Policymakers often set up community participation policies and rarely review the implementation of these practices. Thus the implementation of community participation requires specific directives from policymakers as it may be executed and interpreted differently by those who practice community participation (Bonham & Nathan, 2002). A lack of documentation is partly due to the small scale and weak resource base of NGOs (DeJong, 1991). The shortage of vital information creates a gap between the implementation and documentation of community participation in NGOs (DeJong, 1991).

## **2.5 Policymaking and implementing in health-related NGOs**

As a central principle of the Alma-Ata, community participation was essential in promoting better health for all with a strong focus on health prioritisation and action (Arnestein, 1969). Community participation as prescribed by policymakers ought to be driven by communities while linked with other sectors beyond health. Notably these sectors beyond health refer to sectors of education, agriculture, and food security as well as the environment (i.e. water and sanitation) (Lawn et al, 2008). A major problem in practicing efficient community participation is that policymakers rarely interact with community participants on the grassroots level. Communication between different stakeholders is imperative in order to adequately connect and execute the intention of policies with the implementation of community participation (Khan & Van Den Heuvel, 2007). In the following section the policymaking and implementing processes of community participation in health-related NGOs will be discussed.

### **2.5.1 Community participation policymaking process**

The WHO strongly believes in and advocates for community participation in health enabling programmes. As a result of this endorsement, the World Bank has funded many community participation programmes to assist in the provision of better and more efficient service delivery in health care (Mansuri & Rao, 2012). The community participation policymaking and implementing process was thus of interest to funders and stakeholders in order to ensure that community participation practices are indeed assisting in efficient service delivery, health prioritization and action. However, policymakers acknowledge that in order to set effective community participation policies in health enabling contexts the community members must be involved in the entire process from policymaking to implementation (Mansuri & Rao, 2012).

According to Preston et al. (2009) new policies need to take into consideration already existing policies that could possibly impact the implementation of those new policies. Existing policies could either enhance new policies or form a barrier preventing the effective implementation of new policies. Community participation policies are thus particularly set up based on already existing policies in an organisation. Particularly in health-related NGOs, community participation is employed to enhance health and well-being while serving as a vehicle for behavioural change (Campbell & Murray, 2004). Each health-related NGO has a unique target group or health problem, i.e., alleviating substance abuse, HIV risk groups, frail care patients, etc. Consequently, each health-related NGO is unique and function differently yet they operate under general health policies which may work well for some health-related NGOs yet fail to work in others. Therefore, general and amended community participation policies are prescribed to be set by policymakers in partnership with community participants working in different types of health-related NGOs (Campbell & Murray, 2004; Nkwake et al., 2013).

Key stakeholders undertake to encourage and facilitate clearly defined community participation practices in the general community participation policy and decision making process. During this process stakeholders opt to involve beneficiaries appropriately by working openly and transparently with members of the community (Irvin & Stansbury, 2004). According to Holcombe (1995) the need for community participation increased as it became more apparent that the world's poor suffered as a result of development. It was thus clear that all stakeholders need to be involved in the development of community participatory decisions and implementation. Failure to involve primary stakeholders i.e., communities, in the community participation policy and decision making process could potentially result in; a lack of scope for adequately implementing, evaluating and improving community participation practices; failure

of policymakers to gain legitimacy of decisions and failure to build strategic alliances with the community (Irvin & Stansbury, 2004).

However, as participatory approaches advanced they highlighted the weaknesses inherent in traditional top-down approaches to developing community participation policies (Claridge, 2004). The 1980s was known as the participation boom, a time in which the change from top-down to bottom-up approaches was sparked by acknowledging the value of including local knowledge in the decision making process (Kelly, 2001). Participation grew increasingly during this period, specifically amongst NGOs seeking alternatives to top-down approaches (Claridge, 2004; Kelly, 2001). Thus, according advocates of community participation, involving the community members in the policymaking process yields certain benefits as an alternative to traditional top-down approaches in improving general health and well-being. These benefits of community participation include, improved service delivery in community health, increased livelihood opportunities and optimal management of resources by local communities (Mansuri & Rao, 2012).

According to a study by Preston et al. (2009) community participation is endorsed for its perceived benefits yet there seems to be no evidence base to support these benefits. In their study Preston et al. (2009) states that a lack of evidence does not necessary mean a lack of community participation outcomes. The study found that policymakers reluctantly analyse and measure community participation if the desired outcomes, set by local governments, were successfully achieved. The main aim of the study was to create an evidence base for community participation practices to determine how community participation is practiced and; how it influences community participation outcomes and service delivery by reviewing already existing literature

and building on it. After reviewing 161 papers the study found evidence that community participation often results in favourable outcomes yet highlighted that too few studies reported on the specific role of community participation. The analysis of the reviewed papers indicates that it is impossible to align a specific conceptual approach to community participation in the achievement of particular types of health issues and outcomes. However, studies which often reported positive health outcomes and extensive participation did not always clearly describe the connection between the two. Preston et al. (2009) acknowledged that writing about community participation frequently describes what governments, health systems and organisation propose for it to be as opposed to what community participation truly encompasses.

Daniels, Clarke and Ringsberg (2012) did a study exploring policy development from the perspective of policymakers. A total of 11 policymakers were individually interviewed giving insight into community participation policy development strategies. The study found that policymakers in South Africa often developed, implemented and re-developed community participation policies based on how effective or ineffective the policies were during implementation (Daniels et al., 2012). They found that the ever-changing, working conditions and health needs, in different health-related systems and organisations drove community participation policy re-development. Thus the study highlighted the inability of policymakers to adequately bridge the gap between the policymaking process and policy implementation. Policymakers rather focused on what hinders policy implementation and re-developed community participation policies accordingly. In conclusion, Daniels et al. (2012) indicated that community participation policy re-development focused on resolving issues that caused effective community participation implementation to fail by encouraging feedback from community participants. According to Daniels et al. (2012) policymakers would have more successful

community participation implementation outcomes if community members were allowed to be a part of the policymaking process (Daniels et al., 2012).

In a thorough review, barriers to community participation practices and issues of variability in the role and participation of community members in NGOs were reported (Morris, 2006). In this review Morris (2006) reported findings of inconsistency in the definition, interpretation and implementation of community participation in NGOs. These inconsistencies presented the most significant barriers to achieving positive community participation and health outcomes (Morris, 2006). A Panel of experts on community participation thus interviewed 38 expert witnesses to form a unique perspective on the factors enabling and inhibiting community participation (Morris, 2006). Their comments revealed inconsistency in implementing community participation within and across government departments and NGOs.

Thus, community participation is an effective tool for positive health outcomes, yet there is a lack of documentation showing the manner in which policies about community participation are directly used in the implementation of community participation in practice. In the literature community participation policies are set around existing mutually exclusive policies in order to avoid conflict or barriers to positive community participation outcomes. In order to effectively implement community participation policies, community participants may need a point of reference to guide them in effective implementation. Albeit difficult, some studies indicate community participation ought to be clearly defined and this definition needs to officially be documented. The literature suggests bridging the gap from policymaking to effective implementation; by involving community members in the policymaking process, defining community participation, documenting how it is currently practiced and gaining insight from community members on how it can be improved.

### **2.5.2 Community participation policy implementation**

NGOs make use of community participation and rely on the members of the community to ensure that services are provided. The literature however shows a lack of documentation on community participation practices in health care as well as health-related NGOs. There are perceived benefits of community participation (Kironde & Kahirimbanyi 2002; Egboh n.d.). Due to a lack of documentation of community participation practices from policy to implementation, insight into the translation of policy into practice is needed (DeJong, 1991).

Even though a lack of documentation is evident there are however special cases within the community participation in NGOs where certain policies are practiced and perhaps not documented and not always processed via directors, managers and other stakeholders of health-related NGOs. The policies which are unaccounted for or undocumented within the health-related NGO system needs to be recorded in order to bridge the gap between official community participation policies made by stakeholders and community participation practices within health-related NGOs.

Thus, the need for research to address community participation practices in relation to theory, policies and implementation exists. The current research study, therefore documented current community participation practices specifically in health-related NGOs due to the general lack of documentation showing community participation policies are implemented. Focusing on how community participation is being practiced in health-related NGOs and how policies related to community participation is designed and implemented. Therefore the theoretical framework

focuses on the multi-level ecological perspective employed by the community health psychology approach.

## **2.6 Theoretical framework**

The community health psychology theoretical approach formed the basis of the current study. Community health psychology adopts an ecological perspective in which individuals are seen as embedded in a smaller system, at the individual level of analysis which forms part of larger systems i.e., community and societal levels (Murray et al., 2004). Individuals have certain health needs provided by health-related NGOs in the absence of formal health care. These individuals form part of dynamic groups like families, work, school, church, etc., in turn forming part of communities and social institutions. Community health psychology assists in understanding health promotion and intervention in the context of these mutually exclusive groups within communities. It draws together how different factors influence health outcomes, by assessing health needs of individuals and groups in different communities. If health-related NGOs are fully aware of the health needs in a community, health programmes and policies can be set accordingly and thus foster effective health promotion.

The aim of community health psychology is to investigate the community factors that contribute to health and well-being (Boundless, 2015). According to the literature a factor contributing to positive health outcomes is community participation, thus community participation practices in health-related NGOs was one of the key concerns in the current study. Focusing mainly on whether community participation is implemented in NGOs as per the expectations and instructions of policymakers. Community health psychology was used to assist

in understanding how community participation practiced in different community health initiatives within health-related NGOs in Stellenbosch (Campbell & Murray, 2004). Some examples of community health initiatives include HIV/AIDS awareness campaigns and events, providing free HIV/AIDS testing facilities, etc. These different health initiatives are complex within health-related NGOs because individual, community and societal level interventions all work concurrently yet mutually exclusive in maintaining and promoting positive health outcomes. A multi-level ecological perspective provided a lens through which community participation is developed and aimed to be implemented in the context of health related NGOs.

At the individual level, people within a given community either seek assistance from health-related NGOs or assist in service delivery and health care programmes, to alleviate health issues. Community health psychology supports the notion that individuals within every community have strengths that could richly contribute if they are allowed to be involved in projects concerning themselves. Community health psychology focuses on community empowerment which emphasizes self-determination, democratic participation and power sharing amongst individuals in different communities and contexts.

At the community level, health-related NGOs form the vessels in which services can be provided in partnership with community members as they participate in health programs by delivering adequate health services. The individual level is where community members use their knowledge and skills to foster positive attitudes towards promoting positive health outcomes. Through participation local community members skills, knowledge and competencies are built. Their capabilities and resources are therefore expanded and this is the essences of empowerment. According to community health psychology, individuals are empowered when their skills and knowledge is used to assist in service provision. For the purposes of this study both the

individual and community levels of the ecological approach provided insight via the bottom-up approach to community participation practices and implementation in different NGOs. The bottom-up approach served to understand how community participation is practiced and what level of discretion was used by community participants and NGO staff alike after formal policies were introduced and enforced. While accounting for the amount of capacity building and empowerment by community participants within different health-related NGOs in Stellenbosch in order to make sense of the level of active participation and discretion in terms of implementing community participation related policies. .

At the societal level policymakers and key stakeholders develop community participation policies using the top-down approach in which community members participate and apply themselves in health promotional activities within health-related NGOs. This level is where policies are formally adapted into law by local and national government and the formally acknowledged by the health sector after substantial evidence is provided by NGOs and other organisational institutes confirming positive outcomes for certain programmes i.e., community participation focused programmes promoting health. In terms of the NGO stakeholders in the current study they are governed and often work in partnership with government regarding policies related to the NGO community participation practices. Often these policies are concurrently implemented with other existing policies which are also enforced by local and provincial government.

At the societal level, government sets up policies for NGOs using top-down and bottom up approaches. The bottom-up approach is considered to be done in partnership with NGOs collaborating with the community members and beneficiaries about the most effective policies and how policies can be altered even when they are not yet formally passed but have been tried.

The top-down approach focuses more on professionals designing policies based on previously tested models that could be applied in different contexts. The current study looked at stakeholder perspectives on both approaches and how either approach was used to demonstrate how community participation policies are designed and in turn practiced specifically in NGOs in Stellenbosch.

Community health psychology through the adopted ecological perspective provided the lens to interpret stakeholder's perspectives in relation to the strengths and advantages of involving the community in their NGO initiatives and activities. Thus community health psychology paradigm assisted in understanding how community participation is practiced in health-related NGOs from stakeholder perspectives at different levels in terms of the ecological perspective. In community health psychology value is placed in emphasising the community-level analysis and action, the role of collective action in improving health and the potential role of partnerships between health-related NGOs and community members (Campbell & Murray, 2004).

Fundamentally, communities serve as a mediator between the individual and the society in which the individual functions. Individual forms part of different, sometimes inter-related social communities within a broader society. In reiteration, communities are heterogeneous with homogeneous groups coexisting in one community (Claridge, 2004; Mompati & Prinsen, 2000). Thus, community level of analysis takes into consideration the complexities that encompass working within communities to increase health promotion by reducing prevalent mental and physical illness in implementing health enabling programmes designed specifically for these communities (Campbell & Murray, 2004).

## **CHAPTER 3**

### **Methodology**

This study interpreted stakeholders' perspectives on community participation practices in health-related NGOs. In order to get a detailed understanding of their accounts, qualitative research methods were used to fully understand the depth of the issues in this study. Detailed narratives of this nature would not be possible if quantitative research methods were applied. This chapter presents the research methodology of this study, i.e., research methodology, design and procedure that were followed during the study. The chapter also explains how participants were enlisted to be part of the study and how data was collected and analysed. The ethical related issues and procedures as well as reflexivity which assisted in eradicating potential research bias in order gain validity and reliability for the findings of this study will also be discussed in this chapter (Malterud, 2001; Patton, 1999; Sofaer, 1999).

The current study addressed the following research question:

- (a) How is community participation currently being practiced in NGOs dealing with health-related issues in the Stellenbosch area?

#### **3.1 Aims of This Study**

Three primary aims were explored this study. The aims of the study were to:

- Document the current community participation practices in health-related NGOs in Stellenbosch.
- to examine how community participation is practiced/implemented by these NGOs and how it is formulated in their policies
- to identify which community stakeholders are involved in community participation activities and their roles in the NGOs that formed part of the study.

### **3.2 Research Design**

The present study is a qualitative study that sought to elicit from the various stakeholders in health-related NGOs, which community participation practices and policies they implemented in their respective NGOs. According to Patton (2001) qualitative research allows the researcher to evaluate issues, cases or events in depth and detail. Qualitative research seeks to provide an understanding of a given research problem from different perspectives by gaining specific information from different populations (Mack *et al.*, 2005). The purpose of the study was to interpret information provided by stakeholders in health-related NGOs on their perspectives with regard to community participation and the policies that guide community participation activities in their respective NGOs.

An advantage of qualitative research in this particular research study is that it will allow for an array of detailed stakeholder perspectives to be taken into account. Qualitative research methods are valuable in providing rich descriptions for complex phenomena (Sofaer, 1999; Creswell, 1998). Thick descriptions provide a form of external validity describing phenomena in adequate detail (Holloway, 1997). In this study all stakeholders were asked to give their

individual perspectives in order to ensure unbiased and valid information came from stakeholders who are involved in health-related NGOs (Walt, Shiffman, Schneider, Murray, Brugha, & Gilson, 2008).

Various open ended questions were asked during key informant interviews which lasted between thirty to sixty minutes per interview. These open ended questions related to the community participation practices, policies and the implementation of those policies within the different NGOs which formed part of the study. All NGOs within the study are health-related of which stakeholders at different levels of governance within the NGOs participated as key informants. The aim of the proposed study was to document community participation practices from the perspectives of different stakeholders. Thus, qualitative research methods provided a clear platform to adequately elicit the information needed in this study hence, this approach was the best suited approach to follow.

### **3.3 Research Participants**

The sampling method used for the current study was purposive sampling. A purposive sampling method was used to ensure that people who meet certain criteria were included in this study (Berg, 1998; Coyne, 1996). The participants in the current study were drawn from various health-related NGOs in and around Stellenbosch in the Western Cape. Stakeholders were mainly directors and staff members who design and implement policies; and community representatives who participate in the functioning of each NGO. The research mainly targeted stakeholders, who set up policies for community participation and provide resources for efficiently running NGOs in the health sector for their participation. They were asked to answer open ended questions

related to the aims of goals and existing health-related NGO policies and their experiences or perception of the implementation of these policies.

The participants were selected in order to ensure that the correct information is gathered and the most representative sample was used (Marshall, 1996). Snow ball sampling was also used in order to make those members whom are difficult to locate, especially policymakers and community leaders more accessible (Marshall, 1996).

The participants in this study are also referred to as the stakeholders due to their positions in health-related NGOs. The role of each participant or stakeholder varied depending on the health-related NGO they served in. Stakeholders were managers, co-ordinators, counsellors, board members, etc. within their health-related NGO. The stakeholders who participated in this study were 11 in total. The male participant stakeholders were two out of the 11 stakeholders in turn the other 9 participating stakeholders were female. Participants were not restricted by age to participate in this study and ranged from 30 to 65 years in age. I would like to mention that age and gender did not significantly contribute to responses from the stakeholders. The participants in this study were either directly involved in the community participation practices of the NGO or has a great influence in how the NGO is run or managed by staff and community members. Stakeholders who participated in this study were all in a role of authority or management within the health-related NGOs. These participants' roles were that of management and primarily focused on the successful running of their health-related NGO, policy formulation and policy implementation.

All of the health-related NGOs involved in the study each had their own purpose and target group of people from the community, which they served. The drive, vision, mission and related goals were all dependent on the main purpose of the organisation itself. Although each

organisation served an array of different groups and different needs, they generally served communities in need of better health care, health promotion, health education and some provided training to lay community members to assist in health promotion programmes.

### **3.4 Data collection Procedure**

The participants in this study were all stakeholders in various health-related NGOs in and around Stellenbosch in the Western Cape. All health-related NGOs in the Stellenbosch area formed part of a health network and all the details to these health networks were easily accessible. All participants were emailed a letter inviting them to be part of this study (see appendix C). After this email was sent, I also followed up with a telephone call and in some cases more than one follow-up call was needed to explain anything that was not clear, without giving too much detail about the study. Many stakeholders followed up with me regarding times that best suited them as many participants expressed that they had very tight and busy schedules. All meetings for interviews occurred at the office of each participant. When I arrived at each location it was a very formal procedure of greeting and waiting until my scheduled time. Before the start of every interview participants were given a consent form (see appendix A), which they carefully read and was allowed to ask any further questions pertaining to the consent form before the interview commenced. Participants were also asked for permission to audio record the interview for the purpose of transcribing the interview with accuracy. After permission was granted and the consent forms were signed they handed it back to me immediately.

Data was collected by means of key informant interviews involving respective stakeholders. Key informant interviews enabled me to get a rich detailed narrative from those knowledgeable about the community in which they work, specifically, policymakers, directors

and community members (Marshall, 1996). Topics related to community participation, community participation policies and the implementation of community participation in NGOs were discussed. Stakeholders were thus asked if certain community participation policies existed in their frame of work and if they think there is a difference between policy and the way they implement policy. The interviews followed an interview schedule (see appendix B) that was written before the interview as a guide to the questions the study needed the participants to address.

The interviews were conducted solely by me, for the purposes of my Masters degree at Stellenbosch University. Data was collected over a period of six months in which 11 NGO directors, chairman and managers were interviewed. Due to labour intensive data collection the amount of participants was small hence the study accessed a range of opinions on community participation practices and policies. This access addressed community participation practices in health-related NGOs providing variability (Rutman, 1996). Data was collected until saturation was achieved in terms of grounded theory.

### **3.5 Data analysis**

According to Ryan (2006) the process of analysis means coming up with findings that stems directly from your data. Transcribed data from audio recorded tapes were thematically analysed. Thematic analysis in this study was done within the community health psychology paradigm. The specific approach to thematic analysis employed in this study in which theory is used as opposed to developing themes inductively was grounded theory. The community health psychology paradigm provides a scope for understanding stakeholders' perspectives on community participation practices, policies and implementation in the context of health-related NGOs as it is provided within the data (Braun & Clark, 2006). This paradigm focuses on health

promotion within health-related NGOs, by means of effective community participation implementation (Mcleroy, Bibeau, Steckler, & Glanz, 1988). The community health psychology paradigm addresses the importance of health promotion interventions and programmes i.e., community participation strategies, to be directed at changing interpersonal, organisational, community and public policy factors which support and maintain health promotion and well-being (Girdwood, 2013; Mcleroy, 1988).

The current study data was analysed by means of thematic analysis. One of the benefits of thematic analysis is its flexibility. The interview readings were transcribed and coded (Braun & Clarke, 2006). Thematic analysis is the process of separating raw transcribed data into themes and then further grouping emergent themes until no new themes emerged (Braun & Clarke, 2006). This method of thematic analysis is achieved when patterns in the data set are identified, carefully analysed and later described in detail. Thus, a rich description of the entire data set was thus provided (Braun & Clarke, 2006). Thematic data analysis as proposed by Braun and Clarke's (2006) step-by-step process was followed to effectively and thoroughly analyse the data in this study. Each theme has a main theme that branches out into a subset of related themes. Thematic analysis was used to code and arrange these themes (Braun & Clarke, 2006). The data was thoroughly read, coded and afterwards grouped to sort the different themes by means of thematic analysis (Braun & Clarke, 2006).

Firstly, data from audio tape recordings were transcribed from audio to typed electronic form. Each transcription was manually converted from audio into written form more than one time. This was done in order to cross-reference written transcriptions at a later stage, in case anything was misheard or incorrectly captured the first time. After the conversions were made

from audio to written form, transcriptions were thoroughly read individually in order to make meaning of what was said and what the underlying meanings were (Braun & Clarke, 2006). The second step of the data analysis process the readings were coded and grouped into themes, these themes were further separated into sub-themes related to the aims of the study. The third step of the data analysis process was making sure that sub-themes and related to the themes were including all the data, by reading and processing through all of the data again. The next step of the analysis was to interpret the themes in the context of my study by relating themes to each other and making meaning of these themes. After making sense of each of the themes the data analysis was written up detailing the meanings and findings in the form of a research report.

### **3.6 Reflexivity**

In qualitative research reflexivity is a tool used to legitimise, validate, and question research practices and representations of academic writing (Pillow, 2003). Researcher reflexivity is written by the researcher to account for potential biases by critically assessing the researchers' influence on the data collection process of the research holistically. Reflexivity in research involves reflection on one's self process and self-representation in terms of the research (Sultana, 2007). According to VerLinden (2010) research reflexivity is the process in which the researcher acknowledges that objectivity is not completely attained throughout the data collection process hence the researcher accounts for potential subjectivity during the data collection process.

The data for this particular qualitative study was obtained by means of key informant interviews. These interviews were primarily executed on a one-on-one basis and meant that I spent at least an hour with each of the participants during preparation as well as facilitation of the

research interview itself. It was initially difficult trying to build rapport with individuals of such high status and great influence within the NGOs as well as the community but the level of rapport increased as the interviews continued and a relationship of mutual respect was initiated and formed. I acknowledge that I was nervous at the start of the interview and I may have had unclear enunciation or an inability to articulate the questions clearly, after gaining confidence and clearly repeating or stating questions, participants freely engaged. As my confidence increased and became more apparent during the interviews so did my projection and articulation of the questions. This made it easier to get a response from participants.

My age played a role in the process as I am half the age of most of the participants of which the youngest participant was approximately six years older than I am. Before starting the interviews some of the participations formally requested to know how old I am before proceeding. As most of the participants were double my age, I asked them how they wanted to be addressed during the interview in order to ensure that there was not a lack of respect on my part which might hinder a response from the participants. In formally addressing them as they preferred the interviewing process was more relaxed as mutual respect was initially established.

Interviews were all conducted in English of which not all participants were first language English speaking. Half of the participants were Afrikaans first language and expressed that they had no problem doing the interview in English. This posed a problem with regard to articulation and expressing their opinions and thoughts. Some participants would change to Afrikaans if they got stuck with a thought or an idea which they found difficult to express in English. This made it challenging during transcribing and also data analysis in order to validate the meanings of the expressions translated directly from Afrikaans to English. However, by using notes and taking

into consideration the meaning attached to the Afrikaans expressions, the expressions were translated and not the words verbatim.

Some participants also agreed to avail themselves for at least an hour and somewhat rushed the interview due to organisational tasks which came up during the interviewing process. This means that they will have roughly answered questions according to what they think I wanted to hear in order to speed up the process. Others also took calls during the interview process or often checked their messages on their cell phones meaning that they did not fully pay attention to the interview. By making detailed notes during those interviews and also making sure all the important questions were addressed first during interviews, efficient data was collected throughout the interviewing process.

With each of the key informant interviews I was very aware of not being too leading when I asked questions. I was fully aware that some participants assumed that there was a correct way to answer my questions and some insisted on my input on their answers, to avoid asserting my own ideas I would often relay the discussion back to their health-related NGO practices, stating that each organisation is fundamentally different. This was to ensure that participants are aware that there were not correct ways to respond.

### **3.7 Ethical Considerations**

Ethical approval was sought from the Research Ethics Committee of Stellenbosch University and was fully granted. Permission was formally requested from NGO directors before involving any members of the selected NGOs. All participants were asked to participate willingly. Before commencing with each of the key informant interviews each participant was

asked to sign a consent form. These forms served to inform them that they are allowed and given the option to disengage from the research process should they wish to do so.

All the information provided by them was stored on a safe and secure password protected computer, of which only the person conducting the research had access. All hard copies of study related documentation was stored in a locked cabinet in the research supervisor's office. Pseudonyms were used in the research report and any other publications in order to ensure the confidentiality of participants.

## CHAPTER 4

### Results and Discussion

#### 4.1 Overview of stakeholders, NGOs and funding

This section serves as an overview of the study participants (also referred to in this study as stakeholders) and their positions in the health-related NGO they work in; health-related NGOs and the types of services they provide in the community of Stellenbosch; and the sources of funding that keeps the health-related NGOs operational.

Stellenbosch has a close inter-related group of NGOs all operating concurrently within the same geographical and professional setting. These NGOs have formed a professional network which includes a range of NGO in and around Stellenbosch. The purpose for the network is to ensure that NGOs are able to seek services and help from other health-related NGOs for their clients, patients, community members, whom they are not equipped to help. This network was formed in order to ensure that adequate services are provided to anyone who participates within the sphere of health-related NGOs in Stellenbosch. The network of health-related NGOs has a board of representatives from each NGO providing feedback during regular meetings, regarding health outcomes, issues and community participation within the network of health related NGOs.

##### 4.1.1 Roles of Participants in the Study

Understanding the role of each participant in the study was important in order to understand the perspective they brought to the key informant interviews. The position which each participant in this study had in terms of hierarchy in the network of health-related NGOs

was important. It showed their level of involvement in the decision making process. Some participants were not only managers and directors in their own NGO but also held a position of power amongst all the health-related NGOs i.e., managing the board of NGO representatives, etc.. The participants in this study were either directly involved in the community participation practices of the NGO or had a great influence in how the NGO is run or managed by staff and community members. The NGO representatives who participated in this study were all in a role of authority or management within the health-related NGOs. These participants indicated that their role was that of management and primarily focused on the successful running of the organisation, management and co-ordination of all health-related programmes within the respective NGOs. Health –related programmes included community participation programmes aimed at including community members in order to foster positive health outcomes.

All NGOs involved in the study aimed to cure, prevent or alleviate health issues within the community by focusing strongly on health promotion and wellness programmes. A strong emphasis was placed on health thus these NGOs are referred to as health-related NGOs. Each of these health-related NGOs had its own health focus and target group of people they wished to assist in providing better health. Albeit many of the health-related NGOs had different target groups with different needs, health promotion and positive health outcomes within the community was a common goal in all health-related NGOs. See Appendix D for a tabulated summary of each participant's NGO involvement and focus.

#### **4.1.2 Who Funds the Health-related NGOs?**

Health-related NGOs operate optimally when they are able to provide services that are well funded. The funding for each health-related NGO varied depending on who they aimed to

serve and how severe the health problem was according to national and international health funding organisations and firms. The participants conveyed that their health-related NGO was either funded in abundance or lacking funding overall. The health-related NGOs lacking funding expressed they needed to be creative in order to ensure funds met the financial needs of their organisation. However, some participants were reluctant to speak about funding due to the anonymity of the donors but still managed to give an account of how they kept their organisation running and which types of incentives were received. Smaller health-related NGOs involved in frail care, health care and related training programmes were more inclined to do independent fundraisers and private small donations contributing between R2000 to R5000 towards NGO programmes and projects. Larger health-related NGOs aimed at alleviating poverty, HIV awareness and counselling campaigns, chronic illness, malnutrition, etc. were able to get larger donations at undisclosed amounts depending on how dire treatment and action was perceived to be by donors. Participants also expressed that larger donations meant that they were inclined to report improvements and effective health outcomes to donors in order to ensure that funding was provided regularly or annually. One of the pre-requisites for gaining funding in health-related NGOs was incorporating community participation in health promotion programmes. Funders and donors were said to be reluctant in funding programmes and projects that were not formally advocated for by health professionals, academics and WHO, in the presence of documented positive health outcomes. This advocacy in turn generated interests from donors to invest in projects they perceived would yield positive health outcomes and health promotion.

## 4.2 Data Results

In this section the results that were obtained after careful data analysis will be reported. The discussion of these results will be included in this section in order to give a full descriptive account of the results obtained. Participants in this study gave their insight into community participation practices, policies and implementation in the NGOs they served. The discussion section for these results will discuss the three main themes in the context of Stellenbosch health-related NGOs.

Table 1

Master Themes

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The main themes:

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1. Community participation defined by the stakeholders
    - Community participation as a tool
    - Community participation increasing service delivery
    - Community participation promoting positive health outcomes
    - Community participation difficulties
  2. Community participation related policies
  3. Community participation practices and policy implementation
-

### **4.2.1 Community Participation Defined by NGO Stakeholders**

Stakeholders were asked to define community participation in their respective NGOs from their perspectives. These stakeholder perspectives were defined in terms of ethical and integrated perspectives. Stakeholder perspectives focused primarily on fair assessment of the community's needs by directly involving the community members and taking into consideration the interests and views of both, community members as well as stakeholders within the health-related NGOs. Community participation was thus defined by each one differently but had similar, related themes. Community participation was thus defined as a tool to increase sustainability and empowerment (beneficiaries); to help health promotion in the community by involving community members; and the selection process of getting members of the community involved in health programmes within the health related NGOs.

According to each of the stakeholders community participation was either open for anyone to participate or it was a selection process with specific aims in mind. The criterion was based on the goals of each NGO in terms of the need for health care provision, health promotion and positive health outcomes.

#### ***4.2.1.1 Community participation as a tool***

Community participation is a complex concept. As such, some stakeholders had difficulty articulating exactly what community participation meant in their organisation. The stakeholder perspectives accounted for community participation in the following ways; as community members willingly involved in health projects, as an empowerment tool, and by making health

services available. When asked how they defined community participation, the following responses were obtained ranging from basic to more complex.

Extract 1:

P7: ...we are based directly in the community we serve. Community members come to our offices where we do counselling and HIV testing.

P2: People from the community come to our organisation and say “we need your help”.

P8: We do not turn any child away, if they need sustenance, we provide it.

Extract 1, indicates how community members are seen by stakeholders as “participants” only when they willingly engage or seek help in programmes that will promote their own health and well-being. Examples of their willingness to engage in programmes to promote their health and assist them are expressed when P6 revealed that the NGO is based within the community it aims to assist to make access to HIV counselling more accessible, given that the community members approach the NGO if they are in need of assistance. Similarly, P2 expressed “*the community come to our organisation*”, indicating that participation is when the community seeks health assistance as a form of participation in improving their health. The very basic form of community participation is embedded in the notion that individuals in the community will seek help when they have identified their own health issues and needs. According to community health psychology, individuals are provided with certain services by NGOs to meet their health needs, in the absence of formal health care provision (Murray et al., 2004). Thus, individuals

forming part of a community in which formal health care is not readily available, will seek alternatives like health related NGOs to assist in their needs.

In the most rudimentary form when community members willingly join NGOs to receive some form of health-related assistance it is seen as community participation. Equally, community members may be the beneficiaries to certain health-related programmes designed by NGOs and may not know that they need assistance. These beneficiaries are often solicited by NGO staff to participate in health related programmes. In these cases stakeholders described community participation relatively different.

Extract: 2

P4: We encourage young adults from the poorer communities to join in our programmes; we want to create positive health habits like exercise and to build social skills...to keep them busy... and away from substance abuse.

P1: Our participants are parents of malnourished children. We explain to them why we want them to join our feeding scheme programme.

P11: Our organisation focuses on training unemployed and unskilled people from nearby farms, But they must be able to read and write.

The aforementioned narratives indicate certain conditions play an important role in how participants are solicited for community participation. Terms like, “*we encourage...to join in*”, “*we want them to join our...programme*” and “*Our organisation focuses on...unskilled people*” is an indication of predetermined aims for involving certain communities more so than others. Community members must meet certain criteria in order to be considered for a programme in

these health-related NGOs. After the criterion is met, i.e., health conditions, skill competency, age, income, etc., these factors determine whether or not they will be suitable beneficiaries to health promoting and enhancing programmes (Preston, Waugh, Taylor & Larkin, 2009). In extract 2, stakeholders mention criteria specifically like, P4 “*young adults from poorer communities*”, P11 “*unemployed and unskilled people from nearby farms*” and P1, “*parents of malnourished children*”, if community members did not match the criteria they would not be approached by the NGO to form part of health related programmes promoting health and well-being. The need for improvement should exist, the need for intervention should exist and most importantly the willingness of community members should be established with a strong level of rapport between the NGO and surrounding community.

Stakeholders perceive community participation as a means of empowerment through training and involving community members in assessing their own health needs and the needs of others in their community, by making them aware that they need assistance and further providing the assistance (Minkler, 2005; Murray, 2004). Thus, promoting health by enabling people to gain skills through participating in health programmes specifically designed for them. According to community health psychology, individual level analysis is merely the foundation of larger more dynamic systems. . Individuals gain assistance that is empowering and sustained for a long period because NGOs design health enabling programmes for sustainability purposes as mentioned by P1, “*We try to change their lives to make it more sustainable.*” In extract 2, P4 indicates “*create...health habits*” and P10 mentions “*...training...*” denoting that some form of altering, yet maintained health promoting behaviour is intended with each individual participant.

During the interviews many stakeholders expressed that anyone is free to join but certain groups or communities are targeted to alleviate certain health, social and behavioural problems. In Stellenbosch, health-related NGOs run very specific programmes concurrently and in partnership. When it comes to collaborative work in community health promotion, NGOs either wait for community members to seek assistance or approach community members who need help and assistance. Another form of community participation is when community members help assist people in their community in need of primary health care, in the absence of formal health care (Pollet, 2007; Preston et al., 2009).

#### ***4.2.1.2 Community participation increasing service delivery***

Community participation is primarily based on the risk of deteriorating health and sustainability within a given community, if health services are not made available to those communities (Pollet, 2007). Thus community participation often involves lay community members assisting NGOs in providing adequate health services (Bhuyan, 2004). During key informant interviews, stakeholders mentioned how community participation can be defined by means of directly involving community members. Community members assist in providing better health services when formal health care providers were not available.

Extract: 3

P3: Our volunteers develop skills and abilities to understand the community so they will be able to deliver services.

P4: We have a community support group in which members of the community come to support others in need of help with re-integration.

P7:...it is also when people from the community volunteer to train, serve and help in counselling and facilitation on HIV awareness.

P9: We have wellness advocates living on farms as partners of our NGO.

P11: Train unskilled and employed people...in providing and assisting in health care.

From the abovementioned extract, stakeholders expressed that community participation was not limited to people who seek assistance or community members sought out carefully by NGOs to participate, as previously discussed. Community participation is also the involvement of community members in training programmes empowering them to assist in health care service delivery within their own community. Community members are thus perceived as trained, “*community support*”, “*counselling... facilitators*” and “*wellness advocates*”. These are all terms denoting that knowledge is passed from expert NGO stakeholders to lay community members whom are based within the community. Thus, community participants also act as health liaisons between individuals in need of assistance and the health-related NGOs primarily providing the resources for health care assistance and service provision.

In the community health psychology framework, the contribution of community members in health care service delivery perpetuates the promotion of health and well-being to those communities (Campbell & Murray, 2004). Thus from an ecological perspective trained community members providing more adequate service delivery, serve as mediators between the individual and organisational levels of analysis. Stakeholders conveyed the need for community members based in the community to assist in providing services and accounted for this type of

service delivery and health care provision as community participation. Furthermore, individual level of analysis refers to beneficiaries to health programmes, whereas the community level involves community participants providing services in the context of health related NGOs at the organisational level.

Tethering these different levels, stakeholders expressed that health programmes could only run effectively if community members assisted with adequate training as expressed by P6, “*we need to know our volunteers are reliable and responsible*”. According to community health psychology training lay community members in proficient service delivery creates empowerment and sustainability as information is passed-on within the community by the community.

In the case of P4 in the aforementioned extract social support is structured to support people from the community who helps facilitate counselling. However, P4 also expressed views of social support during community participation as, “*We offer family support...because it’s a gesins’[family] disease*”, in which the family is counselled on how to provide the individual with the assistance while they improve their health and well-being. Family and social support circles are mutually exclusive to individuals in need of health care assistance. Community health psychology accounts for how people fully express their strengths and competencies when they are supported by social systems (Murray et al., 2004). Thus, within the community health psychology framework, the competencies and strengths within a given community can reach an optimal level of functioning if the correct social systems support the individuals.

#### *4.2.1.3 Community participation promoting positive health outcomes*

Often community support is rendered in the form of outreaches and awareness campaigns to prevent illness and promote healthy behaviour. Community participation was also defined by stakeholders as a means of having community members engage with and spread awareness of potential risks to health, within their community. The stakeholders therefore expressed how they also perceive and value the participation of community members in programmes serving as primary prevention measures.

Extract: 4

P8: They [volunteers/community participants] help our organisation with health and HIV awareness.

P3: We do... interventions like our volunteer counselling and testing campaign, and outreach programmes.

P4: ...we served an awareness campaign to promote a healthy lifestyle.

Extract 4 is an indication of how stakeholders interpreted community participation as a means of mediation between the community and health-related NGOs by enlisting and training trustworthy community participants. The mediation is to increase positive health promotion through awareness campaigns and outreaches by community members. Stakeholders used awareness campaigns to ensure that the community is aware of the risks of potential health threats. As mentioned by P3, “outreaches” are a form of intervention, more specifically primary intervention focusing on the prevention of illness aimed at promoting well-being. Similarly, P4

additionally describes community participation as the act of creating awareness to encourage healthy behaviour.

A primary goal of community health psychology is taking into consideration the power dynamics and contextual environments individuals reside in, in order to contest individualistic explanations and interpretations (Wandersman, & Florin; 2003). Power dynamics often exist between individuals, knowledgeable community members and stakeholders. A combination of community support, trained community members and organisational expertise serves to mediate health promotional programmes. Mediation often occurs at the community level of the ecological perspective. In the context of health-related NGOs community members are trained and participate in spreading awareness based on the existing rapport between them and the community as well as the rapport between them and stakeholders.

#### *4.2.1.4 Community participation difficulties*

Stake holders also expressed times when community participation was difficult to define and described noteworthy barriers to community participation. Stakeholders expressed barriers in theory and logistically with regard to defining and executing community participation in the context of health-related NGOs. The following stakeholders expressed exactly what those challenges were.

Extract: 5

P3: The biggest challenge is the term community because we cannot define the community we serve. We want to say Stellenbosch as a whole but mostly students participate in our NGO.

A community can either be defined as geographical or by affinity, as previously defined. In the case of P3, the definition of community was by affinity, restricting active community participants to the student population in Stellenbosch even though community participation was aimed at the geographical and general population in Stellenbosch, known in this study as the community members. It is crucial to identify the community whom the NGO services are aimed at to ensure effective community participation practices and implementation. Similarly other stakeholders identified ways in which community participation was difficult in reality.

Extract: 6

P2: Some community members do not want to be stigmatised and often request after hours participation in our health programmes.

The involvement in some projects required community members to work with health care professionals on projects regarding HIV or TB, which could stigmatise community participants when they return to the communities in which they reside. This fear of being ostracised altered the community participation schedule to suit community members who were interested in participating anonymously without being identified or associated with diseases treated or targeted by health-related NGOs. Community participation is thus often defined in a certain way by health-related NGOs. However, it can be altered later during implementation by taking into consideration the contextual and social issues expressed by community participants. Thus policies pertaining to community participation are structured to assist NGOs in understanding the complexities of community participation practices. Community participation policymaking process is developed to accommodate a structure of practicing community participation with the possibility of altering it while implementing it.

#### 4.2.2 Designing community participation policies in health-related NGOs

Community participation policies are designed using two key approaches, bottom-up or top-down (Matland, 1995; Preston et al., 2009). In some cases both approaches are applied depending on whether the need for accommodating both, yields any benefits to beneficiaries, stakeholders and the health-related NGOs providing services. The bottom-up approach helped to understand how community participants provide feedback regarding policy development, whereas the top-down approach focused on how stakeholders set community participation policies applied in their organisations. Thus, Stakeholders addressed the ways in which community participation policies are designed within and beyond their NGO. While describing the policy development, they also account for those involved in the policymaking process.

Extract: 7

P3: We have our ear on the ground when it comes to community involvement...

P7: We have meetings as a team in our NGO and then we source information from the volunteers or community participants

P9: We might not have the community sitting in our board meetings but we have a form of communication and feedback regarding community participation within our organisation.

P2: We have meetings to review policies about community participation and share it with the Western Cape Provincial board as our contribution.

Extract 7 indicates how policymaking develops at two different levels during the bottom-up approach from the grassroots level to the organisational level. According to the ecological perspective the individual level of community participation development involves gathering information about community participation practices from community participants themselves in order to create better policies or alter already existing policies to better suit the needs of the health-related NGOs. Moreover, the community level assists in linking ideas about community participation policies directly from the community participants to local and provincial government. In this instance NGO stakeholders act as liaisons between the community and government, both local and provincial. By providing a space to exchange ideas about improving service provision, NGOs are assisting in developing and re-developing community participation policies starting with lay community members.

The bottom-up approach also provides a space for NGO staff members to contribute to policy development at the community level, providing a collective perspective from them as stakeholders at the organisational level about community participation policy. Stakeholders responded giving their ideas about community participation policies and how those policies are developed.

Extract: 8

P2: We document and put together feedback of 40 NGO staff from different organisations, make a group decision on which policies work best and optimally for the best results.

Primarily community participation in the health sector and health-related NGOs in Stellenbosch are all interrelated as a health network is formed including different service providing NGOs. These NGOs all gather information in order to contribute towards improving community participation policies by providing feedback from their own organisations and community participants about effective community participation policies. Staff members are thus directly involved in evaluating policies and assisting in re-developing policies when granted an opportunity during local organisational meetings. P 2, also expressed “*meetings are quarterly*” but “*we present it to government every six months*”, indicating that they are consistently trying to provide local and provincial government in their organisational contribution pertaining to community participation policy amendments and adjustments.

Some stakeholders also expressed difficulties in developing community participation policies using the bottom-up approach. Health-related NGOs operate at different levels of community involvement in order to create effective health promoting programmes. For some stakeholders the bottom-up approach hinders the community participation policymaking process in various ways, i.e., unattainable expectations, a disconnection between theory and reality, impractical suggestions and misdiagnosed health problems, and disinterest from community participants. Stakeholders expressed these challenges in the following extract.

Extract: 9

P4: We get a lot of pressure from [people in] the community with unrealistic expectations.

P9: We have a bottom-up approach but it's not always practical, the community will say they struggle with one thing but we will later learn they have a host of other issues.

P3: Involving community members in policymaking is not always easy in reality.

P1: We try to involve them but they are just not interested.

According to Morgan (2001) community participation creates empowerment by means of involving community members directly in the decision making and policymaking process.

However, Rifkin (2009) argues that unrealistic expectations and assumptions by stakeholders and community participants regarding community participation can hinder positive outcomes. Thus community members may have idealistic views and may even misdiagnose health-related issues within their communities unknowingly. This, in turn slows down the process of improving or altering community participation policies to better suit the needs of the community members within health-related NGOs in Stellenbosch. Other problems which may arise during the policymaking process is when community members show less interest in their own health needs and lack the motivation to fully engage and participate in the policymaking process.

In terms of the ecological perspective the community level of analysis allows expert NGO stakeholders to interpret the views of the community participants, to relay these concerns and thoughts to stakeholders at the organisational and societal level. Thus, stakeholders adequately communicate grassroots level issues to formal policymakers, in order to change or alter policies without creating confusion during the bottom-up process of policymaking and development process. Hence, maintaining a level of empowerment and sustainability with

community participants by involving them in the decision making process Remaining mindful not to prohibit or limit involvement but also not to coerce them into participation during the policymaking process.

Contrast to the bottom-up approach to policy development, the top-down approach assists in fully developing and writing up community participation policies which are prescribed by and endorsed by key stakeholders in health-related NGOs (Girdwood, 2013; Preston et al., 2009). This is the more conventional way of developing policies, set and prescribed by government, down to NGO staff and community participants in health-related programmes. Traditionally policies have always been set at the societal level trickling down to NGOs, staff and community participants who later implement those policies. Thus, stakeholders described policymaking in health-related NGOs as prescribed by policymakers and key stakeholders using the top-down approach.

Extract: 10

P2: We cannot make policy decisions in our NGO...we do not write the long term policies.

P6: We have step-by-step instructions on community participation and how volunteers provide services in our organisation.

P11: Government makes the policies, we try our best to do it.

Long term policies have always been formally written by local and provincial government in order to create a sense of consistency within health services by lay community members. Policymaking includes prescriptive policies allocated to NGOs and furthermore

health-related NGOs in order to promote health and well-being. (WHO, 2001). The abovementioned extract highlights conventional policy development is formally written and prescribed by policymakers and key stakeholders without including NGO staff members and community participants in the process of developing those policies. Rather giving guidelines and instructions on what ought to be done on the organisational level. This may obstruct the implementation and execution of community participation in practice as those providing the services may not fully understand the connection between the policy and the implementation (Girdwood, 2013). P8 and P5, describe top-down policy and the disconnection between policy and implementation as follows:

Extract: 11

P9: Policy is a strange tool...and the implementation of it, it makes no sense, it doesn't speak to each other.

P5: The problem with policy is that there is a huge gap between making it and doing it.

The aforementioned extract describes the disconnection between policies set by government and key stakeholders and the implementation. Stakeholders expressed that interpreting policy related to community participation practices is difficult because the link between policy and implementation is often completely missed by many community participants and NGO stakeholders. Community health psychology adopts the ecological perspective which draws on the interrelated levels from individual level to societal level. Including and mutually

excluding these levels often assists in getting communities and organisations involved in health programmes which interest them and their own well-being.

The bottom-up and top-down approaches they are often applied concurrently during the policymaking process. While acknowledging that top-down approaches are the traditional and trusted way of setting policies, stakeholders discussed how using both methods to develop and re-develop policies worked better than choosing only one single approach. Highlighting the need for using both top-down and bottom-up approaches to policymaking to; evaluate how effective community participation policies are; who sets policies and; how those policies are set and later introduced to organisational staff and community participants (Girdwood, 2013; Matland, 1995).

The top-down approach prescribes how existing policies ought to be implemented whereas the bottom-up approach involve community participants who implement the policies for more effective results. Stakeholder's perspectives focus on fair assessment of needs and the direct involvement of people from the community while using the expertise of policymaker to help create effective and practical policies (Laplume, Sonpar & Litz, 2008). While NGO stakeholders use both methods and liaise between the organisational level and societal levels, to bridge the gap between policy development, implementation and re-development. Stakeholders described evolving community participation policies in their NGOs, by allowing discretion in policy implementation and providing evidence of successfully implemented, unofficial policies (Lawn et al., 2008).

Extract: 12

P4: Our policies are set for us, but we adjust them accordingly

P9: We structure community participation policy as we see fit

P10: We use policy as a guide and use what works for our organisation

When asked about community participation policies some NGO stakeholders admitted to using existing policies as guidelines and used their own discretion to alter it according to the needs to the community they serve or adjust it within the scope of services they provide. All health-related NGOs in Stellenbosch follow similar policies but provide different types of health services eradicating and combating different health issues. For these health-related NGOs health promotion and positive health outcomes were the main goals. Thus using the services of community participants in the absence of formal primary health care providers meant that policies had to be adjusted for easy implementation purposes and positive health outcomes.

According to Matland (1995) allowing NGO community participants to use their own discretion with policies can activate more useful practices, by using what best suits the needs of the community and ignoring policies that can unintentionally harm or ostracise community members. According to Girdwood (2013) community participation policies are more likely to succeed when taking into account the expertise of those impacted by the policies. In community health psychology community members possess the ability to adequately assess their own needs while professionals act as a collaborator or means to resources. NGO stakeholders went on to explain how using discretion and sometimes employing unofficial policies lead to formal acknowledgement by policymakers who later added it based on evidence of effectiveness.

Extract: 13

P3: Previously we had to be part of the treatment action campaign (TAC) because there wasn't a formal AIDS system due to officials being anti-HIV/AIDS. This is where NGOs work closely with the community to provide adequate services even if government policy is not there yet.

Extract 13, provides insight into how discretion in applying unofficial policies can lead to the development of formal policies. Policies about community participation and involvement can be accepted by policymakers who previously did not see a need for it but with enough evidence, formally incorporate it due to perceived benefits from unofficial campaign promoting health. Similarly, P2 articulated just how unofficial policies about community participation are introduced in a bottom-up manner as opposed to the traditional top-down manner. While still using discretion and initiative P2 gave an account of the process of developing new policies using a bottom-up approach.

P2: Some of our health care programmes in community participation are not yet part of national policy but we are incorporating it by building a base of information to show results to government and let them decide to change the policies.

As previously mentioned, policy is not always straight forward and the development of community participation policies in health care is done on a trial-and-error basis. Even though policies are traditionally constructed by experts for lay people to implement, it is noteworthy that providing evidence in the form of documentation which indicates positive health outcomes can

nudge policymakers to formally write unofficial policies into national policy. Given enough evidence is provided to show positive health outcomes upon implementation, policies are successfully amended or added on this basis. In terms of stakeholder perspectives, the integrated perspective advocates for considering the views and expertise of all stakeholders from primary stakeholders to key stakeholders. Consequently this will bridge the gap between decisions and actions. Concurrently providing a platform for all stakeholders to provide input on the development of community participation policies, by using both the bottom-up and top-down approaches.

Health-related NGO stakeholders act as vessels of communication between the community members and policymakers at the organisational level. Using their knowledge and expertise to report the need for policies to be amended or added, whilst using rapport to gather information from community members about their health needs. The health psychology paradigm perpetuates the notion of creating independence in the community by giving people the power to voice their concerns about their own lives while assisting them with resources to empower them to be responsible for their own health and well-being as well as those in their community (Campbell & Murray, 2004). Some stakeholders expressed why they think it is necessary to include community members in the process of policy development.

Extract: 14

P5: People from the community share with us their needs. This helps us to help them.

P7: We encourage them [community participants] to make notes. Then we see what works and what doesn't

P9: Try not to isolate your client...empower your client to navigate services.

P3: Community participation lies with the people...the source of information

During the policymaking process community members are involved based on their expertise regarding their needs. Although stakeholders previously mentioned difficulties with relying on community members diagnosing their problems, other stakeholders see the value in including community participants. This creates a symbiotic relationship between the organisation and community, ensuring that health-related NGOs provide sufficient services. In extract 14, stakeholders express that community participation is an empowerment tool used by local communities to voice their needs (Morgan, 2001). The main source of information regarding community health needs and participation efficiency is the community itself, as indicated by P3 (McLeroy, 2003). This collaborative approach encouraging the community to be part of the decision making process promotes empowerment and a sense of responsibility about their own well-being (Khan & Van den Heuvel, 2007). According to Claridge (2004), sourcing information from the community served in Health-related NGOs yields benefits that promotes sustainability and breaks down existing barriers to community participation, increasing health promotion.

Extract 15

P8: If you do not involve the community and they do not accept the decision you make, then you'd be foolish to think you'd be able to make changes in a community that doesn't fully accept you.

From the abovementioned extract, P7's noteworthy response reveals that stakeholder's do not undervalue the power of rapport between health-related NGOs and the communities they serve. That in order for an NGO to successfully operate and provide services, they need to take into consideration the interests, context and views of the community they aim to serve. Community participation provides an opportunity for community members to be involved in diagnosing and solving their own health issues. Some NGO stakeholders tend to involve community participants in various ways, feedback is not always done by writing reports about community participation. Policies often develop from bottom-up responses which draws attention to potential barriers known to community members and unfamiliar to professionals.

The purpose for using both bottom-up and top-down approaches is to connect the policy design process to the policy implementation. Stakeholders like P7, mention different partnerships that exist within the different health-related NGOs in Stellenbosch. Partnerships are imperative for the functionality and existence of NGOs (Campbell & Murray, 2004). Extract 14 and 15, indicate the partnership between NGO staff and the community exists in order to provide better services by sourcing information from community members about the policies and practices that work compared to those which do not work.. While NGOs provide resources to prevent, treat and eradicate potential health issues, the community participants are the vessels that helped provide informal health care and service provision in the absence of formal health care, through partnerships and understanding (McLeroy, 2003).

### 4.2.3 Community participation practices and policy implementation

The partnerships that exist at different levels of the ecological system contribute towards community participation practices in health-related NGOs. Partnerships between the community and health-related NGOs in Stellenbosch employ a collaborative approach to increase service delivery by means of community participation (Sarkissian, Walsh, & Cook, 1997). Community participation is aimed in theory to decrease the prevalence and incidence of health issues by increasing service delivery with the help of community members (Campbell & Murray, 2004). These community members are trained and supervised by professionals to ensure that satisfactory services are provided. This section focuses on how community participants execute participation in health-related NGOs and how they apply policies about community participation. When asked about community participation practices, stakeholders shared their perspectives on ways in which community participation occurs in their NGOs.

Extract: 16

P2: We work in partnership with government.

P4: Working with the system is important to stay afloat as an organisation

When asked about the participation practices, NGO stakeholders made reference to a need for a partnership to exist between government and health-related NGOs. P2 further explained “*if you want to change something, use the system*”, explaining why partnerships

between different institutions, i.e., government and NGOs are important. Establishing a functional relationship between policy makers at the community level and NGOs and community members at the organisational level is therefore vital. A good relationship means that NGO staff can address issues of community participation with the officials in charge of community participation policymaking when health-related NGO stakeholders see the need to change policies and practices. Partnerships are also important for community participation practices. The relationship between individuals, who contribute to community participation in health care service delivery and health-related NGOs, establishes the partnership between the individual level and the organisational level in terms of the ecological perspective (McLeroy, 2003). This partnership is where community participation policies are implemented and community participation is practiced (WHO, 2001). Community members volunteer their time to assist in better service delivery and improve health care in Stellenbosch in various ways; here are a few stakeholder perspectives on community participation practices in health-related NGOs:

Extract: 17

P3: We focus on intervention...we train the community to spread awareness about HIV/AIDS.

P7: Our volunteers are wellness advocates...and counsellors.

P2: Community members assist in palliative care...hospitals are understaffed so we take care of it.

Community participation is practiced at different levels of intervention in terms of alleviating or preventing health issues in Stellenbosch as a community. The first level mentioned by P3, is when the health-related NGO invests time and effort into training community members to participate in health enabling programmes. These programmes enable community participants to bring about awareness in the community in order to decrease incidence of life threatening diseases. Thus, preventing illness by educating the community about the risks involved if precautionary measures are not taken. According to community health psychology, individuals and groups will change their health habits and behaviour when they are given enough information about the risks involved (Campbell & Murray, 2004).

The second level of community participation practiced in health-related NGOs is when community participants are trained to counsel members from their community in need of assistance with health issues and coping mechanisms. At this level community participants in health-related NGOs assist in promoting healthy habits to individuals or groups already suffering from debilitating health habits. In the case of P6, community participants are referred to as “*wellness advocates*”, a termed established by the NGO due to the fact that many of the community participants resides in the communities they counsel, forming relationships with the community due to pre-existing and already established rapport. Other stakeholders mentioned similar forms of community participation, i.e., peer educators, support groups, participant advisors, etc. All denoting that advice is provided in coping with existing health issues in and around Stellenbosch. These health issues involve risky sexual behaviour, substance abuse, malnutrition, etc.

The third level of community participation is caring for people who are already sick and living with illness. Palliative care, is a hands-on manner of caring for terminally ill people in health-related NGOs. This means that more staff is needed and community participants are sought for a more intimate form of participation in health. Thus, P 10 indicated that “*frail care*” and “*holistic care*”, for mentally and terminally ill people in health-related NGOs “*needs the support of the community to assist*” in order to achieve positive health outcome. Further explaining that caring for the health needs of a community as big as Stellenbosch, resources are limited and often the community contributes by assisting in health care service provision if they are not able to invest financially.

Community participation occurs at various levels of the ecological system, and between different groups. Although, prevention of illnesses and promotion of health is primarily the goal of community health psychology, contextual awareness is imperative in order to understand the community’s needs and health-related issues. Thus the act of involving the community in promoting health in the absence of formal health care workers is often employed by health-related NGOs (Arnstein, 1969). Hence partnerships are fostered between health-related NGOs and the community in order to provide better more adequate health services (Mansuri & Rao, 2012). In the following extracts, NGO stakeholders explain how community participation policies and practices evolve as they are implemented.

Extract: 18

P9: Strategic plan and policy go hand in hand, they cannot be separate. Your plan needs to say how we are going to do it. If it doesn't work this year then we need to re-visit it next year and say "this is how we wanted to implement it... but it didn't work so we need to change it" and say how we are now going to do it.

In extract 18, P9 explains the policymaking and implementing process at the organisational level. Labelling the process of community participation policymaking as a "*strategic plan*" which serves as guidelines to community participation policies which shapes community participation practices. This strategic plan is a means of documenting existing community participation practices based on existing policies. In documenting these practices NGOs are thus able to look at policies which were successfully implemented and those which hindered the community participation process (Rifkin, 2014). According to health-related NGO stakeholders, community participation policies are ever-changing and based on the needs of the community. As the health needs of the community evolves so should community participation practices and policies.

P3: our NGO is very connected to the changes happening within the community...we want to stay on par with what is needed.

Stakeholders expressed concerns of remaining relevant and needed in the community. In order to maintain a connection with the community they serve assessing the needs of that community needs to occur regularly. In Stellenbosch, the health-related NGOs network with each other forming community connections between different organisations providing health services. This community of health-related NGOs rely on the assistance of community members to provide health services as well as feedback on services rendered. Community participation in

practice is thus the act of lay people, rendering health services. These services include but are not limited to, basic health care training provided by NGOs, and reviewing community participation policies they have attempted to implement but failed due to the lack of guidance from policymakers. When asked how they kept track of community participation practices which failed, stakeholders responded accordingly.

Extract 19:

P2: building a base of information to show the results

P4: Keep a record of participation practices

P7: Community participants make notes about activities

P5: Community members anonymously give us written feedback

Health-related NGOs review policies from feedback by creating a paper trail to keep a record of how community participation was implemented. Thus determining which methods worked and how policies were implemented. Some stakeholders indicated that “*written reports*” were the best way to show policymakers what worked during implementation and what did not work. Most importantly, evidence is needed to show whether a need policy changes exists. Adjusting policies is sometimes implemented even without the formal go-ahead of local or provincial government.

Depending on the health services provided, stakeholders in different NGOs described policy as being problematic to implement because sometimes community participation policies co-existed with other policies such as child protection policies or confidentiality policies, making

the implementation of community participation practices difficult. Community members have a limited amount of training to assist in health care provision which may be limited if pre-existing policies fall outside their training scope of knowledge. However, other stakeholders described policies as “*not written in stone*” and continuous “*tweaking*” is needed when the implementation of community participation in practice fails.

### **4.3 Conclusion**

The findings of this study had three main overarching themes, community participation defined, community participation policy development and community participation practices and implementation. When defining community participation each stakeholder referred to way in which community members participated in health-related programmes designed by NGO stakeholders and key stakeholders outside health-related NGOs. The definitions of community participation included empower and sustainability by providing community members with skills to take control of their own health or to possess the ability to identify and seek health assistance when needed.

Stakeholders also acknowledged that some community members in need of help, i.e. troubled teens, substance abusers and malnourished children, may be less likely to identify that they need help or that help is available to alleviate health problems they face. Community members are also asked to assist in health-related NGOs to provide services when organisations have a lack of service providers, thus training community members. Thus increasing service delivery and promoting positive health outcomes. Thus, community members provide assistance in health-related NGOs about the needs of the community, have established rapport with the

community and are perceivably the best sources of information for health professionals to gain insight into the needs to the general community.

The policymaking process proves to be complicated due to the traditional top-down manner in which it is formally put into law, however NGO stakeholders admit to altering the policies to better suit the needs of their community participants in order to adequately provide services which is not limited. Community participation policies are ever-changing and easily amended unless they are concurrently applied with a more rigid, pre-existing policies i.e., child protection or confidentiality policy. In the case of the aforementioned policies, community participants have basic training regarding the rigid policies they will deal with during their duties in providing community assisted health care services.

## CHAPTER 5

### Conclusion and Recommendations

The participants in this study accounted for community participation practices in their respective health-related NGOs. They provided detailed descriptions of community participation policy development and implementation in their organisations. Providing an overview of whether community participation policies were implemented as prescribed by policymakers and how community members contributed to policies about participation. The findings of this study indicated community participation policy formulation was indeed formulated using both the top-down and bottom-up approaches. All NGOs employed the traditional top-down approach but admitted to altering and amending policies in order to meet the health needs of the community they aimed to serve. This was achieved through using the bottom-up approach to developing and applying community participation policies and practices. While NGO stakeholders liaised information about community participation policies from the top-down to community participants they also communicated needs and concerns directly from the community to the policymakers, from the bottom-up. Although community participation policies are set for community participants by local and provincial government they are still afforded the

opportunity to contribute to the ever-changing policies regarding participation at the grassroots level.

The limitations and the implications of the research findings to this study is highlighted in this chapter followed by the recommendations for future research on community participation practices, policies and the implementation these community participation policies.

### **5.1 Study Limitations**

One of the main limitations in this study is the amount of participants. Interviews were audio recorded and this adjusted the responses of participants. The knowledge of being recorded made some participants either reluctant to answer some questions or very careful when answering. Participants feared revealing too much information due to certain confidentiality policies in their health-related NGOs. This made them evidently aware of the presence of the audio recorder. Some participants responded to questions how they assumed I wanted them to answer instead of answering the questions in relation to their health-related NGO. Building rapport with some participants was slightly more difficult due to their positions in the community of Stellenbosch health-related NGOs, directors, managers, chairperson, etc. This resulted in some participants relaying questions back to me, asking how I understood the question. During some interviews participants were pre-occupied with their duties or on-call hence cutting some interviews time was cut short due to participants needing to fulfil urgent duties, takes calls or reply to messages, this meant that at times during the interview some participants weren't fully engaged in the interview. This meant that the data collected during interviews were limited because participants rushed through the interview in order to resume their duties.

Community participation is an ever changing concept and evidently in this study, different health-related NGO stakeholders from Stellenbosch described community participation practices in terms their own NGOs. Community participation is traditionally understood as participation of lay community members assisting in health promotion services within their own communities.

This study found that health-related NGO stakeholders in Stellenbosch used two methods in implementing community participation policies, namely the top-down and bottom-up approaches within the community health psychology paradigm. Stakeholder perspectives thus helped to link the way in which policies are intended with how they are implemented in each NGO.

Community members assisted in service provision while given a platform to articulate concerns about community health needs and implementation difficulties. In this regard, NGO stakeholders used their influence as mediators between the grassroots level and the community level, to liaise concerns to policymakers and often expressed altering policies before they are formally changed. Oftentimes formal policy amendments occur due to evidence provided by NGO stakeholders regarding community participation practices yielding positive health outcomes, while dismissing policies which hinder health promotion. When NGO stakeholders were unable to provide a paper trail of evidence for effective community participation practices, they provided results for positive health outcomes to persuade policymakers that a need existed to provide certain health services.

Policies about community participation were executed in relation to other existing policies. These policies were described by stakeholders as rigid, meaning they could not change them. Confidentiality and child protection policies, were two of the policies stakeholders mentioned having to alter and adjust community participation practices around. Stakeholders saw policies set by government as guidelines to setting their own policies within their own health

promotion programmes, in their own health-related NGOs. Some stakeholders felt disengaged from policies set by government and expressed that policies should be formulated in collaboration with those who aim to implement them for effect community participation practices to occur. Health-related NGO stakeholders made reference to documenting community participation practices in order to re-visit and re-evaluate the policies annually, order to correlate how they intended for policies to be implemented, how it was implemented and whether or not policies were implemented correctly. If policies were not correctly implemented stakeholders re-evaluated those policies and improved on it in order to make the implementation of community participation policies more practical.

## **5.2 Recommendations**

Community participation in Stellenbosch health-related NGOs is very unique, because all the health-related NGOs in Stellenbosch work in collaboration with each other. Only 11 stakeholders from various health-related NGOs in the Stellenbosch network of NGOs participated in this study, thus no inference about other health-related NGOs can be drawn from the findings in this study. It would be of great use to cover community participation practices and policy implementation in neighbouring health-related NGO networks, preferably outside of Stellenbosch. Signifying how different communities contribute to the policy formulation and implementation of community participation practices in the Western Cape.

In addition, the study did not include the perspectives of lay community members, volunteers or community members. It would be interesting to conduct interviews with people who make use of health-related NGO services and to gain insight from them regarding how useful they think community participation policies and practices are in promoting their health.

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## APPENDICES

### Appendix A



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jou kennisvenoot • your knowledge partner

### STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

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#### **Community Participation Practices in Health-related NGOs in the Western Cape: A Focus on Stakeholders' Perspectives**

You are asked to participate in a research study conducted by Claudia Alexander (Masters Psychology), from the Department of Psychology at Stellenbosch University. The results of this study will contribute to a Master's Thesis. You were selected as a possible participant in this study because you are currently involved in a health-related NGO in the Western Cape Province.

#### **1. PURPOSE OF THE STUDY**

The aim of this study is to document the current practice of community participation in health-related NGOs in the Western Cape.

## **2. PROCEDURES**

If you volunteer to participate in this study, I will ask you to participate in an individual interview. It will take place at a convenient location. The interview will take approximately an hour long. Interviews will be tape recorded and transcribed. You may request to verify the transcribed material should you wish to do so.

## **3. POTENTIAL RISKS AND DISCOMFORTS**

There are no expected risks, discomforts or inconveniences associated with your participation in the study.

## **4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

There will be no direct benefit for your involvement in the study. The study results will however contribute to research for my Psychology Masters thesis. The results for the study will only be made available to the research supervisor and examiners. The study results will also be presented to participants in the form of a report and will also be disseminated to the broader academic community in the form of peer reviewed journal articles.

## **5. PAYMENT FOR PARTICIPATION**

You will not receive any payment for your participation in the study.

## **6. CONFIDENTIALITY**

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law.

Confidentiality will be maintained by means of pseudonyms and all the information gathered during research will be stored on a safe secure laptop of which only the researcher has access.

## **7. PARTICIPATION AND WITHDRAWAL**

Participation in the study is your choice. If you volunteer to participate in this study, you may withdraw at any time without any consequences. You are allowed to skip questions you do not want to answer and still remain in the study.

## **8. IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about the research, please feel free to contact the study supervisor, Ms Anthea M. Lesch at Tel: (021) 808 3456, E-mail: [alesch@sun.ac.za](mailto:alesch@sun.ac.za), Department of Psychology, Stellenbosch University, Private Bag X1 Matieland, 7602 or the researcher, Ms Claudia Alexander at Cell: +27 (0)714839460, Email: [calexander@sun.ac.za](mailto:calexander@sun.ac.za), Department of Psychology, Stellenbosch University, Private Bag X1 Matieland, 7602.

## **9. RIGHTS OF RESEARCH SUBJECTS**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Fouché [[mfouche@sun.ac.za](mailto:mfouche@sun.ac.za); 021 808 4622] at the Division for Research Development, Stellenbosch University.

**SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE**

The information above was described to me by Claudia Alexander in English and I am in command of this language or it was satisfactorily translated to me. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

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**Name of Subject/Participant**

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**Name of Legal Representative (if applicable)**

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**Signature of Subject/Participant or Legal Representative**

**Date**

**SIGNATURE OF INVESTIGATOR**

I declare that I explained the information given in this document to \_\_\_\_\_ [*name of the subject/participant*] and/or [*his/her*] representative \_\_\_\_\_ [*name of the representative*]. [*He/she*] was encouraged and given ample time to ask me any questions. This conversation was conducted in [*Afrikaans/\*English/\*Xhosa/\*Other*] and [*no translator was used/this conversation was translated into* \_\_\_\_\_ by \_\_\_\_\_].

\_\_\_\_\_

\_\_\_\_\_

**Signature of Investigator**

**Date**

## Appendix B

### KEY INFORMANT INTERVIEW SCHEDULE

**Participant sample 1:** Organisational stakeholders, directors and policy makers in Health-related NGOs.

This interview will cover the following two areas of questioning, namely, community participation and policymaking and policy implementation in respective NGOs.

#### Opening Questions

What is your role in your organization?

What is the main purpose of your organization?

- Who do you serve?
- What type of services do you provide?

#### Area 1: Community Participation in health-related NGOs

How would you define community participation?

How does your organization define community participation?

Describe the current community participation practices within your organization:

Probe for:

- What are the community participation activities exist at your organization?
- Who is recruited for community participation and how are they recruited for your organization?

- What are the roles and responsibilities community members/participants?
- Are community members involved in decision-making in your organization?
- Does your organization give formal training for participation to community members?

### Area 2: Policy implementation in health-related NGOs

Describe the policies regarding community participation practices within your organization?

Probe for:

- Who are the people benefiting from community participation?
- What are your organizational policies regarding community participation?
- How do you strive to effectively implement community participation?

**Participant Sample 2:** Community members who participate in the functioning of the NGO

Opening Questions:

1. What is your role in the organization?
2. How did you become involved in the organization?
3. Which services are provided by the organization you are involved in?
4. Who are the people providing these services?

The following area will be discussed.

1. Questions regarding their involvement in community participation:

Probe for:

- How would you define community participation?
- In which ways are you involved in community participation?
- What form of training for community participation does the organization you are involved in offer?
- How do you report back on what you are doing in the organization you are involved in?
- Can you tell me exactly what the process of community participation in your organization entails?
- How do you think other members of the community can get more involved?

## Appendix C

### Letter to Stakeholders and Directors

Dear Director

My name is Claudia Alexander and I am a student at Stellenbosch University conducting research towards a Masters degree in Psychology. Through my research I am interested in learning about the community participation practices of NGOs that deal with health-related issues. The aim of my study is to learn more about how NGOs are currently practicing community participation.

I am writing to request your organization's participation in my study. Your organization's participation would involve interviews with the respective organisational stakeholders, policymakers and community members who are involved in the functioning of your organization. The purpose of the interviews is to document a range of perspectives regarding community participation practices in your organization.

The research process itself will in no way be harmful to any of the participants. All data collected as part of my study will remain confidential. Your organization and stakeholders who participate in the study will not be able to be identified by name. At the end of my study I will provide you with a report outlining my findings, as well as recommendations for how you can strengthen community participation activities in your organization.

I will be calling you within the next three days to follow-up on my e-mail. Please do not hesitate to contact me directly should you have any further questions or queries.

I ask that you please consider my request for your participation in my research, and sincerely thank you for your time.

Kind regards,

Claudia Alexander

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**Appendix D****Table 1: Study Participant Demographic Details**

<b><u>Participant Number</u></b>	<b><u>Role in Organisation</u></b>	<b><u>Focus of the NGO</u></b>	<b><u>Gender</u></b>
1	Vice Chairperson	Malnutrition awareness	female
2	Chairperson and manager	Stellenbosch Network forum and Hospice services	female
3	Institutional Coordinator	HIV/AIDS awareness	female
4	Social Worker	Substance Abuse	female
5	Social Worker	Substance Abuse	female
6	Head of Community Involvement	Frail care	female
7	Counsellor	HIV/AIDS awareness	male
8	Dietician and Project manager	Malnutrition awareness	male
9	Executive Manger	HIV/AIDS awareness	female
10	Manager	Frail care	female
11	Head of Training	Frail care and caregiving training	female