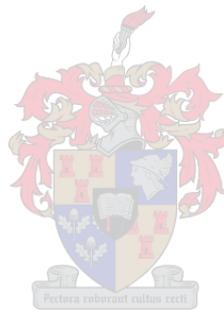


“Spreading the word” – Examining the dynamics of community engagement in HIV vaccine research at an HIV prevention research centre in the Western Cape South Africa.

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Dissertation presented for the degree of PhD (Psychology) in the Faculty of Arts and Social Sciences at Stellenbosch University



Promoter: Professor Leslie Swartz

March 2017

DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof, that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

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ABSTRACT

Community engagement in HIV vaccine research is a complex phenomenon and is articulated as a crucial part of HIV vaccine research. In spite of this, there is a dearth of literature that focusses on community engagement in HIV vaccine research. While there is much social science literature that focusses on the operational and ethical aspects of HIV vaccine research, there is little research that explores the process of community engagement. In order to contribute to understanding community engagement in context, the purpose of my research was to document and explore the dynamics of the current practice of community engagement at an HIV prevention research centre, Research Centre X in the Western Cape, South Africa. Located within a community mobilization approach, the research used the conceptual framework of the symbolic, relational and material contexts as the lens for exploring experiences of research participation and the dynamics of the current community engagement process at Research Centre X.

The study applied a qualitative approach to address the research question and used focus group discussions and key informant interviews to access the perspectives of three key stakeholders who form part of the community engagement process at Research Centre X. Research participants were selected using a purposive sampling technique and included current HIV vaccine trial participants, CAB members who represent the interest of community members in the community engagement process and staff members at Research Centre X who implement community engagement activities. The data were analysed using the thematic analysis approach outlined by Braun and Clarke (2006). Ethical approval for the conduct of the study was provided by Ethics Review Committees at Stellenbosch University and the University of Cape Town.

In the symbolic context, the findings highlight fear and avoidance of HIV/AIDS and HIV/AIDS stigma in the research setting. HVT participants reported that myths, beliefs and

rumours about the HIV vaccine research being conducted at Research Centre X circulate, inhibiting attempts to promote participation in the research and community engagement activities at Research Centre X. In the relational context, the findings reveal that community outreach workers engage in a narrow set of practices in their community engagement activities, generating a set of relational resources to support their activities. Their activities focus primarily on “*spreading the word*”, in other words disseminating HIV vaccine research information in the community setting with a view to meeting participant recruitment targets set by researchers and trial sponsors. The relational context of community engagement in HIV vaccine research at Research Centre X, therefore, offers limited roles for community and CAB members in the process. The material context of community engagement in HIV vaccine research is one that highlights contradictory perspectives on the extent to which it promotes empowerment among HVT participants and CAB members.

My research findings highlight the complexities that accompany efforts to promote community engagement in HIV vaccine research in resource-poor settings and generates recommendations for transforming the HVT context and reframing community engagement process in the research setting.

OPSOMMING

Gemeenskapsbetrokkenheid by MIV-entstofnavorsing is 'n komplekse saak wat 'n kritieke deel vorm van MIV-entstofnavorsing. Ten spyte hiervan is daar 'n gebrek aan navorsing wat fokus op gemeenskapsbetrokkenheid by MIV-entstofnavorsing. Daar is heelwat sosiaal-wetenskaplike literatuur wat fokus op die bedryfs- en etiese aspekte van MIV-entstofnavorsing, maar daar is baie min wat die proses van gemeenskapsbetrokkenheid ondersoek. Ten einde gemeenskapsbetrokkenheid binne so 'n konteks te verstaan, was die doel van hierdie navorsing om die dinamiek van die huidige praktyk van gemeenskapsbetrokkenheid by 'n MIV-voorkomingsnavorsingsentrum, Navorsingsentrum X in die Wes-Kaap, Suid-Afrika, te ondersoek en te dokumenteer. Die navorsing is geïmplementeer binne 'n gemeenskapsmobiliseringsbenadering en het die konseptuele raamwerk van die simboliese, relasionele en materiële kontekste gebruik as die lens waardeur die ervaring van navorsingsbetrokkenheid en die dinamiek van die huidige gemeenskapsbetrokkenheidproses by Navorsingsentrum X ondersoek is.

Ek het van 'n kwalitatiewe benadering gebruik gemaak om die navorsingsvraag te beantwoord en het fokusgroepe gehou en onderhoude gevoer met sleutel informante om die perspektiewe van drie sleutelrolspelers wat deel vorm van die gemeenskapsbetrokkenheid by Navorsingsentrum X, te ondersoek. Navorsingsdeelnemers is deur middel van 'n doelgerigte steekproefnemingstegniek geïdentifiseer en het huidige MIV-entstofproefdeelnemers, GAR-lede (Gemeenskapsadviesraad) wat die belange van die gemeenskapslede verteenwoordig in die gemeenskapsbetrokkenheidproses, en personeel by Navorsingsentrum X wat die gemeenskapsbetrokkenheidsaktiwiteite implementeer, ingesluit. Die studiedata is geanaliseer met behulp van 'n tematiese analisebenadering soos uiteengesit deur Braun en Clarke (2006). Die navorsingsetiekkomitees van die Universiteit van Stellenbosch en die Universiteit van Kaapstad het die navorsing goedgekeur.

In die simboliese konteks wys die bevindinge dat daar vrese en vermyding van MIV/Vigs en MIV/Vigs-stigma binne die navorsingsomgewing is. MIV-entstofproefdeelnemers het aangedui dat mites, oortuigings en gerugte oor die MIV-entstofnavorsing by Navorsingsentrum X die rondte doen, en dit verhinder die bevordering van deelname in die navorsing en gemeenskapsbetrokkenheidsaktiwiteite by Navorsingsentrum X. In die relasionele konteks toon die bevindinge dat gemeenskapsuitreikwerkers gebruik maak van 'n baie nou stel praktyke as deel van hulle gemeenskapsbetrokkenheidsaktiwiteite en hulle sodoende 'n stel relasionele hulpbronne bymekaarmaak om hulle aktiwiteite te ondersteun. Hulle aktiwiteite fokus primêr daarop om die “woord te versprei”, dit wil sê om inligting oor MIV-entstofnavorsing in die gemeenskap bekend te maak om so die deelnemerwerwingsteikens wat die navorsings en proefborge stel, te bereik. Die relasionele konteks van gemeenskapsbetrokkenheid by MIV-entstofnavorsing by Navorsingsentrum X bied dus beperkte geleentheid vir die gemeenskap en gemeenskapsadviesraadslede om betrokke te wees. Die materiële konteks van gemeenskapsbetrokkenheid by MIV-entstofnavorsing beklemtoon die teenstrydige perspektiewe oor die mate waartoe die navorsing die MIV-entstofnavorsingsdeelnemers en gemeenskapsadviesraadslede bemagtig. Die navorsingsbevindinge belig die kompleksiteit van die pogings om gemeenskapsbetrokkenheid by MIV-entstofnavorsing te bevorder in hulpbron-arme omgewings en gee aanbevelings vir die transformasie van die MIV-entstofnavorsingskonteks en vir die herinkleding van gemeenskapsbetrokkenheidsprosesse binne die navorsingsomgewing.

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hope of the slave. I rise, I rise, I rise.” (Still, I rise). As always, my hope for a world that embraces us all is subversive and steadfast and...

To the God of all beings...thank you for grace, abundance, light and divine guidance.

DEDICATION

Ek dra my werk op aan ... / I dedicate my work to ...

My ouma, Naomi, die baanbreker wat hierdie reis vir ons almal begin het;

my Pappa wat met wysheid en visie die deur tot ons drome vir ons oophou;

my Mummy for creating our freedom with her constant refrain “anything is possible,
anything can be”;

and

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dreams

Met al my liefde and diep waardering / With all my love and deepest gratitude

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LIST OF ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
AVAC	AIDS Vaccine Advocacy Coalition
AZT	Azidothymidine Treatment
CAB	Community Advisory Board
CBO	Community-based Organization
CBPR	Community-based Participatory Research
CHP	Community Health Psychology
DOH	Department of Health
GCP	Good Clinical Practice
GPP	Good Participatory Practices
HANC	HIV/AIDS Network Coordination
HAVEG	HIV/AIDS Vaccines Ethics Group
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HVT	HIV Vaccine Trial
HVTN	HIV Vaccine Trials Network

IAVI	International AIDS Vaccine Initiative
IDU	Injecting Drug Users
IMAGE	Intervention with Microfinance for AIDS and Gender Equality
MSM	Men who have sex with Men
NGO	Non-governmental Organization
NIH	National Institutes of Health
PrEP	Pre-exposure Prophylaxis
SAAVI	South African AIDS Vaccine Initiative
STI	Sexually Transmitted Infection
UCT	University of Cape Town
UNAIDS	United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing
VISP	Vaccine-induced seropositivity
WTP	Willingness to Participate

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Chapter 1: Introduction

The impact of the Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS) pandemic globally has been well documented. In Sub-Saharan Africa, HIV/AIDS is the main cause of death, and in South Africa, the location for the present study, an HIV prevalence of 12.2% was recorded in 2012 (Merson, O'Malley, Serwadda, & Apisuk, 2008; Shisana et al., 2014). The pandemic has been described as a socially patterned disease (Farmer, 1992). It follows deprivation and its impact is felt most acutely by poor, marginalized and vulnerable communities, amplifying the socio-economic and other challenges that threaten the well-being of these communities (Merson et al., 2008).

A broad range of HIV prevention strategies have been adopted to stem the tide of HIV infections. These strategies have included knowledge, education and awareness-raising efforts, a wide range of interventions to encourage those at risk of HIV infection to change high-risk behavioural practices and structural interventions that have attempted to address the structural drivers of the pandemic (Padian et al., 2011). Biomedical interventions such as medical male circumcision have also shown some promise in reducing the risk of HIV acquisition in men (Kurth, Celum, Baeten, Vermund, & Wasserheit, 2011; Padian et al., 2011). Despite substantial investment, these HIV prevention approaches have had limited impact on reducing HIV prevalence and incidence to date (Coates, Richter, & Caceres, 2008; Kalichman, 2008).

The development of biomedical HIV prevention technologies, such as vaccines and microbicides, is another category of HIV prevention research that many believe may hold hope for reducing the spread of the HI-virus. MacQueen (2011) points out that biomedical HIV prevention strategies are an important and growing part of HIV prevention agendas. Biomedical HIV prevention technologies offer the potential of conferring life-long immunity

and reduction in susceptibility to HIV infection in populations where HIV risk is high (Kalichman, 2008). This research focusses on the process of community engagement in one such biomedical HIV prevention technology, namely clinical research to develop a safe and efficacious HIV vaccine.

In South Africa, efforts to develop a safe and efficacious HIV vaccine have been underway since the 1990s. HIV vaccine clinical trials (HVTs) are currently being conducted in communities where HIV risk is high, with community members being targeted for their participation in the research process. From the perspective of clinical researchers, funders and vaccine advocates, local communities are regarded as crucial stakeholders in the HIV vaccine research enterprise (Wakefield, 2005). Communities, therefore, occupy a central role in the HIV vaccine research enterprise. This central role is promoted through an emphasis on collaboration, partnership and participation of communities in the research as key factors for ensuring the successful conduct of HVTs (UNAIDS-AVAC, 2011). Without the buy-in, support and mobilization of the communities in which HIV vaccine trials are being conducted, any effort to develop an effective HIV vaccine is unlikely to succeed (Fuchs, Sobieszczyk, Hammer & Buchbinder, 2010; Lau, Stansbury, Gust & Kafaar, 2009).

The HIV vaccine research enterprise is made up of a collective of multiple stakeholders, such as clinical trial site staff, biomedical scientists, trial sponsors, pharmaceutical companies and local communities. At the global level, those involved in the HIV vaccine enterprise form part of global assemblages represented by networks of power and knowledge that influence the way in which stakeholders make sense of their own realities (Ong & Collier, 2005). They are part of the global AIDS industry: their micro-stories and relationships play themselves out at the intersection between scientific experimentation, lay person involvement in science, and the complex social and contextual factors that fuel the HIV/AIDS pandemic (Ong & Collier, 2005; Lau, Swann & Singh, 2011).

At the local level, HVTs are conducted, due to scientific necessity, in communities where HIV prevalence and risk of HIV infection are high (Lesch, Kafaar & Kagee, 2009). As highlighted above, the community settings in which these trials are conducted are characterized by complex socio-political and economic climates; histories of exploitation, and assaults on human dignity and human rights; all of which raise concerns about power imbalances between researchers and community members who participate in their research (MacQueen, 2011; Petryna, 2009). The location of clinical trials in such community contexts also raises concerns about the rights of communities of vulnerable individuals who are asked to participate in clinical research (Petryna, 2006). Emanuel, Wendler, Killen and Grady (2004) point out that research conducted in developing countries carries with it a greater risk of exploiting marginalized and vulnerable groups. The increased potential for exploitation is due to structural inequalities that characterize such local communities that may include a lack of access to resources that promote health and well-being, cultural and language differences between researchers and local communities and low levels of education and scientific literacy of local communities. The social context in which HIV vaccine research is conducted is, therefore, complex, involving interactions between diverse stakeholders with different perspectives, agendas, hopes, beliefs and levels of access to resources and power in the clinical trial process (MacQueen, 2011; Petryna, 2009). Researchers working in this area are challenged to balance the scientific goal of developing a safe and efficacious HIV vaccine with the need to build community capacity and leave communities better off as a result of their participation in HVTs and related research (Swartz & Kagee, 2006).

Much social science research has been conducted to examine the social dimensions of HIV vaccine research. Research on the social dimensions of HIV vaccine research has been conducted in various HVT settings, targeting a range of high HIV risk populations. The body of research generated has predominantly focussed on understanding the factors associated

with willingness to participate (WTP) in HIV vaccine research (e.g., Asiki et al., 2013; Lesch, Kafaar, Kagee, & Swartz, 2006); examining knowledge about HIV/AIDS and HIV vaccines as the basis for WTP and improving informed consent processes (e.g., Kiwanuka et al., 2004; Lindegger et al., 2006); documenting the social harms experienced by community members who participate in HIV vaccine research (e.g., Allen & Lau, 2008; Nyblade, Singh, Ashburn, Brady, & Olenja., 2011); and examining community engagement in HIV vaccine research (e.g., Morin, Maiorana, Koester, Sheon, & Richards, 2003). These studies have focussed on identifying and describing the factors that impact HIV vaccine trial recruitment. Findings from these studies serve as the basis for adjustments to trial protocols to ensure that sufficient numbers of community members are recruited into trials to test candidate HIV vaccines. The available social science literature on HIV vaccine research has, therefore, tended to focus on the operational aspects of clinical trial implementation, framing the social issues that relate to lay community members' participation in clinical trials as ethical issues (MacQueen, 2011).

In spite of the recognition that achieving success in the HIV vaccine enterprise rests on community support, buy-in, partnership, collaboration and the participation of all stakeholder groups (Newman et al., 2015), the issue of community engagement in HIV vaccine research has received scant attention. Various authors call for the active participation of local communities in HIV vaccine research and point to investment in community engagement and recruitment as the key to achieving scientific goals (Frew, Archibald, Hixson, & del Rio, 2011; Lau, Swann & Singh et al., 2011; Newman, 2006). However, the complex local community environments in which clinical trials are conducted, the social processes and networks of relationships that operate in these contexts and the dynamics of community engagement in communities targeted for HIV vaccine trial participation, have not been prioritized as a research focus. Newman (2006) points out that much is invested in the biomedical, scientific and operational aspects of HIV vaccine development; yet crucial

processes of community engagement, upon which the successful development of a safe and efficacious HIV vaccine rests, tend to be approached in an ad hoc manner, and activities are left to trial and error approaches in the local community contexts in which they are conducted.

Given the central role that local communities occupy in the HIV vaccine research enterprise, the dynamic features of the local social contexts in which such research is conducted, and the call to develop a “science of community engagement” (Newman, 2006, p.302), the purpose of this research was to examine community engagement as it is currently being practised at an HIV vaccine research centre, Research Centre X, in the Western Cape South Africa. The research examined the local community context of community engagement in HIV vaccine research (Slevin, Ukpong, & Heise, 2008) in one resource-poor community where the risk of HIV infection is high. My examination of community engagement and the dynamics of research participation at Research Centre X incorporates the perspectives of three key stakeholders who are involved in community engagement activities in this setting. The three key stakeholders involved are the community members who participate in the HIV vaccine research being conducted at Research Centre X, the community advisory board (CAB) members who represent the *community* and liaise and consult with research centre staff, and members of the Community Outreach Team at Research Centre X.

Newman and colleagues (2015) argue that stakeholder engagement in HIV vaccine research is an ethical and scientific imperative. Writing from an international development perspective, Morgan (2001) further highlights the fact that community participation serves as an empowerment tool through which communities may take responsibility for and work to resolve threats to their well-being and development. Campbell and Murray (2004) echo this sentiment and support the notion that participation in interventions shape opportunities for health and well-being. In a context where HIV/AIDS risk is high and the local community

context presents numerous threats to participants' well-being, this multiple perspective examination of community engagement in HIV vaccine research also aimed to investigate the potential that HIV vaccine research participation has as a vehicle for building community capacity, providing immediate benefits to those who participate in the research and leaving communities better off by virtue of their involvement in the research.

I present an outline of the chapters in my dissertation below:

Chapter 2 places the research in context by drawing on selected literature relating to HIV/AIDS prevention approaches and interventions, social science research on HIV vaccines and community engagement in scientific research.

Chapter 3 positions this research on community engagement in HIV vaccine research in context. This chapter starts with my reflexive analysis in which I document the personal context that informs my research. In the remaining parts of this chapter, I discuss my perspective on what constitutes successful HIV vaccine research, meaningful participation in such research, and the role of community engagement in promoting both these aspects; and finally, I explain my use of the key concepts that form the conceptual foundation of my research.

Chapter 4 outlines the rationale for the research and the research aims. I present the theoretical framework for the study, namely the community health psychology (CHP) paradigm. I also introduce the reader to the community mobilization approach with its three key contextual dimensions that I will use as the lens for interpreting and presenting the research findings.

Chapter 5 outlines the procedure followed in the execution of the research. This chapter describes the research setting, outline the aims of the research and the qualitative research design used to address the research aims. The chapter also outlines the sampling, data

collection and data analysis procedures that I adopted, and the steps to ensure the ethical conduct of the research.

Chapter 6 presents the findings of the research on the current practice of community engagement in the research studies conducted at Research Centre X. I integrate the discussion with the presentation of the findings and present the discussion in three parts. I use the three key dimensions of context, namely the symbolic, relational and material contexts, as outlined in Campbell and Cornish's (2010, 2011) community mobilization approach, to describe the context and approaches that frame HVT participation and the implementation of community engagement processes at Research Centre X.

Chapter 7 draws on key ideas on successful HIV vaccine research outlined in Chapter 3 to frame the conclusions on the current practice of community engagement at Research Centre X. In this chapter, I provide recommendations for creating an enabling environment for community engagement that generates immediate, direct benefit for both the local community and the HIV vaccine enterprise at Research Centre X. The chapter concludes with a discussion of the limitations and strengths of the research.

Chapter 2: Overview of the Literature

2.1. HIV Prevention in Context

2.1.1. Impact of the HIV pandemic in South Africa.

In spite of large scale investment in HIV prevention, the number of new HIV infections continues to grow. Most new infections occur in generalized epidemics among heterosexuals in a few countries in southern and eastern Africa, including South Africa (Potts et al., 2008; Shelton, 2007). The HIV/AIDS pandemic has had a devastating impact on the South African population. A 2012 population-based survey recorded an HIV prevalence of 12.2% among the South African population (6.4 million HIV infected South Africans) (Shisana et al., 2014). In addition, in 2012, a South African survey recorded 469 000 new HIV infections (Shisana et al., 2014).

It is estimated that 15.9% of South Africans between the ages of 15-49 years are HIV infected (StatsSA, 2013), with females recording a significantly higher HIV prevalence than men (Ramjee & Daniels, 2013; Shisana et al., 2014). Groups at highest risk of becoming infected with the HI-virus in the South African population include Black African females in the 20-34 age range (31.6%) and Black African males in the 25-49 age range (Shisana et al., 2014). These groups represent two high HIV risk groups who are targeted for their participation in biomedical HIV prevention research, including HIV vaccines.

2.1.2. HIV/AIDS risk in social context.

There is a strong link between HIV/AIDS and social inequality. It has been described as a socially patterned disease (Farmer, 1992) and follows the trend of most epidemics of deadly infectious diseases in that those at risk of becoming infected with the virus are the poorest, most vulnerable and marginalized members in a society (Merson et al., 2008). Warren (2005)

highlights the fact that the HIV/AIDS pandemic undermines local and global change, growth and development, and deepens the conditions of inequality that impact those living in poverty-stricken environments. HIV risk and vulnerability is, therefore, located within a complex web of social, economic, political and environmental conditions.

In South Africa, the main routes for HIV transmission are heterosexual sex and mother-to-child transmission. Risk factors that contribute to the spread of the virus include behavioural, biological and structural risk factors. Behavioural risk factors include factors such as intergenerational sex, multiple concurrent partners, low condom use and excessive use of alcohol (Department of Health [DOH], 2012; Shisana et al., 2014). Biological risk factors, such as low rates of male circumcision and women's increased risk of tissue injury during intercourse, also contribute to HIV risk (DOH, 2012; Ramjee & Daniels, 2013). Structural risk factors that contribute to HIV risk include high levels of poverty, low levels of education, health literacy and access to resources, HIV/AIDS-related stigma and discrimination, gender inequalities, mobility and migration (Harrison, Sullivan, Hoffman, Dolezal & Morrell, 2006; Kagee et al., 2011; MacQueen, 2011; Merson et al., 2008; Parker, Easton & Klein, 2000).

In South Africa, delayed governmental responses and lack of political will to deal with HIV/AIDS has had an impact on the spread of the virus (Merson et al., 2008). AIDS denialism by prominent political leaders perpetuated conflicting messages and misunderstandings about HIV/AIDS (Kalichman, 2014; Rubincam, 2014). AIDS denialism has resulted in communities questioning the causes and transmission of HIV/AIDS and rejecting scientific evidence with respect to the prevention, diagnosis and treatment of HIV/AIDS (Kalichman, 2014; Nattrass, 2007; Rubincam, 2014). In addition, in Sub-Saharan Africa, alternative belief systems rooted in African traditional beliefs and explanations for HIV/AIDS that centre around racial themes and genocide also influences lay understandings

of the disease (Bogart, Kalichman, & Simbayi, 2008; Eriksson, Lindmark, Axemo, Haddad, & Ahlberg, 2013; McNeill, 2009). The most recent South African National Prevalence, Incidence and Behaviour Survey shows that knowledge of HIV transmission and prevention among South Africans is low, with only 26.8% of participants surveyed having accurate knowledge about the sexual transmission and prevention of HIV (Shisana et al., 2014).

The features of individual behaviours and social contexts that drive HIV risk outlined above act as barriers to HIV prevention, contributing to the continued high HIV prevalence and incidence among high HIV risk groups in South Africa. These features also create the local community contexts in which HIV prevention interventions are implemented. Contextual factors create conflicting messages about HIV/AIDS and produce environments that inhibit the adoption of HIV health-protective behavioural practices. HIV prevention interventions that aim to reduce the spread of the HI-virus in settings where the risk of infection is high, must, therefore, consider these contextual challenges to HIV prevention.

2.1.3. Sketching HIV prevention approaches.

The HIV/AIDS pandemic plays itself out in complex and challenging environments. Intervention strategies that target HIV/AIDS prevention, treatment and care must be tailored to address the specific risk factors that act as barriers to HIV infection in any given context. Such intervention strategies must also consider the local realities and complexities that may affect HIV/AIDS interventions. The HIV prevention approaches that have been implemented to date include various strategies that range in focus from the individual to the community context as the target for change. These approaches have focussed on a range of different areas, namely traditional health education approaches, behaviour change approaches that draw on social cognition models, structural interventions targeting features of the social environment that fuel HIV risk and scientific research that focusses on developing biomedical HIV prevention technologies, such as HIV vaccines.

2.1.3.1. Behaviour change interventions.

HIV prevention approaches in this category focus on the individual as the locus of change. Strategies that adopt individual level behaviour change approaches frame HIV/AIDS as a public health problem and emphasize interventions such as increasing knowledge about HIV/AIDS and promoting the adoption of safer sexual practices (Coates et al., 2008; Merson et al., 2008). These interventions are commonly grounded in social cognitive theories and are based on two key assumptions. First, they may assume that people engage in high-risk behaviours related to HIV due to a lack of knowledge about the virus, risk factors associated with HIV transmission and protective factors associated with reducing the risk of infection (Campbell & Cornish, 2010). Second, they may assume that interventions based on social cognitive models provide sufficient insight into how people assess their vulnerability to HIV infection and the costs and benefits associated with adopting health-protective behaviours as the basis for making rational choices in high-risk sexual encounters (Campbell & Cornish, 2010; Roberts & Matthews, 2012). While there is evidence that behaviour change interventions have been effective in some settings, researchers point out that they have not fulfilled their promise of reducing the spread of the HI-virus (Coates et al., 2008; Kalichman, 2008; Padian et al., 2011).

Coates et al. (2008) point out that, when implemented on their own, behavioural HIV prevention interventions are necessary, but not sufficient to reduce the spread of HIV. Their limited success relates in part to the fact that they do not consider how social contexts characterized by a range of risks to HI-infection, enable or inhibit people from adopting and maintaining health protective behavioural practices (Campbell & Cornish, 2010). Effective HIV prevention must, therefore, be embedded in a nuanced understanding of the barriers to HIV prevention and base its strategies on an in-depth understanding of the socio-cultural context, life histories, beliefs, knowledge systems and understandings of HIV/AIDS that

constitute the local community contexts in which HIV prevention interventions are implemented (Roberts & Matthews, 2012).

2.1.3.2. Structural and community mobilization interventions.

According to Roberts and Matthews (2012), structural HIV prevention interventions challenge the notion that individuals are primarily responsible for becoming HIV infected. Structural interventions shift the target for intervention from the individual to the social context by intervening to address the social conditions that contribute to HIV infection. Such prevention interventions focus on the social, economic, political and environmental factors that increase vulnerability to HIV infection, for example gender inequalities, high levels of poverty (Gupta, Parkhurst, Ogden, Aggleton, & Mahal, 2008; Merson et al., 2008; Roberts & Matthews, 2012). They seek to address and disrupt the root causes or structures that may impact individual risk and increase vulnerability to HIV infection (Gupta et al., 2008). Structural interventions take a bottom-up perspective and support the development of local innovation, increasing individual agency and power over the factors that contribute to HIV infection. Structural interventions offer individuals who may wish to make behavioural changes the possibility of adopting health-protective behaviours in contexts where such choices are constrained (Roberts & Matthews, 2012).

Merson et al. (2008) argue that HIV prevention is fundamentally about transforming environments and structures. HIV prevention interventions that adopt a structural approach implement policies and programmes that aim to transform the environments in which people live. They implement community processes that act as catalysts for social and political change and reduce the vulnerability of individuals in high HIV risk settings (Gupta et al., 2008). Structural interventions may use community mobilization approaches to achieve social change, incorporating strategies such as activism, education and awareness-raising, community mobilization and behaviour change into programmes that aim to reduce for

example gender-based inequalities or to shift social norms that impact the spread of HIV (Gupta et al., 2008; Merson et al., 2008; Piot, Bartos, Larson, Zewdie, & Mane, 2008). In spite of some successes, the structural intervention approach has been considered as too diffuse to warrant its use in the broader HIV prevention arena (Gupta et al., 2008). Critics of this approach argue that, with its focus on linking HIV risk to distal factors that are beyond the control of programme staff, it is hard to assess the impact of structural interventions to build an evidence base to support its use (Gupta et al., 2008).

There is, however, some evidence for the utility of the structural intervention approach in building health-enabling social contexts (Campbell, 2003) that support people in adopting HIV-protective behavioural practices. In South Africa, a structural intervention approach was used to build AIDS competence in Entabeni, an isolated rural community with a high HIV prevalence (Campbell, Nair, & Maimane, 2007). A key strategy used in this intervention was working with local community members to identify obstacles to effective HIV/AIDS management in their community. The intervention also focussed on developing strategies that community members could use to support one another and that would make them more effective in accessing help and support from external groups. Another example of a structural HIV prevention intervention in the South African context is the Intervention with Microfinance for AIDS and Gender Equality (IMAGE) project that aimed to reduce gender-based HIV vulnerabilities through a microfinance intervention (Pronynk, Hargreaves, & Morduch, 2007). This intervention enabled women to pursue small enterprises as a mechanism through which they could become financially independent. It also created opportunities for women to discuss and mobilize local action against intimate partner violence (Pronynk et al., 2007). While both these interventions used an empowerment approach to address the social drivers of HIV risk in the communities in which they were implemented, they had variable levels of success. In Entabeni, for example, the success of the

intervention was influenced by difficulties in building bridging partnerships between the local community and outside support agencies that would ensure access to resources and the sustainability of the community response to HIV/AIDS. In the IMAGE project, researchers believed that their intervention showed clear evidence of success from reports of a reduction in intimate partner violence due to women's increased levels of agency in their intimate relationships (Kim et al., 2009).

2.1.3.3. Biomedical HIV prevention technologies.

The appeal of biomedical approaches to HIV prevention is their ability to offer immunity, permanent reductions in susceptibility and diminished infectiousness (Gwandure & Mayekiso, 2012). The most successful biomedical intervention for HIV prevention to date has been the use of Antiretroviral Therapy (ART) to prevent mother-to-child transmission of HIV (Kalichman, 2008; Merson et al., 2008). Building on this success, this area of HIV prevention strategies includes studies to develop microbicides and an HIV vaccine and studies that aim to reduce HIV infection susceptibility through strategies such as medical male circumcision and Pre-Exposure Prophylaxis (PrEP) for discordant couples (Gwandure & Mayekiso, 2012; Kurth et al., 2011; Padian et al. 2011). The effectiveness of medical male circumcision in reducing the risk of HIV acquisition in men has been shown in clinical research (Padian et al., 2011; Potts et al., 2008). While the development of a safe and efficacious HIV vaccine is a long-term endeavour, historically vaccines have been shown to be the best way to stop a virus (Bernstein, 2008).

For biomedical HIV prevention interventions to be implemented, they have to be tested first for safety and efficacy and ultimately for effectiveness. Randomized clinical trials to test candidate products in community settings where HIV risk is high constitute the fundamental building blocks of research into such interventions. For ethical reasons, such trials have to incorporate a range of interventions that may reduce HIV risk in addition to

testing the efficacy of biomedical interventions. For example, while the end-point of a safe and efficacious HIV vaccine may be a long way off, clinical research to test candidate vaccines include features of other HIV prevention approaches, such as VCT services, sexual risk counselling, HIV/AIDS education and quality healthcare and screening services (Asiki et al., 2013; IAVI, 2009; Lesch et al., 2006; Newman et al., 2006; Ruzagira et al., 2009; Sahay et al., 2005, Smit et al., 2005; Voytek, Jones, & Metzger, 2011). HVTs also include community engagement as a key strategy for promoting the participation of community members in the research (UNAIDS-AVAC [United Nations Program on HIV/AIDS-AIDS Vaccine Advocacy Coalition], 2011). In high HIV risk, resource-poor settings, these trials offer community members who are targeted for their research participation with easy access to HIV prevention resources that enable them to stay HIV-free.

2.1.3.4. Reframing HIV prevention – biomedical approaches in context.

According to Piot et al. (2008), the HIV prevention arena has to come to terms with complexity. The available HIV prevention interventions have had a limited impact on stemming the tide of the epidemic due to their individualistic focus and the fact that those interventions that have sought to intervene at the level of the social context have been beset with difficulties. The dynamics of processes of social change and the constantly evolving social contexts in communities where HIV prevention interventions are implemented, create complex problems for researchers working towards the goal of preventing the spread HIV (Friedman et al., 2005). For such interventions to be effective, therefore, they must be embedded in an understanding of the social, economic, political and cultural factors that affect HIV transmission and influence responses to the threat of HIV in communities. Therefore, in-depth insight into the socio-cultural context, beliefs, knowledge systems and understanding of HIV/AIDS in the local communities in which HIV prevention interventions are implemented, is crucial.

Various authors have called for a renewed and revitalized movement for HIV prevention (Coates et al., 2008; Padian et al., 2011; Kurth et al., 2011). Reframing HIV prevention by adopting combination approaches that target multiple levels such as the individual, family, peer and community networks, and including both HIV infected and HIV negative individuals are considered to be crucial in reducing the spread of the virus (Coates et al., 2008; Kurth et al., 2011). Reframed HIV prevention approaches have a number of key features. First, reframed HIV prevention approaches leverage the successes of both biological and social interventions (Roberts & Matthews, 2012) and are based on in-depth knowledge of the dynamics of the epidemic in specific settings (Kurth et al., 2011). They create health-enabling social contexts (Campbell, 2003) for HIV prevention by tailoring interventions to address the local realities that influence the spread of the virus, so that they enable individuals living in high-risk settings to adopt health protective behavioural practices. Second, reframed HIV prevention approaches move beyond a focus on stemming the tide of the disease to focussing on building community capacity. In high HIV risk settings, they build local skills and competencies, strengthening both individuals and the systems that they are part of, including families, groups and local communities. Finally, reframed HIV prevention approaches use participatory approaches and promote the participation of all relevant stakeholders as a crucial component in all phases of the intervention process (Friedman et al., 2005).

2.1.4. A key frontier in biomedical HIV Prevention – The development of an HIV vaccine.

As stated above, HIV prevention requires a range of intervention strategies that target the multiple levels of risk factors that contribute to HIV risk (Kurth et al., 2011; Merson et al., 2008). Biomedical HIV prevention interventions, such as HIV vaccines, form an integral part of interventions to prevent the spread of the HI-virus (Padian et al., 2011). As an HIV

prevention strategy, it is hoped that an HIV vaccine will form part of an integrated approach to HIV prevention that could potentially be combined with other partially protective biomedical strategies, such as male circumcision and behavioural, educational and structural HIV prevention strategies (Coates et al., 2008; Fuchs et al., 2010; Padian et al., 2011). Elements of a range of HIV prevention approaches are embedded in HIV vaccine research studies. Community members who participate in HVTs in high HIV risk settings have access to information and education about HIV/AIDS, VCT services, sexual risk monitoring and HIV vaccines and scientific research over the course of their involvement in the clinical research process.

Across all levels of the HIV vaccine enterprise, the involvement of communities in which HIV prevalence is high in the research process is emphasized as crucial to the successful development of a safe and efficacious HIV vaccine (Lau, Swann & Singh, 2011; Wakefield, 2005). From the perspective of researchers and funders, communities form an integral part of the HIV vaccine enterprise, mediating their access to the dynamics of the local community context, providing input into study-related aspects to improve study recruitment, retention of participants and to ensure the ethical conduct of research in the local community context. The role of the local communities in which HIV vaccine research takes place is, therefore, clearly articulated and focussed on the ethical and operational aspects to ensure successful trial implementation. It is not clear, however, what direct benefits communities will derive from their involvement in the process. In spite of the substantial investment of resources into scientific experimentation to test candidate HIV vaccines in resource-poor, high HIV risk community contexts, the implicit assumption on which this research is based is that the development of a safe and efficacious HIV vaccine presents sufficient benefit to community stakeholders. This assumption requires disruption. Given the multiple risks to health and well-being that characterize the social contexts in which HVTs

take place, researchers and funders must work harder to integrate community capacity building agendas into clinical research, maximizing the utility of the available resources to generate short-term, mutual benefit for all stakeholders involved. Such integration reframes HVTs as a social good, advancing the agenda of the HIV vaccine enterprise and leaving local communities who host HVTs better off by virtue of their involvement in the process.

2.1.4.1. HIV vaccines as HIV prevention.

Vaccines are a powerful and effective public health tool (AVAC, 2013; Leach & Fairhead, 2007). The evidence for the success of vaccines in halting deadly epidemics is well documented. For example, the development of vaccines that target polio, tetanus and measles have been instrumental in lowering the rates of these diseases worldwide (Arevshatian et al., 2007). The timeline for developing vaccines, however, is lengthy, and attempts to develop an HIV vaccine have been ongoing since the early 1980s (Day & Kublin, 2014). Thirty years later, scientists have yet to achieve the goal of developing a vaccine that will prime the immune system to recognize and attack the HI-virus when it enters the body (AVAC, 2013; Kahn, 2005). In spite of the slow progress in developing an HIV vaccine, stakeholders in the HIV vaccine research enterprise continue to believe that a safe and efficacious HIV vaccine is within reach, and that such a vaccine offers the best chance of reversing and ultimately ending the HIV pandemic (AVAC, 2013; Kahn, 2005; Warren, 2005).

Developing an HIV vaccine is a long-term endeavour that incorporates activities at many different levels. It includes animal laboratory studies, preparatory studies in communities that will be targeted for HVT participation, and randomized clinical trials to test the safety and efficacy of the candidate vaccines among target populations at risk of HIV infection (Day & Kublin, 2014; Manhart & Holmes, 2005). Clinical trials to test candidate preventive HIV vaccines in humans typically involve three phases. With each phase of the clinical trial process, larger numbers of volunteers are enrolled and different aspects related to

developing a safe and efficacious HIV vaccine are considered (Collins, 2005). In Phase I clinical trials, 40 to 120 volunteers at low risk of HIV infection are recruited to participate in trials that aim to test if the vaccine is safe in humans (South African AIDS Vaccine Initiative [SAAVI], n.d.). Phase I trials last between 12 and 18 months. Phase II clinical trials enrol hundreds of participants with both high and low levels of risk for HIV infection (SAAVI, n.d.). These trials focus on testing the safety of the vaccine in a larger group of volunteers, with the main focus on assessing the ability of the vaccine to trigger an immune response in research participants who participate in Phase II clinical trials. Phase IIb, or proof of concept trials may follow Phase II trials and aim to generate preliminary evidence of efficacy in shorter, smaller and less costly trials (SAAVI, n.d.). The evidence generated by these trials assist researchers in deciding whether to test the candidate vaccine in a Phase III trial. Phase III trials are the final phase in the process of testing a candidate HIV vaccine and focus on efficacy, in other words assessing whether the vaccine being tested protects people against HIV infection (Collins, 2005; SAAVI, n.d.). Phase III trials enrol several thousand volunteers who are at high risk of HIV infection and may take five to six years to complete (Collins, 2005; SAAVI, n.d.).

Mitchell Warren, an AIDS vaccine advocate and Executive Director of the AIDS Vaccine Advocacy Coalition (AVAC), believes that the pursuit of an HIV vaccine must not influence immediate responses to the HIV pandemic (Warren, 2005). He suggests that while HIV vaccine development is a long-term and ongoing endeavour, this goal must be pursued alongside the range of currently available HIV prevention strategies. Prevention, testing, treatment and trials must, therefore, occur simultaneously (Warren, 2005). HIV vaccine trials are conducted in communities where the risk of HIV infection is high and target HIV negative community members for their participation in the research (Lesch et al., 2009). As mentioned above, current HIV prevention strategies such as HIV/AIDS and HIV vaccine

education and awareness-raising, VCT, sexual risk counselling and monitoring, are key components of HIV vaccine research and are offered to community members who participate in HIV vaccine trials to test candidate HIV vaccines (Asiki et al., 2013; AVAC, 2009; IAVI, 2009; Kirby, Laris, & Roller, 2007; Lesch et al., 2006; Newman et al., 2006; Ruzagira et al., 2009; Sahay et al., 2005, Smit et al., 2005; Voytek et al., 2011). Therefore, while clinical trials to test candidate HIV vaccines are framed as scientific experiments, they also incorporate HIV prevention intervention components that may assist participants in remaining HIV-free over the course of the clinical trial.

2.1.4.2. Making sense of the ‘social’ in HIV vaccine research.

Given that Phase III clinical trials to test candidate HIV vaccines require large numbers of volunteers at high risk to participate in the clinical trial process. Mirroring HIV prevention research, the target populations for HIV vaccine research are groups that are at high risk of HIV infection globally (Smit et al., 2005; Voytek et al., 2011). These target populations represent marginalized and vulnerable groups and include men who have sex with men (MSM), injecting drug users (IDUs), sex workers, and heterosexual men and women in sub-Saharan Africa (AVAC, 2013; Smit et al., 2005). In Sub-Saharan Africa, the HIV prevalence is highest in heterosexual men and women. HIV vaccine research in this setting has, therefore, focussed primarily on these sub-groups (Smit et al., 2005).

In HVTs, the goal of developing a safe and efficacious HIV vaccine moves out of the laboratory and is transplanted into local community contexts in which the research takes place. HVTs bring the scientific process of experimentation into local community contexts in search of large numbers of volunteers at high risk of HIV infection to participate in clinical research. Given the pragmatic objective of enrolling large numbers of HIV negative volunteers at high risk of HIV infection (Ruzagira et al., 2009; Voytek et al., 2011), HIV vaccine research is conducted in communities characterized by socio-economic challenges,

which include poor living conditions, high rates of poverty, unemployment, high rates of violence, HIV/AIDS stigma, and lack of access to resources that promote health and well-being and confer protection against HIV risk (AVAC, 2013; Smit et al., 2005; Voytek et al., 2011). These characteristics represent the lived realities of individuals who reside in these communities and these realities increase their vulnerability to HIV infection and other poor health outcomes (AVAC, 2013; Smit et al., 2005; Voytek et al., 2011). HIV vaccine research is, therefore, conducted at the confluence of key issues relating to its associations with a highly stigmatized disease, such as HIV/AIDS; the dynamics of community members' research participation in resource poor contexts; and concerns about the exploitation and harm of vulnerable populations being targeted for their participation in and support of HIV vaccine research (MacQueen, 2011). Engaging with and understanding the dynamic features of participants, their social networks and the community contexts in which HVTs are being conducted, is crucial for the successful conduct of HIV vaccine research.

HIV vaccine trials require long-term retention of participants and place many demands on trial participants (Smit et al., 2006). Community members who opt to participate in such trials are required to test for HIV and to submit to various screening procedures to assess their eligibility to participate in HIV vaccine trials. Once potential participants meet the criteria for trial inclusion, they are required to make multiple visits to the HVT research centres, test for HIV antibodies at each visit, subject themselves to questions about the most intimate and personal aspects of their sexual behaviours, have blood drawn, participate in educational sessions about HIV/AIDS and HIV vaccines, and adopt or maintain safe sexual practices (Highleyman, 2005).

HIV vaccine research involves multiple stakeholders in the search for a safe and efficacious HIV vaccine. Collaboration and partnership between global and local stakeholders is presented as the crucial foundation of the HIV vaccine research enterprise

(Lau, Swann & Singh, 2011). Stakeholders involved in the HIV vaccine research enterprise include biomedical scientists from multiple scientific disciplinary groups, clinical trial scientists, clinical trial site staff, global not-for-profit organizations and clinical trial networks that support and advocate for the conduct of HIV vaccine research globally, pharmaceutical companies that fund HIV vaccine science and clinical trials (MacQueen, 2011; Newman et al., 2015; UNAIDS-AVAC, 2011), behavioural and social scientists, individual participants, local communities in which HIV vaccine research is conducted and their Community Advisory Boards (CABs) (Lau, Swann & Singh et al., 2011; MacQueen, 2011).

While all stakeholders involved in the HIV vaccine research enterprise share a common goal, for instance a safe and efficacious HIV vaccine, each of these parties enter the HIV vaccine enterprise with their own vision for the vaccine development process (Wakefield, 2005). The HIV vaccine enterprise is, therefore, made up of a network of complex partnerships (MacQueen, 2011) as each stakeholder group brings their own needs, values, agendas and desired outcomes to the process. In addition, each stakeholder group has differential access to resources, power and control over the HIV vaccine development process (MacQueen, 2011; Petryna, 2009). These differences underpin the relationships between stakeholders, shaping and influencing the HIV vaccine development process. Promoting common understanding and goals in the HIV vaccine development process as the foundation for building collaborative partnerships among individuals and groups with varying needs, presents a challenge to researchers. This challenge has spawned a substantial body of social science research that aims to examine the social and human dimensions of HIV vaccine research. Such social science research is framed as ethical and scientific (MacQueen, 2011) and as a consequence of this framing, the priority areas promoted for social science research on HIV vaccines are those that will inform the operational aspects of trial conduct and trial-related activities (MacQueen, 2011; Lau, Swann & Singh et al., 2011; Newman et al., 2015).

As stated above, a substantial amount of social science research has been conducted to explore the various socio-behavioural dimensions considered to be crucial to the successful implementation of HVTs. These research studies have been conducted in the context of community preparedness and HVTs to understand the settings and populations in which trials are being conducted, and research aimed at generating solutions to ethical problems and challenges encountered when conducting research in local communities, such as how to deal with informed consent in various settings. It also endeavoured to address pragmatic operational concerns of trial site researchers, like how to promote the participation of large numbers of individuals in HVTs and retain them over the lifespan of the trial (Lau, Swann & Singh et al., 2011; Ruzagira et al., 2009). Other areas of focus have included documenting the social impact of trials on participants (Allen & Lau, 2008; Fuchs et al., 2007), monitoring the sexual risk behaviours of trial participants (Bartholow et al., 2005; Gray et al., 2013) and examining the acceptability and uptake of future HIV vaccines in various populations (e.g., Newman et al., 2009; Sayles, MacPhail, Newman, & Cunningham, 2009). Given that this research explores community engagement as a vehicle for promoting the participation of community members in HIV vaccine research, I focus my discussion of the available social science research on HIV vaccines on two key areas relevant to this focus, namely understanding participation in HIV vaccine trials and guidance for promoting community engagement in HIV vaccine research.

2.1.4.3. Understanding participation in HIV vaccine trials.

The largest proportion of social science studies on HVTs focus on the factors that influence willingness to participate in HIV vaccine research (WTP). The purpose of these studies is to identify barriers and facilitators to participation in HVT research that can be addressed through intervention to increase the numbers of community members willing to participate in HIV vaccine research. Studies on WTP focus on three key areas. First,

documenting WTP by describing factors that influence it in various high HIV risk populations, and across various setting in which HVTs are conducted. This area of research has generated a substantial body of evidence on factors that influence WTP in HVTs among various high HIV risk target groups, for instance African American women (e.g., Voytek et al., 2011) and ethnic minority communities in the United States of America (USA) (Newman et al., 2006); sexually transmitted infection (STI) and reproductive tract infection clinic attendees in India (Sahay et al., 2005); heterosexual adults and adolescents in South Africa (e.g., Gray et al., 2013; Jaspan et al., 2011; Lesch et al., 2006; Smit et al., 2006); heterosexual adults from a community-based cohort in Uganda (e.g., Ruzagira et al., 2009) and fishing communities in Uganda (e.g., Asiki et al., 2013); and participants at two HIV vaccine research centres in Kenya (Nyblade et al., 2011). Consolidating the findings from these studies, there are number of reviews that have drawn together evidence on barriers and facilitators to HVT participation across a range of different HVT settings (e.g., Dhalla & Poole, 2011; Mills et al. 2004; Rosenblatt & Dorsen, 2011; Smit et al., 2005).

The second key area relates to studies that have examined the role of knowledge of HIV/AIDS and HIV vaccines on WTP in Uganda (Kiwauka et al., 2004) and the USA (Lally et al., 2014). Contributing to this area, Lindegger et al. (2006) explored the effectiveness of assessing understanding of HIV vaccine research using four different measures. These studies examine the impact of knowledge on WTP as both an operational and ethical imperative to assess “good enough understanding for trial participation” (p. 562, Lindegger et al., 2006), among other things, as the basis of informed decision-making about trial participation. The final area of social science research on HVTs that explores issues relating to WTP examines the social impact of research participation on HVT participants in the local community settings where such research is conducted (e.g., Allen & Lau, 2008; Newman et al., 2011). These studies focus on identifying the social harms that HVT

participants may experience by virtue of trial participation with a view to developing mechanisms of support.

The social science research on HIV vaccines, as has been highlighted above, is limited in its focus on generating findings that can be utilized to improve the operational and ethical aspect of clinical trials. While framed as socio-behavioural research using social science methods, this body of research may be viewed as operational research in its emphasis on generating findings that may inform clinical trial implementation. In addition, while studies on the socio-behavioural aspects of HIV vaccine research have used both quantitative and qualitative methods to document the factors that inhibit or facilitate the participation in HVTs, they have failed to harness the potential of the latter. Findings from these studies are presented in a manner that compares findings across various populations and settings, highlighting similarities and documenting differences as new and unique findings. They fail to move beyond this tendency to describe and compare to explore in-depth the dynamics of local communities that host clinical trials, the networks of relationships that influence WTP and other key trial-related activities, and the experiences of those who participate in HIV vaccine research in local communities.

To conclude, the available social science literature on HIV vaccine research is limited in its ability to inform an in-depth exploration of the dynamics of HVT participation and community engagement processes. It is, however, important to document the salient findings of this research as it forms the starting point for my examination of community engagement in HIV vaccine research at the local community level. In presenting findings on the factors that influence WTP in HIV vaccine research from the available literature, I draw on the framework outlined, by my colleagues and I, in previous research examining the enablers and inhibitors to participation in HIV vaccine trials among HVT site community members at three potential SAAVI HIV vaccine trial sites (Lesch et al., 2006). Following this framework,

I discuss the enablers and inhibitors to HIV vaccine trial participation identified at three levels, namely the individual and family level, the community level, and the societal level.

2.1.4.4. Inhibitors to HIV vaccine trial participation.

2.1.4.4.1. Individual level and family level.

Participants' concerns about personal or individual risks associated with HIV vaccine trial participation have been found to be the most prevalent inhibitor to HIV vaccine trial participation. Individual level inhibitors to HVT participation include self-perception of HIV risk, concerns about trial-related procedures, fears relating to the safety of the candidate vaccines being tested and side effects associated with receipt of candidate vaccines, fears of becoming infected with the HI-virus, fears of being assumed to be HIV infected, and pragmatic obstacles that may accompany HVT participation.

Participants' assessment of their own risk for becoming infected with the HI-virus has been shown to act as an inhibitor to HVT participation in a number of studies. In Newman et al.'s (2006) study in the USA, Latina women reported their belief that Latino men would not participate in HIV vaccine trials due to their low perceived risk of HIV infection. They reported that "men ignore the problem" (p. 214). In Uganda, Ruzagira et al. (2009) reported similar findings with respect to the relationship between low perceived HIV risk behaviour and WTP in HIV vaccine research.

Concerns about trial methodology and trial-related procedures have also been cited as an inhibitor to WTP in HIV vaccine trials (Mills et al., 2004). Participants in various studies report fears of being randomized to the placebo arm of the trial, indicating that they would participate if they were assured that they would be receiving the candidate vaccine being tested (Newman et al., 2006; Ruzagira et al., 2009). Additional trial procedures such as the frequent and largevolume blood draws (Asiki et al., 2013; Jaspan et al., 2006; Ruzagira et al.,

2009), aversion to needles, receiving injections and suspicions about the use of disposable syringes (Newman et al., 2006; Sahay et al., 2005; Voytek et al., 2011) and fears of HIV testing (Lesch et al., 2006) have also been reported to act as inhibitors to HVT participation. Participants in Uganda and Kenya also reported concerns about the requirement that they should delay pregnancy if they were to participate in an HIV vaccine clinical trial (Asiki et al., 2013; Ruzagira et al., 2009).

Participants' vaccine-related fears act as an inhibitor to HIV vaccine trial participation. This category of fears relates to their concerns about the safety and efficacy of the candidate vaccine being tested (Asiki et al., 2013; Dhalla & Poole, 2011; Ruzagira et al., 2013; Sahay et al. 2005; Smit et al., 2005). Participants' fear of experiencing potential adverse reactions and unknown side-effects are included as inhibitors to HVT participation in this category (Dhalla & Poole, 2011; Mills et al., 2004; Sahay et al., 2005; Smit et al., 2005). Potential side effects cited relate to the fears of physical harm and experiencing physical side effects, such as losing hair or damage to organs (Newman et al., 2006; Ruzagira et al., 2009), and fear of becoming infected with the HI-virus through receipt of the candidate vaccine (Lesch et al., 2006; Newman et al., 2006). Vaccine-induced seropositivity (VISP) has also been highlighted as an inhibitor to HIV vaccine trial participation (Dhalla & Poole, 2011; Newman et al., 2006). In this regard, participants in Newman et al.'s (2006) study reported that they would experience testing HIV infected as emotionally challenging. Behavioural disinhibition (Mills et al., 2004), and other unforeseen short- and long-term reactions that may have a significant impact on their future health and well-being have also been cited as feared side effects of HVT participation (Dhalla & Poole, 2011; Voytek et al., 2011).

The final category of inhibitors to HVT participation at the individual/family level relates to pragmatic obstacles that participants encounter through their participation in HVTs. Participants in various studies mentioned concerns about the disruption and inconvenience

that HVT participation may cause in their daily lives in terms of time required, distances that they would have to travel to HVT sites, the logistics of trials and study demands, transport challenges and the monetary costs associated with HVT site visits (Asiki et al., 2013; Dhalla & Poole, 2011; Lesch et al., 2006; Newman et al., 2006; Voytek et al., 2011). In addition, participants also mentioned the personal limitations that HVT participation would impose on them as inhibitors to participation. In particular, issues such as relocation to other communities and the difficulties that this would pose for regular trial site visits; restrictions on travel and immigration; and other contingencies such as illness, being imprisoned and lack of a support network to assist with family and caregiving responsibilities, were cited as inhibitors to HVT participation (Dhalla & Poole, 2011; Jaspán et al., 2011; Newman et al., 2006; Sahay et al., 2005).

2.1.4.4.2. Community level.

Inhibitors to HVT participation at the community level include mistrust of institutional stakeholders involved in HIV vaccine research, including researchers, research-related procedures, and fears of experiencing HVT-related discrimination or social harms.

Mistrust of institutional stakeholders including researchers, governments, government sponsored research, research-related procedures and pharmaceutical companies, has been highlighted as an inhibitor to HVT participation across different settings in which HVTs are being conducted (Lesch et al., 2006; Mills et al., 2004; Newman et al., 2006). Participants express concerns that researchers would exploit Black communities, expose participants to risk by testing untested vaccines and medicines in communities, and experiment on participants without their consent (Lesch et al., 2006; Newman et al., 2006). They also express scepticism and concerns about whether candidate vaccines may cause HIV infection in trial participations. Participants mention historical incidences of abuse of vulnerable Black communities, such as the Philadelphia prison experiments (Voytek et al., 2011) and fatalities

in previous medical research (Lesch et. al, 2006). As an extension of the notion of exploitation, community members also report concerns about being treated like guinea pigs by HVT researchers (Allen & Lau, 2008; Mills et al., 2004; Newman et al., 2006; Voytek et al., 2011), articulating these concerns as concerns about being treated like a “lab rat”, “test dummy” and “research monkey” (p. 6132, Voytek et al., 2011).

The primary community level barrier to HVT participation relates to HVT-related discrimination. HIV/AIDS is highly stigmatized in the communities in which HVTs are conducted. In these communities, HIV infected individuals and those associated with them are avoided by others. Potential HVT participants, therefore, express concerns about being stigmatized, discriminated against and avoided by virtue of their HVT participation because of its association with HIV/AIDS (Lesch et al., 2006; Mills et al., 2004; Nyblade et al., 2011; Smit et al., 2005). This discrimination may impact the daily lives of participants and their interactions with their partners, families, neighbours and the wider community. In Kenya, research participants reported fears of being subjected to gossip, finger pointing, and experiencing physical and social isolation (Nyblade et al., 2011). Research participants report that HVT participation may lead to them being stigmatized in their communities and may cause conflict and negative reactions in their spousal, family and peer relationships (Allen & Lau, 2008; Dhalla & Poole, 2011; Lesch et al., 2006; Newman et al., 2006). Related to the fear of being discriminated against by virtue of HVT participation, participants also fear disclosure of their involvement in HIV/AIDS-related research (Nyblade et al., 2011).

In terms of the assumption that research volunteers are HIV infected, participants in Kenya report that their friends, family and community members may assume that participating in an HIV vaccine trial serves as confirmation of a positive HIV status (Nyblade et al., 2011). This finding is echoed across other HVT settings, where study volunteers have reported that fears of being mistakenly presumed to be HIV infected by virtue of HVT

participation, and being stigmatized and discriminated against for this reason, acts as an inhibitor to participation (Lesch et al., 2006; Mills et al., 2004; Sahay et al., 2005).

Participants in Nyblade et al.'s (2011) study further report that the presumption of HIV infection is related to community members' misperception that HVT participants are injected with the HI-virus. Being presumed as being HIV infected by virtue of HVT participation may impact participants' relationships with others, as others may fear contracting HIV through contact with the HVT participant and avoid sexual contact with him/her (Dhalla & Poole, 2011; Mills et al., 2004). The stigma and discrimination reported to exist in various HVT settings is perceived to be largely a result of community members' lack of knowledge about HIV/AIDS and HIV vaccines (Lesch et al., 2006; Sahay et al. 2005).

2.1.4.4.3. Societal level.

At the societal level, patriarchal systems that structure relations in many HVT settings have been identified as an inhibitor to HVT participation. Women in Sahay et al.'s (2005) Indian study reported their belief that men should be offered the vaccine first and that men should make decisions about HVT participation on behalf of their spouses. This finding is mirrored in Asiki et al.'s (2013) study in Uganda where participants reported that community or religious leaders and spouses, particularly husbands, should be consulted before decisions about HVT participation are made. In South Africa, female participants reported that they would need to obtain permission from their boyfriends or husbands before agreeing to participate in HVTs (Lesch et al., 2006). Participants in this study also supported the role of the family in decision-making about HVT participation, reporting that they would have to convince their families to accept their decision to participate in such research (Lesch et al., 2006).

2.1.4.5. Enablers to HIV vaccine trial participation.

2.1.4.5.1. Individual level and family level.

At the individual level, altruism has consistently been identified as an enabler to HVT participation. Motives such as contributing to ending the HIV/AIDS pandemic and participating in HVTs to help others, has been cited by participants in USA, India, Uganda and South Africa as enablers to their participation in HVTs (Asiki et al., 2013; Jaspan et al., 2006; Lesch et al., 2006; Newman et al., 2006, 2012; Sahay et al., 2005; Voytek et al., 2011).

The need for protection from becoming infected with the HI-virus has also been cited as an enabler for HVT participation in HVT settings where the risk of infection is high. Participants cite benefits such as improved quality of life, gaining extra protection from HIV infection and opportunities to live a better life as promoting their WTP in HVTs (Asiki et al., 2013; Lesch et al., 2006; Newman et al., 2006, 2012; Ruzagira et al., 2009).

Access to the incentives associated with HVT participation has also been identified as an enabler to WTP. Research participants across a range of studies identified financial compensation as an enabler to WTP (Lesch et al., 2006; Newman et al., 2006; Sahay et al., 2005; Voytek et al., 2011). In some settings, the financial incentive paid to research participants was viewed as an alternative to other income generating activities in impoverished neighbourhoods. Therefore, for participants in these studies, the financial compensation become salient, coercing them into participation and overshadowing the scientific issues related to HVTs (Lesch et al., 2006; Voytek et al., 2011). Access to other material benefits associated with HVTs have also been identified as enablers. These material benefits include receiving free, quality medical care at HVT clinics, access to confidential HIV counselling and testing services, and receiving medical and life insurance (Asiki et al., 2013; Lesch et al., 2006; Newman et al., 2006; Ruzagira et al., 2009; Sahay et al., 2005, Smit et al., 2005). The opportunity to access health and HIV/ AIDS information and education and

having supportive persons to talk to is also associated with reported WTP (Asiki et al., 2013; Voytek et al., 2011).

Self-perception of risk acts as an enabler to WTP at the individual level. Jaspan et al. (2006) found that adolescents who reported being sexually active indicated higher levels of WTP than those who are not sexually active. In addition, participants in Voytek et al.'s (2011) study reported that HVT participation would prompt them to change current risk behaviours that increase their susceptibility to HIV infection.

Awareness of current HIV vaccine development efforts and knowledge of HIV vaccines have also been found to promote WTP (Kiwanuka et al., 2004; Sahay et al., 2005; Smit et al., 2005). However, the link between knowledge about HIV/AIDS and HIV vaccines and WTP has not been consistent across studies examining this relationship. Evidence suggests that increasing levels of information and education may in fact reduce WTP (Smit et al., 2005).

Finally, at the family level, positive family reactions towards HVT participation has been cited as a factor that may enhance the likelihood of trial participation. Participants point out, however, that support from their families would depend on the level of HIV vaccine research information that their families have access to (Lesch et al., 2006).

2.1.4.5.2. Community level.

At the community level, the high salience of the HIV/AIDS pandemic in communities where HVTs are being conducted acts as an enabler to WTP. In South Africa, participants point out that HIV/AIDS is highly visible in their communities, among friends and families who are HIV infected (Lesch et al., 2006). In addition, they highlight that offering different levels of participation in HVTs by involving HIV infected community members as advocates for HVT participation, would increase the likelihood that people would participate in the research

(Lesch et al., 2006). The visibility of prominent community members' involvement in HVTs would also serve as an enabler to WTP. Finally, in India, Sahay and colleagues (2005) found that participants who understand their own stake in the HIV vaccine development process would be more likely to participate in such research.

2.1.5. Community engagement in HIV vaccine research: Science, citizens and HIV/AIDS.

This research focusses on the process of community engagement that promotes the participation of local communities in HVTs conducted in resource-poor environments. My examination focusses on the current community engagement practices at one HIV vaccine research centre in the Western Cape, Research Centre X. As outlined above, HVTs take place in complex social environments where levels of poverty, unemployment, violence, and HIV/AIDS are high; and access to resources that promote health and well-being are low (Lesch, Singh, Kafaar, Swartz & Menezes, 2013). When HIV vaccine research moves into such local community contexts, it brings with it a range of resources beneficial to communities. Community members' participation in HIV vaccine research mediates their access to these resources as it provides the context in which all trial-related activities take place, including HIV/AIDS and HIV vaccine education and awareness-raising, trial recruitment, and community consultation and representation. HIV vaccine research involves multiple stakeholders with differing interests, needs, priorities and viewpoints. Therefore, while securing the buy-in, support and participation of communities in HVTs through the community engagement process is emphasized as a key ethical, scientific and operational imperative (Frew et al., 2011). At the coalface of clinical trial implementation, achieving authentic, meaningful community engagement that is mutually beneficial, is challenging.

2.1.5.1. Challenges to community engagement in HIV vaccine research.

Promoting the participation of local communities in HIV vaccine research is a complex example of relatively higher risk involvement of communities in clinical trials. The higher level of risk associated with HVT participation results from the various risk factors that fuel HIV risk in the contexts in which HVTs are conducted. These risk factors increase the vulnerability of local community members to co-option and exploitation within the HVT process. Community engagement, the mechanism by which local communities are involved in the research process, is conducted against the backdrop of such complexities, presenting researchers with the challenge of developing strategies to overcome these challenges through their community engagement processes.

Firstly, HIV vaccine research is conducted in communities where concerns about ethical violations and the exploitation of vulnerable communities are salient (Freimuth, Cole & Kirby, 2001; MacQueen, 2011). Public mistrust of scientists and researchers has been well documented as a consequence of the chequered history of the clinical trial enterprise (Emanuel et al., 2004). The most prominent of these clinical trials is the now infamous Tuskegee Syphilis clinical trial conducted to study the natural progression of untreated syphilis among rural African American men in the USA. The men who participated in this study were told that they were being treated for “bad blood” and, while they received free healthcare, meals and burial insurance, their diagnosis was never shared with them. In addition, they did not receive treatment for their disease after it was shown that penicillin is effective in treating the disease (Brandt, 1978). Another prominent case that of Henrietta Lacks: a poor, Black tobacco farmer, whose cells were taken without her knowledge and consent, after she presented for cancer treatment at Johns Hopkins Hospital in Baltimore during the early 1950’s. Her immortal cell line became known as *HELA* and has been

instrumental in developing some of the most important medical interventions available to date, including the polio vaccine, gene mapping and in vitro fertilization. In spite of Henrietta Lacks' substantial contribution to biomedical innovation, her family were unaware that her cells had been taken and continued to live in impoverished conditions, unable to afford health insurance (Skloot, 2010).

In Africa, controversies over the use of placebo in clinical trials to test the efficacy of short-course azido thymidine treatment (AZT) to prevent perinatal HIV transmission, contributes to these debates about ethical violations in research among vulnerable, high risk populations (Petryna, 2009). The development of biomedical HIV prevention technologies, events such as the Ushercell microbicide controversy (Honey, 2007) and the halted STEP/Phambili HIV vaccine trial (Fuchs et al., 2010; Ruzagira et al., 2009) has sharply brought into focus the challenges encountered when involving communities in the experimental process. The phase IIb Phambili trial (a companion to the STEP trial) conducted among heterosexual adults across five HIV vaccine trial sites in South Africa, was halted after interim results from the STEP trial in the USA and Australia among 801 of a targeted 3000 participants, showed that the vaccine probably did not confer protection against HIV infection, but was associated with possible increased risk of HIV acquisition (Fuchs et al., 2010; IAVI, 2007; Lau, Stansbury, Gust, & Kafaar, 2009). While principal investigators at the sites where Phambili was conducted emphasized that volunteers' safety was never in jeopardy, the halting and subsequent unbinding of volunteers in the trial has been considered controversial and has raised concerns about the research among community members (Newman et al., 2015). Lau and colleagues (2009) highlight the fact that such events may contribute to fear of HVT participation by community members. Alerting researchers to the fact that the manner in which they manage and communicate early trial cessations with

communities is crucial to establishing and maintaining trust with communities (Newman et al., 2015).

Clinical trials are, therefore, embedded in histories of racism and social inequalities that gives rise to images of powerful scientists practising deception and compromising the safety of poor, vulnerable, Black communities in which the research is being conducted (Newman et al., 2015). Clinical trials that are perceived to violate participants' rights and cause harm take place in global and local spheres. Their impact filters into local community members' understandings and stories about clinical trials and clinical researchers' co-option, trickery and exploitation of vulnerable communities. Overcoming the legacy of these stories that form the basis of mistrust of science, research and the clinical research process, represents a substantial barrier to researchers seeking to involve communities in HIV vaccine research (MacQueen, 2011).

Secondly, the HIV vaccine development process is part of a global enterprise and involves the active participation of a broad range of stakeholder groups. Each of these groups have their own specific interests in and perspectives on clinical research that may diverge from each other (Baylies 2004; Kafaar et al., 2007, Lindegger et al., 2006). When viewed from the perspective of researchers and funders, clinical trials are experimental processes. From the perspective of individuals and communities who participate in clinical trials, these trials may be deeply personal experiences that may have a potentially enduring impact on their lives and their health. Such trials may also represent a means to access resources and strengthen the health of their communities (Wills & Tyeku, 2000). The differing notions of participation inherent in these perspectives present researchers with the challenge of creating partnerships with local communities and educating them about the scientific research process to facilitate informed participation in the research process.

The potentially diverging perspectives between researchers, individuals and community stakeholders are further affected by expectations that those who implement clinical trials in resource-poor communities should display a commitment to promoting the social good of communities and leave them better off as a result of their involvement in the clinical trial process (Petryna, 2009; Swartz & Kagee, 2006). Clinical trials draw on public resources, redistribute public health resources and are viewed by community members in contexts of poverty as having the potential to leave them better off (Petryna, 2009). Trial participation may, however, be accompanied by a substantial personal risk for participants due to the reported social stigma and other costs that HVT participants face, as highlighted above (Baylies, 2004; Buchbinder et al., 2004; Lesch et al., 2006; McCluskey, Alexander, Larkin, Murgula, & Wakefield, 2005; Milford, Barsdorf, & Kafaar, 2007). Therefore, on an individual level, limited benefits will necessarily accrue to those who participate in the clinical trials to test biomedical interventions. Balancing the individual good with the social good must, therefore, be a priority for clinical researchers (Kafaar et al., 2007).

A third challenge in the HIV vaccine research process is the task of building public understanding of science by educating communities about HIV vaccine research. According to Lindegger et al. (2006), potential participants in HIV vaccine trials must understand a number of HIV vaccine and clinical trial methodological components before enrolling to participate in an HIV vaccine trial. Educating community members about these aspects of trial participation presents a significant challenge to researchers working in the field. There is at present limited research that indicates HVT participants' levels of understanding of the key aspects of clinical trials and the scientific process (Lau, Swann & Singh et al., 2011). In addition, researchers in this area do not have any indication of what baseline levels of knowledge about science, research and HIV/AIDS exist in trial site communities upon which HIV vaccine education can be scaffolded.

Fourthly, HIV vaccine design is complex. A preventive vaccine does not have therapeutic value, but is designed to have a prophylactic effect. In addition, developing an HIV vaccine is complex from an immunological point of view: researchers have to consider issues such as side effects associated with receipt of a candidate vaccine (Buchbinder et al., 2004) and the possibility that participants may become immune to future vaccines (Kerns, 1997). Considering the challenges associated with local community members' involvement in HIV vaccine research, the assumption that trial participation promotes community empowerment must, therefore, be interrogated as it does not take into account the complexities that accompany community members' involvement in HIV vaccine research in resource-poor, high HIV risk local community contexts (Swartz & Kagee, 2006).

2.1.5.2. Frameworks for promoting community engagement in clinical research.

The challenges to promoting the participation of local communities in HIV vaccine research highlighted above raise central questions about how researchers may intervene to address these challenges through community engagement processes that maximize community involvement in the HIV vaccine enterprise. Community engagement is a key component of HIV vaccine research and rests on the development of community-researcher partnerships to support the successful implementation of scientific research in community settings (Emanuel et al., 2004; UNAIDS-AVAC, 2011).

This section outlines a few key contributions that underpin efforts to build community-researcher partnerships that expand the role of local community members in the process and through which all stakeholders involved in the process may derive mutual benefit through their involvement in the research.

The issue of public participation in science has received increased attention, particularly in pursuit of ensuring a fully informed research participant population that derives maximal benefit from the results of the research process (Leach, Scoones, & Wynne, 2005). The scientific literature increasingly recognizes that research participants have much to contribute to the research enterprise. Acknowledging the contribution of research participants, researchers have suggested that communities in which research is being conducted can become co-owners of the research process through their involvement in the scientific process (Green & Mercer, 2001; UNAIDS, 2007). Promoting the role of local communities as co-owners of the research process rests on expanding their role and levels of involvement over the lifecycle of the research. From the co-ownership perspective, therefore, the role of the local community in research studies moves community members away from the role of subjects or consumers of research to one in which they are partners in the process, engaging in dynamic interactions with researchers throughout the lifecycle of the research.

Calls for participant-centred scientific research build on the notion of local community members as co-owners of the research process (Aungst, Haas, Ommaya, & Green, 2003; Green & Mercer, 2001; UNAIDS-AVAC, 2011). Participant-centred scientific research adopts participatory research frameworks. In this context, participatory research frameworks are defined as the “systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or affecting change” (Green & Mercer, 2001, p. 1927). The local community members who participate in participant-centred scientific research includes all stakeholders who will use or benefit from the research findings and may include researchers, practitioners, agencies, their constituents and clients, and community residents (Green & Mercer, 2001). In terms of assessing whether participant-centred scientific research is truly participatory, Green and Mercer (2001) define the upper and lower bounds of participation as ranging from maximum to minimal

participation. At the lower bounds of participation, minimal participation denotes stakeholder involvement at the start of the study to assist in formulating the research questions; and at its end, to provide input into the interpretation and application of study findings. Maximum participation represents the upper bounds of participation and describes a situation in which all stakeholders are actively involved throughout all study stages.

Other perspectives on scientific research that is participatory in nature and reframes the role of lay persons in the scientific process come from Callon (1999) and Nowotny, Scott and Gibbons (2001). Nowotny et al. (2001) argue that due to the socially embedded nature of scientific research, new spaces must be created for lay persons or non-scientists to be involved in the scientific process. Therefore, by creating new spaces for lay person involvement in science, the role of lay persons in the research is reframed as participants, rather than subjects, resulting in the production of more socially robust forms of knowledge through engagement in public spaces open to democratic forms of reasoning and decision-making (Nowotny et al., 2001). Callon (1999) supports the notion of the co-creation of knowledge and considers the role of non-specialists/persons in knowledge production as crucial. He calls for a democratic process of knowledge co-production between scientists and non-scientists/lay people. For Callon (1999), the production of scientific knowledge involves a dynamic and constant process of interaction between lay persons and scientists, resulting in collective learning and the collective production and dissemination of knowledge and know-how. While these ideas about participant-centred science, the use of participatory research frameworks and the democratic process of knowledge co-production between lay persons and scientist offer a useful starting point for reframing the role of local communities in the research process, they do not provide insight into the mechanisms by which the processes may be achieved. In addition, they do not provide clear guidelines or a conceptual framework that those working to engage local communities in the research process in this manner can

utilize to drive such processes of dynamic interaction and ongoing engagement between researchers and local communities that is mutually beneficial.

Finally, community-based participatory research (CBPR) has much to offer in making communities active participants in the research process and generating research that will ultimately benefit them (Aungst et al., 2003; Minkler & Wallerstein, 2008). Such CBPR approaches view community participation as a social process based on the development of a democratic system in which members of the affected community are actively involved in decision-making, implementing the clinical trial, sharing responsibility for their own health problems and needs, and sharing the benefits of the trial (Frolich, 2007). The CBPR framework, therefore, offers one potential framework for implementing a co-production of knowledge process between researchers and communities, the democratization of the research process (Callon, 1999). Lau, Swann and Singh et al. (2011) support the use of CBPR frameworks for engaging and educating communities who are targeted for HIV vaccine participation, pointing out that CBPR techniques may facilitate the collection of important demographic and behavioural data and may also allow researchers to sharpen their focus when intervening to promote HVT participation.

2.2. Promoting Community Engagement in HIV vaccine trials

Building relationships with communities in which HIV vaccine research is being conducted and involving them in the research through community engagement processes, has been highlighted as crucial to finding a safe and efficacious HIV vaccine and for the dissemination of a future vaccine (Frew et al., 2008). From the perspective of HIV vaccine researchers and funders, promoting the participation of local communities in HIV vaccine research is, therefore, an ethical, scientific and pragmatic imperative for researchers conducting HVTs in communities (Newman et al., 2015). When compared to the literature on WTP and trial recruitment in HVT contexts, the issue of community engagement has not

been prioritized as a focus area for investigation in empirical research on the social and behavioural aspects of HVTs. This dearth of research on community engagement is incongruent with the emphasis on the crucial role that local communities are purported to play in the HIV vaccine research process.

The available literature that directly addresses community engagement is reported in the form of concept papers and meeting reports (e.g., Lau, Swann & Singh, 2011; Lesch et al., 2013), research articles that report on multiple stakeholders' perspectives on community engagement activities (e.g., Newman et al., 2015; Upton, 2011). There are also suggestions for meaningful community engagement that ensue from the findings of research articles that focus on understanding WTP and factors that impact trial implementation (e.g., Voytek et al., 2011). There are also various sets of guidelines developed by organizations that fund and oversee the implementation of biomedical HIV prevention trials, for example the HIV Vaccine Trials Network (HVTN), SAAVI, UNAIDS, and AVAC. These guidelines outline systematic ways for engaging communities in biomedical HIV prevention trials. The most prominent of these sets of guidelines is the guidelines for the UNAIDS-AVAC Good Participatory Practice for Biomedical HIV Prevention Trials (GPP) (2011). It was designed to provide normative guidance on community engagement that regulates participatory practices in the same way as operational documents, such as the Good Clinical Practices Guidelines regulates operational aspects of trial implementation (HIV/AIDS Network Coordination [HANC], 2014).

The available guidelines for community engagement and other literature in this area focusses on describing community engagement practices and developing guidelines that advise clinical trial staff on how to ensure the involvement of communities in the research process. In this way researchers can guarantee that their ethical and scientific objectives are met. Researchers seeking to conduct community engagement activities in the context of their

biomedical prevention trials, therefore, have access to a burgeoning body of literature that explores crucial components of successful trial implementation. This section examines the available literature that informs researchers' attempts at "doing" community engagement in biomedical HIV prevention trials to explore key ideas about community engagement circulating in this area.

Across the literature, *community engagement* is conceptualized as an ongoing process of multidirectional communication that enables sustained, collaborative partnerships between all stakeholders who are likely to participate in the research, to be affected by it or to influence its conduct (Frew et al., 2008; HPTN, n.d.; UNAIDS, 2007; UNAIDS-AVAC, 2011). Community engagement processes involve a range of stakeholders, such as trial funders, sponsors and implementers, trial participants, their families and partners, local organizations, service providers and other community groups within the geographical area that constitutes the clinical trial location (Forbes, Sylla, & Yassky, 2008; UNAIDS-AVAC, 2011). These stakeholder groups collaborate on all aspects of the trial, including design, development, implementation, monitoring and the distribution of the results of HIV prevention trials (UNAIDS-AVAC, 2011). The features of community engagement highlighted across these definitions include consultation, dialogue, partnership, mutual education and respect, and consensus building on all aspects of testing the potential biomedical HIV prevention technologies (Frew et al., 2008; Nakibinge et al., 2009; Tindana et al., 2007; UNAIDS-AVAC, 2011).

2.2.1. Focus areas for achieving best practices in community engagement.

The Good Participatory Practices (GPP) Guidelines for biomedical HIV prevention trials (UNAIDS-AVAC, 2011) outline a number of guiding principles that underpin community engagement in HIV prevention trials. The principles outlined are respect, mutual understanding, integrity, transparency, accountability and community stakeholder autonomy

(UNAIDS-AVAC, 2011). Four common themes that encapsulate *best practices* for implementing community engagement activities in high risk communities targeted for participation in biomedical HIV prevention research, emerge from the various guidance documents available. These four themes are: identifying relevant community stakeholders; learning about the community; building partnerships, collaboration and dialogue with communities; and promoting the development of community capacity. In this section, I discuss three of these themes, reserving my discussion on identifying relevant community stakeholders and the conceptualization of community for Chapter 3.

The guidelines recommend that clinical trial sites develop written community engagement plans that have an operational focus, outlining strategies, timelines, and the roles and responsibilities of various stakeholders in the research process for achieving the objectives of their work in the community in which they are conducting their research (Slevin et al., 2008; UNAIDS, 2011). Such written plans should incorporate the four main *best practice* community engagement themes, ensuring that trust is built and opportunities for ongoing dialogue and collaboration between researchers and trial site communities are maximized (HVTN, 2000). Community engagement plans should also outline different tools and mechanisms for implementing participatory strategies, for example community meetings, street theatre and other innovative approaches to engaging the community (Slevin et al., 2008).

2.2.1.1. Theme One: Learning about the community.

In order to ensure successful trial implementation, researchers must understand the complexities of HIV/AIDS at the behavioural, community and societal levels (Lau, Swann & Singh et al., 2011; MacQueen et al., 2011). Understanding not only the science and theories that underpin research, but also exploring the practical realities of research involving high

risk populations is crucial to deepening community engagement activities that support access to target populations and clinical trial implementation (Lau, Swann & Singh, 2011).

The GPP guidelines recommend that clinical trial researchers conduct formative research at the start of their research study (UNAIDS-AVAC, 2011). Understanding the dynamics of the local community context in which biomedical HIV prevention research is conducted and the characteristics of the community, is important in the initial phase of community engagement processes. Through the formative research process, researchers can build trust and lay the foundation for meaningful community engagement in HIV vaccine research. In addition, formative research enables researchers to gain in-depth knowledge of the local community; the local understanding of the HIV/AIDS epidemic; the prevailing socio-cultural norms, practices and power dynamics that structure relations in the community; local perceptions, communication and decision-making networks; and the history of research projects in the community that may influence community attitudes towards scientific research and researchers (UNAIDS-AVAC, 2011). Formative research should also document the needs and priorities of the local community, who are affected by and able to influence the HIV prevention trial. It is not clear how or whether these needs will be addressed over the course of the research and engagement process.

Based on their study on WTP in the USA, Voytek and colleagues (2011) support the need for formative research as a mechanism for generating an in-depth understanding of the local community in which the research is being conducted. They highlight the fact that insight into the structural factors that influence personal agency and participants' thought processes with respect to participation, is crucial to promoting community involvement in HIV vaccine trials. Frew et al. (2008) also highlight the importance of understanding the contextual dynamics of communities. They emphasize focussing on the dynamics of the community setting, the amount of HIV/AIDS and research information available in the

community, the level of competition between community organizations for public involvement, the personal challenges that target groups face, and their motivations for attending HIV vaccine-related events. They point out that understanding these aspects of the community context are important for cultivating and sustaining dialogue between researchers and the community as it builds trust, acceptance and confidence in the HIV vaccine trial site. The focus of these activities, however, continues to serve the agenda of the scientific enterprise, as they emphasize dialogue and relationship building as the foundation for securing community buy-in and recruitment onto HVTs.

2.2.1.2. Theme Two: Building partnerships, collaboration and dialogue with communities.

The basis of participatory community engagement is strong community-researcher partnerships. HIV vaccine trials are conducted in contexts dominated by disparities between various stakeholders. There are disparities in levels of literacy, education and access to resources between researchers, clinical trial site staff and the community members who participate in their research. In addition, clinical research represents the biomedicalization of disease, in other words the reconstitution and extension of medicalization through scientific research (Roberts & Matthews, 2012). The notion of the patient-provider relationship inherent to the biomedical framework is transferred into the clinical trial context, creating a power differential between clinical researchers and their research participants. HVTN (2000) points out that HIV vaccine research raises a number of behavioural, political, social, legal and psychological issues that may best be addressed by establishing active collaborations with community groups that can assist trial sites, their participants and the communities affected by the research in dealing with these issues. Constructive, long-term community-researcher partnerships are crucial to addressing these power imbalances between communities and clinical trial researchers, ensuring community input and investment into the

research and generating community support for the research process (HANC, 2014; HVTN, 2000; UNAIDS-AVAC, 2011). Community-researcher collaborations are also crucial for transforming the research into a shared activity that is mutually beneficial, leaving both communities and the scientific enterprise better off (HVTN, 2000).

The guidelines emphasize the importance of developing partnerships with the local community in which the research is being conducted to ensure community participation in the research (Slevin et al., 2008; HVTN, 2000; UNAIDS, 2011). Such partnerships are the foundation for establishing networks of community-researcher communication and interaction and are promoted as the basis for achieving inclusive, authentic community engagement. The guidelines recommend that clinical trial researchers initiate participatory processes early on in their research to engage stakeholders across the breadth of the community and to continue this engagement across the lifespan of the trial (Newman et al., 2015; UNAIDS-AVAC, 2011). Such relationships may be informal and/or formal, ongoing and substantive, and researchers are encouraged to plan for how they will work to nourish relationships with the community in which the research is being conducted (HVTN, 2000).

The guidelines also promote the idea of shared ownership and equitable relationships between researchers and community stakeholders as the basis for community-researcher partnerships (UNAIDS-AVAC, 2011). According to these guidelines, shared ownership is achieved through collaboration, partnership and community mobilization. Shared ownership of the research holds mutual benefit for researchers and the community in which the research is being conducted. For researchers, shared ownership increases the likelihood of successful trial conduct, ensures better penetration of communities, more acceptable and culturally relevant messages that support trial completion, and improved application of research results (HANC, 2014; Newman et al., 2006). For communities, shared ownership of the research strengthens their stake in the research and promotes their capacity to articulate and address

their own development needs and future priorities through their involvement in the research process (Slevin et al., 2008). While it is not clear how shared ownership of research will be facilitated, the articulation of the benefit that local communities will derive from sharing ownership of the research process, represents a departure from the way in which communities have been positioned in the research process to date. This renewed perspective on the role of communities holds promise for community capacity-building and development agendas that may accompany HVT implementation.

Another feature of community-researcher partnerships emphasized by the guidelines, is ensuring continuous, two-way information exchange and dialogue between the community and the research team during all phases of the research process (Slevin et al., 2008; UNAIDS-AVAC, 2011). Establishing dialogue relates to the value of transparency and ensures open, honest, timely and clear communication between researchers and communities as the basis for transparent, constructive, collaborative and trusting relationships (UNAIDS-AVAC, 2011). Researchers are, therefore, encouraged to establish mechanisms for promoting transparent and ongoing dialogue within trial site communities (Lau, Swann & Singh, 2011; Morin et al., 2003; Sahay et al., 2005). Lau, Swann and Singh (2011) expand on this call for dialogue between researchers and communities, suggesting that creating spaces for dialogue and two-way information sharing between researchers and trial site communities promote mutual learning, increasing scientists' cultural competency and strengthening community members' scientific competence.

Community representation structures, such as CABs, act as the mediators between researchers and trial site communities. Establishing a CAB is a crucial task in the community engagement process. In the context of clinical research to test HIV prevention technologies, CABs represent the interests of communities in the research process and act as the link between researchers and the communities in which the research is being conducted. They

represent the community and its interests and act as advisors to the researchers, contributing their local knowledge about the community to inform ethical and trial implementation issues. CABs offer input into issues such as how to best achieve informed consent; developing effective recruitment and retention strategies and activities to promote community education; and awareness-raising about HIV/AIDs, HIV vaccines and scientific research (HVTN, 2000; Slevin et al., 2008; UNAIDS, 2011). They act as gatekeepers to the community and ensure that those affected by the research at the local community level have a channel through which to voice their needs and concerns and obtain information about the research (HANC, 2014). They also provide a forum through which communities can ask questions and have their questions addressed directly by the researchers.

CABS include volunteers from a range of different perspectives and levels of community who have a vested interest in the research (HANC, 2014). CAB members may include volunteers from non-governmental organizations (NGOs), community-based organizations (CBOs), service and advocacy organizations operating in the community, political leaders and decision-makers who comprise a part of the larger community, local government officials, healthcare workers, HIV infected individuals, religious leaders, trial participants and their family members, and a range of other community groups (HANC, 2014; Slevin et al., 2008).

Choosing CAB representatives involves a complex set of recursive activities and researchers are challenged to include CAB representatives that are acceptable to the local community (Newman et al., 2015; Slevin et al., 2008). The CAB role is a political, advocacy, advisory and oversight one (Reddy, Buchanan, Sifunda, James, & Naidoo. 2010). CABS represent the interests of the community in the research process and ensure that community engagement is conducted in a culturally sensitive and locally responsive manner (Newman et al., 2015). Slevin et al. (2008) point out that defining the boundaries of exactly who must be

consulted to meet the evolving expectations of community and stakeholder engagement is challenging. In addition, Newman et al. (2015) highlight the fact that CAB members must be culturally accepted gatekeepers who understand the community's culturally sanctioned communication networks.

In liaising with CABs, clinical trial site staff must clearly outline the respective roles and responsibilities of each stakeholder involved (UNAIDS-AVAC, 2011). The value of accountability underpins the development of clear roles and responsibilities for clinical trial site staff and community representatives. With respect to accountability, the role of researchers is to be accountable to the community for conducting scientifically valid and ethical research, using participatory practices and responding to input from stakeholders as mutually agreed (UNAIDS-AVAC, 2011). Community stakeholders, on the other hand, are accountable for ensuring that they provide fair and constructive input into the research process (UNAIDS-AVAC, 2011). Such community input respects the scientific process and is in the best interest of the community stakeholders.

2.2.1.2.1. How do CABs view their role in the process?

A number of studies have highlighted the complexities and challenges inherent in the CAB role within the South African context. These studies have reflected on the role and functions of CABs in the research process and the challenges of occupying the role of mediator, acting as a conduit between researchers and the community in which the research is being conducted.

In 2010, Reddy, Buchanan, Sifunda, James and Naidoo published the findings of their study, which examined the functions and operations of CABs in HIV vaccine trials in South Africa. They interviewed multiple stakeholders involved in HIV vaccine research at South African trial sites. Their study participants reported that the function of CABs is to protect

communities, to stop exploitation of communities by researchers and to ensure that research is beneficial to communities. CAB members who were interviewed as part of their study, reported that their role included protection and oversight, advancing research goals, providing information and liaising with their communities and serving as a buffer between researchers and the community. Researchers who participated in the study articulated their expectation that CAB members should play an active role in recruiting study participants and assisting with the timely completion of the research.

The study highlighted a number of dilemmas associated with the involvement of CABs in HIV vaccine research (Reddy et al., 2010). First, researchers' expectation that CAB members assist with recruitment caused dilemmas, especially in relation to CAB members who felt that their primary role related to oversight and ensuring that community interests are protected. Second, at the HVTs who formed part of the study, CABs were selected through purposeful selection and election processes. However, in reality CABs are often established through self-selection processes with organizations indicating an interest in being part of the CAB. In addition, CAB members reported that they are recruited by the HVTs. As a result, CAB members are dependent on the HVT for financial support and materials needed to conduct their activities in the community. They felt that this dependence on the HVT limited their autonomy and agency in executing their role as representatives for the community. Thirdly, CAB members indicated that they have limited influence on substantive decisions associated with the research projects and expressed a desire to have more substantive input into the research process. Due to the fact that CABs in South Africa are researcher-initiated and driven, rather than legislated by the health system, CABs have no authority or legal power and their role is limited to their input as advisor. Based on their findings, Reddy et al. (2010) concluded that HVTs should implement methods and structures that promote

authentic community participation, in an attempt to move beyond the current status of limited CAB involvement, which primarily revolves around consultation and placation.

Upton's (2011) research explored the extent to which CABs play a meaningful political role at South African HIV vaccine trial sites. Her research highlights the complexities of the global context in which health policies are made and the realities of the political avenues open to recipients of such policies. Participants in her study reported that interacting with HIV/AIDS information, vaccine science and networking with wider health and other community-based and civil society organizations, develops agency. Upton's (2011) research shows that the reported ideals of community engagement are often challenged by the political dynamics of CABs. These political dynamics in which CABs functions are perceived to frustrate collective action, create intermittent contact between trial site researchers and CABS, and result in limited representation of heterogeneous communities in the research process.

Based on document and guideline analysis and interviews with community outreach staff, Snyder's (2011) study sought to examine how guidelines for ensuring representation in HIV prevention trial advisory groups are interpreted and implemented in practice. A related aim of her study was to assess the feasibility and acceptability of these guidelines from the perspective of those who implement them in HIV vaccine trial site communities in South Africa. Snyder's (2011) study highlighted problems with defining community as the target population of HIV vaccine research. Participants in her study reported that using such a definition of community excludes certain groups. They suggested that participatory approaches should be used to establish who constitutes the community in the context of HIV vaccine research. In addition, they claimed that the manner in which individuals in the community identify and interact with one another is an important strategy for establishing how people relate to each other in HVT settings. Examining how community members

identify and interact with one another may also highlight which groups within communities might be excluded from prevailing definitions of community. Based on these concerns, participants in this study advocated for the use of participatory techniques to recruit community representatives. They suggested that the use of snowballing techniques may hold promise for selecting representatives who possess characteristics that they consider key to committed CAB members. These characteristics include having peer leadership and interest in and commitment to HIV prevention research.

2.2.1.3. Theme Three: Promoting the development of community capacity.

The final theme highlighted in the guidance documents as key to ensuring *best practices* in community engagement relates to developing the capacity of HIV vaccine trial site communities (HANC, 2014; Slevin et al., 2008; UNAIDS, 2011). Building community capacity enables stakeholder autonomy, in other words the right of communities to support or refuse to conduct research in a particular area, based on the degree of alignment between the community and researchers' needs and interests (UNAIDS-AVAC, 2011). Therefore, developing community capacity serves as the foundation for sharing ownership; equal, collaborative partnerships; and constructive dialogue between all stakeholders.

Developing community capacity includes all activities that aim to educate communities and raise their awareness of HIV/AIDS, HIV vaccines and scientific research. These activities focus on building community stakeholder literacy and competencies to enable them to have greater input and a higher degree of participation in the research process. It also addresses the power imbalances between research teams and community stakeholders by creating a common understanding of the HVT process in the community setting (UNAIDS-AVAC, 2011). Building community competency, while assumed to be targeted at community members and their representatives, also includes clinical trial researchers (UNAIDS-AVAC, 2011). Building community capacity includes developing socio-cultural

competency in researchers and research competency of community members and their representatives.

Socio-cultural competency refers to developing an understanding of socio-cultural issues such as norms, practices and beliefs operating in local communities and the social circumstances that may influence trial implementation (UNAIDS-AVAC, 2011). Research competency refers to enhancing community members and their representatives' understanding of the concepts, purpose, practices, limitations and results of biomedical HIV prevention trials (UNAIDS-AVAC, 2011). Improving community stakeholders' research competency enables and empowers them to provide meaningful input into the research process.

Educational programmes to improve research competency target multiple levels of community, including community members, their families and peers and CAB members (Sahay et al., 2005; Voytek et al., 2011). Focus areas for community education include explaining trial-related concepts, such as randomization and placebo; translating such concepts into local languages and dealing with lexicon challenges; and addressing misconceptions about the research and researchers that hamper effective communication between stakeholders (Lesch et al., 2013; Newman et al., 2015; Sahay et al., 2005; Voytek et al., 2011). In addition, researchers also highlight a need for community education that addresses social harm concerns and community perceptions of risk. Some researchers have suggested that incorporating stigma reduction programmes into community education and awareness-raising activities, would serve to address community concerns, rumours and myths about HIV vaccine research (Kiwunuka et al., 2004; Nyblade et al., 2011).

2.2.1.4. The utility of community engagement guidelines in promoting meaningful community engagement.

The available guidelines for community engagement in biomedical HIV prevention research, particularly the GPP guidelines (UNAIDS-AVAC, 2011), play a crucial role in the implementation of HVTs. In the HIV vaccine enterprise, they provide the blueprint for clinical trial site researchers with respect to promoting the participation of local communities in the clinical research process.

Community engagement guidelines represent an operational manual, mechanistic in nature and outlining actions based on key ideas and strategies for involving communities in the research process. It represents a methodological tool in the design of randomized controlled trials. Further, the guidelines serve the agenda of the scientific enterprise, namely to promote community participation in the research as a mechanism to ensure successful clinical trial conduct. While guidelines outline various sets of principles and activities for engaging local communities in the process, the guidance focusses on the operational and ethical aspects of trial implementation, benefitting scientific agendas over those of the local community. Beyond the necessity for HIV prevention interventions to address high HIV risk in local community contexts, community needs and agendas are not integrated into the guidelines and the research process. The emphasis on partnership and collaboration with local communities, therefore, lacks authenticity, with partnership serving as a means to an end, the end being the development of a safe and efficacious HIV vaccine.

The guidelines co-opt the language of community development and participatory health interventions, for example community competence, partnership etcetera into the clinical trial process. This language originates from a social justice orientation, concerned with addressing social inequalities and promoting access to the resources that promote health and well-being in settings where these are absent. The positioning of local communities as

resources to the HVT enterprise contradicts these social justice goals. It serves to perpetuate and reproduce power inequalities between communities and researchers, leaving little room for the co-production of knowledge (Callon, 1999) and continuing to relegate communities to the role of subjects in spite of the use of participatory language.

In short, while the guidance on community engagement in biomedical HIV prevention represents a useful starting point, it leaves more questions than answers about how to achieve meaningful community engagement in HIV prevention trials. This limitation arises due to the lack of recognition that clinical trials are embedded in the social contexts in which they are conducted. Given this fact, approaches to community engagement must, therefore, move beyond operational plans to plans that view trials as social processes, located in social contexts and framed by the complexities and dynamics of relationships between various stakeholders in the local communities who host. Such exploration calls for the use of theories and models that can illuminate trials as social processes and that can fulfil the notions of true collaboration, partnership and community capacity-building as core components of trials. This will generate mutual benefit for all involved in the research process, changing the everyday realities of community members who participate in the research process.

HIV vaccine research brings resources into resource-poor communities and offers researchers the opportunity to utilize their community engagement processes to generate meaningful roles for communities in the research process: legitimizing their research and constructing new identities for community members who are involved in the research process. The participatory science process through which scientific research is co-produced through community-researcher partnerships (UNAIDS-AVAC, 2011), offers the potential for creating HVTs as health enabling environments (Campbell, 2003). Transforming HVTs into health-enabling environments built on community-researcher partnerships holds much promise, with partnerships serving as the mechanism through which community capacity is

built. HVTs become a social good that offers direct benefit and access to resources that promote health and well-being to the local communities who act as clinical trial hosts. The next chapter explores an alternative set of conceptual tools that holds promise for transforming HVTs as health-enabling environments (Campbell, 2003).

Chapter 3: Contextualizing the Research

The purpose of this chapter is to contextualize the research on community engagement in HIV vaccine research. The chapter is organized in three parts. Part 1 of the chapter sketches the personal context in which the research is positioned. It takes the form of my reflexive analysis, documenting my experiences and role as social science researcher in the HIV vaccine research community and how these experiences have shaped my interest in exploring community engagement in HIV vaccine research as the focus of my doctoral work. In Part 2 of the chapter I discuss my perspective on what constitutes meaningful community participation in HIV vaccine research, successful HIV vaccine research and the role of community engagement in promoting both these aspects. Part 3 of the chapter discusses the key concepts that form the conceptual foundation of the research. I discuss the use of the term “community” in this research and my focus on the local community level of community engagement in HIV vaccine research. The final part of this chapter focusses on the use of the terms community participation, community engagement and community mobilization in the context of the research.

3.1. Part 1: Sketching the personal context - Being a reflexive researcher in the HIV vaccine research enterprise

In reflecting on my role in the research that I conducted, I follow the guidance of authors who suggest that the task of critical reflection is to make plain the researcher’s personal history, values, biases, social status, feeling, experiences, position and location in the study and their relationship with those being researched (Holloway & Bailey, 2011; Willig, 2010).

My exploration of the social dimensions of HIV vaccine research started in 2005 when I was offered a position as research intern with the Socio-Behavioural Working Group of SAAVI. The mandate of our group was to collaborate with HVT sites in South Africa to

build social science research capacity at their sites. I brought to this role my training in industrial, research and social psychology and a keen interest in conducting HIV/AIDS-related research. At this stage of my academic career, my personal position on successful interventions to address social problems was that such attempts should focus on collaborating with those affected: creating space for them in the intervention, developing their skills and providing clear roles for those affected by the problem throughout the intervention process as experts on their own lived reality. I believed, and continue to believe, that interventions should change the lived reality of their beneficiaries. These foundational ideas have endured and continue to ground and direct my work. In the initial phase of my appointment with the Socio-Behavioural Working Group a few things happened that were instrumental in shaping my interest in exploring the dynamics of community engagement in HIV vaccine research.

In the first couple of months in my new position, I visited Masikhulisane, the community involvement arm of SAAVI, to observe HIV vaccine awareness-raising and education workshops being conducted by their community educators. Community representatives from various community organizations, including NGOs, CBOs and governmental service delivery organizations in the areas being targeted for participation in HIV vaccine research, were invited to attend these workshops. The workshops were based on the premise that community representatives would share the information that they acquired during education sessions with their community constituents and through this information cascade, broader community awareness about HIV vaccine research would be promoted. I watched in fascination as Masikhulisane community educators made use of sophisticated PowerPoint slides to present information about HIV vaccine science, ethics in research and community involvement in HIV vaccine research to workshop participants. Their slides were tightly packed with information and diagrams and used academic language to explain complex ethical and scientific concepts. Community representatives sat passively, listening.

At the end of a day-long session, they completed a True or False format knowledge checklist to test their understanding of what they had learnt on that day. I was puzzled by the concept of an information cascade. I was curious to know what these community representatives, who brought varying levels of HIV/AIDS, science and research literacy to the process, would take away from such a technical and information-dense day to be shared with members of their communities.

A year or so later, my colleagues and I travelled to various HIV vaccine research centres across the country to conduct focus groups with community members participating in HIV vaccine research. The purpose of our research was to explore the enablers and facilitators to trial participation. We encountered similar approaches to HIV vaccine education in these settings. Community educators lamented the fact that participants arrived with low levels of knowledge about HIV/AIDS on which they could scaffold their HIV vaccine education. They explained that they spend a substantial proportion of the time that they had in their workshops on providing basic HIV/AIDS education as the foundation for providing information about HIV vaccines, science and clinical trials. In spite of low levels of knowledge, community members continued to show up to participate in HIV vaccine education and research and shared the benefits of participation with us in our data collection activities. Participants received a monetary incentive to compensate them for the time and any costs incurred while participating in the research. In these impoverished contexts where unemployment rates are high, it was hard not to wonder whether it was in fact the incentive that acted as the most powerful enabler to participation, ensuring a steady stream of community members willing to participate in the HIV vaccine education workshops and research studies. These were my first insights into the complexities associated with engaging communities in HIV vaccine research in resource-poor communities in South Africa.

Over the five years before I began my doctoral work, I actively participated in the community of researchers conducting social science research on HIV vaccines. In this context, social science was considered an add-on to clinical trial protocols, serving the purpose of assisting investigators in recruiting and retaining trial participants and providing insight into social harms that may impact the clinical trial process. As the socio-behavioural research community involved in the HIV vaccine research enterprise, we engaged in various activities to advocate for the integration of social science research into HIV vaccine research agendas from the outset. We attended international biomedical HIV prevention and HIV vaccine conferences to showcase our work. Reflecting the position afforded to social science research in this context, conference programmes focussed predominantly on the biomedical aspects of HIV vaccine development, allocating social science research to a singular slot on conference programmes, with the rest of this work relegated to the poster presentation sessions. We planned and participated in workshops funded by the NIH and IAVI, bringing together multiple levels of stakeholders to discuss how social science may be integrated into global HIV vaccine research agendas. We wrote articles theorizing participation and continued to document the factors associated with willingness to participate in HIV vaccine research across various HIV risk groups. We provided input into the development of international guidance documents for promoting community engagement in HIV vaccine research. We wrote funding proposals that proposed to explore and evaluate HIV vaccine research community engagement processes. In spite of all these activities, not much has shifted in the power dynamics that govern HIV vaccine research. Social science research, while expanding, continues to be relegated to add-on status.

At the start of my doctoral work in 2011 and at the time of writing this thesis, the available social science literature on HIV vaccines still consisted predominantly of articles documenting WTP across different settings and populations and some literature on the ethical

aspects of HIV vaccine research. In South Africa, research unpacking the ethical aspects and challenges to ensuring informed consent is conducted primarily by the HIV/AIDS Vaccines Ethics Group (HAVEG). There are, however, a few articles that deal with community engagement in HIV vaccine research that serve as the foundation of my doctoral work. My doctoral research originates from my curiosity about community engagement in HIV vaccine research: how it is practiced in local community contexts, the complexities that it involves and the diverging perspectives about community participation that play themselves out among those who form part of the local community HVT context.

According to Holloway and Bailey (2011), qualitative researchers are deeply embedded in the research process and cannot be excluded from the data collection, analysis and reporting of the research (Holloway & Bailey, 2011). This notion of deep engagement and embeddedness in the research is certainly true for me and has presented me with a few dilemmas in thinking about how to present the findings of my research. I have a long-standing relationship with the research centre at which I conducted my research, having collaborated and worked with various staff members. I have developed good working relationships within this setting and over the course of my research I was received with openness and hospitality. I felt part of the setting during the process of data collection when I would arrive early and sit in the waiting room to observe what was happening at the research centre. In spite of the fact that I was visibly not part of the local community, the participants did not seem curious about my presence. I think that to them I was simply part of the environment. This perhaps reflects community members' familiarity with different, new faces entering the research environment. I also felt this during the research process in the ease with which I was able to build rapport with participants. Throughout this process participants engaged openly with me during the focus group discussions and interviews, sharing their experiences and opinions enthusiastically and without hesitation. The focus group discussions

were vibrant and lively discussions, with research participants offering insight into their experiences, building on and challenging each other's input. Participants in the focus group discussions indicated that they viewed me as a resource, there to provide them with information about how to protect themselves from becoming HIV positive. They did not seem to notice that I was asking questions and not providing any information.

My data collection revealed many contradictions in the descriptions of the process of community engagement in HIV vaccine research at Research Centre X. As a researcher in the HIV vaccine enterprise, I am integrally linked to the setting and the research being conducted. This left me with dilemmas about my position in reporting the findings of my research. Exploring this dilemma with my supervisor, we uncovered a number of possible positions that crystallized, essentially, into three options:

1. dismissing the community engagement activities being conducted as ineffectual;
2. colluding with and perpetuating ideas about community engagement as "*spreading the word*" and recruiting research subjects; or
3. fulfilling my intention of conducting critical research that amplifies, reveals and makes sense of the community engagement process at Research Centre X.

I chose the last position. The presentation and discussion of my research findings represents my critique of the process of community engagement that I accessed through the various stakeholders who participated in my research. In my discussion, I reframe ideas about community engagement practice at Research Centre X by revealing what it is and what it is not in this context; exploring whose agenda it serves and the role that various stakeholders play in the process, while acknowledging the influence of the complex local community context in which it is being conducted.

3.2. Part 2: Documenting my position on community engagement in HIV vaccine research

In outlining my perspective on what constitutes meaningful community participation, successful HIV vaccine research, and the role of community engagement in promoting both these aspects, I comment on a few key aspects: the emphasis on the crucial role of local communities in HIV vaccine research; the notion of mutually beneficial relationships between researchers and local communities; and the utility of current community engagement guidelines for promoting meaningful community participation in HIV vaccine research conducted in high HIV risk, resource-poor contexts.

The global HIV vaccine enterprise is pursuing the development of a safe and efficacious HIV vaccine as the successful outcome of HVTs conducted with high HIV risk populations in various settings. Local communities are considered to have a crucial role to play in achieving this outcome (Wakefield, 2005). Community engagement processes are designed to promote the participation of local communities in HIV vaccine research. As I highlighted in the preceding chapter, there are various sets of guidelines intended to assist researchers conducting biomedical HIV prevention research in local communities with designing and implementing community engagement processes that promote the involvement of communities in their research. These guidelines suggest that creating partnerships and building mutually beneficial relationships with those interested in and affected by HIV vaccine research is crucial to success (HVTN, 2000; UNAIDS-AVAC, 2011). The health promotion and HIV prevention literature considers promoting the participation of local communities in interventions to address risk factors that threaten their health and well-being as highly beneficial to them (Morgan, 2001). Participation is believed to facilitate community capacity-building and the empowerment of local communities (Campbell & Murray, 2004). In HIV vaccine research, however, while the participation of local communities in the

research is promoted and articulated as crucial, the issue of how such participation generates benefits for those who participate in the process is not explicitly addressed. In addition, amidst the constant refrain about the central role that communities play in the HIV vaccine enterprise, it is not clear what constitutes mutually beneficial relationships between researchers, funders and local communities.

The importance of involving local communities to participate in the scientific project of HIV vaccine development is clear and incontrovertible. Communities in which HIV risk is high produce and supply the high HIV risk bodies that are the crucial subjects of clinical trials to test candidate vaccines. Without the participation of individuals who reside in these high HIV risk communities, HVTs cannot be conducted and candidate HIV vaccines cannot be tested. In this scenario, however, in which the emphasis is on community engagement to promote trial participation and where success is articulated as the development of a safe and efficacious HIV vaccine, it is not clear what immediate, short-term benefits community members residing in resource-poor local communities will derive from their contribution to the HIV vaccine enterprise.

The local communities that serve as the settings for HVTs are those characterized by deprivation. They are subject to a configuration of multiple risk factors that threaten community members' health and well-being. Risk factors in these settings range from the individual to the structural and include inter alia high rates of poverty and unemployment, poor living conditions, high HIV prevalence and risk, low levels of HIV/AIDS knowledge and high rates of AIDS-related stigma (AVAC, 2013; Smit et al., 2005; Voytek et al., 2011). These risk factors create community contexts in which individuals lack access to resources that promote health and well-being and that confer protection against HIV infection. While the promise of a safe and efficacious HIV vaccine that will confer protection against HIV infection and reduce HIV incidence in high risk settings holds direct benefit for community

members, this is a far-off promise beset with the uncertainties and complexities that accompany scientific experimentation. For local communities who contribute to the HIV vaccine research process, therefore, an HIV vaccine represents a potential long-term benefit, located in a far-off and indeterminate time in the future. This potential final outcome does not address immediate threats to their health and well-being. Given this context, how, if at all, does community participation in HIV vaccine research generate much needed short-term benefit for those who participate in the research?

In addition to the absence of short-term benefits for local communities, community engagement is conceived from scientific, operational and ethical perspectives, crucial to the successful execution of HVTs. Within the HIV vaccine research enterprise collaboration and partnership with multiple levels of stakeholders in local communities is frequently articulated as the mechanism through which the goal of developing a safe and efficacious HIV vaccine may be realized (UNAIDS-AVAC, 2011). The notion of participation held in the HVT context is limited, however, and community engagement serves the operational purpose of maximizing participant recruitment and retention and fulfilling ethical obligations in local community settings. Local communities, therefore, act as a resource and serve a token role in HVTs (Arnstein, 1969; SAAVI, n.d.). Their function is utilitarian as subjects in the trial and as parties that provide input into operational aspects to improve trial execution. Consistent with this narrow conceptualization of community participation, local community members are offered a limited number of roles in the HVT process that focus on tailoring trial implementation to the local context and maximize recruitment and retention of trial participants. Local community members, therefore, participate in the research as participants in HVTs, HIV vaccine education and awareness-raising events and screening for HVT participation, and community advisory board (CAB) members, representing the community and acting as key informants on the socio-cultural dynamics of their community. Their

decision-making power in this process is limited and does not transcend personal decisions about whether to participate in the research or not. Framed in this way, their participation solely serves the agenda of the global HIV vaccine enterprise. Such a perspective on community engagement does not afford community members a meaningful role in the research process by supporting them in developing strategies for overcoming immediate threats to their health and well-being.

Building community-researcher partnerships is important to the successful implementation of scientific research in community settings (Emanuel et al., 2004; UNAIDS-AVAC, 2011). Authentic community-researcher partnerships move the role of communities from subjects or consumers of the research, to participants or co-owners of the process engaged in dynamic interactions with researchers throughout the life cycle of the research, co-producing knowledge (Callon, 1999; Nowotzky et al., 2001). The predominant operational approaches to community engagement in HIV vaccine research where community members remain subjects in HVTs and have a limited and token role to play in the scientific process, fail to harness the full potential of their participation in the research process. Crucially, such approaches fall short of the ideal of building community-researcher partnerships in which community members are active participants in the process, ensuring that the research being conducted holds benefits for them (Minkler & Wallerstein, 2008). This latter component is particularly important given the lack of direct, short-term benefits that are available to the local, resource-poor communities in which HVTs are conducted. Moving beyond operational approaches to community engagement in HIV vaccine research so that communities are positioned as a resource supporting the scientific enterprise, depends on researchers' willingness to situate their community engagement efforts beyond available guidelines. It also depends on researchers' willingness to pursue community capacity-building as a goal alongside the goals of the scientific enterprise. The development of truly mutually beneficial

relationships between researchers and communities lies in the integration of these goals as interrelated components of a successful outcome for HIV vaccine research. Pursuing mutually beneficial relationships involves expanding the level of participation available to communities in the research process by offering them a range of roles over the lifespan of the research. The existing body of evidence about the beneficial nature of community participation in the areas of health promotion and HIV/AIDS treatment, care and prevention may serve as a useful starting point in this regard.

Current approaches to community engagement in HIV vaccine research, however, do not directly address the notion of mutual benefit. While it is clear what benefit community participation in HIV vaccine research holds for the HIV vaccine research enterprise, the short-term benefits that communities derive from their participation in the process is not addressed. For example, the GPP guidelines highlight the fact that HIV vaccine research cannot succeed without meaningful stakeholder engagement as a basis for achieving recruitment targets for HVTs (UNAIDS-AVAC, 2011). How do community engagement processes operate to ensure that local communities derive mutual benefit through their involvement in the research process?

Biomedical HIV prevention research is a form of combination HIV prevention. Combination HIV prevention approaches integrate biomedical, behavioural and educational and structural HIV prevention strategies (Kurth et al., 2011). HIV vaccine research contains all of these components of HIV prevention, except attempting to intervene to address structural factors that impact HIV risk. Following this combination approach to HIV prevention, clinical research to test candidate HIV vaccines bring resources into resource-poor communities. HVT-related resources include access to health and HIV/AIDS education, quality healthcare and screening procedures, HIV prevention, e.g., VCT and sexual risk monitoring and financial resources in the form of participant incentives. In trial contexts,

success is defined in biomedical terms as a safe and efficacious HIV vaccine. These resources are simply operational components of the clinical trial process, incorporated to maximize the chances of successful experimentation. In the resource-poor, high HIV risk contexts in which HVTs are conducted, participation in HVTs mediates community members' access to these resources, providing them with access to resources that enable them to stay healthy and HIV-free. From their perspective, therefore, trial-related resources are beneficial and supportive and participation promotes the practice of health protective behaviours.

Accessing these benefits through participation in HIV vaccine research carries some risks/costs for community members. The risks/costs associated with participation may include the risk of being stigmatized by virtue of being associated with HIV/AIDS, disruption of daily activities to participate in the research process, dealing with the concerns of significant others about their participation in HIV-related research, frequent blood draws and HVT-related medical procedures and answering questions about the most intimate aspects of their lives (Asiki et al., 2013; Jaspan et al., 2006; Ruzagira et al., 2009). In spite of these costs, access to the resources that accompany trial participation act as enablers to WTP in HIV vaccine research, as has been shown in studies with various target populations and across a number of HIV vaccine research settings.

Bearing the issues raised above in mind, what constitutes success in the HIV vaccine research enterprise? In my view success in the HIV vaccine enterprise transcends the goal of pharmaceutical product development. It devotes as much attention to the dynamic "social" as it does to the science of HIV vaccine development, harnessing the resources devoted to scientific experimentation and product development to generate mutual benefit for both researchers and local communities. Given the vulnerability and potential for exploitation of local communities targeted for their participation in HIV vaccine research, this is a key ethical imperative. In this process, community engagement serves as the vehicle for

promoting meaningful community participation, integrating ethical and operational goals with community capacity-building goals. From this perspective, HVTs are repositioned as a social good, leaving the high HIV risk, resource-poor local communities who participate in the research better off by virtue of their involvement in the process. Such community engagement processes involve communities as co-owners and active participants in the process (Green & Mercer, 2001) and use trial-related resources to create health-enabling (Campbell, 2003), supportive local community contexts for those participating in the research. Within this view of success, however, current guidelines for community engagement are inadequate.

Globally, those who are asked to participate in HIV vaccine research are vulnerable, marginalized and historically exploited. In South Africa, Masikhulisane, the community involvement arm of SAAVI, framed community participation in HIV vaccine research as a human rights issue, arguing that communities have a right to access information about and opportunities to participate in HIV vaccine research. This position is, in my view, incomplete as it does not directly address issues of social justice that accompany a human rights perspective. Given the socio-historical context of South Africa and its history of the oppression and deprivation of those who are targeted for their participation in HIV vaccine research, community engagement in HIV vaccine research is most definitely political. It does have the potential, however, to facilitate the pursuit of social justice, addressing unequal access to power and resources in the local community contexts in which HIV vaccine research is conducted (Visser & Moleko, 2012). When viewed from this perspective, community engagement must be guided by conceptual tools that allow researchers to explore the impact of the social context on health and well-being and participation in HIV vaccine research. Current community engagement guidelines serve the biomedical HIV prevention trial agenda, view success from the perspective of the global biomedical AIDS industry and

focus on procedures that will ensure the successful execution of clinical trials. They do not fully permit the examination of trials as social processes and as community resources.

When HIV vaccine research moves out of laboratories and into local community contexts, it becomes embedded in those local contexts. It is influenced and shaped by those contexts, the social networks and structures that impact community participation in research. What is required, therefore, are theories and frameworks that allow researchers to examine the social. In particular, with the emphasis on community capacity-building and expanding the notion of participation, researchers require frameworks that provide them with the conceptual tools to develop a community health psychology of participation in HIV vaccine research.

If we as social scientists involved in HIV vaccine research enterprise remain inside current community engagement guidelines while ignoring our disciplinary tools, we perpetuate the status quo of imbalanced power relationships between researchers, funders and local communities at the local community level of HIV vaccine research. If we ignore the limitations of these guidelines and continue our descriptive examination of factors associated with WTP and trial-related issues that we have focussed on in the past, we will continue to perpetuate caricatures of communities and researchers who are engaged in clinical research. We must, therefore, explore theoretical perspectives beyond biomedical community engagement guidelines, for example GPP.

Similarly, if researchers do not take greater account of the dynamics and features of communities in which their research is conducted, success will be limited or unlikely. Community health psychology offers an important opportunity to advance the agenda of the biomedical HIV prevention enterprise in complex and marginalized settings. Chapter 4

outlines the application of the community health psychology paradigm to the exploration of community engagement in HIV vaccine research in greater detail.

3.3. Part 3: The use of key concepts in the research

This research examines the local community context of community engagement in HIV vaccine research (Slevin, Ukpong, & Heise, 2008) in one resource-poor community where the risk of HIV infection is high. As indicated in Chapter 2, HIV vaccine research is a global enterprise and involves multiple levels of stakeholders, ranging from the global to the local (Newman et al., 2015; UNAIDS-AVAC, 2011). Though much of the discourse around HIV research is global and couched in dominant scientific and biomedical terms, HIV vaccine research is implemented at the local community level. Community engagement to promote research participation takes place at the local community level. It enters the everyday lives and realities of those who reside in these communities and who are targets for HIV vaccine research and related activities. These key participants who are the objects and potential beneficiaries of research may have little direct involvement with the language and discourses of global biomedicine, but are profoundly affected by them. They contribute to the refraction of dominant global ideas through local experience. By far the bulk of the available literature on community engagement, furthermore, provides insight into notions of community engagement from the perspective of those who implement trials: researchers, funders, international health organizations and advocacy organizations. These stakeholders articulate their perspectives on what community engagement entails, who it should involve, and the activities that form part of community engagement to generate community support, buy-in and participation in the research. This literature does not and cannot incorporate local community members' perspectives such as those who are tasked with implementing community engagement, community members who participate in HVTs and those who represent the interests of the community in the research on their experiences of community

engagement. It is not possible to have global guidelines that incorporate the views of every community or person who will be the object of those guidelines. This level of generality is unavoidable in global guidelines, but has consequences. Where community stakeholder perspectives are accessed in compliance with global guidelines, the focus is primarily on generating community input and experiences of community engagement guideline implementation, rather than on accessing the nuance of local experiences and perceptions of community engagement and research participation (e.g., Newman et al., 2015). My research, therefore, seeks to access the stories of these local community level stakeholders to document their experiences and perspectives on HIV vaccine research, research participation and community engagement as it is practised in the research setting.

The concept of community is central to my research, directing both its focus and theoretical conceptualization. The notion of community and who constitutes the community as the target of research or intervention is the subject of much contention and debate. In South Africa, as elsewhere, the use of the term community is political, bearing the history of Apartheid oppression and discrimination that created the structural inequalities that endure and influence the health and well-being of its poorest citizens. Under Apartheid, the term community was used to promote the separation of people by race and as a euphemism to refer to Black communities (Yen, 2007). In this context the term community, therefore, evokes images of racial oppression, discrimination and unequal access to resources that promote health and well-being.

In global health research, the use of the term community and the task of identifying who constitutes the community is no less challenging. According to Lavery et al. (2010), identifying the relevant community and those who represent its interests is one of the greatest challenges facing biomedical researchers. The process of identifying the community and its relevant community stakeholders serves as the foundation of the community engagement

process, defining the target for and focus of engagement, outlining with whom community-researcher partnerships must be built and who researchers must collaborate with throughout the execution of the research (HANC, 2014; Slevin et al., 2008).

The available guidelines on community engagement in biomedical HIV prevention provide varying input on how to define and identify the community in clinical trial implementation. There are also diverging perspectives on what constitutes community and the role that communities should play in the research process (HANC, 2014) among those who implement clinical trials in community settings. There is agreement on the fact that community represents the target for and hosts of HVTs. However, the notion of community is defined in various ways. Firstly, mirroring the predominant definition of community in health research and interventions, the notion of community in biomedical HIV prevention has tended to be defined in terms of the geographical boundaries within which the research takes place. Such definitions define community as referring to trial participants, their families and partners, other local stakeholders, service providers, NGOs, CBOs and community structures, organizations and representation structures that operate within the geographic boundaries of the trial location (HANC, 2014; Nakibinge et al., 2009; Slevin et al., 2008). Secondly, community is also defined as sub-groups at risk of HIV infection, in other words the population in and for which the research is being conducted. These definitions conceptualize community as those high HIV risk sub-groups who are targeted for their participation in the research, including MSM and sex workers (Forbes et al., 2008).

Third, there are also stakeholder-based definitions of community that incorporate multiple features of community into their conceptualization of community. In 2001, MacQueen et al. published one such definition as a result of their attempts to develop an evidence-based definition of community from the perspective of various stakeholders involved in HIV vaccine research in the USA. Their research generated a definition of

community that defines it as a group of people with diverse characteristics who are linked by social ties, share common perspectives and engage in joint action in geographical locations or settings (MacQueen, 2001). This definition departs from previous narrow and one-dimensional conceptualizations of community. It acknowledges that communities are dynamic, fluid and made up of individuals and groups with diverse characteristics. It also considers the fact that communities may not be pre-existing and homogeneous entities as implied by for instance geographical and risk sub-group definitions, but may take shape in response to particular issues of common concern and interest (Lavery et al., 2010). Building on this definition, the GPP guidelines also bases its conceptualization of community on a stakeholder perspective. Within this approach, stakeholder refers to any individual or collection of individuals who have a stake in biomedical HIV prevention trials (UNAIDS-AVAC, 2011). Their GPP model describes layers of stakeholders, including trial participants, individuals or groups who represent the interests of those who may be recruited or participate in HVTs and others locally affected by the trial.

In spite of these definitions that acknowledge that communities are diverse and dynamic systems made up of multiple levels of stakeholders, in the context in which I conducted my research, community is defined in geographic terms by stakeholders involved in the process. The community in which Research Centre X is located was chosen as the setting for their research because of the high HIV prevalence and HIV risk recorded in this geographical area. The location of Research Centre X in this setting provides it with access to HIV negative individuals at high risk of HIV infection who may be willing to participate in HIV vaccine and other biomedical HIV prevention research studies being conducted. The community targeted by Research Centre X includes those lay community members, HVT participants, community organizations and representatives who reside in the geographical area where it is located. Community engagement at Research Centre X targets lay community

members, HVTs participants and members of the CAB. Given my research focus on exploring the dynamics of research participation and the current process of community engagement at Research Centre X, therefore, my research focussed on the community as defined within the research setting. I acknowledge the limitations of adopting this approach and reflect on this, discussing the impact of this narrow conceptualization of community on the community engagement process, in the concluding chapter.

3.4. The participation continuum – moving from community participation to community mobilization

The second concept central to the research is participation. Since Alma Ata, community participation has been widely held as an important tool for addressing threats to health and well-being and ensuring equitable access to healthcare and other health-promoting resources in resource-poor settings (Morgan, 2001). The participation of those affected by a particular health and psychosocial problem that threatens their health and well-being is promoted in global health, development studies and various social science disciplines as the foundation for generating solutions that are relevant and acceptable to local communities. Community members are offered a number of positions in the participatory process. There are various conceptual contributions that describe the positions offered to community members in the participatory process, for instance Arnstein's ladder of participation (1969) and Campbell's (2014) conceptualization of instrumental, dialogical, social capital and critical approaches to community mobilization. The role of the local community in participatory processes may be viewed as a continuum that ranges from passive, tokenistic participation in which they remain subjects in the process, to increasingly more active participation that involves them in the process as participants, partners and co-producers of knowledge. The positions afforded to community members on the participation continuum are distinguished by the nature of the partnership with local communities and the level of participation and roles they are afforded

in the process. The latter positions on the continuum, which offer community members a more active role in the process, have the potential to facilitate the development of community capacity and empowerment. This pursues the goal of community participation as a health promotion strategy.

An emphasis on the participation of local communities has also filtered into the biomedical HIV prevention arena. In the HIV vaccine context, the issue of promoting community participation in the research process has been raised as a salient concern at socio-behavioural research agenda setting meetings. The salience of this issue is based on the recognition that local communities play a crucial role in the HVT process, and without their buy-in, support and participation in the research process, HVTs are unlikely to succeed in their goal of developing a safe and efficacious HIV vaccine (Wakefield, 2005). Since I first started doing research in this area in 2005, various terms have been used to describe community participation in HIV vaccine research. These terms include community participation, community involvement, community engagement and stakeholder engagement. The meanings of these terms tend to overlap. They are all used to describe efforts that researchers undertake to involve multiple levels of stakeholder groups in local communities who host HVTs in the research process. The conceptualization of community or stakeholder engagement in HIV vaccine research, therefore, seeks to develop communities as an HVT resource, offering them the role of subjects in HVTs and as community representatives providing input on trial procedures. Participation therefore focusses on the operational and ethical aspects of clinical trial implementation that supports successful trial conduct. This represents participation at the tokenistic, passive end of the participation continuum (Arnstein, 1969). It affords communities an instrumental role (Campbell, 2014) in the process, such as serving the agenda of the HIV vaccine enterprise and assisting with the implementation of research conceptualized by researchers (Campbell, 2014). Developing

HIV vaccine research as a reciprocal resource for local communities, in other words as sites of health promotion that facilitate empowerment and community capacity-building via participation, does not receive attention. The one-directional benefit implicit in this view on community participation is problematic given the resource-poor, high HIV risk contexts in which HVTs take place.

Clinical trial implementation guidance is clear on the benefits of community engagement processes for the HIV vaccine enterprise. Community engagement is an ongoing process of multidirectional communication that enables sustained, collaborative partnerships between all stakeholders who are likely to participate in the research, to be affected by it or to influence its conduct (Frew et al., 2008; HPTN, n.d.; UNAIDS, 2007; UNAIDS-AVAC, 2011). Authentic community engagement helps ensure that trials can and will proceed smoothly. Investment in community engagement helps cultivate a sense of community ownership that builds trust and deepens knowledge of local realities, improves the quality of data collected by ensuring that trial protocols, procedures and strategies are acceptable to trial participants and builds on locally understood languages and customs. It also optimizes the likelihood of eliciting high levels of adherence and accuracy of self-reporting (Slevin et al., 2008; p.2). The features of community engagement highlighted across these definitions include consultation, dialogue, partnership, mutual education and respect and consensus building on all aspects of testing the potential biomedical HIV prevention technologies (Frew et al., 2008; Nakibinge et al., 2009; Tindana et al., 2007; UNAIDS-AVAC, 2011) as strategies for successful trial implementation. These strategies, if implemented with notions of authentic engagement in mind, have the potential to shift the ratio of benefits that accrue to researchers and communities to a more equitable level.

Given notions of participation and community engagement in the HIV vaccine enterprise and the lack of focus on HVTs as a resource for community stakeholders who act

as partners and collaborators in the research process, I conceptualize participation from a community engagement perspective in this research. This research adopts a community mobilization approach that offers greater potential for developing mutually beneficial partnerships with local communities. Lippman et al. (2013) believe that community mobilization has a key role to play in the effective implementation of biomedical interventions. Community mobilization approaches create room for local community members to actively participate in the research process, building their capacity and facilitating their access to power and resources that promote health and well-being (Campbell & Murray, 2004; Campbell & Cornish, 2010). Such an approach moves beyond ethical and scientific goals to the integration of community development goals with the research process. It emphasizes meaningful social participation and builds enabling partnerships between local communities and external partners (Rifkin & Pridmore, 2001). In addition, it focusses on participation in collective action as a mechanism for increasing participants' confidence and empowerment to exercise agency in those matters that threaten their health and well-being. These features of community mobilization interventions are crucial in HVT settings where access to health promoting resources is limited and where HVTs are accompanied by such resources. The use of the community mobilization approach is, therefore, better placed to provide local communities with an authentic and mutually beneficial role in the HIV vaccine research process.

Chapter 4: Research Rationale and Theoretical Framework

4.1 Research rationale

The research examines two areas integral to the successful development of a safe and efficacious HIV vaccine, namely the dynamics of participating in HVTs and the community engagement processes that target community members at high risk of HIV infection to elicit their involvement in the HIV vaccine research enterprise. The literature reviewed in Chapter 2 highlights a number of key issues that serve as the foundation for this research focus.

In spite of the investment made in averting the spread of the HI-virus, the rate of infection continue to grow among vulnerable, marginalized populations in resource-poor social contexts, including South Africa (Merson et al., 2011). HIV/AIDS thrives in areas of deprivation and inequality where features of the social context, such as poverty, unemployment, gender inequality, high levels of violence, and lack of access to resources fuel the spread of the virus (AVAC, 2013; Smit et al., 2005; Voytek et al., 2011). Available HIV prevention interventions have had a limited impact in stemming the tide of the pandemic in certain settings (Campbell & Cornish, 2010; Coates et al., 2008). Their limited impact may be due to their tendency to focus on changing individual behaviours, while paying scant attention to the influence of risk factors that originate in the local community contexts in which individuals at high risk of HIV infection live (AVAC, 2013; Lesch et al., 2006; Mills et al., 2004; Newman et al., 2006; Ruzagira et al., 2009 Smit et al., 2005; Voytek et al., 2011). In addition, HIV prevention interventions are often imposed on communities in a top-down-manner, targeting them as passive recipients of intervention rather than as active participants and partners in programmes that aim to improve their health (Campbell & Cornish, 2010). Those seeking to intervene to disrupt the spread of HIV are, therefore, challenged to develop approaches that target behavioural (DOH, 2012; Shisana et al., 2014), biological (DOH, 2012; Ramjee & Daniels, 2013) and structural risk factors (Harrison et al.,

2006; Kagee et al., 2011; MacQueen, 2011; Merson et al., 2008; Parker et al., 2000) that impact the spread of HIV.

Various authors agree that current approaches to HIV prevention are necessary, but not sufficient to reduce the rate of HIV infection in contexts where risk is high (Coates et al., 2008; Kalichman, 2008; Padian et al., 2011). Two HIV prevention approaches are perceived to hold much promise for preventing the spread of HIV in high risk contexts, namely structural and biomedical HIV prevention approaches. Structural approaches to HIV prevention shift the focus of intervention from the individual to the social context by attempting to address the social conditions that contribute to HIV vulnerability (Gupta et al., 2008; Roberts & Matthews, 2012). Structural approaches target multiple levels of risk factors, are guided by social change agendas and utilize community mobilization as a key strategy for addressing HIV risk factors.

Biomedical HIV prevention interventions focus on developing biomedical technologies, such as HIV vaccines, and are considered to hold promise in effectively preventing the spread of the HI-virus by offering immunity, reducing susceptibility and diminishing the infectiousness of those at risk of HIV infection (Gwandure & Mayekiso, 2012). Biomedical technologies are tested in randomized clinical trials in community settings where HIV risk is high. While they may have the endpoint of developing a safe and efficacious HIV vaccine, clinical trials to test candidate HIV vaccines include a range of HIV prevention approaches, for example risk reduction counselling and HIV/AIDS education (Asiki et al., 2013; Lesch et al., 2006; Newman et al., 2006; Ruzagira et al., 2009; Sahay et al., 2005, Smit et al., 2005; Voytek et al., 2011).

Developing combination approaches to HIV prevention that integrate structural and biomedical HIV prevention intervention is one way of renewing HIV prevention approaches

(Padian et al., 2011; Piot et al., 2008). Combination approaches are tailored to social contexts and responsive to local community needs. HIV vaccine research, with its inclusion of biomedical, behavioural and community engagement components, embodies such a combination approach. In South Africa, HVTs implement biomedical and behavioural HIV prevention strategies in complex, resource-poor community contexts where the risk of HIV infection is high. Community engagement processes form part HVTs and focus on building partnerships with local communities who serve as a resource, participating in HVTs and providing input on clinical trial implementation to maximize chances of success. Community engagement processes, therefore, aim to create an enabling community environment that facilitates clinical trial implementation, focussing on generating community buy-in, support for and participation in the research process. These community-researcher partnerships (Mercer et al., 2001) focus on the agenda of the clinical trial enterprise and do not take into account the needs of the local community. The nature of the partnerships with local communities raise questions about how HVTs may become a resource for the hosts of such trials. In addition, the existing operational guidelines that form the foundation for the implementation of the community engagement process have limited utility in facilitating and exploring the value of clinical trials in resource-poor community settings as social processes that hold mutual benefit for both the HIV vaccine enterprise and the local community.

Sustained community participation in HIV vaccine research is a key ethical and scientific imperative in ensuring the successful conduct of clinical trials to test candidate HIV vaccines (Lau, Swann, & Singh, 2011; Newman et al., 2015). Historically, attempts to examine HVT participation and community engagement have been conducted using two kinds of approaches. Firstly, studies have focused on the individual level, attempting to describe the factors associated with research participation from the individual perspective. In addition, mirroring dominant approaches to HIV prevention research, researchers focusing on

understanding these correlates of participation have utilized individual level explanatory frameworks and concepts to understand the human and social dimensions of HIV vaccine research (Lau, Swann & Singh et al., 2011). Such research makes an important contribution to HVTs by identifying the factors that enable and inhibit participation in HVTs. They are, however, limited in their ability provide insight into the experiences of HVT participation and the dynamics of the local community contexts in which HVT participation takes place.

Secondly, at the level of HVT implementation, research participation and community engagement worked according to the strictures of research protocols that conform to randomized clinical trial methodology. This aspect of HIV vaccine development is guided by criteria for the ethical conduct of clinical trials and is governed by sets of procedures such as Good Clinical Practices (GCP) and GPP (UNAIDS, 2007; UNAIDS-AVAC, 2011). These guidelines emphasize community-researcher partnerships, shared ownership, mutually beneficial research and ongoing dialogue between researchers and communities. They also stress the importance of building the socio-cultural competence of researchers and research competence of community members (Slevin et al., 2008; UNAIDS-AVAC, 2011). There is, however, limited research on how these key components of community engagement manifest in practice and how they are affected by the dynamics of the local community contexts in which HVTs are conducted (Lau, Swann & Singh et al., 2011).

Viewing HVTs as primarily scientific endeavours in which researchers and their expert knowledge control and structure the process, while community members are resources that contribute their local knowledge to achieve the goals of the scientific enterprise, creates a limiting view of the role of communities in HVTs. MacQueen (2011) highlights the fact that the social, behavioural and ethical challenges that plague clinical trials result from an inability to recognize that trials are fundamentally about social relationships. The scientific process is social, political and deeply embedded in the social context in which it is conducted

(Nowotny et al., 2001). When clinical research moves out of the laboratory into community settings, it becomes part of the community context and the complex dynamics and networks of social relationships that constitute the community HVT setting. Community members who participate in HVTs bring crucial insider perspectives and knowledge about their communities and how they function. This is crucial to the successful implementation of clinical trials. In order to access these community insider perspectives, Newman (2006) calls for a move away from ad hoc and trial-and-error approaches to community engagement in HIV vaccine research. He challenges researchers to apply their best science to achieve scientific and community engagement goals. Understanding how biomedical interventions function as components of community contexts and the mutual influence that structures relationships in the HVT context is a crucial part of achieving the goal of developing a “science of community engagement” (MacQueen, 2011; Newman, 2006, p. 302).

With calls for participatory science, the co-production of knowledge and community-researcher partnerships, the terrain for research on community participation in scientific research has been mapped out. To deepen research on community participation in HVTs, researchers must shift their focus from descriptive to evaluative accounts of current practices of community engagement and locate the *social* in HIV vaccine research in comprehensive contextual frameworks (Lau et al., 2009; Lau, Swann & Singh et al., 2011). HVTs bring health and HIV prevention resources into communities and invite community members at high risk of HIV infection to participate in clinical trials. This research initially developed based on the following perspective: through promoting participation in HVTs in local settings, clinical trials present an opportunity to integrate the ethical and scientific imperative of HVT implementation with community capacity-building agendas in resource-poor community contexts. By integrating these agendas, HVTs may become a resource that is mutually beneficial to all stakeholders who form part of the HIV vaccine research enterprise.

Adopting such an approach promotes scientific innovation, creates health-enabling social contexts for community members in high HIV risk settings (Campbell, 2003) and maximizes opportunities for HVTs to become a social good.

The central focus of the research is, therefore, on the community participation in HVTs, and the community engagement process that promotes such participation. It focuses on exploring the possibilities that participation in the research process presents for lay community members to participate in the process of science as a means of accessing resources, skills, knowledge and competencies, empowering them to address threats to their health and well-being. This research represents, to my knowledge, the first study that examines community participation in HVTs and the community engagement process that promotes participation in the research process, from a community capacity-building perspective.

4.2 Research Question

This research is grounded in an interest in examining current processes of community engagement in HVTs as a process that is mutually beneficial to researchers and the communities in which clinical trials are conducted. In order to explore this interest, the research focusses on the local level of community engagement (Slevin et al., 2008) by focusing on the current community engagement practices at one HIV Prevention Research Centre, Research Centre X. It documents the community engagement process at the Research Centre X from the perspective of three key stakeholders involved in the process, namely community members who participate in the research, community outreach workers who are responsible for implementing community engagement processes that support clinical trial implementation at Research Centre X, and CAB members who represent the interests of the community in the research process. The research was guided by the following question:

How do HIV vaccine researchers operate to achieve the goal of promoting meaningful community engagement in HIV vaccine research in a resource-poor community?

4.3 Research Aim and Sub-aims

The primary aim of the research was to document the current practice of community engagement in HIV vaccine research at Research Centre X in the Western Cape, South Africa.

The research sought to illuminate the process of community engagement in HIV vaccine research and the local community context in which it is implemented.

The sub-aims of the research were to:

- gain insight into the local community context in which HIV vaccine research is currently being conducted from the perspective of community members who participate in HIV vaccine research and community engagement activities at Research Centre X
- examine the current community engagement process at Research Centre X from the perspective of the stakeholders involved. This included examining the community engagement practices and activities used to promote community participation and the roles of each stakeholder in the process.
- utilize the community mobilization approach and the conceptual framework as a lens for interpreting the current process of community engagement at Research Centre X. This approach and framework outline three dimensions of social context, namely the symbolic, relational, and material contexts. Each context either undermines or supports community mobilization efforts, as outlined by Campbell and Cornish (2010, 2011). This aim includes probing the extent to which this approach enables or inhibits meaningful community participation in HVTs in this setting.

4.4 Theorizing community engagement in HIV vaccine research

Clinical trials are assumed to represent a social good in the resource-poor community contexts in which they are conducted (Petryna, 2009; Swartz & Kagee, 2006). However, community participation in HIV vaccine research is a complex and dynamic phenomenon. A number of studies addressing the social aspects of HVT participation suggest that the contexts in which people make decisions about trial participation influence their participation in the research process (Lau, Swann & Singh et al., 2011). Swartz and Kagee (2006) argue that researchers conducting research on HVT participation must exercise caution when making assumptions about the relationship between HVT participation and empowerment of those who participate in clinical trials. Such assumptions do not take into account the complexities involved in trial participation and the configuration of socio-cultural, political, behavioural and economic factors that influence decisions about WTP.

In addition, in 2007 my colleagues and I argued that HVT researchers and community members may hold competing narratives about participation in HVTs (Kafaar et al., 2007). For researchers, trial participation may be considered an operational and bureaucratic requirement associated with the scientific and ethical requirements of trial implementation. For community members, by contrast, trial participation may fulfil a health-promotion agenda, providing them with access to resources and the opportunity to stay HIV-free in settings where the risk of HIV acquisition is high. In the latter narrative, trials may represent health-enabling social contexts (Campbell, 2003). This perspective that positions trials as health-enabling social contexts (Campbell, 2003), may underpin community participation in HIV vaccine research and may hold the potential for aligning researchers' and community members' narratives about trial participation. Aligning these two sets of narratives may create a space where the needs, inputs and perspectives of all participants may be

incorporated into HVT research agendas, creating opportunities for community members to become active participants in the HVTs through the community engagement process.

Given the issues outlined above, the research findings of this study were interpreted within the CHP paradigm and in particular, community mobilization approaches to HIV prevention, treatment and care (Campbell & Cornish, 2010). This paradigm supports the focus on the local community level of engagement in HIV vaccine research. The rationale for departing from a community engagement perspective lies in the ability of the CHP paradigm and community mobilization perspectives to create active roles for community members in the intervention process, to build their capacity and to facilitate their access to power and health-promoting resources (Campbell & Cornish, 2010). These features of community mobilization approaches may serve as the mechanism for generating mutual benefit for both researchers and local communities through their involvement in the research.

The CHP paradigm emphasizes the importance of examining the community contexts that influence how people construct their lives and their behaviours (Murray, Nelson, Poland, Maticka-Tyndale, & Ferris, 2004; Visser & Moleko, 2012). It frames health promotion in the social, political and cultural contexts targeted for intervention and utilizes community capacity building, community mobilization and social transformation as the mechanisms for creating health-enabling social environments (Murray & Poland, 2006; Murray et al., 2004). The focus in CHP is, therefore, on creating health-enabling social contexts, in other words community environments that support and enable the adoption and maintenance of health-enhancing behaviours (Campbell, 2003; Campbell & Cornish, 2010, 2011). Through the use of this theoretical paradigm, this research reflects on the possibilities that community engagement processes may hold for transforming HVTs into health-enabling social contexts (Campbell, 2003) that address the scientific and ethical imperatives of the scientific

enterprise and the community development needs in the resource-poor settings in which such research is being conducted.

As highlighted above, in the context of this research, community engagement in HIV vaccine research is examined within the framework of the fourth generation, community mobilization approach outlined by Campbell and Cornish (2010). Community mobilization approaches recognize that communities have strengths and resources that can be mobilized to benefit both themselves and the scientific enterprise (Rifkin, 2009). These strengths and resources form the foundation of community mobilization. However, their effectiveness may be hampered by the dynamics of the local contexts in which such community mobilization efforts are implemented. These contexts are, therefore, crucial determinants of the success or failure of such interventions, either supporting or inhibiting community mobilization (Campbell & Cornish, 2010, 2011).

In examining the process of community engagement in HVTs at Research Centre X, I used the conceptual framework that incorporates the three dimensions of context that are likely to support or undermine community mobilization outlined by Campbell and Cornish (2010, 2011), namely the symbolic, material and relational community contexts. This conceptual framework has been utilized in various contexts to examine responses to HIV/AIDS prevention, treatment and care, including examining the range of dimensions of context associated with the engagement of local communities with HIV/AIDS initiatives in Gambia (Cassidy, 2010); the impact of traditional leadership on shaping responses to HIV/AIDS in rural communities in Zimbabwe and South Africa (Campbell et al., 2013; Nhomo, Campbell, & Gregson, 2010) and stigma reduction interventions in India (Blankenship, Birdavolu, Jena, & George, 2010). Below I discuss the symbolic, material and relational contexts and the socio-psychological processes that act as the mechanisms through which participation influences health, namely social capital, dialogue and empowerment.

4.4.1 The symbolic context

The symbolic context refers to the world of culture as it is expressed through the meanings, ideologies and world views circulating in a given community context (Campbell & Cornish, 2010, 2011). The symbolic aspects of local community contexts frame how people understand themselves and others in their social environment and the activities that they engage in. It is the mechanism that regulates which groups are valued and respected and which groups are excluded and stigmatized. Symbolic recognition and the symbolic location of marginalized groups in the local context enable our understanding of the symbolic dimensions of context. The symbolic context, therefore, affects how community members are treated by others and how they feel about themselves. By recognizing community members' worth, dignity, concrete achievements and legal rights to equality, this context facilitates their empowerment (Honneth, 1995 cited in Campbell & Cornish, 2011).

In this research the symbolic context refers to the dialogue about HIV/AIDS, HIV vaccines and the research being conducted at Research Centre X among community members. The research examines how the nature of the dialogue circulating in the social context enables or inhibits participation in the research and community engagement processes implemented by community outreach workers at Research Centre X.

4.4.2 The relational context

The relational dimension of social context facilitates the possibility for transformative communication to take place in community mobilization interventions (Campbell & Cornish, 2010, 2011). The relational dimension constitutes the space in which those living in conditions of poverty and marginalization are enabled to demand the fulfilment of their political rights through democratic and accountable leadership, and to advance their economic interests. A key feature of the relational dimension is the extent to which it promotes the full participation of the poor in the leadership and decision-making structures of

projects of which they are the intended beneficiaries. The relational context, therefore, focusses on mobilizing and building social capital in the context of interventions.

In this research, the relational context refers to the roles, responsibilities and levels of participation of each stakeholder in the community engagement process at Research Centre X. It also examines the extent to which meaningful community engagement in HIV vaccine research is pursued at Research Centre X. For the purposes of this research, meaningful community engagement includes offering opportunities for full participation to community members and CAB members who take part in the research and community engagement activities.

4.4.3 The material context

The material context refers to the socio-economic features of communities, including the levels of poverty and the opportunities for economic gain or lack thereof associated with participation in community mobilization interventions (Campbell & Cornish, 2010, 2011). The material context examines the extent to which community projects support community members in dealing with the features of their contexts that undermine their health and well-being. The material context has two components, namely resource- and experience-based agency (Campbell & Cornish, 2010, 2011). Resource-based agency refers to those resources that people have access to in the settings that they live in. It forms the basis for promoting symbolic recognition and esteem in resource-poor communities and includes opportunities to access financial resources, food, paid employment, funding for community projects and education. Experience-based agency refers to the extent to which the social context provides concrete opportunities for community members to practise their skills and exercise agency. In environments where experience-based agency is present, a process of scaffolding is initiated that increases community members' levels of confidence and competency and enables them to act to achieve more ambitious goals.

In this research, the material context refers to the opportunities that participation in HIV vaccine research and community engagement activities may offer community members who participate in HVTs and CAB members to access resources that promote the development of resource- and experience-based agency.

4.5 Key concepts in community mobilization approaches

Community mobilization approaches utilize three socio-psychological processes that act as the mechanism through which participation influences health and well-being (Campbell & Cornish, 2010, 2014). Community mobilization approaches, therefore, create health-enabling social environments (Campbell, 2003) for HIV prevention interventions by building social capital, creating opportunities for dialogue and promoting the empowerment of community members who are targeted for their participation in these interventions.

4.5.1 Social capital

In the context of this research, I utilize Bourdieu's social constructivist notion of social capital, which defines social capital as access to durable networks of socially advantageous relationships of mutual acquaintance and recognition (Bourdieu, 1986). Viewing social capital in this way acknowledges that, in spite of their limited access to material resources, community members have access to social networks and resources that they can draw on in pursuit of their goals (Carpiano, 2006).

Social capital is a property of communities. Without access to sufficient social capital, conditions of poverty and social disadvantage that inhibit individuals from exercising agency in improving their health and well-being are perpetuated (Campbell, 2000; Campbell & Cornish, 2010). Building on this idea, Wakefield (2005) describes social capital as an "important facilitator for and outcome of community development" (p. 2822). Building social capital is facilitated through partnership and participation (Campbell & Cornish, 2010).

Two forms of social capital are important in community mobilization approaches, namely bonding and bridging social capital (Campbell & Cornish, 2010). Both forms of social capital focus on the extent to which community members have access to networks of support. Bonding social capital refers to within-community solidarity (Saegert, Phillip, Thompson, & Warren, 2001). It is represented by community members' access to relational networks that create feelings of solidarity, trust and mutual support (Campbell et al., 2007). Access to bonding social capital holds a number of benefits for communities. It provides the context for dialogue and community conversations in safe social spaces, promotes a sense of ownership and responsibility for tackling HIV/AIDS among community members and builds their feelings of agency and confidence in their own strengths (Campbell et al., 2007). In this research, bonding social capital refers to the presence of supportive relationships between community members, HVT participants, community outreach workers and CAB members.

The second form of social capital highlighted as important is bridging social capital (Campbell & Cornish, 2011). Bridging social capital refers to community members' access to networks of support outside the community. It is represented by marginalized community members' supportive relationships with outside individuals and organizations who hold political and economic power and can utilize their power to assist community members in achieving their goals (Campbell et al., 2007; Campbell & Cornish, 2010, 2011). In this research, bridging social capital refers to the extent to which HVT participants, community outreach workers and CAB members are able to access support and resources for their community engagement activities and goals from powerful individuals and organizations, both within and outside of Research Centre X.

4.5.2 Dialogue or transformative social spaces

The second core socio-psychological process by which community mobilization approaches achieve their goals is through the creation of safe social spaces for dialogue (Campbell &

Cornish, 2010, 2011). Ongoing, sustained dialogue between all stakeholders in the HVT context has been cited as crucial to generating support, buy-in, mobilization and building trust and mutual respect between researchers and communities (UNAIDS-AVAC, 2011). Dialogue is also the space where mutual learning between researchers and community members takes place. Community mobilization approaches, therefore, have to facilitate the spaces for such dialogue to take place (Campbell & Cornish, 2010). Community conversations that bring people together to engage in discussions that explore the underlying factors fuelling the HIV/AIDS epidemic in their social context, are successful in creating safe social spaces for dialogue (UNDP, 2004; Gueye, Diouf, Chaava, & Tiomkin, 2005; Esmā'el, Dolamo, Beleke & Kaso, 2015). Community conversations have a social justice orientation and represent a departure from conventional, prescriptive methods of conducting HIV/AIDS education and awareness-raising lectures in target communities (Gueye et al., 2005). According to Gueye et al. (2005), lecture approaches that incorporate the use of pamphlets and other visual aids, deny the benefits of dialogic approaches.

Community conversations are a form of social mobilization that uses participatory processes and interactions with community members to build their capacity to develop responses to HIV/AIDS in their community contexts (Esmā'el et al., 2015; Gueye et al., 2005). Local community members who hold the trust of the community and have a vested interest are trained as facilitators of community conversations (Gueye et al., 2005; UNDP, 2004). Ideally, dialogue in community conversations is transformative and focusses on helping marginalized groups identify obstacles to effective HIV prevention, explore their concerns and generate concrete strategies for improving their health and addressing the complex challenges of HIV/AIDS (Campbell & Cornish, 2010; Esmā'el et al., 2015; Gueye et al., 2005).

The dialogue in community conversations is at best reflexive and analytical (UNDP, 2004). Community members assess the socio-cultural, demographic and economic conditions that fuel the HIV/AIDS pandemic in their community. In the dialogic process community members use their material wealth, social knowledge and positive norms to explore the possibility of a more effective response to HIV/AIDS in their community (Campbell et al., 2007; Esmā'el et al., 2015). Dialogue in safe social spaces is often absent in settings where HIV risk is high (Campbell et al., 2007). Creating spaces in which such dialogue is facilitated supports critical thinking, problem-solving and mutual learning between those engaged in the process (Campbell et al., 2013).

Dialogue may offer community members the opportunity to explore what they and others in their community know about HIV/AIDS, allowing them to draw on each other as resources. Participants interrogate their own and others' perspectives, discuss their concerns, engage in dialogue about taboo topics, break silences that surround HIV/AIDS, take ownership of unfamiliar medical and scientific information, state their doubts and confusions, ask questions, access new information, and collectively brainstorm how they can incorporate new information into their existing worldview and practices (Campbell et al., 2007; Campbell et al., 2010). Dialogue, therefore, serves as the foundation from which community members develop new perspectives and exercise creativity and agency in developing solutions that can transform their collective response to HIV/AIDS in their community and help them implement solutions for change (Gueye et al., 2005).

The use of community conversations has been successful across a range of rural and urban settings with varying political, social and economic environments (Gueye et al., 2005). It increases general HIV/AIDS knowledge and awareness, generates help for people living with HIV, reduces stigma and discrimination in settings with high HIV risk and deals with misconceptions surrounding the disease (e.g., Campbell et al., 2007; Esmā'el et al., 2015).

This research explores the extent to which safe spaces for transformative dialogue exists in the communities that participate in HIV vaccine research. I will also examine whether opportunities for the open, transparent dialogue promoted by GPP (UNAIDS-AVAC, 2011) are embedded in the community engagement process at Research Centre X.

4.5.3 Empowerment

The final socio-psychological process of interest relates to the empowerment of community members in communities affected by HIV/AIDS (Campbell & Cornish, 2010, 2011).

Empowerment is health-enhancing and is facilitated through participation and representation of community members in community and structures that shape their lives (Campbell, 2000; Campbell & Murray, 2004; Lubek et al., 2014). Wallerstein (1992) argues that people are most likely to feel empowered to take control of their health if they are able to exercise agency in other areas of their lives. Community mobilization approaches, therefore, focus on facilitating the empowerment of community members by involving them in interventions and projects that aim to create “health-enabling social environments” that support the adoption of health-enhancing behaviours (Campbell & Cornish, 2010, p. 1569).

Drawing together aspects of Laverack’s (2006) and Rappaport’s (1987) definitions of empowerment, empowerment in this research refers to the health-enabling process by which marginalized individuals work together to gain mastery and control over events that impact their lives and health. By this definition empowerment is facilitated through the participation of community members in projects for which they are the intended beneficiaries. It occurs on multiple ecological levels; is developed in conditions where those who have access to it work together with those who want to obtain it; and it includes a psychological sense of personal control, social influence and political power (Laverack, 2006; Rappaport, 1987).

Empowerment is health-enhancing and is facilitated through participation and representation of community members in community and structures that shape their lives (Campbell, 2000; Campbell & Murray, 2004; Lubek et al., 2014). Participation is, therefore, an empowerment tool through which local communities take responsibility for diagnosing and working to solve their own health and development problems (Morgan, 2001). Participation has a social justice orientation and acts as a catalyst for social change by becoming involved in political processes that promote access to resources (Cornwall, 2008; Rifkin, 1996, 2009). Community members' participation in collective action may be linked to an increase in their confidence and exercising agency in taking control over their lives. Empowered individuals are more likely to adopt health-promoting behaviours (Campbell & Murray, 2004).

Participation in health has been conceptualized in various ways. Cornwall (2008) argues that in promoting participation, we are charged with moving beyond promoting the involvement of community members in projects intended to benefit them. Our approaches should create spaces for people to have an influence on the project. In the context of clinical trial research, opportunities for participants to have an influence on trials throughout their lifecycle are articulated through calls for participatory science and the co-production of science (Campbell, 2003; Lengwiler, 2008; Nowotny et al., 2001; Robins, 2008). In the HIV vaccine context, the South African AIDS Vaccine Initiative conceptualizes their community involvement approach as a ladder of participation (SAAVI, n.d.). Their ladder of participation is reminiscent of Arnstein's (1969) typology of participation that moves from non-participation to participation, offering citizens increasing access to power through the participatory process as they move up the rungs of the ladder of participation. SAAVI's ladder of participation is adapted from UNICEF's approach and includes eight steps, namely manipulation, decoration, tokenism, assigned but not informed, consulted and informed,

researcher starts the project and shares decision-making, community starts the project and directs it and finally, the community starts the projects and shares the decision-making. With each rung up the ladder, community members' empowerment is facilitated, providing them with access to increasingly more power, control, input and access to resources through the participatory process. SAAVI advocates for the ongoing participation of communities in the HIV vaccine research process towards the top levels of the ladder. This research utilizes the ladder of participation approach adopted by SAAVI to examine the roles and levels of participation that have been afforded to stakeholders in the community engagement process at Research Centre X.

Chapter 5: Method

The research is guided by the following research question: How do HIV vaccine researchers operate to attempt to achieve the goal of promoting meaningful community participation in HIV vaccine research in a resource-poor community? The research adopted a qualitative research approach to examine the current process of community engagement in HIV vaccine research at Research Centre X in the Western Cape South Africa.

5.1. Research design

The research focussed on examining the current practice of community engagement to promote community participation in HIV vaccine research at Research Centre X from the perspective of three key stakeholder involved in the process, namely community members who participate in HIV vaccine research and community engagement activities at Research Centre X, members of the community outreach team and CAB members. The qualitative research approach has the potential to empower marginalized groups in society by facilitating the process through which they discover, create or voice their stories (Stein & Mankowski, 2004). My research utilized the potential of qualitative research to discover and access accounts of participation HIV vaccine research and the community engagement process from the perspective of these stakeholders. In addition, qualitative research offers researchers the ability to investigate complex social processes within the social, political and cultural contexts in which they occur, which of great use in this research (Mason, 2006). It focussed on generating a story about HIV vaccine research and the community engagement process that reflects the meanings, perspectives and experiences of those who form part of the process in the local community who hosts the work of Research Centre X (Holloway & Bailey, 2011). In adopting a qualitative approach, therefore, the research focussed on accessing the voices of those involved in community engagement processes to support the implementation

of HIV vaccine research in a resource-poor context as a pathway for gaining insight into their experiences and perspectives on the process (Stein & Mankowski, 2004).

Various authors who produce social science research on HIV vaccines lament the fact that such research rarely engages in in-depth, reflexive social science that examines the dynamics of local community contexts and the impact of the trials on these contexts (e.g., MacQueen, 2011). They call for research that moves beyond description to analyses of community engagement that locate the “social” in HIV vaccine research in comprehensive contextual frameworks (Lau et al., 2009; Lau, Swann & Singh, et al., 2011). The “social” in HIV vaccine research is complex. HIV vaccine research involves relationships between multiple levels of stakeholders, from the local to the global, with different perspectives and goals for the process. Using a qualitative research design in my research, therefore, produced an account that documents and makes sense of the complexities that accompany efforts to involve local communities in the global HIV vaccine enterprise.

5.2. Research setting

According to Morgan (2001), context is crucial in participation studies as it provides insight into the range of factors that may influence participation. In selecting the context for my research, I used a representative or typical case sampling strategy (Yin, 2009) to select the research setting that offered me the opportunity to capture everyday HIV vaccine research and community engagement practices. The setting for the research, Research Centre X, is the setting for HIV prevention research across a range of biomedical HIV prevention technologies, including vaccines, microbicides and PrEP. It forms part of the Desmond Tutu HIV Foundation and is a recognized HIV prevention clinical trial site for a range of multinational clinical trial consortia including SAAVI, HVTN, HPTN and IAVI.

Research Centre X is located in a peri-urban community in the Western Cape South Africa and is home to approximately one million people. It has a predominantly Black South African population and has been conducting HIV prevention research in this area for more than 10 years. An adult HIV prevalence rate of up to 30% was recorded among antenatal care attendees in the district within which Research Centre X is located, and a population wide mean adult HIV prevalence of approximately 23% was recorded in the Klipfontein component of this district (email communication, Melissa Wallace).

The community that Research Centre X is located in is characterized by high population density, low socio-economic status, high unemployment rates and high levels of violence (Kirby, 2014). Community members live mostly in informal or semi-formal dwellings and have access to municipal infrastructure such as roads, overhead electricity and shared ablutions, including shared tap water. Within the community, primary healthcare is administered from 35 public sector health facilities, 22 of which administer ART. Additional healthcare services are provided by a series of Community-based Organizations that provide VCT, wellness and care support. Research Centre X also operates two mobile clinics in the area that act as referral sites for study protocols.

5.3. Selecting the research participants

Selecting participants involves identifying and recruiting individuals who will act as representatives of those whose voices we wish to “amplify or reveal” (Stein & Mankowski, 2004; p. 23). I used a purposive sampling technique to select “information rich” sources in relation to the purpose of my research (Babbie & Mouton, 2010; Patton, 1990 cited in Coyne, 1997). Using this sampling technique, I accessed the voices, opinions and experiences of the three key stakeholders of interest for my research. These individuals served as expert witnesses, providing their first-hand experiences of the community engagement process at

Research Centre X (Morse, 1991 cited in Coyne, 1997). The pre-determined criteria that I used to select participants for my research included:

- Participants were members of the key stakeholder groups whose perspectives were of interest for the research, namely community members who participate in the HIV vaccine research and community engagement activities at Research Centre X, community Outreach Team members and CAB members at Research Centre X;
- Participants had to be over the age of 18 years old;
- All research participants and CAB members had participated in at least one HIV education, outreach and awareness-raising activity conducted by Community Outreach Team members at Research Centre X.

Beyond the inclusion criteria outlined above, I did not attempt to stratify participants by age, gender or any other socio-demographic characteristics. Such characteristics were not of concern for my research, which focused on documenting the perspectives of those stakeholder groups currently involved in the community engagement process at Research Centre X. My focus was, therefore, on ensuring that the research included those community members who typically participate in the research and community engagement activities of Research Centre X.

HIV vaccine research samples HIV negative individuals who reside in contexts where HIV risk is high. Community outreach workers conduct education and awareness-raising activities in various community locations, partnering with local organizations such as governmental community healthcare centres and HIV/AIDS-related NGOs, to expand the reach of their activities and to maximize the numbers of potential research participants who visit Research Centre X. My research sampled those community members who are already participating in the research and community engagement activities being conducted at

Research Centre X. I recruited these participants with the assistance of a staff member at Research Centre X, Mandla (pseudonym). Initial meetings with staff members at Research Centre X revealed that recruiting participants to participate in its activities is challenging. This is due to inter alia the stigma attached to HIV/AIDS in the community and suspicion and mistrust of Research Centre X and its activities. Given these challenges to recruitment, I opted to utilize the assistance of staff members at Research Centre X who have experience and knowledge of the local community, to act as a conduit between myself and potential research participants, assisting me in recruiting community members who were participating in the activities of Research Centre X.

Community members who were at the time participating in the research and community engagement activities at Research Centre X were, therefore, recruited using the existing recruitment mechanism at the research centre. Mandla served as the conduit between potential research participants and me. He approached potential participants to elicit their interest in my research. He explained the study aims, goals and activities and invited them to participate in the research process. Once participants had agreed to participate in the research, he booked them into the focus group timeslot that best suited them.

Recruitment for the two other participant samples of interest for my research, namely, community outreach workers and CAB members, entailed different procedures. Firstly, a member of the Community Outreach Team, Sizwe (pseudonym), assisted me with recruiting CAB members to participate in my research. These outreach team members are the primary point of contact between the CAB and Research Centre X, regularly interacting and consulting with the CAB. My research was introduced to the CAB members at their monthly meeting and they were invited to participate in the CAB focus group. There were a number of challenges in setting up the focus group with CAB members. These challenges were due to the competing schedules and levels of availability of CAB members. Eventually it was

decided that I would use part of the regular Friday afternoon CAB meeting slot to conduct a focus group.

Secondly, the final participant sample of interest for my research was the members of the Community Outreach Team. The Community Outreach Team Liaison Officer at Research Centre X introduced my study to members of his team and provided me with their contact information. I contacted each member individually to elicit their participation in my research process and scheduled interviews with them according to their individual schedules.

5.4. Data collection

I used two primary data collection techniques to generate the data for the research, namely focus group discussions with community members who participate in the research and community engagement activities at Research Centre X and with CAB members; and key informant interviews with members of the Community Outreach Team.

5.4.1. Focus group discussions.

The aim of this data collection activity was to gain insight into the local community context in which HIV vaccine research is conducted. It accessed the views of community members who participate in the research and community engagement activities of Research Centre X. These focus group discussions documented community members' descriptions of the dialogue in their communities about HIV/AIDS and their own and other community members' views and opinions about the HIV vaccine research being conducted at Research Centre X and their role in it. The focus group discussion method, which uses group interaction to explore people's knowledge and experiences in relation to a set of socially relevant issues (Kitzinger, 1995; Marková, Linell, Grossen & Orvig, 2007) was well-suited to achieving the aim of understanding of the community context and atmosphere in which HVT participation takes place, participants' perception of their role in the research, and the

community engagement process. An additional benefit of the focus group discussion approach for this research was the fact that focus group discussions create a setting in which participants who have a shared and common experience respond to and build on each other's views, generating a range of opinions, ideas and experiences in the process (Litosseliti, 2003). The use of focus groups in my research afforded me the opportunity to identify shared and common knowledge (Kitzinger, 1995) with respect to HIV vaccine research, research participation and community engagement at Research Centre X. Through its interactive nature, participants shared their experiences: confirming, contesting and amplifying their perspectives and generating a rich narrative that represents multiple viewpoints (Litosseliti, 2003) on participation in HIV vaccine research and community engagement activities.

I conducted a series of four focus groups with community members who participate in the research and community engagement activities at Research Centre X. Twenty-four community members participated in these focus groups. I was assisted in this process by a note-taker and an interpreter who acted as translator for participants who do not speak English or who preferred to communicate in Xhosa. Lindelwa, a Xhosa-speaking research assistant with extensive experience in collecting data in health-related projects in community settings, acted as the interpreter in my focus group discussions. In working with Lindelwa, I adopted the steps suggested for maximizing the effectiveness of working with an interpreter as outlined by Williamson et al. (2011). In the introductory phase of the focus group discussion I partnered with Lindelwa in the facilitation of this phase of the process. I introduced the study and our team to the focus group participants, and Lindelwa facilitated the completion of the informed consent documentation, reading through the form and explaining key sections to the research participants. As suggested by Williamson et al. (2011), her inclusion in the facilitation served to build rapport and enhance participants' comfort with her presence. Prior to the focus group discussions, I trained Lindelwa on the

content to be covered in the focus group discussion and the process to be followed. After each focus group discussion, we debriefed, discussing our experiences of the focus group discussion process, clarifying our understandings of the process and content and our interpretations of our observations throughout the focus group discussion.

In planning for the focus group discussions, we aimed to recruit 8-12 participants to participate in each focus group. Due to various pragmatic obstacles such as transport, inability to reach participants via the telephone numbers that they provided, participants' competing commitments on the day of the focus group discussions, on average between six and seven participants arrived to participate in the research. This number falls within the acceptable range of a typical size for focus group discussions (Litosseliti, 2003). I developed and used a focus group guide (Appendix 1) containing a few areas of discussion aimed at uncovering participants' shared and common knowledge and perceptions with regard to HIV/AIDS, HIV vaccines and participation in HIV vaccine research. I followed the focus group guide, monitoring the discussion throughout the process, adding questions and probes, reflecting back content to participants and attempting to draw quieter participants into the discussion. A total of 24 community members who had participated in HIV vaccine research, education and awareness-raising activities at Research Centre X participated in the focus group discussions.

All focus groups were conducted in the boardroom of Research Centre X. We set up the focus group space in a circle format in the middle of the room to create a space that would facilitate conversation. Lindelwa and I sat in the circle and at opposite ends of it to facilitate communication between us, and between ourselves and the research participants. We placed two audio-recorders inside the circle to ensure that we produced a reliable record of the discussion. The note-taker sat on the outside of the circle, at a desk behind the group, where he could observe the interactions, document key points discussed and document patterns of

interaction between participants. The notes taken by the note-taker and the debriefing process between Lindelwa and I, served to support the audio-recordings and the process of generating an authentic description of the focus group discussion process.

At the start of each focus group discussion I introduced the study and the focus group team to the research participants. I also explained my research, the purpose of the focus group discussions and their role in the research. Participants were given the opportunity to ask any questions or to request clarification of the information that I had shared with them at this point. Lindelwa assisted me in responding to questions and queries from participants, and once we had addressed all these questions we proceeded by handing out informed consent forms. Informed consent forms were available in both English (Appendix 2) and Xhosa (Appendix 3). Lindelwa explained the information in the informed consent forms to the participants in Xhosa, highlighting key issues in the forms and assisting them in completing them. After signing the forms, participants were asked to complete a form requesting biographical information, information about their involvement in the HIV vaccine research and educational activities being conducted at Research Centre X (see Appendix 4). The focus groups lasted between 60-90 minutes each.

Information about the community members who participated in the focus groups is outlined in the table below.

Table 1: Descriptive information – Community members who participate in HIV vaccine research and community engagement activities at Research Centre X

Demographic variables	Focus group <i>n</i> = 24
<u>Age (years)</u>	
16 – 20	1 (4.17%)
21 – 25	8 (33.33%)
26 – 30	7 (29.16%)
31 – 35	6 (25.00%)
36 – 40	1 (4.17%)
41 – 45	0
46 – 50	0
51 – 55	1 (4.17%)
56 – 60	0
<u>Sex^a</u>	
Female	14 (58.33%)
Male	8 (33.33%)
<u>Level of Education^b</u>	
None	
Grade 1-7	0
Grade 8-11	7 (29.17%)
Matric	10 (41.67%)
Tertiary	1 (4.17%)
Honours	0
Masters	1 (4.17%)
PhD	0
<u>Employment^c</u>	
Yes	3 (13.64%)
No	19 (79.17%)
<u>Home language^d</u>	
English	1 (4.17%)
Sesotho	0
Xhosa	20 (83.33%)
<u>Have you attended a vaccine information/ discussion group?</u>	
Yes	100%
No	0

^a Missing data for two participants

^b Missing data for five participants

^c Missing data for two participants

^d Missing data for three participants

The focus group with CAB members at Research Centre X followed the same procedure as outlined above. In addition to accessing CAB members' views on research participation, the research and community engagement activities being conducted at Research Centre X, I also used this focus group to elicit CAB members' experiences of their role as representatives of the community in the community engagement process. I facilitated this focus group without the assistance of an interpreter, as I was assured by Sizwe that all CAB members were able to converse and interact in English. I was assisted in the focus group discussion process by a note-taker. The interview guide for the CAB focus group is outlined in Appendix 5. The focus group with CAB members covered a number of areas that included their role and activities in the HIV vaccine research and community engagement process at Research Centre X and their experiences of their role as representatives of the community. After introducing my study and the purpose of the focus group discussion, I explained the informed consent form to CAB members and they completed these forms (see Appendix 6). They also completed the participant information form (see Appendix 4).

We recruited 12 participants for this focus group discussion. However, on the day of the focus group discussion, only eight CAB members arrived to participate in the process. The CAB members who participated in the focus group discussion represented various community organizations and constituents, including organizations that provide health-care and support services to people with TB and living with HIV/AIDS, support to children at risk, or that focus on community development through advocating for provision of services and access to resources for community members. All CAB members described themselves as advocates for social justice, citing histories of political activism in the fight against Apartheid. A number of CAB members also identified themselves as members of the African National Congress (ANC). CAB members had joined the CAB at Research Centre X via two routes: they had been identified as community leaders by members of the Community

Outreach Team and invited to join the CAB; they had been introduced to members of Community Outreach Team via a referral system through members of their own social networks. The focus group discussion with CAB members lasted approximately 90 minutes. Information about the CAB members who participated in the focus group are outlined in the table below.

Table 2: Descriptive information – Community members who serve on the CAB at Research Centre X

Demographic variables	Focus group <i>n</i> = 8
<u>Age (years)</u>	
31 – 35	1 (12.50%)
36 – 40	0
41 – 45	5 (62.50%)
46 – 50	0
51 – 55	2 (25.00%)
56 – 60	0
<u>Sex</u>	
Female	5 (62.50%)
Male	3 (37.50%)
<u>Level of Education</u>	
Grade 8-11	2 (25.00%)
Matric	2 (25.00%)
Tertiary	3 (37.50%)
Honours	1 (12.50%)
Masters	0
PhD	0
<u>Home language</u>	
English	1 (12.50%)
Sesotho	1 (12.50%)
Xhosa	5 (62.50%)
<u>Have you attended a vaccine information/ discussion group?^a</u>	
Yes	7 (87.50%)
No	0%

^a Missing data for one participant

5.4.2. Key informant interviews.

In the final data collection activity, I conducted key informant interviews, in other words interviews with people who have direct and expert knowledge of the subject being studied, (Family Health International, n.d.) with Community Outreach Team members at Research Centre X to gain insight into the process of community engagement as it is currently practiced and understood by those who operate at the coalface. These are the people responsible for creating and implementing community engagement practices and activities at Research Centre X. I conducted interviews with staff members involved in community

engagement activities at Research Centre X, three men and two women. These interviews covered two areas, namely current community engagement processes, practices and activities at the trial site and the stakeholders involved in these processes (see Appendix 5).

All interviews took place in the board room at Research Centre X. Each interview started with a description of the study and its aims and an overview of the informed consent form (see Appendix 6). Due to the fact that the focus of the interviews was on participants' experiences of their roles within the research centre and the challenges associated with those roles, participants were reminded of confidentiality of the interviews and the handling of the data collected.

5.5. Data analysis

All focus group discussions and interviews were recorded with the permission of the research participants. Audio-recordings were transcribed by a transcription service. Focus group discussions that contained extracts in Xhosa were transcribed and translated by language experts in the Department of Modern and Foreign Languages at Stellenbosch University. Their transcriptions and translations were verified by an independent Xhosa-speaking translator.

In preparing the data for analysis, I verified all transcriptions against the audio-recordings of the focus group discussions and key informant interviews. Once I was satisfied that the transcriptions were an accurate record of participants' reports during the data collection process, I uploaded the transcripts into Atlas Ti 4.2, a computer program that assists with the analysis of textual data.

I analysed my study data using the thematic analysis approach outlined by Braun and Clarke (2006). I used an inductive approach, in other words a bottom-up strategy to generate themes that are grounded in the data. I coded the data without trying to fit it into an existing

coding frame (Braun & Clarke, 2006). The data analysis proceeded through a number of phases. In Phase 1 of the data analysis process, I read through each focus group discussion and key informant interview transcript a number of times to familiarize myself with the data. I focused on reading the “data as data” (p. 205, Braun & Clarke, 2013), actively engaging with the data collected and reflecting on what it reveals about HIV vaccine research participation and community engagement at Research Centre X from the perspective of the research participants. During this process of reading and familiarizing myself with the data, I borrowed from the grounded theory approach outlined by Strauss and Corbin (1998), creating memos to note down my initial ideas about the data, issues to explore across my analysis of the data set and the salient ideas that were emerging from the reading of the data. In the second phase of my data analysis process, I proceeded to first level coding by going through each transcript and coding the data line-by-line, using both *in vivo* (Strauss & Corbin, 1998) and descriptive coding (Miles & Huberman, 1994). Through this process of complete coding (Braun & Clarke, 2013), I worked across my entire dataset, namely focus group discussions and key informant interviews with all research participants, to identify and label anything of interest to the research and related to the research question. I worked through the transcripts, coding data line by line, labelling sections of the data with a relevant descriptive label. This line-by-line coding process generated an extensive list of preliminary codes. I used a process of constant comparison (Strauss & Corbin, 1998) to refine and cross-reference coded concepts with the data as a whole. In the third phase of my data collection, I printed out the list of codes and focused on identifying common codes that could be collapsed into categories within the dataset. I created diagrams in AtlasTi to assist me with the process of creating themes that represented “central organizing concepts” (p. 224, Braun & Clarke, 2013) in the data. Within this notion of a theme representing a pattern within the dataset, the next level of analysis involved deriving sub-themes that represent different ideas and aspects of the

“central organizing concept” (p. 224, Braun & Clarke, 2013). I listed the themes and sub-themes in an Excel spreadsheet, including representative quotes from the transcripts for each theme and sub-theme. I arrived at my final list of themes and sub-themes and finalized the descriptive label for each theme and sub-theme by working through the Excel spreadsheet generated and checking the consistency of the themes and the alignment between the theme label and the quotes that represent it. In the final phase of my data analysis, I created a thematic map, generating an overall story about community engagement in HIV vaccine research from the multiple perspectives of the research participants (Braun & Clarke, 2006). I also selected quotes or extracts of participants’ descriptions that I could use to report their perspectives in my study findings (Braun & Clarke, 2006). In the presentation of my findings I have selected the quotes that best represent the central idea/s being expressed by the participants in each theme.

I worked closely with my research supervisor throughout the data analysis process, documenting each phase in the process and presenting him with the output that I generated from each phase of my data analysis for verification and checking.

5.6. Ethical issues

Ethical approval for my research was granted by the Committee for Human Research of the Faculty of Health Sciences at the University of Stellenbosch (see Appendix 7), as well as the Human Research Ethics Committee of the Faculty of Health Sciences at the University of Cape Town (see Appendix 8). All participants were drawn from stakeholders involved in community engagement activities at Research Centre X. Community members who participated in the research were recruited using the existing recruitment mechanisms utilized by the research centre staff. All research participants were over the age of 18 years.

At the start of data collection, the research and its aims were described to potential participants and they were invited to participate in the research. Once they agreed to participate in the research, I obtained written informed consent from them using the forms provided in Appendices 2, 3 and 6. Informed consent documents were available in both English (Appendix 2) and Xhosa (Appendix 3), the language spoken by the majority of people in the local community. Community members who participate in the HIV vaccine research and community engagement activities at Research Centre X and the CAB members received R75 as compensation for their time spent participating in the focus group discussions. This amount was calculated in consultation with staff members at Research Centre X and is consistent with that offered as compensation for once-off visits to the research centre. Focus group discussion participants were also provided with refreshments. Members of the Community Outreach Team who participated in the research were not offered a participant incentive.

The study adhered to strict guidelines for maintaining confidentiality and ensuring the safety of data. No identifying data were collected and participants were assigned a participant number on the participant information form. In instances where participants' names were mentioned in focus groups or key informant interviews, pseudonyms are used in the presentation of the data. I use a pseudonym to replace the name of the research centre, and the staff members who assisted me with recruiting participants throughout my dissertation. All audio-recordings and transcriptions of interviews and focus group discussions are stored on a password protected computer to which only I have access. In addition, all forms completed and other study documentation are stored in locked cabinets in my office in the Psychology Department at Stellenbosch University. I am the only person with access to these cabinets. Research participants were informed of the data protection procedures to be followed in the informed consent document.

There were no risks associated with participating in the research. The benefits of the research include providing stakeholders with the opportunity to articulate and reflect on their experiences of their involvement in HIV vaccine research and community engagement activities at Research Centre X. It also provided them with a forum in which they could provide input into the ways in which the process of community engagement in HIV vaccine research at Research Centre X may be transformed.

Chapter 6: Findings and Discussion

This chapter utilizes the community mobilization approach and Campbell and Cornish's (2010, 2011) conceptual framework that incorporates three dimensions of context that may inhibit or support effective community mobilization efforts to present the findings of the research. I present the findings and discussion in three parts that document the research participants' perspectives on the symbolic, relational and material contexts of community engagement in HIV vaccine research at Research Centre X. The thematic map below outlines the themes and sub-themes that provide the framework for the discussion of the research findings.

Table 3: Thematic Map

Overarching themes	Themes	Sub-themes
The symbolic context <i>“Coming to fetch AIDS”</i>	Fear and avoidance of HIV/AIDS in the community	
	HIV/AIDS surveillance in the community	Surveillance of community members’ bodies
		Surveillance of community members’ movements
	Myths, beliefs and rumours about HIV vaccine research	Myths, beliefs and rumours about Research Centre X
		Myths, beliefs and rumours about HIV vaccine research participants
		Myths beliefs and rumours about HIV vaccine research
The relational context <i>“I am the mouth”</i>	Community Outreach Workers’ understanding of community engagement and their role in the process	
	Building relational networks in the local community	Building partnerships with lay community members
		Building partnerships with organisations in the community
		Building partnerships with the CAB
The material context <i>“I am taught how to take good care of myself”</i>	Participation promotes empowerment	Learning about HIV/AIDS and accessing health-related information
		Access to quality healthcare and supportive relationships
	Representing the community in HIV vaccine research is challenging	

6.1. PART 1: “Coming to fetch AIDS” - The symbolic context of community engagement in HIV vaccine research

This section discusses the research findings with respect to the symbolic context in which community participation is being conducted at Research Centre X. The symbolic context relates to the worldviews, values, culture and beliefs that operate in a social context (Cornish & Campbell, 2010). The GPP guidelines recommend that researchers gain in-depth knowledge of the local community in which they will conduct their research (UNAIDS-AVAC, 2011). Researchers must, therefore, explore local understandings of HIV/AIDS, social norms, perceptions and communication and decision-making networks that may influence community members’ attitudes to scientific research and researchers. In this section, I examine local understandings of HIV/AIDS, worldviews, values, culture and beliefs about HIV/AIDS, HIV vaccines and the research being conducted at Research Centre X that create the symbolic context in which community participation in HIV vaccine research takes place.

Gilbert and Walker (2010) point out that stigmatization has endured as a core feature of people’s experiences of HIV/AIDS. HIV/AIDS continues to be accompanied by stigma and discrimination and people living with or perceived to be associated with the disease are stigmatized, rejected and discriminated against across various settings, ranging from the most personal and intimate to the public. In this section I present three themes and their related sub-themes in which my research participants describe the stigmatization of HIV/AIDS and anything related to it in their communities. These themes represent the symbolic context for community engagement in HIV vaccine research at Research Centre X, and I shall discuss each in turn:

- Fear and avoidance of HIV/AIDS in the community
- HIV/AIDS surveillance in the community

- a. Surveillance of community members' bodies
- b. Surveillance of community members' movements
- Myths, beliefs and rumours about HIV vaccine research in the community
 - a. Myths, beliefs and rumours about Research Centre X
 - b. Myths, beliefs and rumours about HIV vaccine research participants
 - c. Myths beliefs and rumours about HIV vaccine research

6.1.1. Theme 1: Fear and avoidance of HIV/AIDS in the community.

In South Africa HIV/AIDS-related stigma has been described as a cause of discrimination and inequality, impacting on willingness to test for HIV, acknowledge HIV risk and initiating HIV treatment (Gilbert & Walker, 2010; Naidoo et al., 2007; Skhosana et al., 2006).

Research participants described their community environment as one in which HIV/AIDS and anything related to it evokes reactions of fear and avoidance. They report that HIV/AIDS is associated with death and community members fear contracting the virus and testing positive for HIV. In this context, talking about the disease and encouraging people to test for HIV and to practise safe sex is difficult. Participants report:

*They don't want to hear anything about what is HIV.
(FGD 1, Community Members, Female)*

*We live among people who has the fear to know their own statuses.
(FGD 1, Community Members, Male)*

Participants ascribe community members' avoidance of HIV/AIDS as rooted in the fact that there is no cure for the disease and people therefore equate an HIV diagnosis with death. These fears of dying endure in spite of the knowledge that treatment is available for those living with HIV. Community members are reported to dismiss the availability of treatment and are said to continue to view an HIV positive diagnosis as a death sentence. Fatalistic notions therefore continue to accompany discussions of HIV/AIDS, with death

perceived as the final and inevitable outcome of an HIV positive diagnosis. The quotes below illustrate this point:

I think it's a matter that that many people are afraid of HIV and AIDS because there's no cure, it's not like TB. If ever there was a cure for HIV and AIDS it would, it would be accepted in and around the communities such as TB. Because if ever a person has the TB it's not, it's a big issue because they, you know er its six months treatment then you (inaudible recording). So I think that's the problem. Whereas, there's no, there's no cure for HIV and AIDS and lack of education to other people I think it's that.

(FGD 1, Community members, Female)

And what they make people die about HIV. Why? It's every day that I see in my community. They didn't accept that thing. I've got this virus and need, what do you need to do if the doctor say ok there's the treatment? We going to give antiretrovirals is difficult it's less than to worried then you need to to start to eat. Those are antiretrovirals and therefore most of people, what they say, no I don't care about those things. Because I'm still dead. So there's no life. You see?

(FGD 4, Community members, Female)

Because they are, they they tell all, they say they are already dead, already dead. Others say "it's one the same, I'm gonna die, what's the use of taking treatment".

(FGD 2, Community Members, Female)

According to Goffman (1963), the most stigmatized diseases are those that are progressive, incurable and poorly understood. The participants' reports in the quotes above highlight community members' beliefs that, in spite of the availability of treatment, HIV/AIDS is a death sentence. HIV/AIDS is distinguished from TB, which is understood to be treatable within a given timeframe, while HIV/AIDS continues to be viewed as incurable and fatal, rather than treatable and manageable with ARV treatment.

HIV/AIDS is also feared because it brings with it concerns about becoming HIV positive and being rejected by family, friends and others in the community. In the quotes outlined below, participants report how people who are HIV positive are judged and rejected by others:

Er, for example, if you tell me about your problem. You have HIV, I'm gonna judge you. And I don't want to hear anything from you. And I'm also gonna criticize you.

(FGD4, Community Members, Female)

If like I tell them that I'm HIV positive they will tell me 'oh Lydia she's HIV positive' I don't want to be her friend anymore.

(FGD 2, Community members, Female)

And then whatever you're saying to the family you think it doesn't considered because you got HIV. Nothing positive can come of your of your mouth. The only thing its negative will come out your mouth. Well they think it. You of, you've got that virus or that disease.

(FGD 4, Community Members, Male)

These quotes describe people's fears of being rejected by people in their community, their peers and their families. These fears were also articulated by participants in Gilbert and Walker's (2010) study with patients at an HIV clinic in South Africa. In their study, participants reported fears of being rejected by their families, partners and other people in their communities. Families were identified by some participants in this study as stigmatizing, labelling and rejecting family members who are HIV positive. Rejection by friends, as described in the quote above, may also reflect courtesy stigma (Goffman, 1963), where people who are HIV positive may be rejected by their friends due to their fears of being stigmatized by being associated with someone who possesses a discrediting attribute, like being infect with the HI-virus. Fears of rejection by those in their inner circle may continue to create fears of HIV/AIDS or testing HIV positive, and may contribute to avoidance of HIV/AIDS and anything associated with it, including HIV vaccine research.

The research participants reported that people who are HIV positive are feared and avoided. They are viewed as being untrustworthy and having a malicious intent to infect others with the virus by virtue of their diagnosis or discrediting attribute (Goffman, 1963). Participants express distrust of people who are HIV positive and fear for their safety in interactions with such people as they perceive them to be interested in purposefully infecting others with the virus, starting a network of infection. The quotes below illustrate these views:

Er, for people who says they won't die alone they will rather have to infect other people er, to to kind of, using their own kind of judgement. Right? That you you should also infect the other person when you are infected.

(FGD 1, Community members, Male)

He said also when ... also when they find out they are HIV positive they don't ... they, they expose their, they expose the other people on the, on the disease because they don't use condoms to protect. (Translated by Interpreter)

(FGD 4, Community members, Male)

Women who participated in the research reported that men in their communities avoid discussing HIV/AIDS or testing for HIV. The reluctance of men to get tested for HIV has been documented in other studies (e.g., Skovdal, Magutschwa-Zitha, Campbell, Nyamukapa & Gregson, 2013). In this context, HIV is referred to as “TB” by women to denote their belief that, like TB, it is treatable and no longer a death sentence. They report that their partners refuse to visit healthcare clinics to be tested for HIV, and use the women’s test results as markers of their own HIV status. The quotes below illustrate this:

They don't want to go to the clinic, and especially the men. You can see now it's only one man on us. You can see it's only one... The men, I don't know there is something about the men, they don't want to go to the clinic. You can see even, even here they say I must come with my boyfriend. My boyfriend don't want to come. That's the other problem. That is why this, you say it's what, that's why this TB, it's not now, it's not HIV anymore. That's why, this TB, you know? It's because the men don't want to go to the clinic and get treated. That's the problem.

(FGD 1, Community Members, Female)

I understand it. It's like I'm pregnant now ne? I went to the clinic everything, but when I'm telling my boyfriend that he must go for a check-up he'll say “you are” he's telling me “you are safe mos¹” (agreement and laughter). I will see on the baby that you are OK. If the baby is okay, even me I'm okay.

(FGD 2, Community Members, Female)

¹A conversational device used to elicit confirmation or agreement.

A few female participants also reported how men blame women for becoming HIV positive and accuse them of being unfaithful:

Men are doing that because they are pointing fingers. Saying “I don’t have HIV because you the one who is sleeping around”.

(FGD 2, Community Members, Female)

But I think, even if, even if it’s STD too, ja, they will say you are the one who is doing this. Last time, the last time I slept with you I got this.

(FGD 2, Community Members, Female)

The unwillingness of men to acknowledge or learn about HIV/AIDS, accompanied by “unhelpful male attitudes to HIV/AIDS prevention and care” (p. 714, Campbell et al. 2012), has also been found in a rural community in South Africa. In addition, Skovdal et al.’s (2013) findings from their study examining masculinity as a barrier to men’s use of HIV services in Zimbabwe may also offer some explanation for men’s avoidance of HIV testing. Participants in their study reported that they delay testing for HIV due to their fear of the disease and their fear of how an HIV diagnosis may impact their social construction of the masculine as strong, superior and resilient. Another finding from Skovdal et al.’s study (2013) that may be relevant in this context, is the finding that men view healthcare settings as female spaces and are, therefore, reluctant to visit healthcare clinics. This was evident in this research as, mirroring the demographic profile of those who participate HIV vaccine research and related activities, few men participated in the focus group discussions with community members who participate in HIV vaccine research and community engagement activities at Research Centre X. In the context of this research, therefore, men may be reluctant to test for HIV due to their fear of the disease and a positive diagnosis. In using their partners’ HIV status as a proxy for their own status, they may believe that they have a marker of their own status and have no need to enter the female space of the healthcare setting.

Finally, in this context where HIV/AIDS is associated with death, judgement and rejection by family and friends, participants reported that people in their communities are

afraid of going to clinics to test for HIV as they fear having their HIV status exposed by healthcare staff. They report a lack of trust in healthcare staff who live in their communities and a belief that staff will not keep their status confidential. The quotes below highlight this fear:

And another people they scared to go to the clinic to check HIV. They blame, me, most of them, I blame, I blame, uhm, the counsellors. Maybe I will find the counsellor who knows me when I got there to check HIV and the counsellor she's suppose to, to take that secret information, you understand? For her. But tomorrow when she's go out there, she will tell everyone that "I know her she is HIV, she's what. She was my, er, participant, you understand? And I saw her she was nega-, positive I mean." That's what I hate another thing. Me, I prefer to check with the person who doesn't know me, who stay far because I'm talking from experience. There's a woman there was working there, at the clinic he told everyone about those people who was, e, having a HIV, but she's still working there, that's the thing I don't understand. You understand? That's why, that's why some people they don't want to go into the clinic and check, because they know I'll find Naledi there, she's my counsellor and then Naledi is gonna tell Michelle, she's gonna tell everyone, Amanda "Joh², Anthea she's got HIV", you understand? That's what I hate about, e, most of the people they don't know that. (FGD 2, Community Members, Female)

Most of them are, are, we are staying with them in our community so they know us. If, if, I go to, to NY 1 TB clinic and I, and I'm going maybe to test myself and at the, they find me positive, she's gonna tell my next door, next door neighbour, you know "I, I, I found Rene positive she was there yesterday".

(FGD 2, Community members, Female)

Simbayi et al. (2007) contend that HIV/AIDS is potentially the most stigmatized medical condition. The discussion presented in this theme resonates with this statement as it highlights the stigmatization of HIV/AIDS and those who are HIV positive in the local community contexts in which the research participants reside. In this setting HIV/AIDS and an HIV diagnosis is viewed as a deeply discrediting attribute (Goffman, 1963) and is feared and avoided in conversations between community members.

²A conversational device used to express disbelief or shock.

6.1.2. Theme Two: HIV/AIDS Surveillance in the community.

Surveillance of community members' bodies and movements within their communities is another feature of HIV/AIDS stigma described by participants in the research. Goffman refers to this form of stigmatization as the stigmas of the body (1963). Participants in this research describe an atmosphere of hypervigilance prevailing among community members as they engage in constant evaluation of each other's bodies and visits to various settings in the community. Community members engage in an ongoing process of looking for signs and symptoms of HIV infection in others who they interact with. If they suspect infection, they withdraw from that person/s to protect themselves from infection. There are two kinds of surveillance under way in the community contexts where the research participants reside, namely surveillance of community members' bodies and surveillance of community members' movements in the community setting. In this community context, people mistrust, judge and accuse each other of being HIV positive as the quote below illustrates:

Hey hey wena, wena³ you are positive" I, I'm just telling you, "You are pointing me and the four fingers are pointing to you.

(FGD 2, Community Members, Female)

Goffman (1963) describes the process of excluding and disqualifying someone from group membership as being based on the identification of physical, behavioural or social traits that are perceived to diverge from the group norm. In this setting, surveillance becomes an HIV prevention strategy where people's bodies (physical traits) and movements (behavioural traits) are under constant observation for visible signs of and associations with HIV/AIDS. Those judged to possess perceived signs of HIV infection by virtue of changes to

³Literally means "you". Used in conversation to affirm that the speaker is addressing the listener specifically.

their bodies and the HIV/AIDS-related healthcare settings that they visit in the community, are excluded and relegated to outgroup status.

6.1.2.1. Sub-theme 1: Surveillance of community members' bodies

The surveillance of community members' bodies refers to people's observations and scrutiny of community member's bodies for physical changes such as weight loss that are perceived to be associated with being HIV positive. In the quote presented below, a participant describes people in his community as '*marrow-minded*'⁴ and as judging people's HIV status based on what can be seen with the eye where any change in physical appearance or illness is regarded as evidence that the individual is HIV positive. He states that:

Let's say I'm sick, I like got maybe, er diabetic like you know and then my, my immune system is very low. So what they will do, they will just know that ok I'm dying of HIV and AIDS. Whatever disease you've got they know it's, they don't even, even if you have a, a what you call it a virus. They know it's a disease it's AIDS. They don't say no you got you got HIV. They say ok you've got AIDS simple as that.

(FGD 4, Community members, Male)

The participant quotes below describe how body weight is scrutinized and monitored for indications that people are HIV positive. Those community members who are seen to have lost weight are presumed to be HIV positive.

And then I'm gonna judge you because of your thin. You got HIV, I don't have HIV. I'm well and I'm fat, I'm present. Because by the looks you can't say that one is HIV, this one is HIV. By the looks. Even the fat one can get HIV.

(FGD 4, Community Members, Male)

In 2007 the time that I was, I was sick. The whole 2006 I was spending my time in the Jooste⁵. I was very sick. Because I, I had a kidney problem so I had to took that kidney out. So I was very thin. Thinner than this pen. I was very thin really.

⁴ The participant was intending to use the word "narrow-minded".

⁵ A local governmental hospital.

So they will, they will say to my mother, no my mother must tell the truth she she knows the, her daughter is positive why don't she take her daughter to ... for counselling and all those things. So I just, when, when I came, when I came back from the hospital I just showed them I, I've got a scar full of blood to prove what I, what I have, what I've been through. "No, no, no, she's telling lies. She must tell the truth". Now I'm, now I'm gaining they say "Oh! The, the drugs, the drugs are, are taking, are taking care of her" and I said, "Joh! How are the people?"

(FGD2, Community Member, Female)

The association of HIV/AIDS with weight loss has been documented in other studies (Dickinson, 2014; Ezekiel et al., 2009). Participants in Dickinson's study in South Africa reported that they could identify people likely to be infected with HIV by looking for visual clues of the disease, such as weight loss. They reported that they believed that fat people or healthy-looking people are not infected with HIV. In addition, based on changes in physical traits, Ezekiel et al. (2009) found that among his research participants in Tanzania, people believed that it was possible to tell if someone was infected with HIV with "the naked eye" (p. 961).

The quotes presented above illustrate, how in the study setting where HIV prevalence is high and people fear anything related with the disease, participants believe that they are able to identify people who are HIV positive by looking for visual clues in the form of changes in weight. They discard alternative explanations for weight loss and remain suspicious of community members who have for instance lost weight due to surgery. In addition, they associate weight gain after surgery with being on ARVs as outlined in the quote above. The function of surveillance in this context mirrors that outlined in Ezekiel et al. (2009), namely using visual clues to identify those who are HIV positive as the basis for avoiding them and relegating them to the out-group (Goffman, 1963).

6.1.2.2. Sub-theme 2: Surveillance of community members' movements

Surveillance also extends to people's movements within their communities. Community members are monitored and observed when they visit settings perceived to be associated with

HIV/AIDS testing and treatment. The quotes below illustrate how people are judged to be HIV positive due to behavioural traits (Goffman, 1963) such as visiting healthcare facilities that offer HIV/AIDS services in their communities:

Even there by the clinic nê⁶? There's the, I think there's the TB side, there's the HIV side, there is the family clinic side. All the sides. So nê? I'm passing nê? Maybe I'm going to abortion side. You see mos I'm gonna pass, so they know that there is abortion. After five minutes you sit and "Woe! I did see Karen, she was going to do the abortion. They don't even what I was doing there in that room, so that's why the people like are so scared to go there because maybe my neighbours is gonna be there. She's gonna see, see me sitting in HIV side.

(FGD 2, Community Members, Female)

Because. I think, as Naledi says, said, someone will see you there and have that mind pointed at you that "you are HIV positive because I saw you going in that room". So obviously, what are you doing in that local clinic, there's a TB, there's a HIV nothing else. They don't think that there like people are sick that they just flu or something like that, they need to be checked. They don't see like that. People don't see they like that. They want, if they put their mind on something that is that. Nobody can change their minds.

(FGD 2, Community members, Female)

The participants also report that, in their community environment, requesting information is scrutinized and regarded with suspicion. Such questioning leads to conclusions about the person asking for information. As a participant states below:

And then also like you find out now if that, er, situation, it's gonna be difficult even if to go to the clinic because it's gonna ask you why you asking that. Even if you say my friend got this - because we all know everybody if he's asking something, he'll say my friend. Where he is the one with the problem.

(FGD 2, Community Members, Female)

The quotes above highlight how alternative explanations are discarded in favour of a conclusion that labels the individual as HIV positive by virtue of their visits to healthcare

⁶Used as a device to keep the listener engaged or to express questioning such as "really?"

settings that provide HIV-related services. In this context, people are afraid of being seen or simply asking questions that may result in conclusions about their HIV status.

The surveillance of bodies (physical traits) and movements (behavioural traits) (Goffman, 1963) within the community as described by participants in this theme are based on the assumption that judgements of HIV status can be made by looking for visual clues (Ezekiel et al., 2009). Based on this assumption, research participants describe how community members engage in constant surveillance of others in their community environment, searching for visual clues or bodily signs of HIV infection. They withdraw from those perceived to be HIV positive on the basis of their observation of such discrediting attributes. Moller and Erstad (2007) attribute such actions of withdrawal to the fact that the transmission of HIV is poorly understood and therefore people feel threatened by the mere presence, or as in this case, the perceived presence of the disease. In this context, surveillance becomes an HIV prevention strategy as community members use it to protect and distance themselves from people who they perceive to be “active agents of HIV transmission” (Ezekiel et al., 2009, p. 962). Surveillance also creates an atmosphere in which community members are afraid to talk about HIV/AIDS for fear of being associated with it.

6.1.3. Theme 3: Myths, beliefs and rumours about HIV vaccine research.

The preceding themes outlined participants’ descriptions of fears and beliefs about HIV/AIDS and people living with HIV in their community contexts. Moving the focus to HIV vaccine-related beliefs, this theme presents participants’ reports of the factors that may inhibit participation in the HIV vaccine research being conducted at Research Centre X. HVT-related discrimination has been identified as a community-level barrier to HVT participation. HIV/AIDS is highly stigmatized in communities in which HVTs are being conducted, raising the potential for HVT participants to be stigmatized, discriminated against and avoided by virtue of their participation in the research and its associations with

HIV/AIDS (Lesch et al., 2006; Mills et al., 2004; Nyblade et al., 2011). Such discrimination may impact the daily lives of participants, with research participants reporting fears that they will be stigmatized by virtue of their participation in HVTs.

In my research, participants report that there are myths, beliefs and rumours about the research centre, people who participate in the research and research-related procedures circulating in their communities. These myths, beliefs and rumours form the basis for the stigmatization of research participants and the research being conducted at Research Centre X. The myths, beliefs and rumours about Research Centre X and its activities are consistent with the narratives of harm outlined by Saethre and Stadler (2013) in their research on community perceptions of microbicide research in South Africa. Based on participant reports, Research Centre X and the research being conducted there are viewed as harmful to the community and as contributing to the spread of HIV in the community.

6.1.3.1. Sub-theme 1: Myths, beliefs and rumours about Research Centre X.

As discussed in the preceding themes, HIV/AIDS-related stigma in the communities targeted for their participation in HIV vaccine research at Research Centre X has created a community context in which HIV/AIDS and anything associated with it is feared, avoided and viewed with suspicion. The research participants report that Research Centre X is viewed with suspicion by community members who speculate about the function of the research centre and its activities. They report that their family members, friends and other community members are sceptical about the activities of the research centre and its association with HIV/AIDS. In the quotes below, community outreach workers highlight some of the responses to Research Centre X that they encounter during their attempts to promote participation in the research:

I've mentioned before, about the myths and misconceptions about the site, I think that gives a bad picture to those who are participants here at the site. Now we

are trying to create a good platform or a good way for them to be accepted in their own communities, because the stigma is attached even to them when they are entering the site. Now if there is a stigma attached to them when they are entering the site, that would make our job very difficult because everyone would try to hide him or herself when he or she has to come to the site. If we can take the information and give it to them, what the site is all about and what the people who come in and out of here are busy doing, then that would make it easy for everyone to feel welcome when they come here.

(Key informant interview 2, Community Outreach Worker, Male)

We have found that there's a lot of stigma attached to the site, specifically. Because you would see participants coming in and out here, but there are those who are standing at a distance and looking at them and saying, everyone who comes into the centre is HIV positive, or everyone who is working here at the centre is HIVpositive. So these are the responses that you get when you go to the communities and talk to people about what our job is. Then they would tell us, no, we know that place as 1, 2 and 3, and make up about this and that and that. It's totally different from what we are actually doing. So these are the things that we need to go out there and rectify and correct, and clarify to the community exactly what we are doing there.

(Key informant interview 2, Community Outreach Worker, Male)

First of all they ask them where they stay they say oh we stay here in Crossroads. Ok have you heard about Research Centre X? Somebody will say what's that it's a Research Centre I don't know about it what's research? What do they do? Who are they? Then they say Mmm (Yes) ok we've seen some people here. Some White people drive in and out but we don't know what they do, I mean who they are. We thought maybe they are doing their own stuff.

(Key informant interview 5, Community Outreach Worker, Female)

The quotes presented above highlight the misconceptions and erroneous beliefs about Research Centre X that community members hold. People are uncertain about its purpose and the agendas of the White researchers who occupy the space. In this community context, its associations with HIV/AIDS creates scepticism and stigmatization of the Research Centre, its activities and the people who are seen to visit it. Community members who visit it, do so in secrecy for fear of the community surveillance system by means of which their movement into the research centre would be monitored and they would be judged to be HIV positive. Subsequently, the lack of knowledge about Research Centre X and its purpose leads to

community members making their own interpretations about its purpose, attaching an HIV diagnosis to those who visit the research centre. In this way narratives of harm (Saethre & Stadler, 2013) about Research Centre X and the stigmatization of the centre and its staff and research participants are created based on lack of knowledge, fear, anxieties and taboos about HIV/AIDS in the community (Deacon & Stephney, 2007).

Extending the narrative of harm associated with the research centre, research participants report that there are rumours about the activities of the research centre. In particular, a participant describes “*being stigmatized and being called those guinea pigs*”. Labelling of participants as “guinea pigs” and “lab rats” in experiments has been cited in other studies documenting social harms and discrimination experienced by HVT participants (Allen & Lau, 2008; Mills et al., 2004; Newman et al., 2006; Voytek et al., 2011).

In addition to being labelled as “*guinea pigs*”, participants report that community members are suspicious about the “*needle*” and believe that they are being injected with HIV by researchers at Research Centre X. Participants state:

They say that when you come to Research Centre X, they are coming to fetch AIDS and then more specially when they were get ... when they were injected.

(FGD 4, Community Members, Female)

Like I said before they said “that vaccine needle is going to give you HIV”. They can participate at the start and get the money of the transport but at the end they don’t want to participate when it comes to the needle part.

(FGD 3, Community Members, Male)

In an extract from Focus Group Discussion 2 in which all participants were female, participants reported:

Participant: Oh you say they put you something here...

A few participants together: They put HIV!!

Participant: That’s they only thing they say.

Participant: OOO, Joh, Joh, you have HIV!

Participants laughing.

Participant: Don't go dig your own grave.

Interpreter: She say that when you come here they think you are diagnosed with HIV.

Interviewer: So they think you HIV positive?

Participant: Ja.

Participant: I don't care what they say about me as long as I know my HIV status.

Another participant suggests that even healthcare staff at the clinics who conduct HIV/AIDS education and awareness-raising activities hold inaccurate perceptions and myths about the research and research centre that have to be addressed. A participant describes an interaction with a nurse at one of the clinics:

I talk to the nurses and they were like Mmm (Yes) we've heard of that place but we don't trust you guys. Why is it that they come all the way to come and test their stuff here? Is it because you are poor? Is it because when we hear that small bit of giving us more money you use our bodies to test things that are so foreign we don't understand so even the nurses themselves don't understand. So it's like more community education must be done.

(Key informant interview 5, Community Outreach Worker, Female)

Participants in other HIV vaccine related studies have echoed this fear that scientists exploit Black communities, purposefully exposing them to HIV risk by testing untested medicines in their communities and experimenting on them (Lesch et al., 2006; Newman et al., 2006). Various other studies have also reported myths of purposeful infection of poor Black populations by White scientists. Bogart, Kalichman and Simbayi (2008) reported the existence of myths that the HI-virus is a secret weapon developed by White people to reduce, control and eliminate the Black population. In addition, in the context of microbicide research in South Africa, Saethre and Stadler (2013) reported rumours among their research participants that clinical trials are a tool through which malicious White people infect participants with HIV and sell their blood. These beliefs may also reflect the impact of AIDS

denialism through which conflicting messages and misunderstandings of HIV/AIDS were perpetuated and communities rejected scientific explanations for HIV/AIDS (Kalichman, 2009; Natrass, 2007).

6.1.3.2. Sub-theme 2: Myths, beliefs and rumours about HIV vaccine research participants.

The prevailing belief about HIV vaccine research participants reported by the research participants is the belief that people who participate in HIV vaccine research at Research Centre X are HIV positive. They report that visits to the site are associated with being HIV positive and therefore anyone seen entering the premises is assumed to be HIV positive. The quotes below highlight this belief and accompanying feelings of mistrust in research participants who are believed to be “*disguising*” and encouraging others to come to Research Centre X to be infected with HIV:

Maybe they think the reason we come to this clinic is because we are positive. We are just disguising and if they also come here they will also be positive. We are calling them to come here and be injected by these needles and get infected by HIV.

(FGD3, Community Members, Female)

Er some think that the site is being attended by the HIV positive people. Whenever one gets into the site then they will think that we are all positive living people. We are all infected to HIV that's why we attend the Research Centre X.

(FGD 1, Community members, Male)

About the, about their ... I think about the lives of the people. If I ... about the lives of the people because maybe someone they said Research Centre X or those people they came here to visit the Research Centre X and they came here they said you got HIV. It's just ... When you just get in in that gate... it will be obvious you've got that issue.

(FGD 4, Community members, Male)

Related to the surveillance of movements described in the preceding theme, research participants describe how they are subjected to scrutiny and interrogation by fellow community members when they are seen leaving Research Centre X:

I met some people here at the clinic they asked “are you also here in this study” then I said yes, they said “We just want to know our status” (Translated from Xhosa)

(FGD3, Community Member, Female)

He said support, support for his statement because the other day when he came out of here, the people and there were people standing outside, they looked him all the way around the corner. (Translated by Interpreter)

(FGD4, Community Member, Male)

The research participants’ experiences of being presumed to be HIV positive by virtue of their involvement with Research Centre X is consistent with findings from other studies across various settings. These studies show that, like the participants in this study, HVT participants are often presumed to be HIV positive by their families, friends and other community members who use their participation in the research as the basis for judging them to be HIV positive (Nyblade et al., 2011). Mistaken presumptions of a HIV positive status have resulted in HIV vaccine research participants being targets for stigma and discrimination. These mistaken presumptions are believed to result from community members’ lack of knowledge about HIV/AIDS and HIV vaccines (Lesch et al., 2006; Sahay et al., 2005).

6.1.3.3. Sub-theme 3: Myths, beliefs and rumours about HIV vaccine research.

With respect to misconceptions, rumours and stories about the research and research-related procedures, the participants report that community members who had visited the centre, but were not participating in the research, have an attitude of scepticism towards HIV vaccine research and the procedures involved in the research process. In particular, participants who had undergone screening to assess their eligibility to participate in the research being

conducted viewed these processes with mistrust and avoided returning to the research centre or participating in the studies being conducted. The source of the mistrust and scepticism is the possibility of testing false positive, concerns about the being injected with HIV and suspicions about other research procedures.

With respect to the possibility of testing false positive, a participant stated that:

There are still some who do not strongly believe unto being false positive.

(FGD 1, Community members, Male)

According to the participants, the possibility of testing false positive is misinterpreted by other organizations in their community and strengthens the suspicions that people are being injected with HIV at the research centre. The quotes below illustrate:

Now the next thing that happens when one gets er into the study you get this er, false positive results that is now what I've learnt and being on this study for quite a time. Er, then the other NGO's would, would misinterpret this and say that you would be injected with HIV already because when you go for a test somewhere you will be testing HIV positive.

(FGD 1, Community members, Male)

Because, they told me, what they told me, my friends, they said no you ... that thing has been made by AIDS. Hehehe. So when you, when they vaccinate you right, there's a AIDS on that er whatever it is right, there's AIDS. So there's a possibility right there's chances that you can be affected by HIV/AIDS.

(FGD 3, Community members, Female)

In my community people spread wrong rumours about the vaccine saying that it gives people HIV. According to my understanding, vaccine in Xhosa is called prevention. It prevents certain disease from being infected by HIV, like sexual transmitted diseases so that you are not infected with HIV so easily. When we explain this to people they say the vaccine is going to draw disease to them. I am talking about my community but still they are concerned when you try to explain to them they don't want to come to Research Centre X.

(FGD 3, Community members, Female)

A participant speculates on the reasons why people do not return to the research centre after undergoing screening to assess their eligibility to participate in the research:

For example the taxi fare is R6 then its R12 for return, can you see that the money is more than enough there is even change. I don't think the money is the problem I think the injection is the problem, the vaccine injection. Because when you start here the number is 48 but you end up having only 10 people because of the injection. People do not want to get involved because of the injection. The main thing is about testing whether the vaccine works but it was discovered that the vaccine does not work at all, including the placebo. (Translated from Xhosa)

(FGD3, Community Members, Male)

Concerns about vaccine-induced seropositivity (VISP) have been highlighted as an inhibitor to trial participation in other studies (e.g., Dhalla & Poole, 2011; Newman et al., 2006). In Newman et al. (2006), participants who cited concerns about VISP as an inhibitor to their participation, reported that they would find testing HIV positive as emotionally challenging. In the context of this study, it appears that people's concerns about VISP relate to their misunderstanding of the concept. This may be attributed to the difficulties in educating lay community members about complexities of HIV vaccine science in contexts where levels of education and scientific literacy may be low. Newman et al. (2015) cite vernacular vocabularies across multiple languages, belief in traditional healers and lack of experience with research as key challenges to explaining important scientific concepts to community stakeholders. These researchers also found misunderstandings about VISP in the communities in which they conducted their research.

Community members are also suspicious of the purpose of trial-related procedures that involve blood draws. They are reported to believe that participants sell their blood to the researchers. A few of the participants report conversations with community members who believe that their blood is being sold to the researchers, with the participant incentive serving as payment for blood taken.

I told them that sitsala amagazi (blood is taken) (Translated from Xhosa), then they say "they are going to use your blood, sell blood and get money".

(FGD 3, Community Members, Female)

I don't know. Maybe because you are giving us money after taking blood... They think you are buying us to take the blood and so to sell it.

(FGD 3, Community Members, Female)

Yes most people ask when we give blood "how much are you going to get"
(Translated from Xhosa)

(FGD 3, Community Members, Male)

Members of the community outreach team also report encountering the myth of the sale of blood and other body fluids in their HIV/AIDS and HIV vaccine education, outreach and awareness-raising activities. Community members are suspicious of blood draws and providing samples of other body products as they perceive it to be related to witchcraft and bewitchment. The quote below represents an attempt to correct the perception that research participants' blood is sold:

Of course you tell them no listen this is how the blood story comes. This is a vaccine trial and maybe they need to test your blood and the only way how they can test your blood is to draw your blood and then you ask them have you ever gone for HIV testing? They say yes. How do they do it? They draw blood. You say you see they draw your blood so that they can test this otherwise if they don't then they can't know that's how they draw your blood. They don't take it to sell it so then they're like ok I didn't understand because why is it that every time they draw my blood I thought maybe you guys sell blood. So it's just giving them more information and explaining to make them understand.

(Key informant interview 5, Community Outreach Worker, Female)

Concerns about frequent and large volume blood draws, as articulated in the quotes presented, have also been mentioned by research participants in other study settings. It has been cited as an inhibitor to HIV vaccine trial participation among participants in studies in South Africa, Kenya and Tanzania (Asiki et al., 2013, Jaspan et al., 2011; Ruzagira et al., 2009). Perceptions of blood draws and the sale of blood were also found by Saethre and Stadler (2013), where participants are believed to sell their blood to researchers for money. In Gambia, Leach and Fairhead (2007), reported that rumours about blood stealing accompanied

their research. Inhabitants believed that researchers steal good African blood to be used in Europe or America for transfusions or to make medications.

Finally, in relation to trial-related procedures, participants report that fellow community members, friends, and family members communicated suspicion about the physical examination and routine medical procedures that they were required to undergo as part of the screening procedure. The quotes below provide further insight:

I also brought 4 people here who are my friends, who said we get money here. I said to them they must come here and find out about themselves, I left them here it was Thursday. When I went to visit them again to find out how was their visit at Research Centre X, they said “that place is not right they asked us to undress and show them our private parts”, so I did not know what to say (how to respond) to them. (Translated from Xhosa)

(FGD 3, Community Members, Male)

I also told my cousin that at the study I did pap smear, because they want to check if there is anything wrong with my private parts. She said “Wow, why do they do that you are so young for that” I said it is a process of the study then she said “Wow, now I don’t trust this study” (Translated from Xhosa)

(FGD 3, Community Members, Female)

They also report that community members are unwilling to take contraceptives to protect themselves from pregnancy while they are participating in the research for fear that it will impact their future fertility:

The other thing is that there are young girls who do not want to come because they will be required to use contraceptives. They do not want to use prevention they want to do stuff without prevention. That is the requirement of the study and they say they are going to struggle to have children. (Translated from Xhosa)

(FGD3, Community Member, Female)

The use of routine medical screening procedures that are unfamiliar to potential participants are, therefore, also articulated by participants as causing concern and contributing to their scepticism and mistrust about the research being conducted at Research Centre X. Concerns about reproductive screening procedures have not been mentioned in other HIV vaccine studies. However, concerns about the need to delay pregnancy and take

contraceptives for the duration of participation in HIV vaccine research has been reported as an inhibitor to HVT participation by participants in Uganda and Kenya (Asiki et al., 2013; Ruzagira et al., 2009).

6.1.4. Summary: The symbolic context of community engagement in HIV vaccine research

Goffman (1963) highlights the fact that stigma is attached to diseases that are progressive, incurable and poorly understood. All these features are present in community members' understanding of HIV/AIDS as reported in the study data. The findings outlined above highlight a number of features of the symbolic context of community engagement in HIV vaccine research at Research Centre X that inhibits participation in such activities. First, the research participants' reports provide insight into how high levels of HIV/AIDS stigma in their community context frame community members' engagement with HIV/AIDS, people living with HIV and the HIV vaccine research being conducted at Research Centre X. In their community context, community members describe HIV/AIDS as being associated with death, judgement and the rejection of those believed to be HIV positive. People living with HIV are viewed with mistrust and suspicion and has having malicious intent to infect others with the deadly virus. HIV/AIDS and anything or anyone associated with it, is therefore, feared and avoided in their community contexts.

The second feature of the symbolic context that inhibits community engagement in HIV vaccine research follows from the stigmatization of the disease among community members and relates to the surveillance of community members' bodies and movements in the community setting. Due to the fear, avoidance and secrecy in which HIV/AIDS is shrouded in this setting, surveillance is utilized as an HIV prevention strategy. Surveillance is based on the assumption that signs of HIV infection are "visible to the naked eye" (p. 961, Ezekiel et al., 2009). Community members observe the bodies of others for weight loss, a

perceived marker of HIV infection. They also monitor people's movements into HIV-related healthcare settings in the community setting to observe whether they are "*sitting in the HIV side*", another perceived marker of HIV infection. Surveillance is used as the basis for withdrawing from those who are perceived to be "active agents of HIV transmission" (p. 962, Ezekiel et al, 2009).

The final feature of the symbolic context of community engagement in HIV vaccine research that inhibits participation, relates to the narrative of harm (Saethre & Stadler, 2013) that has been created about Research Centre X and the research being conducted there. These narratives position the research as harmful to the community and as contributing to the spread of HIV in the community. As a result Research Centre X, the research being conducted there and the research procedures are viewed with mistrust and scepticism. Issues of race and power are also evoked by the narrative of harm created. In these narratives malicious White people at Research Centre X are perceived to be buying good African blood and testing foreign products on community members.

Deacon and Stephney (2007) point out that the expression of stigma within a given setting is a social construct and its impact is exacerbated by the presence of fear, ignorance, anxiety, lack of knowledge, denial, shame, taboo, racism and misleading metaphors. Many of these contributing features are present in the research setting. In the community setting described by the research participants, the possibility of community conversations (Gueye et al., 2005) or dialogue about HIV/AIDS in safe social spaces (Campbell et al., 2007) is inhibited by the atmosphere of active avoidance and fear of HIV/AIDS and people perceived to be associated with the disease.

Safe spaces for open dialogue about HIV/AIDS and HIV vaccine research (Campbell et al., 2007) is crucial to the collective exploration, challenging and reconstruction of

perceptions, misconceptions, beliefs and rumours about HIV/AIDS and HIV vaccines circulating in this community setting. A key benefit of open dialogue is that it offers community members the possibility of exploring their own and other's knowledge about HIV/AIDS and to use each other as resources (Campbell et al., 2007). Such open spaces for dialogue have been shown to increase HIV/AIDS knowledge and awareness, to reduce stigma and discrimination and resolve misconceptions surrounding the disease (Campbell et al., 2007; Esma'el et al., 2015).

In the community context described by the research participants, however, dialogue about HIV/AIDS, the benefits of mutual learning and breaking the silence around HIV/AIDS through dialogue is not possible given that people avoid talking about the disease for fear of being discriminated against by others. For the research participants, this fear holds even in settings where their confidentiality is guarded by legislation and healthcare professionals are prohibited by law from disclosing information about patients. In this setting, therefore, the research participants report that people do not feel safe engaging in health-protective behaviours such as seeking information and knowledge about HIV/AIDS and accessing HIV testing services for fear of being associated with the disease. Through the absence of dialogue in safe social spaces, the status quo about HIV/AIDS and people living with the disease in the research setting may, therefore, endure and people may continue to live in fear of contracting HIV, of dying and of participating in the research being conducted at Research Centre X.

6.2. PART 2: “*I am the mouth*” – The relational context of community engagement in HIV vaccine research at Research Centre X

In this section I present and discuss the findings with respect to the relational context of community engagement at Research Centre X using Campbell and Cornish's (2010, 2011) conceptualization of the relational dimension of community mobilization, and the associated socio-psychological processes of social capital and empowerment through participation. I

present this discussion for the perspective of the community outreach workers who are responsible for implementing community engagement processes that support clinical trial implementation, and CAB members who provide input into the research and represent the interests of the local community in the research process. I present the discussion using a number of themes that represent the relational context of community engagement in HIV vaccine research at Research Centre X:

- Community Outreach Workers' understanding of community engagement in HIV vaccine research and their role in the process.
- Building relational networks in the local community.
 - Building partnerships with lay community members
 - Building partnerships with organizations in the community
 - Building partnerships with the CAB

In the summary section of this chapter, I reflect on the extent to which the relational dimension of community engagement at Research Centre X facilitates empowerment and access to social capital for local community members, including the CAB.

6.2.1. Theme 1: Community Outreach Workers' understanding of community engagement and their role in the process.

At the time at which the data for this research were collected (2012 to 2013), community outreach workers were aware of the newly published GPP guidelines, but had not received training on how to use it in their community engagement activities. Their community engagement activities were framed by the prescriptions and requirements of various trial sponsors and the training that they received on operational and ethical requirements for community involvement at the start of each new trial. This created various challenges for

community outreach workers in executing their role of implementing community engagement at Research Centre X.

When asked to describe the purpose of community engagement, community outreach workers articulated the operational and ethical goals of community engagement, for instance developing establishing linkages and collaborations that facilitate trial implementation. The quote below illustrates:

Primarily really it's to link the site to the community from a community involvement point of view; from a recruitment and retention point of view; as well as general awareness or education around err clinical trials.

(Key informant interview 1, Community Outreach Worker, Male)

Building on these aspects and echoing community engagement guidance documents (e.g., GPP), they describe the community engagement process as a collaborative one in which partnership and working “together with” a range of community stakeholder groups is of crucial importance.

One of, of, of the important roles of community engagement is liaising with the community through the community advisory board, and liaising with the general community stakeholdership through other organizations and structures that are in the community so that, you know, they know what is happening here. And in any other way, if they are not part of er, the community advisory board, they can take part one way or the other, and really to ensure partnership overall in terms of reaching out to the community with other stakeholders within the health or HIV and AIDS field.

(Key informant interview 1, Community Outreach Worker, Male)

Their efforts, therefore, focus on taking the research into the community through various community structures that act as mechanisms through which they generate community support for and interest in the research process. From this perspective, one of the community outreach workers indicated that community engagement involves: “*trying to please everyone! (laughs)*”, providing some insight into their experience of their role in the research process and juggling interactions with multiple stakeholder groups, each with different needs and requirements.

A key challenge that they experience in implementing community engagement at Research Centre X, relates to the pressures placed on them to meet recruitment targets as set by clinical trial protocols. In contrast to the community engagement guidelines that promote partnership and collaboration between all stakeholders across the lifecycle of the trial (Green & Mercer, 2001), they report that their input is not sought in clinical protocol development and operational planning of clinical trials. The quote below illustrates the frustration that they experience with their lack of input and limited access to power and agency in the process:

So that's what I think is what I find really frustrating. There's always constraints that stand in the way of us being as good of this as we really could be...it always ends up being top down because our top is in the States. We're not at the top of the food chain here. So we're beholden to them and their timelines.

(Key informant interview 3, Community Outreach Worker, Female)

Expanding further, they explain that recruiting participants, a key function of their role as it plays itself out in practice, is:

Ja, it is very, very, very challenging. It's extremely challenging.

(Key informant interview 3, Community Outreach Worker, Female)

Participant: Yeah like drawing blood from a stone.

Interviewer: Oh wow.

Participant: Yeah and that's the sort of stuff that people who are writing the protocols don't think about when they're designing it. No one's talking to say Martha who's everyday like desperately wracking her brain trying to find creative solutions to this recruitment issue. Asking her is this feasible?

(Key informant interview 3, Community Outreach Worker, Female)

While the purpose of community engagement is building community-researcher partnerships with the community in which HIV vaccine research is being conducted to ensure their continuous involvement in the process and there is mutual respect and shared ownership of the research (Frew et al., 2008; UNAIDS-AVAC, 2011), the community outreach workers refer to “*recruitment*” and encouraging community members to visit Research Centre X, as

the primary objective of their community engagement activities. Community outreach workers have little input and power in the process of executing meaningful community engagement that moves beyond recruitment. Meeting timelines by which clinical trials operate and enacting their role, takes priority over their community engagement role, as they are challenged to get bodies for experimentation into clinical trials by “*drawing blood from a stone*”.

Furthermore, community engagement guidelines emphasize the crucial role of socio-cultural competency, insider perspectives and local knowledge (UNAIDS-AVAC, 2011), yet as reported in this context, those who hold such insider perspectives are not consulted about the feasibility of recruitment targets set in the local community context. Crucial consultation with community outreach workers about the feasibility of such targets within the local community context and climate relating to HIV-related research does not form part of the target setting process. This has important implications for ensuring the successful implementation of clinical trials. Therefore, as community outreach workers’ reports illustrate, at the coalface of community engagement, none of the guiding principles of community engagement guidelines are enacted and power continues to reside outside of the local community context, with clinical trial researchers and funders. These tensions and frustrations felt by community outreach workers in their role constitute the context in which relational networks are built and in which community outreach workers build partnerships with community stakeholders. Their articulation of community engagement falls far short of the goals of participatory science that focus on creating room for the active involvement of community members as co-producers of knowledge in the research throughout its lifecycle (Callon, 1999; Green & Mercer, 2001).

In response to the challenges that they face in implementing community engagement activities and meeting participant recruitment targets, community outreach workers create a

supportive network of relationships with stakeholders in the local community, including lay community members, local community organizations and CAB members. The purpose of these relationships, which make up the relational dimension of community engagement at Research Centre X, is to support community outreach workers in “*spreading the word*” about the research being conducted and recruiting community members onto studies being conducted, thereby fulfilling operational and ethical requirements crucial to successful trial implementation.

6.2.2. Theme 2: Building relational networks in the local community.

The relational dimension of community engagement at Research Centre X is expressed in the supportive network of relationships created by community outreach workers. In order to support their community engagement activities, community outreach workers utilize the socio-psychological process of social capital to build a supportive network of relationships or partnerships with key community stakeholders, forming networks of social advantage through relationships of mutual acquaintance and recognition (Bourdieu, 1986). Social capital is built through partnerships and participation (Campbell & Cornish, 2010), and in their efforts to build social capital, community outreach workers offer varying levels of participation to community stakeholders. Community engagement at Research Centre X as described by community outreach workers, therefore, takes place in the context of multiple levels of relationships with multiple stakeholders and focusses on building bonding social capital or within-community solidarity (Saegert et al., 2001). These partnerships constitute three key relational resources that they draw on for support in disseminating information and educating the community about HIV vaccine research and ultimately, recruiting community members into such research. The three relational resources are: partnerships with lay community members (including current HVT participants); partnerships with other HIV-

related health organizations and government community health centres; and partnerships with CAB members.

6.2.2.1. Sub-theme 1: Building partnerships with lay community members.

The participation of community members who reside in the community in which the research is being conducted has been cited as important to successful trial implementation and the development of a safe and efficacious HIV vaccine (Fuchs et al., 2010; Wakefield, 2005). Local community members are the target for the first relational resource created by community outreach workers as part of the relational dimension of community engagement. In developing this relational resource, community outreach workers draw on and establish partnerships with lay community members, including current HVT participants. Building these relationships on which they draw and tap into to expand their reach into the community and maximize access to potential new research participants represents a key source of bonding social capital or within-community solidarity for community outreach workers (Saegert et al., 2001).

Community outreach workers describe the focus of their community engagement activities as centred on taking the research into the community and “*spreading the word*” to recruit community members into the research being conducted at Research Centre X. Their focus is, therefore on providing information, raising awareness and educating community members about HIV vaccines and the research being conducted at Research Centre X. Their starting point in taking the research into the community is:

But I think a lot of community outreach would really identify where do you find your stakeholders? Where are they? So our stakeholders are the people in the community, so we find them at the clinics, you know at the public service centres, at clinics, errr social service departments, libraries and, to, to an extent, schools. You know? So those are the main places where you'd find groups of people going for services. So basically, I can't really say who decided on those, but I think it's really standard practice to say, where are the people that you looking for? Where do they go?

(Key informant interview 1, Community Outreach Worker, Male)

In the interviews with community outreach workers, many describe how they identify locations in the community that afford them access to large numbers of local community members who may be potential research participants. They move into local settings, both formal and informal, “*anywhere where they get a big gathering*” to find an audience for their awareness-raising and education activities. They also use ad hoc strategies, approaching community members in informal settings. They report that they go door-to-door in sections of the community and stop to talk to community members about Research Centre X wherever they encounter groups of people on the streets. The quote below illustrates:

What we do, we've got a strategy that we call door-to-door campaign where we go to knock at peoples' doors with the aim of recruiting the, recruiting people that will be interested for our studies. We also go to train stations where we also recruit there as a team. We also go to taxi ranks where we also go as a team and recruit there. We also go to ... I mean we go to everywhere that there is a lot of people.

(Key informant interview 4, Community Outreach Worker, Male)

Therefore, any setting in the community is utilized for community outreach and awareness-raising and education about HIV/AIDS and HIV vaccines. Community outreach workers use their local knowledge and membership of the community to access community members for this purpose. Their purpose in these encounters is to establish initial contact with lay community members, providing information, generating interest, inviting lay community members to Research Centre X and collecting contact information that they can use to maintain contact.

In addition to taking the research into settings in the communities where “*there is a lot of people*”, the community outreach team also describe using a snowball sampling strategy (Sadler et al., 2010), using the social networks of existing research participants to access new participants. Sadler et al. (2010) have highlighted the benefits of using this

strategy that focusses on using people's social networks to recruit participants with similar characteristics as a vehicle for overcoming recruitment challenges.

Using the language of partnership, liaising with community members and ongoing dialogue are suggested as key to building community-researcher partnerships (HANC, 2014; Slevin et al., 2008; UNAIDS-AVAC, 2011). In the quotes below, community outreach workers describe how they network with community members and outline the roles that are available to them in the HIV vaccine research process:

They are the people who go out from the site to the community to say there is a site there, and it's doing this, you can take part in this way. Er, you can take part either by supporting the site, by being a trial participant, or by being a CAB member, or just by spreading the word of what we are doing out in the community.

(Key informant interview 1, Community Outreach Worker, Male)

Community outreach worker descriptions outline a number of roles for lay community members in the research process that includes traditional research participant roles such as information and awareness-raising event participant, research participant and CAB member, representing the interests of the community. These roles are offered at the lowest rungs of the participation ladder, ranging from manipulation (community members are involved to serve the goals of research with no role in decision-making processes) to three rungs higher up the ladder to a position called "assigned, but informed" (researchers start the project and make decisions, assigning community members roles in the project and keeping them informed about the project) (SAAVI, n.d.). These low levels of participation do not allow community members access to power, control and decision-making in the research process. This will not facilitate empowerment of community members to equip them to deal with immediate threats to their health and well-being in the community setting.

In utilizing communities as a resource to expand their information dissemination activities, community outreach workers use a snowball sampling recruitment technique,

creating a “chain-referral” network (Sadler et al., 2010, p. 3) through which community members introduce their friends and family to the activities of Research Centre X by “*spreading the word*” and “*starting a dialogue with their friends or family or neighbours*”.

In the quote, below a member of the community outreach team explains how he uses community members’ credibility within their family and friends’ networks to access potential participants:

I would tell a particular participant, look here, organize me a group of your friends, relatives or whomever that you can find, then phone me or send me a please call so that I can come and do a short presentation. Then from that short presentation that I'll be doing for them, and then they would believe it because they have already seen their sister or their cousin down at the site. That is what I'm actually doing

(Key informant interview 2, Community Outreach Worker, Male)

Another community outreach worker describes how existing community structures can be used as a resource for keeping community members informed about education and awareness-raising events:

We usually make sure that we go out there in advance and then inform the community. We usually work hand-in-hand with the street committees of the areas that we are going to be hosting the event in. Then we would go there maybe a week before the event, and then that day before the event we would go and make door-to-door campaigns so that people are aware of the event that is coming to their shores. Then on the same day, in the morning, we go there again just to remind them that the event is today at ten o'clock or nine o'clock, so we would like everyone to be there.

(Key informant interview 2, Community Outreach Worker, Male)

Community outreach workers also have a supporter role that utilizes community members as supporters of Research Centre X, assisting with the dissemination of information about the research to others in their community. The roles of CAB members and supporters outlined by community outreach workers are consistent with promoting the active participation (UNAIDS-AVAC, 2011) of community members in the research process and represent a departure from the role of community members as subjects in the research process (Green & Mercer, 2001; UNAIDS-AVAC, 2011). These roles involve community members

in actual research practices (Lengwiler, 2008) such as sharing information, raising awareness of the research and assisting with recruitment of community members into the research. In these roles, community outreach workers utilize community members as a resource to support the achievement of their goals in the research process, namely spreading the message about the research and recruiting community members to participate in the research being conducted.

The articulation of the supporter role for community members is promising and has the potential to serve as the foundation for constructing new identities for communities in the research process, fostering a sense of empowerment, agency and voice of community members over the lifespan of the trial (Frew et al., 2008; UNAIDS-AVAC, 2011). The level of participation currently afforded to community members in the process, limits the potential for constructing new identities that may facilitate lay community member empowerment through their participation in the HIV vaccine research process. Based on their descriptions, the role assigned to community members in the community participation process aligns with the “assigned but informed” position on the ladder of participation (SAAVI, n.d.). In this position, projects are initiated by researchers who retain decision-making power. Researchers keep the community informed about their project and assign them roles in the project. In assigning community members, this level of participation in the process, consultation and incorporation of community members’ views and needs, and their involvement in the planning of community participation activities is absent.

Therefore, while community outreach workers capitalize on and have the advantage of the support of lay community members through the bonding social capital that they have built, this bonding social capital is not a resource available to lay community members, given the low levels of participation and limited roles that they are afforded in the research and community engagement process. This is due to the narrow practice of community

engagement by community outreach workers at Research Centre X. Lay community members are utilized as tools in the process, serving as a mechanism through which community outreach workers may disseminate their message deeper into the community and access more research participant to meet their recruitment targets.

6.2.2.2. Sub-theme 2: Building partnerships with organizations in the community.

The second key relational resource that community outreach workers develop in their community engagement efforts is partnering with other organizations and integrating their own HIV prevention messages into existing forums. This may be viewed as a form of relationship-building where members of the community outreach team establish themselves as trusted insiders and build solidarity (Campbell et al., 2007) with organizations who share their HIV prevention objectives.

In the quotes below, members of the Community Outreach Team describe the community organizations that they engage, collaborate and establish partnerships with in the execution of their community participation role:

So clinics are our primary contacts within the community, so we go to a clinic. So the clinics have got targets that they have, as required by the Department of Health. So if they have to have HIV testing, this much HIV testing this much, family-planning and so on. So we work with them because we also have similar kinds of targets. So let's all go to a certain community and say, go to the clinic for HIV testing. Go to family-planning. Go and treat STIs and so on. You know, we have those contacts. So mainly that is how we (inaudible recording) the community structures: if we have an organization that is doing community education, we work with them to say, okay, if we have these companies...for instance, the World AIDS Day...it's an effort that involves everybody to say, okay, the clinic within that area, Yabonga, which is another organization that's doing like youth outreach and so on, let's all meet and let's go to a community. This is who we are, and this is how we are sort of working together to try and develop the community.

(Key informant interview 1, Community Outreach Worker, Male)

As described above, community outreach workers report that they collaborate and build partnerships with various organizations in the study setting who they believe share their agenda of raising awareness, educating and promoting participation in HIV/AIDS prevention activities. The process of building partnerships is facilitated by the fact that members of the community outreach team reside in the community setting. Gueye et al. (2005) support the use of local community members in the implementation of community conversations about HIV/AIDS. Local community members hold socio-cultural competence about the community (UNAIDS-AVAC, 2011) and may be viewed as trusted insiders who have a vested interest in the well-being of the community (Gueye et al., 2005). The trusted insider status of community outreach team members may be beneficial to the creation of partnerships that serve as the relational networks within which community engagement in HIV vaccine research at Research Centre X takes place.

In their partnership strategy to build bonding social capital and within-community solidarity (Saegert et al., 2001) with healthcare clinics, NGOs and HIV-related organizations, community outreach workers focus on developing solidarity and mutual networks of support that are socially advantageous and supportive of their community participation goals (Bourdieu, 1986; Campbell et al., 2007). They integrate their community engagement activities into existing infrastructure for HIV prevention in the community, for example healthcare clinics that target high HIV risk groups, using these settings to disseminate information about HIV/AIDS, HIV vaccines and HIV vaccine research. Through this strategy, they ensure that the message about HIV vaccine research and Research Centre X is shared with multiple levels of stakeholders throughout the relational network of community resources created. It also assists them in drawing on the expertise of healthcare staff who have the trust of community members to support their research and influence lay community members' view of the research:

Because some of the people would go to the clinic and hear about the Desmond Tutu HIV Foundation, then the nurses or whoever are there needs to explain to whoever is asking questions around that, what is Desmond Tutu all about. The nurses should have some information on what we do, because we go there almost every week, on each and every day to do sessions. Now, they need an explanation, maybe not from me, but from the other sources like the nurses and the doctors.

(Key informant interview 2, Community Outreach Worker, Male)

Various sets of community engagement guidelines promote the establishment of consultation, dialogue and active partnerships between stakeholders in the HIV vaccine research process (Frew et al., 2008; Nakibinge et al., 2009; UNAIDS-AVAC, 2011). The community outreach team's descriptions of the partnerships established with related organizations in the research setting, focus on partnership development as a resource on which they draw in their efforts to raise awareness about HIV vaccines and the research being conducted at Research Centre X. While they mention the objective "*to strengthen the relationship between different stakeholders*" through their activities, the extent to which the collaborations developed by the community outreach team constitute the active and mutually beneficial partnerships promoted by "best practice" guidelines (UNAIDS-AVAC, 2011), is not clear from participants' descriptions. Their descriptions emphasize their own access to existing networks and does not provide insight into whether such partnerships incorporate bi-directional communication and input of community stakeholders into their activities and vice versa. In fact, one may speculate that the organizations with which they partner do not derive benefit from the partnership, and serve merely as a source of support and mechanism through which they can access lay community members and achieve trial implementation goals.

6.2.2.3. Sub-theme 3: Building partnerships with the CAB.

The final relational resource that community outreach workers develop is partnerships with the CAB. CABs act as community representation structures and link researchers to the community in which the research is being conducted (Quinn, 2004). The development of partnerships with the CAB serves as the third key resource that forms part of the relational

network created by community outreach workers and a source of bonding social capital that they draw on in “*spreading the word*” about the research and recruiting participants. Much of the CAB reports about their understanding of their role in the community engagement process and their experiences as CAB members working with Research Centre X mirrors the understanding and experiences reported by community outreach workers. Firstly, community outreach workers and CAB members both report their understanding that the CAB plays a linking role:

CAB they play a very big role in terms of the message. What’s happening at the site we educate them we give them information. We let them understand what the research is and then their role is to go and talk about it in the community you know and hear what the community will say and the community will have some questions and then the CAB will come back and say you know what this is what the community says you know. So we will talk to them and say this is the question that the community, they come so these are the questions coming from the community and then we try to answer those questions and then they will go back and you know. So we work with them like that and then we give them the information and then they go and give them you know because we cannot reach the whole entire community but also ourselves.

(Key informant interview 4, Community Outreach worker, Male)

Members of the CAB echoed the elements of their role in the research process outlined by the community outreach workers:

Ja we, we as this CAB, we actually try to practise the ... I mean for us, how to be very well known by the community we ... it actually started with us, trying to move around them and be very, very much active within our community, in working together with the site. We have tasked each other on certain events together with the site going into the community and doing and introducing us ourselves to the community at the site as well.

(FGD CAB members, Male)

CAB members are chosen on the basis of their membership in key organizations in the community (HANC, 2014). CAB members at Research Centre X were invited to serve on the CAB as they are all members of organizations providing healthcare and social support to at-risk groups within the community. By virtue of their experience of working in these organizations in the community and because they reside in the community, they bring their

socio-cultural competence or local understanding of the social context in which community members make decisions about research participation (Quinn, 2004; UNAIDS-AVAC, 2011) to their relationship with researchers, the community outreach team and the lay community members who they interact with. Members of the CAB echoed the elements of their role in the research process:

Ja we, we as this CAB, we actually try to practise the ... I mean for us, how to be very well known by the community we ... it actually started with us, trying to move around them and be very, very much active within our community, in working together with the site. We have tasked each other on certain events together with the site going into the community and doing and introducing us ourselves to the community at the site as well. As we now just from the event our will vaccine they, that we had within the community and introduced ourselves and the doctors had to do some representation about this site so that we can also be known by the CAB by the community at large.

(FGD CAB members, Male)

The descriptions above highlight an understanding of the CAB role as a linkage one that is consistent with perceptions of their role in HIV vaccine research reported by CAB members who participated in Reddy et al.'s (2010) study. At Research Centre X, the community outreach workers use their partnership with the CAB as a resource to extend the reach of their HIV vaccine research message into the community. The CAB acts as a gatekeeper to the community (HANC, 2014) and facilitates information exchange between Research Centre X and the community. The information exchange facilitated through the mediation role of the CAB constitutes a bi-directional communication and feedback system between the two entities. Information about the research is shared at multiple levels of the community through the CAB and community members' complaints and questions about the research are fed back to the Research Centre through this informational exchange. The CAB, therefore, serves as the foundation for enacting a form of community consultation (Quinn, 2004). Consultation, however, focusses solely on addressing community questions about the

research being conducted at Research Centre X, and does not appear to take into account community needs, views and opinions.

Community outreach workers offer CAB members training to facilitate CAB members' effectiveness as a source of bonding social capital in the community. This expands their research competency (UNAIDS-AVAC, 2011). This training is intended to enable them to accurately disseminate information about HIV vaccines and HIV vaccine research within the community. CAB members are, therefore, offered a level of participation in the community engagement process that moves high up the ladder of participation. Their level of participation is a position referred to as "consulted and informed", which denotes a situation where researchers start the project and make decisions, but consult the community and take their views seriously (SAAVI, n.d.). Parties offered this level of participation are involved in the planning of the project, executing it and are kept informed of all research-related activities. While CAB members provide input into study documents, community engagement activities and recruitment of trial subjects and are kept updated about HVT implementation, it does not appear that they have any substantive input into the HVT implementation process that aligns it with community views and needs. Based on reports by CAB members who participated in Upton's (2011) study that their interaction with HIV/AIDS information, vaccine science and networking opportunities developed their sense of agency, the involvement of CAB members at Research Centre X in such activities may similarly promote their sense of agency. From their reports, however, it appears as aspects of their participation acts as a barrier to their empowerment.

In spite of a common understanding of the linkage role between the CAB and community outreach workers, CAB members express an additional component of their role that they view as central to their role as CAB members at Research Centre X. Moving beyond their role as mediators between the research and the community, serving the agenda of the

scientific enterprise to ensure successful HVT implementation, they assign themselves the role of social change agent in the research setting. Many of the CAB members who participated in the focus group discussion reported involvement in political and social activism. Based on these personal histories, they articulate their social change agent role as being activists in the research context, ensuring that community members are not exploited in the research process (Visser & Moleko, 2012). CAB members articulate their role as a political one, describing it as engaging in advocacy and taking leadership in representing the community interests in the research process. They use the language of community mobilization used by organizations such as the TAC campaign for access to ARVs (Robins, 2008), describing themselves as activists for AIDS, fighting the political struggle and campaigning for the rights of members of their communities. CAB member describe his perceived advocacy role in the HIV vaccine research process in the quotes below:

I've been doing this work of advocacy for quite some time now you see because at school, at a younger age I was at school advocacy, advocating for the rights of accessing books free from the department during the apartheid era you see. Advocating that, there should be free education, advocate you see it's all those things. So I've been in that, in the work of advocacy for some time.

(FGD CAB members, Male)

CAB members describe themselves as guardians of community interests in the HIV vaccine research process, protecting the community interests by acting as “*the mouth*” to ensure that historical experiences of human right violations are not repeated. They report that they execute this component of their role by overseeing the research activities, questioning the researchers on research-related issues and ensuring that the products generated through the research are culturally acceptable to the community. In the quotes below they articulate this:

We have to look for the interest of the communities in that sense but also from an HIV prevention point of view the products can be there but if there is no one to be tested on and worst part of it is that because of our vulnerabilities I would encourage people from our communities to take part in the study because we do

not want products that have been tested in communities ... Products that will not work for us. Because there are things that just won't work for us for many, for cultural reasons, for many different reasons there are things that won't work for us. So sometimes when a product is tested from that particular community, you cannot get the sense of whether it'll work for that community and also the fact that we've got very high HIV communities or from those vulnerable communities it's more the reason why we really have to be part of it.

(FGD CAB members, Female)

The notion of CAB members protecting community members was also evident in the contributions of other CAB members. In this regard CAB members report how they engage critically with issues that researchers ask them to consider. In the extract below, they describe their role in protecting and representing their community:

We need communities buy-in also you know and not say but if you look at research most of the scientists and researchers coming into Black communities are White people you know and we are there to avoid that tension and issues and suspicion you know and make people understand to say but we are representing you and we are scratching you know. We are on the research side, we are looking around.

(FGD CAB members, Male)

The South African struggle for liberation and the exploitation of marginalized, Black communities is expressed as CAB members use political struggle discourse such as “protecting people”, “I’ll die for the community” and rights-based language to articulate their role in the community engagement process. They frame their involvement as rooted in the pursuit of social justice for the community whose interests they represent. The CAB descriptions of their role in protecting and preventing community members from being exploited by researchers were also found by Reddy et al. (2010) in their study on the role and operations of CABs in HIV vaccine trials in South Africa. In addition, in the quotes, issues of mistrust of researchers are articulated by CAB members who express their concern about White scientists coming into Black communities to conduct their research. Historical mistrust was also reported among South African participants in Newman et al.’s (2015) study. Community stakeholders who participated in their study reported mistrust of scientists

resulting from the historical oppression and exploitation of Black people in Africa. The myth of Research Centre X infecting community members with HIV also surfaces in CAB members reports. This belief, that people are harmed in HIV vaccine trials, was also found in Newman et al.'s (2015) study. Therefore, mistrust of researchers and the exploitation of vulnerable, Black communities frame the relational context and influence how stakeholders construct their role in the community engagement process. CAB members, therefore, report that they are involved in the community engagement process at Research Centre X to perform an oversight and monitoring role, assuring that the research is being scrutinized and that community interests are protected, and rights realized.

The tension between the CAB members' roles as representatives and gatekeepers of their community and their political role as social change agents in the research process, creates frustration and tensions for CAB members with the way in which they are engaged in the research process. This frustration and dissatisfaction relates to the limited level of participation that they are offered in the process. First, they report their dissatisfaction with the fact that community consultation and involvement was not initiated before the start of the research. Establishing dialogue and two-way information exchange with communities early is suggested as important as the basis for transparent, constructive, collaborative and trusting relationships between research teams and communities (Lau, Swann & Singh, 2011). The CAB reports that this early engagement was not fulfilled and that this has served to create a sense of mistrust in community members about the research centre and its activities. The quote below illustrates:

Ja rather than just it's there and then you go to them they'll say ok they come and then they just want to use us but we don't know what they're even doing because they just come like you'll hear about the blood and stuff and say oh maybe they came there because they knew we can provide what they want. So they can't imagine it's for their own good you see ja.

(FGD, CAB members, Female)

Secondly, CAB members also reported their frustration and discomfort with the way researchers seek their input into the procedural aspects of the research is sought. CAB members report that their input into the design of study documentation is often sought at the last minute, offering limited opportunities for consultation with the community members who they represent. This frustration is articulated in the quote below:

Participant: You get frustrated. You know especially...

Interviewer: Why?

Participant: Especially when trials are conducted and you get a informed consent document and information sheet to say this you need to quickly review and you know the thing is going to Ethics Committee, I mean I serve at UCT's Ethics Committee and sometimes I find out that the thing is on the meeting schedule and it's just been given to the CAB you know and people, some of people is not available who are competent enough to review these documents now we must make time and go through it hastily you know, we don't have time to go out to consult like I said we need to operate on a mandate and ask are you comfortable with the changes that we are asking...

Interviewer: Yes.

*Participant: You know that process because it is a sponsor chasing, now the thing must go through, the trial must start and all that. You know so that is something that we are battling with.
(FGD CAB members, Male)*

This mirrors the issue of power and agency in the process expressed by community outreach workers, where timelines for trials take precedence over meaningful community input into the process. This may create feelings of dissonance where CAB members are assured that their input is valued, but are not treated in ways that support this notion, nor given sufficient time to provide the input for which they are sought.

Providing input into study documentation is a key part of the advisory and oversight role of CAB members, ensuring community input into the research process and ensuring that study documentation is tailored and adapted to the local community context (Quinn, 2004; Reddy et al., 2010; Slevin et al., 2008). In addition, Lavery et al. (2010) promote early

community involvement in research activities as a way of ensuring that communities do not feel rushed into making decisions of which they have not fully considered the implications to meet researcher timelines. The current engagement with CAB members on this key aspect of their role results in them feeling hampered in the consultation role for which they have been sought as there is often no time for them to consult with the community who they represent about key aspects of study documentation. Their role becomes performative, lacking authentic and meaningful input into the process in which the power is held by researchers and sponsors. UNAIDS-AVAC (2011) points out that it is important to recognize the power inequalities between various stakeholders in the HIV vaccine research process and to address it. If such power inequalities remain unaddressed, they threaten the notion of equal community-researcher partnerships and hamper opportunities for CABs to prevent ethical lapses (UNAIDS-AVAC, 2011). They may also impact CAB members' belief in the authenticity of their role in their process and their power to influence the research process (Quinn, 2004), as is evidenced from CAB members' feelings about their involvement at Research Centre X above.

6.2.3. Summary: The relational context of community engagement in HIV vaccine research at Research Centre X

Community engagement is considered crucial to the successful HVT implementation in the HIV vaccine research context. Community engagement guidelines emphasize collaborating and building partnerships with local community stakeholders to support operational and ethical aspects of trial implementation. Guidelines such as the GPP further emphasize principles such as community-researcher partnerships, shared ownership, mutually beneficial research and ongoing dialogue between researchers and communities (UNAIDS-AVAC, 2011). Building such community-researcher partnerships, however, rests on the ability of community engagement processes to build strong relational networks with local community

stakeholders. When built with the focus on achieving authentic and meaningful community engagement in the research process, such relational networks have the potential to ensure the successful development of a safe and efficacious HIV vaccine, and promoting community development in the high-HIV risk, resource poor communities that host HVTs. In presenting the findings on the relational context of community engagement, I sought to explore how community outreach workers at Research Centre X operate to build a relational network to support their community engagement activities. I framed the exploration in the relational dimension of Campbell and Cornish's (2010, 2011) conceptual framework and the related socio-psychological processes of social capital (Bourdieu, 1986) and empowerment through participation (Laverack, 2006; Rappaport, 1987).

The exploration revealed a number of features that characterize the relational dimension of community engagement at Research Centre X. First, my results revealed the fact that the activities of those who implement community engagement activities at Research Centre X, namely community outreach workers, are heavily regulated by "outside experts" such as clinical trial researchers and funders who place pressure on outreach workers to meet recruitment targets. Community outreach workers have limited access to power and agency in this process in which their primary function becomes to source research participants to participate in the research process. The result is that, at the coalface, they engage in a very narrow set of activities: awareness-raising, education, recruitment that has come to represent the community engagement process at Research Centre X. In the pressurized environment that community outreach workers operate, they are not afforded time to conduct formative research to illuminate the contextual complexities that may impact their activities and that permits them to develop community engagement strategies that maximize the role of the local community in the research process. In addition, the narrow set of strategies that they utilize to access potential participants results in them accessing community members who already

display agency in accessing healthcare and other resources. They are not accessing hard-to-reach populations who may be eligible to participate in the research and who may benefit from participating in the HIV vaccine research being conducted at Research Centre X. Further, in their emphasis on information provision and education as the vehicle to recruiting participants, they appear to assume that decisions about participating in HIV vaccine research rests on access to information about HIV/AIDS, HIV vaccines and the research process. From this perspective, “*spreading the word*” will lead to an increase in the number of community members WTP in the research being conducted at Research Centre X. This assumption, as pointed out by Swartz and Kagee (2006), may not hold true and does not take into account the dynamics of the personal, family, community and broader social contexts that may impact decisions about participation in HIV vaccine research.

Secondly, community outreach workers draw on the language and terminology of best practice guidelines to describe the set of activities that they engage in to promote community participation in the HIV vaccine research being conducted at Research Centre X. Drawing on key features emphasized for building community-researcher partnerships and promoting community participation in biomedical HIV prevention research, they refer to their activities as building partnerships, liaising and collaborating with stakeholders and promoting dialogue about the research in communities (e.g., HANC, 2014; Slevin et al., 2008; UNAIDS-AVAC, 2011). The application of this language to describe the activities that constitute community participation in this setting, namely HIV/AIDS and HIV vaccine education and recruitment, is discomfiting as it denies the complexities, inherent power dynamics and socio-political, cultural and economic features of the social context that deeply impact the community participation process. These aspects hamper the extent to which the goals of best practices are achievable, and/or relevant within the social constraints of local clinical trials contexts.

Thirdly, successful community engagement is one that is mutually beneficial, serves the goals of the scientific process and the community development agenda. It builds social capital in the community and empowers community members to address threats to their health and well-being. It promotes active participation of community members in the research process. At Research Centre X the examination of the relational dimension highlights the fact that the community outreach workers operate in an environment where there is tension between community engagement goals and trial implementation goals, raising questions about the implications of such an approach on how community outreach workers operate to build a relational network through which they can recruit community members. The data reveals that community outreach workers have developed a set of three key relational resources, generating social capital and within-community solidarity (Saegert et al., 2001) that they draw on in the execution of their community engagement agenda. Their relational network consists of partnerships with lay community members, local organizations and the CAB. Community outreach workers attempt to generate within-community solidarity for their HIV prevention agenda as the basis for building bonding social capital (Campbell & Cornish, 2010; 2011; Saegert et al, 2001).

In the relational network created, the roles afforded to CAB members and lay community members represent limited community consultation and involvement in the community process. The extent to which their partners' capacity-building needs and objectives are incorporated into the partnerships created is not clear. It is also not clear to what extent their interactions with community outreach workers, as representatives of Research Centre X and the resources that it brings into the community, serves as either a source of bonding or bridging social capital (Campbell et al., 2007; Campbell & Cornish, 2010, 2011) for lay community members and CAB members that they can draw on in the pursuit of their own agendas and as a resource for promoting their health and well-being. The

process by which they offer members of their relational networks roles in the community engagement process, serves to deny them an active role in the process and limits their access to the social capital available. The within-community solidarity or bonding social capital, therefore, exists simply as a resource, for community outreach workers do not promote the empowerment of community members and CAB members through their participation in the process. In this scenario, the research is not mutually beneficial and solely serves the agenda of the scientific enterprise. Bringing the agenda of biomedical HIV prevention and community development into closer alignment requires support from those who hold power in the research context, clinical trial researchers and funders.

Biomedical HIV prevention research can become a social good for local community members who participate in the research process. Given the extensive resources invested into the science of HIV vaccine development and the limited resources available in communities who host clinical trials, such research has an ethical imperative to ensure that it leaves communities who host their research better off. The goal of leaving communities better off while simultaneously pursuing the goal of developing a safe and efficacious HIV vaccine, cannot be realized if social processes, such as community engagement, are treated as an add-on to the process and are limited to focussing on operational and trial implementation goals. If clinical trial procedures continue to be prioritized over processes that illuminate the dynamics of the local community contexts that support these trials, the notion of community members as subjects of research will continue to be perpetuated, impacting both the objectives of the HIV vaccine enterprise and the local communities who host clinical trials.

6.3. PART 3: “*I am taught how to take good care of myself*” - The material context of community engagement in HIV vaccine research at Research Centre X.

In this section, I present and discuss my findings with respect to the material context of community engagement in HIV vaccine research at Research Centre X. The material context

refers to the socio-economic features of the community contexts in which community mobilisation interventions are conducted (Campbell & Cornish, 2010, 2011). The material context has two components: resource- and experience-based agency that permits an examination of the extent to which community projects, in this context, HIV vaccine research and community engagement processes, support community members in dealing with those features of their local contexts that undermine their health and well-being (Campbell & Cornish, 2010, 2011). Resource-based agency refers to those resources that people have access to in the settings that they live in and includes opportunities to access financial resources, food, paid employment, funding for community projects and education. Experience-based agency refers to the extent to which the local context provides concrete opportunities for community members to practice their skills and exercise agency. Both resource- and experience-based agency promote the empowerment of individuals.

As I have highlighted in earlier chapters, the local communities who host HIV vaccine research are characterised by deprivation and multiple risk factors that threaten community members' health and well-being. Risk factors range from the individual to the structural, including high rates of poverty and unemployment, poor living conditions, high HIV prevalence and risk, low levels of HIV/AIDS knowledge and high rates of AIDS-related stigma (AVAC, 2013; Smit et al., 2005, Voytek et al. 2011). These risk factors create community contexts in which individuals lack access to resources, including health promoting resources that confer protection against HIV in high HIV risk, high HIV prevalence environments. It is, therefore, crucial that efforts to develop a safe and efficacious HIV vaccine provide short-term and ongoing access to health promoting resources to community members who participate in the research process.

HIV vaccine research is conducted in complex social contexts and involves interactions amongst diverse stakeholder parties who participate in the clinical trial process

with different perspectives, agendas and levels of access to power and resources (MacQueen, 2011; Petryna, 2009). In Part One of this chapter, research participants described the symbolic context of community engagement in HIV vaccine research as one in which HIV/AIDS and anything associated with it is highly stigmatised, feared and avoided, and in which the myths, beliefs and rumours about HIV vaccine research and Research Centre X that circulate in the community and inhibit participation in its activities. In this setting, the symbolic context is described as one that lacks opportunities for open dialogue in safe social spaces (Campbell et al., 2007; Gueye et al., 2005). The lack of safe and supportive social spaces in the local community in which people can talk openly about HIV/AIDS, their fears, and its impact on their own and others' lives is also illustrated in participants' descriptions of the surveillance networks that operate in their communities. Thus, in this context, the lack of safe social spaces, inhibits participation in the activities of Research Centre X, limiting opportunities to transform the community dialogue about HIV/AIDS, the factors that fuel its spread and HIV-related stigma and fear (Campbell & Cornish, 2010; Esma'el et al., 2015).

In addition, descriptions of the relational context of community engagement in HIV vaccine research at Research Centre X highlight the fact that community engagement is characterised by the performance of a narrow range of strategies with the objective of recruiting sufficient numbers of participants into the research being conducted. Community members who participate in the research and community engagement activities at Research Centre X, and CAB members are crucial resources in the relational network created by community outreach workers to support them in the execution of an operational task that is experienced by those responsible for implementing it as *"like drawing blood from a stone"*. In their role as relational resources in the community engagement process, the participatory positions offered to community and CAB members fall far short of ideals for participatory science and community-researcher partnerships that position community members as co-

producers of knowledge (Callon, 1999; Lengwiler, 2008; Slevin et al., 2008; UNAIDS-AVAC, 2011). As reported, community and CAB members are offered levels of participation at the lowest rungs of the participation ladder. These participatory roles range from manipulation to assigned but informed (SAAVI, n.d.) and limit their access to power, control and decision-making in the research process. Providing opportunities for those who participate in the research to access power, control and decision-making are the crucial foundation upon which community and CAB members may develop resource- and experience-based agency. Such opportunities may also facilitate their empowerment through the development of skills and mastery that equip them to address threats to their health and well-being in the local community setting.

Empowering community members is a core component of, and catalyst for achieving social change in community mobilisation interventions (Cornwall, 2008). Empowerment is a health-enabling process that uses participation as an intervention strategy and mechanism by which community members access knowledge and resources and build skills and competencies through collective social action (Campbell & Murray, 2004). Participation is, therefore, the pathway through which community members gain mastery and control over the social conditions that undermine their health and well-being (Laverack, 2006; Lubek et al., 2014; Rappaport, 1987). Given the complex social contexts in which HIV vaccine research takes place and the description of symbolic and relational contexts that inhibit meaningful community engagement in the research being conducted at Research Centre X, in the presentation of the findings and discussion outlined below, I examine the perspectives of community and CAB members who participate in HIV vaccine research and community engagement activities on the material context of community engagement and the extent to which it offers them opportunities to access resources that facilitate their empowerment: developing resource- and experience-based agency that supports their health and well-being

(Campbell & Cornish, 2010, 2011). I discuss the material context of community engagement in HIV vaccine research at Research Centre X using the following themes and sub-themes:

- Participation promotes empowerment
 - Learning about HIV/AIDS and testing for HIV
 - Access to quality healthcare and supportive relationships
- Representing the community in HIV vaccine research is challenging

6.3.1. Theme 1: Participation promotes empowerment

HIV vaccine trials take place in complex social environments where levels of poverty, unemployment, violence and HIV/AIDS are high and access to resources that promote health and well-being are low (Lesch et al., 2013). These features of the social context limit access to health-enabling resources and undermine the health and well-being of community members who reside in these contexts. As highlighted above, when clinical trials enter resource-poor community settings, they expand the levels of health-related resources available to community members. HIV vaccine research is a form of combination HIV prevention that integrates biomedical, behavioural and educational HIV-prevention strategies (Kurth et al., 2011). HIV prevention strategies such as HIV/AIDS and HIV vaccine education, VCT, sexual risk counselling and monitoring are embedded in HIV vaccine trials as key components of trial design (AVAC, 2009; IAVI, 2009). Participating in HIV vaccine research, therefore, mediates community members' access to health promoting and HIV-prevention resources. It facilitates their empowerment by providing them with access to three key health promoting resources, namely, information and education about HIV/AIDs, quality healthcare and screening and supportive relationships with knowledgeable others that enable them to address contextual threats to their HIV status. Access to health promoting resources is crucial in light of the symbolic context in which participants report that they and others in their community lack access to such resources.

In this theme, participants report their motivations for participating in the research and community engagement activities being conducted at Research Centre X. In contrast to the negative and inhibiting views about the research and Research Centre X that they ascribe to their friends, families and other community members, they report that they derive numerous benefits from their participation. Their descriptions of their participation highlight the fact that they view Research Centre X centre as a key resource that provides them with access to HIV-prevention services, quality healthcare, support and other related resources.

6.3.1.1. Sub-theme 1: Learning about HIV/AIDS and accessing health-related information

Accessing information about HIV/AIDS and HIV vaccine is the first health promoting resource that participants highlight as an enabler to their participation in the activities of Research Centre X. Access to health and HIV/AIDS information (Asiki et al., 2013; Voytek et al., 2011) and confidential HIV counselling and testing services (Asiki et al., 2013; Lesch et al., 2006) have also been cited as enablers to HVT participation in a number of other studies. This sub-theme focusses on participants' reports of access to opportunities to learn more about HIV/AIDS and testing for HIV that serves as the basis for protecting and monitoring their own risk of becoming infected with the HI-virus, through their participation in the activities of Research Centre X. Participants report that their interest in learning more about how to take care of their health motivates them to continue participate in the research and other activities being conducted at Research Centre X:

*I like being part of the study because I am taught how to take good care of myself.
(Translated from isiXhosa)*

(FGD 3, Community members, Female)

In discussing the benefits that they derive from participating in the activities of Research Centre X, the participants reported how they were initially told about the research centre by others in their social networks:

I heard about the status from my cousin and I was very curious and I like to know about my status because I know, other conversations that I'm taking to and therefore I like to find out what is this AIDS all about.

(FGD 4, Community members, Male)

To get the info. Because the guy that, in fact not the guy. I think the lady, he was working here. No longer working here. Alright. He introduced, he approached me to come to Research Centre X and then what he did, he said no go there. You'll get a R20.00.

(FGD 4, Community members, Male)

We all started together with this young man attending. Then we were told to come here and the class was going to come out at 10. Other people did not accept that because people put money first. The information came later when we came here the one we got from school was little. What made me to keep on coming here is the information I received. (Translated from isiXhosa)

(FGD 3, Community Members, Male)

Mirroring findings of previous studies (e.g., Lesch et al., 2006; Voytek et al., 2011)

participants report that visiting Research Centre X offers them access to material benefits.

Their initial research screening visits were, therefore, motivated by their curiosity to know

their HIV status, access HIV/AIDS information and because of the financial incentives

attached to research screening visits. Access to material benefits associated with HIV vaccine

participation, e.g., incentives, has consistently been documented as an enabler to HVT

participation across a number of settings in which vulnerable, marginalised populations are

targeted for their participation in HIV vaccine research (Lesch et al., 2006, Newman et al.,

2006; Voytek et al., 2011).

In a 2006 study conducted by my colleagues and I to investigate enablers and inhibitors to participation amongst HIV vaccine trial site members, participants stated that they would be likely to participate in HIV vaccine research if they received a financial reward for doing so (Lesch et al., 2006). A participant in this study explained his perception that in poor communities, being offered a financial reward for HVT participation would overshadow people's concerns about the science associated with HIV vaccine research. In these settings, therefore, there are concerns about participant incentives serving as perverse incentives to

community members to participate in research in resource poor settings. While these incentives also serve as a form of resource-based agency, as highlighted in the quotes above for the participants in my study incentives served as an initiating enabler to their participation. Community members soon move their focus beyond the financial to the opportunities available to access other forms of resource-based agency and experience-based agency (Campbell & Cornish, 2010, 2011). These forms of agency take the form of three key health promoting resources available to them through participating in the activities of Research Centre X, namely, opportunities to learn more about HIV/AIDS and their health, access to quality healthcare services and access to supportive relationships with knowledgeable others, i.e., staff members at Research Centre X who they interact with via their participation.

In a local community context where HIV is salient, carries high levels of stigma and fear and where community members lack safe spaces to access information and talk about HIV/AIDS due to the community surveillance system, research participants highlighted access to information about HIV/AIDS and confidential VCT services as enablers to HVT participation. The quotes below illustrate the importance of accessing information and knowing their HIV status:

Because it's, it's, it's, ... I think it's, it's very exciting. Maybe about about myself. I think it's very exciting that you just know your status and therefore you know where you where you stand. And therefore to take forward. That's where I am.

(FGD 4, Community members, Male)

For instance, it motivates me a lot, you see to find out where I am with my status and then afterwards, I told myself everything I do, every time I have a sex practice, I'll use a condom, not matter how. Just to stay positive. So it's helped me a lot.

(FGD 4, Community members, Male)

And therefore I told myself anything would happen I would assist myself. Because I've got brain, I've got eyes to see and therefore it depends for me.

(FGD 4, Community members, Male)

Accessing information in this context is accompanied by the second key health promoting resource that participants describe, namely access to HIV testing in a safe and confidential environment. In the quotes below, participants describe how they engage in repeated HIV-testing as part of their HVT participation. While testing for HIV at each research visit is a component of the research process, in this context they explain that knowing their HIV status serves a health promotion function, motivating them to practice safe sex to ensure that they continue to test negative for the HI-virus.

I want to add to what sisi⁷ is saying. I believe it is better to know your status than not to know. I believe in the saying that “Knowledge is powerful” When you don’t know you can get sick and not knowing you will be forced to go to the doctor and they will test you because they want to know what is wrong with you. You will end up knowing your status and sometimes it’s too late. If you know your status early maybe your CD4 count is still low then they will tell you what to do so that you don’t get sick. But if it is late then you might get very sick and even die because your system is weak. (Translated from isiXhosa)

(FDG 3, Community members, Male)

Ja. I’ve been there tested so many times. Nineteen times as u-Nomfundo said, many times so I’m fine (laughter). So I’m, I’m definitely fine, so I will not go with my boyfriend or I will not go to other places and get tested. So it just, it’s just me and myself and I, nobody else but me and myself and I.

(FDG 2, Community members, Female)

What I can say is that what makes me different in my community is that I know my status. Whatever do I do it safe more than the one who does not know his status he sleep wherever he wants to. So I do as what I am told here. (Translated from Xhosa)

(FDG 3, Community members, Female)

In this sub-theme, as highlighted in the quotes presented, research participants report that participation in the research being conducted at Research Centre X provides access to health promoting resources in the form of access to HIV/AIDS information and VCT. These

⁷ Sister

resources form the basis of their learning about how to protect themselves from HIV-infection. They report that the HIV/AIDS knowledge that they acquire empowers them to adopt HIV protective practices. Their participation, therefore, becomes a form of personal health surveillance and monitoring by which they develop resource-based agency (Campbell & Cornish, 2010), i.e., access to health promoting resources such as HIV/AIDS information and VCT. Their HVT participation also provides them with access to experience-based agency (Campbell & Cornish, 2010) through the monitoring and personal surveillance system that it promotes and whereby they monitor their own sexual risk and implement safe sexual practices in order to ensure that they continue to test HIV-negative. Their participation and the HIV information and education that they access is, therefore, utilized to implement health promoting and HIV-protective practices in their everyday lives in-between HVT visits.

The results in this sub-theme also highlight the fact that research participants credit HVT participation with improving their self-efficacy and increasing feelings of empowerment mastery, control and agency in an environment in which they report that it is *“every man for himself when it comes to HIV/AIDS”*. Their reports indicate that they experience their participation as empowering: it facilitates their ability to exercise mastery and control over the threat of HIV/AIDS that they report as salient in their local community. Their reports also provide evidence that participation in the research and other activities of Research Centre X builds another component of empowerment, i.e., it promotes a psychological sense of personal control over their health and well-being (Laverack, 2006; Rappaport, 1987). For my research participants, participation thus serves as a health promotion intervention, providing them with access to information and creating a supportive context in which they can practice health protective behaviours.

6.3.1.2. Sub-theme 2: Access to quality healthcare and supportive relationships

Another element of resource-based agency (Campbell & Cornish, 2010) that participants report having access to due to their HVT participation relates to the quality healthcare, and the accompanying supportive relationships with knowledgeable others, that they access through their participation in the activities of Research Centre X. This represents the third key health promoting resource that participants identify as an enabler to their participation. Free quality medical care at HVT clinics has been cited as a material benefit that promotes HVT participation other studies on WTP (Asiki et al., 2013; Newman et al., 2006). In the quote below, the participants in my research report that they value the quality of healthcare and screening that they receive at Research Centre X:

And the other thing is, it's very important to to to to make people aware of the benefits of coming here in terms of knowing about their health. Because it's not just vaccination and er those blood that are drawn and taken to to the UCT laboratories or whatsoever. They, they people there in those Labs they check a lot of things they don't only check your, your status you understand? So people should be make, even the doctors they say each and everyone should go for check up.

(FGD 2, Community members, Female)

Well I'm just have to add on to what you have now said that I mean the site's benefits is now actually the most, first one is the whole screening of one and er you don't get er injected with anything unless you you have going through the screening which you don't easily get from any other clinics. If you go to Day Hospital⁸, ...you gonna be checked what you have came for and not be thoroughly screened and that's the very first benefit that you gain from the site.

(Focus Group 2, Community members, Female)

Because I find that to my advantage. Firstly I get a doctor free, I don't pay and then I like er yeah, and then also if ever I've got a problem no matter I've got a diarrhoea or vomiting, I phone. Like a, I've got like a medical aid similar but for free. So, it's a advantage.

(FGD 4, Community members, Male)

⁸Community health centre where Primary Health Care services are available.

The same participant expands on the healthcare benefits that he derives through his participation in the activities of Research Centre X:

...Like firstly like, the, the what you can get cause I chose this place than going to the clinic. Firstly in the clinic I have to woke up early in the morning, roundabout past 4. Right? And then wait until 8 o'clock the gate has been opened and then there's a long line. Right? So I arrive at my place around about 3, whereas I wake up at 4. But, here I wake up maybe sometimes maybe about 8 and then here, I [Inaudible] and then five minutes or, ok, and then even I don't take a taxi. I just walk right, and then for a few minutes right. I've got my own thing. Sorted. So I chose this place I'm going to the clinic.

(FGD 4, Community member, Male)

The quotes provided above highlight participants' belief that the healthcare treatment and screening that they receive at Research Centre X is easily accessible and of superior standard to that offered at the community clinics in the area. They highlight the fact that screening at Research Centre X is thorough, moving beyond simple testing for HIV. A lack of resources characterises the healthcare experience of community members who live in impoverished communities in South Africa. It is not surprising, therefore, that these features of the healthcare provided at Research Centre X are reported as a benefit associated with participation in a context where overcrowding, long waiting times and short, cursory consultations characterise the overburdened governmental healthcare system in South Africa.

Consistent with findings from other studies examining WTP (Asiki et al., 2013; Voytek et al., 2011), my research participants also report that, at Research Centre X, access to information and healthcare is provided in the context of what they perceive to be supportive relationships with the staff members who they engage with. Their perceptions of these supportive relationships are outlined in the quotes below:

I have learnt a lot of things here. They've ere r er, they've got a good approach. They've got respect. All those views that you look for for other person and therefore you are unable to say anything that you want. Because they are free. Because this space there is open for anybody maybe she needs help or he needs help you see and therefore they, where were you from those years. Why you came

here to know about your status. They didn't ask those question. They just focus where am I supposed to go from here to go on. I think is the best they told me.

(FGD 4, Community member, Male)

For instance, I've got someone. He's going to assist me. And therefore here, what you said earlier on, this place commercial (?) and therefore I do believe that thing. And therefore there's a lot of people that can speak to. Even to the counsellor, the doctor, you are free to ask anything that you'd like to know. And therefore those people, they know their job.

(FGD 4, Community member, Male)

The quotes highlight the fact that in the context of the relationships described, they believe that they have access to valued expert HIV/AIDS knowledge in a setting where they are respected, and are allowed to ask questions in an open and non-judgmental environment. The supportive relationships described, therefore, contrast with the prevailing atmosphere of stigma, fear and avoidance of HIV/AIDS in their environment, and represent a safe social space (Campbell et al., 2007) in which they can engage in dialogue about HIV/AIDS with experts at Research Centre X, gathering information to maintain their HIV-negative status. These supportive relationships with staff at Research Centre X also serve as form of bridging social capital (Campbell et al., 2007; Campbell & Cornish, 2010, 2011). From the perspective of community members who participated in my research, it provides them with access to networks and relationships of support with staff members at Research Centre X, who are external to the community, and who facilitate their access to resources that assist them in achieving their goal, i.e., remaining HIV-free in an environment in which HIV-infection presents a threat to the health and well-being of community members.

As outlined above, in my research, participants report that HVT participation provides them with access to health promoting resources that promote their active engagement with their health. They report that HVT participation makes them feel empowered to adopt health protective behaviours as it mediates their access to quality healthcare and supportive relationships with healthcare staff. In the participant narrative, therefore, HVT participation

fulfils a health promotion agenda. This competes with the researcher narrative in which community members serve the role of subjects in the process of scientific experimentation. These competing narratives highlight the complexities associated with HVT participation in resource-poor settings. In such settings, judgements about the opportunities that HVT participation affords for participants to access resources that facilitate their empowerment rest with community members who make decisions about HVT participation with consideration of the ways in which their local social context undermines their health and well-being. In these settings, as expressed by my research participants, HVT participation offers community members access to resources that they can use to address health threats, empowering them to become active agents in matters of their health and well-being.

6.3.2. Theme 2: Representing the community in HIV vaccine research is challenging.

“You are not a scientist, you are not a researcher, therefore you need to represent the community. You are the mouth”.

(FGD CAB members, Male)

A CAB represents the interests of the community in the research process. CABs are expected to act as gatekeepers to the community, performing the crucial function of relaying and translating information between researchers and community stakeholders (HANC, 2014; UNAIDS-AVAC, 2011). In the discussion presented of the relational context, CAB members described their role in the community engagement process at Research Centre X as a political one. As described in Chapter 5, the CAB members who participated in my focus group discussion represented various community organisations and constituents that provide healthcare and support services to community members. All CAB members reported histories of political involvement and activism in the fight against Apartheid, and articulated their involvement in the activities of Research Centre X as a political one, representing the interests of the community, and ensuring that the community is not exploited and harmed in

the context of the research process. They emphasize key features of their role in the research process, including: linking the research to the community, representing community interests in the research and protecting the community from having their rights violated. In this theme, CAB members describe how the material context of community engagement in HIV vaccine research impacts their ability to execute their role in the research process.

In contrast to research participants, who report that participation in the research and activities of Research Centre X affords them access to material benefits, CAB members' reports of the material context represents an extension of their frustration with their role in the community engagement process at Research Centre X in the relational context. They report that they feel hampered by the material context in which they play the community representation role. In this role, they report that lack of access to material resources that they perceive to be crucial to performing their advocacy and community protection role inhibits their ability function effectively. The quotes below illustrate:

Participant: Yes and like I said we're restricted because of resources.

Interviewer: Ja, ja.

Participant: You know to have public meeting wherever and talk to the community and stuff like that. So that is one of the challenges that we face. You know we don't have the resources to do what we really feel like being done out there.

(FGD CAB members, Male)

In the extract below, CAB members expresses their frustration with the lack of financial and structural resources at the disposal of the CAB to support their operations and activities:

Participant: So that they know exactly what we are planning there are resources that's needed you know and sometimes we've got to scale down our plan.

Interviewer: Yes.

Participant: Because of there is not enough resources.

Participant: Lastly our frustration I told my treasury, you'll see we mentioned is of the, of the budget. We playing without any budget. You don't see the budget.

Interviewer: Yes.

Participant: That we have a CAB that's frustrating us. We are good in terms of putting things in black and white just a protocol because our Comrade has said because there is a challenge we count in terms of the resources we are not more pulling the weight all of us because of the resources that we don't have. Had that been in (inaudible1.01.48) where we were advocating to have this side...

Interviewer: Ja.

Participant: We're been told that the CAB will have an office but today we don't have a office.

(FGD CAB members, Male)

They also report that lacking access to their own bank account as a CAB separate from the rest of the research centre, inhibits their ability to build bridging social capital by accessing support from organisations that hold economic and political power (Campbell & Cornish, 2010, 2011):

Participant: I was given a mandate. I don't care really but I went to a director of community building in the City of Cape Town trying to hook that particular person for our event that is coming. She bought in everything, you know what she ask what's your account...

Interviewer: Your account? Your bank account?

Participant: Yes. Ja the community advisory board their structure, do you have an account. I said no. You know she said now how am I going to give money, I can't give X Foundation because it's a big foundation, it's rich such things. I'm glad that he touched that thing, I don't want to touch over money, I don't want to handle monies but this thing is of a higher person who asked me what's your account number, I will be the part, I'll be talking because I am the community director in your community there and I'll be pumping something so that refreshments and everything can be done in that particular day. I said I'm going back to my CAB again.

(FGD CAB members, Female)

Finally, a member of the CAB reports feeling that they lack the research competency and literacy to assess the documentation that they are provided with by the researchers to

explain HIV vaccine science in a way that is accessible to community members. The quotes below highlight:

And another issue is that science does not invest on cover (inaudible1.00.09) the CAB and then come up with documents where, because my main issue is that this documents all of them including the SOP and the, at the end of the day it is for each one of us to clean our conscience to say it was a fair process, I mean being a South African I've seen that in with the consultation processes of this country. So when that document comes to us we must be able to read it and when we say yes, when I sign this contract form that you've given me I must make sure that I understand exactly what does this mean to me. So I don't think there is much effort that is spent on by science to ensure that we understand. So for us at least we must read it because sometimes you are nice to the, because you want the (inaudible1.00.58) to go on but at the same time we are not sure if we are really standing now for what we must stand for really in terms of our communities (inaudible).

(FGD CAB members, Female)

Reddy et al. (2010) points out that CAB members are recruited by and depend on HVT sites for access to resources that they require in order to execute their role in the research process. The material context of community engagement for CAB members at Research Centre X is one in which these resources have not been provided. The material context that they operate in, therefore, is one characterised by a lack of access to resource- and experience-based agency (Campbell & Cornish, 2010; 2011). The absence of resources includes funds to conduct their community events, office space at the research centre, a bank account and sufficient knowledge about HIV vaccine science. The absence of these resources creates a material context that, according to CAB members, inhibits their ability to execute their community representation and linking role effectively. As a consequence, they feel that the integrity of their function within Research Centre X is compromised, leaving them feeling disempowered both by the lack of mastery and skills that they are able to develop within the Research Centre to execute their role effectively, and also by the limited roles that are afforded to them in the community engagement process.

6.3.3. Summary: The material context of community engagement in HIV vaccine research

The findings on material context of community engagement highlight contradictory perceptions of the community engagement process as promoting the empowerment of those who participate in the research and community engagement activities being conducted at Research Centre X. From the perspective of community members who participate in the research, participation is perceived as empowering as it provides them with access to three health promoting resources that assist them in adopting health protective behavioural practices and remaining HIV-negative. They also report that access to bridging social capital (Campbell & Cornish, 2010, 2011) in the form of supportive relationships with staff at Research Centre X in which they are able to ask questions and access information about how to maintain their HIV-negative status. For research participants, therefore, participation in the research being conducted at Research Centre X provides them with access to resource- and experience-based agency and bridging social capital (Campbell & Cornish, 2010, 2011) and facilitates their feelings of empowerment and promotes their active engagement with their health and HIV-status.

The data on the symbolic context highlighted the fact that, due to the lack of opportunities to access information about HIV/AIDS and the fear and avoidance of HIV/AIDS in the community setting, people in the community use the surveillance of the bodies and movements of others as an HIV prevention strategy. In the material context participants' reports that "*knowledge is powerful*", echo notions about the importance of information and "*spreading the word*" in promoting participation in HIV vaccine research articulated by community outreach workers. In the case of community members, however, it appears that knowledge forms the foundation of action and engaging in health-protective behavioural practices, e.g., testing for HIV and practising safe sex. This finding is important

as, in the context of HIV prevention, it has been argued that providing individuals with knowledge as the platform for behaviour change is likely to have limited chances of success (Coates et al., 2008). However, in this context, participants implicate increased knowledge about HIV/AIDS as the foundation for adopting health-protective behavioural practices. This finding may suggest that, while the local community environment does not permit open engagement with HIV/AIDS and inhibits access to information and discussion about the disease, Research Centre X, creates a supportive context in which individuals can access information and implement HIV-protective practices. Thus, in the provision of HIV-education and information and other HIV-prevention strategies that form part of the research process, Research Centre X creates a transformative social context that supports and motivates individuals to practice health promoting behaviours and engage in personal health surveillance in between visits to the research Centre.

CAB members, by contrast, report that the material context of community engagement at Research Centre X in which they operate stymies their efforts to act as representatives of the community, and creates feelings of disempowerment. They report that they lack access to resource-based agency in the form of financial and structural resources. Access to resources also serves as markers of symbolic recognition and esteem (Campbell & Cornish, 2010, 2011), the absence of which may impact their levels of confidence and competency. In addition, their expressed lack of adequate research competency also creates dilemmas for CAB members and impacts their ability to provide authentic, meaningful and impartial input into study documentation and perform their role in disseminating HIV vaccine information to community members who they represent. This dilemma that CABs face is explained by Reddy et al. (2010) as a function of their dependence on HVT sites, inhibiting their ability to form independent opinions on study-related aspects. While CAB members have been afforded a central, crucial linking role, role in the community engagement process,

they lack access to the resource- and experience-based agency that facilitates empowerment (Campbell & Cornish, 2010, 2011). This, they report, impacts their feelings of competence and integrity in executing their role within the process.

In contrast to findings in the symbolic and relational contexts of community engagement at Research Centre X that document the factors that inhibit meaningful community engagement in HIV vaccine research in this setting, the findings on the material context form basis upon which community engagement in HIV vaccine research at Research Centre X may be transformed into health enabling environments. The material context, as constructed in the accounts of community members who participate in the research being conducted at Research Centre X, provides direct, immediate benefits to these individuals, allowing them to access health promoting resources and bridging social capital that facilitate their empowerment and equip them to address threats to their health and well-being. From the perspectives provided in reports on the material context, therefore, HIV vaccine research at Research Centre X is a social good for this group of research participants that uses trial-related resources to create a health enabling context (Campbell, 2003), that leaves them better off by virtue of their involvement in the process. This process of empowerment and the supportive context that has been created may serve as the foundation for expanding the role of those who participate in the research in the community engagement process, and involving them as co-owners and active participants in the process (Green & Mercer, 2001). Such an expansion will permit the integration of the agendas of the HIV vaccine research enterprise, i.e., developing a safe and efficacious HIV vaccine; with the agenda of the local community, i.e., access to resources that build their capacity and facilitate their empowerment, enabling them to address threats to their health and well-being.

Chapter 7: Concluding comments

7.1. Introduction

My research focussed on the local community level of community engagement (Slevin et al., 2008) in HIV vaccine research and examined the process of community engagement in HIV vaccine research at Research Centre X from the perspective of those stakeholders involved in the process. In Chapter 3, I discussed what I consider to be success in the HIV vaccine enterprise. In my view, successful HIV vaccine research integrates the goals of HIV vaccine science with those of the local communities that host the research. Integrating the goals of these respective parties, involves investing as much in developing the ‘social’, as is invested into the process of scientific experimentation. An integration approach uses the HIV-prevention and the other resources that accompany HIV vaccine research to create clinical trial contexts that generate mutual benefit for all stakeholders involved in the process. The analysis of my data was guided by a community mobilisation approach. I interpreted the perspectives of stakeholders in the community engagement process at Research Centre X using Campbell & Cornish’s (2010, 2011) framework that incorporates the symbolic, relational and material contexts that support or undermine community mobilisation.

In this concluding chapter I comment on a few key aspects of my research. Firstly, I sketch a few aspects of my conceptualisation of successful HIV vaccine research that I outlined in Chapter 3 to frame my conclusions on the current practice of community engagement at Research Centre X. Secondly, I comment on my research findings and the conclusions that using a community mobilisation approach to examining community engagement at Research Centre X has generated. I reflect on how using the community mobilisation approach may act as a starting point for viewing HIV vaccine research in resource-poor contexts as health enabling environments that offer immediate, direct benefits to local community members who participate in the research. I also outline key recommendations for creating a health enabling

context for community engagement in HIV vaccine research at Research Centre X in the symbolic, relational and material contexts. Finally, I outline the limitations and strengths of my research on community engagement in HIV vaccine research at Research Centre X.

7.2. Reframing Success in the HIV vaccine Research Enterprise

As I have highlighted throughout this thesis, the participation of local communities is believed to be crucial to developing a safe and efficacious HIV vaccine (Wakefield, 2005). Implementing HIV vaccine research in community settings is political, personal and deeply embedded in the local social and historical contexts in which HVTs are conducted (Nowotny et al., 2001). HIV vaccine research occupies a position at the intersection between the complex global and local relationships between science, society and the social context of the HIV/AIDS pandemic. The relationship between scientists and local community members who host such research is plagued by histories of mistrust, abuses of power, and violations of the ethical and human rights of vulnerable, marginalised populations (MacQueen, 2011; Newman et al., 2015). In addition, the features of local communities in which HIV vaccine research is conducted includes high levels of HIV/AIDS-related stigma and lack of access to resources, which fuel the spread of the virus and complicate efforts to involve communities in the research process. The findings of my research highlight the fact that, while efforts to engage the local community in the scientific process are complex and challenging, they are also experienced as empowering by those who participate in the research. Participants report that they experience their participation in HIV vaccine research as empowering and beneficial in equipping them to address threats to their health and well-being. This finding is promising and highlights the potential for integrating the agendas of the global HIV vaccine enterprise with those of the local communities who host the research.

The community engagement process is an integral component of successful HIV vaccine development. It focusses on developing community-researcher partnerships to support HVT

implementation and promoting the participation of the local community in the research process (Emanuel et al., 2004; UNAIDS-AVAC, 2011). In Chapter 3 I suggested that successful HIV vaccine research integrates ethical, operational and community capacity-building goals and uses the community engagement process to transform HIV vaccine research into a health-enabling context (Campbell, 2003). Transforming HIV vaccine research in resource-poor environments into health-enabling contexts starts with a commitment by those who design, implement and fund such research to move beyond the best practice guidelines and the focus on the ethical, scientific and operational vaccine development, to a position that incorporates community capacity-building as an integral part of HIV vaccine research. A health-enabling HIV vaccine research context position the research as a social good and incorporates three key components to promote the empowerment of local community members. Firstly, it generates mutual and immediate benefit for the local communities who host the research. Secondly, it provides local community members who participate in the research process with access to power and health promoting resources that enable them to address threats to their health and well-being in the resource-poor environments that they reside in (Campbell & Murray, 2004; Campbell & Cornish, 2010). Thirdly, it builds community-researcher partnerships (UNAIDS-AVAC, 2011) that offer local community members an active role in the research process and moves their participation beyond the level of tokens or subjects of research.

7.3. Creating a Health-enabling Community Context for HIV Vaccine Research at

Research Centre X: Key Findings and Recommendations

In this section I comment on my research findings and the extent to which the three key components of facilitating local community members' empowerment via their participation highlighted above are reflected in my interpretation of the symbolic, relational and material contexts of community engagement of HIV vaccine research at Research Centre X. I also

provide recommendations for transforming the symbolic, relational and material contexts of HIV vaccine research in this setting.

7.3.1. On the symbolic context of community engagement in HIV vaccine research at Research Centre X

The findings on the symbolic context of community engagement at Research Centre X highlight a community dialogue about HIV/AIDS and anything associated with it that inhibits willingness to be involved in HIV vaccine research at Research Centre X. The inhibiting factors reported by the research participants in my study mirror those found in other studies examining the correlates of WTP (e.g., Dhalla & Poole, 2011; Lesch et al., 2006; Nyblade et al., 2011) and include fear, avoidance, judgement and rejection of HIV/AIDS and anything associated with it. These features of the community dialogue about HIV/AIDS inhibit the potential for transforming the symbolic context of HIV vaccine research at Research Centre X into a health-enabling context. It also inhibits local community members' access to the three key components that may promote their empowerment via their participation in the research process.

Participating in the HIV vaccine research and community engagement activities at Research Centre X carries risks for those who participate. Local community members risk being stigmatised and discriminated against due to being mistakenly presumed to be HIV positive by association with Research Centre X. The community surveillance system that serves as an HIV prevention strategy by which community members' bodies and movements within the community are scrutinised for signs of HIV infection, contributes to this risk, and the stigma, discrimination and rejection that may accompany participation in the research. Local community members, therefore, must overcome these barriers in order to openly participate in the HIV vaccine research and community engagement activities at Research Centre X. The narrative of harm about Research Centre X that labels it as a place where people

are injected with HIV and are ‘*coming to fetch AIDS*’ also inhibits the transformation of the symbolic context of HIV vaccine research. The narrative of harm directly impedes attempts to position the research being conducted as social good from which local community members may derive benefits and through which they may access resources. The features of the symbolic context of community engagement in HIV vaccine research at Research Centre X, therefore, represent the most significant barrier to transforming the research into a health-enabling context and generating a supportive context for community participation in the research and community engagement processes that take place in the local community.

7.3.1.1. Recommendations for transforming the symbolic context of community engagement at Research Centre X

Initiating dialogue about HIV/AIDS at the community level is integral to addressing the HIV/AIDS stigma and discrimination in the study community where participants report that HIV is salient but not discussed. The findings highlight the fact that in the research context, where HIV/AIDS is cloaked in secrecy, fear and avoidance and accompanied by surveillance, rejection and judgement, community members lack access to safe social spaces in which to discuss the disease and their fears about it. Creating safe social spaces (Campbell et al., 2007; Esma’el et al., 2015) in which the local community can have open community conversations about HIV/AIDS is crucial to transforming the current community dialogue and atmosphere about HIV/AIDS in this setting. In the research setting, creating safe social spaces for open community conversations about HIV/AIDS may also assist with reducing the stigma that inhibits engagement with HIV/AIDS and anything associated with it, as has been shown in other settings (Esma’el et al., 2015). Without it, attempts to transform the research being conducted at Research Centre X into a health-enabling environment based on community-researcher partnerships and active participation that mediates community members’ access to the HIV prevention resources embedded in the research, is unlikely to succeed.

Creating safe social spaces for community conversation and dialogue about HIV/AIDS and the research being conducted at Research Centre X is, therefore, the foundation upon which the research being conducted may be transformed into a health-enabling context. In these safe social spaces, community members can share their HIV/AIDS knowledge, challenge different perspectives on HIV/AIDS and research and collectively construct their understanding of HIV/AIDS and the HIV vaccine research in their community. They can also explore how they may participate in the research in ways that are meaningful within their own personal contexts. Engaging community members in discussions about HIV/AIDS would rest on overcoming their fears and avoidance of HIV/AIDS.

There are two potential strategies that may be used to initiate community dialogue about HIV/AIDS. Firstly, local community members who participated in my research suggested that initially, information should be provided in what community members may perceive as a non-threatening environment. Providing information about HIV/AIDS may be integrated into community health events that deal with less stigmatised and less threatening illnesses, e.g., screening for diabetes and hypertension, TB, and providing information on adopting health-promoting behaviours that address the threat of these illnesses. Secondly, building on this strategy, community outreach workers who participated in my research reported the importance of taking the message about HIV/AIDS, HIV vaccines and the research into any setting where community members congregate, e.g., taxi ranks, clinics. They also reported how they utilise lay community members as a relational resource to access members of their social networks, conducting HIV vaccine education and awareness-raising sessions in these community members' homes. The opportunities created for dialogue through this strategy may also be used to create safe social spaces for dialoguing about HIV/AIDS in micro-settings in the community, i.e., community members' homes. Given the current climate and dialogue about HIV/AIDS in the community, starting the dialogue in micro-settings may be a usual starting point,

destigmatising discussion of HIV/AIDS and acting as a conduit for moving such conversations into larger settings in the community. This may include Research Centre X, which current research participants describe as a safe and supportive space in which they access health promoting resources and the input of experts.

7.3.2. On the relational context of community engagement in HIV vaccine research at Research Centre X

Given the purpose of my research, that sought to examine the current process of community engagement at Research Centre X, the findings that my research generated on the relational context are unique. In the relational context, my findings provide insight into the understanding and practice of, and the networks of social relationships that support the community engagement process. These findings are new in the available social science research on HIV vaccines, where examinations of community engagement have tended to mirror the focus of research on the correlates of WTP, i.e., focussing on identifying the factors that impact community participation and stakeholder engagement (e.g., Frew et al., 2011; Newman et al., 2015).

The success of HIV vaccine research rests on the networks of relationships between the stakeholders involved (MacQueen, 2011). Findings in the relational context highlight the fact that, when clinical trials move out of laboratories and are transplanted into community settings, they become an integral part of the local community and the networks of social relationships in the HIV vaccine research setting. These relationships serve as the foundation for the development of the third key component of successful HIV vaccine research, namely, community-researcher partnerships. Community-researcher partnerships that promote active participation and meaningful community engagement of community members in the research are instrumental in developing community capacity in HIV vaccine research contexts.

There are key features of the relational context of community engagement that act as barriers to the task of transforming HIV vaccine research at Research Centre X into a health enabling environment that require interrogation. Community outreach workers report that, in their daily practice, they face the ongoing challenge of navigating the tension between community engagement and trial implementation goals. Pursuing trial implementation goals and pressures to meet recruitment targets are imposed on them by clinical trial researchers and funders. Navigating these tensions impact their community engagement practices on two levels. Firstly, it impacts how they operate to build a relational network through which they can recruit community members to fulfil the recruitment targets set by funders. They develop three relational resources to assist them in fulfilling recruitment targets: partnerships with lay community members, community organisations and the CAB. These partnerships serve as a source of bonding social capital and within-community solidarity (Campbell et al., 2007; Saegert et al., 2001) on which community outreach workers draw to achieve their recruitment goals. The roles that they offer their partners in the community engagement process, denies their partners an active role in the process and limits their access to the social capital available through the partnership. The within-community solidarity or bonding social capital (Campbell et al., 2007; Saegert et al., 2001), therefore, exists simply as a resource for community outreach workers and does not promote the empowerment of community members and CAB members. In this scenario, the research is not mutually beneficial and solely serves the HIV vaccine research agenda. This is deeply problematic given the context in which the research is conducted.

Secondly, given their limited access to agency and power in executing their community engagement role, community outreach workers engage in a very narrow set of activities that centre around '*spreading the word*'. This narrow set of awareness-raising and educational activities that focus on recruitment has come to represent the community engagement process

at Research Centre X. In their descriptions of their community engagement activities, community outreach workers draw on the language and terminology of the best practice guidelines, referring to the activities that they engage in to promote community participation in the research as building partnerships, liaising and collaborating with stakeholders and promoting dialogue about the research in communities (e.g., HANC, 2014; Slevin et al., 2008; UNAIDS-AVAC, 2011). The application of this language to a community engagement process that focusses on education, awareness-raising and recruitment is contradictory and may not be appropriate in this context given the focus of the community engagement process and the current consultation roles and levels of participation offered to lay community members and CABs in the research. It ignores the contextual complexities that impact community engagement and the extent to which the goals of best practices are achievable, and/or relevant within the social constraints of local clinical trials contexts.

7.3.2.1. Recommendations for transforming the relational context of community engagement at Research Centre X

There are four areas that require intervention to facilitate the task of transforming the relational context of community engagement in HIV vaccine research at Research Centre X into a health enabling context. Firstly, given the tensions that community outreach workers navigate and their frustrations with the challenges that they encounter in executing their role, the development of a fourth relational resource in the form of supportive relationships to address their experience that: *It always ends up being top down because our top is in the States. We're not at the top of the food chain here.* Such relationships will connect community outreach workers on both global and local levels of the research that impact their daily practices and the challenges that they face. Supportive relationships with community outreach workers will create a space for open and ongoing dialogue between community outreach workers and those who set recruitment targets that draw on their input as experts with socio-cultural competence

(UNAIDS-AVAC, 2011) about the local community. Community outreach workers' input, rather than clinical research operational timelines should, therefore, frame recruitment targets and timelines to bring these into closer alignment with the realities of recruitment in the local community context. Targets and timelines, rather than being imposed from the outside, can be developed in collaboration with those who implement the research in the local community context, with closer attention to the barriers to recruitment that they encounter.

Secondly, given the narrow set of activities and the strong recruitment focus that has come to represent the community engagement process at Research Centre X, the notion of community engagement must be refocussed to its core function, i.e., building sustained, collaborative partnerships with multiple levels of stakeholders who may participate in, be affected by or influence the conduct of the research in the local community context (Frew et al., 2008; HPTN, n.d.; UNAIDS, 2007; UNAIDS-AVAC, 2011). Refocussing the process will generate the various components suggested for promoting meaningful community engagement in the research, and gaining community support for the research. For example, relieved from the pressures of meeting recruitment targets, community outreach workers could engage in rigorous formative research in the local community context to inform their community engagement strategy. Formative research will initiate an ongoing dialogue with community members that allows community outreach workers to access the myths, misconceptions and stories about HIV/AIDS, HIV vaccine research and Research Centre X, that act as barriers to participation in this context. It will illuminate the social networks within the community and how they operate as the basis on which outreach workers may expand their community engagement activities into multiple layers of the community, including hard-to-reach groups. It will also create a platform for creating community-researcher partnerships that allow local community members and CABs to provide input into the implementation of the research, and articulate their preferences, needs and goals. While not directly focussing on the meeting

recruitment objective, such community engagement activities promote recruitment by creating a supportive local community context for the research participation.

A third strategy, related to the refocussing of the community engagement strategy, relates to ongoing training and development to build community outreach workers' capacity. In my research community outreach workers indicated that they often engaged in ad hoc strategies to recruit community members into the research, e.g., using existing participants' social networks and using any setting in the community as an opportunity for "*spreading the word*" about Research Centre X. Ongoing training and development facilitate the development of community outreach workers' skills to access the dynamics of the local social contexts, the personal, family, community and broader social contexts that may impact decisions about participation in HIV vaccine research. Such training will also focus on introducing community outreach workers to a range of strategies and techniques for promoting community involvement in the research, e.g., initiating community dialogue about HIV/AIDS in safe social spaces (Campbell et al., 2007), creating interactive learning spaces that facilitate deep learning (Marton & Saljo (1984) of HIV/AIDS, HIV vaccine, research knowledge and promote the development of participatory competence (Radebe, 2012). Expanding on the range of strategies currently being utilised expands opportunities for providing community members' access to resource- and experience-based agency (Campbell & Cornish, 2010, 2011), and empowering them through their participation in the research.

Finally, given the rigid methodologies that govern randomised controlled clinical trials, it is unlikely that community members will participate fully in all stages of the HIV vaccine development process. In addition, there are power inequalities between the various levels of stakeholders involved in the HIV vaccine research process at the global and local levels that challenge the notion of equal partnership. The focus for development of this area is, therefore, providing community members with more meaningful roles in the process that moves their

level of participation further up the ladder of participation (SAAVI, n.d.). Given the nature of clinical research, that is researcher initiated, local communities will not move to the upper level of the ladder of participation. Their involvement can, however, be moved to the level where they share decision-making with researchers about key aspects of the process and implementation of research in the community. They can, e.g., provide input into how to tailor the research to the local community so that it promotes participation in the research. While not making communities co-owners (Green & Mercer, 2001) of the process, this does make them co-producers (Callon, 1999) of meaningful local knowledge. In addition, models of peer education, mentorship, and opinion leader models may be used to provide community members more active roles in the research, empowering them through giving them the opportunity to build experience-based agency (Campbell & Cornish, 2010, 2011) as they ‘*lead the way into the community*’.

7.3.3. On the material context of community engagement in HIV vaccine research at Research Centre X

Mutually beneficial community-researcher partnerships and access to resources that promote health and well-being are crucial components of health enabling HIV vaccine research in resource-poor contexts. As highlighted above, HIV vaccine research is a form of combination HIV prevention and brings resources into communities that host the research. These resources include: HIV/AIDS education and awareness-raising, confidential VCT services, health screening procedures, sexual risk monitoring and financial incentives (Lesch et al., 2006, Newman et al., 2006; Voytek et al., 2011). Participation in HIV vaccine research mediates community members’ access to the resources that accompany HIV vaccine research. Through participation, the needs, goals and agendas of the local community may be integrated into the research process.

Alongside the challenges associated with promoting community engagement in HIV vaccine research highlighted in the symbolic and relational contexts, the strongest evidence of the potential of HIV vaccine research to be transformed into a health-enabling context (Campbell, 2003) comes from the results generated in the material context of community engagement at Research Centre X. In contexts where HIV/AIDS is salient and levels of access to resources are low, HIV vaccine research brings a range of valuable resources into the communities that host the research (Lesch et al., 2006). These resources shape the material context of community engagement in HIV vaccine research. Participants in my research report that they derive benefits, in the form of access to HIV/AIDS education and health promoting information, quality screening and healthcare and supportive relationships with expert staff members, from their participation in the research. These resources represent resource- and experience-based agency that facilitate participants' feelings of empowerment to deal with the threat of HIV/AIDS in their community (Campbell & Cornish, 2010, 2011). Through their access to the trial-related resources, participants report that they feel empowered to actively engage with their health and adopt health protective behavioural practices. Participants also report that their participation allows them to access bridging social capital (Campbell & Cornish, 2010, 2011) through the supportive relationships that they have access to with expert staff at Research Centre X. These relationships represent an important resource and stand in stark contrast to their interactions with healthcare staff in the overburdened public healthcare system. Both these aspects generate mutual benefit for the HIV vaccine enterprise and the community members who participate in the research.

In contrast to community members who participate in the research, CAB members involved in the activities at Research Centre X report that they lack access to the resource- and experience-based agency that facilitates empowerment (Campbell & Cornish, 2010, 2011). They report that they lack access to resources, power and control over their role in liaising with

the community, linking the community to the research centre and providing authentic input into research-related activities. This has an impact on their feelings of competence and in their confidence in executing their role within the process. The material context of community engagement, therefore, leaves CAB members feeling frustrated and disempowered.

7.3.3.1. Recommendations for transforming the material context of community engagement at Research Centre X

Access to HIV/AIDS education and information at Research Centre X is highlighted as a key resource that promotes the development of resource- and experience-based agency (Campbell & Cornish, 2010, 2011) amongst research participants. This information is provided in the context of the narrow set of practices that community outreach workers engage in to encourage community members to participate in the research being conducted at Research Centre X. Information is provided in various community settings, and in HIV vaccine discussion groups held at Research Centre X. The strategy of “*spreading the word*” is believed to be instrumental to increasing the numbers of community members willing to participate in the research, as emphasised by all stakeholders who participated in my research. This perspective, that focusses on information as the key facilitator to participation is problematic. It highlights the simplistic assumption that information is the key success factor to increasing community participation in the HIV vaccine research being conducted at Research Centre X. Participants articulated this assumption through their beliefs that “*pour us some more and more and more information*” and “*education to open people’s minds and eyes*” is the key to dealing with HIV/AIDS stigma, fears and avoidance and myths and misconceptions about HIV/AIDS in the community. This emphasis on lack of knowledge is reminiscent of the “first generation approaches” to HIV prevention outlined by Campbell & Cornish (2010, p. 1571) that focus on raising awareness as the foundation of behaviour change and use the chalk and talk, didactic approaches conjured by expressions such as “*pour us some more and more and more information*”. Articulating the

challenge in this manner is limiting and fails to consider the dynamics of social contexts that impact people's views about HIV/AIDS, scientific research, and their participation in it. It also perpetuates static notions of community members as subjects in the research process and vessels for information to be transmitted to, rather than co-creators of their own understanding and use of information. Building community capacity and empowering community members is not solely a function of information provision, it also involves providing people with supportive environments in which to process and discuss the information and work out how and if it will be useful to them. The notion that lack of information is the key barrier to participation, as well as strategies and methods that use passive, didactic methods of information transfer to educate communities about HIV/AIDS and HIV vaccine research require transformation and innovation.

A first step in the process involves incorporating and assessment of the levels of knowledge about HIV/AIDS, HIV vaccines and scientific research that community members have into the formative research process. This includes identifying myths and misconceptions about HIV/AIDS, HIV vaccines, HIV vaccine research and Research Centre X. The vignette and narrative methods for assessing understanding of key HIV vaccine research concepts developed by Lindegger et al. (2006) may be useful in this regard. Secondly, community outreach workers must transform their approach to information provision. This involves both the content and language used, as well as the method of delivery. Using transformational, dialogical and interactive approaches to engaging with lay community members in group settings will facilitate this process.

The CAB can partner with community outreach workers and play an instrumental role in transforming the way in which information about HIV/AIDS, HIV vaccines and scientific research is shared with community members. Involving them in this aspect of the process may act as one way of alleviating CAB members' feelings of disempowerment in the process. CAB

members and lay community members can also partner with community outreach workers in the process of creating community dialogue about HIV/AIDS and the research being conducted at Research Centre X, generating mutual benefit for all involved in the process as they serve as a supportive network and resource to each other. Through this, supportive network bonding and bridging social capital (Campbell & Cornish, 2010) may be built that serves as a source of support to all stakeholders involved in the process. In addition, lay community members who participate in the research at Research Centre X have reported feeling a psychological sense of control and agency that equips them to stay HIV-free. Involving them in the process of community dialogue about HIV/AIDS, further develops community-researcher partnerships and offers them an active role in the process, expanding their levels of resource- and experience-based agency (Campbell & Cornish, 2010, 2011). Evidence-based strategies that have been used in community-based health interventions and HIV prevention interventions, such as peer education, mentor and opinion leader models can be evaluated to assess which strategy offers the best-fit in this context.

Finally, the feelings of disempowerment experience by the CAB members require attention. At present the relationship between the CAB, Research Centre X and the community outreach workers is perceived as one-directional. Linking the CAB with the Principal Investigators and funders at the research centre to voice their concerns and collectively generate solutions is an important first step. While it may simply fulfil a symbolic function, it will ensure that CAB members feel that they are being heard, and ensure that those who hold power in the research process have clear information about CAB members' expectations. Such conversations may also include developing strategies and timelines that allow the CAB to fulfil on their community consultation function. Providing additional training to CAB members that develop their participatory competence (Radebe, 2012) in executing their role is also important in this regard. Finally, CAB members reported that they lack access to financial resources to

host community engagement activities. This suggests that clarification of the role of the CAB in the research process is required. Providing CAB members with more active roles in the community engagement process, whereby they work closely with community outreach workers in the execution of their activities, may address their desire to be involved in community engagement activities, rather than being limited to providing input into research-related documents and clinical trial implementation aspects.

7.4. Limitations and Strengths of the Research

In the section below I highlight the key limitations and strengths of my research.

My research focussed on the community engagement activities being conducted at one research centre and presents the perspectives of stakeholder parties involved in community engagement activities that are tied to the local community context. This may limit the applicability of my research findings to other settings. However, aspects of my findings may have relevance to other research centres who share characteristics with my “typical case” selection of Research Centre X.

My research and its findings are also limited by the conceptualisation of community used. By adopting the conceptualisation of community utilised by Research Centre X, i.e., the high HIV-risk, geographical location in which the research is located, I achieved my goal of examining the current practice of community engagement in the research setting by gathering the perspectives of a sample of ‘typical’ HIV vaccine research local community stakeholders. These research participants display agency in terms of knowing where to access resources in an environment in which resources are limited. In my research, they served as the proxy for the broader community, sharing community perspectives and beliefs about HIV/AIDS, whilst simultaneously distinguishing themselves from others in their community. However, this conceptualisation limited the perspectives on community engagement that I accessed.

Stakeholder based conceptualisations of community promoted by MacQueen et al. (2001) and UNAIDS-AVAC (2011) allow for conceptualisations of community as multi-dimensional. Such definitions consider the fact that communities may not be pre-existing and homogeneous entities as implied by, e.g., geographical and risk sub-group definitions, but may take shape in response to specific issues of common concern and interest (Lavery et al., 2010). Stakeholder based definitions may be incorporated into the current conceptualisation of community in the research context to add nuance and access broader perspectives on the HIV/AIDS, the research and the community engagement process. Applying such definitions may also permit researchers and community outreach workers to access broader levels of community than they are currently accessing. Due to pressures to meet recruitment targets, community outreach workers take an ad hoc approach to targeting community members for their participation in the research process. The result is that the perspectives of multiple layers of the local community remain absent from the research.

Due to challenges associated with recruiting community members to participate in HIV/AIDS-related research in the research setting, I opted to use the existing recruitment system at Research Centre X. I was assisted by two staff members at Research Centre X who extended invitations to research participants to volunteer for my research. In taking on this role, these staff members may have unwittingly invited volunteers who they believed would present a favourable view of the research being conducted at Research Centre X.

In documenting the current practice of community engagement in HIV vaccine research at Research Centre X, I accessed the descriptions of the process through interviewing community outreach workers and CAB members. I only have access to their reports of community engagement practice and have no way of verifying the extent to which their descriptions match actual practices. Ethnographic observations of community engagement

activities may have served to illuminate the extent to which descriptions and rhetoric match practice.

My research design, data collection and interpretation represents one possible way of interpreting the data. There is much about the dynamics of community engagement in HIV vaccine research at Research Centre X that remains unexplored in data that I collected that may be illuminated through future analysis using different data collection and analytic techniques and theoretical lenses. My research points to a need to explicitly connect the global to the local level of community engagement in HIV vaccine research, to further explore the relational networks and power relationships that regulate the interactions between stakeholders in this context and to formulate new questions to address the issues that plague HIV vaccine research in local community contexts. Such questions will move beyond a focus on description to in-depth evaluations of the dynamics of HIV vaccine research as a complex social process.

As mentioned in Chapter 3, in executing my research I chose the position of conducting critical research that amplifies, reveals and makes sense of the community engagement process at Research Centre X. A key strength of my research lies in the contribution that it makes to the social science literature on HIV vaccine research. Within this body of literature, community engagement is framed as a key clinical trial process that facilitates successful trial implementation. My research is, to my knowledge, the first study that examines the local context of community engagement, documenting the activities, roles, responsibilities, and relationships between stakeholders in an HIV vaccine research setting in the South African context. In addition, my research departs from the accepted practice of community engagement guidelines as the foundation for community engagement activities, and highlights the limits of such guidelines to examining dynamics of the local context in which HIV vaccine research is conducted. It positions HIV vaccine research as a social process, and questions the current ways in which local communities, who are considered to be crucial to HIV vaccine

development, are involved in the research process. It also reflects on how such research may become mutually beneficial and provide immediate benefits to community members in the resource-poor communities that host the research.

My research is also unique in that it is the first HIV vaccine research study to depart from community engagement frameworks, adopting a community mobilisation framework to respond to questions about how the research may become a social good that leaves communities better off as a function of their participation in the research process (Swartz & Kagee, 2006). In this regard, it provides a nuanced and systematic impression of the community engagement process at Research Centre X, the social context in which it is implemented and those who participate in it. In acknowledging that the goals of the HIV vaccine enterprise and local communities are not mutually exclusive, my research reframes the definition of success adopted by the HIV vaccine research enterprise, i.e., the development of a safe and efficacious HIV vaccine. It highlights how the project of integrating the goals of the HIV vaccine enterprise and local communities may be achieved by transforming HIV vaccine research into a health-enabling context (Campbell, 2003).

There are limits to my application of the community mobilisation approach to the HIV vaccine research context. For example, collective action and active participation are key components of community mobilisation approaches (Campbell & Murray, 2004). Due to the rigid clinical trial methodologies that are the architecture of HVTs, it is unlikely that either of these components will become part of the community engagement process that supports HIV vaccine research. While local communities may not contribute to the scientific agenda of the research, they can contribute to the social process that such research is transformed into when it enters community contexts. Through their involvement and participation in the social process of HVTs they can access trial-related resources that accrue immediate, short-term benefits to them and others in their community. This is crucial in HIV vaccine research contexts

where HIV risk is high, and access to resources is low. The far-off benefit of a safe and efficacious HIV vaccine offers cold comfort to local communities in such environments. Adopting a community mobilisation approach to community engagement in HIV vaccine research, moves community engagement beyond “*spreading the word*” towards a more meaningful process that is mutually beneficial, promotes access to health-promoting resources and facilitates the empowerment of local community members. In such community engagement processes, local community members become partners and (more) active participants in the process, rather than remaining bodies in and subjects of scientific experimentation.

References

- Allen, M. & Lau, C-Y. (2008). Social impact of preventive HIV vaccine clinical trial participation: A model of prevention, assessment and intervention. *Social Science & Medicine*, 66, 945-951.
- Arevshatian, L., Clements, C. J., Lwanga, S. K., Misore, A. O., Ndumbe, P., Seward, J. F., & Taylor, P. (2007). An evaluation of infant immunization in Africa: Is a transformation in progress? *Bulletin World Health Org.*, 85, 421-500.
- Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners*, 35, 216-224.
- Asiki, G., Abaasa, A., Ruzagira, E., Kibengo, F., Bahemuka, U, Mulondu, J. ... Kamali, A. (2013). Willingness to participate in HIV vaccine efficacy trials among high risk men and women from fishing communities along Lake Victoria in Uganda. *Vaccine*, 31, 5055-5061.
- Aungst, J., Haas, A., Ommaya, A., & Green, L.W. (Eds.). (2003). *Exploring challenges, progress and new models for engaging the public in the clinical research enterprise*. Washington, DC: The National Academies Press.
- AVAC (AIDS Vaccine Advocacy Coalition). (2009). *Report: Piecing together the HIV prevention puzzle: AVAC report assesses progress in AIDS vaccine, microbicide and PrEP research and calls for urgent coordination and leadership in advance of upcoming results* [Press release]. Retrieved from <http://www.avac.org/press-release/piecing-together-hiv-prevention-puzzle-avac-report-assesses-progress-aids-vaccine>

- AVAC. (AIDS Vaccine Advocacy Coalition). (2013). *AVAC report: Research and reality*. Retrieved from http://www.avac.org/sites/default/files/resource-files/AVAC%20Report%202013_0.pdf
- Babbie, E. & Mouton, J. (2010). *The practice of social research*. Cape Town: Oxford University Press.
- Bartholow, B. N., Buchbinder, S., Celum, C., Goli, V., Koblin, B., Para, M... Mastro, T. D. (2005). HIV sexual risk behavior over 36 months of follow-up in the world's first HIV vaccine efficacy trial. *Journal of Acquired Immune Deficiency Syndromes*, 39, 90–101.
- Baylies, C. (2004). Cultural hazards facing young people in the era of HIV/AIDS: Specificity and change. In N.K. Poku, & A. Whiteside (Eds.), *The political economy of AIDS in Africa* (pp. 71-84). London, UK: Ashgate.
- Bernstein, A. (2008). AIDS and the next 25 years. *Science*, 320, 717.
- Blankenship, K. M., Biradavolu, M. R., Jena, A., & George, A. (2010). Challenging the stigmatization of female sex workers through a community-led structural intervention: Learning from a case study of a female sex worker intervention in Andhra Pradesh, India. *AIDS Care*, 22, 1629-1636.
- Bogart, L. M., Kalichman, S. C., & Simbayi, L. C. (2008). Endorsement of genocidal HIV conspiracy as a barrier to HIV testing in South Africa. *Journal of Acquired Immune Deficiency Syndromes*, 49, 115-116.
- Bourdieu, P. (1986). The forms of capital. In J. Richardson (Ed.), *Handbook of theory and research for the Sociology of Education* (pp. 241-258). New York, NY: Greenwood Press.

- Brandt, A. M. (1978). Racism and research: The case of the Tuskegee Syphilis study. *The Hastings Centre Report*, 8, 21-29.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research*, 3, 77-101.
- Braun, V. & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London, UK: Sage.
- Buchbinder, S. P., Metch, B., Holt, S. E., Scheer, S., Coletti, A., & Vittinghoff, E. (2004). Determinants of enrollment in a preventive HIV vaccine trial: Hypothetical versus actual willingness and barriers to participation. *Journal of Acquired Immune Deficiency Syndromes*, 36, 604-612.
- Callon, M. (1999). The role of lay people in the production and dissemination of scientific knowledge. *Science, Technology & Society*, 4, 81-94.
- Campbell, C. (2000). Social capital and health: Contextualising health promotion within local community networks. In S. Baron, J. Field, & T. Schuller (Eds.). *Social capital: Critical perspectives*. Oxford, UK: Oxford University Press.
- Campbell, C. (2003). *Letting them die: Why HIV/AIDS prevention programmes fail* (African issues, 1st ed.). Bloomington, Indiana: Indiana University Press.
- Campbell, C. (2014). Community mobilisation in the 21st century: Updating our theory of social change. *Journal of Health Psychology*, 19, 46-59.
- Campbell, C., & Cornish, F. (2010). Towards a “fourth generation” of approaches to HIV/AIDS management: Creating contexts for effective community mobilisation. *AIDS Care*, 22, 1569-1579.

- Campbell, C., & Cornish, F. (2011). How can community health programmes build enabling environments for transformative communication? Experiences from India and South Africa. *AIDS & Behaviour, 16*, 847-857.
- Campbell, C., & Cornish, F. (2014). Reimagining community health psychology: Maps, journeys and new terrains. *Journal of Health Psychology, 19*, 3-15.
- Campbell, C., & Murray, M. (2004). Community health psychology: Promoting analysis and action for social change. *Journal of Health Psychology, 9*, 187-195.
- Campbell, C., Nair, Y., & Maimane, S. (2007). Building contexts that support effective community responses to HIV/AIDS: A South African case study. *American Journal of Community Psychology, 39*, 347-363.
- Campbell, C., Nhamo, M., Scott, K., Madanhire, C., Nyamukapa, C., Skovdal, M., & Gregson, S. (2013). The role of community conversations in facilitating local HIV competence: case study from rural Zimbabwe. *BMC Public Health, 13*, 354-369.
- Carpiano, R. M. (2006). Toward a neighbourhood resource-based theory of social capital for health: Can Bourdieu and sociology help? *Social Science & Medicine, 62*, 165-175.
- Cassidy, R. (2010). Global expectations and local practices: HIV support groups in the Gambia. *AIDS Care, 22*, 1598-1605.
- Coates, T. J., Richter, L., & Caceres, C. (2008). Behavioural strategies to reduce HIV transmission: How to make them work better. *Lancet, 372*, 669-684.
- Collins, H. (2005). Vaccine development: From concept to licenced product. In P. Kahn (ed.). *AIDS vaccine handbook: Global perspectives*, (pp. 37-43). New York, NY: AIDS Vaccine Advocacy Coalition.

- Cornwall, A. (2008). Unpacking 'participation' models, meanings and practices. *Communitary Development Journal*, 43, 269-283.
- Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing*, 26, 623-630.
- Day, T. A. & Kublin, J. G. (2014). Lessons learned from HIV vaccine clinical efficacy trials. *Current HIV Research*, 11, 441-449.
- Deacon, H. & Stephney, I. (2007). *HIV/AIDS stigma and children. A literature review*. Cape Town, South Africa: HSRC Press. Retrieved from http://ovcsupport.net/wp-content/uploads/Documents/HIVAIDS_stigma_and_children_A_literature_review_1.pdf.
- Dhalla, S. & Poole, G. (2011). Barriers of enrolment in HIV vaccine trials: A review of HIV vaccine preparedness studies. *Vaccine*, 29, 5850-5859.
- Emanuel, E. J., Wendler, D., Killen, J., & Grady, C. (2004). What makes clinical research in developing countries ethical? The benchmarks of ethical research. *Journal of International Diseases*, 189, 930-937.
- Eriksson, E., Lindmark, G., Axemo, P., Haddad, B., & Ahlberg, B. M. (2013). Faith, premarital sex and relationships: Are church messages in accordance with the perceived realities of the youth? A qualitative study in KwaZulu-Natal, South Africa. *Journal of Religion and Health*, 52, 454-466.
- Esma'el, J. K., Dolamo, B. L., Bekele, T., & Kaso, M. (2015). Community conversation experiences regarding HIV/AIDS awareness and beyond awareness in rural community of Ethiopia: A qualitative study. *Family Medicine and Medical Science Research*, 4, 168.

- Ezekiel, M. J., Talle, A., Juma, J. M., & Klepp, K-I. (2009). "When in the body, it makes you look fat and HIV negative": The constitution of antiretroviral therapy in local discourse among youth in Kahe, Tanzania. *Social Science & Medicine*, 68, 957-964.
- Family Health International. (n.d.) *Rapid ethnographic guide intro*. Retrieved from <http://www.FHI.org/en/HIVAIDS/pub/guide/RapidAssessmentGuide/rag5.htm>
- Farmer, P. (1992). *AIDS and accusation: Haiti and the geography of blame*. Berkeley, CA: University of California Press.
- Forbes, A., Sylla, L., & Yassky R. (2008). *The first 55 steps: A report of the microbicide development strategy's civil society working group*. Washington, DC: Global Campaign for Microbicides.
- Freimuth, V., Cole, G., & Kirby, S.D. (2001). *Issues in evaluating mass-media health communication campaigns*. Geneva, Switzerland: WHO.
- Frew, P. M., Archibald, M., Hixson, B., & del Rio, C. (2011). Socioecological influences on community involvement in HIV vaccine research. *Vaccine*, 29, 6136-6143.
- Frew, P. M., del Rio, C., Clifton, S., Archibald, M., Hormes, J. T., & Mulligan, M. J. (2008). Factors influencing HIV vaccine community engagement in the urban south. *Journal of Community Health*, 33, 259-269.
- Friedman, S. R., Lieb, S., Tempalski, B., Cooper, H., Keem, M., Friedman, R.,... Flom, P. L. (2005). HIV among injection drug users in large US metropolitan areas, 1998. *Journal of Urban Health*, 82, 434-445.
- Fuchs, J. D., Durham, M., Mclellan-Lemal, E., Vittinghoff, E., Colfax, G., Gurwith., M., & Buchbinder, S. (2007). Negative social impacts among volunteers in an HIV vaccine efficacy trial. *Journal of Acquired Immune Deficiency Syndromes*, 46, 362-368.

- Fuchs, J. D., Sobieszczyk, M. E., Hammer, S. H., & Buchbinder, S. P. (2010). Lessons drawn from recent HIV vaccine efficacy trials. *Journal of Acquired Immune Deficiency Syndromes*, *55*, 128-131.
- Gilbert, L. & Walker, L. (2010). 'My biggest fear was that people would reject me once they knew my status...': Stigma as experienced by patients in an HIV/AIDS clinic in Johannesburg, South Africa. *Health & Social Care in the Community*, *18*, 139-146.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. New York, NY: Simon and Schuster.
- Gray, G. E., Metch, B., Churchyard, G., Mlisana, K., Nchabeleng, M., Allen, M., ... Bekker, L-G. (2013). Does participation in an HIV vaccine efficacy trial affect risk behaviour in South Africa? *Vaccine*, *31*, 2089-2096.
- Green, L. W. & Mercer, S. L. (2001). Can public health researchers and agencies reconcile the push from funding bodies with the pull from communities? *American Journal of Public Health*, *91*, 1926-1929.
- Gueye, M., Diouf, D., Chaava, T., & Tiomkin, D. (2005). *Community capacity enhancement strategy note*. New York: HIV/AIDS Group, Bureau for Development Policy, United Nations Development Programme.
- Gupta, G. R., Parkhurst, J. O., Ogden, J. A., Aggleton, P., & Mahal, A. (2008). Structural approaches to HIV prevention. *Lancet*, *372*, 764-775.
- Gwandure, C. & Mayekiso, T. (2012). Reservations on the use of the new HIV prevention technologies in HIV prevention in Sub-Saharan Africa. *Journal of Human Ecology*, *37*, 3, 173-184.

- Harrison, A., O'Sullivan, L. F., Hoffman, S., Dolezal, C., & Morrell, R. (2006). Gender role and relationship norms among young adults in South Africa: Measuring the context of masculinity and HIV risk. *Journal of Urban Health*, *83*, 709-722.
- Highleyman, L. (2005). A guide to clinical trials. Part 1: Understanding clinical trials. *BETA*, *17*, 42-49.
- HIV Prevention Trials Network [HPTN]. (n.d). *About the HPTN* [Web page]. Retrieved from <http://www.hptn.org/AboutHPTN.htm>.
- HIV/AIDS Network Coordination [HANC]. (2014). *Recommendations for community engagement in HIV/AIDS research*. Retrieved from <https://www.hanc.info/cp/resources/Documents/Recommendations%202014%20FINAL%206-5-14%20rc.pdf>.
- Holloway, I. & Bailey, F.C. (2011). Being a qualitative researcher. *Qualitative Health Research*, *21*, 968-975.
- Honey, K. (2007). Microbicide trial screeches to a health. *Journal of Clinical Investigation*, *117*, 1116.
- HVTN (HIV Vaccine Trials Network). (2000). *Ethical considerations in HIV prevention vaccine research* [UNAIDS Guidance document]. Retrieved from http://data.unaids.org/publications/IRC-pub01/JC072-EthicalCons_en.pdf
- IAVI. (International AIDS Vaccine Initiative).(n.d). *AIDS vaccine in perspective: FAQs* [Fact Sheet]. Retrieved from <http://www.iavi.org/publications/file/58-vaxlit-aids-vaccines-in-perspective-fact-sheet>.
- IAVI. (International AIDS Vaccine Initiative). (2009). *The AIDS Vaccine Literacy Core Content* (2nd ed.). Retrieved from <http://www.iavi.org/vaxlit>

- Jaspan, H. B., Berwick, J. R., Myer, L., Mathews, C., Flisher, A. J., Wood, R., & Bekker, L-G. (2006). Adolescent HIV prevalence, sexual risk, and willingness to participate in HIV vaccine trials. *Journal of Adolescent Health, 39*, 642-648.
- Jaspan, H. B., Flisher, A. J., Myer, L., Mathews, C., Middlekoop, K., Mark, D., & Bekker, L-G. (2011). Sexual health, HIV risk, and retention in an adolescent HIV prevention trial preparatory cohort. *Journal of Adolescent Health, 49*, 42-46.
- Kafaar, Z., Kagee, A., Lesch, A., & Swartz, L. (2007). Is participation in HIV vaccine trials a health promoting behaviour? *AIDS Care, 19*, 1307-1309.
- Kagee, A., Remien, R. H., Berkman, A., Hoffman, S., Campos, L., & Swartz, L. (2011). Structural barriers to ART adherence in South Africa: Challenges and potential ways forward. *Global Public Health, 6*, 83-97.
- Kahn, P. (2005). *AIDS vaccine handbook* (2nd ed.). New York, NY: AIDS vaccine advocacy Coalition.
- Kalichman, S. C. (2008). Time to take stock in HIV/ AIDS prevention. *AIDS and Behavior, 12*, 333-334.
- Kalichman, S. C. (2009). *Denying AIDS: Conspiracy theories, pseudoscience, and human tragedy*. New York, NY: Springer/Copernicus Books.
- Kalichman, S. C. (2014). The psychology of AIDS denialism: Pseudoscience, conspiracy thinking, and medical mistrust. *European Psychologist, 19*, 13-22.
- Kerns, T.A. (1997). *Ethical issues in HIV vaccine trials*. Basingstoke, England: Macmillan.
- Kim, J., Ferrari, G., Abramsky, T., Watts, C., Hargreaves, G., Morison, L.,...Pronyk, P. (2009). Assessing the incremental effects of combining economic and health

- interventions: The IMAGE study in South Africa. *Bulletin of the World Health Organization*, 87, 824-832.
- Kirby, D., Laris, B. A., & Roller, L. A. (2007). Sex and HIV Education Programs: Their Impact on Sexual Behaviors of Young People throughout the World. *Journal of Adolescent Health*, 40, 206-17.
- Kitzinger, J. (1995). Qualitative research: Introducing focus groups. *British Medical Journal*, 311, 299-302.
- Kiwanuka, N., Robb, M., Kigozi, G., Birx, D., Philips, J., Wabwire-Mangen, F., ... Gray, R. H. (2004). Knowledge about vaccines and willingness to participate in preventive HIV vaccine trials: A population-based study, Rakai, Uganda. *Journal of Acquired Immune Deficiency Syndromes*, 36, 721-725.
- Kurth, A. E., Celum, C., Baeten, J. M., Vermund, S. H., & Wasserheit, J. N. (2011). Combination HIV prevention: Significance, challenges and opportunities. *Current HIV/AIDS Reports*, 8, 62-72.
- Lally, M., Goldworthy, R., Sarr, M., Kahn, J., Brown, L., Peralta, L., & Zimet, G. (2014). Evaluation of an intervention among adolescents to reduce preventive misconception in HIV vaccine clinical trials. *Journal of Adolescent Health*, 1-6.
- Lau, C-Y., Stansburg, J. P., Gust, D. A., & Kafaar, Z. (2009). Social and behavioral science in HIV vaccine trials: A gap assessment of the literature. *Expert Reviews*, 8, 179-190.
- Lau, C-Y., Swann, E. M., & Singh, S. (2011). Behavioral and social science in HIV vaccine clinical research: Workshop report. *Vaccine*, 29, 2509-2514.

- Lau, C-Y., Swann, E. M., Singh, S., Kafaar, Z., Meissner, H. I., & Stansburg J. P. (2011). Conceptual framework for behavioral and social science in HIV vaccine clinical research. *Vaccine*, *29*, 7794-7800.
- Laverack, G. (2006). Improving health outcomes through community empowerment: A review of the literature. *Journal of Health, Population and Nutrition*, *24*, 113-120.
- Lavery, J. V., Tinadana, P. O., Scott, T. W., Harrington, L. C., Ramsey, J. M., Ytuarte-Nunez, C., & James, A. A. (2010). Towards a framework for community engagement in global health research. *Trends in Parasitology*, *26*, 279-283.
- Leach, M. & Fairhead. J. (2007). *Vaccine anxieties. Global science, child health and society*. London, UK: Earthscan.
- Lengwiler, M. (2008). Participatory approaches in science and technology: Historical origins and current practices in critical perspective. *Science, Technology & Human Values*, *33*, 186-200.
- Lesch, A., Kafaar, Z., & Kagee, A. (2009). Participation in HIV vaccine trials. In P. Rohleder, L. Swartz, S. C. Kalichman, & L. C. Simbayi (Eds.), *HIV/AIDS in South Africa 25 years on* (pp. 337-351). New York, NY: Springer.
- Lesch, A., Kafaar, Z., Kagee, A., & Swartz, L. (2006). Community members' perceptions of enablers and inhibitors to participation in HIV vaccine trials. *South African Journal of Psychology*, *36*, 734-761.
- Lesch, A., Singh, S., Kafaar, Z., Swartz, L., & Menezes, A. (2013). Research agenda to facilitate community participation in HIV vaccine research: A participatory approach. *Journal of Psychology in Africa*, *23*, 375-378.

- Lindegger, G., Milford, C., Slack, C., Quayle, M., Xaba, X., & Vardas, E. (2006). Beyond the checklist: Assessing understanding for HIV vaccine trial participation in South Africa. *Journal of Acquired Immune Deficiency Syndromes*, *43*, 560-566.
- Lippman, S.A., Maman, S., MacPhail, C., Twine, R., Peacock, D., Kahn, K. & Pettifor, A. (2013). Conceptualising community mobilisation for HIV prevention: Implications for HIV prevention programming in the African context. *PLOS One*, *10*. E78208.
- Litosseli, L. (2007). *Using focus groups in research*. London, UK: Continuum.
- Lubek, I., Lee, H., Kros, S., Wong, M. L., Van Merode, T., Liu, J., ... Campbell, C. (2014). HIV/AIDS, beersellers and critical community health psychology in Cambodia: A case study. *Journal of Health Psychology*, *19*, 110-6.
- MacQueen, K. M. (2011). Framing the social in biomedical HIV prevention trials: A 20-year retrospective. *Journal of the International AIDS Society*, *14*, S3.
- MacQueen, K. M., McLellan, E., Metzger, D. S., Kegeles, S., Strauss, R.P., Scotti, R., ... Trotter, R. T. (2001). What is community? An evidence-based definition for Participatory Public Health. *American Journal of Public Health*, *91*, 1929-1938.
- Manhart, L. E., & Holmes, K. K. (2005). Randomized controlled trials of individual-level, population-level, and multilevel intervention for preventing sexually transmitted infections: What has worked? *Journal of Infectious Diseases*, *191*, s7-s24.
- Marková, I., Linell, P., Grossen, M., & Orvig, A.S. (2007). *Dialogue in focus groups: Exploring socially shared knowledge*. London, UK: Equinox.
- Marton, F. and Säljö, R. (1984) 'Approaches to learning' in Marton, F., Hounsell, D. and Entwistle, N. (Eds.). *The Experience of Learning*. Edinburgh: Scottish Academic Press.

- Mason, J. (2006). Mixing methods in a qualitatively driven way. *Qualitative Research*, 6, 9-25.
- McCluskey, M., Alexander, S. B., Larkin, B. D., Murgula, M., & Wakefield, S. (2005). An HIV vaccine: As we build it will they come? *Health Affairs*, 24, 3, 643-652.
- McNeill, F. G. (2009). 'Condoms cause aids': Poison, prevention and denial in venda, South Africa. *African affairs*, 108, 353-370.
- Merson, M. H., O'Malley, J., Serwadda, D., & Apisuk, C. (2008). The history and challenge of HIV prevention. *Lancet*, 372, 475-488.
- Miles, M. B., & Huberman, A. M. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). London, UK: Sage.
- Milford, C., Barsdorf, N., & Kafaar, Z. (2007). What should South African HIV vaccine trials do about social harms? *AIDS Care*, 19, 1110-1117.
- Mills, E., Cooper, C., Guyatt, G., Gilchrist, A., Rachlis, B., Sulway, C., & Wilson, K. (2004). Barriers to participating in an HIV vaccine trial: A systematic review. *AIDS*, 18, 2235-2242.
- Minkler, M. & Wallerstein, N. (Eds.). (2008). *Community based participatory research for health: Process to outcomes* (2nd ed.). San Francisco, CA: Jossey Bass.
- Møller, V., & Erstad, I. (2007) Stigma associated with tuberculosis in a time of HIV/AIDS: Narratives from the Eastern Cape, South Africa. *South African Review of Sociology*, 38, 103-119.
- Morgan, L. M. (2001). Community participation in health: Perpetual allure, persistent challenge. *Health Policy & Planning*, 16, 221-230.

- Morin, S., Maiorana, A., Koester, K. A., Sheon, N., & Richards, T. A. (2003). Community consultation in HIV prevention research: A study of community advisory boards at 6 research sites. *Journal of Acquired Immune Deficiency Syndromes*, *33*, 513-520.
- Murray, M., Nelson, G., Poland, B., Maticka-Tydale, E., & Ferris, L. (2004). Assumptions and values of community health psychology. *Journal of Health Psychology*, *9*, 323-333.
- Naidoo, J., Uys, L., Greeff, M., Holzemer, W., Makoae, L., Dlamini, P., ...Kohi, T. (2007). Urban and rural differences in HIV/AIDS stigma in five African countries. *African Journal of AIDS Research*, *6*, 17–23.
- Nakibinge, S., Maher, D., Katende, J., Kamili, A., Grosskurth, H., & Seeley, J. (2009). Community engagement in health research: Two decades of experience from a research project in HIV in rural Uganda. *Tropical Medicine & International Health*, *14*, 190-195.
- Nattrass, N. (2007). *Mortal combat: AIDS denialism and the struggle for antiretrovirals in South Africa*. Pietermaritzburg, South Africa: University of KwaZulu Natal Press.
- Newman, P. A. (2006). Towards a science of community engagement. *Lancet*, *367*, 302.
- Newman, P. A., Duan, N., Roberts, K. J., Seiden, D., Rudy, E. T., Swendeman, D., & Popova, S. (2006). HIV vaccine trial participation among ethnic minority communities. Barriers, motivators, and implications for recruitment. *Journal of Acquired Immune Deficiency Syndromes*, *41*, 210-217.
- Newman, P. A., Lee, S.-J., Duan, N., Rudy, E., Nakazono, T. K., Boscardin, J., ... Cunningham, W. E. (2009). Preventive HIV vaccine acceptability and behavioral risk

- compensation among a random sample of high-risk adults in Los Angeles (L.A. VOICES). *Health Services Research*, 44, 2167–2179.
- Newman, P. A., Rubincam, C., Slack, C., Essack, Z., Chakrapani, V., Chuang, D-M., ... Lindegger, G. (2015). Towards a science of community stakeholder engagement in biomedical HIV prevention trials: An embedded four-country case study. *PLOS One*.
- Newman, P. A., Yim, S., Daley, A., Walisser, R., Halpenny, R., Cunningham, W., & Loutfy, M. (2011). “Once bitten, twice shy”: Participant perspective in the aftermath of an early HIV vaccine trial termination. *Vaccine*, 10, 451-458.
- Nhomo, M., Campbell, C., & Gregson, S. (2010). Obstacles to local-level AIDS competence in rural Zimbabwe: Putting HIV prevention in context. *AIDS Care*, 22, 1662-1669.
- Nowotny, H., Scott, P., & Gibbons, M. (2001). *Rethinking science: Knowledge and the public in an age of uncertainty*. Malden, M.A.: Blackwell.
- Nyblade, L., Singh, S., Ashburn, K., Brady, L., & Olenja, J. (2011). “Once I begin to participate, people will run away from me”: Understanding stigma as a barrier to HIV vaccine research participation in Kenya. *Vaccine*, 29, 8924-8928.
- Ong, A. & Collier, S. J. (2005). *Global assemblages: Technology, politics and ethics as anthropological problems*. Oxford, UK: Wiley-Blackwell.
- Padian, N. S., McCoy, S. I., Karim S. S. A., Hasen, N., Kim, J., Bartos, M., ... Cohen, M. S. (2011). HIV prevention transformed: The new prevention research agenda. *Lancet*, 378, 269-278.
- Parker, R. G., Easton, D., & Klein, C. H. (2000). Structural barriers and facilitators in HIV prevention: A review of international research. *AIDS*, 14, 22-32.

- Petryna, A. (2006). Globalizing human subjects research. In A. Petryna, A. Lackoff & A. Kleinman (Eds.), *Global pharmaceuticals: Ethics, markets, practices* (pp. 33-60). London, UK: Duke University Press.
- Petryna, A. (2009). *When experiments travel. Clinical trials and the global search for human subjects*. Princeton, New Jersey: Princeton University Press.
- Piot, P., Bartos, M., Larson, H, Zewdie, D., & Mane, P. (2008). Coming to terms with complexity: A call to action for HIV prevention. *Lancet*, 372, 845-859.
- Potts, M., Halperin, D. T., Kirby, D., Swindler, A., Marseille, E., Klausner, J. D., ... Walsh, J. (2008). Reassessing HIV prevention. *Science*, 320, 749-750.
- Pronynk, P. M, Hargreaves, J. R., & Morduch, J. (2007). Microfinance programs for better health: Prospects for Sub-Saharan Africa. *Journal of the American Medical Association*, 298, 16.
- Quinn, S. C. (2004). Ethics in public health research. Protecting human subjects: The role of community advisory board. *American Journal of Public Health*, 94, 918-922.
- Radebe, N.B. (2012). Prevention and empowerment. In M. Visser & A. G. Moleko. (2012). (Eds). *Community Psychology in South Africa*, 2nd ed., 147-159. Pretoria: Van Schaik.
- Ramjee, G. & Daniels, B. (2013). Women and HIV in Sub-Saharan Africa. *AIDS Research and Therapy*, 10, 30.
- Rappaport, J. (1987). Terms of empowerment/exemplars of prevention: Toward a theory for community psychology. *American Journal of Community Psychology*, 15, 121-148
- Reddy, P., Buchanan, D., Sifunda, S., James, S., & Naidoo, N. (2010). The role of community advisory boards in health research: Divergent views in the South African experience. *Journal of Social Aspects of HIV/AIDS*, 7, 2-8.

- Rifkin, S. B. (1996). Paradigms lost: Toward a new understanding of community participation in health programmes. *Acta Tropica*, 61, 79-92.
- Rifkin, S.B. & Pridmore, P. (2001). *Partners in Planning: Information, Participation and Empowerment*. London: MacMillan Education.
- Roberts, E. T. & Matthews, D. D. (2012). HIV and chemoprophylaxis, the importance of considering social structures alongside biomedical and behavioural intervention. *Social Science & Medicine*, 75, 1555-1561.
- Robins, S. L. (2008). *From revolution to rights in South Africa: Social movements, NGOs & popular politics after apartheid*. Pietermaritzburg, South Africa: University of KwaZulu-Natal Press.
- Rosenblatt, A. & Dorsen, C. (2011). Barriers to volunteer enrollment in HIV preventive vaccine clinical research trials: A review of the literature. *Journal of the Association of Nurses in AIDS Care*, 22, 330-334.
- Rubincam, C. (2014). *Alternative explanations about HIV and AIDS: Re-examining distrust among young adults in Cape Town, South Africa* [CSSR Working Paper No. 342.]. Cape Town, South Africa: Centre for Social Science Research, University of Cape Town. Retrieved from <http://cssr.uct.ac.za/pub/wp/342/>
- Ruzagira, E., Wandiembe, S., Bufumbo, L., Levin, J., Price, M. A., Grosskurth, H., & Kamali, A. (2009). Willingness to participate in preventive HIV vaccine trials in a community-based cohort in south western Uganda. *Tropical Medicine and International Health*, 14, 196-203.
- SAAVI. (South African AIDS Vaccine Initiative). (n.d.). *Community involvement and participation?* [Fact Sheet]. Retrieved from <http://www.saavi.org.za/factcom.pdf>

- Sadler, G. R., Lee, H-C., Lim, R. S-H., & Fullerton, J. (2010). Recruiting hard-to-reach United States population subgroup via adaptations of snowball sampling strategy. *Nursing and Health Sciences*, *12*, 369-374.
- Saegert, S., Thompson, P., & Warren, M. R. (Eds.). (2001). *Social capital and poor communities*. New York, NY: Russell Sage Foundation.
- Saethre, E., & Stadler J. (2013). Malicious Whites, greedy women, and virtuous volunteers: Negotiating social relations through clinical trial narratives in South Africa. *Medical Anthropology Quarterly*, *27*, 103-120.
- Sahay, S., Mehendale, S., Sane, S., Brahme, R., Brown, A., Charron, K., ... Paranjape, R. (2005). Correlates of HIV vaccine trial participation: An Indian perspective. *Vaccine*, *23*, 1351-1358.
- Sayles, J., MacPhail, C., Newman, P. A., & Cunningham, W. E. (2009). Future HIV vaccine acceptability among young adults in South Africa. *Health Education & Behavior*, *27*, 193-210.
- Shelton, J. D. (2007). Ten myths and one truth about generalized HIV epidemics. *Lancet*, *370*, 1809-1811.
- Shisana, O., Rehle, T., Simbayim L. C., Zuma, K., Jooste, S., Zungu, N., ... Onoya, D. (2014) *South African National HIV Prevalence, Incidence and Behaviour Survey, 2012*. Cape Town, South Africa: HSRC Press.
- Simbayi, L. C., Kalichman, S. C., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A. (2007). Internalized AIDS stigma, AIDS discrimination, and depression among men and women living with HIV/AIDS, Cape Town, South Africa. *Social Science & Medicine*, *64*, 1823-1831.

- Skhosana, N., Struthers, H., Gray, G. & McIntyre, J. 2006. HIV disclosure and other factors that impact on adherence to antiretroviral therapy: The case of Soweto, South Africa. *African Journal of AIDS Research*, 5, 17-26.
- Skloot, R. (2011). *The immortal life of Henrietta Lacks*. London, United Kingdom: Pan Books.
- Skovdal, M., Campbell, C., Madanhire, C., Mupambireyi, Z., Nyamukapa, C., & Gregson, S., (2011). Masculinity as a barrier to men's use of HIV services in Zimbabwe. *Globalization and Health*, 7.
- Slevin, K. W., Ukpong, M., & Heise, L. (2008). *Community engagement in HIV prevention trials: Evolution of the field and opportunities for growth* (Working Paper no. 11). Retrieved from <http://www.path.org/publications/detail.php?i=1647>
- Smit, J., Middelkoop, K., Myer, L., Lindegger, G., Swartz, L., Seedat, S., ... Stein, D. (2005). Social-behaviour challenges to phase III HIV vaccine trials in Sub-Saharan Africa. *African Health Sciences*, 5, 198-206.
- South African AIDS Vaccine Initiative [SAAVI]. (n.d.). *HIV vaccine research and development* [Face Sheet]. Retrieved from <http://www.saavi.org.za/resources.htm>
- South Africa. National Department of Health. (2012). *The National antenatal sentinel HIV and syphilis prevalence survey, South Africa, 2011*. Pretoria, South Africa: NDOH.
- Stadler, J. (2003). Rumor, gossip and blame: Implications for HIV/ AIDS prevention in the South African Lowveld. *AIDS Education & Prevention*, 15, 357-368.
- Statistics South Africa [StatsSA]. (2013). *South African Statistics, 2013*. Pretoria: Statistics South Africa.

- Stein, C. H. & Mankowski, E. S. (2004). Asking, witnessing, interpreting, knowing: conducting qualitative research in community psychology. *American Journal of Community Psychology*, 33, 21-35.
- Strauss, A. L. & Corbin, J. M. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. London: Sage.
- Swartz, L. & Kagee, A. (2006). Community participation in AIDS vaccine trials: Empowerment or science? *Social Science & Medicine*, 63, 1143-1146.
- Tindana, P. O., Singh, J. A., Tracy, C. S., Upshur, R. E. G., Daar, A. S., Singer, P. A., ... Lavery, J. V. (2007). Grand challenges in global health: Community engagement in research in developing countries. *PloS Medicine*, 4, 1451-1455.
- UNAIDS-AVAC [Joint United Nations Program on HIV/AIDS - AIDS Vaccine Advocacy Coalition]. (2011). *Good participatory practice guidelines for biomedical HIV prevention trials* (2nd ed.). Geneva: UNAIDS.
- Upton, M. E. (2011). *The politics of health: Community engagement in South African HIV vaccine clinical trial sites* (Unpublished doctoral dissertation). The Open University: United Kingdom.
- Visser, M., & Moleko, A.G. (2012). (Eds). *Community psychology in South Africa* (2nd ed). Pretoria: Van Schaik.
- Voytek, C. D., Jones, K. T., & Metzger, D. S. (2011). Selectively willing and conditionally able: HIV vaccine trial participation among women at “high risk” of HIV infection. *Vaccine*, 29, 6130-6135.

- Wakefield, S. (2005). Community advisory boards. In P. Kahn. (Ed.), *AIDS vaccine handbook: Global perspectives* (pp. 117-122). New York, NY: AIDS Vaccine Advocacy Coalition.
- Wallerstein, N. (1992). Powerlessness, empowerment, and health: Implications for health promotion programs. *American Journal of Health Promotion*, 6, 197-205.
- Warren, M. (2005). An epidemic that rages on. In P. Kahn. (Ed.). *AIDS Vaccine Handbook*. New York: AIDS Vaccine Advocacy Coalition.
- Williamson, D. L., Choi, J., Charchuk, M., Rempel, G. R., Pitre, N., Breitkreuz, R., & Kushner, K. E. (2011). Interpreter-facilitated cross-language interviews: A research note. *Qualitative Research*, 11, 381.
- Willig, C. (2008). *Introducing qualitative research in psychology* (2nd ed.). Berkshire, England: McGraw Hill.
- Wills, C., & Tyeku, V. (2000). Community participation is essential in clinical trials. *British Medical Journal*, 321, 833.
- Yen, J. (2007). A history of community psychology in South Africa. In N. Duncan, B. Bowman, A. Naidoo, J. Pillay & V. Roos. (Eds). *Community Psychology: Analysis, context and action*, 51-65. Cape Town: UCT Press.
- Yin, R.K. (2009). *Case study research: Design and methods* (4th ed.) Thousand Oaks, CA: Sage.

APPENDIX 1: Focus Group Discussion Schedule

(Participant sample: community members who have attended HIV vaccine education activities conducted at the trial site).

The focus group discussions covered three areas.

1. What kinds of HIV vaccine education activities have you participated in at the trial site?
2. What are some of the beliefs in your community about HIV/AIDS, HIV treatment, vaccines and research? How do you think this may influence efforts to educate the community about HIV vaccines?
3. How do people in your community get information about HIV vaccines?

Probe for:

- Who can they talk to?
- Where can they go to get information about HIV vaccines?
- How do people share information that they get about HIV vaccines with each other?

APPENDIX 2: English Informed Consent Form

INFORMED CONSENT – FOCUS GROUP DISCUSSION

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Building scientific literacy: A case study of community participation in HIV vaccine research

REFERENCE NUMBER: N10/11/366

PRINCIPAL INVESTIGATOR: Ms Anthea Lesch

ADDRESS: Department of Psychology, Stellenbosch University, Matieland 7602

CONTACT NUMBER: (021) 8083456

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The study will be conducted at the HIV vaccine trial site of which you are a community member, HIV vaccine trial site researcher, HIV vaccine educator, HIV vaccine recruiter or community advisory board member in the Western Cape, South Africa. Approximately 110 participants will be recruited to participate in this study.

The aim of this study is to find out about the HIV vaccine education activities that have been taking place at your trial site and to learn more about how community members participate in the HIV vaccine education activities that have been held at your trial site. The information collected from the study will be used to develop a model for teaching members of your community about research and HIV vaccines. The researcher will work with community members, HIV vaccine researchers, HIV vaccine educators and recruiters and community advisory board members at your trial site to develop this model.

Data for the study will be collected using interviews, focus groups, observations, questionnaires and trial site documents.

Why have you been invited to participate?

You have been invited to participate in this study because you have attended HIV vaccine education workshops or other education events conducted at the HIV vaccine trial site.

What will your responsibilities be?

You will be asked to participate in a focus group discussion which will be conducted by the researcher and an interpreter. You will be asked questions regarding the community education activities that you participated in at the HIV vaccine trial site. The focus group discussion will last approximately 90 minutes.

Will you benefit from taking part in this research?

There are no personal benefits associated with your participation in this research. The data collected from this study will be used to collaborate with stakeholders at your trial site to design a community-based education model to promote understanding of research and HIV vaccines in the trial site community.

Are there in risks involved in your taking part in this research?

There are no risks associated with your participation in this research study.

Who will have access to your personal information?

All information collected as part of this study will be treated as confidential and protected. If information is used in a publication or research thesis, your identity will remain anonymous.

All documentation containing identifying information and other confidential documentation collected will be stored in locked cabinets and only the researcher will access these records.

The focus groups will be tape-recorded. The recordings will be stored in locked cabinets and only the researcher will have access to the recordings. The recordings will remain in locked storage at the completion of the study.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study but your transport and meal costs will be covered for your study visit. There will be no costs involved for you, if you do take part.

Is there anything else that you should know or do?

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled Building scientific literacy: A case study of community participation in HIV vaccine research.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2011.

Signature of participant

Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (*place*) on (*date*) 2011.

Signature of investigator

Signature of witness

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*) using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

Signature of interpreter

Signature of witness

APPENDIX 3: Xhosa Informed Consent Form

INCWADANA ENGOLWAZI NGOMTHATHI-NXAXHEBA KUNYE NEFOMU
YEMVUMELWANO

ISIHLOKO SEPROJEKTHI YOPHANDO: Building scientific literacy: A case study of
community participation in HIV vaccine research

INOMBOLO YONXULUMANO: N10/11/366

UMPHANDI OYINTLOKO: Ms Anthea Lesch

IDILESI: Department of Psychology, Stellenbosch University, Matieland 7602

INOMBOLO YOQHAKAMSHELWANO: (021) 808 3456

Uyamenywa ukuba uthathe inxaxheba kule projekthi. Nceda uthathe ixesha lakho ekufundeni
iinkcukacha nolwazi oluqulethwe kolu xwebhu, noluphathele nesi sifundo sophando.

Ukhululekile ukuba ubuze nayo nayiphi na imibuzo malunga naliphi na icandelo lesi sifundo
sophando, okanye ubuze nayiphi na into ethe yangakucaceli ngesi sifundo sophando.

Kubalulekile ukuba woneliseke ukuba uziqonda ngokupheleleyo zonke iinkcukacha
eziphathelene nesi sifundo sophando, kwanendima ozakuthi uyidlale kuso. Ngaphezu koko,
ukuthabatha kwakho inxaxheba kwesi sifundo sophando ukwenza **ngokukhululekileyo, yaye
unganyanzeliswanga** (ukwakhululekile ukuba ungavumi ukuthabatha inxaxheba xa uthe
wangathandi). Ukuba awuvumi ukuthabatha inxaxheba, loo nto ayizi kukuchaphazela
nangayiphi na indlela. Ukwakhululekile ukuba urhoxe kwisifundo sophando nangaliphi na
ithuba, nditsho nokuba ubuvumile ukuthabatha inxaxheba.

Esi sifundo sophando siphunyezwe yiKomiti Ejongene Nemigaqo Yezifundo Zophando
kwiYunivesithi yaseStellenbosch, yaye siza kuqhutywa ngokwemigaqo ephathelene

nezophando kwizifundo zophando-zifundo ze-Helsinki, South African Guidelines for Good Clinical Practice kwakunye ne-Medical Research Council (MRC) Ethical Guidelines.

Simalunga nantoni esi sifundo sophando?

Esi sifundo sophando siza kuqhutywa kwicandelo lovavanyo-machiza oluhlola intsholongwane ye-HIV kwingingqi yakho yasekuhlaleni, nalapho ungumphandi wesifundo saloo ndawo, okanye ufundisa ngentsholongwane ye-HIV, okanye usenza izimemelelo zokuhlola ngentsholongwane ye-HIV, okanye ulilungu elikwibhunga elinika ngeengcebiso kwiPhondo laseNtshona Koloni, eMzantsi Afrika. Ngokomlinganiselo, bangama-110 abathabathi-nxaxheba abazakuthi bamenyelelwe ukuthabatha inxaxheba kwesi sifundo sophando.

Injongo yesi sifundo sophando kukufumanisa ngokubanzi malunga nemfundiso ngentsholongwane yamachiza e-HIV, mfundiso leyo esele ilithuba iqhuba kwingingqi leyo omiselwe kuyo, kwanokufunda ngokubanzi ngeendlela abathi abantu basekuhlaleni bathabathe ngayo inxaxheba kwiinkqubo zokufundisa ngentsholongwane ye-HIV ebeziqhutywa kuloo ngingqi yakho yovavanyo-machiza. Ulwazi oluqokelelwe kwesi sifundo sophando luza kusetyenziswa ukuphuhlisa indlela yokufundisa kwanokuxhobisa abantu basekuhlaleni kwingingqi yakho ngokuphathelene nophando lwesifundo kwanamachiza e-HIV. Umphandi uza kusebenza namalungu okanye abantu basekuhlaleni, nabaphandi bamachiza, abafundisa ngamachiza, kwanabo bamemelela abantu ekuvavanyeni amachiza e-HIV, kwakunye namalungu akwibhunga elinika ngeengcebiso kwingingqi leyo yokuvavanya omiselwe kuyo, ngeenjongo zokuphuhlisa le ndlela isetyenziswayo yokufundisa ngentsholongwane ye-HIV.

Lingqokelela zolwazi oluthe lwaphuhliswa nolukwavezwe sesi sifundo sophando, ziza kuqokelelwa ngokuthi kusetyenziswe udliwano-ndlebe (okanye uluhlu lwemibuzo),

neengxoxo ezenziwa ukuxovulula imiba ethile ebuziweyo, nokubeka iliso kukwajongwa abo bathabatha inxaxheba, noluhlu lwemibuzo oluqulethwe kwiphepha-mibuzo, kwanamaxwebhu axela imo yengingqi leyo yovavanyo-machiza.

Ingaba kutheni umenywa ukuba uthabathe inxaxheba kwesi sifundo sophando?

Umenyiwe ukuba uthabathe inxaxheba kwesi sifundo sophando kuba sele ukhe wangomnye wabo bantu bathe bafumana imfundiso yovavanyo lwamachiza e-HIV okanye ezinye iimfundiso ebeziqhutyelwe kuloo ngingqi yovavanyo lwamachiza e-HIV.

Ingaba yintoni omelwe kukuyenza xa uthabatha inxaxheba kwesi sifundo sophando?

Uza kucelwa ukuba uthathe inxaxheba kwingxoxo egqalileyo yeqela eza kuqhutywa ngumphandi netoliki. Uza kubuzwa imibuzo mayela neenkqubo zemfundo zasekuhlaleni okhe wanenxaxheba kuzo kwindawo yolingo lwesitofu se- HIV. Ingxoxo egqalileyo yeqela izakushicilelwa kwaye iza kuthatha malunga nemizuzu engamashumi alithoba (90).

Ingaba uza kuxhamla (okanye wenze inzuzo) ngokuthabatha kwakho inxaxheba kwesi sifundo sophando?

Akukho nzuzo ozakuyifumana ngokuthi uthabathe inxaxheba kwesi sifundo sophando.

Ulwazi oluqokelelwe kwesi sifundo sophando luza kusetyenziswa ukubambisana phakathi kwabo basebenzela loo ngingqi omiselwe kuyo, khon'ukuze kusekwe eyona ndlela eyiyo yokufundisa abantu basekuhlaleni ukuphuhlisa indlela ebhetele yokusiqonda kakuhle isiseko sophando lwesifundo ngamachiza e-HIV kwingingqi leyo yovavanyo yasekuhlaleni.

Ingaba bukhona ubungozi obukhoyo ekuthabatheni inxaxheba kwesi sifundo sophando?

Akukho bungozi bayanyaniswa nokuthabatha kwakho inxaxheba kwesi sifundo sophando.

Ngubani ozakuthi afikelele kwinkcukacha zakho (nothe wazinika ngokuphendula kwakho imibuzo)?

Lonke ulwazi oluqokelelwe kwesi sifundo sophando lulwazi lwabucala, noluza kuthatyathwa njengolungafikelelwa nangubani na, yaye aluzi kuxelwa komnye umtu. Ukuba iziphumo zesi sifundo sophando ziyapapashwa kumaphepha ashicilela iziphumo zophando lwesifundo, ulwazi oluphathelele nawe (kwanegama lakho, nendawo ohlala kuyo) aluzi kwaziswa xa kushicilelwa olo lwazi. Wonke amaxwebhu aqulethe ulwazi olungasingisela lula kuwe, nazo zonke ezinye iinkcukacha zabucala malunga nawe, ziza kutshixelwa kwiindawo zokugcina ulwazi lwabucala, yaye ngumphandi oyintloko kuphela oza kufikelela kolo lwazi.

Ingaba uza kubhatalwa (uhlawulwe) ngokuthabatha kwakho inxaxheba kwesi sifundo sophando? Ingaba kukhona ezinye iilahleko ozakuthi ujongane nazo ngokuthabatha kwakho inxaxheba?

Hayi, awuzi kubhatalwa (awuzi kuhlawulwa) ngokuthabatha kwakho inxaxheba kwesi sifundo sophando, kodwa uza kubuyezwa ngeendleko zokuqabela kwakho imoto, i-taxi okanye uloliwe (kwaneendleko zokufumana into etyiwayo) xa usiya kwindawo yesifundo sophando. Awuzi kuba nazilahleko ngokuthabatha kwakho inxaxheba kwesi sifundo sophando.

Ingaba ikhona enye into ongathanda ukuyazi okanye ukuyenza?

Ungaqhakamshelana necandelo le-Health Research Ethics Committee kwiSebe lwezobuNzulu-lwazi kwezeMpilo, kwiYunivesithi yaseStellenbosch, ngokuthi utsalele le nombolo yomnxeba ethi: 021-938 9207, ukuba unazo naziphi na izinto ongathanda ukuzibuza okanye othe wangaziqondi, okanye mhlawumbi othe wanezikhalazo ezithe azasiwa so (zaze zangahoywa ngendlela eyanelisekayo) ngumphandi.

Khon'ukuze ukwazi ukumana uzijongela (kwanokuzigcinela ngokwakho ulwazi oluphathele nesi sifundo sophando), uza kufumana uxwebhu olukwafana nolu luqulethwe kule mvumelwano uyifundayo kungoku nje.

Isifungo somthathi-nxaxheba

Ngokuytyikitya ngezantsi, Mna ndiyavuma ukuthatha inxaxheba kwisifundo sophando semfuzo esibizwa ngokuba (*faka ishloko sesifundo*).

Ndazisa ukuba:

- Ndilufundile okanye ndalufunda olu lwazi kunye nefomu yemvumelwano kwaye ibhalwe ngolwimi endiliciko nendikhululekileyo kulo
- Bendinalo ithuba lokuba ndibuze imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyakuqonda ukuba ukuthatha inxaxheba kolu phando kube **kukuzithandela kwam** kwaye andikhange ndinyanzelwe ukuba ndithathe inxaxheba.
- Ndingakhetha ukusishiya isifundo naninina kwaye andisayi kohlwaywa okanye uqal' ugwetywe nangayiphi indlela.
- Usenokucelwa ukuba usishiye isifundo phambi kokuba siphele, ukuba ugqirha wesifundo okanye umphandi ukubona kuyinzuzo kuwe, okanye ukuba andisilandeli isicwangciso sesifundo, ekuvunyelenwe ngaso.

Kutyikitywe e-(indawo) ngo-(usuku) 2011.

Umtyikityo womthathi-nxaxheba

Umtyikityo wengqina

Isifungo somphandi

Mna (*igama*) ndiyafunga ukuba:

- Ndilucacisile ulwazi olu kweli xwebhu ku-.....
- Ndimkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndiyaneliseka kukuba uyakuqonda ngokwanelisayo konke okumalunga nophando okuxoxwe ngasentla.
- Ndisebenzise/andisebenzisanga toliki. (Ukuba itoliki isetyenzisiwe kumele ityikitye isaziso ngezantsi.

Kutyikitywe e-(indawo) ngo-(usuku) 2011.

Umtyikityo womphandi

Umtyikityo wengqina

Ugunyaziso lwetoliki

Mna (*igama*) ndigunyazisa ukuba:

- Ndimncedisile umphandi (*igama*)
ekucaciseni
-

- iinkcukacha zalo mqulu ku(igama lalowo uthatha inxaxheba)
-
- Ndisebenzisa ulwimi lwesi-Afrikansi /IsiXhosa njengonxibelelwano .
-
- Simkhuthazile ukuba abuze imibuzo athathe nexesha eloneleyo ekuphenduleni imibuzo.
-
- Ndidlulise inguqulelo eyiyo njengoko bendiyichazelwe.
-
- Ndonelisekile ukuba umthathi-nxaxheba ukuve ngokupheleleyo konke okuqulathwe
-
- loluxwebhu lwephepha-mvume kwaye nemibuzo yakhe yonke iphenduleke
-
- ngokwanelisekayo.
-
-

Ityikitywe e (indawo) ngomhla2011

.....

.....

Utyikityo lwetoliki

Utyikityo lwengqina

APPENDIX 4: Demographic Information**DEMOGRAPHIC INFORMATION**

PARTICIPANT ID

DATE

INTERVIEWER NAME

Interviewer administered: Please complete the following by circling the appropriate answer or filling in the appropriate details:

1	Age (in years):	16-20	21-25	26- 30	31- 35	36- 40	41- 45	46- 50	51- 55	56- 60	
2	Sex:	Male					Female				
3	Level of education:	None		Grade 1-7		Grade 8-11		Matric			
		Tertiary		Honours		Masters		PhD			
		Other (Specify)									
4	Are you employed?	YES / NO									
5	If yes, what is your occupation?										
6	Home Language:										

7	Marital status:	Married	Permanent partner	Single
		Casual relationships	Other (Specify)	

8a	We understand that there is a long process people go through to enrol in trials. Please list the stages of the vaccine trial process that you have been through to date?		
8b	Have you attended a vaccine information/discussion group?	Yes	No
If yes, how many sessions have you attended?			
8c	Have you attended sessions with an individual counsellor?	Yes	No
If yes, how many individual sessions have you attended?			
8d	Have you received any written material on the vaccine trials?	Yes	No
If yes, what material were you given?			

8e	Have you undergone screening for a vaccine trial?	Yes	No
8h	Are you enrolled in an HIV vaccine trial?	Yes	No
8i	If yes, which vaccine trial?		
8j	Have you received any other education material?	Yes	No
8k	If yes, specify what other educational material you have received.		

APPENDIX 5: Key Informant Interview Schedule

OPENING QUESTIONS

What is your role at the HIV vaccine trial site?

How would you describe your role and responsibilities?

What activities do you perform in your role?

AREA 1: Role of the CAB

What is your role in the activities of Research Centre X?

What is your role in your community? Who is the community that you serve?

How did you become a part of the CAB at Research Centre X?

As a CAB member, what do you think your goal is in the activities that you conduct in that capacity?

In your capacity as CAB member, whose interests do you represent? How do you communicate with your constituents and the CE team at the research centre? How often?

What activities do you engage in to achieve the above objectives?

What are some of the local norms, beliefs, views and concerns about HIV, and HIV vaccines that you have encountered in your community? How do you respond to these?

What kinds of issues/information have you assisted the research centre with? (translation of information in that which is digestible to the community)

What training have you received to execute your role? Do you feel that this training is adequate?

What role do you think you could play? Recommendations for expanding the involvement of CAB members in trial site activities.

AREA 2: DISCUSSING COMMUNITY EDUCATION ABOUT HIV VACCINES

Describe the **community education strategy** in place at your trial site.

Probe for:

- Which sectors of the trial site community is it targeted at?
- What is the broad community education strategy of the trial site?
- What are the community education activities currently undertaken at your trial site?
- What materials and didactic techniques, dissemination strategies are used in your community education strategy?

CLOSING QUESTIONS

- How do you understand the relationship between community participation and community education at your trial site and in the execution of your employment role?

Appendix 6: Informed Consent Form for Key Informant Interviews

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Building scientific literacy: A case study of community participation in HIV vaccine research

REFERENCE NUMBER: N10/11/366

PRINCIPAL INVESTIGATOR: Ms Anthea Lesch

ADDRESS: Department of Psychology, Stellenbosch University, Matieland 7602

CONTACT NUMBER: (021) 8083456

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The study will be conducted at the HIV vaccine trial site of which you are a community member, HIV vaccine trial site researcher, HIV vaccine educator, HIV vaccine recruiter or community advisory board member in the Western Cape, South Africa. Approximately 110 participants will be recruited to participate in this study.

The aim of this study is to find out about the HIV vaccine education activities that have been taking place at your trial site and to learn more about how community members participate in the HIV vaccine education activities that have been held at your trial site. The information collected from the study will be used to develop a model for teaching members of your community about research and HIV vaccines. The researcher will work with community members, HIV vaccine researchers, HIV vaccine educators and recruiters and community advisory board members at your trial site to develop this model.

Data for the study will be collected using interviews, focus groups, observations, questionnaires and trial site documents.

Why have you been invited to participate?

You have been invited to participate in this study because you are a community advisory board member at the HIV vaccine trial site.

What will your responsibilities be?

You will be asked to participate in a focus group discussion which will be conducted by the researcher. You will be asked questions related to your involvement in community participation and community education activities at the HIV vaccine trial site. The interview will last approximately 90 minutes.

Will you benefit from taking part in this research?

There are no personal benefits associated with your participation in this research. The data collected from this study will be used to collaborate with stakeholders at your trial site to design a community-based education model to promote understanding of research and HIV vaccines in the trial site community.

Are there in risks involved in your taking part in this research?

There are no risks associated with your participation in this research study.

Who will have access to your personal information?

All information collected as part of this study will be treated as confidential and protected. If information is used in a publication or research thesis, your identity will remain anonymous. All documentation containing identifying information and other confidential documentation collected will be stored in locked cabinets and only the researcher will access these records.

All interviews, focus groups and workshops will be tape-recorded. The recordings will be stored in locked cabinets and only the researcher will have access to the recordings. The recordings will remain in locked storage at the completion of the study.

Will you be paid to take part in this study and are there any costs involved?

No you will not be paid to take part in the study. You will receive a reimbursement for your travels costs. There will be no costs involved for you, if you do take part in the study.

Is there anything else that you should know or do?

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled Building scientific literacy: A case study of community participation in HIV vaccine research.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2011.

Signature of participant

Signature of witness

Declaration by investigator

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (If an interpreter is used then the interpreter must sign the declaration below.

Signed at (*place*) on (*date*) 2011.

Signature of investigator

Signature of witness

Appendix 7: University of Stellenbosch Ethical Approval



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

04 April 2011

MAILED

Ms A Leech
Department of Psychology
Main Campus

Dear Ms Leech

Building scientific literacy: A case study of community participation in HIV vaccine research.

ETHICS REFERENCE NO: N10/11/388

RE : APPROVAL

At a meeting of the Health Research Ethics Committee that was held on 29 November 2010, the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 4 April 2011 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above mentioned project number in ALL future correspondence

Please note that a progress report (obtainable on the website of our Division: www.sun.ac.za/irb) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit. Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 463 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Approval Date: 4 April 2011

Expiry Date: 4 April 2012

04 April 2011 11:33

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Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences



Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -staan · Division of Research Development and Support

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Yours faithfully

MS CARLI SAGER

RESEARCH DEVELOPMENT AND SUPPORT

Tel: +27 21 938 9140 / E-mail: carlis@sun.ac.za

Fax: +27 21 931 3352

04 April 2011 11:33

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Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences



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Appendix 8: University of Cape Town Ethical Approval

UNIVERSITY OF CAPE TOWN



Faculty of Health Sciences
Human Research Ethics Committee
Room E52-24 Grootte Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6626 • Facsimile [021] 405 6411
e-mail: shure.eth.comas@uct.ac.za

04 April 2011

A/Prof LG Beldcer
Desmond Tutu, HIV Foundation
IIDMM
Medical School

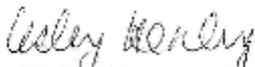
Dear Prof Beldcer

Re: Protocol Title: Building scientific Literacy: A case study of community participation in HIV Vaccine research.

Thank you for notifying that this PhD study will be undertaken under your supervision. Since the protocol has been approved by a registered human research ethics committee we do not consider it necessary to duplicate the ethics review process.

We have noted and filed that the study is being conducted under the auspices of the Human Research Ethics Committee in the Faculty of Health Sciences at the University of Stellenbosch.

Yours sincerely


PROFESSOR M BLOCKMAN
CHAIRPERSON, HSE HUMAN ETHICS

pp

S Thomas