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The Politics of Health:

Community Engagement in South African HIV Vaccine Clinical Trial Sites

Mary Ellen Upton

14th February 2011

The Politics of Health:
Community Engagement in South African HIV Vaccine Clinical Trial Sites

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Mary Ellen Upton
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ABSTRACT

This research responds to limited evidence of the social and political aspects of health biotechnologies. Reaching beyond the literature on trial participation, it explores the extent to which members of Community Advisory Boards (CABs) play meaningful political roles in South African vaccine clinical trial sites. The thesis confirms the need to understand the socio-economic, political and historical contexts in which local health initiatives are situated, by identifying the combined impact of negative social norms and the politics of HIV/AIDS which limit access to health. Interviews, focus groups and observations gathered in trial sites and documentary data reveal complex interrelationships between global and national health governance and local agency. Concepts from theories of social justice, governance, power and citizenship develop the literature on health activism beyond the descriptive by providing a theoretical framework to understand that complexity.

Empirical data reveal the complexities of the lives of people who are at the receiving end of global health policy and the realities of the political channels open to them; shedding light on previously unexplored factors enhancing or inhibiting community participation in health governance. Information on HIV/AIDS and vaccine science increases opportunities for negotiating rather than reacting to decisions over health strategies. Networking with wider health and other community-based and civil society organisations develops that agency. However, the ideals of community engagement are challenged by: the political dynamics of CABS which frustrate collective action; intermittent contact between trial site researchers and CABs; the accountabilities of researchers to donors and communities; and limited representation of those heterogeneous communities. The impact of multiple forms of stigma on marginalised and vulnerable women, Men Who have Sex with Men (MSM) and migrants confirms the value of looking at health inequalities in terms of variable health needs in context rather than seeking equal distribution of health resources.

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ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment
ASRU	AIDS Social Research Unit
AVAC	AIDS Vaccine Advocacy Coalition
CAB	Community Advisory Board
CLO	Community Liaison Officer
CSO	Civil Society Organisation
DTHC	Desmond Tutu HIV Centre
DTHF	Desmond Tutu HIV Foundation
GHG	Global Health Governance
HIV	Human Immunodeficiency Virus
IAVI	International AIDS Vaccine Initiative
HAVEG	HIV/AIDS Vaccine Ethics Group
HSRC	Human Sciences Research Council
HVTN	HIV Vaccine Trials Network
LGBT	Lesbian, Gay, Bi-sexual and Transgender
MCC	Medicines Control Council
MRC	Medical Research Council
MSM	Men who have Sex with Men
NIH	National Institute of Health
NSP	National Strategic Plan
PHRU	Perinatal HIV Research Unit
PI	Principal Investigator
PMTCT	Prevention of Mother to Child Transmission
PPP	Public-Private-Partnership
PrEP	Pre-Exposure Prophylaxis
REC	Research Ethics Committee
SAAVI	South African AIDS Vaccine Initiative
SATVI	South African Tuberculosis Vaccine Initiative
SBRG	Socio-behavioural Research Group
TAC	Treatment Action Campaign
TB	Tuberculosis
UCT	University of Cape Town

UNAIDS	The Joint United Nations Programme on HIV/AIDS
WITS	University of Witwatersrand
VCT	Voluntary Counselling and Testing

CHAPTER 1

INTRODUCTION

This research explores the problem of global health inequalities in South Africa, where HIV prevalence rates are among the highest globally (UNAIDS, 2009) and where the impacts of the epidemics are far-reaching. With a focus on community engagement in two HIV vaccine clinical trial site communities, the research examines the ways in which political activity generated from within "invited spaces" of participation (Cornwall, 2002) may have an impact on the health and socio-economic problems of people living in trial site communities. The research responds to a concern with whether or not science and technology initiatives "enhance the well-being of the poorest and most marginalised in empowering ways" (Mohan and Yanacopulos, 2007b, p. 233). These people are the intended beneficiaries of health resources who seek confirmation of ethical procedure and recompense for their contribution to research (Benatar, 2002). Therefore, analysis of the ways that communities may use opportunities for recompense is important in itself. This is of particular importance as the number of clinical trials increase across developing countries. Further, through that analysis, the perceptions of the different actors involved on how longer term development might occur in the process of community engagement can be identified.

This chapter begins by outlining the research problem and the empirical gaps to be addressed; principally by tracing the process of community engagement in terms of the wider activities around trial participation. The following section deals with theoretical gaps yet to explain that community engagement process. The concern is to develop a theoretical synthesis to generate an understanding of socio-economic citizenship, by focusing on activities within those institutional boundaries and across wider health governance networks. The research questions developed in response to those empirical and theoretical gaps are followed by the global and international health governance background and the South African national political environment. This provides the wider

context for this local level research focus on the two HIV vaccine clinical trial sites. As Cameron (2005, p. 210) points out:

> AIDS over the last (thirty years) has cast a sharp light on medical practice, scientific discovery, government power and extragovernmental activism. It has led to an irreversible shift in the relationship between medical science and the public.

These are the principal elements in the governance of HIV/AIDS which inform my study and provide the focus to the research problem to be defined.

1.1 THE RESEARCH PROBLEM

Meaningful community engagement is integral to the legitimacy of global health governance and to the efficacy of trial site research. The thesis seeks to answer how that legitimacy is manifest and how communities may play meaningful political roles through the engagement process. In doing so, community engagement may help to facilitate community health and empowerment in poor communities where the impact of health inequalities and HIV/AIDS is most acute. My research interest is in exploring the ways in which health initiatives of this kind can support those efforts, by seeking to understand how communities use that support to gain access to health. These are the conditions in which "subjects act as citizens" in "acts that may not be considered as political" (Isin, 2008, p.18).

It is most likely that this power to influence health governance will be constrained by the institutional boundaries in which engaged communities operate. Those boundaries at local, national and global level need to be explored, to understand the social, cultural and political factors which drive health inequalities and how people are finding ways to gain access to health. At local level there are said to be tensions between clinical researchers and trial site communities due to their different agendas (Swartz and Kagee, 2006; Kafaar, Kagee, Lesch and Swartz, 2007). On the other hand, the goal in finding a successful vaccine is mutual. Those being engaged may also be enabled through the support of donors, researchers and wider civil society activity. That wider influence of civil society

politics may have an impact on those who work in both claimed and invited political spaces.

1.1.1 Empirical gaps

This research responds to the need for empirical evidence of the community engagement process extending beyond immediate efforts to engage trial participants. This is the arena in which deliberation over the longer term health of communities may occur, and where communities may be making claims for social justice through their roles in health governance. There is a lack of evidence of the wider impact of community engagement beyond concerns to ensure ethical trial conduct (Lindegger and Richter, 2000; Milford, Barsdorf and Kafaar, 2007) and willingness to participate in trials (Newman, Duan, Lee, Rudy, Seiden, Kakinami and Cunningham, 2007; Lesch, Kafaar, Kagee and Swartz, 2006). The impact of community engagement in the trial sites, their communities and wider health and development outcomes is not explored. Questions as to who speaks for whom, how entitlements are regarded and how identities as participants are perceived may provide evidence of how people use spaces "to realise inclusive, active citizenship" (Cornwall 2002, p. 28).

The suggestion that participants make claims from within invited spaces, and sometimes operate simultaneously in claimed local and national spaces (Cornwall, 2002), draws attention to the potential impact of the claimed on the more circumscribed invited activity. These participatory spaces are a valuable source of knowledge as to what kind of negotiation over longer term health governance occurs. Just as institutions may constrain agency, so they may support that agency; stimulating access to the valued health resources which Ruger (2007) claims are an essential element in access to health. The motives of trial site researchers may be based on pragmatism driven by the primary agenda to find a vaccine, but this priority requires community acceptance and, moreover, may include commitments developed through relationships built during that engagement with poor communities under duress.

Advocacy literature and institutional mission statements convey the ideals of community engagement with some promoting transformative health practice (Levendal, 2006). These community engagement ideals are discussed below in some detail. The primary focus tends to rest on models of engagement and advocacy for 'good practice' in terms of the recruitment and retention of trial participants and the ethical considerations involved, without explanations of wider community engagement and how that good practice can be achieved. Without data on the ways that people manage power relationships and use those invited spaces, valuable evidence of community empowerment remains hidden. The limitations to empowerment may reveal important gaps between those ideals expressed by advocates and the realities of community engagement as experienced by those involved at trial site level.

These forms of participation give some insight into the impact of decision making and accountability on the immanent[1] process of development (Mohan and Yanacopulos, 2007b, p. 234). Science and technology innovations are governed by a diverse range of stakeholders from public and private sectors; hence the need for more research on the impact of these relatively new political configurations on health governance. This focus on their impact at grassroots level may reveal influences on that immanent process of development and its constraints. What happens in those local arenas will be affected by the higher levels of health governance. Just as higher level support for local communities may enhance that immanent process, disconnections between global, international, national and local levels of health governance may frustrate efforts to develop meaningful engagement for poor communities.

1.1.2 Theoretical gaps

Such questions on community engagement stimulate my focus on the under-researched governance of health biotechnology innovations local trial site levels. In particular, the 'hardware' of innovation systems is more often researched than "the 'software' of social

[1] This is a concern with the underlying processes of development, rather than that which is 'willed' through development intervention (Mohan and Yanacopulos, 2007b, p. 233).

and political relations of the actors involved and their influence on science and technology agendas" (Leach and Scoones, 2006). This focus on ongoing active engagement (Arce and Long, 2000) in HIV/AIDS prevention may help to shape local health practice and influence wider policy in ways conducive to community development. A theoretical framework which explains how health governance is negotiated and the power relationships involved, and which explores the potential of health citizenship responds to current theoretical gaps. A conceptual synergy is essential for lending insight into the complexity of the political, social and cultural aspects of biotechnology initiatives as they operate in different contexts.

Theories of governance encapsulate the range of different actors involved and offer some means to explain the community engagement process. Yet, without analyses of power relations (Allen, 2003) they lack the capacity to show how relationships of power can inhibit as well as enable that process. That focus develops governance theory by acknowledging the ways that power relationships influence social realities. At the same time, a focus on political spaces (Engberg-Pedersen and Webster, 2002) and power relations shows how new ways to address health deficits are being developed by those involved in the governance of trial site activities through community engagement and beyond those arenas. Those power relationships operate in different dimensions (Hardy and Leiba-O'Sulllivan, 1998) and across networks of power (Mann, 1986; Keck and Sikkink, 1998; Henry, Mohan and Yanacopulos, 2004; Kahler, 2009).

From that local focus, the influence of this trial site activity on the wider governance of health rests with the capacity of participants to voice claims and to gain response. Therefore, this perspective develops an understanding of how macro levels of governance can be enhanced through insights into "how local institutions assign needs, build relationships and manage change" (Mohan and Yanacopulos, 2007a, p. 232). From this perspective, the factors which enhance access to valued health resources (Ruger, 2007) can be identified. As such, the political activity of those more often seen as the governed is revealed. Further, analysis of the role of global and national civil society groups in

health governance predominates over research on local activity where efforts to stimulate change are being missed. As Chazan (2008) points out, there are many unanswered questions surrounding local mobilisation and its political effects.

I have linked this potential for political agency with a theoretical perspective which identifies "acts of citizenship" as transformative (Isin, 2008). A focus on efforts to find solutions to the problem of access to health shows how community participants are developing the capabilities to function in that quest (Sen, 1999). By situating this research in terms of social justice, the problems and gains made by engaged communities can be identified. I use a set of key principles which suggest that: equal access to health is more assured when health resources are of good quality,[2] when health agency is socially supported and where social conditions and health norms[3] are conducive (Ruger, 2007).

In this context, I suggest that those social conditions are further influenced by particular historical and political precedents which may enhance or inhibit the development of health citizenship. Therefore, efforts at local levels to gain access to health need to be situated within those wider historical, political and institutional contexts. In this research, the ways in which HIV/AIDS has been governed, both globally and nationally is reflected primarily in the perspectives of those working in the local contexts where communities are being engaged in trial site activities.

More specifically, the aim in focusing on local participation is to lend insight into those health resources valued by communities, engaged as they are in trial site activity in their contribution to wider health governance. An evaluation of these resources and the support for the agency to use them identifies the ways that local health initiatives work with communities to increase access to health for people living in poor communities. The

[2] Ruger (2007) defines good quality as that which is valued by those seeking access to health. This is explored more fully in Chapter Two and reviewed in the data Chapter Five.

[3] Ruger's (2007) concern with health norms, related to the ways in which they influence social and personal choice, is discussed in Chapter Two and reviewed in the data Chapter Four.

following research questions have been devised to gain an understanding of what those people identify as essential pre-requisites to good health.

1.1.3 Research questions

Main question:

'To what extent can communities play meaningful political roles in local health initiatives?

Sub- questions*:*

- 'How do participants involved in local HIV clinical trial site activities perceive community engagement and their roles in this engagement?'
- 'What resources are available and what resources do engaged communities bring to local HIV vaccine clinical trial sites?'
- 'What problems are being experienced during the community engagement process and how are those being addressed?'
- 'In what ways are those involved in community engagement developing the capacity to stimulate change?'

1.1.4 HIV/AIDS in context

I return to the research questions in the methodology chapter, in the data chapters, and in Chapter Seven where key data findings will be reviewed in response to those questions. This following discussion sets the research focus in its wider global health governance context. It begins by outlining the disparities in HIV infections and AIDS deaths: exemplified most clearly in South Africa where prevalence is the highest globally (UNAIDS/WHO, 2008).

These data explain the global disparities in health which are influenced by socio-economic inequality and, in turn, have an impact on development. The most productive generations are unable to work and care for their families unless they have access to antiretroviral treatment (ART) before they become too ill to survive. If they die, they leave vulnerable

children without care. The impact has been to reverse some of the gains made in some African countries following independence. The following data confirm that Sub-Saharan Africa (SSA) continues to be the region most affected by HIV/AIDS. The South African data reveal the difficulties which face the majority population; in stark contrast with its progressive constitution which gives specific reference to inequalities yet to be addressed. These are the environments in which engaged communities do their work in local health initiatives, requiring high levels of commitment over long periods of time.

The following data give some indication of those environments. In 2008, 67% of all people living with HIV and 72% of AIDS deaths were concentrated in SSA (UNAIDS, 2009, p. 21). Therefore, of the 33.4 million people living with HIV globally, 22.4 million live in SSA and 5.7 million in South Africa (p. 7). Of the 2 million global deaths from AIDS during 2008, 1.4 million have occurred in SSA (p. 21). In that year, more than 14 million children had lost one or both parents to AIDS (ibid). Despite some levelling off of rates of HIV infection in some cases, the numbers of people living with HIV remain high due to rising levels of treatment in some countries. This saving of lives is a significant step forward and yet, it is difficult to reach optimum levels of treatment, especially where rates of infection are so high. This has deep repercussions on socio-economic development.

South African data show that, with its population of 50 million, it has the largest number of people globally living with HIV at 5.7 million (UNAIDS, 2009, p. 4). Women are disproportionately affected reflecting underlying inequalities due to poverty and gender inequality.[4] In women aged between 25-29 years, one in three (32.7%) are HIV positive, whereas the peak age range for men is 30-34 years, of whom one in four (25.8%) are infected (Shisana, Rehle, Simbay, Zuma, Jooste, Pillay-van-Wyk, Mbelle, van Zyl, Parker, Zungu, and Pezi, 2009, p. xvii). These are the health conditions in which poor communities live, with the rates of infection the highest amongst those living in informal

[4] Although women are more vulnerable physiologically to infection, socio-economic inequality is a co-factor in their particular vulnerability.

settlements (Rehle, Shisana, Pillay-van-Wyk and Zuma, 2007).[5] In addition, South Africa is home to the largest number of people infected with tuberculosis (TB), which is often associated and now stigmatised with HIV/AIDS (Bond and Nyblade, 2006).

Those data show a decrease in rates of HIV infection for young people aged between 15-24 years from 10.3% to 8.6% in 2008 with evidence suggesting that HIV prevention measures are having an impact (Shisana et al. 2009, p. xvii). Local health initiatives may play their part in this success. Overall these South African data reflect the historical inequalities of the apartheid era which remain since its demise, in part due to the intertwined politicisation and stigma surrounding this disease. This forms the background to Chapter Four which offers qualitative data on how this works.

The key factors which have caused ambivalence in dealing with HIV/AIDS are as follows. Firstly, the politics of AIDS is not specific to South Africa, but has been a significant factor in the slow policy response to rising levels of infection. According to Nattrass (2007), the South African response has been distinctive and those specific elements will be explored in Chapter Four. Secondly, that response has been in reaction to the global stigma surrounding the disease due to its transmission, linked as it is with issues of morality. Again, data on those reactions will be presented in Chapter Four.

The historical lack of effective policy in response to the problem of HIV/AIDS has been a determining factor in its global spread, although some governments have given a more proactive response than others. The politics and stigma associated with this disease have influenced global and national health policy reflected in the high rates of infection and deaths outlined above.

[5] While 8.7% of the total South African population lives in urban informal settlements, 29% of the total estimated number of new HIV infections were found there in 2005 (Rehle et al. 2007, p. 198).

The South African response

National policy incoherence has had a significant impact on HIV infections and AIDS deaths,[6] exemplified by inadequate national, regional and local government health services. Lack of political leadership has caused delays in a unified multi-sectoral response and the politicisation of HIV/AIDS has caused petty corruption (Schulz-Herzenberg, 2007), such that funds are not used to the optimum benefit to those most in need. The political confusion over the source of HIV infection, the dispute over its prevalence, and the consequent resource deficit, is an important element in the story of how the efforts of South Africans and their supporters to find ways to address the HIV/AIDS problem have been hindered further. This situation is often compared with other countries where early positive governmental responses have been more effective in stemming the rates of HIV infection and AIDS deaths, such as Brazil (Calcagnotto, 2007; Bastos, 2008) and Uganda (Jones and Koffeld, 2008).

Much has been written of the previous President Mbeki's attitudes to HIV/AIDS (Nattrass, 2007; Gumede, 2005), with his denials of scientific explanations (Geffen, 2006) and criticisms of the motivations of Western science (Schneider, 2002). This stance is based on his rejection of outside interference in African affairs. It reflects the historical memory of colonialism more broadly and apartheid more specifically (Posel, 2005), causing delays in treatment and the above-mentioned unwarranted deaths. The qualitative effects on daily life arise in the narratives of those people who are the focus of this research. I return to this politicisation and those narratives in Chapter Four.

The negative political response to scientific evidence on HIV/AIDS has been reinforced by the stigmatising of those infected and affected by HIV. Reactions have mirrored other conditions, where distance from sufferers is maintained through stigma (Joffe, 1999). Where options are limited, blame on others for the condition is a form of self-protection. Stigmatisation continues to permeate horizontally at local level, by influencing attitudes to

[6] Data suggest that annually 330,000 people have died and 35,000 children have been infected with HIV as a consequence of inadequate provision of ART between 2000 and 2005 (Chigwedere, Seage, Gruskin, Lee, and Essex, 2008).

those infected with and affected by HIV/AIDS in many contexts. These are the environments in which local health initiatives exist and where efforts to challenge social norms are circumscribed. Even where HIV testing and treatment is available, fears of rejection or violence prolong decisions to take action where stigma prevails. The sources and origins of stigma form the substance of Chapter Four, along with the politics of HIV/AIDS: both influencing each other to frustrate efforts to contain the spread of infection and death.

In South Africa, women, men who have sex with men (MSM) and 'foreigners'[7] experience multiple forms of stigma, provoking violent reactions which continue despite the spread of information and treatment.[8] Damaging social norms[9] exclude vulnerable people from access to health and from participating in political activism of any kind. Those who do participate show great courage in the face of that stigma. These experiences are a key factor in this research in that they identify the difficulties in challenging norms around HIV/AIDS and the health inequalities which result. Challenges made from global to local levels have coalesced into a significant force in health activism.

1.2 HIV/AIDS AND GLOBAL HEALTH GOVERNANCE

Global health governance has been defined as "the totality of collective regulations to deal with international and transnational interdependent problems in the health sector … characterized by numerous and changing patterns of co-operation and conflict" (Bartsch and Kohlmorgen, 2007, p. 117). I now turn to the diverse range of organisations involved in global health governance to explain the ways in which each has made efforts to address the HIV/AIDS problem. I begin by focusing on civil society[10] health activism,

---

[7] These are immigrants from conflicts in Mozambique and latterly Zimbabwe, with others from Nigeria, Malawi, Pakistan and Somalia.

[8] Lesbian women are especially vulnerable (Joseph, 2008), as are MSM (Smith, Tapsoba, Peshu, Sanders and Jaffe, 2009). Escalating violence and the deaths of sixty two 'foreigners' occurred in May 2008 (Bloch, 2010, p. 235).

[9] Norms become established where social actors are influenced by widely shared sets of beliefs and sanctioned behaviour (Yanacopulos, 2005, p. 262). This concept is explored in detail in Chapter Two.

[10] Civil society is defined overleaf in 'AIDS activism'.

moving on to consider the key actors in global health governance who have been the focus of those health activists in their efforts to engage in that governance. The growth of global civil society activity[11] has had positive impacts on the delivery of global public goods[12] (Ruggie, 2004) by re-shaping public health in practice and as an academic discipline (Orbinski, 2007). That action is reframing the discourse around HIV/AIDS in two principal ways. It has influenced the psychological and material aspects by reducing levels of stigma and promoting the 'roll-out' of ART. This activity is replicated across layers of governance at national and local levels.

HIV/AIDS activism

Civil society activism around HIV/AIDS has played a key role in health governance by developing understanding of the impact of stigma and in campaigns to expand access to ART. Kaldor (2003, pp. 44-45) defines civil society as "the medium through which one or many social contracts between individuals ... and the political and economic spheres of power are negotiated and reproduced". Those social contracts are distinguished from legalistic contracts but involve institutional outcomes generated through "reason and sentiment and not just the conflict of interests and passion". They are, at the same time, part of the every day politics of public engagement. Kaldor (2003, p. 11) distinguishes three contemporary civil society perspectives as activist, neoliberal and postmodern; all of which describe a normative political project and "an actually existing reality, which may not measure up to the goal".

Such distinctions between civil society perspectives are useful in identifying the range of interests and agendas which proscribe activities. The activist focus is on the empowerment of individuals and the extension of democracy in a shared cosmopolitanism. The neo-liberal aim is to extend global capitalism and the post-modern is to gain recognition of national, religious and other identities in a break with grand

[11] Global civil society is defined overleaf in 'AIDS activism'.

[12] Smith (2009, pp. 123-124) defines public goods as goods and services that are 'non rival' in that no one can be excluded from any benefits and 'non-excludable' in that consumption by one person does not exclude others. Such goods are global when benefits relate to more than one country and none can be excluded. Global public goods for health involve addressing the global spread of infectious disease.

narratives aligned to states (ibid). Each of these perspectives reveals the different ways that civil society operates and the potential influence of that activity on communities in their capabilities to play meaningful political roles in local health initiatives.

Global civil society has been defined as “a macro-society” or “society of interlocking societies [consisting] of a myriad of social interactions [comprising] a multitude of different parts, which are connected in a multitude of different ways [integrating] both serially and in parallel (Keane, 2003, p.17). They “produce effects that are often both simultaneous and sequential”, normally generated locally but with “emergent properties that are global” (ibid). Each set of civil society goals do not exist in isolation from the others. Hence, this “special form of unbounded society marked by constant feedback among its many components” (ibid) reveals the ways that HIV/AIDS activism coalesces across different global arenas to influence health governance. At the same time, it encompasses the goals of other political projects which may enhance or constrain that activism, as exemplified by the donors involved in supporting vaccine trials.

Thus, Civil Society Organisations (CSOs) operate at different levels, with some confining their political and social activities within the national sphere and others operating across all governance levels. The significant political, operational and empowerment role of health CSOs, especially in response to deficits in health systems and through international action over diseases such as HIV/AIDS, involve political functions in co-operation and conflict in coalitions with International Governmental Organisations (IGOs) and nation-states (Bartsch and Kohlmorgen, 2007). Those political functions and elements of co-operation and conflict can be seen in the operations of the most prominent South African CSO, the Treatment Action Campaign (TAC), which has been successful in generating support for its goals, including court action in 2002 against the government for restricting supply of ART[13] (Sachs, 2009), but also in collaboration with government in earlier attempts to bring down the costs of ART (Cameron, 2005).

[13] Nevaripine for the prevention of mother to child transmission of HIV (Sachs, 2009, pp. 198-201)

The activities and affiliations of the TAC range from international to local levels where unemployed women form the basis of their grassroots membership. This local level political activity is significant to this research as part of the wider activity which exists within trial site communities. The TAC promotes health activism primarily in terms of HIV treatment literacy and access (Robins and von Lieres, 2004). More recently other campaigns reach beyond its original remit.[14] This suggests a more holistic approach to health and wider socio-economic development, to reflect the inspiration driving the people involved in building the constitution as apartheid ended.

The new South African constitution is one of the most progressive globally. It has been described as "perhaps South Africa's most successful democratic institution of the transition", which has displayed wisdom and restraint, yet has the capacity for "unmistakable power" (Cameron, 2005, p. 117). For Justice Albie Sachs, it signalled a change from a "culture of authority to a culture of justification" (Sachs, 2009, p. 204). As Hunter (2006) points out, the constitution has enabled women to become empowered through their collective action in legal challenges against domestic violence. That empowerment gives opportunities for women to address one of the key underlying factors in their vulnerability to HIV/AIDS. In such ways, the constitution specifies public participation, social services including rights to health care, food and social security and including a clean environment (Sachs, 2009).

Constitutional rights to freedom from discrimination including that against MSM are of particular interest to trial site researchers, due to the stigmatising of such 'high-risk' populations whose HIV prevalence is highest (Smart, 2009) and whose need for HIV prevention is most acute. This stigmatising is exemplified in the disparity between constitutional rights and daily realities for MSM in this South African context, to be discussed in the data chapters below.

[14] These activities include taking a primary role in supporting refugees following the civil unrest and deaths occurring in May 2008 (Sichone, 2008) and which I discuss in Chapters Three and Five.

At the same time, the widespread TAC grassroots membership has contributed to changes in health norms and practice, therefore global civil society action is mirrored at local level. Just as predominant international and national political agendas influence proceedings from the 'top down', individual and collective community agency are potentially influential in that process from the 'bottom up'; even though dominant agendas and prevailing unequal power relationships limit the impact in some contexts more than in others. In this South African context, as national HIV/AIDS policy has been challenged by health activists across national and local arenas, that activism has influenced, and been influenced by, developments in wider global health governance.

In challenging the damaging social norms around HIV/AIDS and the predominant health governance focus on individual behaviour, this health activism has influenced patterns of health governance over time. For example, the moral underpinnings of HIV prevention towards the ABC approach promoting abstinence, fidelity ('be faithful') and condom use (in that order of preference) has driven American policy and conditional aid to developing countries. This perspective on the individual behavioural aspects of HIV prevention has been challenged for its narrow focus and failure to acknowledge the "structural violence"[15] (Farmer, 2005) which underpins health inequalities.

More specifically, with regard to gender Susser (2009) criticises the patriarchal foundations of this socially conservative approach, said to have been instrumental in ignoring gender inequalities globally and thereby contributing to inequalities in HIV infection in that omission. Her research into women's activism suggests that they play a significant role in finding ways to address the problem of HIV/AIDS in their midst, especially at the local levels where this research is focused. In response to criticisms of the narrow global policy focus, poverty and gender inequalities have been incorporated into more recent health governance literature and policy.

[15] In his work as an anthropologist and doctor in Haiti Farmer (2005) was alerted to the connections between what he termed social forces and the "structural violence" of poverty and unequal gender relationships with the unequal impact of HIV/AIDS on poor people.

1.2.1 Global health partnerships

Along with academic challenges, health activism has played a role in stimulating those changes in approaches to HIV/AIDS at global health governance levels. Key actors now involved in that governance include states, intergovernmental UN organisations, international institutions, NGOs, health foundations, multinational companies and philanthropists (Orbinski 2007, p. 37), with an increasing number of global Public-Private-Partnerships (PPPs) for health (Bartsch and Kohlmorgen, 2007) supporting the local level health initiatives such as in this research. But the unease over the disjuncture between global health governance and local experience of disease continues, with uncertainty focused on PPPs.

Public private partnerships

These partnerships are responding to health problems which the pharmaceutical sector has not been willing, and the public sector in developing countries has more often not been able, to address. As funders of vaccine trials, questions of accountability to trial participants and communities in recompense for contributions to science are the concern here. Questions have been raised over the impact on health and whether or not PPPs are building the capacity to reach the poor people whom they claim to support (Chataway, Hanlin, Muraguri, and Wamae, 2009). Efforts to address health deficits by global health partnerships and biotechnology innovations may be significant but not sufficient in providing frameworks for sustainable development. The following concerns guide my research into the experiences of those who play a key role in contributing to the clinical research at community level.

The benefits of PPPs are claimed to be in their expertise, efficiency and sharing of risk in partnership and collaboration (Bull and McNeill, 2007). Critics point to their market driven agendas (Bartsch, Hein and Kohlmorgen, 2007) which raise problems of funding priorities as vaccine development costs rise through the different trial stages (Craddock, 2007) and the fragmentation of international health organisations (Zammit, 2003) challenging efforts in coordinated global health governance and access to health. The disease focus of

PPPs (Reid and Pearse, 2003; Ollila, 2005) reinforces the “medicalisation” of HIV/AIDS which is claimed as the source of disconnection between global health policy and local experience (Seckinelgin, 2008).

In this view, people are medicalised by being reduced to the status of patients or risk groups as objects of medical knowledge; with little understanding of the experiences of those people and the complexities of their socio-economic and cultural lives. Such a narrow perception of health is said to betray a short-sighted, and detrimental scientific and technical focus on solutions to global health inequalities (Birn, 2005). Global health policy which does not take account of the complexities of people’s lives and the health inequalities which they experience continues to be inadequate. That narrow scientific and technical focus may not respond to the concerns of communities where local health interventions, such as vaccine clinical trials, operate.

Ultimately, the demands of the market predominate, with repercussions across the different levels of PPP governance. In that competition for funds, community level activity becomes a potential loser as a lower priority than clinical research and the supporting infrastructure. The impact on communities as the intended beneficiaries of that research may be ignored in that market process. This highlights the need for empirical evidence at local level. I return to these issues in Chapter Five when considering the support given to community engagement by donors, AIDS vaccine initiatives, advocates and researchers. This leads me to the AIDS vaccine initiatives and advocates which support the clinical trial sites where this research is focused.

1.3. THE RESEARCH CONTEXT

I begin this focus on the research context with an outline of the key questions asked by advocates supporting vaccine initiatives, moving on to examine the claims made by those initiatives in supporting the communities where clinical trials are conducted. This is followed by an introduction to community engagement and the ethical remits which guide

clinical practice. This chapter ends with an introduction to the trial sites where this research was conducted, with an outline of key research being undertaken.

1.3.1 AIDS vaccine initiatives

Since HIV treatment may not be a sustainable solution, a vaccine is promoted as a crucial element in prevention strategies, as part of longer term health. To these ends, biotechnology initiatives have been supporting infrastructures and clinical researchers in product development and in preparing high HIV prevalence communities for clinical trials. To promote ethical vaccine initiative practice the global AIDS Vaccine Advocacy Coalition (AVAC)[16] grew from its origins in volunteer aids activism in America to become the AVAC: the Global Advocacy for HIV Prevention, with the widening remit of HIV prevention science.

The AVAC follows guidelines for biomedical research in advocating for research which leaves "low-resource countries or communities "better off than previously or, at least, no worse off", so that "as far as possible" populations should be left "in a better position to obtain effective health care and protect its own health" (CIOMS,[17] cited in AVAC, 2004, p. 28). This is to be achieved by developing "an informed, action-oriented global coalition of civil society and community-based organisations exchanging information and experience" (p. 56). The goals of clinical research are seen as compatible with reducing poverty, promoting development and strengthening women's rights (Mellors, 2005).

The International AIDS Vaccine Initiative (IAVI) has spent considerable efforts in advocacy with increasingly more involvement in vaccine research and development (Chataway and

[16] AVAC is a non-profit coalition operating as an advocacy network that promotes: "A biomedical prevention research field that invests as much in socio-behavioural research and community partnership to understand participant risk during and after trials, as it does in scientific evaluation of prospective candidates" (AVAC, 2010). This includes "community engagement and research literacy outside the context of any trial" (www.avac.org). .

[17] CIOMS stands for the Council of International Organisations of Medical Sciences.

Smith, 2006), in programmes across the world in particular in developing countries[18] including South Africa (Chataway, Brusconi, Cacciatori, Hanlin and Orsenigo, 2007). The IAVI aim is "the development of a safe, effective, accessible, preventative HIV vaccine for use throughout the world".[19] Again, the concern is with how poor communities can be left "better off" as trial participants by AIDS vaccine scientists even if the results of the trial are less effective than anticipated, since participating communities "are contributing knowledge that is a global public good and should benefit in return" (cited in AVAC, 2004, p. 25).

The South African AIDS Vaccine Initiative (SAAVI), makes explicit references to contributions to "education and development", and "broader health issues". In doing so, it appears to endorse community development beyond vaccine recruitment. Meaningful collaboration with the SAAVI community stakeholders is expressed in its vision as: "A South African society working in a mutually beneficial and meaningful partnership with the AIDS vaccine researchers within a vibrant human rights environment" (Levendal, 2006). The SAAVI mission statement expresses those ideals.[20] Here, community involvement is seen as a "means to an end (a successful vaccine) and an end in itself (individual and community development)" (www.saavi.org.za).

As a national initiative, SAAVI has the scientific and technological capacity to develop a vaccine and to retain national control over health governance. However, the political situation in South Africa is highly charged, especially regarding matters of institutional governance. Government influence on the Medical Research Council (MRC) has provoked leadership changes (Nattras, 2007), with repercussions on SAAVI, which is governed by the MRC and has been experiencing internal governance problems and

[18] IAVI has in-country programmes eleven countries globally and the European region, working on different 'clades' of HIV and developing vaccine concepts and candidates (www.iavi.org).

[19] Source: www.iavi.org.

[20] The SAAVI mission statement: "A sustained, accountable learning organisation, founded on a human rights ethos to ensure an informed and educated South African society with active and sustained community involvement in the AIDS vaccine development process".

funding difficulties (Keeton, 2008). Funding withdrawals[21] have compounded difficulties and restricted the activities of their Community Involvement Project (CIP), with impacts on local community engagement in the trial sites.

Conflicts and frustrations have compounded the difficulties of those attempting to work together in this uncertain institutional and wider political environment. Trial site researchers more reliant on SAAVI support have been forced to seek funding elsewhere,[22] and so the political balance has changed. The supply of valued community engagement resources has been intermittent and support for national vaccine development compromised. The IAVI moved into this political vacuum leaving SAAVI, the flagship biotechnology initiative, in a lesser political position with other sources of support flowing from donors in America and Europe.

This shift in power relationships between vaccine initiatives suggests that national control over health policy and delivery have been frustrated, especially given the political controversy which has marked the years of President Mbeki's leadership. These are the ongoing politics of health governance which form the background to my focus on local level clinical research initiatives. They reveal the repercussions of this wider politics of health on the trial sites and community engagement.

1.3.2 The ethics of community engagement

Concepts of community and community engagement are discussed in detail in Chapter Two. This outline explains the rationale and process of community engagement as it relates to trial participation. The focus of vaccine development on high prevalence areas is due to the need to develop effective measures to prevent HIV infection in these

[21] Withdrawals by Eskom in 2007, the private electricity supplier, were followed by rumours that the Department of Science and Technology had done so. This followed government reviews of SAAVI governance and leadership problems (personal communications, October, 2008) and reconsiderations over funding made by the Department of Health (Keeton, 2008). Subsequent arrangements were made for new funding patterns (personal communication, November, 2008).

[22] This information was offered in confidence in November, 2007.

contexts,[23] and to find sufficient numbers of healthy high risk HIV negative people willing to participate in trials. At those local levels, community advocates in vaccine trial sites emphasise the need for wide community representation, independence from the vaccine trial recruitment process and the protection of vulnerable people.[24] HIV vaccine trial site communities are being engaged in projects with the aim to provide information on HIV prevention and clinical research in order to preserve the health of trial recruits and to generate interest in and support for trials in the wider community. This provision of information is part of a sustained education policy to alleviate the stigma of trial participation and to prevent information decay (Lesch, Kafaar, Kagee and Swartz, 2006).

The role of science and knowledge and the engagement of partner communities in that political process are significant. Vaccine initiatives aim to ensure ethical and sustainable trials through attention to the social and cultural fit between the trial site communities and the research. Recruitment and retention in clinical trials are crucial to their sustainability. The engagement of communities in this endeavour plays a pivotal role. As Hanlin (2008) has found, successful innovation requires the recognition of a wider range of actors in collaborative activity than assumed, including community members.

Although a clinical trial process which reflects those most in need is of mutual benefit, there are inevitable tensions between agendas at trial site levels (Swartz and Kagee, 2006) and at interfaces between vaccine initiatives at international and national level, as pointed out. Conflicting agendas may have impacts and reverberations down to local levels, despite positive collaborative policy aims. This has implications for the capacity for communities to develop meaningful political roles within those systemic boundaries. While the commitment to vaccine development is a primary concern of donors, the protection of communities *via* information on HIV prevention and the skills to share that information is a fundamental concern of trial site communities, even though they have a mutual goal in successful vaccine development.

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[23] The most prevalent Clade C HIV virus in SSA is distinguished from Clade B found in other global areas.

[24] Observations recorded at the Socio-behavioural Research Group Workshop, Durban, June 8th- 9th 2007.

Tensions of this kind between researchers and communities are difficult to reconcile with the pressing task of securing funding for an increasingly expensive research process which, at the same time, gives due regard to ethics. Attempts to find suitable cohorts are ethically challenging; hence efforts to engage communities in trial site activity in ways which are meaningful to participants and of mutual benefit. Just as information can result in decisions not to participate in trials, lack of information can result in offers to become recruits (Swartz and Kagee, 2006), suggesting a gap between ethical remits and reality.

I return to community engagement in Chapter Two where the conceptual perspectives are explored. In Chapter Five, data provide insight into the ways that those views of community and engagement together influence the ideals and realities in practice. For now, an outline of the clinical trial sites which are the source of data on those views and that practice follows.

1.3.3 The clinical trial sites

The first research phase was based at The Desmond Tutu HIV Foundation, in the Faculty of Health Sciences in the University Cape Town (UCT) in the Western Cape Province. Established in 2004 in its present form, its origins began in 1996 elsewhere as one of the first public clinics to offer ART. Current activities include clinical and social science research and the provision of HIV prevention and TB treatment. The second research phase was conducted at the Perinatal HIV Research Unit (PHRU), affiliated with the University of Witwatersrand (WITS) and based at the Chris Hani Baragwanath Hospital in Soweto in the Gauteng Province. As the name suggests, the PHRU began with prevention of mother to child transmission of HIV in 1996. Services now include HIV prevention, care and support, with studies into a range of HIV prevention approaches. It too was one of the first to provide ART before the policy to begin the ‘roll-out’ was agreed by government in 2003 (Cameron, 2005).

As explained above, community engagement is a crucial factor in trial site governance for Principal Investigators (PIs) and scientists, whose primary concern is to ensure ethical and sustainable trial participation.[25] As part of that engagement, vaccine education is provided for potential trial recruits. Counsellors operate within the clinics to provide one-to-one support for trial participants, whose concerns are then relayed back to the researchers so as to conform to ethical remits and improve participant retention during the trial process. This research concerns the trial site activities which support the clinical research and is focused primarily on the work of volunteers who work together on Community Advisory Boards (CABs) in their liaison role between researchers and the communities which they serve. The CABs provide information about the research and convey community concerns back to the researchers. The ideals embodied in this work and the ways that it operates in practice are the focus of this research.

1.4 CONCLUSION

The outline of the research problem has identified the empirical and conceptual gaps which will help in understanding how communities are engaged in HIV vaccine clinical trial sites in the two case studies chosen, and how engaged community members may use those opportunities to achieve their goals in that participation. The background to this research illustrates the context of high South African HIV prevalence and AIDS deaths. This chapter has provided an outline of the politics and the related stigma attached to HIV/AIDS and their influence on global and national health governance and has highlighted the influence of civil society on that health governance. The South African Constitution gives some indication of what can be achieved collectively by those seeking access to health. In its attention to socio-economic inequalities, the constitution has provided a foundation for building health and related policy and given a forum for civil society challenges to those inequalities. Finally, the role of vaccine initiatives in support of trial site research has been introduced to preface their influence on community engagement in trial sites.

[25] The aim is to gain sufficient participants and to ensure their retention over long periods.

The next chapter offers a theoretical framework for understanding the problem of how people living in poor communities gain access to health, the factors which limit that access and which influence their capabilities to play meaningful political roles in trial site activities. Chapter Three describes the methodological approach underpinning this research which is designed to discover what factors enable or constrain those political capabilities; combining a deductive and inductive approach to data collection in two urban case studies using qualitative methods. Periods of reflection and conceptual reiteration allowed theory building in the light of evidence being collected, predominantly focused on the local health initiatives and from the different perspectives of those involved. This is supported by the literature and documentary evidence of other community engagement projects.

In Chapters Four to Six, I use Ruger's (2007) three principal elements to analyse the data which define factors claimed to be significant in determining social justice and access to health. These elements concern: healthcare quality; the ability to pursue valued health goals; and the environment in which particular social health norms flourish. They reveal the ways that each element influences capabilities to negotiate a healthy life. The data chapters begin with the contextual issues, namely, the environment where social norms and politics influence those capabilities in Chapter Four, followed by the ways that capabilities are being developed to ensure access to valued health resources in Chapter Five. Chapter Six explores the ways that agency in the use of those resources has a potential influence on access to health. In each chapter, community engagement ideals and the practical realities reveal the distinctive ways in which community engagement is conceived and experienced by researchers and communities in trial site activities in these two South African case studies.

CHAPTER 2

COMMUNITIES ENGAGING IN HIV/AIDS GOVERNANCE

Mann (1986, p. 32) suggests that throughout history "the most significant problems of our own time are novel. That is why they are difficult to solve". He goes on to say that such problems are:

> … interstitial to institutions that deal effectively with the more traditional problems for which they were set up. But … all societies have faced sudden and interstitial crises, and in some cases humanity has emerged enhanced (ibid).

In this chapter, I explore the concepts which may help in understanding how such novel crises are being governed and where communities may be playing meaningful political roles in local health initiatives by addressing such crises. Those efforts may contribute to that enhancement in terms of health governance in the longer term. A concept of social justice which considers the capabilities necessary to gain valued resources (Ruger, 2007) to those ends provides the basis of my theoretical framework, which seeks to understand what resources may be gained in the process of community engagement and how they are used. Identifying the power relationships involved in that process of capability building reveals the ways in which those resources may be negotiated across the different levels of health governance.

Power acts as a constraint, but also may enable communities to secure health needs from within those different spaces of power from institutional levels and across trial site, national, international and global networks. This focus on capabilities and power relationships helps to define the political and socio-economic conditions where community engagement is being developed. It reveals how power may work to enable some people, whose acts of citizenship break established patterns of power which, in turn, influence those conditions. In doing so, it shows how this kind of activity in invited spaces (Cornwall, 2002) can move beyond the immediate environment with the potential for contributions to health as a fundamental element of development more broadly.

By addressing each core element offered by Ruger (2007) as pre-requisites for access to health, her concept of social justice identifies the resources for meaningful community engagement. It allows consideration of impediments to the governance process and identifies the ways in which valued health resources might be gained by communities in their contribution to wider socio-economic development in the longer term.

The conceptual framework is explained in the following way:

1. It begins with social justice as it relates to health from the capability approach; with its focus on how communities may use the resources gained through engagement in local health initiatives in their quest for health. This section explains the distinctive ways in which agency is highlighted as a key factor in health access.
2. Here, I present concepts of community engagement which explain the ways that different forms of engagement may enhance or inhibit health access in these particular historical, political, socio-economic and cultural settings.
3. The participatory spaces which communities inhabit are distinguished using the key concepts of invited and claimed spaces, to identify the different bases of political activity with the former as the focus of this research.
4. The process of community engagement within trial sites is theorised using concepts of purposive governance in particular. Concepts of accountability provide a key to understanding the process of communication between researchers, communities, and other stakeholders in such health initiatives.
5. A focus on power relationships lends insight into the ways that engaged communities may use their agency to gain the resources needed to achieve good health.
6. Finally, the concept of acts of citizenship completes the theoretical synthesis by identifying how that agency may be enacted.

2.1 SOCIAL JUSTICE

Here, I draw from Ruger (2007; 2010a) whose work derives from Sen's capability approach (1999; 2010). Her focus on health emphasises the role of social norms and

agency in the pursuit of valued health resources. This approach is distinguished from those which consider justice in terms of equal access and the distribution of resources to those ends.[26] By focusing on access to valued health resources and the individual and collective use of those resources to promote good health through community engagement in local health initiatives in these particular contexts, situations where communities may be developing the capabilities to gain access to health and what might be constraining those activities are brought to light.

2.1.1 The capability approach

The capability approach takes a different perspective from the Rawlsian "resource orientation" concern with removing barriers to fair competition, equal opportunity and the distribution of resources,[27] rather than a "results orientation" (Ruger, 2007, pp. 83-84). From this perspective, equal access does not consider how basic services might be guaranteed. Impediments to health functioning cannot be reduced to a matter of material wealth, or fair procedure, in distributing health care based on measures of hypothetical choice. Requirements differ due to the variety of capabilities, health conditions and populations in terms of the personal characteristics which some are able to use in the pursuit of health needs, the diversity of experience and the variability of health needs (ibid). Consequently, injustice can result from the deprivation of capabilities to be healthy due to low quality health care, inhibited agency and oppressive social norms. Arguments focused on equal opportunities ignore the role of society in fostering the freedom to be healthy, through the provision of services as a matter of justice (Emmanuel, cited in Ruger, 2007, p. 82).

Ruger applies the capability approach in its focus on what people are able to do in her aim to provide "a realistic sense of their freedom to pursue the lives they have reason to

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[26] Sen (1999; 2010) and Ruger (2007; 2010a; 2010b) make a distinction between their focus on capabilities to function in gaining access to health with that of Rawls (1958), whose focus lies in developing institutions to provide the means to justice through equal access to resources. They argue that it is not so much the institutions which are the crucial element in that access, but the means by which individuals can develop the capabilities to attain access.

[27] The key element in the health capabilities approach lies in what is valued in terms of health rather than equal access. Different resources might be needed by different people to achieve good health.

value" (Ruger, 2007, p. 84). By focusing on peoples' capability to take action in that quest for health, it distinguishes the ways in which health needs can be met by trial site communities and the appropriate resources for that goal. This conception stimulates questions on what kind of development is possible, who is able to influence the development process and in what ways. Capabilities can be enhanced by public policy, but this works both ways so that "the direction of public policy can be influenced by the effective use of partnership capabilities by the public" (Sen 1999, p. 18).

Access, then, becomes a matter of collective action, rather than medical or public health in itself, with participation in collective decision making around health a valued freedom (Ruger, 2004). The "ethical aim: to ensure the social conditions in which all individuals have the capability to be healthy" incorporates an examination of injustices "besides inequitable distribution of healthcare resources", since equal access does not guarantee equal opportunities for health (Ruger, 2007, p. 79). From this capability approach, "resources (the means for a flourishing life) have no intrinsic value. They are good only insofar as they promote human functioning" (p. 83). By identifying the constraints on functioning experienced by many people, "the relevant personal characteristics that govern the *conversion* of primary goods into the person's ability to promote her ends" (Sen, 1999, p. 74, author's emphasis) become clear.

2.1.2 Access to health

Although mobilisation may result in the inclusion of marginalised people, this requires the skills to communicate effectively in that engagement (Cornwall and Coelho, 2007). The ability to represent oneself and others can be limited[28] and with it, access to valued health resources. Ruger's (2010b, p.47) conception of health capability involves:

> Confidence and ability to be effective in achieving optimal health given biologic and genetic disposition; [the] intermediate and the broader social, political, and economic environment; and access to the public health and health care system.

[28] Ricoeur (2006, pp.18-19) focuses on recognition and the capability to act, to argue that part of an essential step in that process towards effective communication begins with self recognition (as a form of action) leading to mutual recognition, and from self esteem to social esteem. The capabilities to speak, to act and to tell form part of that process.

As outlined in Chapter One, her three principles determining access to health are: i) the quality of resources, such that differences are unjust in that they undermine capacities for health functioning; ii) the degree of social support for agency in efforts to gain those resources and; iii) the role of health norms in inhibiting or enhancing the ability to function (Ruger, 2007, p. 84). Each element is an intrinsic part of a process whereby choices for a healthy life are navigated. In each case, the ways that community engagement occurs in local health initiatives will influence that process. In each respect, wider political support for developing those valued resources and positive health norms will be influential.

Ruger's (2007) key elements in terms of resources, agency and norms may provide a more productive analysis than approaches which rest with issues of equal opportunity to pursue health objectives. The three elements raise questions as to what resources are deemed necessary and what individuals and communities can do with those resources in the environments in which they operate and where negative health norms around HIV/ AIDS prevail. Each of the three elements is now discussed. In the first instance, decisions over resources involve a combination of procedural and substantive principles, with both clinical and economic considerations to be decided by physician and patients on what is of medical necessity and what is appropriate rather than focusing on equal access to health.

Equal access to health becomes a matter of finding effective health care which allows individual capabilities to function and these capabilities may differ. In this developing country context, where the disparity in health care is more marked, the concern is to ensure care of high quality that is evidence based, rather than the kind of sub-standard care which many people experience. People involved in clinical research at community level are bound to the ethical principles developed in consequence and which concern socially and culturally appropriate interventions. Two gaols are achieved. Successful trials, in terms of recruitment and retention of trial participants, are more likely and morally just commitments to communities are fulfilled.

Secondly, Ruger's (2007, pp. 89-90) definition of health agency concerns the ability of individuals and groups to pursue valued health goals such as health knowledge and the capabilities for self-management, informed decision making and control of personal and professional situations to pursue health, in order to convert health resources into health functioning. Without those capabilities, she argues that access to health and scientific knowledge, early diagnosis, skilled professionals, treatment and management, contacts and other services are less likely. For example, diabetics need current scientific knowledge and the ability to make judgements on that knowledge so as to take action. Likewise, trial site communities need access to skilled professionals and early diagnosis of health conditions such as HIV/AIDS. Health decisions then "effectively translate available resources into improved physical, mental and social functioning" (ibid). I return to these three elements in health functioning in Chapter Five, where engaged community members discuss their valued health needs.

Cleaver (2009) would agree that agency is based in practice as well as decision making and she considers the social world in which agency may be exercised, but she stresses the relational elements involved. In doing so, she draws from Bourdieu's concept of "habitus"[29] to consider the "interlinked constraints" which can influence the ability to exercise agency, in institutional, cultural and individual terms. Actors are constrained by habit and routine. As she suggests, this focus tempers the tendency to emphasise the reflexive and deliberative elements of agency,[30] allowing room for consideration of "routine practices and unconscious motivations" (ibid). Her perspective on "the coexistence of empowerment and subordination" suggests the possibility of norm change through agency (Cleaver, 2009, p. 139). At the same time it highlights the persistence of norms and the constraints on that agency.

[29] I refer to Webb, Shirato and Danaher (2002, p. 36), who explain Bourdieu's habitus as "the partly unconscious 'taking in' of rules, values and dispositions … gained from our cultural history that generally stay with us across contexts". In this view, we may improvise, but are most influenced by our cultures.

[30] Cleaver (2009, p. 130) refers here to Giddens and Long.

This concern with norms resonates with Ruger's (2007, p. 91) third element influencing access to health in that health norms have an impact both on society and personal choice. She cites norms around HIV/AIDS which influence peoples' access to health. Addressing stigma and the underlying negative health norms is to be achieved through informing people of science based health information and by encouraging positive norms that honour the moral worth of those seen as inferior due to their infection with HIV. She considers a norm-based approach as an integral part of health promotion since equal access to resources does not suffice where norm-based inequalities persist. Indeed, norms act as constraints, embedded as they are in social structures which influence "valued communities" (Keck and Sikkink, 1998, p. 34). From a different perspective, the capability approach takes account of those social structures by embracing human diversity as "a fact of life" rather than an abnormality (Ruger, 2007, p. 91). Each of these issues of health norms, health information and diverse health needs are taken up in Chapters Four and Five.

As Navarro (2006, p. 19) points out, norms are the "hidden power mechanisms of social domination". Recognition of both agency and structural constraints provides an important balance to my analysis of community engagement in local health initiatives. That balance is necessary in assessing Ruger's (2007) normative approach to health access. Although she recognises lack of political will, for instance, as one of the "remaining barriers to success" (Ruger, 2006, p. 122), my concern lies with analysis of the ways in which HIV/AIDS governance influences the capabilities of civil society agency in general, and engaged communities in particular, to challenge structural constraints on access to health. The activities of local engaged communities in this respect are discussed in Chapter Six.

Further, an understanding of the impact of socio-historical processes on health (Denuelin, 2006)[31] is of particular importance in the ways that global HIV/AIDS governance has developed more generally, and more specifically in this South African context. I draw from

[31] This development of the capability approach suggests that "socio-historical narratives … offer an important source of information for analysing the processes which made certain policy decisions possible" and their influence on the ways in which opportunities for promoting human freedoms are opened up or closed down" (Denuelin, 2006, p. 135).

the concept of historical traces to identify the reasons why "shared health governance"[32] (Ruger, 2010a) has been fraught with difficulty and how those difficulties are being addressed.

In summary, health resources should be appropriate to individual and group health needs which can differ. Evaluations of justness relate to "effectiveness in preventing, ameliorating or eradicating deprivations in individual health functioning capability" (Ruger, 2007, p. 87). First, the quality of health resources should be determined by those who experience such deprivations. Second, that effectiveness should be determined by skills to convert those resources for health functioning. Third, in order to use resources for "maximal levels of health functioning", social environments must be conducive since health norms "bear on society and personal choice" (pp. 89-90). Finally, whether or not "shared health governance" (Ruger, 2010a) is evident will offer some understanding of the realities in this South African context.

The kinds of belief influencing norms surrounding stigmatising conditions, in particular, can inhibit fulfilment whatever the degree of skill in using resources. Norms can prevent people from seeking knowledge about HIV/AIDS and HIV prevention, early testing, or skilled professionals for access to appropriate treatment and services, even where available. Under those circumstances, decisions not to test are not based on fear of the results alone. They are determined by the degree of stigma arising from status disclosure and the potential isolation from family and community (Mills, 2006).

That environment in which particular health norms flourish has an impact on the opportunities for poor people to pursue health needs and is determined, in some measure, by the degree of support. In this case, this would include the support of governments, Public-Private-Partnerships (PPPs) for health and Global Health Partnerships (GHPs). In

[32] The concept of "shared health governance" requires that "individuals, providers and institutions work together to create a social system and environment enabling all to be healthy" involving "consensus-building around substantive principles and distribution procedures, accurate measures of effectiveness, changes in attitudes and norms, and open deliberations to resolve problems" in a "joint scientific and deliberative process" (Ruger, 2010a, p. xiii).

environments where social conditions are challenging and where political support is lacking, capabilities to use health resources are in short supply. Even so, where those health norms are challenged fortunes can change. Barriers to access to health can be removed. Thus, the capability approach considers means as well as ends; lending itself to this research into the process of community engagement and the different outcomes which may arise in different contexts.

The previous South African government has been equivocal in its support of HIV prevention programmes, as outlined in Chapter One. This prevarication over health governance has been compounded by the slow initial global reaction to HIV/AIDS in comparison with its response to other more recent potential epidemics.[33] In drawing from Ruger's (2007) theoretical framework, I suggest that those seeking health capabilities may be focused on: identifying valued health goals, prioritising those health resources, and making decisions in the pursuit of community health. What different individuals can do with resources may depend on the kinds of personal characteristics which encourage individuals to claim valued resources and to use them. In this regard, community advocates may play a key role. It is to this community engagement activity that I now turn.

2.2 COMMUNITY ENGAGEMENT

Conceptions of community and community engagement define the context and parameters of that activity. The widespread ambiguity over definitions of community defies conceptual clarity. It is a highly problematic concept, in itself, without the disputed definitions of community consultation, involvement and engagement. The concept of community is vague and value-laden, suggesting equality and collaboration in arenas more often characterised by diversity and conflict; a problem said to be intensified by the proliferation of community programmes (Head, 2007). Identities and values are not shared by those living in "place- based communities" where "a microcosm of the wider social inequalities that undermine people's health" may exist (Campbell and Murray, 2004,

[33] The response to the threat of SARS is a case in point.

p. 189). And yet, in this research community implies a cohesion which engagement requires. Such difficulties in defining community suggest that community engagement may be problematic in itself. One of the underpinning difficulties in generating effective communications through CAB mechanisms has been due to debates over definitions of community (Marsh, Kamuya, Rowa, Gikonyo and Molyneux, 2008).

Concepts of community

The difficulties over definitions of community derive from the normative connotations, where unproblematic notions of homogeneity confound reality. By necessity, placed-based notions of community define the parameters of trial site research. In such contexts, community has been defined 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, McLellan, Metzger, Kegels, Strauss, Scott, Blanchard and Trotter, 2001, p. 1936).

Weijer and Emanuel (2000, p. 1142) offer a set of characteristics and types of community relating to medical research so as to measure community cohesiveness and the potential for community protection in that research process. The characteristics include: geographic localisation; a common culture and shared history; legitimate political authority; representative groups and individuals; a common economy and shared resources; and self-identity as a community. I return to these characteristics in the data chapters where the detail of community engagement is explored, but at this point it is important to explore some of the difficulties that such place-based definitions offering key characteristics might present.

Cohen (1985, p. 15) suggests that community is:

> that entity to which one belongs, greater than kinship but more immediately than the abstraction we call 'society' … where one learns and continues to practice how to 'be social' … we could say it is where one acquires 'culture'.

This fluid and dynamic definition, based on symbolic meaning and practice, defines the boundaries of community through common perceptions of belonging through common culture, which has become more resonant as social change breaks structural boundaries. When outsiders trespass, the 'insiders' feel that their "sense

of self is debased" such that change becomes synonymous with loss (p. 109). Seen in this light, in the competition for resources in engaged communities may be less likely to work collectively for the good of 'the community' so defined.

This is where the normative connotations with homogeneity become problematic. That uncertainty over inclusive definitions of community is raised by Gupta and Ferguson (1997, p. 13) who have little confidence in the conception of "cultural similarity or social contiguity", emphasising community as "a categorical identity that is premised on various forms of exclusion and construction of otherness". Further, Rose[34] (1999, p. 176) argues that community has become "a sector of government", where strategies of "self-management and identity construction, of personal ethics and collective allegiances" predominate. From this perspective, community engagement is then the means to "foster moral dialogue" around core values and acceptable behaviour (Rose, 2000, p. 1403). Each perspective lends insight into the realities of local health initiatives where community engagement takes place.

In this research context, the different views of communities as cohesive, diverse, exclusionary, or depoliticised characteristics of South African communities can be diverse in terms of class, ethnicity, culture, sexuality and regarding gender relations. That diversity cuts across a common community identity based on place and social ties. Where communities can be riven by fragmentation and conflict, boundaries between people can provoke the exclusion of some people deemed not to belong, especially where material resources are limited. Community cohesion is difficult to sustain due to a complex set of historical and contemporary events. Past forced removals and migrant labour patterns have been followed by rapid industrialisation and new migration patterns across the wider Southern African region.

[34] Rose's (1999, p. 18) ideas derive from Foucault's on governmentality as the extensive reach of government into all aspects of life to engender self-governance. This is achieved without recourse to coercion and where government objectives extend across space and time and into our thoughts.

The quest for community representation in vaccine trial site activities within such dynamic environs is fraught with difficulty. This has fundamental implications for community engagement, where community representation lies at the heart of successful communication over community needs and concerns relating to clinical research and where success relies on the legitimacy of representation (MacQueen et al. 2001). Therefore, differences in the quality of community engagement may determine the degree of understanding of health needs and the response to those needs.

Moreover, the problem of defining community persists. According to practitioners involved in community engagement and social scientists in its research:

> … the fact that there is no single definition of who constitutes 'the community' of interests in HIV research … is further complicated by the fact that community exists at many levels and may include a broad range of stakeholder groups (Socio-behavioural Group, 2009, p. 6).

These stakeholders include trial participants, their communities, CABs, trial site staff, vaccine educators, funders, international organisations and other local stakeholder groups. To Emmett (2000), the problem lies in the assumptions that there is 'a community' which is able to participate in a project and that interests and relations are place-based when in reality they transcend community boundaries. As he says, power and resources distributed between communities, and the structures which transcend them, limit what can be accomplished within communities being engaged in trial site activities.

Community engagement

Amongst practitioners, there is consensus over the importance of community engagement (Marsh et al. 2008; Lasker and Weiss, 2003; Tindana, Singh, Shawn Tracey, Upshur, Daar, Singer and Frohlich, 2007) but little agreement over definitions. The ambiguity over terms is reflected in different perceptions of engagement between state and society or, more specifically, between clinical trial site researchers and communities participating in trial site activities[35] whether or not living in the immediate geographical area. Community

[35] Those activities encompass engagement beyond trial participation.

engagement, partnership and collaboration have different meanings for different people, hence the conceptual power in that the term can be used for different purposes according to different agendas.

Community consultation, involvement and engagement are used interchangeably, with no clear distinction over what is involved or what outcomes are envisaged by whom. In consequence, expectations vary considerably and are more likely to be unmet. A diversity of participants on an equal footing is said to be a pre-requisite for empowerment, community ownership and sustainable collaboration over time, but in reality these ideals are not easily achieved (Lasker and Weiss, 2003). This has repercussions on health goals, where inequality and exclusion prevail.

Attempts to clarify distinctions have had little success. Consultation is "perhaps more episodic" (Head, 2007),[36] with involvement more consistent. This is not as enduring as engagement, defined as the deepest and most meaningful political activity with the greater potential for ongoing active relationships of deliberation (Barnes, Newman and Sullivan, 2007; Socio-behavioural Research Group, 2009). A practical approach asks who should be involved and in what ways, to generate a broad-based influence and strengthen capacities to solve complex problems (Lasker and Weiss, 2003). Suggested goals are to ensure: research relevance; cultural and practical acceptability; minimal community disruption; avoidance of exploitation and to account for ethical hazards (Tindana et al. 2007). These goals rest on the ethical issues of protection of vulnerable populations who participate in trials.

Other advocates suggest goals which go beyond protection to promote more idealistic goals, to ensure protection, respect, empowerment, partnership building and equitable distribution of benefits to trial participants (Marsh et al. 2008). These require negotiation and deliberation over those goals, suggesting that communities may have a

[36] A more comprehensive continuum of levels of engagement ranges from providing information, to consultation, to involvement, to collaboration and empowerment (Head, 2007, p. 445).

transformative role. Again, these different ways of conceptualising community engagement tend to focus on trial participation rather than the wider activities which this research addresses.

Theoretical approaches to public and community engagement are more circumspect. Writing of the European context, Rose (2000) argues that the dominant neo-liberal agenda precludes any meaningful political engagement. The proliferation of participatory fora is claimed to be part of the modernisation agenda of the UK Labour government in response to the perceived democratic deficit (Barnes, Newman and Sullivan, 2004). There are concerns that participants are constrained by new forms of regulation and control (Newman, 2005). In this view, publics and communities are co-opted into new fields of power and governance (Rose, 2000). No longer governed by the state, we are liberated to seek our own and society's destiny for which we are now held responsible. These new forms of governance are mere technologies of government (Conway, Crawshaw and Bunton, 2007) producing "new hierarchies of expertise and new forms of potential exclusion" (Newman, 2005, p. 202).

In this view, community has become "the object and target for the exercise of political power, while remaining somehow external to politics and counterweight to it" (Rose, 2000, p. 4401) with responsibility shifting from government to community (Conway et al. 2007). The "real issues" and concerns of involved communities remain unmet. Issues arising from a UK project[37] include problems of definitions of 'community' and 'involvement', community representativeness, funding shortages, and initiative fatigue (p. 214), each of which will be considered below in the data chapters. Such concerns are voiced in South Africa, where government attempts to engage communities in local schemes such as waste management are viewed with suspicion as efforts to privatise services and depoliticise participation in voluntary activities, with empowerment reduced to economic dimensions and thus dislocated from citizenship claims (Miraftab, 2004).

[37] Conway et al. (2007) analyse the role of Health Action Zones.

Hart (2008, p. 690) challenges this view, arguing that Anglo-Foucauldian arguments based upon governmentality and "neo-liberal rationalities of rule" provide little purchase on "some of the most urgent and compelling forces at work" in South Africa. As research into an urban health initiative in South Africa[38] reveals, daily realities are reflected by "the ambiguities and complexity of actions, motivations, intentions and political subjectivities" of actors involved (Colvin, Leavens and Robins, 2009, p. 25). This more nuanced approach captures more "subtle processes at work", sometimes with values and objectives shared between officials and community participants working to stimulate alliances in local government initiatives for health and other sectors (Barnes et al. 2004, p. 276).

Alliances may confirm the co-option of "organisational insiders", but this idea of "capture" may be "too blunt an instrument" to describe what happens in different engagement encounters where different power dynamics operate (Barnes et al. 2007, p. 185). Inequalities in power relationships are important but do not give account of the different types of relationships which are built between citizens and officials. The focus on ubiquitous power and structural constraints does not allow consideration of what people do with the opportunities that arise and their perceptions of those experiences.

In this respect, forms of alliances, the prioritising of valued health domains, the decisions made in their pursuit, and their impact, give insight into the dynamics of such deliberative spaces, whereby new relationships and identifications may form to stimulate capabilities for meaningful political roles to develop. The proliferation of such fora "may generate fundamental shifts in relations between state and citizens, public bodies and publics" to invoke "new meanings capable of transforming [policy] discourses" and public participation (Barnes et al. 2004, p. 275). The deliberative spaces describe arenas where knowledge exchanged between citizens and experts can enhance understanding of complex policy problems (Barnes et al. 2007, pp. 35-38). This conception of deliberative

[38] This research was undertaken in Khyelitsha, one of the areas of metropolitan Cape Town which has similarities with my first phase of research.

democracy draws from Habermas[39] for its potential in transformations in views which may occur between equal participants. At the same time, it recognises the difficulties involved in such ideal type scenarios pointed out by critics.[40]

Such a perspective on alliances allows us to consider whether or not voice leads to recognition, respect and action, with opportunities for transformation; in which case change may occur not only for "the engaged" but also for the "engagers" (Barnes et al. 2007). Epstein (2008, p. 3) is equally sceptical about explanatory models that suggest binary oppositions between "insiders" and "outsiders", or between experts and lay activists which do not take account of the "hybrid political forms that span these (and other) divides". These nuanced views of political relationship give insight into the dynamics of health governance and trial site community engagement. It is then possible to analyse the role of beliefs, values and commitment in shaping change through new forms of engagement which Barnes et al. (2007, p. 194) consider and how they might arise within political spaces with the potential for social change.

2.2.1 Political Spaces

The spaces of political engagement and the conceptual value in distinguishing between them now highlight the potential benefits and limitations for those who operate from within them. I consider the concept of political space (Engberg-Pedersen and Webster, 2002) to distinguish the parameters of activity and influence before moving on to consider the South African context, where civil society activity suggests that it is not possible to make clear distinctions between claimed and invited spaces (Ballard, Habib, Valodia and Zuern, 2006). Here, just as binary oppositions between insiders and outsiders may not be sufficient analytically, community engagement may not fit easily into either claimed or invited spaces. The imprint of historical traces on present day civil society may have

[39] Barnes et al. (2007, pp. 36-37) describe Habermas's 'communicative rationality' (1984; 1990) as an effort to stimulate free and equal deliberation over dominant scientific rationality and forms of decision making.

[40] Fraser and Young argue that unequal power relations limit free and equal participation and for Young, what is considered to be rational argument excludes people whose narratives and communication styles may be rejected as anecdotal and inappropriate (cited in Barnes et al. 2007, pp. 37-39).

implications for political activity across formal and informal boundaries, where synergies may present a greater potential for substantial changes in health governance.

The strategies used by poor people to change their circumstances have been distinguished in two ways (Engberg-Pedersen and Webster, 2002). This view differentiates political spaces which can be used to gain resources and assets and those to effect wider change by influencing others' actions and policy. While the former is considered to be a coping strategy, the latter seeks to redistribute resources through institutional change. In this case, political spaces are sites of contestation and challenge and the emphasis on outcomes "rooted in specific political histories" (p. 11). This emphasis on institutions and agency is significant when considering the complex South African political and social history. This distinction between political spaces in terms of use and outcome lends insight into those processes which may occur in this research context.

Gaventa (2006) has developed concepts of political spaces by distinguishing three forms of power (visible, hidden and invisible), levels of power (global, national and local) and spaces of power (closed, invited and claimed, or created). As he says, the dynamics of power depend on the configurations between each element. The more private forms of power, in terms of internalised values and identities, may influence the ways in which people are able to operate, whether or not in invited or claimed spaces, and the levels at which they may reach in that activity across horizontal and vertical networks of power. I return to a discussion of networks below. For now, I consider the spaces of power in which engaged communities operate.

Invited spaces

Cornwall's (2002) concept of invited spaces is the key to understanding the activities of those working at the local interfaces between researchers and communities within the vaccine trial sites. This "participatory sphere" lies outside formal politics and is different

from activities such as protest and direct action. Her distinction between organic (popular) and invited spaces reveals the ways in which civil society challenges the *status quo*; from outside or within the trial site institutional spaces. CABs operate from within invited spaces in the community engagement programmes of HIV vaccine initiatives. The distinction between these institutional spaces and those claimed suggests less room for manoeuvre and a greater potential for co-option, as Rose (2000) argues. Empowerment bestowed may be less meaningful than that which is claimed. Just as alliances may build between researchers and communities, the dynamics of those relationships may tend towards the co-option of communities.

Even so, those dynamic forms of alliance may produce something more transformative. Those spaces claimed by participants emerge organically rather than created by others and have more freedom to develop without institutional control. However, claimed spaces can be more exclusive than invited spaces, due to the common identities of those who come together to challenge the *status quo* (Cornwall, 2002). The political activity that occurs may be more focused yet less sustainable, but in reality the boundaries between each of the invited and claimed spaces are often blurred. Cornwall (2002, p.7) argues that invited spaces "exist alongside those claimed and shaped by a range of other actors … what happens in one impinges on what happens in others, as relations of power within and across them are constantly reconfigured". From this view, some spaces for participation may not be radical in themselves, but the activity of those working in invited spaces may be "more radical in their scope for the reconfiguration of formal governance institutions" (p.15).

Through power gained in one space, Gaventa (2006, p. 27) points out that "new skills, capacity and experiences, can be used to enter and affect other spaces" with transformative potential. He suggests that "when well crafted, institutional spaces for participation come together with champions for change on the inside, and well-organised, mobilised social groups on the outside, positive changes for previously excluded groups may be seen" (Gaventa, 2007, p. xvi). This perspective guides my exploration of the ways

in which those communities engaged in trial site activities may operate across those boundaries and the interrelationships which form in consequence. As explained above, in South Africa, Ballard et al. (2006) find the boundaries between claimed and invited spaces as porous as Cornwall (2002) suggests. There does not appear to be a dichotomy between claimed and invited spaces, so that clear distinctions between activities cannot be made with confidence. Yet, in this particular context where the highest degrees of inequality and HIV/AIDS converge, the kind of longer term civil society action across horizontal and vertical alliances which Gaventa (2006) describes may be less assured. As he suggests, it is rare that actors are able to work effectively across each dimension of power.[41]

In the immediate post-apartheid era, civil society political activity reduced with the movement from resistance to government, leaving a vacuum until unchanging socio-economic conditions began to stimulate new challenges (Ballard et al. 2006). At the same time, initiatives to involve citizens in deliberations are being developed by the government.[42] This activity marks the rise in civil society political activity across informal and formal political spaces. Participants in this research context may operate simultaneously in invited and claimed spaces outside the immediate trial site environs, with repercussions on their role within both arenas.

Claims may be made from within those invited spaces whether or not political activity extends beyond trial sites. But the more involvement in different arenas, the greater potential for synergy. In this way, volunteer community participation which draws from experiences beyond trial site institutional boundaries may promote longer term social and political change. Therefore, community engagement may provide the seeds for empowerment, especially where a sense of mutual obligation exists between researchers and community volunteers.

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[41] I return to the dimensions of power as they relate to institutions below.

[42] Miraftab (2004) provides a critical view of local government Integrated Development Plans and Reconstruction Development Programme fora created in communities and townships for participation and decision making.

Of course, agendas will differ, and effectiveness relies on access to information whereby people can deliberate, or mobilise to exert their rights and gain democratic accountability (Cornwall and Coelho, 2007). Understanding the process towards substantive change moves the focus to the governance process. That focus requires an exploration of the impact of power relationships, and the dimensions of power, on the potential for meaningful political roles to develop within trial site communities. As Cornwall and Coelho (2007) found, where different interpretations of participation and democracy and different agendas arise, contestation and collaboration coexist. Interpretations of 'good' health governance may differ. The ways that such differences are deliberated guide my analysis of community engagement in process.

2.3 GOVERNANCE

An outline of conceptions of governance identifies the different perspectives and how they inform this research. The aim is to understand how governance shapes political processes and the social consequences of that governance (Leach, Bloom, Ely, Nightingale, Scoones, Shah and Smith, 2007). My focus on the procedural aspects is to understand the process of health governance within the trial sites and beyond into higher levels of health governance. Through the political interactions between actors involved, the opportunities for engaged communities to play meaningful political roles in that governance process will become evident. This conceptual approach provides some purchase, but not without consideration of matters of accountability where conceptions of community engagement may differ, where priorities over agendas may conflict and where the least powerful actors will be less able to exert their influence on that governance process. Attention to the multiple accountabilities of different actors operating within and beyond trial sites will reveal the constraints on the shared health governance which Ruger (2010a) claims is possible.

2.3.1 Concepts of governance

Governance is said to involve "self-organising, inter-organisational networks, characterised by interdependence, resource exchange, rules of the game and significant

autonomy from the state" (Rhodes, 1997, p. 15). In this view, governance implies the kind of shared goals in activities beyond the reach of government and formal authority (Rosenau, 1992, p. 4) which Ruger (2010a) envisions. The distinction between governance and government lies in the former case in the acceptance of rules and government which can function without that acceptance. Concepts of governance emphasise efficiency and the sharing of responsibility, with government playing a steering and guidance role (Stoker, 1998).

Yet, critics of the trends to markets and privatisation are wary of the ways that sectoral interests of consumers are prioritised and where issues of civics and citizenship which markets cannot address are neglected (Kazancigil, 1998). In this view, the focus on the effectiveness of PPPs (Smouts, 1998) draws attention away from politics where market forces set the rules (Swyngedouw, 2005), where "the game is rarely played amongst equals, and powerful groups … generally carry the day" (Kazancigil, 1998, p. 71). Such concerns with power and politics guide my analysis of the new spaces for citizen engagement arising in this apparent shift from formal state institutions to governance through informal networks and non-governmental actors (Papaioannou and Tsekouras, 2006).

In principle, governance assumes a significant role for those non-governmental actors. Yet, these "new modes of co-ordination of interdependent activities at local, regional, national and supranational levels", involve a complex interaction through those scales of governance (ibid). Governance, therefore, concerns more than efficiency and shared responsibility. It involves power relations beyond nation states to reveal the complexities of "the motive forces, threats, opportunities and varieties of strategic considerations facing the participants of any specific instances of governance" and especially the "difficulties and dilemmas facing the less powerful governance actors" (Yanacopulos, 2005, p. 265).

The community members in this research are the least powerful governance actors whose health choices are the most constrained by unequal power relationships and resources,

whether or not given opportunities to participate in 'self-organising networks'. It is suggested that governance promoted as marking change from relationships of "hierarchy and imposition" to "heterarchy in concert and through negotiation" (Kazancigil, 1998, p. 71), and identifying co-ordination and consensus requires empirical work (Smouts, 1998, p. 87). The connotations of the term partnership (Richter, 2004) may obscure the variable degrees of influence which different vaccine initiative partners may have on those procedures, with community level partners least likely to have an impact on health governance. Swyngedouw's (2005) warning of normative and idealised forms of horizontal interaction, which claim regular iterative exchange between partners with guaranteed access, gives focus to analyses of governance in practice.

Data will provide evidence on the those interactions, exchanges and questions of access focusing on the decision making process, the power relationships involved in those deliberations, and the people who are least likely to become engaged in trial site activities. The gap between the ideals of participatory governance and the realities of the exclusion of poorer and more marginalised citizens is inevitable (Cornwall and Coelho, 2007). Such challenges to inclusive representation[43] and voice may be defined by power relationships across levels of governance, from trial site, to national and global arenas.

Explanatory and purposive governance

Governance as both an explanatory framework and a purposive activity (Yanacopulos, 2005) shows how it interconnects across these global to local interfaces. It takes into account internal and external pressures at the institutional and community level and the different agendas involved which may exclude marginalised groups. The explanatory framework highlights changing relationships between state and non-state actors involved. Seen in this light, governance identifies degrees of agency and implications for access to health at each level more clearly. The ways in which GHPs, PPPs and governments may work together to support access to health defines that wider governance arena.

[43] My use of representation here is distinguished from formal political representation and is related to the ways that civil society makes claims over health governance.

Alternatively, gaps between ideals in collaborative governance and the political realities may have impacts at the local level.

The purposive element identifies governance in process (Yanacopulos, 2005). This guides my exploration of ways in which communities are engaged and the implications of that engagement. This focus on procedural issues connects with Ruger's (2007) as crucial to access to health. Defining governance in this way helps to identify how issues are framed and steered. It gives a focus to norm and agenda setting, policy formation and decision making; all of which have impacts at community level in terms of decisions over policy, funding allocation for resources and decisions over what resources are provided and utilised. Decisions over access to resources for any participatory engagement would need more than material assets, such as information. Social and political connections are key (Cornwall, 2002) and, as above-mentioned, opportunities for voice are not sufficient without respect, recognition and action (Barnes et al. 2007). Indeed, opportunities for "direct dialogue" have been found to be valuable by others operating from within invited spaces (Johannson and Hvinden, 2009, p. 21).

Thus, procedural governance reveals the quality of such political relationships and how issues are framed and norms established by organisations as they influence governments and "publics" (Newman, 2007). As discussed in Chapter One, advocacy has been a crucial purposive activity of health governance in generating interest and securing the support of public-private initiatives. This applies to the field of biotechnology in particular, where cost and risk are significant factors; hence the considerable financial investment in advocacy by influential PPPs such as IAVI (Chataway and Smith, 2006).

2.3.2 Governance and accountability

However, the problem of political accountability to those in most need of health care becomes more difficult with the rise in PPPs. Concerns are raised by those who argue that "self-organisation is not necessarily a political process that enjoys democratic

accountability and transparency" (Papaioannou, 2009, p. 31), or legitimacy and trust (Kazancigil, 1998, p. 77), or representation (Swyngedouw, 2005, p. 2000). In South Africa, civil society challenges to government accountability have been effective in gaining HIV treatment through political activity and successful challenges in the courts (Nattras, 2007), as explained in Chapter One. However, lines of accountability (Swyngedouw, 2005) between PPPs and the publics are less clear.

Firstly, there is a lack of understanding of local capabilities, where geographical distance from global partners is greatest and where drug delivery is not assured (Chataway and Smith, 2006). Secondly, due to the uneven power relationships involved, some partners may be able to exert more influence on proceedings than others. Thirdly, at all institutional levels, conflicting loyalties to donors and communities may compound those problems of accountability. The focus has implications for sustainable development in the longer term. Responsibilities of more powerful partners to the less powerful are not guaranteed without transparent and effective accountability mechanisms. Therefore, equal benefits cannot be assumed during the process of trial development and access to vaccines, once developed, cannot be assured.

Additional tensions can arise from 'multiple accountabilities' both downwards and upwards (Edwards and Hulme, 1996). Given unequal power relations, even where there are adequate accountability mechanisms, the pull to account to the latter rather than the former tends to prevail. Moreover, predominant interests are difficult to reconcile with increasingly expensive funding requirements which influence decisions over resources allocated to community engagement. This affects the quality of that engagement and, in consequence, the opportunities to develop the capabilities to function for the most vulnerable partners in the vaccine trial process. They may be provided with opportunities for voice, but may lack the means of ensuring accountability through adequate feedback mechanisms.

In summary, governance as a purposive activity, played out in co-operation and conflict at different actor interfaces across the political arena, has significant implications for health delivery and the sustainability of health innovations. Kooiman (2003) usefully differentiates governance as that which concerns finding solutions to immediate social problems, or that conceived as creating social opportunity. In this respect, governance can encompass involvement in the broader development process. Despite the uneven power relationships, one of the key features of governance is that it has allowed more political space for such deliberations. Outcomes will be determined by forms of engagement, the political spaces in which that engagement takes place, what is discussed, who is involved in decision making and how power relationships are managed within those institutional spaces.

2.4 POWER

I now return to the above discussion on spaces of power to explore the ways in which power operates within them. Relationships of power are a key to understanding how different actors operate across different interfaces in the process of health governance. Those relationships highlight the fluidity of power, as it circulates within and across institutions and where communities may find opportunities for developing health generating capabilities. Having been invited into institutional spaces, some community members may develop the agency to use networks[44] for building alliances within and across trial sites; reaching into higher levels of health governance at national, international and global arenas, as do health activists in other political spaces. Although outcomes may be influenced by alliances developed, those higher levels are where substantial change occurs in terms of policy development. Even so, less obvious but longer term change can occur within communities where people devise ways to address health problems in their midst. These different spaces may generate capabilities to negotiate health goals with the agency to follow them through.

[44] Networks are discussed below in detail.

2.4.1 Relationships of power

A focus on power in use, rather than as a possession used to exert power over others, helps to identify the ways in which it works as "an interplay of forces" (Allen, 2003, p. 98), played out *"in and through social interaction* (p. 40, author's emphasis). This approach challenges concepts of power as that which emanates from one centre, by offering a view of power as a series of capabilities produced through mobilisation, where "the ability of an agent to act, to intervene in events" (Allen, 2008, p. 1614) comes to the fore. It is "reflected through the uneven experience of those on the receiving end [and] points up the more tenuous side to institutional and organisational power" (p. 1618). This view of power resonates with that of participation as "a contingent, contested process" to reveal "the micro-politics of encounters in participatory arenas" with different political and cultural histories (Cornwall and Coelho, 2007, p. 11); elements of which combine to affect the governance process. Seen in this light, power is mutable and, therefore, a resource in collective "spaces of power" (Allen, 2003; Gaventa, 2006); with room for manoeuvre by those with fewer resources and which may be transformative.

Foucault's perspectives on power in its fluidity (Clegg, 1989) and its productive possibilities (Cornwall, 2002) helps to identify the ways in which capabilities to meet health needs can be realised and recognised as politically significant. This flexibility and mutability of power presents a picture of "a more or less stable or shifting network of alliances extended over a shifting terrain of practice and discursively constituted interests", so that "points of resistance will open up at many points in the network" (Clegg, 1989, p. 154), through the deployment of different resources. This emphasis on action and practice (Allen, 2003) resonates with the capability approach where capabilities to function underpin access to health (Ruger, 2007). That emphasis on capabilities to influence policy (Sen, 1999) draws attention to the ways that people use resources to build networks of control, alliance, or coalition (Clegg, 1989), and what happens when a "cross-cutting, tangled set of forces come together in one location" (Allen, 2008, p. 1619). The workings of power show how individual and collective capabilities to function play a part in the complex set of power relationships which influence health outcomes.

Although power in its fluidity points to productive possibilities which help to understand this research problem, I agree that seeing power as "some pre-packaged force from afar", or as "some ubiquitous presence" is less helpful when the focus needs to rest on "the *particularities* of power, the diverse and specific *modalities* of power that make a difference to how we are put in our place, how we experience power" (Allen, 2003, p 2, author's emphasis). This emphasis on the effects of power is useful in showing how engaged communities and the trial site researchers experience relationships of power and how they may be "placed by power" (Allen, 2008, p. 1623) in different ways through those trial site relationships. As much as capabilities to function may stimulate change in health governance to benefit trial site communities, their capabilities may be constrained by relationships of power and their capabilities to play meaningful political roles diminished. A return to Gaventa's (2006) forms, spaces and levels of power directs the attention to how and where those dynamics of power are enacted.

2.4.2 Dimensions of power

As discussed above, power relationships operate at different interfaces within and across institutions at local, national and international governance levels. I return to an exploration of the dimensions of power as experienced within invited spaces to give focus to the key arenas where community engagement takes place at trial site levels. Communities engaged in local health initiatives may enjoy opportunities for empowerment and yet they still operate within the institutional bounds of their invited political spaces where they may be placed by power (Allen, 2008). Researchers, too, may be placed by power in the wider spheres of health governance to be constrained in their work, as engaged communities most likely are, but in different ways. My focus rests for the moment with the immediate institutional boundaries of the trial sites to identify the dimensions of power as they influence health governance.

Four dimensions of power are offered by Hardy and Leiba-O'Sullivan (1998, p. 460) in terms of: i) the use of resources to influence decision-making; ii) the control of access to those processes; iii) the legitimising of power through cultural and normative

assumptions,[45] and iv) the systemic properties of power where it is "embedded in the very fabric of the system".[46] This perspective on the institutional aspects of power relates to organisations and their employees, but nonetheless may have some resonance to this research based as it is in the invited spaces of clinical trial sites and investigating power relationships involving both employees and voluntary CAB members.

According to Lukes (2005 p. 58), the one dimensional view of power is "blind to the ways in which [the] political agenda is controlled" by the political system. The second dimension reveals that bias but "it lacks a sociological perspective within which to examine not only decision-making and non decision-making power, but also the various ways of suppressing latent conflicts within society" (p. 59). The first two dimensions give perspective on the resources given to communities which they may use to achieve good health. From this view, community capabilities to influence decisions are dependent on the support of those who control access to those resources and processes. The third dimension of power shows how this access can be limited by assumptions of what community engagement involves and how far those norms can be challenged. Here, latent conflicts may persist unrecognised, and so where no conflict arises "inaction may be the result of power" (Hardy and Leiba-O'Sullivan, 1998, p. 456). As Lukes (2005) suggests, this implies that actors may have acted differently.

The fourth dimension of power goes further in suggesting that all involved in these institutional arrangements are governed by systemic power. And so the power to negotiate the terms of proposed research on communities depends on the institutional arrangements in which these engagements take place and the "networks of relations and discourses" of institutional power in particular (Hardy and Leiba-O'Sullivan, 1998, p. 458). Organisations involve contracts which are rarely reciprocal and without conflict or equal

[45] This third dimension draws from work by Lukes (2005, first edition 1974) in response to the then current views of first and second dimensions of power which he found lacking in their focus on the observable exercise of power. He deemed that behavioural focus on decision making as too individualistic and limited to observable conflicts of interest. His contribution was to consider the ways in which "*potential* issues are kept out of politics, whether through the operation of social forces and institutional practices or through individuals' decisions" and which "can occur in the absence of actual, observable conflict" (p. 28, author's emphasis).

[46] This fourth dimension draws from Foucault in suggesting that power permeates into every aspect of life and where no-one is absolved from its influence.

exchange. However, as Clegg (1998) argues organisational control is not total, in part due to agency which gives room for manoeuvre amidst complex sets of relationships and interests. In his view, power is the result of negotiation, contest and struggle between different agencies.

Allen (2008) agrees that, due to the provisional nature of power outcomes are not pre-determined. His concern is with how "what happens between 'here and there' makes a difference to the workings of power" (Allen, 2004, pp. 24-25), since power relationships are constituted differently in space and time. The fact that community volunteers work across institutional boundaries suggests some form of mutual influence between those spaces. Ultimately, outcomes are dependent on context, events and actors as they attempt to influence power relationships and so some degree of empowerment can be enjoyed by some people in "benefits not previously experienced" (Hardy and Leiba-O'Sullivan, 1998, p. 462) as they relate to the three dimensions of power.

Those three dimensions involve the resources to influence decisions, access to decision making processes and heightened political consciousness around the dominant management of meanings exerted within institutions. Latent conflict between communities and researchers may not be recognised nor heeded, given the dominant power relationships involved, the institutional constraints and the wider agendas of donors, governments and other partners. Thus, within the institutional context, the political relationships developed between different actors determine governance cultures and procedures. As above mentioned, some of the actors in this research offer their services – to communities and researchers – as volunteers. It might be assumed that voluntary status confers a certain freedom to withdraw those services, but the realities may suggest a more complex set of power relationships. There may be too much to lose through withdrawal, or contesting dominant power relationships. Resources gained through voluntary activities may be of value and in short supply elsewhere. Decisions to stay and devise different strategies using resources available may be productive, even though conflict may remain latent.

Thus, the four dimensions of power reveal the “complexity and ambiguity of empowerment as it is experienced by those being empowered” (Hardy and Leiba-O’Sullivan, 1998, p. 467). This focus on experiences resonates with Allen’s (2003) on the experiences of power and the forces involved. It reinforces the need to explore “the expedient ways” in which resources are used to produce “the tenuous effect that is power” (Allen, 2008, p. 1622). It is this emphasis on use which connects with Sen’s (1999) capability approach from which Ruger derives her focus on agency and the use of resources in securing good health. As she says, this agency requires social support.

For now, it may be assumed that the support of health initiatives and of the communities where CAB members operate and live may be a significant element in successful community engagement. Alternatively, the dynamics of power relationships and the ways that they can work to exert control and “exercise us in place” (Allen, 2008, p. 1623) can limit the support needed for health agency. Even so, that focus on dynamics may reveal collaborative relationships evolving through encounters between researchers and trial site communities.

Those relationships and encounters may be another element in successful community engagement. Institutions may play “a crucial role in constructing feelings of compassion, feelings of awareness of undeserved sufferings”, in a “two-way relationship between institutions and individuals who build them up and maintain them” (Denuelin, 2006, p. 84). This focus on mutual obligation binding people together recognises those attachments which may develop between those working in trial sites as employees and volunteers. Such attachments may play a role in health governance. As Barnes et al. (2007) argue, alliances may develop between the different actors involved.

In summary, power may be negotiable, yet limited by the systemic nature of power which affects all involved within the institutional boundaries of trial sites and across wider networks of health governance. And yet, the provisional nature of power makes outcomes indeterminate such that some benefit may be gained; hence the need for empirically

based explanations of how power works. The capacity of GHPs, governments, PPPs and trial sites to support the governance structures essential for good health are likely to be determined by the dynamics of institutional power and the political relationships in networks within and across spaces of power.

2.4.3 Networks of power

Development networks involve "a strategic response to the challenges and opportunities facilitated by the globalisation of capital and by technological changes" (Henry et al. 2004, p. 839). The networks relating to this research encompass those organisations connected in some way to trial site communities as part of the 'community of interest' around the HIV vaccine research enterprise mentioned earlier (Socio-behavioural Research Group, 2009). Those connections span political spaces across global, national and local arenas. As "networked interactions at points distant across space and time" (Allen, 2004, p. 29), they become an important element in any analysis of power relationships between actors across those health governance arenas.

It is those power relationships within and between networks and how they operate which are of interest here, along with the role of values and norms as a primary element in establishing and maintaining networks (Henry et al. 2004). Networks are dynamic with a potential for marginalised groups to participate. As both agents and structures they shape and are shaped by their environments. Kahler (2009, pp. 4-5) describes how, as structures, networks influence members' behaviour to produce "consequential network effects" and as actors they work collectively with the potential to change international outcomes and national policies. Networks operate to effect purposive governance by the framing of issues and agendas (Yanacopulos, 2005). For example, advocates promote an HIV vaccine as a key element in HIV prevention and CSOs lobby government policy over HIV treatment.

Mann's (1986) conception of societies as organised power networks gives a focus for analysing power relationships within and across those institutional arenas and the "myriad social networks that humans set up to pursue their goals". Of Mann's four power sources,[47] I focus here on the political and ideological. Political power sources differ from the others in that they are centralised and territorial, as in the South African state whose influence in health governance is mediated by the different civil society political projects which Kaldor (2003) discusses. South African health activists form part of the global health activism network having developed the capabilities to play key roles in health governance at national and global levels. The TAC members have contested the power of government and collaborated with them in different times (de Waal, 2006).[48]

As Clegg (1989) reminds us, power and resistance exist in relation to each other, although not all forms of political alignment revolve around resistance (Allen, 2004). And so, in the exchange of information, ideas and people in networks of power (Mann, 1986), TAC has been successful in building a civil society organisation in ideological challenge to the economic power of pharmaceutical companies and the political power of government at different times. That success is underpinned by its use of the power of HIV/AIDS information in the battle of ideas over prevention, treatment (in particular) and care, and in networking from global to local levels. That global exchange of ideas, information and people presents opportunities for civil society health activism to emerge in other political spaces.

Communication across networks of power may be a stimulus for shifts in the political relationships and balance of power and, with it, the greater the opportunity for meaningful community political roles to develop. This account of networked interactions and resource mobilisation helps to understand the effects of power relationships. The focus on the use of resources (information, ideas, people and contacts) and their control and reproduction and the "patterns of association and interaction [that] bind people and people together in

[47] These are economic, ideological, military and political power sources (Mann, 1986).

[48] TAC was concerned to change policy, not the government (de Waal, 2006) and so worked to gain cheaper drugs with the government and challenged the government when treatment was slow to be delivered.

the pursuit of certain ends" (Allen, 2003, p. 47) may help to understand networked power relationships around vaccine development.

I focus on what is considered to be the key element in network activity, in terms of information sharing and its impacts on international and domestic debates and their participants (Keck and Sikkink, 1998). This focus shows how networks have the potential to influence policy by "pressing more powerful actors to take positions" and where outcomes depend upon the social and political contexts where networks operate (p. 9). That influence of information and ideas may reach from wider health activism into the invited spaces of local trial sites. Although institutional agendas may limit the impact of that influence, by conceiving power as relational and fluid, the potential for some influence within those bounds comes to light. Seen in this way, some CAB members may be placed by power (Allen, 2008) in local invited spaces, where they may lack the capabilities to use the invited spaces to make claims when ends are unmet. Yet, others may benefit from resources available within those trial sites and from political capabilities honed through networking with others in global political spaces. This kind of empowerment can be inclusive, by bringing new people into health activism. Alternatively, it may be exclusionary and divisive, to work against the ideals of community engagement.

In researching the efforts of AIDS activists to claim political space in America, Epstein (1996) found that lay experts tended to move closer to the world view of researchers and away from fellow activists. This suggests a widening gap between those who become empowered and those who are excluded from such opportunities. Whether operating in invited or claimed spaces, health activists may become distanced from the most vulnerable people whom they represent. That tendency to exclusivity can restrict the scope of decision making over Ruger's (2007) valued health domains. Thus, resources gained can be mobilised in different ways, with different effects (Allen, 2008), here in terms of personal or community interests.

The key point to be reinforced here is that “the ability to act, to intervene in events so as to make a difference is also a form of power” (p. 1614). It is those acts which make a difference to community health that I now consider. Such acts can be detrimental, but they can work in more positive ways. Either way, their impact can be significant. In the process, “new opportunities for participation can be ‘schools for citizenship’, by creating new, unexpected forms of action, and planting seeds for further change in the future” (Gaventa, 2007, p. xvi). In particular configurations of power, a mix of purposeful and chance encounters (ibid), can influence the governance process.

2.5 CITIZENSHIP

I now turn to concepts of citizenship which promise to enrich understandings of the ways that civil society provokes political change and where capabilities for community health governance may be developing in local health initiatives. A focus on how citizenship is conceived, by whom, and “what sort of participatory engagement is envisaged” (Leach and Scoones, 2005, p. 21) guides this research into the political arenas offered, or claimed, where citizens exert their rights and perform their duties. Situations where challenges do not arise, or are confounded, provide reflection on the reasons why participation does not appear to be relevant to some people and what conditions inhibit effective participation when the ultimate aim is to fulfil citizenship rights and obligations.

Concepts of citizenship have evolved from a specific focus on civil and political rights and responsibilities to include socio-economic rights. Here, I trace these developments and consider the ways in which multiple and, more often, conflicting identities may work against health activism in such difficult environments. Where state protection and support of citizens is most obviously lacking, an understanding of the imprint of historical patterns of colonialism (Mamdani, 1996) provides insight into contemporary daily realities as they have developed over time in particular places. The realities of community diversity and conflict can thwart ideals of cohesion and collaborative political engagement. Political relationships in such contexts tend to be divisive, with implications for the shared health governance endorsed by Ruger (2010a). Finally, I explore the potential of the concept of

"acts of citizenship" in understanding how social behaviour may provoke social change (Isin, 2008).

2.5.1 Concepts of citizenship

Turner (1993, p. 2) conceives citizenship as involving legal, political, economic or cultural practices "which define a person as a competent member of society, and which as a consequence shape the flow of resources to persons and social groups". This encapsulates contemporary perspectives on citizenship developed from different roots in liberal, communitarian and civic republican thought. For the following outline of conceptions of citizenship as they inform development I draw from Leach and Scoones (2005). Firstly, the liberal focus is on a concept of universal political and civil rights and responsibilities, where citizens are deemed to have the choice to act as individuals in pursuit of their interests as rational beings, with no need to engage in or to challenge agenda setting. This assumes a benevolent political system in which all are able to participate as beneficiaries of protection and rights. The emphasis is on the ascribed status of citizenship (Kabeer, 2002) and representative political systems (Heater, cited in Gaventa, 2002).

Secondly, communitarian perspectives focus on citizens in their relationship to others as they work together in pursuit of the common good in self-governing local environs, where the role of the state is limited if not irrelevant and where communities are assumed homogenous. The distinction here is to do with claimed status and political action. Local knowledge plays two roles as a resource and in defining membership. Citizen activity, though more often locally specific, can include notions of global connectivity in the wider pursuit of the more universal common good. As Leach and Scoones (2005) point out, this perspective has guided development projects since the 1980s.

A third thread of ideas around citizenship seems to meld aspects of both liberal and communitarian views into civic republicanism. Here, citizenship incorporates legal rights

and responsibilities as well as the practices whereby individuals and groups work to confirm existing rights or to claim new rights (Isin and Wood, 1999). The emphasis is on the collective, working in forms of deliberative democracy, either as an alternative or as a complement to formal mechanisms, to provide the organising framework for political dialogue (Leach and Scoones, 2005). The ways that knowledge and experience have informed citizenship claims is exemplified in HIV/AIDS activism and other health and environmental concerns.

Gaventa (2002, p. 7) suggests that contemporary theory attempts to incorporate threads through "the liberal emphasis on individual rights, equality and due process of law, with the communitarian focus on belonging and the civic republican focus on processes of deliberation, collective action and responsibility" in order to "bridge the gap between citizen and state by recasting citizenship as practices rather than given". Thus current theories of citizenship incorporate those struggles reaching beyond traditional, formal political arenas and beyond state-society configurations where politics is practised. This movement away from a narrow conception of civil and political rights and responsibilities, to include social and economic rights politicises social rights in particular (ibid). In post-apartheid South Africa "multiple identities around struggles over concrete issues" (von Lieres and Robins, 2008, p. 50) are found. Despite the normative impulse behind contemporary citizenship theory,[49] the socio-economic perspective brings into view the ways that:

> … human beings are tunnelling ahead to achieve their goals, forming new networks, extending old ones, and emerging most clearly into our view with rival configurations of one or more of the principal power networks (Mann, 1986, p. 16).

Yet, each of the three perspectives assumes a citizenship cohesion which often belies the reality (Leach and Scoones, 2005). This recognition guides the search for concepts of citizenship which encapsulate more inclusive forms of participatory engagements between state and society. As Gaventa (2002) points out, when rights are not set into specific

[49] Jones (2006) highlights the normative underpinnings of citizenship theories to warn us that not only does research into citizenship reflect the failure of citizens and their institutions to meet those ideals, in its broadest of definitions citizenship tends to lose its meaning.

political and historical contexts, differences in understanding of rights, and the ability to make claims, leads to different outcomes. An understanding of different historical legacies offers a more solid foundation for recognising present day lived realities and how the politically marginalised have been excluded, or incorporated and depoliticised. Such differences in terms of gender and different global contexts are discussed below.

2.5.2 Multiple identities and citizenship

Perspectives on citizenship flowing from this development of ideas deriving from models of Western liberal democracy have been challenged by those who question notions of universal access to rights (Lister, 2007; Kabeer, 2002). Recognition of difference (Fraser, 2005) has helped to identify what it means to be a citizen to those who struggle to gain citizenship rights and Lister's (2003) focus on gender has extended conceptions of citizenship to include the private realm previously isolated beyond the public sphere of politics. By considering "the intimate and domestic, the local, the urban, the regional and the global" (Lister, 2007, p. 55), her gender perspective incorporates those private arenas where gender violence and poverty combine to effect higher rates of HIV infection and limited access to HIV treatment or public heath care. More recent attention to the rights of children and disabled people aims to track the development of "a more grounded understanding of citizenship" as it is experienced in different contexts (ibid).

However, such expanded notions of citizenship have been challenged by those whose understandings differ from those Western conceptions. Mamdani (1996, p. 297) questions prevailing notions of civil society where forms of governance have had a different history from those experienced in the West and where African civil society resistance has "floundered on the walls of customary power". Even South Africa, with its rich legacy of powerful resistance against apartheid, has not escaped the fate of a rural-urban divide marking the pattern of a bifurcated state and contemporary civil society of two classes separating those urban publics who engage politically and rural, or migrant, publics who "form a class that is in civil society but not of it" (ibid). Hence, an understanding of different contexts across those urban and rural divides adds another

layer of complexity where historical traces continue to influence contemporary civil society activity.

This focus on rural-urban difference is not identified to highlight rural political marginalisation, as such, but to illustrate how that colonial incorporation of rural populations into forms of customary power and ethnic pluralism fragmented and limited opportunities to democratise rural power. The imprint of this political act, initially dividing populations to secure power and to destabilise a potentially united civil society, endures. This legacy of power relations has derived from the incorporation of rural publics into political programmes rather than their marginalisation from them, which presents a different set of problems around notions of co-option and exclusion.

In her anthropological work in rural Nigeria on contemporary notions of citizenship, Jones (2006, p. 1) found that "different types of citizenships are constructed through the dynamics of people's everyday lives, [where] institutions, identities, belongings, rights and duties they compromise are valued". She discovered a diverse set of interrelated subject positions where each identity is more prominent at different times, in different ways and in different spaces. This presents a picture of citizenship bounded by a complex set of interests and identities, elements of which are fluid, sometimes in conflict and not necessarily combined in a coherent conception of citizenship. Her recognition that citizenships involve sub-national memberships[50] and may be constructed "when it makes sense to do so" (p. 23) guides my own research into the ways that engaged communities may experience citizenship in their daily lives. In this case, the two classes of civil society which of Mamdani (1996) writes coalesce in urban South Africa through complex patterns of migration over time and which contradict simplistic notions of citizenship identity, or of an urban-rural dichotomy.

[50] With reference to Mamdani (1996), Jones (2006, p. 3) includes sub-national memberships of ethnicity, clan, traditional chieftaincy and local community.

Hence, from these African perspectives, citizenship as a formal political status is not sufficient means alone. It requires attention to issues of poverty and other social inequalities which exacerbate other inequalities derived from ethnicity, gender, sexuality and disability and which form the basis of claims to good health. People engaged in civil society activity negotiate multiple identities which may limit their capacity for sustainable community engagement. Family and social duties and obligations may detract from that activity. Structural difference or the inter-relationships involved (Jones, 2006) can also work to limit engagement and capabilities for citizenship whether or not encouraged and supported by health initiatives. Such questions of identity and difference are significant factors in political exclusion.

The critical eye on normative conceptions of citizenship cast by Jones (2006) reflects the ways in which citizenship is perceived and manifest in everyday life. Conceptions of citizenship may have little currency where more immediate concerns predominate. For instance, concerns involve personal safety in communities with high levels of violence against those deemed to be breaking social norms, or considered to be outsiders as non-citizens. As Mamdani (1996) argues, the roots in the denial of the rights of non-citizen migrant labour are not specific to South Africa. However, patterns of migration increasing more recently may have exacerbated contemporary conflicts, diverting attention away from the deep socio-economic inequalities experienced by the majority of the South African population. To be a 'foreigner' is not necessarily determined by legal and political status. The disenfranchised not considered to be citizens are rejected along with those migrants with citizen status.

Exclusions from civil, political and socio-economic citizenship have an impact on the capability to use resources available to gain access to health. Instances where challenges to socio-economic inequalities do not arise (due to the lack of capabilities to take action), or are confounded (due to social exclusion), bring out the sharp cleavages in heterogeneous community settings; to highlight limits to more inclusive participation and citizenship. Such diversity and multiple citizen identities are likely to exist where local

health initiatives attempt to engage communities, therefore one way of researching such activities is to seek to understand what people do, rather than to ask them what they think about such an abstract concept with so many meanings attached. That focus on what people do connects concepts of capabilities to function (Sen, 1999) with the following concern with acts of citizenship (Isin, 2008).

2.5.3 Acts of citizenship

A perspective on citizenship highlights acts rather than the status of the subject, to reveal how "governing subjects" constitute themselves as citizens (Isin and Nielson, 2008, p. 2). In this view, acts which break with habitus[51] provoke new "modes of conduct", to "rupture socio-historical patterns" (ibid). Such acts follow purposive decisions – whether or not intended – which result in completion of that purpose (Isin, 2009, p. 378). An example given to illustrate one of those acts of citizenship is the famous Montgomery Bus Boycott in America which began in 1955, where a seat designated for white people was claimed as a civil right by Rosa Parks who refused to surrender her place to a white person (Isin, 2008, p. 18).

Such acts of citizenship are distinguished from notions of active citizenship, where scripts already created by government for instance, are followed rather than self-directed. Where the active citizen may pursue a more regulated and proscribed set of claims for justice, the activist citizen writes the script and through such act "the order of things will no longer be the way that it was" (Isin, 2009, p. 379). From this perspective, through the disruption of "routines, understandings and practice" (ibid), activist citizens become *answerable* to *justice* (p. 381, author's emphasis).

I suggest that such routines can be found in habitual conceptions of HIV/AIDS as they are reflected in understandings and beliefs as to the causes and consequences of such a devastating disease. Those responses will be evident in everyday practice enacted in

[51] Isin (2008, p. 17) explain Bourdieu's habitus as the ways in which ways of thought and conduct are internalised.

more formal encounters with health officials and in wider social relationships. In challenging such routines, understandings and practices, acts of citizenship can be creative and potentially transformative through new modes of problem-solving in new political spaces. Thus, activist citizens may pursue their claims for justice in political spaces other than those created by government or, in this case, by local health initiatives.

This conception of activist citizenship resonates with Allen's (2008) purposeful encounters in which people may intervene in events so as to provoke change. Others have interpreted creative acts as those arising when we do not know how to act (White, 2008). In South Africa, difficulties in finding ways to respond to the HIV/AIDS epidemics – not knowing how to act – have been exacerbated by the political controversy, as explained in Chapter One. In White's (2008) view, citizenship claims are being made through "genuine encounter", where people are forced to act creatively in response to crisis (p. 46).

Response to crises can be negative or positive. Where socio-historical patterns influence stigmatising behaviour people may stigmatise others, or they may challenge those stigmatising behaviours to encourage inclusion of the stigmatised. Therefore, just as social behaviour can arise through intolerance to effect exclusion it can also be beneficial. In doing so, social contributions with significant political impact may be made. Acts of citizenship performed within the trial site communities may play an important role in breaking routine and established patterns of behaviour and, in the process, create new subjects of citizenship. Isin and Turner (2007) emphasise the importance of citizenship in its role in promoting what they call effective democratic societies. Therefore, citizenship rights extend to the responsibility to support measures to ensure good health. In this sense, participation can constitute "being political" in purposive acts of citizenship (Isin, 2005). Analysis of such potential acts will drive this research forward in seeking answers to the ways that communities may play meaningful political roles in local health initiatives.

In sum, recognition of different and multiple identities helps to identify what citizenship means to those who struggle to exert their rights and the limits to inclusive community

engagement in health initiatives or any other development programme which might build on capabilities for political agency. A focus on the everyday lives and the acts of citizenship which may arise when people have the capabilities to do so gives some idea of the ways in which people perceive citizenship through their actions in response to crises such as HIV/AIDS in their midst. Indeed, Mamdani (1996, p. 19) suggests analysing "actually existing civil society so as to understand its formation rather than as a promised agenda for change". By analysing citizenship in practice, efforts to perform acts of citizenship will be given due regard.

2.6 CONCLUSION

This chapter began with the main research question asking to what extent communities can play meaningful political roles in local health initiatives, such as the HIV vaccine clinical trial sites which are the focus of this study. The conceptual framework which followed suggested the ways that those roles might be achieved; firstly by considering how the capability approach to social justice may identify the resources, agency and social norms influencing health access. Ruger's (2007) approach to social justice and health is not concerned with equal access or rights, so much as the impact of healthcare on capabilities to function. Her key requirements for access to health stimulate questions on the specific ways that resources are used.

Contested concepts of community and community engagement illustrate the challenges in developing capabilities within the invited spaces of trial sites. Cornwall's (2002) distinction between invited and claimed spaces lends insight into the ways that civil society seeks the accountability of institutions where it operates, or may challenge the *status quo* from the outside. However, as she has argued, this political activity is far from discrete in many cases. People can operate politically across those spheres, so that both kinds of political activity have repercussions on each other. Much as those interrelationships may help to generate positive change for poor people, identifying where this may be more difficult gives insight into constraints, their origin and the consequences for health governance and other kinds of resource. Those constraints will arise more often from the different

political agendas of the various actors and institutions involved in health governance from local to global levels. Where those agendas converge, access to health is more assured.

The concepts of governance and power laid out in this chapter will help to explain those multilevel interactions across those local and wider arenas. In this case, each level of health governance will have an impact on local initiatives where the process of community engagement, and the accountability of health programmes to communities, is negotiated by local health initiatives and community advocates. Relationships of power influence the quality of community participation in such initiatives and, in consequence, the political capabilities which the most vulnerable partners in the vaccine trial process are able to develop. I focused in particular on procedural aspects of health governance, so as to understand how community engagement is being developed, and then moved on to consider how donors, researchers and communities may hold each other to account for their expressed commitments in their different roles in health governance.

The enabling and relational aspects of power have resonance with the capability to function to secure valued health resources. Power becomes a resource through relationships with others. Power as agency identifies the ways that it can be used to gain access to health. In this respect, I have suggested that institutions may enhance or inhibit that process, whether operating at local, national or international levels. People working in local health initiatives, national governments, PPPs and global health institutions all play their part in the fortunes of communities seeking valued health resources. Efforts made to exert rights to health citizenship may be encouraged, through community engagement, or curtailed by more powerful agendas, with little room for negotiation and manoeuvre over valued health resources. In this latter case, meaningful political roles in development played by communities are less likely.

Such political configurations play out under particular socio-historical conditions. When such conditions are not conducive, the capacity for acts of citizenship to have influence is more limited. In poor communities, many are denied the opportunity to claim full

citizenship rights. This challenges the very foundations of community as a cohesive, inclusive concept. In reality, where material resources are limited, people are more often preoccupied with daily survival and so lack the capabilities to be healthy, or to pursue their constitutional socio-economic rights. Alternatively, where participants are able to pursue the lives they have reason to value, acts of citizenship may have impact beyond efforts to respond to immediate health needs. The following chapter explains the methodological approach and the research methods best suited to understand the environments where this might occur.

CHAPTER 3

METHODOLOGY

Chapter Two laid out the theoretical framework which guides this research. It provided the foundations for the empirical research to be carried out in field work. In this chapter I outline the research approach beginning with a review of the research questions, followed by: the key theoretical and empirical challenges of this research; the research approach and design; the research context and methods. This is followed by the phases of data collection and their analysis. The chapter ends with a discussion of ethics in terms of procedure which provided access and the ways that ethics played out in the field. Aside from this historical and political context, HIV/AIDS is a complex topic in itself with impacts from the most private to public spheres and from local to global arenas. Therefore, in this setting, an exploration of health governance and community engagement required a conceptual synthesis to explain that complexity and to prepare for the empirical challenges.

This complexity required some deliberation over research approach, design, choice of methods and preparations for analysis in response to those challenges. The politicisation of HIV/AIDS and the sensitivities involved in this kind of research gave some pause for reflection throughout the research process. Awareness of that politics and sensitivity would be the overarching considerations in finding ways to understand how HIV/AIDS is governed. As explained in Chapter One my focus was primarily on the perspectives of local communities engaged in trial site activities.

3.1 THE RESEARCH QUESTIONS

I return here to the research questions designed to interrogate that governance process to review the research focus and key factors involved. The sub-questions identify those key factors in terms of the expectations of roles and responsibilities in community engagement and the realities which face those attempting to fulfil those expectations. These questions are designed to find answers to what those involved in community engagement consider

as valued resources and how they use them to what ends. The problems that arise identify the gaps between those ideals and the realities experienced by people living in poor communities where trials are based. Each question leads back to the main question which seeks to understand the ways that community roles may be politically meaningful.

Main research question

'To what extent do communities play meaningful political roles in local health initiatives?'

Sub-questions

- 'How do participants involved in trial site activities perceive community engagement and their roles in this engagement?'
- 'What resources are available and what resources do engaged communities bring to local health initiatives?'
- 'What problems are being experienced during the process of community engagement and how are problems involved in community engagement being addressed?'
- 'In what ways are those involved in community engagement developing the capacity to stimulate social change?'

3.1.1 Research challenges

The challenge here is to find ways to set into operation the key concept of meaningful political roles. To engage politically suggests decisions to change social conditions and how this can be achieved. What is meaningful is determined by those who seek that change. In this case, communities engaged in trial site activity may be driven by the desire to achieve health, or by other more immediate concerns. They may be concerned with wider development issues. Whatever the desired outcome, the ways that engaged communities see their actions as fulfilling those goals are essential in understanding what is perceived as a meaningful political role. However, personal fulfilment is only part of the story of the process towards making wider political impact and these are the fundamental issues which needed attention.

I began by observing the trial site governance process using the concept of procedural governance (Yanacopulos, 2005) discussed in Chapter Two. In the same way, Allen's (2003) modalities of power gives focus to the power relationships observed during meetings. With the growing familiarity between my respondents and me, plans for focus groups and interviews were made. I began to perceive gaps between the ideals of community engagement endorsed by advocates and the realities, confirming that the commitment to those ideals and efforts to 'do' community engagement need to be seen in context. The difficulties of everyday life and the frustrations in achieving those goals reveal the limits to meaningful political engagement in poor communities. Whether or not resources are valued, building the capabilities to use them can be thwarted by those difficulties. The frustrations of 'doing' community engagement would become evident through those conversations, meetings, and more formal interview and focus group encounters.

In essence, exploring whether or not people are able to express concerns and make changes may be important measures of the practical aspects of community empowerment which make their roles meaningful. Kabeer's (1999) conceptualisation of empowerment requires evidence of the resources (preconditions), agency (process) and achievements (outcomes) involved. The first two resonate with Ruger's (2007) principles discussed in Chapter Two. The ability to make choices and the kind of choices that can be made which guide Kabeer's (1999) evaluations of empowerment are commensurate with Sen's (1999) capabilities to function. Deep-rooted constraint on that ability to choose is taken to be disempowerment manifest (Kabeer, 1999).

For some, these roles may be played out in their everyday lives in one-to-one encounters, and for others it may involve attempts to make impact at trial site or higher political levels. Valued resources may be material or less tangible, but opportunities to make choices over those resources may be definitive, as suggested (ibid). Further, what can and cannot be achieved from within these invited spaces may be heavily circumscribed by external forces. Therefore, the impact of donors and advocates and wider social norms on such

local initiatives must be explored. The problems faced by people who are working to engage communities would give some sense of the scale of their problems and the ways that they find to overcome them. At the same time, their conceptions of successful engagement and the ways that they might feel empowered would begin to build a picture of what are considered to be meaningful political roles.

3.2 RESEARCH APPROACH

Accordingly, this research approach is guided by a "subtle realist" perspective (Hammersley, 1992; Snape and Spencer, 2003) in a process of deductive and inductive enquiry. My concern here is whether or not the chosen concepts and theoretical framework can help to explain health governance in a particular socio-economic and political context, through the two case studies set within that wider global and national arena. The politicisation of HIV/AIDS gives this health condition an exceptional quality which drives this aim to understand the experiences of those involved and their interpretations. As outlined in Chapter One, much has been written about the impact of this politicisation (Schneider, 2002; Gumede, 2005; Geffen, 2006; Nattrass, 2007), but the perspectives of those taking the brunt of the HIV/AIDS epidemic need recognition so that effective means to better health can be achieved. The history of political activism against apartheid suggests a legacy influencing present community activism in the face of this new challenge. These assumptions would need to be tested through my own engagement with those whose lives have an imprint of that political legacy as they endure this current health crisis.

The research approach chosen was "subtle realism", to frame my understanding of those diverse subject realities as they exist within the wider social world independently of those understandings (Snape and Spencer, 2003, p. 11). This combination of social constructionist and realist approaches accepts that knowledge is uncertain, but that "knowledge claims can be judged in terms of their likely truth" (Hammersley, 1992, p. 66). Different interpretations of reality yield different understandings existing within a "diverse and multifaceted" external reality (Snape and Spencer, 2003, p. 19). This "meaning in

context" (Willig, 2001, p. 141), draws the attention to different perceptions of community engagement, HIV/AIDS, health and development. At the same time, those perceptions are framed by historical events which have influenced health policy and social norms around HIV/AIDS.

By revealing inherent tensions and contradictions (ibid) between the stories of different actors in that historical context, and how these interrelate at clinical trial site level, the epistemological approach serves three key purposes. It shows: the ways in which people with different histories and experiences process phenomena and recall events; the countervailing pressures involved in developing the capabilities to stimulate change, in part, borne of those experiences; and instances where those diverse and multifaceted perspectives coalesce into potentially transformative ideals and actions.

3.2.1 The case study approach

The case study approach, as a framework for a school of methods and data collection (Thomas, 1998), would best encompass the diversity of experience in contexts which generate common features and what Stake (1995) calls the particular. This approach is useful for generating explanatory claims and to explore causality, that is, to record events and to explain why and how decisions are made, how they are implemented and with what consequences (Yin, 2003; Thomas, 1998). As such, an understanding of concept, theory or social process can develop (Schwandt, 1997). With the development of the conceptual framework, a greater understanding of political agency and its consequences grows. In addition, the case study approach is the most appropriate in helping to explore communications between partners in networks (Yanacopulos, 2007) across those local environs.

This approach does not provide proof, but seeks to find evidence for or against an idea by using multiple perspectives and data collection methods (Thomas, 1998). One such idea might be that community activism enhances health. This kind of exploration has been compared to a series of uncontrolled scientific experiments with unpredictable results, as

the story evolves (ibid) through ‘real life’ phenomena (Yin, 2003). Flexibility grants opportunities to follow new leads which may challenge ideas. Correspondingly, factors which seemed important can be rejected when found to be less significant and factors which have been accepted as less significant prior to field work may take a new prominence during that research process.

Unexpected developments reveal new insights and those unexpected factors become part of the story. For instance, the political unrest during the first research phase had direct repercussions on the data collection process (see 'ethics in the field' below for a more extensive discussion of these events). At the same time, it would stimulate further reflection on concepts of citizenship in this South African environment. With the escalating violence against ‘foreigners',[52] questions of exclusion shifted the focus from those who appeared to be enacting citizenship, to those whose rights were being challenged and whose access to health was circumscribed by their new status as refugees, whether or not officially South African citizens.

As the field work took its course, informal discussion with academics and practitioners in the field gave pause in the more formal daily efforts to collect data. Their insights became new data and helped to shape the research. Those insights were essential to an understanding of this sometimes bewildering array of information and perspective in such a politically charged environment. Stories gathered whilst “hanging around” (Hammersley and Atkinson, 1995) in clinics were as revealing as political commentary, if not more so. Brief recollections by people as they managed their lives at such times gave immediate and striking impressions which leave a vivid imprint on the memory.

This open-ended approach gives sufficient attention to context, allowing “distinguishing characteristics … to act as a springboard for theoretical reflections about contrasting findings” (Bryman, 2004, p. 55). This flexible approach would be enhanced by the two

[52]“Foreign Africans” (Makwerekwere), are the victim of prejudice and violence as “a convenient scapegoat for [South African] ills” (Sichone, 2008). I return to this discussion below and in detail in Chapter Five.

periods of field research in two geographical contexts in a reflexive and iterative process. During the intervening time, a re-appraisal of method and theory building gives space for new ways of explaining phenomena (Woodhouse, 1998). Again, this flexibility can enrich data by revealing unforeseen factors and problems, to stimulate new insight and new questions to be explored as part of the deductive and inductive theoretical process.

3.3 RESEARCH DESIGN

With the insights gathered from prior knowledge of the complex South African socio-political and cultural context, some time was taken to consider how to approach this development problem. In the search for potential cases to be explored I was guided by Lewis (2003), who acknowledges the need for clear thinking before making decisions over different comparisons between different actors within a single case, between cases, and between groups of participants across cases. The complexity of case study research has much to offer, but the criteria for selection need careful consideration as a key factor in research success (Jupp, 2006).

The case studies

Plans to produce a coherent study across several trial sites could be compromised by many local political and socio-cultural factors. The composition of cases, along with who participates in the research and how much variation across cases is acceptable (Lewis, 2003) are weighty considerations. Although differences are instructive, questions over differences in populations and the degree of consistency across cases, in addition to the number of cases and participants within each, are inevitable.

Given the research boundaries of a PhD, a full range and diversity of case types and key players would stimulate too large a sample. Therefore, following Lewis (ibid), a compromise was made between breadth and depth of case coverage. Yin (2003) suggests that even a two case study approach offers substantial analytic benefits and therefore improves the chances of producing a good piece of research. In this way, the

potential hazards of an unwieldy study are avoided, though still producing rewarding data from contexts of considerable complexity. Practical considerations also intervened. Choices were limited by approvals for access to clinical research sites. Therefore, whilst deliberating over potential research sites, options narrowed during that approval process (see 'site selection' below).

Two sites with the potential for comparison provided opportunities for findings in common across cases. As Bryman (2004) suggests, these can be as interesting and important as those in contrast. Although patterns might offer the potential for analytic generalisation, given the qualitative approach none can be made in any statistically significant way. Even so, it might be possible to make general theoretical conclusions from a small number of case studies, or even one, as Thomas (1998) suggests.

Just as much as there are myriad differences across multiple arenas, case study research does not guarantee control over data and prejudice can be confirmed rather than challenged. Since objectivity is not assured, systematic procedure, reflexivity and transparency supports the validity of research findings (Woodhouse, 1998; Thomas, 1998). Therefore, a triangulation of approach and method directed: i) the choice of data collection and the range of research participants and: ii) the iterative process of design, interview, analysis evaluation and redesign, to test working hypotheses and to confirm evidence. In the latter case, redesign of interview questions becomes a logical part of the research process as confirmation of evidence proceeds.

In research terms triangulation involves taking bearings to reduce uncertainty regarding the methodological approach, theoretical framework, and method, to clarify different perspectives. Efforts to ensure a range of data are reinforced by the selection of research participants. A broad spectrum of research participants gives multiple perspectives on roles, motivations, identities and the everyday realities of working lives, both in employed and voluntary capacities. This taking of bearings extends to asking different questions posed in different ways on particular issues; enhanced by reviews of secondary data to

highlight comparisons and contrasts. At the same time, triangulation provides a framework for data analysis of these different components. Such a flexible methodological approach to encompass a range of data and to reduce uncertainty needs to be framed within distinct research boundaries.

Research boundaries

Given the methodological considerations and the above-mentioned socio-cultural and political complexity, research boundaries were considered at the research design stage. The intention was to investigate community engagement activities within trial sites with no attempt to interview community members who were not directly involved in those activities. Within those local geographical boundaries, I could focus on the trial site activity and, at the same time, set that research into its wider health governance context. Even so, I was hesitant about my ability to do research in this South African context. There are inherent tensions over who is entitled to speak on behalf of others and this needs vigilance during the research process (Tomlinson, Swartz and Landman, 2006).

However, in South Africa, “there are complex layers of being inside and outside”, such that I might be viewed with less suspicion than a white South African researcher (ibid) whose socio-cultural 'baggage' can be inhibiting in this historical and political context (personal communication, July 2007). One interviewee explained that South Africans were more hesitant to allow others to research them than they were to do research in other countries and assured that it was necessary to have an outside perspective. The suggestion was that important questions on socio-political issues are less likely to be avoided by researchers living outside this complex environment.

3.3.1 The research context

South Africa was an attractive research proposition in its key global role in biotechnology innovation and development. As a middle income developing country, it has resources for science and technology capacity building and yet, there is little empirical evidence of

those resources at the local level. Advocates promote communities as the intended beneficiaries of the clinical research in which they are engaged. The detail of the research site selection is followed by a summary of the extensive ethical procedures which allowed research access.[53] I go on to describe the activities of the two clinical research sites, with community engagement as the key defining feature.

Research site selection

The combination of pioneering clinical research and a strong civil society contrasts with political delays in adequate HIV/AIDS health policy, as outlined in Chapter One and given detail in Chapter Four. That lack of political support has reverberated across South Africa. Consequently, efforts to challenge social norms around HIV/AIDS have been constrained by the political confusion spreading down to community level. How communities deal with such political controversy provides important measures of political empowerment, at times in conflict between government and civil society, but also in concert across claimed and invited spaces (Cornwall, 2002). Within this national context, two research sites would reflect some of the socio-cultural diversity and yet retain some measure of control over potentially unwieldy data from that diversity.

Within the SAAVI umbrella, there are several clinical trial sites across the country, ranging from the well established to newly formed sites in both urban and rural areas. I had been in contact with the Director of the Cape Town trial site and so pursued this option. The idea of a contrasting rural site for the second research phase was attractive, but requests to research in one favoured rural area of KwaZulu-Natal were rejected by the Director of the Durban trial site during the first research phase in Cape Town. People working in Cape Town suggested another site in the northern gold mining areas, but my initial application was met with requests for additional research which would limit my research time and compromise that research. At the same time, the Perinatal HIV Research Unit (PHRU) in Soweto accepted my application with no requests attached.

[53] A full account is made in Appendix 1.

I began the approval procedure for research in this other urban 'site of excellence' for its potential for comparisons to be made with the Cape Town site. These complementary sites might stimulate theoretical generalisations. The combination became increasingly attractive due to their pioneering work as early providers of ART – eight years before government provision – and their current research focus on TB and high risk vulnerable groups, such as MSM and adolescents,[54] thereby widening access to health to include those most vulnerable to HIV/AIDS. In addition, mobile testing facilities for a range of health problems travel across the surrounding areas to reach those who are unable or unwilling to visit the clinics.

This progression of earlier pioneering work would help me to explore issues of inclusion and exclusion and the links with concepts of citizenship in particular. Initial fears over working in Johannesburg, with its legendary crime rate, were outweighed by such an opportunity and the need to move into the final research phase. Such key clinical research sites would reveal community engagement at its best. Given optimum resources in this South African environment, this research should give some insight into the opportunities available and the extent to which communities might be able to exert health agency for vulnerable groups of people.

On a personal note, the clinical research sites were situated at the epicentres of the anti-apartheid resistance movement where I might explore the potential of this heritage on current health activism and fulfil a longstanding aim to visit the sites of earlier research into anti-apartheid resistance.

Research phases

An initial visit in 2007 allowed two weeks of contact building; with one week in Cape Town and one in Durban where I attended the third annual South African AIDS Conference. Here, my understanding of HIV/AIDS in this South African context could develop. I could

[54] See the Desmond Tutu Research Foundation at: www.desmondtutuhivcentre.org.za, and the Perinatal HIV Research Unit at: www.phru.co.za

meet trial site Directors and others involved in AIDS vaccine work and make arrangements for future research. Following the conference, I was invited to join the SAAVI Socio-behavioural Research Group (SBRG) workshop on community engagement sponsored by IAVI and SAAVI. This provided an opportunity to observe the interactions and power relationships between those two international and national bodies and AIDS vaccine advocates and scientists as they collaborated with CAB members over issues of best practice for community engagement.

These observations highlighted the tensions between the two international and national vaccine initiatives and the ways in which the tensions between trial site researchers and communities are negotiated. This primed me for eventual explorations of health governance across those national boundaries and at trial site levels. At the same time, it revealed deliberations over community engagement in process. Informal discussion with CAB members, community educators and trial site clinicians gave insight into the daily experiences of community engagement and the negotiations across national and global networks. I returned the following year to build on relationships and to do my research in the two clinical research sites between April and November.

3.3.2 Research sites

The first part of the research was conducted between April and June in 2008 in Cape Town and based at the Desmond Tutu HIV Foundation and the research was conducted in and around four clinics. One is based in the Health Sciences Faculty and three others situated in outlying townships based in the Cape Flats in Nyanga and Guguletu and in Masiphumelele[55] in the outlying South Peninsula. I began by getting to know the counsellors – who were CAB members – and they were the first people that I interviewed. I wanted to gain some insight into the daily lives of community members and their concerns and to orientate myself socially and culturally. Over the following two months, observations of meetings, interviews and a focus group were held in clinic waiting rooms,

[55] Translated from isiXhosa meaning 'We will survive' and commonly known as 'Masi'.

treatment rooms (including a shipping container), a canteen and a local primary school. That research is detailed below.

Since there are eleven official languages in South Africa, I made no attempt to learn any of these languages. I was offered translators, but this was not necessary and so the interviews and focus groups were conducted in English. Had we experienced difficulties, I would be able to draw on those resources. In the event, I was able to benefit from direct face-to-face in interviews and other encounters, thereby maintaining confidence in anonymity when requested and control over the data collection and transcription.

The next research phase was based in Soweto at the Perinatal HIV Research Unit (PHRU) linked to the Health Sciences Faculty of the University of Witwatersrand in Johannesburg. As explained in Chapter One, the unit is based in Soweto at the Chris Hani Baragwanath Hospital (commonly known as 'Bara'). Soweto (South Western Townships) is one of South Africa's largest urban populations and so the logistical problem of organising meetings across this expansive area have been resolved by inviting CAB members to meetings held at the research unit. This is where observations, a focus group session and interviews for this last phase of my research were held. During this research period, I returned to Cape Town to attend the second AIDS Vaccine Conference organised by the Global HIV Vaccine Enterprise and to visit earlier research participants informally.

3.4 RESEARCH METHODS

I begin with secondary data which included advocacy materials and ongoing media reports for those wider contextual issues. Discussion of primary data collection methods – observation, focus groups and semi-structured interviews – follows.

Secondary data

Advocacy materials and policy documents on 'best practice' provided by international and national stakeholders highlight the community engagement ideals. In particular, notions of

partnership, participation and engagement could be compared with interviewees' perceptions, through observations during focus groups and by hanging around (Hammersley and Atkinson, 1995) in clinics. Grey literature was gathered online from advocacy organisations, vaccine initiatives and national NGOs and trial site literature gathered during the research process.

Other data included that gathered from a series of academic seminars at the Universities of Cape Town and Witwatersrand on socio-economic and health issues in particular. Working Papers collected from the UCT Centre for Social Science Research (CSSR) and the AIDS and Society Research Unit (ASRU) helped to deepen my understanding of contextual issues, as did AIDS reviews from the Centre for the Study of AIDS at Pretoria University. Further, media reports on political and socio-economic issues, events and debates framed this research. In particular, during the first research phase, vivid reports of the civil unrest and the following commentary gave a wider perspective on the community disarray which preoccupied us all: not least those living or working in the townships.

In the second research phase, rapid political change at national governmental level was having an impact on HIV/AIDS policy which provoked more commentary and debate. Attending political meetings and cultural events gave more insight into the wider public responses to political events. The following discussion begins with an account of observations of those national events and daily activities in the trial site clinics.

3.4.1 Observation

By observing and recording actions and interactions those public events became new data which framed the more focused trial site research. Although this research was not an ethnography, I would take a similar approach by being immersed in social settings for some time to observe, listen and gain understanding of the culture of social groups (Bryman, 2004). Observation was chosen for its benefit in analysing naturally occurring behaviour and interactions and to investigate the process (Ritchie, 2003), in this case, of

how efforts to engage communities were being made in particular. The primary distinction is made when the researcher “slips the gear” between seeing and observing, with “the stimulus to be necessarily aware” (Sanger, 1996, p. 3).

The ways in which people organise and communicate across trial site power interfaces provided data to compare and contrast with data gathered through other research methods. Observation of what people do, rather than what they are thinking (Silverman, 2001), for example in CAB meetings, would be compared with what they say during focus groups and interviews. By observing proceedings, I could develop an understanding of their aims in community engagement work, both individually and collectively. In that process, their reactions to my presence would be noted for the ways in which this may influence their discussion.

Further, Sanger (1996, p. 4) raises the problem of researcher responses:

> Far from being a first line of defence and the search for objectivity, [observation] can be a leaky, permeable membrane … which allows as much to issue from the observer as hits her wall of consciousness from the outside with that satisfying but deceptive thump of factuality.

This caveat relates to the history beyond the moments being observed. For example, my perceptions of apartheid history and its repercussions would be challenged by the different experiences of interviewees. As I found, the problem of researcher subjectivity and the limits to how data are gathered, whatever the method used, are important. The key events, both within the immediate trial site and beyond, with reflections on that process, the data being collected and considerations made for future investigations using other methods are laid out here.

Observing national events

Observations were made at the two very different conferences in Durban and Cape Town. The third South African AIDS conference in Durban in 2007 provided contextual information on South African approaches to HIV/AIDS. Delegates ranged from academics to community based organisations working to develop HIV/AIDS prevention, treatment

and care. The community engagement workshop which followed provided introductions to some of the people that I would meet during the two research phases the following year. The issues raised there gave focus to community engagement debates in the clinical trial sites which would guide the initial preparations for the field work.

At the AIDS vaccine conference in Cape Town in 2008, a small social science component deliberated over ethical and practical concerns relating to trial participation. Most of the presentations reflected the more broad clinical HIV prevention approach already evident at trial site level. This was having an impact on community engagement, such that each CAB member needed a wider base of knowledge to correspond with the increasing range of clinical research and to respond to community questions and concerns.

The more complex issues around HIV prevention and new 'hard-to-reach' research cohorts had implications for trial site governance and additional challenges for voluntary CAB members. These new challenges in understanding the complexity of new scientific developments were discussed during interviews, focus groups and CAB meetings (see Chapter Five). A workshop to develop information on the legal aspects involving adolescents and children in clinical and social science research revealed another layer of complexity which forms part of the community engagement process in terms of processing and communicating information to communities and of their involvement in decisions over the age of consent.

Observing trial site governance

Phone calls and text messages were the main means of contact to plan meetings and other events with research respondents. Outreach workers were often travelling between clinics, broadband connections were slow and unreliable, electricity supplies were intermittent and few community members had electronic access. Records of daily procedures included informal discussion with staff, with individuals and groups in their

daily working lives, plus key events involving external visits from advocates and donors in their support of community engagement.

In Cape Town, these events included the official opening of the vaccine clinic in Nyanga on World AIDS Vaccine Day in May where the community were invited to visit the clinic. This was an opportunity to observe the reactions of the wider community to community engagement, to hear about the work being done during informal conversations and to find future respondents. As those conversations unfolded, people began to reveal personal stories which helped to orientate me. Their reflections on their work helped to clarify interview and focus group questions. Community leaders and older men unused to visiting clinics filed in to see what the clinic offered and to hear about how to help their communities and families who were ill. Later, we gathered in the local community hall to hear talks about the vaccine research and to be entertained and fed. This was community engagement in action and these encounters with people with HIV or AIDS were the first of many during the research and whilst spending time in clinics.

I then observed meetings including a global donor and CAB conference call where CAB members asked questions about plans following the failure of vaccine trials in the previous year.[56] This meeting was one of several which gave me some insight into the political interactions between CAB members. Other observations included four CAB meetings with the two functioning CABs in the Cape Town site and two meetings held jointly with the IAVI Programme Manager for Southern Africa, staff and CAB members as they made decisions over IAVI support and resources available. In Soweto, I observed three vaccine CAB meetings and one 'global CAB'[57] meeting with donors and advocates from America. This joint CAB meeting, which I return to in Chapter Five, gave insight into community engagement in other countries and important questions about the longer term implications of eventual withdrawal of clinical trials from the communities.

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[56] These were major Phase IIb trials involving large numbers of participants in America and South Africa which were halted due to higher rates of infection occurring in some vaccine groups.

[57] This is a term used for trial site meetings which bring together different CABs in one location, as well as the global meetings which involve CAB across within and across national boundaries.

In summary, observation provided a significant set of data on the wider context in which this research was set and where unexpected events would be an essential component of the more formal data collection. I was able to gain the trust of potential focus group participants through spending time observing meetings and events and building relationships with the Community Liaison Officers (CLOs) and CAB Co-ordinators as the official gatekeepers.

3.4.2 Focus groups

Focus groups were chosen to combine elements of observation and interview, not in substitute but to generate data not obtained easily with either of those two methods (Morgan, 1988). Focus groups provide an opportunity to observe a large amount of interaction on a topic in a limited time period and under the observer's control, providing a key to attitudes, cognitions and challenges (ibid). By identifying group perceptions, priorities and power relationships, that influence on the community engagement process is revealed. Some limitations include the operational difficulties and the tendency to group consensus. This latter problem was explored during subsequent individual interviews, to explore further than what people think to why they think as they do (ibid).

I took a semi-structured approach with the two focus groups, one in each trial site. A set of questions could be expanded upon if interest was shown, or abandoned if appearing irrelevant; much the same as in a semi-structured interview, though in a different format revealing different kinds of information. The contrasts between recommendations for procedure and our focus group experiences show limitations, but in the process unexpected information and events provided further data.

<u>The Cape Town CAB focus group</u>

In the absence of a fully functioning vaccine CAB, and the Nyanga PI's reluctance to allow me to observe meetings with the small core of members building a new CAB, my time was divided between CABs in Masi and Cape Town. These CABs were not designed to focus

specifically on vaccines and no vaccine trials were in process at that time. The Masi CAB was in difficulty made worse by the civil unrest as it gained pace in May, and so I was unable to plan a focus group with these people in the time available. Another practical problem arose. Both groups had meetings on the same day of each month, and so this limited the contact time spent with each one. I divided my time over between them the eight week period and managed to build their trust and interest in agreeing to be interviewed in the interim.

The Cape Town focus group was delayed while the CAB members deliberated over dates. They appeared unsure of themselves and lacked the leadership to come to any decision, and so I waited until they agreed to have the session on my last day in South Africa. This session lasted for over two hours while different CAB members turned up over the morning. Seven was an ideal number (Carter and Henderson, 2005), but a fragmented experience since all were not present at the same time from the beginning. The focus group began with four women who were joined by three men. The initial discussion focused on my questions on community engagement until the men arrived. This session was disjointed and interrupted – by their arrivals and by refreshments – and it was difficult to maintain the group focus with the late arrival of those members. I let the discussion take its course realising that more immediate issues than community engagement itself were more pressing for some members.

The flexibility of this focus group approach was beneficial in that issues most important to participants were raised and these were issues debated with some intensity. In previous work analysing data from Ethiopia, I found stigma to be a key concern. That research revealed fears of the unknown since the epidemics had not reached the rural areas where the research had taken place. In urban South Africa where rates of HIV infection and AIDS deaths are high, I had not expected stigma to be so central and to become a key theme in my data analysis. This may explain why dilemmas over HIV status disclosure in the workplace took precedence during this session. These were the kind of environmental

issues which distracted some participants from their obligations as CAB members and ultimately their capacity to 'do' community engagement.

The challenges that arose reinforced Morgan's (1988) point about the value of focus groups. One member began to withdraw in frustration over the dominance of this discussion which she felt took attention away from those community engagement obligations. That frustration had been expressed when discussing CAB meetings with her in an earlier interview. This focus group tension highlighted the difficulties in CAB management and the variable experiences of members. Some were more vulnerable to the stigmatising effects on HIV positive people than others. This revealed the limits to capacities for agency in such environments, where negative social norms around HIV/ AIDS were being challenged but remained potent.

The Soweto CAB focus group

In Soweto, the numbers of participants exceeded the ideal. The twelve CAB members had already spent several hours in a regular CAB meeting before the focus group could begin. In contrast to the Cape Town session we agreed to keep the session to approximately thirty minutes given the decreased levels of concentration, a noisy semi-tropical storm which rattled the tin roof and their flagging concentration. Again, this did not meet with the ideal where all are committed to spending time on an in-depth discussion (Carter and Henderson, 2005). Yet, my decision to shorten the time was appreciated to the extent that members queued after the session to make appointments for subsequent interviews. Having been less than enthusiastic at the outset they were then concerned that I had not got "enough data" from this session and so committed themselves to further time by offering to be interviewed. The interviews planned then gave me the opportunity to explore issues raised in that focus group. Those who felt dominated by more powerful members could reveal their frustrations in confidence and those who dominated could give their perspectives.

During this focus group session, my assumptions of a prevailing gender imbalance amongst CAB members were challenged. In contrast with the lack of women's confidence in the Cape Town focus group once the men arrived, in Soweto women leaders were more assertive. This may be due to their longstanding experience of local CAB management, their prior employment and wider global CAB involvement. Those personal histories were explored in the interviews. Where these and other key figures dominated the responses, despite my efforts to engage others, no challenges arose as had in Cape Town.

Unlike that earlier session, this focus group was held prior to interviews where consensus unravelled in stories of frustration revealing feelings of disempowerment. These issues are discussed in Chapter Five in some detail. These experiences, in the first focus group of the withdrawal from the discussion and in the second in apparent consensus, gave insight into the value of using different research methods. By observing interactions in focus group and through one-to-one discussion in confidence, interviews revealed new data as described in the following section.

3.4.3 Semi-structured interviews

The decision to do interviews was made to explore a range of perspectives and an accumulation of insight from a set of interviews to understand the life-worlds of those involved in trial sites. Again, a semi-structured approach allows the interviewer some freedom to explore those life-worlds. This would allow me to explore the 'how' and 'why' questions (Woodhouse, 1998). I could gather specific information from the particular populations and sub-groups (Thomas, 1998) working in the trial sites, both in employed and voluntary capacities. This research method would encourage perceptions and views of participants to emerge, such as the perceptions of meaningful community engagement held by community members and trial site staff. In that process, the political relationships between them which may inhibit or enable this process would unfold in confidence. I begin the following discussion with the sampling of interviewees, followed by the formal interview process with some discussion of informal interviews conducted and meetings attended.

Sampling interviewees

Decisions were made to interview a range of clinic staff and community advocates. Access was gained through consultation with the CAB Co-ordinators. A purposive selection of key vaccine trial site staff and community members was made to identify: motivations for engagement; perceptions of roles and responsibilities; perceptions of community engagement; key problems and successes; interactions with others; and future expectations. The aim was to understand contextual factors, such as health beliefs and valued resources, rather than quantifying difference (Lewis, 2003). In this way, the health beliefs which frame the approach to community engagement and the resources valuable to capacity building are revealed along with the different priorities and problems of participants in that engagement. Here, the ways in which the tensions between people were negotiated and the impact on community engagement could be explored.

Requests for interviews with those external to the trial sites to gather perspectives on the wider issues of health policy were accepted by academics. They were rejected by government ministers, perhaps due to the ongoing state of flux in health policy in general and the sensitivities surrounding deliberations over the funding of SAAVI in particular. There were no responses to several emails and phone calls to the Department of Science and Technology until a final call was met with hostility. Fears were expressed that I was a journalist and informal discussion with an academic confirmed that my difficulty in communicating with government departments was not unusual.

Overall, I had plenty of guidance on what CABs are and what they should be doing from the literature, but the interviews were essential in providing opportunities to ask members in confidence for the first time about the ways that they worked and whether or not they had other views and experiences which they had not been able to express in public. The discussion of interviews held will arise from within the data chapters to follow. Tables of interviewees show the range from in-house to outreach staff and community members within the two research sites and the communications with others external to those sites.

Formal interview process

The interviews were designed to elicit meanings and to understand events and processes (Rubin and Rubin, 2005). The meaning of empowerment and interpretations of community engagement events are cases in point. At the same time, the intention was to glean both cultural and topical data (ibid); with the former requiring more active listening to description of what is important to the interviewee, or to discover assumptions and norms and in the latter case taking a more active role in guiding the interview and probing particular issues in more depth. As suggested, both approaches tend to involve each 'ideal type'. In the former case, norms around HIV/AIDS could be explored and alternatively, the earlier trial failure mentioned above could be explored for its impact and the ways it had been managed. Different interpretations of that crisis began to emerge with those probes.

The interviews were designed to provide detail of individual experiences, principally of motivations for and issues around community engagement (see Appendix III). For many voluntary and some employed interviewees, their experiences and those of family and friends living with HIV/AIDS was the impetus for involvement in this work. Therefore, despite the aim to discuss community engagement rather than personal experience, issues of particular sensitivity arose borne of those experiences. One such interview was emotionally charged following a story of the death of a family member and so I made a follow-up phone call (as explained below in the section on ethics). More often, there was much laughter, especially when the interviews were conducted with two or three people, in stark contrast to the experiences which many described.

Having taken time to build a good rapport interviews were often held in rapid succession which left little time for reflection between them, but this problem was outweighed by the need to build confidence between us. Often, interviews began with a proscribed time frame chosen by the respondent and then continued for longer to produce rich detail when interviewees relaxed and began to elaborate on deeply felt views on their work.

The range of interviews across site staff and community members and the flexible design of interview schedules produced different perspectives. Patterns and differences across that range of experience emerged, despite the primary mutual goal in supporting vaccine trials. By tracing experiences “from separate yet overlapping angles” I hoped to become “more hesitant to leap to conclusions” and to develop a “more nuanced analysis” (Rubin and Rubin, 2005, p. 4). For example, counsellors, as both staff members and embedded within the trial site communities, have intimate personal knowledge of the lives of the trial participants. At the same time, their roles as counsellors continue into their lives outside unbidden but difficult to avoid. Their understanding provided fine detail of the daily lives which extend beyond those immediate boundaries of the clinics where they work and which influence their approach and responses to community engagement.

On a different level, researchers and trial managers focus on developing appropriate protocols, the intricacies of carrying out the trials and responding to donors’ requirements in that process. Each set of perspectives, from those embedded in communities to those involved in clinical research, differed but did not necessarily conform to expectations and so gave a rounded and more revealing view of community engagement at this grassroots level. Aside from these formal interviews, arrangements were made and opportunities arose impromptu which developed another layer of data through informal discussion, for example, the issue of ‘foreigners’ and government health and other policies.

Informal discussions

Informal discussions help to flesh out the contextual detail which can then be further explored in focus groups and formal interviews. They gave a sense of the immediate concerns which preoccupy people without the commitment to reliable evidence. 'Off the record' comments could be explored through other avenues without breaking confidentiality. Topics which I had been asked not to report during meetings arose unbidden in other encounters. Each of these encounters lent insight into HIV/AIDS policy, health governance, community HIV/AIDS programmes and the sense of urgency in dealing with such an acute health problem with long term repercussions.

An academic at the UCT discussed her involvement in the new National AIDS Plan which had been redrawn whilst the health minister was indisposed. This gave the Deputy Health Minister the opportunity to intervene before she was dismissed. In consequence, I was able to gain insight into political battles over national health governance as they unfolded. Seminars at the AIDS Social Research Unit (ASRU) on local and national issues surrounding my research gave local contextual detail to wider HIV/AIDS research. I had a chance to update events and information during a visit to the academics at Stellenbsoch University, with whom I had spent time the previous year at the Durban workshop and who were then researchers of the SAAVI Socio-behavioural Group. No longer funded to do their research under the SAAVI auspices, they were free to discuss things previously 'off the record' about the politics of national health governance and community engagement.

Meetings with AIDS vaccine initiatives helped to flesh out their activities. I had met the SAAVI Acting Director and her staff the previous year and spent informal time with her and a colleague at the vaccine conference. More formally, I met the Acting Director of the Southern African IAVI headquarters based in Johannesburg where we discussed IAVI's role in community engagement. I spent time with her programme manager whom I had met the previous year and at conferences, the Durban workshop and trial site visits to CABs in the Cape Town area. A meeting with the Global Campaign for Microbicides[58] (GCM) African Project Leader in Johannesburg and a phone call to the GCM Director in her Washington headquarters were both helpful. Microbicide researchers' experiences of negative reactions to trial failures had increased efforts to develop more effective community engagement. Informal meetings with those involved in the South African TB Vaccine Initiative (SATVI) gave additional dimensions to perceptions of community engagement and its realities in practice. These public and private meetings became another source of data through those interactions. They were as important as the more local research in providing the wider perspective on community engagement and health politics.

[58] A microbicide is a product applied topically to prevent HIV infection.

3.5 RESEARCH PHASES

In Cape Town, twenty one interviews were conducted with twenty two people. One was a joint interview with two community educators and one interview was unrecorded. In addition to those clinic based interviews, I had one other (untaped) with the co-ordinator of Triangle, a community outreach organisation for LGBT[59] populations in Cape Town and the surrounding areas, which liaises with the DTHF Men's Health Project Manager. In Soweto, fourteen interviews with eighteen participants were conducted, one of which was unrecorded. Two of those joint interviews were with two people and one with three. Interviews and meetings external to the Soweto trial site included two taped interviews, six informal meetings and several phone conversations. These encounters are laid out in table form below, to give an indication of the spread of respondents across the trial sites and including those beyond those arenas.

Cape Town research phase one

Trial site staff	**Community liaison staff**	**Community participants**
The DTHF Director	2 CLOs	7 CAB members from 3 CABs
2 community clinic PIs	2 HIV treatment counsellors	2 HIV vaccine community educators (interviewed together)
1 clinical investigator	1 Socio-behaviourist and CAB co-ordinator	
1 Socio-behaviourist	1 Clinical Trials Unit manager	
	1 Men's Health Project Manager	

Soweto research phase two

Trial site staff	**Community liaison staff**	**Community participants**
2 PHRU Co-Directors (interviewed together)	1 Co-ordinator for vaccine, treatment and adolescent CABs	8 vaccine CAB members (2 joint interviews, one with 3 people)
1 Clinical Research Site Director vaccine trials	1 Co-ordinator of an MSM project	
1 Socio-behaviourist	1 Community Educator/Recruiter/Counsellor (un-taped)	
1 Adolescent Programme Director		

[59] Lesbian, Gay, Bi-sexual and Transgender.

External interviews and meetings

Taped interviews	Informal meetings	Phone calls
1 Health policy academic	Discussions with Health Policy students and seminar attendance at WITS University	Dept. of Health Co-ordinator of Health Research
1 Director of an AIDS research centre	IAVI Acting Head (Southern Africa) and Regional Clinical Programme manager	Department of Science and Technology contact
	IAVI (Southern Africa) Community Programme Manager	US Director of the Global Campaign for Microbicides (GCM)
	US Director of the AIDS Vaccine Advocacy coalition (AVAC).	
	Meetings with members of the Global Campaign for Microbicides	

3.6 DATA ANALYSIS

I chose thematic analysis (Braun and Clarke, 2006) for the primary data analysis for its logic and procedural clarity. The search for patterns (themes) of meanings and issues of interest arising from across the data set can be developed from a constructionist or realist position, or a combination of the two.[60] Consequently, my methodology would "reflect reality and [help to] unpick or unravel the surface of 'reality'" (p. 81), especially where particular interpretations differed.

My approach to document analysis reflects those positions in a combination of content and textual analysis. Here, I was more concerned with "the manifest content" of documents than a systematic collation of frequency of particular elements (Wharton, 2006), such as the number of times empowerment might be mentioned. Detail of the documents analysed follows further explanation of thematic analysis of primary data below.

3.6.1 Primary data analysis

Thematic analysis begins with immersion in the data with repeated readings, to generate codes and from there to building, reviewing and naming themes; with writing playing an integral part at each stage, from notes to codes and so on (Braun and Clarke, 2006).

[60] The authors term this approach to thematic analysis as "contextualist" in that it considers both the ways that individuals make meaning of their experiences and the impact of the wider context in which they live (Braun and Clarke, 2006, p. 81).

Although the process takes five steps before the final writing up these steps are not linear, but involve moving back and forth between the data set, the coded extracts and the developing analysis. Mind maps helped to visualise relationships between codes, themes and levels of themes, with reviews of the theoretical assumptions driving the analysis forward. What distinguishes key terms relates to whether or not it captures an important aspect of the main research question.

The suggestion to use memos on method, documents and emerging themes[61] helped to keep some control over the data (Richards, 2005). I returned to the tapes after transcription to be reminded of the context in which the interview took place and the manner in which the interview proceeded. That reminder of context continued in periodic review of the data sets[62] before returning to trace the coding and theme building and pausing to delve into particular aspects of the data which needed more intensive analysis. And so the immersion in the data continued in an evolving process until the analysis was complete. Interview data were supplemented by observation data and reflections recorded in diaries.

3.6.2 Secondary data analysis

Analysing documents began as they were gathered, beginning before the field work and continuing subsequently. Through a focus on the "manifest content" of documents gathered, the intention has been to understand whose interests documents serve and what those interests might be (Wharton, 2006) through identifying themes (Spencer, Ritchie and O'Connor, 2003), rather than the frequency of occurrence. For example, I combined the manifest content with an interpretation of the meanings of empowerment which the documents might reveal. Neither approach requires an in depth analysis, only to understand what documents might express, in terms of community engagement advocacy for instance, and what underlying purpose can be detected through

[61] However, as Braun and Clarke (2006) remind us, themes do not emerge as if by magic from the data, but are developed by the researcher in an active process of selection.

[62] Richards (2005) advises this revisiting to check the development of categories and the discovery of new ones until the final stages.

interpretation. Documents include those produced by: the vaccine initiatives at both national and local level; their donors; the advocacy organisations which aim to generate support; and workshop reports. Media reports of specific events relating to clinical research were collected along with commentary on more general South African socio-cultural and political issues and events.

3.7 ETHICS

I now turn to ethical concerns which played a prominent part in this research. These relate to the ethics of data collection and analysis, access requirements from the different Research Ethics Committees (RECs), ethical matters in the field and the reflections which followed.

Generic ethical considerations involve matters of consent, confidentiality and protection from harm and include researcher independence, honesty and impartiality. In this endeavour, the benefits of research to participants are important considerations. The topic of HIV/AIDS presents significant ethical considerations due to its highly sensitive nature. As above-mentioned, the purpose was not to seek personal information related to individual HIV/AIDS status, although that status was often revealed as a crucial aspect of personal identity. Some of this research involves working with vulnerable people, aside from their HIV status. The political disparity between researcher and some interviewees is often significant. This yawning gap between material resources requires sensitivity and skill in building relationships to enhance understanding and to avoid harm; especially with those who may feel that they lack options to refuse participation. However much participation is emphasised in consent forms as entirely voluntary, concepts of “voluntariness” differ (Barsdorf and Wassenaar, 2005).

<u>Ethics and research participants</u>

With respect for research participants as a key ethical requirement, the aim is to balance recognition of the vulnerabilities of those whose relative material resources and options in

life are limited, with an objective to gather important information about the human condition which influences access to health in such contexts. This requires a balance between empathy towards others and research objectivity which is difficult to maintain. In addition to the political disparity between researchers and their community based participants, external researchers have been accused of "parachuting in" to do research in developing countries, where data are collected and nothing of value is left behind for participants (Tomlinson et al. 2006). My response to this criticism was to take time getting to know people to gain their trust before the formal research process began and to offer some reflections in draft reports.

Ethical approval procedures

A substantial amount of time has been spent on ethical approvals for this research, the detail of which can be found in Appendix 1. This aspect of my research was challenging in terms of that time taken up with preparation and revision of protocols during a period of crisis within the trial sites in particular, where the repercussions of a major trial failure in 2007[63] were felt most keenly. This drew the attentions of the Cape Town PI towards the immediate concerns of managing that crisis and its physical and emotional consequences. A brief summary here explains the four procedures and my reflections.

The first application to the Open University for preliminary approval for the initial trip in 2007 was straightforward, with small adjustments made following advice in full application in the following year. The South African process was more extensive, involving contact with four institutions over several months, including one application which was rejected by SAAVI. This redirected my research focus to become a more grounded study at trial site level. At the same time, the rejection reinforced evidence of the health governance problems and political sensitivities around SAAVI which unfolded during the field work. In addition, the resubmissions to the national research ethics committee – the Human

[63] This Phase IIb 'test of concept' HIV vaccine trial begun in 2007, the largest to be conducted in South Africa, was halted due to its lack of effectiveness in preventing HIV infection (www.saavi.org.za).

Sciences Research Council (HSRC) – were frustrating, but helpful in terms of the guidance which helped to develop consent forms more appropriate in context.

3.7.1 Ethics in the field

On reviewing the ethics applications, I found that the most useful guidance points made by the RECs were those concerning cultural matters. This useful guidance continued through discussion with two Cape Town REC members, one of whom was a social scientist who offered support and encouragement during several informal meetings during the first research phase in Cape Town. She appeared to be the motivator behind efforts to involve community members in REC decisions. Consequently, the other REC member had been recently invited as a CAB representative during this local trial site ethical approval procedure. This CAB member discussed his role during a formal interview.

This concern to extend access to committees more often presided over by elites, with a limited understanding of the lives of the participants of proposed research, may not be considered as community engagement as such. By involving community members in those deliberations, they were attempting to extend that engagement. This requires some effort on the part of the REC experts in adapting to accommodate people who do not have the required knowledge and understanding of their procedures. A course on ethics was available to bridge that gap and enhance meaningful participation.

The development of that participation would include the kind of medical knowledge which communities require to fulfil their roles as CAB members. At best, this shows that science and society can be involved in a process of mutual transformation, through the exchange of medical, social science and socio-cultural knowledge between REC members reaching beyond the immediate trial site environs. Key to that exchange is the ethical commitment to the understanding of consent and its implications. The realities evolved in the following way.

Consent

Although formal applications and guidance on consent forms focused on clinical research and the drawing of bloods, the cultural advice was useful. For example, a formal greeting is an essential introduction to a consent form before explanations of research begin. The initial application to the Open University had not prepared me for such cultural differences. Although guidance on simplicity and brevity was important, in this clinical research environment people had experience of lengthy medical consent forms and so were surprised to be presented with such a brief form.

Confidentiality

During interviews some staff members preferred complete anonymity due to fears that their more critical comments might be traced back to them. Others wished their identity to be known in recognition of their work. I had not been prepared for that possibility. Following the literature on ethical procedure, my focus had been on preserving confidentiality. Therefore, adjustments were made to the consent forms to accommodate for this unexpected response.

Avoidance of harm

On avoiding harm to research participants, my protocol committed me to deal with any unresolved issues arising during interviews. To my knowledge, two incidents needing attention occurred. As explained above, I called one interviewee who had become upset during the interview on reviving memories of her sister's death, to help her to resolve any issues if needed. In another, I called a focus group member who had become withdrawn during the discussion, to see if she had anything to discuss. In this case, she did and our conversation continued. These were some of the incidences which I felt reasonably well prepared to deal with. It was a question of making respondents aware of their rights to further support after sensitive issues had arisen should the need arise. This involved being an observant researcher taking stock of people's reactions and making plans to

contact those who appeared to be unhappy. Thankfully, this unhappiness was not a common occurrence.

Physical safety

One issue which had not been raised by the RECs was that of participants' physical safety. In South Africa, crime rates are high and safety issues for all involved in my research was a primary concern when in transit between township locations and within cities. I had explained in my protocol how I would keep myself safe, but this need to consider physical safety extended to the participants, in particular in Cape Town where, as night fell, travel became more dangerous for us all with the approaching winter. This was a primary consideration during that phase of research.

Moreover, the political unrest which developed in May, during the first research phase in Cape Town, could not have been anticipated. Political commentators had discussed this burgeoning problem of more isolated acts of violence against 'foreigners'[64] blamed for the high demand on services. This blaming was now fuelled by rising food prices as the economic recession began to take effect. On planning the township interviews, those violent reactions and deaths increased across the country and 'foreigners' were driven out of the townships to be transported into refugee camps where they lived through that winter in tents. I was advised to stay at home until this turmoil passed, primarily due to the fact that community meetings attempting to reconcile fractured communities took precedence over trial site activities at this time. Detailed media reports and commentary developed my understanding of the underlying socio-economic and political factors which surround these events.

In any event, CAB members were often busy with other community matters, and so had little time to spare for interviews in general, and none at this time. As the violence subsided, research in those areas resumed. From that time, trial site staff recommended

[64] Anxiety over rising prices combined with perceptions that 'foreigners' were adding to already strained services erupted into violence, sixty two deaths, and relocations to refugee camps (Bloch, 2010, p. 235).

making enquiries on whether or not roads were open and my safety could be assessed. It became routine to call in daily to explain my movements. This was something which I had stated that I would do in my protocols, but had not made routine until these events occurred. Therefore, this might be emphasised as an important consideration for any researcher in potentially volatile environments. This civil unrest influenced the research process in fundamental ways. That unrest and its repercussions became new data on the impact of violence on community engagement efforts and in terms of exclusions of the victims who were targets of that violence.

By October, and the second research phase in Soweto, the unrest had subsided. More generally, CAB members travelled to the hospital in daylight hours. During that time I returned to Cape Town, primarily to attend the AIDS Vaccine Conference, but also to revisit my research participants to offset the effects of 'snapshot' research. As evenings were drawing out in the South African springtime, and as the violence had subsided, safety issues were less of a problem for people attending meetings. The fortunes of those involved in community engagement seemed to be changing. The CABs were said to be gaining more members and had benefited from networking opportunities provided by SAAVI and IAVI in the interim.

One respondent had suffered a violent attack unconnected to her CAB role and had taken several months to recover her confidence. This reinforced a growing understanding of the ways that the environments in which people live have substantial repercussions on their psychological wellbeing and political agency. These experiences challenged the literature which tends to reify the strength and endurance of people who live with such uncertainty. I return to this issue of endurance in Chapter Six. Therefore, the motivation and capabilities needed for community engagement activities rests as much on the personal resources of participants to maintain involvement as those resources provided within trial sites.

Personal responses

Aside from issues of physical safety and the emotional vulnerability of research participants, I had taken measures to ensure my own physical safety as far as possible, but I was unprepared for my own emotional reactions to this field work experience. During interviews, although I was not asking about personal lives, inevitably stories of illness and poverty would arise, so immediate is the impact on most people's lives in such settings. It was difficult to maintain the balance between empathy and objectivity which I had hoped to achieve as I prepared the research. These issues have important implications for the ethical requirement for researcher independence and impartiality which are easy to theorise but difficult to practise. Of necessity, I had been focused on participants' potential vulnerability, but my experience suggests that vulnerability should be seen in the round.

Taking time to gain the trust and interest of research participants proved to be good advice, bearing in mind participant vulnerability and criticisms of external researchers who spend little time in the field and take information away, often leaving nothing of value in exchange. Having taken that time to develop relationships, most of the formal research was done towards the end of the research periods. Consequently, there was less than ideal time for reflection between interviews - at times with no break between them - and for reflection on data collected each night as well as prepare for the next day of interviewing. In this way, the ideals of ‘good practice’ in the field were frustrated by events.

Over-research

My hesitancy in doing the research had been reinforced by the lengthy ethical procedures and the literature which emphasised the dangers of intrusion (Tomlinson et al. 2006; Nama and Swartz, 2002). I made decisions to explore questions of over-research during the field trips to gain responses. The first opportunity arose unbidden on arrival at the vaccine clinic in Nyanga, where a researcher from the Bill and Melinda Gates Foundation had recently been investigating trial site researcher and community responses to the earlier failed trial. That heightened my awareness of my own intrusion into what had

appeared to be a sensitive issue, to be confirmed through subsequent interviews in both trial sites in Cape Town and Soweto.

More generally, gracious though some responses may have been, in most cases the opportunity for time to talk and reflect on their work was welcomed. Responses of this kind challenged those perceptions of poor people as passive and reactive rather than agents in their own and others' health, and as involved community members organising to address their social problems. The opportunity to respond to my draft reports was appreciated for their potential for helping to develop community engagement practice.

Some community respondents had roles in the research protocol approval process and so were more powerful than the literature suggests. They valued their roles as gatekeepers in protecting communities from unapproved researchers. That political sophistication extended to decisions to withhold information considered potentially damaging to communities. My motives as a researcher could not be guaranteed. Therefore, I reflected on guidance that decisions to withhold information deemed potentially harmful should be respected and the consequences of publication of findings need to be considered (Hammersley, 2005, p. 181).

3.8 CONCLUSION

In this chapter, I have explained how the methodological approach and research methods have been designed to respond to the key research question in its concern with how community roles in trial sites may be politically meaningful. This requires opportunities for those involved to explain how they perceive their roles and how they use them to what ends. This research approach to peoples' perceptions and lived experiences in these South African contexts reveals the socio-economic conditions which they face and the historical and political environment in which health governance has developed.

In that process, reflections on the flexible methodological approach, with the triangulation of method and range of participants, reinforced the benefits of research which can encompass unexpected events. This approach has highlighted the potential for

theoretical development and wider generalisation to other contexts where community engagement in local health initiatives might prove to have political purchase for those who are the intended beneficiaries. The range of perceptions of community engagement from those lived experiences and the ideals expressed by advocates are compared and contrasted within and across the two case studies. The flexible approach and range of research methods allowed unexpected events and issues to be taken into account as new data.

In the following data chapters, evidence suggests that communities do play meaningful political roles in local health initiatives. However, the key constraints on that activity are: high rates of socio-economic inequality; a lack of national political support during the period of rapid rises in rates of infection; and negative social norms around HIV/AIDS. For those who are excluded from opportunities for health agency, the ideals of community engagement and access to health care are out of reach, despite the efforts of those involved in health initiatives to include them. Consequently, "social injustice occurs when individuals are deprived of capabilities to be healthy as a result of sub-optimal health care, inhibited health agency and oppressive social norms" (Ruger, 2007, p. 92). These are the key principles which are the focus of my data chapters, beginning with the latter contextual aspects which underpin health care and health agency. Data are arranged in key themes which address those factors as they influence access to health, with chapters broken down in the following way.

In Chapter Four, the context in which individuals find themselves in pursuit of "valued health resources" (Ruger, 2007) is determined by prevailing socio-economic conditions and negative health norms which discriminate against poor people and limit opportunities for health agency. In this case, norms stigmatise those infected or affected by HIV/AIDS, some of whom experience other forms of discrimination which impose multi-layered barriers to good health. Health norms discriminating against others who are blamed for their illness build upon existing unequal power relationships to increase health inequalities. The historical roots of political controversy over the cause of HIV/AIDS, and

their resolution, are interwoven with those health norms, with devastating impacts on those living in poor communities in particular. The story of the ways that those interrelated political, social and cultural factors influence the daily lives of people living in these communities, as they attempt to deal with HIV/AIDS, unfolds in this chapter.

Chapter Five responds to Ruger's (2007) principle that health resources should be of good quality to be effective in supplying valued health needs, since access to health is not sufficient, in itself, without valued health resources and community capabilities to use them. Those engaged in trial site activities provide evidence of those valued health resources and those which remain unmet. Here, ideals of community engagement and the health resources flowing from it that support shared health governance (Ruger, 2010a) are evaluated alongside stories of: i) the power relationships involved in trial site governance and; ii) the realities of living in communities where poverty, diversity and conflict arising from stigma against vulnerable populations limit opportunities to be involved in trial site activities and to use those health resources in wider claims for socio-economic citizenship. That exclusion compounds vulnerabilities to HIV/AIDS and reinforces inequalities in health.

Chapter Six describes the ways in which those trial site projects are attempting to engage vulnerable populations. It considers the individual and collaborative efforts of those already engaged as they use health resources to achieve good health for themselves and others in their communities. The personal resources which they bring to trial sites enhance health activism within their communities. This agency is strengthened through involvement in other community based organisations and through national and global networking across the boundaries of trial sites. The capacity to act politically within and beyond those environs is developed through those networking opportunities. Two events suggest the possibility of change in health governance and health outcomes. Changes in government policy on HIV/AIDS and decreases in HIV infection rates amongst young adolescents suggest a more optimistic future in the longer term.

CHAPTER 4

SOCIAL NORMS AND HEALTH POLITICS

In this chapter, I argue that social norms and the politics of HIV/AIDS have been key factors in the rapid progression of HIV/AIDS in South Africa. The initial wider global and, in some cases, national reluctance to address the problem have compounded health inequalities in particular national and local contexts. The two interlocking factors – stigma and politics – have limited efforts to find solutions to this devastating health problem. Daily life for the majority of the population is difficult enough without this additional burden. These are the environments of social injustice which frame this research, where the oppressive social norms described by Ruger (2007) and political confusion over HIV/AIDS thwarts communities attempting to play meaningful political roles in local health initiatives.

This chapter begins by explaining the ways that stigma underpins the kind of social norms which isolate those blamed for their condition, making them less likely to seek the health resources which may help them to recover their health. I go on to describe the impact of stigma on individual identities and the trial site communities attempting to challenge those who perpetuate stigmatising behaviour. As we shall see, the initial global response to HIV/AIDS reflects the stigmatising of those deemed to be undeserving of attention. In this South African case, efforts to challenge negative social norms have been confounded by a South African government reluctant to take responsibility, in part, due to that stigma and the shame which it provokes.

To some extent, the underlying reasons for the lack of attention at global levels can be found in the initial focus on individual behaviour as a cause of HIV infection. Associations with morality moved the focus away from the complex structural factors involved. I argue that the lack of a coherent national HIV/AIDS policy and the stigmatising impact of negative social norms have added to the fear and uncertainty which epidemics of this kind bring. The spreading confusion has had repercussions on efforts to engage communities in trial site activities. Thus, socio-cultural understandings of health interrelate with wider

political controversy at national levels. That national level response has been fuelled by the initial international response to HIV/AIDS as a problem of sexual (or other) behaviour. These factors have combined to delay the search for effective solutions and contribute to HIV/AIDS as a "long-wave event", with widespread and far-reaching repercussions (Barnett and Whiteside, 2006, pp. 19-22).

In such conditions where history and rapid social change collide, the beliefs surrounding HIV/AIDS and the ways that those beliefs coalesce into stigma influence health choices. Those beliefs circulate beyond households, to communities and national health governance arenas, to be met with political controversy which then permeates back down throughout South African society. Given the lack of a cure, in any environment stigmatised conditions such as HIV/AIDS provoke controversy and blame, more so where prevalence rates are high and where historical events provide the foundations for controversy to take root.

The confusion flowing from national level political controversy over HIV/AIDS has provided fertile conditions for heightened uncertainty and the circulation of social norms which work against those ideals. An understanding of how locally-based people view the ways in which HIV/AIDS is governed globally and nationally, and how they deal with the health norms that arise, shows how they are developing the capabilities to play meaningful political roles in local health governance.

4.1 SOCIAL NORMS AND STIGMA

An explanation of stigma relating to the reasons why it takes place and the ways in which stigma manifests itself begins this discussion. Analysis of the beliefs and stories of HIV/AIDS illustrates the influence on perceptions of the epidemics, their cause and solutions. The impact of those beliefs on communities as they struggle to find ways to deal with this problem brings to light the experiences of some of the people infected and affected by HIV/AIDS. It shows how health norms are influenced by predominant beliefs and

sanctioned behaviour (Yanacopulos, 2005), to limit capabilities to use opportunities to gain access to health, even when information is available. Insight into how people deal with that information, alongside the beliefs and stories which circulate at community and national levels, reveals the problems involved.

4.1.1 Concepts of stigma

Stigma is a way of making sense of catastrophe, manifest in the blaming of those seen to have transgressed social norms (Joffe, 1999). This blaming can be directed inwards, as illustrated in my findings. Shame and self blame can be as destructive as that directed towards others, to limit capabilities to seek health care. Stigma is multi-layered, reflecting power relationships between men and women and between those whose sexual orientations differ. Further, those who are not recognized as South African, even if granted official citizenship status, are more vulnerable to stigma. Where poverty and multiple layers of stigma combine, access to health care is less likely. As HIV infection progresses to AIDS when left unattended, the physical symptoms of HIV/AIDS become visible and it is difficult to hide one's medical status.

Stigma is "a complex social problem involving interplay between social and economic factors in the environment and psychosocial issues of affected individuals" (Ogden and Nyblade, 2005, p. 7). Parker and Aggleton (2003) build on Goffman's (1963) concepts of the "damaged" identity and its impact with "abominations of the body", "blemishes of the individual character" and "tribal stigma", to highlight inequality and the role of stigma in producing and reproducing power relations. According to Wood (1985, p. 5) labelling involves "processes of control, regulation and management … largely unrecognised by the actors themselves" involving relations of power invoking conflict and authority.

Seen in this light, people who are stigmatised become "placed by power" (Allen, 2008, p. 1623). Wood's perspective provides crucial foundations for theorising HIV related stigma and policy beyond matters of individual behaviour. Such power relationships and inherent

inequalities work together, where poverty is clearly connected to the degree and persistence of stigma (Bond and Nyblade, 2006). Some beliefs about HIV transmission work against prevention measures based on scientific evidence. It is those perceptions and beliefs surrounding stigmatisation that are key to understanding how HIV prevention measures can be developed and how claims to health rights can be made.

The more rapid the spread of HIV/AIDS the greater the levels of uncertainty and so stigma takes root as a way of understanding such phenomena. The purpose of stigma is to eliminate that uncertainty and to preserve a sense of social solidarity and stability through isolating those who are perceived to be transgressing social and cultural norms (Ogden and Nyblade, 2005). In times of rapid social change, the impetus to maintain distance from the perceived sources of crisis becomes more acute. When fuelled by political controversy efforts to combat those problems are confounded. The combined stigma and lack of political leadership have impacts on those infected and affected and their propensity to make favourable health decisions.

The threat to predominant community values and social solidarity is greatest when perceived deviant behaviour is involved, such as that involving sex and injected drug use. The role of morality and norms in stigmatisation is “exacerbated by the seriousness of the illness, its mysterious nature, and its associations”, with such sensitive or illegal behaviour (Joffe, 1999, p. 20). Fear and incomplete knowledge of transmission brings with it an increase in the sense of risk (Joffe, 1999) and blame (Campbell, 2003), with greater impact on those experiencing other related forms of stigma. The result is to damage and demotivate those blamed for their condition. Their capabilities to make health choices are the most severely restricted by the daily reinforcement of stigma.

Stigma and blame

The tendency to blame the 'other' is supported by historical evidence.[65] When faced with risk and crises such as HIV/AIDS, the general response is to stigmatise others, thereby preserving ones own identity and alleviating anxiety over the possibility of contamination with a disease that others deserve through that immoral behaviour. The contemporary 'other' in South African townships and informal settlements provides the target and rationale for avoidance of personal responsibility for HIV/AIDS (Campbell, 2003). That stigma and blame extends beyond immediate localities, to include people seen as 'transgressors' in urban areas, across regions and further, to stigmatise those living in other countries or continents (ibid). In this way, the condition and its deviant connotations serve to distance the moral and restrained from danger. The disease can, therefore, be contained within 'out-groups' suspected to be infected with the HIV virus or dying of AIDS.

Blame on others for a condition for which there is no cure and which concerns issues of sexuality is a significant element in the building of beliefs and stories. Witchcraft is one of the ways used to explain the causes of HIV/AIDS: it absolves others who have not been cursed. The following explanation was given by an HIV positive man, whose wife and child had died, for his reasons for not needing ART:

> He just said he is not HIV positive himself. And he never used protection with his wife, because the HIV that the wife had, it was not the HIV that we have, that we, we get it from having unprotected sex. But with hers, it was – she was bewitched. The witches gave her that type of HIV. So he said he is still negative (Flora Thobela,[66] Cape Town CAB member and counsellor).

Such norms which exist as a psychological form of protection from risk and harm perpetuate the kind of institutional, cultural and individual constraints on agency which Cleaver (2009) identifies. The HIV positive man whose story Flora describes made a choice and this was a form of agency. And yet, this choice would result in his death: subordinated as he was to those social norms and stigma around HIV/AIDS.

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[65] The stigmatising of those infected with syphilis is a case in point (Joffe, 1999, p. 25).

[66] This interviewee asked to be named, saying that confidentiality can be detrimental in that "an HIV positive woman from Cape Town" would take away the power of her contribution to this research.

Stigma can be enhanced where religious beliefs are associated with behaviour judged as immoral, and when accompanied by physical disfigurement and a difficult death when access to treatment is not available, or declined due to that stigma (Mills, 2008). God's wrath and punishment of the rejected for their immoral behaviour is contrasted with those who are "saved" having changed their ways.[67] In such cases, HIV/AIDS does not need discussion. I was told by the primary school headmaster from a Cape Town site that:

> Some of the church leaders, they tell us that – they say to us "I'm not [an] HIV/ AIDS pastor … I don't have [a] slot for HIV and AIDS" (Michael Tyhali,[68] primary school Headmaster and CAB member).

This uncertainty over the causes of HIV/AIDS is exacerbated by national political ambivalence, to further stimulate rumour, gossip, and "pointing fingers".

Self-blame compounds the impact of stigma. As Cameron (2005, p. 53) found, this is "a most poignant and most impenetrable" aspect of stigma in that some of its impact seems to originate from within. He writes that this "most intractable element of stigma is the disfiguring sense of shame that emanates from the internal world of some with HIV or AIDS" (p. 70). One CAB member explained that he, and other South Africans, were "stubborn" in their attitudes to HIV/AIDS, and their situation unique; suggesting that traces of historical oppression endure. I was told that white people are perceived as more attractive, educated, successful (an NGO project manager from Cape Town) and, to some, immune to HIV infection. As one CAB member related:

> We had a discussion about youth asking me saying "are there any white people who are infected with HIV?" And I said "yes, there are", and they said "no, you're lying to us". I said "why?" They said "we never saw any one of them, even in like the hospitals we only see black people"... they only said "looks like this HIV is for us" (a young male vaccine CAB member from the Soweto site).

The complexities of blame, shame and disbelief meld into "spontaneous philosophies" that people exchange in order to make sense of their worlds (Joffe, 1999, p. 91). The accompanying "chatter" has a "material force" as influential as "more physical entities" (ibid), to inhibit the capacity to assert rights to health.

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[67] Several respondents discussed the different ways that religious leaders explained HIV/AIDS.

[68] This interviewee asked to be named.

Gossip provokes fear of status disclosure and the social isolation which can follow, since:

> People love to be loved by other people ... We wait for other people to accept and love us. Now, if I have HIV, then I will feel that nobody will ever love me (Flora Thobela, Cape Town CAB member and counsellor).

Then, one will be seen as:

> A non-person, so it makes it that people [do] not actually recognise you as a human being. They just know you as *none*, you are like *nothing.* In English, none is something else but, for us, none is – you are *nothing* (a middle aged male CAB member from the Cape Town site, his emphasis).

Such experiences can be compounded by inequalities in power relationships and multi-layered forms of stigma.

4.1.2 Multi-layered stigma

Different layers of stigma coalesce to exacerbate inequalities in power relations, between men and women and between those considered as South Africans and outsiders. The circulation of stories is one of the most significant vehicles for stigma, with women in particular blamed for bringing HIV/AIDS home. Through attendance at pregnancy clinics women are more likely to be diagnosed. Men are not as well connected to the health system and often reluctant to know their status. Hence, women can be the targets of blame as carriers of HIV and transgressors labelled as prostitutes (Campbell, 2003). Women are the ones most burdened with caring for the sick and, at the same time, are often the most politically active in HIV/AIDS campaigns at grassroots level (Chazan, 2008).

Consequently, women “bear the strongest brunt” of HIV/AIDS, due to their perceived role in upholding moral values and traditions (Ogden and Nyblade, 2005), and their responsibilities for caring for sick people, as well as for engaging in wider health activities. As explained in Chapter One, due to physiological and socio-economic factors, young poor women are most likely to be infected with HIV, along with older men, but at higher rates (Shisana et al. 2009, p. xvii). Thus, women are victims of sexual double standards (Ogden and Nyblade, 2005); subordinated further through stigmatisation. As victims of

violence due to that labelling, they experience Gaventa's (2006) visible forms of power, reinforced by hidden forms in social norms and stigma. These are the social forms of domination which Navarro (2006) identifies. As Flora Thobela explained to me, "we struggle, we're struggling Mary. There are so many things. People are very, very, very poor". She went on to explain that women in particular were not empowered and so were unable to do the things that needed to be done to protect themselves and their children.

Sex workers and people whose sexual orientations are considered immoral are more vulnerable to gossip, abuse and violence and are more prone to HIV infection due to that vulnerability. Those labelled as 'foreigners' are similarly vulnerable. They are victimised, yet also the source of "jealousy" (older female CAB member and counsellor from the Cape Town site): all are targeted as threats due to contamination and as undeserving claimants of social welfare (Mills, 2008). As expected, those who show symptoms of AIDS are particularly vulnerable to labels described as "a shadow across reality which can be useful disguises", especially where resources are limited (Wood, 1985, p. 19).

The physical manifestations of HIV/AIDS

It is difficult to ignore the physical manifestations of AIDS when treatment has not been available or has been received late. Physical changes are easy to identify. Hair and weight loss and skin conditions provoke comment. In some cases, taboo precludes direct associations. To avoid mentioning HIV/AIDS, phrases such as "that thing", "the big thing", "playing the lotto", "wearing the red scarf" (ribbon), and "God the Father and the Holy Ghost", are used (Squire, 2007, p. 6). Yet, in other cases, the approach is more direct. I was told that:

> They are not afraid to ask you "are you HIV? Why do you look like this? … You, you are so thin. I'm sure you are HIV". You see all those things. It's happening (an older female counsellor and CAB member from the Cape Town site).

The same person offered solutions to those experiencing such prejudice, by suggesting to a patient on treatment: "You can just say I'm dieting, I'm in diet". Strategies such as this appear contradictory, to work against the ideal of challenging stigma and health norms.

Those contradictory strategies may perpetuate the health norms which hinder access to health, but the daily efforts to manage stigma require a more complex management of health problems; riven as they are with stigma and the need to maintain social bonds and, at worst, avoid physical harm.

4.1.3 The impact of stigma

Where stigma prevails and no treatment is guaranteed, some avoid testing for HIV until it is too late to recover health. Treatment is then blamed as a cause of death. This blaming of ART was reinforced by the controversy over Western medical interventions, provoked at the time by President Mbeki and his Health Minister (to be discussed below). A poignant story of lengthy but thwarted efforts to avert a sister's death gave an insight into such dilemmas:

> I said to her "you need help but you don't get it, why don't you get tested?" She said "I'm not ready"... And then I said "there are so many people who are HIV positive and they live with it. You just need to change your behaviour and then you live with it. We will support you as a family", and then she said "OK, maybe next time". She tested in there, in the last minute, like I can say she tested this week and then next week she died … we take it in different ways, so that's why people are dying (a young female vaccine member from the Soweto trial site).

This story shows how HIV/AIDS stigma and disbelief over treatment causes some people to feel hopeless, even with support, and yet others are able to resist those fears. Loss of trust between partners can cause family bonds to break, so that decisions to disclose are delayed through fear of social isolation and loss of security. Unemployment levels are high and social welfare exists, but only for children, elderly people or those who have low CD4 counts.[69] When asked by counsellors why patients don't tell their partners, they say they will be left alone. This stimulated a CAB member to speculate about the number of people that she meets daily, by asking:

> How many young girls [are] positive and how many young men? Because no-one is telling no-one. No-one is telling no-one Mary. It's like "no, no I'm not going to tell my boyfriend, he's going to leave me"... It's all about survival (a middle aged female counsellor and vaccine CAB member from the Soweto site).

[69] CD4+ T cells are the body's defence against infection. Over time, and in most cases, the HIV virus takes over and the CD4+ T cells decrease, so that the immune system is compromised and AIDS-related illnesses develop. Keeping CD4 counts as high as possible involves maintaining a good diet and living as healthy a life as possible whilst living with HIV infection.

That impetus for survival can result in unenviable decisions, such as keeping CD4 counts low to retain social grants rather than help the immune system fight infection levels. Overcome by fatalism and loneliness, some move away and spread infection (a middle aged male CAB member from Cape Town). Others stay and choose to infect each other and die together as Lane (2009) found in her research with young people in the Cape Town area.

Joffe (1999) maintains that it is possible to change the perceptions of others regarding stigma and risk. However, her description of peoples' avoidance of contact does not take into account those instances where some ignore risk to others or to themselves. The complexity surrounding stigma identifies the difficulties in challenging health norms. All of these factors contribute to family and social dysfunction and limits to agency. As explained by one of the women during a focus group, one can shut oneself away into a "cocoon" of "loneliness and isolation, to die slowly alone", or "come out" and "spread the gospel" (a middle aged female CAB member from the Cape Town site).

Stigma and freedom are seen in opposition by those who become overwhelmed by their condition, while others manage to find ways to change their lives through engaging in local health initiatives. Wood (1985) argues that the contradiction lies in the ways that labelling works by "*dis*organizing the dominated" (p. 22, author's emphasis). On the other hand, there is "the potential of *re*organizing interests around the solidarities which the labelling might itself engender" (ibid). This stimulates questions as to what makes some people avoid the impact of stigma by hiding away, while others become health activists. It draws the attention towards the lives of those who withdraw and, alternatively, the kind of resources that activists draw from.

These different lives and the resources from which some are able to draw in their health activism are the focus of the following data chapters. Where some remain objects of stigma, others become subjects in the collective fight against its impact. That process can involve disclosing their HIV status and encouraging others to break the cycle of stigma

and illness. In this way, I argue that they are playing meaningful political roles by stimulating new health norms to pave the way for better access to health. However, taking such steps can be difficult.

HIV status disclosure

Stigma generates a complex process of decision-making over disclosure of HIV status within the family, in the workplace and the community and in the wider public sphere. This has negative influences on local health initiatives and efforts to improve access to health. The isolating effects of stigma work against the kinds of individual and collective agency needed to address the problems of HIV/AIDS. Preoccupation over status disclosure diverts attention from effective community engagement and the benefits of that engagement. Yet, those benefits may contribute to meaningful political roles in challenging the socio-economic inequalities and the underlying politics of HIV/AIDS influencing access to health.

Status disclosure is a complex business, requiring much thought, consideration and courage. On recalling two incidences where women who had disclosed had been raped and killed, one interviewee told me:

> … you can't just disclose. You don't know the people that you are mixing with because people don't even want to hear the word HIV. They will say, “you're the one who is killing us”... You are to keep your eyes always open. But I think it is a good idea to disclose your status because you show that you are brave and you can cope and you are encouraging others. So, I think that disclosure is very important. It is a powerful tool, but when and where and with whom ... (a young female CAB member and counsellor from the Cape Town site).

The focus group in Cape Town discussed in Chapter Three revealed preoccupations and the complexities involved. Questions over the mechanisms by which one could disclose at work and the sensitivities involved - especially where unemployment rates are high - ended in heated debate over the need to disclose, the difficulties over preserving patients confidentiality, and the assumed immorality of not disclosing a patient's status and thereby “letting them die” (a middle-aged male CAB member from the Cape Town site). This is a complex process of selective disclosure due to the vigilance needed over safety,

avoidance of isolation and loss of employment and potential physical harm. It reveals power as it is experienced (Allen, 2003) by engaged communities, the daily negotiations involved and the ways that political relationships are negotiated. Through recognition of others' isolation, loss of employment and physical harm, strategies are devised to avoid such outcomes.

Here, trust is an essential element in the process of dealing with the politics of HIV/AIDS in particular, since the conditions bring with them concerns over the potential of community exclusion and safety. One can be labelled and placed by power (Allen, 2008, p. 1623) as HIV positive if associated with CAB membership, or as a TB or HIV counsellor. Strategies are devised for self-protection and to protect others being counselled:

> They don't want to be seen ... and in the clinic there are still the people that cannot come. If they come you have to hide them. They can't wait in the waiting room. They come and sit somewhere in the corner somewhere, because there might be a neighbour in the waiting room (Flora Thobela, counsellor and Cape Town CAB member).

Fearful people are whisked away out of a back door and counsellors are careful not to show public recognition unless prompted by people whom they have met in support groups or as patients. They make elaborate detours when visiting people in their homes, so as not to be seen to be visiting patients. That complex decision making process – on behalf of oneself and others – distracts from efforts in combating HIV/AIDS stigma and is symptomatic of the combined and interrelated problems of HIV/AIDS and poverty. As one of the CAB members from Soweto said during a discussion of apartheid: "We have two enemies now, HIV and poverty" (a young male vaccine CAB member from the Soweto site).

As the literature suggests, stigma is widespread, with "remarkable consistency" between countries albeit with local differences (Ogden and Nyblade, 2005). Such contextual differences – apparent in my research – are being addressed through the participation of those involved, most of whom are infected or affected in some way due to the high South

African HIV/AIDS prevalence. These are political actions, since they are instrumental in paving the way towards access to health. Given the local proximity to those with such direct experiences, their actions may be more effective than global HIV prevention campaigns. As Seckinelgin (2008) suggests, the socio-economic and cultural complexities of daily life do not register at global health governance levels.

The CAB members made frequent references to 'this scourge of HIV/AIDS', with war analogies involving “attacking HIV” in “the fight” against “this killing pandemic”, so as to defend South Africans.[70] For one of my respondents, evidence that women are dying in greater numbers is reinforced by daily experience. In a focus group, he told us that he feared that his “three sisters will end up with AIDS. That is what is happening in our community. We end up losing all our sisters” (a middle aged male Cape Town CAB member).

The high HIV/AIDS prevalence and the recognition that South Africa had become a focus for global health governance may have contributed to the perception of this CAB member that South Africans were “unique” in these circumstances. During the field work period, President Mbeki was said to be equally stubborn in his denial of the realities. This same CAB member explained that: “The President himself has said ‘HIV is HIV, but it's not AIDS' … Now they made people more stubborn than ever”. Thus, denial at national level intertwines with the local.

In order to find ways of changing patterns of thought, it is important to understand meanings made of material threats and how people understand and process threat, rather than the threat itself or ‘biased’ interpretations (Joffe, 1999). The underlying causes of HIV/AIDS related stigma have been identified to be lack of knowledge exacerbated by moral judgement (Ogden and Nyblade, 2005). As such, education on stigma is promoted

[70] These were the phrasings used by my respondents.

as a key intervention to alleviate the doubt, uncertainty, anxiety and fear over HIV/AIDS which hinders agency.

However, for people living in poverty and lacking the means to respond to education, perceptions of the inevitability of death following infection are a reality. Mills' (2008) ethnographic findings show some lack of understanding of the differences between HIV and AIDS due to lack of knowledge of ART, but treatment is not universal even though knowledge and information are more widespread, especially in urban areas. Deaths from AIDS continue due to the time lapse between the onset of infection and death and where treatment has not been available until very recently. The deaths of those undiagnosed, or not receiving treatment due to shortfalls, or having treatment too late, continues. Hence, stigma and politics collide.

4.2 THE POLITICS OF HIV/AIDS

Those interrelated factors fueled the national political controversy over the causes and solutions to the problem of HIV/AIDS, in a polarisation of views with irreparable consequences. Although global health governance is changing perspectives on ways to address HIV/AIDS, this has little impact where national governments are reluctant to respond, or differ in perspective. The effect on policy and impact on community level health governance is significant. In this South African context, a divided health system has been stretched in its capacity to cope with the impact of such high HIV/AIDS prevalence.

Global health governance

As explained in Chapter One, at global health governance level the initial focus on the biomedical and individual behavioural aspects of HIV transmission, to the exclusion of socio-economic and political factors, reinforced the stigma of HIV/AIDS and delayed policy response. This kind of prejudice supported by authority works to “relegate some issues or categories of people to very low priority” (Moncrieffe, 2007, p. 3). In America, once civil

society challenges to the lack of treatment in the 1980s gained momentum with policy response (Epstein, 1996) that political action moved into the global sphere to widen the focus to include advocacy for attention to HIV/AIDS in developing countries.

The targets of initial global policy were high risk groups, with HIV prevention measures more often inappropriate: not least due to the lack of recognition that poverty limits personal choice over behaviour. The subsequent Western response to requests for treatment was to suggest that people living in developing countries were not able to maintain ART regimes. Such framing[71] and labelling influences policy debates and discourse (Moncrieffe, 2007, p. 2). That labelling of others may be seen as "a rationing and allocation activity, and thus, is essentially political" (Wood, 2007, p. 24). It occurs at "different levels and within different arenas of interaction" (Moncrieffe, 2007, p. 20).

At the same time, labelling can be resisted, since labelling can be part of a dynamic process in response with "new forms of mobilization and voice" (ibid). And so, civil society groups urged governments to respond. In doing so, the balance in power relations between government and civil society began to shift. At the same time, advocates argued that structural violence (Farmer, 2005) and other contributory factors (Stillwaggon, 2003)[72] should be considered as influential in the spread of HIV infection and AIDS and so began to play their part in changing the global approach to HIV/AIDS policy. Although the global health governance focus on behavioural change widened to become more comprehensive following such challenges, that initial focus stimulated resistance from those who felt victimised due to the associations with sexual promiscuity.

At the local level, NGOs in general and Principal Investigators of clinical trials in particular have been attempting to balance their work and the ongoing search for funding.

[71] Framing works to identify which perspective takes precedence and which aspects are left unattended and different frames produce different labels and policy responses (Moncrieffe, 2007, p. 8).

[72] Stillwaggon (2003) argues that HIV/AIDS research and policy has been biased by a Western construction of African sexuality to deny evidence of links between parasitic infection, malnutrition and other biological conditions with HIV transmission.

Meanwhile community members grapple with the daily problems of dealing with the impact of both stigma and the lack of political leadership in a unified response. These following data show how those health norms and the surrounding political controversy work together to increase rates of HIV infection and health inequalities.

4.2.1 The South African response

In South Africa, taboos around sex had been exacerbated during the apartheid era (Posel, 2005), to become significant social and political barriers to public discussion: sex and sexuality were heavily censored and policed.[73] Rapid change following the end of apartheid and the impact of globalisation combined to provoke uncertainty as taboos built during the colonial and apartheid eras were challenged and HIV prevalence began to rise (ibid). The response by President Mbeki was to refute scientific explanations for HIV/ AIDS and civil society calls for treatment. His response has generated a political controversy and many interpretations (Nattrass, 2007; Gumede, 2005; Schneider and Fassin, 2002), the details of which are less important here than the need to understand the causes and consequences.

Given the global focus on Africa as the region most affected, and that initial biomedical and behavioural health governance approach, the political response in some cases was to assume distance from the implied racism driving Western health governance initiatives. This confluence of perceived racism gained force with painful memories of past damaging medical interventions;[74] to combust into political controversy, spreading uncertainty and confusion down to poor communities most afflicted by HIV/AIDS. Cameron's (2005, p. 213) passion is clear:

> The challenge to medical science of AIDS that sought to defend the human rights and dignity of Africans led instead to a tragic delay in concerted action during which many African lives have been lost amidst hideous suffering.

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[73] Sex across racial divides was prohibited (Posel, 2005, p. 128).

[74] For example, the Tuskegee syphilis experiment where people were left to die as part of a scientific experiment (Marshall, 2005). These kinds of experience add to the suspicion that communities have of such interventions. That suspicion has been compounded by experiences of violent acts committed during the apartheid era.

The impact of politics between global health governance and national governments was most keenly felt at local community levels. These are the external pressures and different agendas which are identified in the explanatory conception of governance (Yanacopulos, 2005).

According to Posel (2005), the key underlying factor driving President Mbeki's agenda in distancing himself from the orthodox approach to HIV/AIDS was his reluctance to acknowledge sexual behavior as one of the causes of HIV infection,[75] and his resistance to corresponding efforts to generate a public discussion of matters of sexuality. His motivation was rooted in the politics of race, class, generation and nation-building, such that talking about sex has provoked some of South Africa's "deeper cleavages and uncertainties, which form the politics of nationalism post-1994 well beyond the subject of sex" (p. 150).

President Mbeki's political project was built around African renaissance ideals, prompting a search for African solutions to African problems, thereby provoking debate over the causes of and solutions to HIV/AIDS. In his view, the causes lay in poverty and economic development would be the cure. Those supporting the Western scientific approach to HIV/AIDS health governance were accused by him of racism due to the initial emphases on sexual behaviour, the biomedical focus and the use of African participants for drug trials said to generate profits for Western Pharmaceutical companies (Nattrass, 2007). More recent clinical trial failures have perpetuated that suspicion and criticism. Posel (2005) suggests that the distancing from an orthodox science focus on sex prompted President Mbeki's dispute of the statistics on HIV prevalence and AIDS deaths and his criticism of public concerns voiced about sexual violence and promiscuity.

In response to my questions about stigma and denial, a community member stated that:

[75] Nattrass (2009) suggests that poverty may play a role, but that social and behavioural factors (concurrent sexual relationships in particular) are the primary cause of the high rates of infection, despite the role of poverty.

> I think it is the way HIV/AIDS was introduced. Firstly, the impression was that you only get it because you are promiscuous and secondly, it was said once you are HIV positive you don't have a hope, you're going to die (an older female vaccine CAB member from the Soweto site).

Treatment was criticised by President Mbeki and his supporters as poisonous and the 'roll-out' delayed until election time. This congruence of a history of past harms, suspicion of present research and political ambition form part of the socio-historical processes which Denuelin (2006) suggests influences health. Such harms and suspicion have reinforced concerns at community level, where stories of clinics injecting people with HIV circulate:

> You know, in this country we have a history of apartheid, you know, racial issues, so you find that when the research came into Soweto … you find that there were people who thought that this is another way for the white people to destroy the black people ... so it took a long time for people to actually believe in this research … to trust this research (a young male vaccine CAB member from the Soweto site).

And:

> I think people do talk wrongly about a trial. They think people are being forced or they are made guinea pigs, do you understand, so they don't understand that this is a voluntary thing a person was given to choose whether he wants [or] if he doesn't want (an older female vaccine CAB member from the Soweto site).

Political interference in the Medicines Control Council (MCC) and the promotion of untested alternative health strategies ensued (Nattrass, 2007):

> [The government wants] to bypass the MCC with certain issues … there is that distance between our government departments and the research being done ...Western science has proven itself … But now, the mindset of the people that went through the doctors, they want to change the viewpoint, they want to bring the people back to traditional medicines and stuff like that (a middle aged male vaccine CAB member from the Cape Town site).

Health norms and politics became intertwined, with local level responses to wider suspicions at those higher political levels. A staff member from the PHRU in Soweto told the story of the controversy surrounding a woman's health:

> Even though [this woman] died of AIDS they're like "she died of poisoning you know she was bewitched" and then the President, like: "No HIV doesn't cause AIDS" and people believe him, and you go there and they're looking at you like "what's all the fuss about the research and the vaccine" they go "oh if you get the vaccine and then you stop – oh – if you get HIV it does not necessarily mean that you get AIDS" (a middle aged female outreach worker from the Soweto site).

At national level, the polarised views between those disputing the link between HIV and AIDS and those who supported scientific evidence of that link has stimulated accusations from both sides. President Mbeki and his supporters were vilified for their refusal to accept the value of medical science. At the same time, they fuelled that polarising of views with unwarranted criticism of their opponents for their apparent singular focus on science to the exclusion of the socio-economic problems underlying poverty. These sharply defined views frustrated efforts of those who tried to reach across those boundaries. In either case, they were seen as sympathetic with 'denialist' views or, alternatively, in support of Western scientific imperialism. Civil society challenges over government positions and claims for constitutional rights ensued, forcing government capitulation over treatment provision.[76] Such conflict over health policy contradicts concepts of governance suggesting that government takes a steering role in sharing responsibility for health.

With that lack of accountability to citizens, government legitimacy has been challenged and trust in its capacity to play its role diminished. With democracy still in transition, a lack of political infrastructure, and fragmented health systems inherited from the apartheid era, there have been many competing priorities. Even so, gains have been made (Geffen and Cameron, 2009). Despite the centralising efforts of President Mbeki, the government was not united behind him,[77] and some provincial governments did not comply with his delays in treatment provision.[78] The result has been to strengthen the activities of non-governmental actors (Schneider, 2002).

Even so, the lack of political co-ordination and political leadership at national government level has had reverberations down through province to local public health system level. Since Schneider's (2002) observations were made, six years later respondents talked to me of the "completely dysfunctional [health] department" (personal communication,

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[76] As explained in Chapter One, the Constitutional Court ordered government to 'permit and facilitate' the use of Nevaripine to reduce the risk of mother-to-child transmission of HIV (Sachs, 2009, pp. 198-201).

[77] A small group of cabinet members supported him.

[78] The Western Cape Province is governed by the Democratic Party.

October 2008), where everything had to be passed through the Health Minister (personal communication, May 2008), with those challenging her dismissed. Although efforts to develop democratic structures across provinces and local government have been made, including the development of HIV/AIDS capacity, those involved in research have found this to be lacking. They identify:

> Huge problems with local government, lack of capacity. One of the [Integrated Development Plan] managers was a boiler maker ... there is corruption … there's uncertainty because of the political dynamics. There is uncertainty, there has been with Thabo Mbeki not being supportive of HIV issues. All that runs through … so how do you mobilise local political leadership to take the lead and for people to realise that HIV isn't just with the health department … but it is integral to informal settlements, it's integral to housing, integral to poverty responses and social welfare issues … and for the community people to be empowered to be able to hold them to account, to develop a plan that is for the best of that community and taking those issues forward? (an HIV and development researcher, WITS School of Public Health).

That lack of capacity has been exacerbated by the over-burdened public health sector and more recently, the burden of ART provision which has proved difficult to sustain.

In general, I found a lack of criticism of government policy at community level and few people broached this subject without my direct questions on these issues. This may suggest a strong ANC loyalty which is understandable given its role in resisting apartheid. One interviewee declined response to my questions about President Mbeki's stance; only to mention denial through local stigmatising practices. Another contact talked of her regret for the way that he had been demoted, rather than choosing an outright condemnation of his policies, despite her passion for her health work (a young female outreach worker in Soweto).

In general, the connections made by the President's critics between rates of HIV infection and policy delays were made by academics and others at national levels and tended not to be made explicit at community level in my research, apart from criticism of their treatment by staff at local government health clinics. With the legacy of political opposition to apartheid, the ANC has enjoyed loyalty from the majority and, as suggested by one academic, compliance. Just as:

> … whites [had] never challenged the white government much, blacks [don't] challenge the black government. And if the whites challenge the government,

> it's the 'race card', and we all just assume terrible things. And when I hear people say “oh, but this is Africa”, my heart sinks, and I think why, why's that our yardstick? Surely the bar has to be higher than that? … nobody is prepared to say “what kind of post AIDS society do we want? How do we live through this epidemic? How do we rethink families? How do we rethink identity and belonging? How do we rethink community?” And, in a way, “how do we rethink society?” … People don't complain ... It comes from a long history. But how do we break it, how do we understand that democracy means calling people to account, that government means actually delivering and servicing the people - that you can't run a country and fight an epidemic on rhetoric? (Director of an AIDS research unit).

This view reveals some of the political sensitivities around HIV/AIDS and the impact on health governance which I observed. Yet, Posel (2005, pp. 144-145) points to the paradox that “Mbeki's efforts to refute the sexual connection have reasserted the salience of the issue”, so that “AIDS activist, health educators, community leaders, and many citizens ... grew more resolute and insistent” in discussing the sexual transmission of HIV.

Since the above interview, there has been a change in government, with moves towards a more coherent health policy involving a mass HIV testing and treatment programme. During my time in South Africa rapid political changes were taking place, marking the changing state and non-state relations (Yanacopulos, 2005) and anticipating new forms of health governance. At the AIDS Vaccine Conference in 2008, the relief of public figures as the newfound freedom of expression began to change public discourse was palpable. Following that change, one interviewee agreed that:

> Within two weeks, it's amazing what political change does because, within two weeks we've changed our direction our trajectory in this country which is exciting (Professor Glenda Gray, Co-Director of the PHRU in Soweto).

Another added that the interim Health Minister had:

> … knocked down barriers that will be very hard to put back up ... Whether she stays or not … it will be very, very hard to put them back up (Professor James McIntyre, Co-Director of the PHRU in Soweto).

But, there was some hesitancy over predictions about the extent of those changes. Those working at community level echoed that hesitancy:

> There is, there still is (stigma) even though people think – ah – we don't judge them, but it's the actions that still charge. Verbally they don't charge but there are actions that show fear of being infected and also now it makes people want to stay away, that's a way of stigmatising. And one thing you still find some people that stigmatise even verbally, but generally people don't … but their actions … it hasn't totally changed it's just that there's some minimal change. There were times when people said rude things … but now they're

> not saying them that much … but we still need to speak about stigma (an older female vaccine CAB member from the Soweto site).

Efforts to do this at community level are discussed in the following chapters. The challenge is in stimulating change where stigma prevails in more covert ways. This change has signaled what Stein (2003) calls “the new dirty secret”. Just as racism becomes less easy to declare in many public spaces, stigma appears to be changing. It may be more difficult to detect, but still potent in its impact and so challenging stigma is not as straightforward as is often presumed.

As indicated, changing entrenched health norms cannot be isolated from wider socio-economic deprivations and politics. Previous research suggests that it is possible to change perceptions of risk and underlying stigmatising behaviour (Joffe, 1999). Changing perceptions can have a positive impact on existing prevention policy and practice, some of which has been criticised as counter productive in this respect (Ogden and Nyblade, 2005). Those who challenge dominant representations of those who are victims of stigma are changing perceptions, across different scales of health governance from global to local levels. In doing so, they are playing meaningful political roles. However, my evidence suggests that stigma and risk are more complex than assumed, where knowledge provision is not sufficient without understanding socio-cultural contexts, suggesting that a more sensitive HIV/AIDS policy to reflect those complexities might have more impact. The trial site researchers are attending to developing community engagement which addresses those complexities through the provision of resources and this is the subject of the following chapter.

4.3 CONCLUSION

The aim in this chapter has been to provide insight into how stigma and politics operate in this particular context. It shows the ways that health norms and politics surrounding HIV/AIDS constrain efforts to gain access to health, through the blaming of those infected with HIV, so as to maintain a distance and to preserve social stability. Prevailing health norms, infused with political controversy and exacerbated by poverty, limit the health options of

those who find it difficult to resist the impact of stigma and seek access to health. These data show how stigma acts to deter people from testing for the virus and disclosing their status.

The social exclusion of those perceived to be affected, or likely to be, is a crucial factor inhibiting the agency of those who are stigmatised. This inhibits HIV prevention, treatment and care. As explained, similar patterns and impacts have been identified across countries and cultures, with far reaching implications for the course of HIV/AIDS; especially in countries where resources such as ART are limited and where stigma is more prevalent. The political nature of this condition and its complex implications will continue to influence responses. My data confirm the significant impact that stigma is still having in South Africa, where material resources are limited and where rates of infection continue to rise within vulnerable populations. At the same time, the data confirm the dynamism of this process and the potential for change in health norms and health outcomes, although the direction of change does not suggest a universal solution.

I have argued that the combination of stigma and political controversy limits capabilities to function. That political controversy has caused uncertainty and a polarisation of views, with little room for the kind of “practical reasoning” over social injustice promoted by Sen (2010), or Ruger's (2010a) shared health governance, at national or local levels. South Africa is no different in that historical patterns and poverty have fuelled stigmatising practices. Given the political and socio-economic complexity, the ideals of eradicating stigma are elusive goals without concerted efforts to challenge discrimination in communities and at higher political levels.

As suggested, the rights and freedoms guaranteed in the South African Constitution allowed President Mbeki to be challenged without the repression of his critics (Geffen and Cameron, 2009). This capacity for legal redress is said to bode well for future challenges over any lack of progress in healthcare matters (ibid). However, although past successes are encouraging, opportunities to make legal claims are limited for the majority with no

means without collective civil society engagement arising from within communities where social injustice is felt most acutely in both formal and informal ways. The burden of political activism is too great for poor people to carry. The provision of health information on HIV prevention in particular is not sufficient without the understanding that those who ignore that information, or adapt it to suit their situation, are making practical decisions given their situations. Historical and socio-cultural contexts provide important knowledge for understanding how people make decisions about health and the ways that they work with those norms to find appropriate mechanisms for change.

As Barnett and Whiteside suggest (2006), where global strategies to prevent HIV infection have failed in general, smaller efforts at community levels across countries might have more impact than recognised. Those devised by those most afflicted, namely, the "ordinary people made extraordinary" through their experiences of HIV/AIDS described by Dowden (2009, p. 348), who may be the most likely to succeed, given appropriate support. Therefore, removing barriers to access to health requires an understanding of the experiences of those who are dealing with HIV/AIDS in their daily lives.

These data have given context to my evaluation of the ideals of community cohesion and engagement and the daily realities experienced by poor people in the following chapters. Stigma and poverty are key challenges for those working to change health norms and to influence decisions over the kinds of resources which supply their particular health needs. Those resources for community engagement in local health initiatives are explored in Chapter Five, where communities work within the invited spaces of clinical trial sites. The use of those resources is explored in Chapter Six, where wider community, national and global connections are interlinked with that local activity; to strengthen and build upon their daily activities at community level.

CHAPTER 5

COMMUNITY ENGAGEMENT AND RESOURCES FOR HEALTH

Having set community engagement in local health initiatives into the South African socio-political context in Chapter Four, I now focus on the HIV vaccine trial sites and the engagement of communities as they pursue valued health needs. Here, I consider Ruger's (2007) principle concerning the quality of health resources, such that differences in health resources are unjust in that they undermine capacities for health functioning. Engaged communities are invited into trial site initiatives and, therefore, vulnerable to co-option. However, my focus is on what they do within these invited spaces and how they can develop the capabilities to use the resources available to play meaningful political roles in that dynamic process at different times. The significance here is in the value of those resources and the capability to convert those resources for health functioning (ibid), such as in dialogue within trial site communities and, as discussed in Chapter Six, deliberations across those boundaries.

This chapter lays out the key factors involved in that potential for agency, beginning with an overview of the key actors working within trial site projects and the ways that different perceptions of community engagement inform different approaches to their work. The key roles and responsibilities of CABs are outlined with an exploration of CAB dynamics, followed by the resources for community engagement provided at local, national and international levels for CAB capability building. The focus then moves to the daily process of health governance in trial sites and the power relationships involved, to reveal the influence on community engagement of the multiple accountabilities of researchers to donors and between researchers and communities.

Finally, I discuss the limits to community engagement and the achievement of health goals for the majority of the trial site populations, where the most vulnerable people whose rates of HIV infection are the highest are the least likely to be engaged in local health initiatives. Some of these excluded people are the current focus of trial site researchers in the two

case studies. The ideals of community engagement – manifest in policy documents and often expressed by people involved – are set into perspective against the political realities of trial site governance and those wider impediments to health functioning in these South African contexts, as discussed in the previous chapter.

And so first, I turn to the local health initiatives where community engagement takes place, beginning with trial site staff and community member reflections on community engagement. These are the invited spaces of community engagement which Cornwall (2002) discusses. As argued in Chapter Two, these are ambiguous spaces (Johansson and Hvinden, 2009) such that, during the process of liaison between communities and trial site investigators, elements of co-option and empowerment can be in operation at different times in different ways. Therefore, outcomes can be unexpected, dependent as they are on those complex interactions between the different actors involved.

Whether or not co-opted or empowered, some community members may be motivated to become engaged in trial site activities, but lack the capacity to do so. Intentions are thwarted by other constraints and so political subjectivities are not given the chance to take expression. Just as some develop the capabilities for health agency, others are unable to promote their own particular valued health resources. As discussed in Chapter Four, some groups are stigmatised due to their sexual orientation; adding to the greater risk and burden of HIV/AIDS and isolating them from community engagement in health initiatives.

Further, the overriding demands of poverty and community instability are exacerbated by high rates of mobility and migration, so that other groups are stigmatised and excluded; this time due to their perceived status as non-citizens. This community diversity and the exclusion of some groups impedes health functioning for those groups; affecting the longer term inclusive aims of community engagement initiatives and conceptions of shared health governance (Ruger, 2010a).

5.1 COMMUNITY ENGAGEMENT

An outline of the roles of outreach staff and engaged community members, as key to this research focus, is followed by an exploration of how perceptions of those involved in community engagement influence their approach. The ideals and realities identify some of the difficulties in putting community engagement into practice, some of which are context specific and others more general. I move on to explore the governance and power relations involved in community engagement and the potential for empowered communities. The section ends with an exploration of CABs and the dynamics between members which challenge ideas of shared health governance (Ruger, 2010a) at this local level.

Community outreach staff include community educators, who spend time within the trial site communities providing information on HIV prevention and research. The role of CAB coordinators, or Community Liaison Officers (CLOs), is to do as their names suggest. They work to help in the management of CABs and to facilitate the liaison process between the researchers and CABs. Different perceptions of community and community engagement show how such definitions influence approaches to local health governance, and thus, the potential for communities to benefit from that engagement and to play meaningful political roles in that process.

As discussed in Chapter One, the ideals of community engagement are to ensure that communities are better off as a consequence of their engagement (Swartz and Kagee, 2006). This involves community engagement which addresses the fundamental concerns of communities through interaction between researchers and communities. In conversation with the two Directors of the Soweto trial site, I suggested that this relationship between science and society might be changing and that this was exciting. Their response reflects that excitement and gives some insight into the realities at the same time:

> It's good and that's what's exciting is that scientists have to pay attention to the community, which they never did before. They would jet in and execute their science and then wonder why it didn't work. Well of course it's not going

> to work because "you told me to stop breast feeding my baby, but there is no milk, shek[79] I've got no money" (Professor Glenda Gray, Co-Director of the PHRU in Soweto).

Such considerations over local needs illustrate the gaps between the "stated objectives of participatory governance and the actual experiences of citizens and civil society actors", as described by Johansson and Hvinden (2009, p. 6). On the subject of microbicides, the challenges of HIV prevention unfold. The same Co-Director explained a typical scenario, where a participant might say:

> "You make these microbicides, but did anyone ever think about how (many) boxes (of them) am I going to have to hide under my bed and slap into my vagina every time I have sex?" … so those are the kind of issues we have to deal with. Even now, with circumcision, there is this huge backlash because circumcision works, but men are attached to their foreskins, and now they find it useless hiding all these excuses (Professor Glenda Gray, Co-Director of the PHRU in Soweto).

Without this kind of understanding of the realities of the lives of trial participants, the research is less likely to succeed and its benefits not distributed to those communities. This kind of 'inside knowledge' gleaned through community engagement can enable effective health research and, at the same time, the capacity to generate valued health care for those communities. I was told that medical staff in particular could sometimes be dismissive of cultural concerns raised by communities, but are urged by the Cape Town Director to:

> ... understand when you move into the community territory, it's on the community's terms … it's not my terms, and that is a hard lesson for us medics to learn. This is the furthest thing from our thinking … medics have a bus to catch most of the time … it's exacting, because one can't do it wrong. It's often unforgiving so you've got to not mess up (Associate Professor Linda-Gail Bekker, Director of the Cape Town trial site).

Even though her work was considered as an investment "both morally as well as financially" and her work was "not about a single trial or a single study – it's a relationship" in which she had invested personally, as had many of the staff whom I met, the process of health governance is complex and the communications between trial site staff and communities not easy to maintain.

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[79] This is a colloquial expletive.

5.1.1 Perceptions of community engagement

Evidence of the ideals and realities of community engagement are discussed here. The ideals in contributing to community development expressed in policy documents and mission statements show high expectations when set within the daily experiences of those living in trial site communities. The positive conceptions of community cohesion and inclusivity underpinning those expectations belie the experiences of those working in communities. Even though the aims are to achieve the deeper form of engagement true to those high ideals, what occurs tends to be more complex and less assured. Some of the following statements made by advocates and service providers begins this discussion, from the perspective of an AIDS NGO and moving on to those initiatives directly involved in AIDS vaccine advocacy.

The aims of the AIDS Alliance[80] (2007) in community engagement include mitigating stigma and discrimination and increasing community awareness of and access to services. Keys to this conception are local action, community education and skills development. The emphasis on knowledge building and partnership highlights the ideals in equal power relationships between communities and the NGO. More specifically, that emphasis on partnership is found in a UNAIDS/WHO document (2004, pp. 17-19) on the ethical considerations in HIV prevention trials which advocates “an open, iterative, collaborative process” aiming to strengthen local ownership of the research and overcome structural power imbalances between communities, researchers and sponsors. Each of these ideals will be reviewed in this chapter.

More specific to AIDS vaccines, AVAC (as introduced in Chapter One) is a principal vaccine advocacy organisation which defines community engagement as “a meaningful participatory process” of stakeholder involvement in the trials process, from the design of protocols to the dissemination of results (AVAC, 2010, p. 9). I have selected some of the core principles of their publication on Good Participatory Practice with UNAIDS to identify

[80] AIDS Alliance is a global partnership supporting community action on AIDS in developing countries.

issues which arise in this research. They include: scientific and ethical integrity; respect; autonomy; transparency and the building of research literacy (UNAIDS/AVAC, 2007, p. 13). The aim to empower communities, as "decision-making agents and advocates in the research process" (pp. 31-32), will be assessed through data on community engagement below. Those ideals are embodied in the aims of the SAAVI HIV/AIDS Vaccines Ethics Group (HAVEG), where community participation is encouraged as creating democratic systems and procedures and empowering communities as joint partners in trials (Sibisi, 2005, p. 59).

According to the Socio-behavioural Group (now no longer funded by SAAVI), it cannot be assumed that trial participation facilitates empowerment, since what happens in practice is that:

> Complex social issues surrounding community participation in HIV vaccine research tend to be regarded as epiphenomenal, rather than serious research questions. In the context of the real need for getting the trial done efficiently, any challenges, difficulties, concerns can become irritants to get out of the way (or hide) when the trial agenda may be conducted efficiently (Swartz, Lesch, Martin and Giocos, 2007).

On the subject of community engagement in more general terms, one of the key problems identified at the Durban workshop in 2007 was the absence of adequate feedback mechanisms for monitoring information disseminated to communities and among stakeholders. Workshop findings suggest that existing mechanisms were unclear, sporadic and inadequate for the kind of multi-level feedback needed at individual, CAB and community level (Socio-behavioural Working Group, 2009, p. 19). Again, these are issues which arise in my own findings below.

As discussed in Chapter Two, the debate around community engagement focuses on degrees of participation from consultation, to involvement, to engagement; with the latter as the most beneficial in ensuring that community voices are heard with meaningful responses made (Barnes et al. 2007; Socio-behavioural Research Group, 2009). This suggests a linear process, whereas in reality there is often a loose definition of terms with different forms of communication operating at different times. Researchers use the terms

to differentiate between levels of community participation at different times across the life span of a trial, as determined by the size of the research in question. From this view, it does not make sense and is too costly to engage communities in small trials where consultation is all that is required.

I was told that South African politicians tend to use the concept of community engagement, rather than community involvement, to endorse their commitment to responding to community concerns in meaningful ways. The Cape Town CAB members use those terms interchangeably and in Soweto community involvement was preferred. As one of the CAB members explained, the different terms are a matter of semantics:

> When we're talking to people, where you say involved or engaging them, what does it mean? Which one do they understand better? We did not sit down to say: “we should have involvement”, we’re talking of the language [and] which makes more sense to the people (an older female vaccine CAB member from the Soweto site).

Even though this veteran CAB member had a clear conception and, as she said, the choice is a matter of meaning and pragmatism, this fluidity of terms and definitions may also reflect some of the confusion over what is required of CAB members and what can be achieved for communities. As Cornwall and Brock (2005, p. 18) suggest, “the terms we use are never neutral”.

A PHRU staff member agreed that “community involvement, engagement, participation are more often times interchangeable”, but went on to say that community involvement means involving communities in decision making over research, where “we give a platform” to say “the research is risky”, or “we are comfortable”’ (a young male CAB member from the Soweto trial site). As I found across the sites, people valued the transparency of researchers in explaining the risks of research. His suggestion that they worked collaboratively by responding to suggestions is less clear. As explained below, feedback mechanisms are not always in place, so that this collaboration is not guaranteed throughout the duration of a trial period. He told me that “we capacitate them to understand – they don’t just have to work in the darkness” (ibid).

Although being 'capacitated' with valued resources has its benefits, this view casts communities in a reactive rather than a proactive position as joint partners. As another staff member conceded, some people conflate terms, she a agreed that "it depends where you really, really distinguish these terms ... they are not the same thing" (a young female outreach staff member from Soweto). She explained that working with communities is a process whereby they are prepared beforehand and consulted on their needs. They are asked where they see themselves fitting in and then they are engaged through constant research updates and communication up to the stage where results are disseminated. The aim, still, is to generate smooth trial operation which attends to the needs of communities but which suggests their reactive position. And so their political engagement rests with influencing that immediate research process through providing community concerns about trials and trial participation rather than play a more proactive role.

Again, a lengthy explanation of the role of community educators suggests involvement in research, but still one which is reactive, rather than proactive:

> Community engagement, I think, is quite complex. It's not a single entity. Community engagement for me is not only getting the community to take part in your studies and to support you if they are not taking part, but just support you as a general community ... including them … as part of the whole education process. Through the education … you can get them to engage in their own health as well. They'll tell the next person and that's how it will spread your education throughout the community. Also, to get them to a point where they can see themselves as some part of the research, that they will feel comfortable to feed back, to say "this is what we don't like and this is what we think is not working and for our community, it will be better if you do something this way" (a female Clinician from the Cape Town site).

And yet, the goal is said to be empowerment though that engagement:

> That is where, for me, the Community Advisory Boards fit in very well, because they mediate that communication and because they are people from the community, that they recognise that the community should feel comfortable to communicate through them with the researchers … I think it's them just taking part in what you do -- it needs to go both ways. And if you do community education, obviously, it's a very important component of our work. It's not just doing the studies, its educating the community. You need to be able *to empower them in some way,* and even if they're not eligible to take part in the study, they still get something out of it … so for our education programme we don't just tell them about HIV vaccines, we do general HIV education as well, and VCT,[81] where they can go for help, where they can get tested and where they can get treated, things like that. And through that we at

[81] Voluntary Counselling and Testing facilities.

> least empower them in some ways to take care of themselves (ibid, with added emphasis).

That empowerment was emphasised by three of her outreach staff who held that "knowledge is power", in that it helped trial participants come to informed decisions over their health. However, as discussed in Chapter Four, HIV/AIDS information is essential, but not sufficient in situations where stigma prevails. A deeper form of engagement is required than the dissemination of information. The two young community educators interviewed talked of the beliefs which some people hold and their presentation of the scientific view in counterbalance. However, as explained in Chapter Four, social and cultural beliefs are reinforced by the experience of stigma and the politicisation of AIDS which make it difficult for people to come forward for trials, or to become engaged as CAB members.

Others working in the trial sites are more circumspect in their assessment of the realities. A scientist working with MSM groups described his ideal and the realities drawing from his experience of outreach work in the search for trial participants:

> I think my response [to community engagement] has to be squarely defined as in public health. I mean, I think that community engagement is … it's integral to the research products that we develop both in terms of which subjects or issues are researched and then again in how that research is brought to fruition in terms of targeting communities, doing outreach … the community input, community engagement, is very important, and then I think that builds upon the dissemination of actual results, of actual interventions. For me, the part of the public is very lost at the moment. It seems like we're all about gathering information … [getting] our numbers on this pile of papers and then wash our hands of it ... I think that by engaging with the community to begin with *they can actually own that data* and they can do something with [it], we don't have to wait for this large cumbersome organisation to take over (a young male Programme Manager from the Cape Town site, with added emphasis).

And so to him the reality is in information gathering, but his ideal is in ownership so that communities may use that information beyond the boundaries of the trial site. This conception befits Ruger's (2007) key principle as a valued health resource. In this case, MSM groups would then find ways of directing their own HIV prevention and health strategies as well as being involved in trial site activities. The potential for influence back and forth between those informal and formal spaces may be mutually productive through

the exchange of information and skills in building valued health resources. I return to this issue of networking in Chapter Six.

Another interviewee had reservations about the realities of community engagement:

> In the context of the vaccine trials it means the communities being involved, not only in the vaccine trials but from the beginning. If you are going to do a trial … before you even start, let the community know here what they think and how they feel, what might be the challenges and that's how, to me, that's what it means. *Whether it happens or not is another story*[82] (with added emphasis).

Her reservations reveal the shortfall between ideals and realities through her daily experience of working to achieve that ideal form of community engagement.

A wider and more grounded view of community engagement, beyond health to reach into the realms of community development, comes from Michael Tyhali:

> Community engagement or community involvement to me it means to work hand-in-hand with the community. Being involved in whatever project is going on in the community, like, focusing your attention on - on housing, because many parents don't have houses – getting involved in 'clean-up campaigns'… And getting involved in job-finding for parents … because some of the learners are coming to school without a slice of bread …. Community involvement in the sense of starting soup kitchens … in the sense of even during the weekends … to be deeply involved in all the activities that are happening in the community, because as long as we are working in the community we are part of this community (CAB member and Headmaster of Masi primary school).

Of course, this holistic view of community engagement goes beyond the remit of clinical researchers and yet, it reveals the wider socio-economic conditions which influence health and the community capabilities to "pursue and achieve health outcomes they value and have reason to value" (Ruger, 2010a, p. xv). It shows the limits to the realities of achieving those outcomes for those living in poor communities.

In summary, these views reflect the kinds of meanings in context that Willig (2001) tries to unravel, where the ideals of community engagement and its derivatives can be seen as they play out in reality. Now, more specifically, I turn to the key participants in community

[82] This interviewee asked to remain anonymous.

engagement and the perspectives of those involved on their roles and responsibilities to those ideals.

5.1.2 Community Advisory Boards

As outlined in Chapter One, CABs are the principal conduit between communities and researchers. They have a pivotal role in liaison between researchers and communities, by providing information on HIV prevention and research and ensuring that community concerns about the research are fed back to the researchers. As such, they are promoted by donors, advocates, researchers and community participants as the key to effective trial site governance and community development in their capacity to convey information to communities on HIV prevention and clinical trials and for feeding back cultural and social concerns to researchers.

The following elements of community engagement are discussed: i) the ideals embodied in CABs found in advocacy and donor documents; ii) the community profile of CABs and issues of representation and; iii) CAB dynamics and the impact on capability building. I begin with the ideals, moving on to perceptions of different actors as to what is involved and how CABs do their work. Again, those perceptions identify ideals unmet in reality, which reveal the problems involved in achieving meaningful political roles for trial site communities.

<u>Perceptions of CAB roles and responsibilities</u>

Vaccine initiatives have an investment in the capabilities of CABs to perform their roles in community-researcher liaison. Without them, the research is less likely to be effective and may not fulfil ethical requirements. According to IAVI, the goal of CABs is to build a strong relationship between researchers and communities and to ensure community input into research through close involvement in the planning and management of vaccine trials (Kresge, 2006). As we found in the discussion above, this is to be achieved through the exchange of information, with CABs as a conduit in that exchange. The SAAVI guidelines

for CABs (or Community Advisory Groups) include the mission to: increase community understanding of research; voice community concerns; help to resolve grievances; and advocate for human rights (SAAVI, 2007).

Minimum good practice guidelines include the requirement that CABs are “empowered and knowledgeable to provide meaningful input into the development and conduct of trial and trial-related activities” and able to communicate with broader research affected communities (UNAIDS/AVAC, 2007, p. 32). A key point raised by those involved in community-based research is that PIs who listen to CAB concerns and seek feedback from its members may be a key element in effective CAB functioning (Strauss, Sengupta, Quinn, Goeppinger, Spaulding, Kepeles, and Millet, 2001). Limitations raised include the problem of maintaining resources when study budgets are cut and research priorities take precedence (ibid).

And so, the remit for ethical research procedure, the key feature of community engagement, is for communities to ensure the conduct of ethical research and for researchers to convey ongoing information about that research and to take heed of community concerns. CABs do not recruit for trials although, in reality, the lines between engagement and trial participant recruitment can be blurred. Others find community engagement difficult in itself due to their lack of understanding of their roles and responsibilities and lack of skills to communicate beyond the immediate CAB arenas.

That fundamental lack of understanding of roles and responsibilities extends to communities where CAB profiles are low and where it is difficult to find new members to represent the different community structures and sectors. As explained to me, “people don’t know about CAB. People don’t know what CAB is doing. Few of them know” (a young female CAB member from the Cape Town site). Like others in her group, this CAB member felt the need for support from:

> … the doctors and whatever, in order to recruit, talk about CAB. We do organise. We do recruit [CAB members], but I do not think we are strong enough. We are not fully equipped to convince people about the CAB (ibid).

Then, CABs would be able to provide information that was lacking, since: "People don't know about the studies. People don't know about the research. They don't know about HIV and vaccines" (ibid).

A key aspect of this process is to ensure that the CAB membership reflects the different community sectors, such as churches, political organisations, women's groups, traditional healers and youth groups. In reality this is difficult to achieve. In the Cape Town site, I had no access to the vaccine CAB which was undergoing 'restructuring'[83] and the others were experiencing problems in developing a representative membership in the turbulent times during the civil unrest outlined in Chapter Three.

This key problem of community representation is not site specific and nor was the unrest the only causal factor. In such cases, community concerns are not expressed through those different sectors back to the researchers. In turn, the researchers have a less clear picture of how they might develop a sustainable trial process. At the same time, the lack of community representation results in the exclusion of those who might benefit from the resources which researchers bring, such as VCT, HIV prevention information and access to treatment. In such cases, the ideals of leaving communities better off (Swartz and Kagee, 2006) are not realised.

CAB dynamics

For one of the Cape Town site CABs, the difficulty was in moving forward due to more fundamental problems of CAB management and dynamics. For some members the meetings were being used as an opportunity to discuss their lives in 'safe spaces'. As

[83] This involves reforming a CAB which has lost members, to find a better representative body from community sectors, or changing the structure of CABs into executive and non-executive bodies.

Campbell, Nair and Maimane (2007) suggest, those valuable spaces for discussing HIV issues are an important resources in contexts such as South Africa, where stigma still prevails and where access to safe spaces is limited. Although community members are invited into trial sites to liaise between communities and researchers, some are more preoccupied with personal issues relating to their HIV status and experiences of the stigmatising behaviours of others. This explains why the lengthy debates within the Cape Town CAB focus group on HIV status disclosure took priority over the process of community engagement.

Yet, I argue that these invited spaces provide opportunities for respect and recognition of their rights to present arguments (Ansell and Gash, cited in Johansson and Hvinden, 2009, p. 6), although the action which Barnes et al. (2007) include is an essential element in social change. Without it, opportunities to build meaningful political roles in trial sites cannot be developed. As explained in Chapter Two, steps towards action begin with recognition, and this includes self-recognition and mutual recognition, where narrative identity and the capability to tell one's story leads from self esteem to social esteem (Ricouer, 2006). Such opportunities for recognition are valued by CAB members whose need for support and friendship are an important part of the process towards potential empowerment. Without that recognition and esteem generated collectively from within the CAB spaces, capabilities to take action and to communicate effectively in the wider trial site environs may be less likely to develop.

This preoccupation with personal issues was not shared by CAB members who may enjoy the self esteem necessary to be more focused on the practicalities of community engagement. Thus, where some use those political spaces for resources as coping strategies, others have the capabilities to use those spaces for redistribution to effect the wider change through influencing others' actions and policy that Engberg-Pedersen and Webster (2002) discuss. Conflicts of this kind over agendas suggest that CAB dynamics are a crucial element in the shared health governance which Ruger (2010a) promotes as key to deliberations over health.

Those deliberations may include important issues around personal experience. For example, during one meeting a counsellor discussed treatment detail with another CAB member. This discussion was opportune and welcomed for that member, but is not considered part of the CAB roles and responsibilities in the formal and practical sense supported by advocates, donors, trial site staff and more confident CAB members. That process of capability building may take longer than the donors and researchers, as key actors in supporting community engagement, acknowledge. I return to this issue of trust and expectations when discussing multiple accountabilities below.

Where those CAB members use the space for building confidence through a discussion of personal health and related decisions, other members become frustrated and disenchanted with the slow progress of more practical matters of CAB management and wider community engagement. As explained in Chapter Three, this can cause alienation and withdrawal from meetings. And so without a core group of people with those capabilities to function beyond the immediate safe spaces, and whose agendas are in tune, CABs are less likely to develop the collective agency to use those opportunities to transform health norms and governance. However, I argue that by easing individual isolation and offering opportunities for building self-esteem, they are part of the process in transforming the social norms around HIV/AIDS.

Therefore, the political dynamics between researchers and CABs and within CABs determine whether or not the wider, overarching agenda of meaningful and collaborative community engagement can be achieved. Further, the high CAB membership turnover due to conflict over agendas, lack of leadership and more pressing commitments widens the gaps between longstanding members and new recruits who can feel undermined by that experience and assumed authority. Through my observations of CAB meetings, focus groups and interviews, including the in-between moments as people congregated before events and as they dispersed, a complex mixture of community engagement ideals and reality occurs across the different trial sites and city environs.

CAB meetings in Soweto were more structured events where strategy was being discussed, albeit amongst some of the core set of members rather than the majority who remained silent throughout or who made little contribution. This difference in confidence signified the experience and confidence which leaders had gained over time, in contrast with those whose membership had begun more recently. The Soweto CAB consists of long-standing members whose confidence levels have grown with their community profile and through wider national and global networking opportunities. They are considered to be “international icons” (a young female outreach worker from Soweto), whose stories are related to trial site visitors. At the same time, those stories raise social esteem to inspire others in that work. Their confidence in the unity of their CABs in collaborative projects, where I was told that no-one is left behind, is confounded by those less assured members whose revelations in interviews gave a more circumspect view.

My sense that some CAB members were not comfortable was reinforced by the experiences of two vaccine CAB members who described their own discomfort on arrival as new members. As one said, “I’m the new one and everyone knew about protocols” so that people made it difficult for her to contribute: “They made me feel as if I didn’t know what was going on” (a middle aged female CAB member from Soweto). She discovered later that she had relevant experience which she could not express due to lack of confidence and the negative reactions of CAB members. As her friend said ‘they didn’t give her a chance”, consequently they were “not growing” (a young female CAB member from Soweto). This is the reality of community engagement, where the ideals of equal partnership as a pre-requisite for empowerment (Lasker and Weis, 2003) are confounded.

In this kind of scenario, where political relationships between CAB members constrain that potential for empowerment, the role of the CLOs and CAB coordinators, in mediating between CAB members and finding ways to intervene in the CAB dynamics, is crucial. They mediate when political relationships cause conflict and work to encourage those less confident members by finding ways to develop that confidence, for example through training so that they can return to the CAB meetings to relate new knowledge and

understanding. By sending these two women quoted above to workshops, the CAB Coordinator helped to heal frustrations and conflict between CAB members. As one of the women said, “now I feel empowered, more empowered … and no-one is going to pull me down anymore … [the CAB members] listen to us now” (the above-mentioned middle aged female CAB member from Soweto). Having been placed by power (Allen, 2008) by the veteran CAB member, she and her friend had become able to change the balance in those relationships. Moreover, the conflict between veterans and new members was to be resolved by moving the former into an ‘Executive CAB’, so that new younger members would be less likely to leave and more able to generate new ideas on CAB activities.

CAB restructuring is an ongoing process, either through loss of members, or through attempts to re-develop existing structures, as above-explained. Now, this kind of reformation of CAB structures can be seen as a form of technological ‘fix’ as part of a process of governmentality (Rose, 1999), whereby more combative CAB members are selected out, leaving co-opted members to aid the smooth running of clinical trial operations. From this perspective, the invidious reach of government into our lives is reinforced through discourses of self-governance, as a form of non-coercive control. CAB members may be co-opted to perform self-governing roles, ultimately controlled in this case by vaccine initiative donors and trial site researchers. Indeed, as an interviewee told me:

> If they [CABs] somehow disagree with what we want them to do, if they somehow disagree with what we think is right, then the CAB is not functioning well, forgetting that they actually represent the community … there’ll be cases where our opinions differ and somehow we want them to be “yes, yes, yes”, to say “yes, yes, yes” to everything that we do. If they don’t see it that way then there’s a problem.[84]

Of course, that smooth operation of trials is an uppermost concern for the researchers and the relationships which develop between the CLOs, or CAB coordinators, and CABs, and their capacity to respond to the concerns of CAB members is pivotal in the success of community engagement. The CLOs are an important conduit for relaying information and concerns between researchers and CABs. Those relationships between CABs and their

[84] This interviewee wished to remain anonymous.

co-ordinators are an important part of the empowerment of members less confident in their abilities to play their roles to their satisfaction. I was told that a very shy CAB member from the adolescent CAB in Soweto had been offered a place in a workshop led by HAVEG,[85] to return emboldened by her knowledge of ethics and human rights and highly assertive in her dealings with others in her CAB.

That facilitating role played by the CLOs helps to generate newfound confidence. On the other hand, the CLOs can also act as a buffer between the CABs and researchers, thereby limiting opportunities for direct dialogue (Johansson and Hvinden, 2009) between them, especially when contentious issue may arise. Overall, opportunities to play meaningful political roles can arise through the agency developed from CAB membership through their relationships and alliances built with CLOs. And, although distance between the researchers and communities can be frustrating for CAB members, there are opportunities to develop the capabilities to use the information and skills training provided by the trial sites, by national and international AIDS vaccine initiatives and by donors to build opportunities for agency.

5.2 RESOURCES FOR COMMUNITY ENGAGEMENT

Community engagement resources are valued by CAB members for their quality in health care provision; in particular where public services are often lacking and private health care is beyond the means of the majority. The relationships of mutual respect and trust in confidentiality are valued in contrast with experiences of local public health services, where lack of trust breeds fear of HIV status disclosure. Insights into the value of those resources to communities sheds light on their use in developing capabilities for health functioning which is the focus of Chapter Six. This focus on community engagement resources responds to concerns with the ways that local institutions manage resource needs, relationships and change (Mohan and Yanacopulos, 2007a, p. 232). It shows how health governance operates in those local institutions.

[85] The HIV/AIDS Vaccine Ethics Group - part of the SAAVI partnership - attends to ethical issues around clinical trials (www.saavi.org)

Key resources are information and training in communication skills which enable some CAB members to increase their capabilities for decision making over personal health and, in some cases, to extend those capabilities into the wider social arena. These form part of the valued health resources which CAB members endorse. Those with communication skills are able to convey that information to others and widen that access. Understanding complex HIV prevention technology – vaccine information in particular – is a challenge for any lay person and especially for those with limited formal education. Further, converting that information into appropriate and meaningful resources in such diverse socio-economic and cultural contexts requires particular skills of interpretation. And, as discussed in Chapter Four, the impact of stigma and political confusion on decision making over health confounds notions of a clear linear process between information provided and action.

5.2.1 HIV/AIDS knowledge and information

The engaged community members whom I met value information on HIV/AIDS and HIV prevention to guide them in making decision over their health. They value guidance on access to ART, care and other services essential to maintaining health. However, stigma and political confusion around HIV/AIDS has made it difficult for people to gain access to knowledge and information and to feel confident in making informed decisions over trial participation, or wider involvement in trial site activities and personal health choices. In her study of treatment uptake in a Cape Town community, Mills (2008, p. 28) discovered that people battle with conflicting views, suggesting that there is a need to "better understand how knowledge around AIDS science is interpreted, negotiated and lived" and where "deep fears" of stigma and of the side-effects [of treatment] persist alongside these forms of knowledge". She identifies the role of hope and belief in health decisions, such that death may occur if one is not 'ready' to take treatment.

As I was to find, hope and being 'ready' were significant considerations in beliefs about health prospects. Here, "political equivocation and biopsycho-social responses to illness and treatment" add to the complexities of knowledge transmission (p. 31). Such

equivocations may explain why some people avoid scientific approaches to HIV/AIDS. Traditional healers whom the majority of South Africans consult do not present the dilemmas of facing stigma through association with public or private clinics. In any event, differing views can be held, as Robins (2005, p. 15) found in his research, where a "complex mix of religious, communal and activist discourses" coalesce into ways of interpreting illness.

Even when scientific knowledge is sought by communities, the eleven official languages are an additional challenge for those whose responsibility it is to be interpreters, for those whose levels of literacy may be low and where science education in post-apartheid South Africa remains inadequate for the majority. A Sowetan CAB member explained this problem and the dilemma in seeking as wide a community representation as possible on her CAB without excluding valuable people with those formal educational deficits:

> Another challenge would be the language, the scientific language that we also have to get to the level of, firstly, us understanding the scientific language, to be able to pass it on. Because there are certain terms that are not very easy in our African languages to be able to pass over to the community to say this, and they can never also be changed to get to that level, but to the best of our ability to understand them first so that we can be able to pass that information to the community (an older female vaccine CAB member from the Soweto site).

Here, confidence in expressing that difficulty is an important element in communicating those problems so that understanding can be developed and passed on to the wider community. That confidence is more likely to develop where there is some measure of equality in the relationships between staff and communities.

When asked if doctors found it difficult to communicate their science, one CAB member felt able to say "this is where you're using your jawbreakers.[86] You have to come down and get to our level" (an older male Sowetan vaccine CAB member). This suggests that concepts of partnership embodied in the ethical remits of HAVEG may be achievable in some trial site contexts. In this case, the ideals in scientific and ethical integrity and the

[86] This is a colloquialism for difficult scientific terminology.

building of research literacy promoted by advocates (UNAIDS/AVAC, 2007) is evident to some degree.

Conveying that scientific language is a challenge and yet, in societies where several languages can be used in one sentence, in the media and in everyday conversation, people are accustomed to finding innovative ways to communicate and explain vaccine science and its concepts, once that knowledge is secure. For example, the concept of a vector[87] is explained by using the analogy of a spoon to get sugar from a bowl into a cup of tea. Such simple explanations cross divisions in terms of cultural understanding and educational levels, especially where deficits in science education for the majority population continue.

The better the cultural understanding the more effective the message being conveyed. For instance, bridging the gap in cultural understanding between the HIV Vaccine Trials Network (HVTN) sponsors in Seattle and South African trial site communities is an essential part of communicating information in accessible ways. Apart from language and literacy issues, presentation matters. It was explained to me that "[HVTN] like to have pamphlets with eight pages. It doesn't work in Soweto … people don't read them, they don't have the time to read" (a young female outreach worker from the Soweto site). And no-one will relate to poster images unless appropriate:

> They look and "who is this white person? We don't have white people here". So, we would rather have someone black … with a 'township' look, with, you know, a cap (she laughs), rather than clean-shaved (ibid).

Conveying culturally astute messages may attract potential CAB members as well as the intended trial participants, so that the potential for wider community empowerment in health governance increases. By being involved in trial site activities, CAB members and community educators have opportunities to build on their knowledge through training in presentation skills, to convey that information to communities. Ideally, this generates

[87] An adenovirus was used as a vector for the HIV vaccine candidate in the trials of 2007. This vector was suspected of causing one of problems leading to the failure of that candidate to protect some participants from being infected with the HIV virus.

discussion and responses, which then feed back to researchers who, in turn, can then provide valued health resources to the communities as they develop their clinical trials. Ethical remits are then fulfilled.

One of the Cape Town staff explained that older CAB members tend to focus more on the protection of their communities, stimulated by recollections of instances where past damage has occurred through unethical clinical practice. One of the CAB members stressed his concern to protect communities from being "guinea pigs" so that "justice" can be achieved (an older male CAB member in Cape Town). The adolescents, however, are more forceful in their community engagement roles. The Cape Town adolescent CAB[88] call themselves 'Freedom Fighters', in reference to the resistance movement against apartheid, and yet, their more pragmatic aims are to develop those life skills. Just as I had noticed changes in the confidence of CAB members met the previous year, the outreach staff noted positive changes in the self esteem of the adolescent CAB members. In this way, community engagement is evolving from concerns with protection to more assertive claims for resources which are valued by a wider range of CAB members.

Each of those resources, from the less tangible psychological to the more material and practical, contribute to efforts to provide appropriate interventions in local health initiatives. They form part of the physical, mental and social elements which Ruger (2007, p. 90) argues are key to health functioning. In building those skills, CAB members are gaining the means to make claims for access to health and wider community development resources. Those capabilities can be translated into employment and, therefore, opportunities for socio-economic citizenship. Those employment opportunities arise from within the trial sites where the intention is to expand on community capacities where trials are conducted.

[88] I spent informal time with adolescent CAB members and asked questions of their CAB co-ordinators. I did not ask for access in order to do research with them. The sensitivity of my research topic coupled with an already lengthy ethical approval process in this context where the laws on consent were changing would have extended my research further than was practical.

National and international support

Wider support mechanisms provide additional resources in terms of information and training for CAB members. Again, that support is focused on the smooth running of trials and ethical research practice. Of necessity this support relies on community acceptability. The donors and vaccine initiatives are bound into this ethical and practical provision of resources to ensure that trials are locally appropriate and sustainable, otherwise ethical and financial costs are incurred. That information and the training resources cover a wide range of topics, including human rights, suggesting a more comprehensive skills building capacity than the core topics concerned with community engagement.

However, these resources were intermittent during the research period. National health governance was having repercussions on resource provision at local levels. Funding deficits and government hesitancy in renewing funding, due to the above mentioned SAAVI leadership and governance problems, has had reverberations down to community level. Gaps in training opportunities had repercussions on community engagement. Moreover, problems over territory have caused past conflict between the trial site PIs and SAAVI over the local community engagement remit.[89] As a vaccine initiative, SAAVI is a potentially valuable advocate as a national institution in a position to offer valuable culturally sensitive HIV information. Its remit is to work at national level by bringing CABs and community educators together for training and information exchange and to complement the wider SAAVI role as an advocate for vaccine research at national and international levels. Those earlier disputes between the SAAVI and trial site investigators over the SAAVI remit had caused friction and weakened its role in health governance, leaving the International AIDS Vaccine Initiative (IAVI) to assume leadership and political weight during the more recent SAAVI funding crisis.

Those levels of health governance, and the distancing of trial sites from SAAVI, have impacts on community engagement. Despite the earlier friction between the trial sites and

[89] This friction over territory between trial site PIs who had felt that SAAVI intervention into their communities contravened the SAAVI remit to provide national level support. In turn the SAAVI Acting Director was driven by her concern to develop her Community Involvement Programme within those trial site environs.

SAAVI, their guidelines for trial participants and CABs have now been agreed by the PIs. One interviewee was critical of the deficits in community engagement practice,[90] one of which was that the Cape Town adolescent CAB members were used for fundraising rather than engagement within their own communities. This is a conflict in agendas where their public profile in performances is raised, but the focus is taken away from the protection of communities and representing their concerns. With those SAAVI guidelines, she felt more confident in having wider endorsement of her ideas:

> Yes, if right now we have clear guidelines then I can say the CAB is not supposed to be doing this according to SAAVI also, but I also want the kids to know what they're supposed to do, to know those guidelines so that they can answer themselves to say that "this is what we're supposed to be doing" … CABs should be affiliated to organisations, the structures within the communities, so that they represent someone, they are not just individuals, so I'm sure after we've done that community involvement and its meaning will improve, because in that way we'll know that at least will be getting feedback from the broader community through the structures … in that way, we can say to some extent we have some meaningful community involvement.[91]

This confirms the value of SAAVI resources to people working to develop community engagement. They value opportunities to develop skills and to explore the issues arising from their work. The conflict between the PIs and SAAVI over remits and territory is not felt by community members who value that support. Another interviewee from Soweto[92] was aware of the longstanding problems of SAAVI governance and the politics involved, but felt that by promoting a questioning approach to their work, SAAVI encouraged CAB members and educators to feel free to "question everything" rather than to take a reactive position in communicating with trial site researchers.

However, instances where criticism occurs in reality have been difficult to find. This could be interpreted as one of those situations where, as Lukes (2005) puts it, latent conflict exists but remains unrecognised. Although, inaction may be the result of power in this institutional setting (Hardy and Leiba-O'Sullivan, 1998), community members have much to gain through their engagement, given their limited options, and so may weigh up the consequences of dissent. On the other hand, their mutual need for a vaccine may be the

[90] Some of her different criticisms are reflected by others and explained in this chapter.

[91] This interviewee wished to remain anonymous.

[92] This interviewee wished to remain anonymous.

deciding factor. In this case, their answer to the question posed by Lukes (2005) as to whether or not they might have acted differently would not apply, since conscious decisions over access to valued resources and benefits not previously experienced (Hardy and Lieba-O'Sullivan, 1998) have been made.

More often, and in Soweto in particular, CAB members told me that they had no need to complain since everything was functioning well and that they were satisfied with their relationships with trial site staff with whom they had easy access if needed and that research protocols needed few adjustments having been through the well regarded REC and their own committee. Alternatively, one of the outreach workers was hesitant in her response to my questions over access to the PIs and some complaints were made to me by CAB members in the Cape Town site concerning lack of access to researchers. This general lack of criticism was highlighted by one interviewee[93] from Cape Town as problematic. Much as she felt that the staff commitment and integrity was not in question, she felt that there remained a need to avoid the 'rubber stamping' of research which tends to occur where no substantive challenges are made. More recent changes in leadership in government (including the Department of Health) and efforts to restructure SAAVI suggests that the more regular support which community educators and CAB members and their coordinators value may be available.

Other forms of support come from international advocates, such as the AVAC, compilers of the Good Participatory Practice guidelines with UNAIDS (2007) which have been developed though consultation with trial site staff. The latest version has been re-worked in response to complaints from CAB members that they had not been consulted. Those kinds of communications between advocates and community members show how more culturally and socially appropriate resources can be developed and, in turn, how communities can play meaningful political roles in that process, by ensuring that research is relevant to their communities and by holding positions whereby challenges can be made over trial site activities and health governance more broadly.

[93] This interviewee wished to remain anonymous.

Visits to trial sites from advocates show their support to communities by asking questions about longer term aims which people working at grassroots level are too busy and close to their immediate work to ask. At a meeting with visiting advocates, Sowetan CAB members were asked if they had considered what their long term plans might be when trials end. Notes were taken and 'slots' in meetings planned to discuss this issue, thereby building on that opportunity for communities to step back from their daily activities and think about community health in the longer term. Those kinds of opportunities to engage with international organizations help to facilitate those longer term development debates. Through that communication process, the potential remit of CABs, and community engagement more broadly, can be developed beyond the more immediate concerns of governance to enhance longer term community development, albeit from within those invited spaces.

This means for deliberation over how those goals in community development might be achieved resonates with the capability approach, where the ends and means of development are not only to do with life as lived, but what is available through a set of vectors of 'functionings' (Sen, 1999, pp. 77-78). Again, those opportunities opened up by advocates are potential 'vectors' in capability building through the direct dialogue that Johansson and Hvinden (2009) endorse as potentially fruitful. Yet, where there is a lack of CAB capacity in terms of leadership and organisational skills, this stops members from developing those communication strategies and playing a role in health governance by negotiating agendas. Without a clear conception of what CABs can do through their deliberations, opportunities to play meaningful political roles and to engage others in that agency in health governance are lost. Less confident CAB members lack the capacity to promote their work, which then compromises efforts to engage excluded populations. This lack of leadership and organisational skills mirrors deficits at higher local, provincial[94] and national government levels to reflect on health governance.

[94] Those working to support democracy building at these local and provincial levels confirm this deficit (personal communications, May and October 2008).

Moreover, along with finding funds for providing valued information to communities on HIV prevention and research in these challenging contexts, finding the resources for training in presentation skills can be difficult. One of the Cape Town site clinical trial managers explained that her own staff needed training and, in any event, CAB members had reneged on training opportunities so that no-one benefitted. Overall, health governance is determined by the politics of accountability where donors take precedence over funding decisions which, in turn, influences the time spent on community engagement. The potential to provide opportunities to use community engagement resources within the trial site and wider health governance arena in meaningful political ways is influenced by those higher health governance agendas.

5.3 HEALTH GOVERNANCE AND ACCOUNTABILITY

Those power relationships between actors operating at different levels of trial site health governance show how community engagement is both enabled and constrained at different times, and in different ways, and how that engagement can work to the benefit of communities beyond immediate goals in health care or their detriment. These are the environments in which shared health governance (Ruger, 2010a) can develop within and across networks of health governance and where CABs are the principal means by which communities can influence that health governance. But as explained, it is difficult to achieve ideals based on partnership. Multiple accountabilities across levels of health governance can inhibit the process of community engagement conducted day to day. These multiple and conflicting accountabilities affect communications: from researchers to donors; from researchers to CABs; from CABs to communities; and back to researchers *via* the CABs.

5.3.1 Multiple accountabilities

A lack of adequate support in managing these different agendas over funding, and the multiple accountabilities of researchers to donors and communities can cause conflicting loyalties, especially downward to communities where donor and trial site agendas take priority over outreach work. These are the multiple accountabilities which resonate with

Edwards and Hulme (1996). The pull upwards to the more powerful shifts accountability towards the demands of sponsors and the market driven agendas of PPPs (Bartsch et al. 2007) raised in Chapter One. As part of that pull to higher accountabilities to donors, meetings and training workshops must be attended, reports written and new funding proposals completed. This distraction from community engagement can overburden CAB coordinators and health workers in their community liaison roles.

In these contexts, health governance problems can affect the flow of funds for community engagement which, in any event, tend to be the first casualties in the competition for trial site resources. As I was told:

> We're struggling to get doctors on board and the last thing we can afford is to hire someone to do a special training for our health workers, even though they are the bread and butter of the organisation (a young male Programme Manager in Cape Town).

As explained, this kind of community engagement is essential to reach trial participants, and so:

> [however] great the ideas, what kind of a facility we have, or health care we provide, if no-one's there, then who cares? So it's incumbent on us to invest … to be a site that proves that we can recruit people … for long periods of time, for interesting and complicated things (ibid).

The economics of funding for the whole range of resources needed, including community engagement, is a challenge. For example, HIV information needs to be translated into several languages. This is a costly exercise of which researchers are well aware. If priced out of the market, donors move elsewhere and local health initiatives of this kind are left without funds.

Under such conditions, the capacity of researchers to fulfil their commitment to community engagement can conflict with the primary remit to maintain the scientific project within the designated time restrictions. Here, scepticism over heterarchical forms of governance is reinforced by such evidence of powerful groups who "generally carry the day" (Kazancigil, 1998, p. 71). As the Cape Town trial site Director explained, her multiple roles include finding funds (hence the use of adolescent CABs for fundraising efforts), printing T-shirts

(for events to raise funds) and vaccinology (her primary role). These conflicting loyalties and the strategic considerations of governance (Yanacopulos, 2005, p. 254) strain the capacity to respond to communities however great the commitment to them. As Richter (2004) points out, variable degrees of influence on governance renders the term partnership questionable.

In general, CAB members tend to see scientists when trials begin, or when a problem arises, but less so after that initial visit to explain the research. This was evident in two of the Cape Town CABs where some expressed frustration with the lack of ongoing contact with researchers once trials had begun. As one interviewee explained:

> Most of the time the [sites] would contact the CAB if we need advice from them, but when it comes to feeding back, that doesn't really happen … at the beginning of the study if we need advice, or if there (are) concerns on ethical issues we call a CAB meeting, we do a workshop and discuss those issues, but after the study has been approved there is no constant feedback as it is supposed to be and some CAB members have complained to say "you only using us as consultants now if you need advice".[95]

In Soweto, the PIs were physically more readily accessible to the CAB members who met in a central location and had been able to build relationships of trust. Here, access was said to be a matter of booking time with the PIs. In contrast, some of the Cape Town CABs members with whom I spent time were more critical in their responses to questions about access to researchers. Asked if there were formal meetings around CABs, one interviewee told me that:

> They do discuss whether or not CAB is working', but that 'its just a question of what we define as *working* … Does working mean that they're having their regular meetings and there are enough people in them … Does the CAB feel free to object? We don't have meetings around that[96] (interviewee's emphasis).

This was another view of this process:

> I think we need to facilitate the feedback … so it's both positive and negative … there's a lot of focus on dissemination of information … we are good at making information that can be understood by the people, we also need to make it easy for them to communicate back to us (a young male Programme Manger from the Cape Town site).

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[95] This interviewee wished to remain anonymous.

[96] This interviewee wished to remain anonymous.

This feedback loop and accountabilities back and forth is a continuing challenge, identified by my respondents and others beyond these trial sites (Socio-behavioural Research Group, 2009). That lack of accountability has significance for trial site communities. If CABs cannot gain information and training from the researchers, they are limited in their capabilities to gain valued health resources. If CABs cannot communicate with the trial site communities, those communities cannot benefit from that information. It then becomes less likely that meaningful political roles can develop, since the interests of the diverse populations where trial sites operate are not fed back to the researchers.

As several respondents told me, there is no clear monitoring process to ensure that feedback from communities to CABs and from CABs to researchers:

> There's no real way of ensuring that they actually represent the views of their communities and they actually go back. Sometimes we find … that these are individuals, not representing anybody … CABs were supposed to come from community organizations. That way you know that they are representing a large group and that way they would go back and disseminate [to their own groups].[97]

This lack of confidence in effective feedback mechanisms was expressed by the PHRU Co-Directors and their staff. As one of the clinicians working in Soweto suggested, the aim is to move beyond consultation but, from his viewpoint: "that relies in part on individuals who participate in that process to take on their due responsibilities and inject the views of communities in that process". This depends on whether or not CAB members are fully aware of those responsibilities and able to fulfil them, but it does raise the problems for both researchers and CABs in meeting the ethical requirements of gaining a comprehensive picture of community concerns.

In reality, meeting such ethical obligations in community representation is impossible. As one of the vaccine CAB members in Cape Town has explained, the twenty two members that had since joined his CAB could not reach the population of Nyanga (IAVI, 2009, p. 7). This does not conform to definitions of communities as enjoying the kind of common culture and shared history which Weijer and Emanuel (2000, p. 1142) deem to be

[97] This interviewee asked to remain anonymous.

necessary for the protection of communities involved in medical research. Correspondingly, in Soweto, the vaccine CAB cannot serve an estimated population of at least one million where informal settlers live alongside middle class people who – I was told – have no active interest in community engagement. Others spoke of the challenges in communicating across cultural divides. For example, Zulu women need the consent of male family members to participate in trials.

Ultimately, community engagement is difficult to balance with other family and social commitments. In addition, CAB members have different priorities over their involvement in trial site activities and, therefore, in their commitment to that work. Family and other social obligations influence the quality of that involvement. This has an impact on the ability to use the available resources. Consequently, in the medium term the quality of engagement and health resources suffers. Those whose daily lives become too demanding to balance those commitments abandon this work.

For those living in informal settlements, resources are most strained and the struggle for survival is all consuming. Their vulnerability due to higher rates of HIV infection suggests the need for involvement in health initiatives. Yet, they are the least likely to become involved due to extreme poverty, political disempowerment and social marginalization, as Colvin et al. (2009, pp. 22-23) found in this context. This challenges conceptions of cohesive community. Where social inequality prevails capabilities to be healthy are compromised (Campbell and Murray, 2004).

Other excluded populations are not able to become involved due to multiple forms of stigma. This exclusion, self induced as a pragmatic decision as protection from that stigma, challenges the ideals of shared health governance (Ruger, 2010a). Multiple family and social roles compete for time and energy, especially when balanced with the difficulties of maintaining personal and family treatment regimes due to HIV infection. Keeping those roles in harmony is a challenge which some people do not have the capacity to balance. Representing communities can take second place to more

immediate responsibilities. In some cases, other problems take priority over health. The combination of efforts to find food, housing and employment, and the obligations to work in other community projects, consumes time and deflects attention away from community engagement in health initiatives.

That lack of community representation in CAB liaison roles challenges conceptions of community which MacQueen et al. (2001, p. 1936) suggest are defined by linked social ties, common perspectives and joint action. Two staff members in Soweto described two different scenarios arising in one of the poorest local communities. Where one told me that social ties through common experiences of deprivation force people to act collectively, another described distraught community members whose houses were collapsing in the semi-tropical storms and who waited in vain for local politicians to respond. Therefore, action and inaction can be juxtaposed, with the latter most likely to prevail especially where HIV/AIDS prevalence is highest. Despite increasing levels of HIV treatment, the impact of the disease is evident in the number of funerals. Whilst showing me around Soweto, the CAB Co-ordinator told me that funerals are now held each day of the week rather than confined to the traditional weekend time on Saturday. Social and cultural obligations to attend are pressing and the costs for families debilitating.[98]

Problems involved in living in poor communities were described by one of the researcher as she related an incident which took place several years ago whilst working at the Masi clinic, opposite the local primary school where a riot arose due to overcrowding and other issues:

> So, because it's right there by the clinic, we were sneaking people out the back of the clinic. It did settle down very quickly … But all the negotiation, the community and the facilitating process between the different parties continues. And so it distracts people. And winter in these communities is very difficult. In Masi, it floods in the wetlands area, every year the marshes rise, so people's homes get flooded in that section. And people use paraffin for cooking, heat, fires, and so it's not uncommon for a paraffin lamp to be knocked over, and a fire started. It spreads very quickly in shacks made of wood… So these are the challenges. We have an agenda and we have needs that need to be met

[98] Funeral costs were discussed by home-based carers during a church sponsored training session in Johannesburg in October, 2008.

> from our sponsors' point of view, and then there's the real life of living in one of those communities (a Senior Investigator from the Cape Town site).

Many of those living in trial site communities do not have diaries and so keeping CAB members informed of meetings involves written, phoned or verbal reminders: "sometimes this one is here and next week it is somebody else. We always have new faces in our CAB, or else the members, they just don't pitch up" (Michael Tyhali, Masi primary school Headmaster and CAB member). This scenario is far from the ideals which Weijer and Emanuel (2000) identify as significant for the protection of communities in the research process. The representative groups and individuals which they mention were not evident in Masi at the time of my research and, according to one staff member, nor was there consistent legitimate political authority (Ntando Yola,[99] one of the Cape Town CLOs). In such communities, high crime levels influence decisions to participate in CABs, especially when winter descends. As explained in Chapter Three, where meetings are held after work, travel under darkness is a safety issue for all involved and so attendance can decline in the winter months.

That turnover of CAB membership means that valuable time is spent educating and training new members in the skills required for effective CAB management, public communication and decision making. With that turnover, the gaps in knowledge of HIV/AIDS, and vaccine science in particular, between CAB veterans and newcomers become more difficult to bridge. As discussed above, it excludes new members who lack confidence in their own knowledge and skills and distracts from more active and effective engagement in the broader community.

5.4 COMMUNITY REPRESENTATION AND EXCLUSION

As explained in Chapter Two, representation is used to define a specific embedded form unrelated to formal electoral processes. Here, the lack of representation of different community groups can result in exclusion from the community engagement process and the attendant resources. For the researchers, current efforts to reach vulnerable groups

[99] This interviewee said that he was happy to be named.

and to include them in trial site research, as well as in CABs, are being made so that their valued health needs can be met. The 'unreachable people' include: the potentially 'reachable', such as those who fear association with HIV projects and clinics and the negative responses arising from families; and those who experience multiple forms of stigma. In the latter case, such difficulties in reaching these excluded people are compromised by that marginality.

Efforts to develop research with MSM, and to develop ways of engaging such vulnerable populations, become more urgent with the rise in HIV infection within those groups and the need to engage them in health initiatives. I now focus on the vulnerable groups of people who are stigmatised due to their sexual orientation or their status as 'foreigners'. As discussed above, one of the key aims of researchers and CAB members is to avoid a high turnover of members and, at the same time, to develop wider community representation. The low community profiles of these vulnerable people exacerbate the problems of trial site researchers seeking trial participants, and those involved in community engagement who are seeking a more representative set of concerns over that research so as to become more accountable to those communities. By including those 'hard to reach' people, community representation becomes more meaningful and the South African constitution ideals, in access to health, freedom from social persecution, and opportunities for participating in decision making more likely to be met.

5.4.1 Multiple discrimination

The men in the study by Colvin et al. (2009) expressed their frustration and humiliation due to HIV/AIDS, chronic unemployment and the inability to support families. Their respondents claimed that efforts to find employment diverts attention away from community engagement in voluntary activity around health and when attempts to find work fail, a sense of fatalism ensues. Where women are more likely to be found to be HIV positive through their contact with pregnancy clinics, men tend to remain at the periphery of health services. Negative attitudes are experienced in public clinics by men assumed to be irresponsible and who are treated with "serious disrespect" and "even disdain" by

clinic nurses for “waiting until they are almost dying before they go to the clinic” (p. 21). The negative experiences of both men and women are reflected in my research and others (Mills, 2006), where fear of recognition by neighbours hinders access to health, as described in Chapter Four. The reluctance to engage with public clinics increases when those negative attitudes are compounded by the stigmatisation of MSM. In consequence, their low profile in health initiatives contributes to their vulnerability to HIV/AIDS.

These ‘hard-to-reach groups’ experience multiple forms of stigma and discrimination due to HIV/AIDS, and their sexuality, with a greater risk of abuse and violence in consequence. Trial site studies show a “shocking number of people being abused” who are in hiding (a young male Programme Manager from the Cape Town site). Avoiding contact with officialdom, MSM are less likely to give information to researchers. As I was told, living in a country with “one of the most advanced liberal constitutions in the world” does not necessarily result in a “trickle down” effect at community level, where “individuals [are] being forced out of their homes” (ibid). This research conducted in the Cape Town site includes human rights issues, with data on evidence of physical abuse so as to understand some of the fundamental reasons for exclusion.

As Ruger (2007) argues, valued health resources differ according to particular needs. Community engagement in order to define those needs is a key element in access to health. The diversity of MSM groups and their geographical spread across different locations hinders efforts to find them and to understand these variable health conditions and needs. In such cases, in both sites social networking has been found to be the best way to reach such “shy” groups, as a means to develop community engagement and representation and to identify their concerns and health needs. That use of networking to target vulnerable groups is being developed by researchers through health workers. Scientists need those with skills to recruit trial participants and to gain feedback from communities on needs.

It is not possible to reach such vulnerable groups in public places, since "people don't think that same sex practices between consenting adults takes place at all" (the young Programme Manger quoted above). Just as those involved in community engagement are involved in finding ways to increase the representation of different groups of people with different health needs, scientists are attempting to reflect those different needs. Studies using pre-exposure (PrEP)[100] and post-exposure HIV treatments[101] are extending the wider scientific and medical research remit beyond HIV vaccines. This is due to the lack of successful vaccine candidates to date and the recognition by scientists that collaborations across the prevention and treatment fields increases the potential for finding solutions to HIV infection in different contexts and amongst different vulnerable groups. This is endorsed as one of the ways that scientists and community advocates are "offering something back and taking that and doing something meaningful" (ibid).

The problem of including groups stigmatised for their sexuality is reflected in responses to 'foreigners' who settle in South African townships. In this case, the experiences of those living in communities in competition for scarce resources contrast with those of exiles during the apartheid era who now occupy positions in government and academia. Politicians endorsed the reconciliations[102] as due regard to those who supported them during the resistance movement.[103] However, one interviewee from Soweto explained to me several months later that politicians knew nothing of the realities of living in resource poor communities. As she said, the trauma of apartheid had not been resolved and continuing socio-economic deprivation continues to mark such radically different perceptions of history and contemporary violence.

As explained in Chapter Three, the combined effects of socio-economic and political change post-apartheid and conflict in other African countries has led to increasing

[100] Pre-exposure prophylaxis treatment to avoid infection.

[101] These treatments are designed to offset HIV infections where 'risky' unprotected sex has taken place.

[102] In May 2008, attempts were being made to reintegrate 'foreigners' back into the communities following conflict.

[103] Many of those killed during the unrest in May 2008 were Zimbabweans. South African resistance fighters were hosted by them during the 1980s before apartheid ended.

migration flows resulting in periods of civil unrest especially during economic crises. This blaming of 'foreigners' for socio-economic deficits is not country specific. Questions of citizenship and rights over public services bring the focus onto those deemed to be outsiders. Just as in the case of exclusions due to sexual orientation, social exclusions exacerbate other experiences of stigmatisation due to HIV/AIDS which then limits access to health. Exclusions of this kind define the parameters of community engagement and opportunities for health activism. The problem is not whether or not engaged communities are co-opted or empowered, but that the most vulnerable people – even when they have formal citizenship status – have severely limited options to participate in local health initiatives and have little opportunity to influence health governance in any way. Under those circumstances, communities are in conflict rather than in collective engagement in health activism. That problem of conflict over strained resources was reflected in the earlier Cape Town responses during the unrest.

Such examples of community diversity illustrate the limits to inclusion of those whose vulnerabilities to ill health persist. As Cohen (1985) points out, the threat to common perceptions of belonging provokes a sense of loss when outsiders trespass. The valued common culture and shared history (Weijer and Emanuel, 2000) is in jeopardy. During interviews and informal conversation, some regarded 'foreigners' as outsiders and, therefore, not considered as potential CAB members, or they were said to "keep themselves to themselves" and thus were not interested in joining CABs, or that the timing was not right since CABs were not ready to include them. 'Foreigners' were considered to be potential health risks, contributing to communicable diseases easily spread in over-crowded informal settlements without sanitation. Such responses indicate the limits of community engagement and efforts to develop an inclusive representation of those with health needs which, again, may differ from the wider community.

Ultimately, the difficulties which researchers experience in efforts to be accountable to MSM, as excluded high-risk populations, and the difficulties for 'foreigners' to represent themselves results in neither groups of people being able to be engaged in local health

initiatives and to gain access to health. In the first instance, social norms over sexual orientation may change, but the social norms and stigma underlying antipathy towards 'foreigners' will not be easy to change without addressing the socio-economic conditions in which most South Africans live. Without the means to participate in collective decision-making around health, they do not enjoy that "valued freedom" (Ruger, 2004). Even with formal citizenship, they do not enjoy the universal civil and political rights assumed in the liberal conception of citizenship and assumptions of the communitarian perspective on belonging and working together are not evident here.

5.5 CONCLUSION

In this chapter, Ruger's (2007) principle concerning the quality of health resources helped to identify the kinds of resources available and their value to communities. I have explained why these resources are not available to especially vulnerable populations. Thus, on the one hand, this chapter shows how community engagement can make shared health governance (Ruger, 2010a) a possibility and, with it, meaningful political roles in gaining access to valued health resources to develop from within local health initiatives. On the other hand, it shows the limits to that shared governance. As we have seen, community engagement and CABs provide benefits ranging from the provision of 'safe spaces' to more practical resources in terms of information and training. Both psychological and material resources generate confidence in the ability to deal with health problems, with the potential to encourage meaningful political roles to develop.

More broadly, stigma reduction projects to challenge health norms have the potential to make changes in social responses to HIV/AIDS. Those challenges to prevailing stigma feed into wider challenges to national government policy. Loyalties to an ANC government which has not provided the necessary support for shared HIV/AIDS governance have mitigated against those efforts. These are part of the complex historical traces still influencing contemporary politics. Memories of apartheid infuse current perceptions of resistance against the "new enemies", as one of my young Sowetan respondents explained. The intermittent provision of community engagement resources

by SAAVI are symptomatic of internal governance and interlinked wider national health governance problems discussed in Chapter Four. At these levels of health governance, opportunities to build collaborative efforts to resist those new enemies by addressing the stigmatisation of HIV/AIDS and promoting HIV prevention and access to health have been missed.

The enduring problems in retaining regular CAB membership show how difficult it is to gain a consistent representation of community members with the capabilities to engage in trial site activities. This demonstrates one of the ways that injustice undermines capabilities for health functioning (Ruger, 2007). Those most in need of health resources are not able to be involved, due to their sexual orientation or their perceived lack of formal citizenship. Others are unable to engage with health initiatives in any politically meaningful way. Excluded groups are the least likely to benefit without the efforts of local health initiatives to include them. Each of these factors illustrates the countervailing elements in community engagement.

Yet, despite such complexities of community engagement in local communities under economic and social duress, some community members are able to use invited spaces in ways that are not ostensibly political, but they contribute to building capabilities in their efforts to gain access to health, where otherwise they might not have come together without the collective efforts in community engagement. Some are able to build on their personal resources to use community engagement to promote community health, and, in some cases, development on a wider scale. This kind of agency is discussed in Chapter Six.

Just as much as alliances can develop between CAB members and researchers which may compromise independence and political autonomy, some members use resources and develop relationships built through community engagement to network beyond those community boundaries, to influence the process of health governance at national and global levels. In turn, this work has an impact on local levels where experiences and

knowledge are fed back to inform and inspire others to act. Such people have developed the capabilities to work across those governance levels. The potential to develop capabilities to function arises through a complex set of relationships made, and opportunities encountered along the way. It is to these capabilities for agency that I now turn.

CHAPTER 6

AGENCY AND HEALTH

Chapter Five explored the resources for health which are valued by communities and the limits to the availability of these to the wider communities, despite the efforts of researchers and CABs to extend their reach. Here I argue that some community members are able to build upon those resources and challenge the social norms which stigmatise those seeking access to health. Those who develop that agency are playing meaningful political roles in stimulating change at different levels, from the local to wider health governance arenas. Those who work simultaneously from within the invited spaces of CABs and in claimed spaces beyond the trial sites increase the potential for political influence on community engagement through that synergy. The foundations for that agency are in the "relevant personal characteristics" that Sen (1999, p. 74) suggests are important in converting resources into "the person's ability to promote her ends".

To these ends, this chapter explains how trial sites and wider institutions provide the support for the agency which Ruger (2007) suggests is essential for those seeking access to health, and which CAB members gain through engagement in trial site activities. It traces the ways in which trial site researchers are attempting to engage marginalised and vulnerable populations and shows how engaged community members use those resources in their quest for health. This community agency reaches beyond the accumulation of knowledge, to develop the capacity to make informed decisions and to consider questions on how longer term development can be achieved.

This is the kind of ongoing active engagement (Arce and Long, 2000) that reaches into the "software" of science and technology which Leach and Scoones (2006) argue needs attention. Through that engagement, CAB members are converting resources into health functioning, specifically by stimulating improvements in physical, mental and social functioning (Ruger, 2007). These are the political spaces – the "schools for citizenship" – where Gaventa (2006) suggests seeds for future change may be found.

The chapter begins firstly by focusing on the motivation driving community members to become involved in trial site activities and their intentions in that involvement. The personal resources which they bring with them form part of the synergy with others in collective political action. Secondly, it shows how the capabilities for meaningful political roles can develop within and across trial site communities and, thirdly, beyond them across national, international and global arenas. This wider networking involves a combination of activities across invited and claimed spaces. The experiences of community members involved in such activities coalesce into different political subjectivities which inform those different actions. Finally, the chapter ends by considering how these different levels of political activity are effecting change in trial site and wider health governance.

The different ways that people engage themselves in local health initiatives, and the different intentions and political subjectivities involved challenge criticism that such interventions necessarily result in the co-option of engaged community members. At times, they appear to comply with vaccine initiatives in their mutual need for vaccines. Yet, at other times, they use the resources available in their community engagement work to find their own ways to address the problems faced and to stimulate change. The motivations to become involved in community engagement activities and the intentions of those who take those steps are explored below.

6.1 COMMUNITY ENGAGEMENT AND AGENCY

Here, I focus on the motivation and commitment which people bring to community engagement – principally through their work in CABs – and the action and practice of power which Allen (2003, p. 109) suggests is a useful focus. The effects of that practice on the lives of others encountered through acts of citizenship (Isin, 2008) shows how challenges to health norms provoke shifts in understanding HIV/AIDS. That understanding and those shifts in consciousness give confidence to others to make informed health decisions. While some people become traumatised in the face of the enormity and immediacy of the problem, others have developed the capacity to rise to the

challenge. In Ruger's (2007) terms, the latter are converting resources for health functioning and contributing to improvements in physical, mental and social functioning.

6.1.1 Motivations for engagement

Whether as researchers, or as CAB members, many respondents talked of their passion for involvement. Most often, a combination of motivations drives engagement in health initiatives. In such contexts where community resources are limited and HIV/AIDS rates are high, the need for immediate response is uppermost. Motivations include: i) a fundamental concern with community safety; ii) the need for information on HIV/AIDS and HIV prevention, as well as an understanding of the biomedical research which might be of use to themselves and their communities; iii) the need for skills for communicating that information and; iv) to generate employment. Many are driven by more immediate personal experiences of the epidemics and others by altruism and concern for the greater good of communities inflicted with HIV/AIDS. In each case, religious faith plays a prominent role as solace when problems and circumstances are overwhelming and as a source of inspiration and collective motivation for agency.

As argued in Chapter Five, some use the invited spaces of CABs by working together to maintain treatment regimens and physical functioning. By building self-esteem, they generate improvements in social functioning. As explained in Chapter Two, political spaces are used for resources or to effect wider change (Engberg-Pedersen and Webster, 2002). And so, some people use those spaces as a coping strategy and some engage others in HIV prevention as part of the redistribution of resources to effect social change. This activity requires high levels of motivation and commitment in any context. In resource poor settings, the stigma of HIV/AIDS presents difficulties in finding ways to challenge those prevailing social norms.

When asked why he was involved in this work, a CAB member said: "I think the bigger picture here [is] to be part of the solution" (an older male vaccine CAB member from

Soweto). As his friend said, they want to be part of history: “some of us have lost friends and family to HIV … I cannot just sit and watch when things are happening … it’s part of being the soldiers that are trying to fight HIV/AIDS” (a young male CAB member form Soweto). This sentiment is echoed by another:

> We do this because of the love of it and because we want to help the community. We want to know about what is happening within the research … and then take it back to our community (a young female CAB member from the Soweto site).

Each of these CAB members expressed a commitment to making a difference and despite the difficulties that this involves, they felt that they had “the ‘power to’ … intervene to bring about social change” (Allen, 2008, p. 1622). One of the ways in which change occurs may be manifest in acts of citizenship (Isin, 2008).

6.1.2 Acts of citizenship

The young vaccine CAB member quoted above was motivated, too, by more immediate personal experiences of family crisis and death. As described in Chapter Five, her efforts to keep her dying sister alive had failed. And yet, she talked of her community, her country and the fact that she had “nothing to give but her body” (through participation in trials) and her voluntary work. Consequently, she felt “better off than before” and “very much empowered”, since: “people [weren’t] afraid to just pick up the phone and call [her] and say I need to talk to you. I need your advice”. This valued recognition supports points made by Barnes et al. (2007) and Ricouer (2006) who emphasise this important part in the process of political empowerment. Her clear intention was to build upon that response, but her actions were spontaneous in this following case. On travelling to her rural home in a taxi,[104] there were:

> … many young people who were talking like HIV is not existing …I just listen and listen. In the end, I just said to them “may I please explain what is HIV?” And then I explain everything. They ask me questions. At the end, one guy, young man, said to me “thank you Sis”. It’s my first time to come across with somebody who explain this thing very much”… I was very happy because I’ve done something. I’ve empowered somebody else with my knowledge (the young female CAB member from Soweto cited above).

[104] These ‘kombi’s’ provide the means for the majority to travel and they usually accommodate twelve or more people.

Through her use of the information gathered from her engagement as a CAB member, she had taken action by challenging social norms affecting health.

Thus, through individual acts of citizenship and new modes of conduct some develop the capabilities to break with 'habitus' (Isin, 2008). In this "rupture [of] social-historical patterns" (p. 2) which have developed around HIV/AIDS, such acts have an impact on others whose norms shift and whose access to health is enhanced. Through this "genuine encounter", she was compelled to act creatively (ibid). She had found that, by providing information, she had used a new model of problem solving in a new political space. In Allen's (2008) terms, she was able to intervene in events and to provoke change in perspectives which, I argue, is a form of power. In that encounter, she had helped to break established patterns of power by challenging prevailing health norms and, in doing so, enabled another to reconsider his health. In Isin's (2009) terms, she had changed the order of things. With this knowledge, the young man gained the power to make decisions over his health.

The taxi had broken down and this young woman's decision to speak, as the passengers waited for their long cross-country journey to resume, had potentially dangerous consequences. Uncertainty surrounds public discussion of this topic and so courage is required. One is often assumed to be HIV positive through association, and this is more likely to be the case. Stories of those experiences build upon individual self-esteem and stimulate others to take action. Through those creative acts, those who take such steps become further inspired by the response of others to do more. As Isin (2008) suggests, those acts help others to become new subjects of citizenship capable of driving change. The motivation driving personal responsibility extends beyond families to wider communities, rooted as it is "in a collective notion of the imperative to provide for others" (Colvin et al. 2009, p. 20). These data conflict with the more Western preoccupation with the individual as the "responsibilized citizen" incorporated into the wider dominant agenda through governance at a distance (Rose, 1999).

This sense of responsibility to community extends beyond employment roles and CAB work to daily encounters with individuals who might need help. Thus, for Michael Tyhali, the Masi primary school Headmaster, his concerns extend beyond his pupils and their parents to other community members in one of the Cape Town trial site communities. This need to "respond to crisis with an invention" (Isin and Nielson, 2008, p. 4) was driven by his concern to engender social support and community development. Again, in his dilemma over how to act, this Headmaster was compelled to act creatively (White, 2008). This kind of response requires careful planning, due to the stigma and sensitivity involved in discussing such personal issues.

Given that sensitivity, on hearing rumours that a woman had "signs of HIV", the only way to approach her was to involve the woman suspected to be HIV positive with another woman in a discussion about the importance of VCT. This is what Michael Tyhali (the Headmaster from Masi) told me:

> I said to her, to both of them, "you know, I have to go for a test. I just want to know my status"… I came back and called them … I reported [to] them "I am HIV negative". And they were so excited (a middle-aged male CAB member from the Cape Town site).

This encouraged the women to get tested. The woman suspected of being ill was diagnosed HIV positive. He had prepared her for this possibility and with his encouragement she began treatment and stayed alive. He is satisfied that their mutual honesty had paved the way for her access to health. Through consultation with her, he had found the right time to help her, when she was "ready" and had confidence in treatment decisions (Mills, 2004).[105] This matter of 'readiness' was mentioned by one of my interviewees in Chapter Four. Such cultural understanding on which the trial site researchers rely is crucial to the effectiveness and sustainability of health interventions.

[105] Mills (2004, p. 30) raises the issue of hope and belief in treatment in her research, where decisions are based on feelings of readiness. Confidence in the capacity off treatment to restore health is a key requirement.

Understanding the socio-cultural context is the foundation upon which honesty and trust build between people attempting to gain the confidence to deal with the stigma of HIV/AIDS. Mr Tyhali's actions reach beyond his professional remit and the more formal community engagement which CAB members are encouraged to develop. It moves community engagement into more creative and spontaneous acts in response to problems which, as my respondents told me, could not be discerned, nor dealt with, from afar. They require particular socio-cultural understandings and, therefore, contribute to community development in ways which are beyond the capacities of those who instigate local health interventions. Without that understanding, those interventions are less likely to be sustainable.

Such acts tend to remain unrecognised by those who seek more dramatic evidence of social change and yet, in each of these cases, changes in social norms occur; either in the one-to-one encounters described, or other engagements which extend beyond the immediate trial site research agendas into schools and other arenas. As such, I argue that these CAB members are playing meaningful political roles. These are some of the ways in which the daily lives of others are touched by personal and more formal social encounters, with the potential to stimulate further acts of citizenship. Without the support of community leaders, and others who involve themselves in community engagement, these acts are less likely.

The South Africans whom I met have a political awareness that runs counter to images of people passive in the face of such a crisis, and submissive to governance from afar. In this developing country context, the state has never provided the majority population with the means to socio-economic citizenship. As explained in Chapter Two, there are many forces at play which run counter to such conceptions of neo-liberal rationality (Hart, 2008). One of the Co-Directors from the trial site in Soweto told me that:

> There is a whole new dynamics. We have a vibrant civic society … they are vocal and they're tuned in … They're not these subservient quasi-apartheid communities any more. These are vibrant, eloquent and they know their rights (Professor Glenda Gray, Co-director of the PHRU in Soweto).

That political awareness is stimulated by networks and alliances built within and beyond the invited spaces of vaccine trial sites. With the combined motivation for health activism, CAB members engage with communities so that community concerns about health and HIV research become recognised. When that feedback mechanism works they are able to influence research design and decisions over the research protocols which affect their communities. Thus, political identities are developed through negotiation over resources within those spaces, strengthened by the experience of working in other political environments. Through that activity, communities are developing meaningful political roles through engagement in local health initiatives and sometimes beyond those immediate arenas.

6.2 NETWORKS AND ALLIANCES

This section explores the networking opportunities used by community members to those ends; beginning with informal encounters and exchanges, followed by networks, at national level and into the global health governance arena. It illustrates the ways in which information, ideas, people and materials are exchanged (Mann, 1986), to facilitate the spread of knowledge about HIV/AIDS and develop the means to prevent HIV infection. For CAB members networking alleviates isolation. It provides opportunities to exchange ideas and experiences and builds upon their knowledge and skills. In the pursuit of community health, their political capabilities develop as they contribute to decisions (Ruger, 2007) through those networking opportunities.

Those with roles on ethics boards and other research committees are in a position to influence that process and, with that proximity in face-to-face encounters, to educate medical and social science professionals. These are valued opportunities for the direct dialogue which Johansson and Hvinden (2009) describe in the Western state-society engagements in their research. The kinds of agency generated through the use of those resources are discussed here. That agency is enhanced through networks across national and global levels. Where networking extends to the global invited spaces of donors, opportunities to influence decisions at international vaccine trial network level

arise. Given the institutional power dimensions (Hardy and Leiba-O'Sullivan, 1998), they may reproduce donor discourses around community engagement. At the same time, they may use those opportunities to influence those discourses at global health governance levels.

Informal networking

At the same time, within communities, those who influence the health decisions of people in their daily lives are extending community engagement deeper into more private arenas. Some acts of citizenship are stimulated by contact with others and their experiences coalesce into creative forms of participation. In this following story, a visiting actor suggested working together with a woman from the Cape Town trial site. This woman then turned the experiences of the people she counsels in her work into public performances. As she told me:

> I am fortunate, or not so fortunate, to listen to many stories …they are things that I never thought existed in life', but, 'there's no way that I can go out and say "Mary was here. Mary told me ABCD". And, the community will never be aware that certain things do exist. Instead, history will repeat itself (a young female CAB member from the Cape Town site).

Her religious faith had given her "a very powerful voice to say all the difficult things, in difficult language, that many people are struggling to do". She has begun to put some of those difficult stories into plays.

In her motivational speaking as a counsellor in a government 'Wellness clinic',[106] she gauges the relevance of her story to the audience, in order to gain the maximum response, to generate discussion, to explore perceptions around HIV/AIDS and to stimulate change. In one case, the story concerned a woman raped in her flat. Her rationale was that:

> It's easier for people to interact than going and telling people [what to do]. People won't listen to you. But saying to them "this is the real thing …there is someone out there that has experienced what I've just shown you. And then,

[106] These clinics were mentioned by my interviewees as a valued resource where holistic approaches to health were encouraged. Such projects may be criticised for their emphasis on personal responsibility, as discussed in Chapter Two, but in reality the clinics formed a significant part in their efforts to maintain a positive attitude while dealing with HIV/AIDS.

> people change. Through telling them as it is … then they start to interact and talk to you and then you start getting exactly to how they think … and then you start listening to people talking … We're talking about practical issues here. And it works (ibid).

To her, this is less important than her employed capacity as a counsellor in a VCT programme, since testing for HIV infection does not, in itself, invoke wider change. But, through networking and the support of an actor-activist, she was able to help people "to change the way that they think about certain issues", so that they could become "fully informed", to know what they can do to protect themselves "from whatever will happen". I argue that this was a purposive act of citizenship, where participation constitutes being political (Isin, 2005). In this case, it challenged the oppressive gender relations contributing to linked high rates of violence against women and higher potential for HIV infection. In this way, people involved in community engagement develop their capabilities to play meaningful political roles through a combination of their paid and voluntary work, and informal networking with others.

Others described their empowerment through such encounters. In the Cape Town area, Flora Thobela explained how that process worked for her as an HIV positive woman with an infected child who had not benefitted from treatment. During a particularly difficult period in her life, when no other resources were available, she had been told that her child would die by the time he was four years old. At that time, she met an HIV positive visitor to South Africa who had an infected child and was involved in a CAB in the UK. Through the encouragement of this visitor, Flora found the courage to "stop worrying about so many things, about the treatment". From then, she told me that she "stopped worrying and then … took a step". Just as she had taken courage from her "role model", she felt that she had become a role model to others in similar situations. Again, she became a governing subject in the process of constituting herself as citizen (Isin and Nielson, 2008).

This sense of responsibility and commitment to others corresponds with others whom I met who wanted to "make a difference" in their communities. It reflects Allen's (2008, p. 1614) interest in the ways that people can develop the power to make a difference where

"the ability … to act, to intervene in such events so as to make a difference, is also a form of power". As Isin and Nielson (2008) suggest, acts of citizenship are determined by social behaviour, rather than civil or political status, and are a response to one's conscience as a "way of being with others". Just as social behaviour can be detrimental, as in the stigmatising of those infected and affected by HIV/AIDS, it can be beneficial in the challenging of such norms. The key element here is in the deeds rather than the status of the subject. The motivation to make a difference may have something to do with national citizenship status, but that motivation compels some community members to develop more formal networking opportunities across national and global arenas of health governance. Through the exchange of information and ideas in collaboration with others, those resources are used to promote valued health needs.

Formal networks

National fora for CABs and community educators organised by SAAVI and IAVI are valued for the information and training and through opportunities to exchange experiences with others across South African trial sites. Communities differ and knowledge of that diversity increases capabilities to function collectively in gaining access to health. Here, CAB members and community educators work together to prioritise the most important resources. At such fora, decisions are made about who should represent CAB members nationally and internationally. Representatives rotate to allow the widest possible exposure to the challenges of participating.

Efforts to build the confidence of new members are made so as to develop the capabilities of as many people as possible. CAB members explained how they mentor less confident members at national meetings who may not be literate, or fluent in English, in efforts to develop their capabilities. Even if literate and fluent, mentors help those who suffer from 'stage fright' so that they can participate as public speakers. As Cornwall and Coelho (2007) suggest, marginalised people are limited in their ability to represent themselves without the skills to communicate effectively in that engagement. In this way, the capacities of CAB members and community educators are developed, so that more

community members are able to engage their own communities and increase their agency at higher levels of engagement in health governance.

However, this kind of national support from SAAVI has been sporadic due to the governance problems and funding deficits, as described in the last chapter. This has influenced community engagement and the ways in which political roles in community health research have developed. As explained, the more pivotal role in community engagement assumed by IAVI has left the nationally based SAAVI with a less prominent role. Those changing political relationships, and the distancing of trial sites from SAAVI, have impacts on community engagement and health governance more broadly; with the funding of vaccine initiatives and trial site activities more dependent on international bodies.

Such changes in the political positioning of vaccine initiatives suggest that the original aim to develop a national vaccine initiative with a key role in South African biotechnology development has been less promising than anticipated; with missed opportunities to develop more indigenous forms of health governance. Even so, other opportunities to enhance local forms of health governance are being taken up by community members as they assume roles in governing health research on ethics boards and research committees.

Community engagement in research committees

CAB members are involved in other forms of networking within national arenas, where opportunities to influence the agendas of Research Ethics Committees (RECs) are being built. One of the CAB members has been studying for qualification in research ethics which led to his role on the Health Sciences Faculty REC at the UCT. As he told me:

> If you have a CAB member on the ethics committee then there is a better collaboration between the local community and the ethics committee … in the CAB, we didn't know who the ethics committee was … How do we really get to know the operation of the ethics committee to assure our community to say that your protection is in the hands of competent people? Not people that's just being paid to 'rubber stamp' protocols … So, now I'm there, I know what is

> happening … I am learning. I'm not just sitting there … I have input … I look at the proposals. I do my reviews at home. When we get there, we debate issues … we can evaluate committees (an older male CAB member from the Cape Town site).

He felt able to say to the other committee members:

> "Are you really knowing what you are doing if you talk about research being done in Guguletu? Do you *know* the community?" Does the scientist who wrote the protocol know the dynamics of the community. Do you understand? … and we, like I said, we are learning what is happening within the research, and we can avoid a lot of social harm that's being done, by being at certain levels within these structures, we can say "but guys, before you approve, rather change that" … so that engaging with the community, I think, is a new process and it's going to be very exciting and very beneficial (ibid, his emphasis).

This work provides a forum for higher level political engagement on behalf of communities which, at the same time, develops the capabilities of CAB members. In this case, the opportunity arose due to the encouragement of a social scientist and ethics board member keen to develop an ethical community engagement process which takes account of socio-cultural concerns. It illustrates one of the ways that political relationships are fluid in a network of alliances (Clegg, 1989) to enable community members to assume more powerful positions from which to challenge inappropriate research decisions in already highly researched communities.

Other opportunities to assume decision making roles in health research are being taken by CAB members who use those resources to determine the kinds of interventions in their communities. This is the kind of support for agency in access to valued health resources which Ruger (2007) endorses. For example, in Soweto, one of the older and longstanding female CAB members is a community representative on the National Health Research Committee; appointed by the Minister of Health and involving all medical and social science research protocols across South Africa. Thus, in their role as community representatives, CAB members have the power to influence decisions on what kinds of research are appropriate and evaluate their potential benefit to communities. In such ways, confidence in the capacity to govern the process increases through influencing agendas (Yanacopulos, 2005).

In response to my questions about over-research in their communities, Sowetan vaccine CAB focus group members told me that there were many researchers, but “they must come through the correct people, the correct gatekeepers, people that are known in the community” (an older female vaccine CAB member from the Soweto site). This CAB member said that I could not “just walk in”. In the past, researchers came and left without giving information, but now they have the power to ensure that researchers come from “a reputable institution, so that nobody just comes and takes advantage of [us] as a community” (ibid). As explained in Chapter Three, my protocol for this clinical research site was approved by a team of CAB representatives and staff from the PHRU as well as the medical Human Research Ethics Committee at WITS. Their concerns to protect their communities from unwanted intrusion had formal support. At the same time, they are able find ways to use research to their advantage in their search for access to health and community development in the longer term.

The governance of ethics procedure is now mediated by the impetus to protect communities ‘from below’ as well as ‘from above’. That shift changes the impetus from paternalism, to one of self protection by community members whose interests now inform the research process in more direct ways. As explained, this protection of communities from damaging research arose due to past experiences. Those experiences are reflected in contemporary concerns for ethical research practice. Throughout my field research, people talked of the ‘old days’ of apartheid when they had not been given due respect. This was contrasted with the trust which my community respondents had for the trial site researchers and the appreciation of opportunities to be engaged in the research. Equally, the researchers were keen to encourage community members to raise their profiles at national and international conferences and other events.

Through the need for community acceptance of their research, trial site researchers and donors support community members in those wider engagements. Although opportunities to participate in events beyond the trial site communities fulfil part of the personal relations remit of researchers, by displaying their commitment to trial site communities, those

communities use those resources to develop their capabilities in such arenas. In doing so, they are in a position to influence decisions over access to health.

The CAB member elected as a community representative on the National Health Research Committee continued the story of her progression to international fora. Asked to present "something on community participation" to reflect her experiences of daily life in Soweto, this community nurse was daunted by the prospect of facing "all those big guns from Africa" (an older female CAB member from Soweto). Yet, she felt that she needed to take this opportunity "to say something", and so she decided that she would "do it to the best of [her] ability", bearing in mind that she "may not have the same chance again". As she said, this was:

> …one of those exposures that really brought me my presence and, as I say, meeting other people, getting to hear what others are doing in different countries.

That presence resonates with Ricouer (2006) in his discussion of the progression from self-esteem (gained through her work as a CAB Co-ordinator) to social esteem through that recognition.

With that recognition and respect she was able to take action (Barnes et al. 2007). In conveying her beliefs, values and commitments she is a conduit for change between the "engaged" and the "engagers" (ibid). That national presence led to another opportunity as a Global CAB Co-chair at HVTN meetings in Seattle. Those experiences and the information gained are relayed back in reports to local CABs, so that others can develop their understanding of scientific developments in HIV prevention. Such opportunities to influence health research through such flows of information are a key element in effective global networking (Keck and Sikkink, 1998). Although facilitated by trial site researchers and donors, in their need for effective research they are compelled to support the health agency of community members who use those opportunities in ways that support their valued health needs (Ruger, 2007).

Global CABs

As explained in Chapter Five, the HVTN is a major sponsor of trials, with a significant input into the trial site governance process and a built-in community engagement component extending to a global CAB network system. That network involves regular conference calls with CAB members across all of the trial sites.[107] The experience of other CAB members across national boundaries provides opportunities for members to develop their capabilities to influence health governance through the kind of network of communications between partners which Yancopulos (2007) might envision. Three Sowetan CAB members have been elected as Co-chair with others from America, one of whom told me that this was:

> … another very good learning experience [since] you'll find that, in some of the CABs in the US, a lot of doctors[108] belonging in the field and they understand so much … now they want to solve our problems as CAB members or educators … understanding this very scientific language … but we managed (a young male CAB member from the Soweto site).

Here, they discuss their own different social and cultural assets and problems across African countries and South African regions. Those experiences are then fed back to new trial sites, thereby increasing the understanding of researchers in how to adapt their practices and increase the involvement of those who might otherwise be excluded. At the same time, as new CAB members and community educators, their abilities to use their agency to seek valued health resources are enhanced through that networking process.

These kinds of experience are recognised as a valuable means of developing knowledge and the skills to make claims for those resources. Five of the CAB members[109] whom I met, from the two trial sites where this research was undertaken, had operated at this global level; to attend international retreats and conferences and to represent their local CABs by developing research protocols and through their involvement in Scientific

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[107] CAB members invited to participate in this meeting were from the USA, Latin America, Africa, the Caribbean and China.

[108] CAB members vary, with some CABs having professionals with medical knowledge. This is not the case in the CABs which I researched. I return to this point about the different composition of CAB membership below.

[109] Two vaccine CAB members were from the Cape Town site and three were from the Soweto site.

Working Groups. At the retreats, community members receive training in ethics, vaccinology and related scientific terminology. One CAB member explained:

> So, from being a lay person to being a lay scientist … we learn a lot. And ... at the conferences, we are exposed to what is happening globally within the research world (a middle aged male CAB member from the Cape Town site).

From this kind of exposure, community members go on to train others in reviewing research protocols and informed consent materials.

Through that work, other opportunities to use that understanding and those communication skills arise. For example, that same CAB member serves on the Networks Evaluation Committee, where he:

> … gets insight into what is happening within the network, all their sites and how they are operating …which is very important for us as a country that's starting out in vaccine research. [This is] part of an active process. It is not like you are a community member out there, you have no say. You get tasks to evaluate certain sites, contribute as a reviewer, so you learn a lot (ibid).

The Haitian site that he evaluated gave him insight into different ways of organising in a different context from his own, and the means to communicate across those socio-cultural and political spaces. As part of this work, he is learning two languages so as to communicate directly with others in the HVTN global CAB network. These skills enhance opportunities to challenge research decisions at global level over what research is done, how it is undertaken and where it takes place.

The confidence gained, through networking and participating in global fora, enables less experienced community representatives to voice concerns from countries where health activism is less established. At one such global conference call, a CAB member from America asked challenging questions which reflected the longer term agency developed there over the last twenty years of AIDS activism. Through that exposure to more politically assertive CAB members, less experienced members develop the confidence to become more assertive in their communications with donors and with other more experienced CAB members, where agendas and health priorities might differ.

Those shifts in the balance of power, between donors and other CAB members, influences the kinds of research decisions made. That "interplay of forces" (Allen, 2008) is reflected in the ways that donors and scientists communicate with 'lay experts'. The benefits of research are then more likely to reach trial participants and those working to engage communities in trial site activities in resource poor communities. As discussed in Chapter Five, this depends upon the efficiency of feedback mechanisms at community levels.

The African profile is raised in such global health deliberations, which suggests that mechanisms for Ruger's (2010a) reasoned agreement and shared health governance are possible. An HIV/AIDS counsellor and vaccine CAB member described the significance of her global experiences in this regard. In response to questions as to whether or not she felt that she had made a difference through her work, she replied:

> Ja, particularly personally, participating in the study was great for me, developing the protocol … being there from the onset … it was great for me and having to raise the African issues within Seattle … being part of the protocol team … they were relying on me to give information not only for South Africa, because I was the only person from Africa. So, before I went there I did my research … I had the right information, so when I got there I was fully equipped … so that wherever they decide to kick up that particular study they've got the right information from my side (a middle aged CAB member from the Cape Town site).

Through her paid work, her prior knowledge of other African country responses to HIV/AIDS issues and vaccine studies helped in that process of knowledge exchange.

In addition, she felt confident that, should it not "feel right" for her country, she had the power to influence decisions over research protocols. The rationale in her terms was that:

> Someone needs to be fully informed about science and the study of everything regarding HIV. And, without that kind of information you – one cannot make an effective CAB because we'll say "yes" to whatever the scientists say …and I am a very challenging person … if I don't get it, I don't get it (ibid).

As she said:

> Having to take that information myself to our scientists and our PIs here … my scientists having to rely on my feedback regarding that particular protocol, for me it was great (ibid).

She feels confident that she has the capabilities to make independent decisions over research which affects her community. She is “a competent member of society” and a citizen with the capabilities to “shape the flow of resources to persons and social groups” (Turner, 1993, p. 2). In Ruger’s (2007) terms, this CAB member is converting valued health resources into health functioning, albeit from invited spaces, but at different levels reaching beyond the local, to influence global health governance. In order to fulfil those responsibilities, she has developed the skills of self-management, informed decision-making and the control of personal and professional situations to pursue health (ibid). In doing so, she is gaining access to health through scientific knowledge. Moreover, where the feedback of information to local communities works, it stimulates that process of empowerment, such that meaningful political roles can develop both within and beyond those invited spaces.

Although invited into these global political spaces to facilitate the research process, the ways in which those opportunities are used by community members to engage in this global exchange of ideas and information (Mann, 1986) to suit their needs helps to determine the process and outcomes of health governance. Whether or not this exchange involves “pressing more powerful actors to take positions” (Keck and Sikkink, 1998, p. 9) is less clear, but the potential for this to occur lies in the combined activities across different political spaces that CAB members occupy elsewhere, in addition to those exchanges between members at this global level. Exchanges of information and ideas across those different spaces may generate change over the longer term, through the activities of these “champions for change” on the inside working with well-organised, mobilised groups on the outside (Gaventa, 2007, p. xvii). By including previously marginalised people (ibid), they are more radical in their scope for reconfiguring such formal governance institutions (Cornwall, 2002, p. 15).

Those opportunities to work beyond local levels provide valued health resources which community members use to communicate across the different trial sites, in both formal and informal capacities. As community members organise themselves and decide

priorities over their valued health resources, they achieve a degree of independence from the donors and trial sites. Each CAB member devises ways of communicating with other members to suit daily routines. Hence, email and phone contact between different members takes place aside from those organised by donors from within those formal arenas. They use the resources of invited spaces (Cornwall, 2002) to communicate and deliberate over health agendas according to community needs through those more informal networking opportunities. This suggests that outcomes are not pre-determined, as Allen (2004, p. 29) points out when he writes about what happens "between 'here and there' across space and time" in networked interactions.

Ultimately, the power relationships between donors and CAB members are uneven and the governance process is steered towards the primary agenda in the efficient operation of trials. This suggests that these global CAB members are more likely to be placed by power in Allen's (2008) terms. Even so, all parties are concerned with this smooth path to a successful vaccine and the informal spaces created by those global CAB members can be used to exchange information and experiences, to discuss other concerns and to act as a conduit between their local communities and donors. On the other hand, engagement in higher levels of health governance can shift alliances away from communities which CAB members represent to donors at global levels and to researchers in trial sites.

Networks and shifting alliances

Through their engagement in national and global fora, some CAB members become 'lay experts', as one of my respondents agreed. This provides opportunities to build upon these wider connections and reinforce trial site alliances. I have argued that such expertise is a valuable community asset. And yet, just as researchers can experience conflicting accountabilities to donors and communities, community members can find themselves in similar positions between researchers and the communities which they represent. As CAB members become closer to staff through their community engagement work, the problem of shifting identification can arise and, with it, challenges to CAB

autonomy. Alliances between CAB members and researchers, to mutual benefit, provoke shifts in allegiances and discourse around community engagement. The more senior CAB members are comfortable in those research environments. Those from both trial sites align themselves with the trial site researchers in their use of 'we' when discussing their community engagement work. Epstein's (1996) research into AIDS activism in the USA is instructive. The tendency for lay experts to move closer to the world view of researchers and away from fellow activists highlights the problem of accountability discussed in Chapter Five. As members become more knowledgeable, their accountability to the people they represent becomes less assured.

This potential to shift alliances from CABs and communities to researchers is compounded by the additional problem of remuneration for voluntary work. That lack of community independence, in part, due to the prevailing socio-economic conditions in resource poor communities, may limit their freedom to act politically within those invited spaces. As mentioned by respondents in Chapter Five, difficult questions do not get raised. This may be a consequence of that lack of autonomy. As much as researchers try to encourage CAB independence, poverty limits the extent to which CABs can be supported financially by their communities. As above-mentioned, the more senior CAB members go on overseas trips:

> They go to conferences. We pay, and they need to do that, so basically they need to be there and they need to be visible and they need to be hearing what other community members are saying, but they rely on scientists to pay for them to go, so a true community advisory board, in a society that was wonderful, there would be mechanisms, that the community would fund the participation … so sometimes I worry because we're paying…. we sort out their passports, we do everything and sometimes one wonders how neutral one can be, when you are supported heavily by the scientists and not by the community (Professor Glenda Gray, Co-Director of the PHRU in Soweto).

There is a tendency for alliances to shift towards researchers as lay expertise develops and through that remuneration process. As Barnes et al. (2007) suggest from their work in different Western contexts, institutionalism can develop over time. Despite the key role of CABs in community liaison, there is a growing discussion amongst community advocates around those mechanisms as the most effective means of engagement. In South Africa, those advocates were concerned about the need to engage communities on

deeper levels than so far achieved. The potential for “new hierarchies of expertise and new forms of potential exclusion” (Newman, 2005, p. 202) may arise in any context.

And so, on the one hand, these ambiguous spaces can provide valued opportunities for direct dialogue (Johansson and Hvinden, 2009) and, on the other, community allegiances can shift across to the researchers involved in the vaccine initiatives and donors who provide the valued national and global networking opportunities across those invited spaces. Accountability to communities can be compromised by those loyalties, thereby defusing more challenging claims.

Effective political agency on behalf of communities requires political positioning in order to use resources and networks, in a balance between furthering opportunities to make changes at higher levels whilst maintaining horizontal allegiances to communities which they claim to represent. The ideal balance between commitments to researchers and communities may be difficult to maintain in reality, as enthusiasm for community engagement increases and as those opportunities to learn and to develop the capabilities to function beyond the trial site arenas arise. However, a more complex picture emerged through my research. I argue that alliances are not clear cut between those who provide the invited spaces and those who inhabit them, as Barnes et al. (2004) found in their research on local government initiatives in the UK.

In this trial site context, that division between research staff and communities can be ambiguous where, despite their employment status, staff members employed from within the trial site communities have loyalties to communities where they work and live. Evidence of this kind of empathy which develops between researchers and communities and the use of opportunities for decision making over health become lost in the political debate over the “medicalisation” of people living in poor communities (Seckinelgin, 2008). Such debate tends to polarise positions and overlook the “more subtle processes at work” that Barnes et al. (2004, p. 276) discovered, where values and objectives are shared and where alliances can stimulate change in local government initiatives for health and other sectors.

Epstein (1995, p. 420) found that AIDS activists in America "*wanted* to see the trials conducted" so that "the relationship [between scientists and activists] became a powerfully symbiotic one" (author's emphasis) and so not all forms of political alignments are to do with resistance (Allen, 2004). As described in Chapter Five, some staff members who work closely with CABs balance allegiances to their work with those developed with CAB members. In pointing out their frustrations with the realities of community engagement, trial site staff are claiming those allegiances and working to overcome the problems arising.

These complexities illustrate the provisional nature of power which makes outcomes indeterminate (Allen, 2008). Alliances can shift across the research and community arenas in unexpected ways. Again, this resonates with Clegg (1989, p. 154) in his conception of power as a "shifting network" extending over a "shifting terrain of practice and … interests". Indeed, the CAB members whom I encountered took different routes in generating community engagement, within and across local trial site arenas and beyond into higher health governance levels. Some were allied with the researchers through their roles as counsellors, but more grounded in their work as CAB members at local levels in their one-to-one encounters, or in using performance to local audiences, as explained above.

The headmaster from Masi took another route. Although still involved in the CAB, he was concerned less with developing alliances with the researchers (whom he felt distanced from) than with education departments and local faith groups. Alternatively, other CAB members had developed alliances with researchers and were also involved in alliances with other activist groups unconnected with the trial sites. This suggests a more complex picture of political allegiance and more independent political activity operating from different local to more national political spaces. Each of these activities has an impact on the ways in which community engagement develops. At the same time, their span of influence can reach further than the immediate trial site communities.

6.2.1 Health activism and collaborations

Therefore, through those alliances, some CAB members use those opportunities gained through their roles, such as information and skills, to extend their newfound powers to operate in different political spaces through other affiliations with community based and civil society organisations operating in claimed spaces within and beyond the invited trial site arenas. In such networks, more independent collective forms of activism over health and socio-economic justice are developing beyond the trial sites, which influence the political subjectivities of CAB members. In turn, those experiences reflect back into those more immediate invited spaces. Again, as Cornwall (2002) suggests, information acquired is not sufficient without social and political connections across different political spaces.

Most of the community members in this research had some form of connection to other organisations. These range from small community based support groups which some had established themselves in response to immediate needs as they arose, such as helping orphans and vulnerable children, or in providing support for people infected with HIV, or in youth groups where they invited speakers to talk of their experiences of being HIV positive. These form part of the myriad of social networks which Mann (1986) describes. As I found, those involved in higher level national organisations, such as TAC, were the most politically astute, and their questions about other CABs and organisations the most searching. Since the reach of TAC spans community to national levels, some are active beyond the immediate trial site arenas. That involvement in networking across trial sites, the African continent and internationally influences community engagement through the exchange of values and norms which Henry et al. (2004) identify as key to activist networks.

I was told that many researchers seek information, so that research becomes a “constant process … with one research activity complementing others, in partnership” (a middle aged male CAB member from Cape Town). This openness to research confounded my reticence in concerns in contributing to ‘over-research’ (discussed in Chapter Three) which

had been reinforced by ethics committee concerns with protection of communities. To this CAB member, this opportunity to exchange research marked a “dynamic shift in society”, where the need for cross fertilisation of ideas was crucial in driving forward change (ibid). In this view, each exchange brings to light issues that are pertinent to the community, and that those issues could be better addressed by establishing an advocacy group to lobby government. Insights drawn from the lobbying work of AVAC, in its support of community engagement, had stimulated this plan.

Cross fertilisation of ideas and experiences such as these contribute to community engagement in local health initiatives. Further, this CAB member’s networking across different organisations includes TAC. In collaboration, they are finding ways to develop CABs as complementary civil society structures to challenge government. This political action responds to the perceived distance between government departments and health research and this CAB member’s frustration with SAAVI which, as he says, “is supposed to be *prominently* introducing vaccines” (ibid, interviewee’s emphasis).

In the absence of such vertical levels of political advocacy due to the lack of leadership at national level, civil society organizations such as TAC are supporting efforts to fill those gaps and to stimulate changes in health governance at higher levels. Those efforts to gain political recognition for CABs are complemented by those to gain legal recognition. They illustrate the ways in which health governance is developing through the work of civil society beyond trial site environs. These examples confirm that formal participation is not necessarily disempowering, that political spaces are not discrete and that learning takes place whereby “experiences from one space are transported and transformed consciously or unconsciously in different new spaces” (Hickey and Mohan, 2005, p. 252).

This CAB member is working within and beyond the invited spaces of trial sites, to reconfigure the landscape of health governance and research, by challenging government through collective work with civil society organisations working in claimed spaces. In turn, that collective work influences the ways in which CABs operate at local levels, where

community engagement is influenced by those other national civil society agendas. Through such concurrent efforts to promote change, the interactions and influences between claimed and invited spaces reflect on each other, to develop new forms of participation and political engagement. As explained in Chapter One, the close interactions between different civil society organisations and groups experienced by South Africans (Ballard, Habib, Valodia and Zuern, 2005), supports this cross fertilisation of ideas. As such, they may be seen as the kind of "schools for citizenship" which Gaventa (2007, p. xvi) describes through purposeful and chance encounters across those political spaces.

6.2.2 Community engagement and change

This complex set of political interactions operating at different levels of health governance show that deficits in public services have different consequences. In one sense, they limit opportunities for communities to improve the socio-economic conditions in which they live. Alternatively, those deficits have stimulated wider civil society responses which have influenced political activity across claimed and invited spaces. I now trace the influence on community engagement, through claims made and the events which have stimulated changes in the political relationships between researchers and communities. This reveals a more holistic approach to community engagement in a wider conception of health than immediate health needs.

Although the development of meaningful political roles in such resource poor settings has been compromised by governance problems at higher political levels, where deficits in public services undermine those efforts, change is occurring over time. As health activism develops to include a broader spectrum of socio-economic rights,[110] that activity reflects on community engagement within the invited spaces of trial sites. The response of researchers to the claims made by young people, and the changing relationships following the crisis in vaccine development discussed in Chapter Five, suggests that communities

[110] As mentioned above, during the first research period in Cape Town, TAC played a major role in supporting the refugees who fled the townships following civil unrest.

are developing meaningful political roles in HIV vaccine trial sites in response to those changes. In recognition that valued health needs in such contexts are wider than medical, the terms of community engagement are changing. With those changes, the original remit of researchers to conduct effective HIV vaccine trials has expanded as relationships have been developing between them and the communities where they operate. This has stimulated researchers to envision a wider conception of community engagement.

As the scientific approach to HIV/AIDS has changed to become a more collaborative approach in HIV prevention, community engagement has become more attuned to the particular needs of the people involved. As explained in Chapter Two, Barnes et al. (2007) found change occurring not only for "the engaged" but "the engagers". CAB members discussed a more holistic view of health beyond HIV/AIDS and health more generally. When asked about longer term visions that CAB members might have, one said that community engagement models could be used to address other social problems, such as crime, which form part of the wider social fabric of daily life.

As I was told, an holistic view considers that these social problems hinder access to health and wider socio-economic development. Community engagement is developing in tune with a wider conception of health beyond the immediate clinical remit and an expansion of the original CAB function (Morin, Morfit, Maiorana, Aramarattana, Goicochea, Mutsambi, Robins and Richards, 2008). This suggests that meaningful political roles are developing, to drive social change beyond the immediate problems of HIV/AIDS; to challenge criticism raised in Chapter One of PPPs and their focus on disease (Reid and Pearse, 2003; Ollila, 2005); and on their technological solutions to inequalities (Birn, 2005).

This concern with a more broad approach to health includes developing resources for adolescents. The clinical research priority in engaging young people as high-risk groups vulnerable to HIV infection has expanded to include the building of youth centres where they decide which priorities are important to them in that engagement. As an outreach

worker involved in adolescent programmes explained, where unemployment levels are high the most valued resource is the opportunity for career development. Those efforts do not fall into distinctive patterns, with researchers necessarily focused entirely on technical aspects of community engagement and CABs on the empowerment of communities. Efforts to develop a deeper engagement within communities, to strengthen horizontal links and to empower 'hard-to-reach' groups via social networking are being made by outreach workers in both sites.

As part of those efforts to increase sustainability, 'global' CAB networks between the different trial site communities were being discussed in Cape Town. These restructuring plans are in recognition of CAB members' requests for opportunities for more specific science information across those different HIV treatment and vaccine CABs, so that they can respond to questions asked in their communities. Proactive elements increase with their capabilities to function and in that dynamic process local health governance changes. For similar reasons, plans for an executive CAB were being discussed in the Soweto trial site.

Aims to strengthen CAB roles to develop stronger links across other clinical research sites (such as TB networks), and between vaccine HIV vaccine trial sites and local government initiatives (such as AIDS councils), indicate efforts by CAB members to develop the political roles of CAB members beyond the trial site environs. This focus on strengthening community engagement mirrors the concerns of the PIs in Soweto who pointed out the lack of monitoring and valuation processes. In the former case, the concern is to develop different ways of raising the political profile of CABs. In the latter case, the smooth running of CABs may be the primary concern, but these examples illustrates the ways in which community engagement discourses are being both reproduced and reconfigured in different ways across different political spaces.

Ultimately, the key problem for CABs is their need to develop a more independent representative community body. Mindful of the lack of CAB autonomy, the PIs in Soweto

contemplate a situation where CABs are self supporting, in a more indigenous form of civil society engagement, where:

> … the ideal situation would be that they would be community structures that basically support community representation in science and not the other way round, that's, I suppose that's another model one would have, you know, if the scientists aren't paying for the community, then who would? … We try and be democratic. We have a constitution and we have a term of office, a revolving chair, so one always tries to be, to try and be democratic. When we're developing the CAB, we invite members of different stakeholders and they get to represent their organisation on the CAB … (Professor Glenda Gray, Co-Director of the PHRU in Soweto).

That lack of community independence, in part, due to the prevailing socio-economic conditions in resource poor communities, limits their freedom to act politically within those invited spaces. As much as researchers try to encourage CAB independence, poverty limits the extent to which CABs can be supported financially by their communities, where other forms of health activism are independent and self-sustaining.

AIDS activists of the 1980s in America (Epstein, 1995, 1996) claimed their political spaces and remained independent from the institutions which they confronted to a greater degree than those who work within the invited spaces of vaccine trial sites. In America, the problem of shifting alliances still arose, as explained above, but in developing countries such as South Africa, political autonomy is more likely to be compromised by that closer affiliation to the trial sites and the CAB reliance on financial support. Payment is given to trial participants for travel, as they are to CABs who also receive food during meetings.[111] CAB member expectations can exceed those remunerations and trial participants choose the trial with the best payment. Moreover, CAB members who do not contribute to meetings are accused by others of attendance for that remuneration when their participation in meetings appears to be lacking.

These concerns over autonomy illustrate the ongoing debate over the CAB model itself and its implications for independence. This debate involves practitioners and community advocates ranging across the different trial site locations and including designated TB and

[111] I provided refreshments for each focus group in keeping with tradition in such environments.

microbicide research sites.[112] The debates highlight efforts to achieve the ideals of community ownership raised by Lasker and Weiss (2003). As discussed in Chapter Five, this issue of political autonomy has an impact on CAB accountability to communities. Yet, this is not a problem specific to these South African cases. As it was pointed out:

> … no-one has taken community participation further than CAB and the model should evolve over time and I don't think it has to that much. I think you need a model where the community drives and sets the agenda and that's not going to happen for many years anywhere, not even in America, not even in Sweden does the community drive the research agenda, so that's the ideal model (Professor Glenda Gray, Co-Director of the PHRU in Soweto).

This lack of autonomy, the long term vaccine development process and fragmented links with local health systems are significant impediments to achieving such wider development goals. The need to engage communities over long periods of time presents difficulties for those balancing other commitments in resource poor communities. Those difficulties are compounded by the problem of engaging populations most at risk. Through involvement in HIV vaccine trial site activity, some community members are building their capabilities to function in the pursuit of valued health resources. In that process, community engagement can facilitate development more broadly. As argued, even though the remit of such local health initiatives may be in HIV prevention and treatment, the ways that community engagement develops can stimulate unexpected results, with meaningful political roles evolving in trial site communities.

6.3 CONCLUSION

These data suggest that capabilities to convert community engagement resources into longer term health and development are being developed in this South African context, despite the socio-economic conditions exacerbated by the stigma and politicisation of HIV/AIDS as discussed in Chapter Four. The valued health resources discussed in Chapter Five provide evidence of some of the ways in which shared health governance (Ruger, 2010a) within trial sites can be achieved. With the involvement of more marginalised groups, crucial knowledge of their valued health needs is increasing. In this chapter, the

[112] These data were collected in communications with other health initiatives during the field work.

ways that those needs are being addressed shows the ways in which resource poor communities are gaining access to health.

The people encountered through this research are highly motivated, more often beyond personal gain. Their concerns about their families, friends, communities and country are reflected in efforts to develop sustainable community engagement alongside more immediate needs for remuneration and employment. Their gains illustrate some of the meaningful political roles that are developing in trial site communities. Their acts of citizenship which often go unnoticed can have a significant influence on communities and the wider political arena over the longer term. In helping others to alleviate the isolation of illness and stigma, through raising awareness of health issues, those acts change lives and promote agency in those otherwise lacking in the confidence to make the kind of decisions which generate change. Those acts are significant, but less often acknowledged by those seeking evidence of political empowerment. Community members use those spaces to develop the capabilities for agency. The dominant agendas of more powerful actors are not as all consuming as it might appear.

Those who build other connections beyond the trial sites use those opportunities to represent their communities in national and global arenas. A combination of their employment, voluntary work and experiences of HIV/AIDS, contributes to their knowledge and skills. With those resources they are developing the capabilities to use opportunities to become involved in decisions over research which affects their communities. The interactions between the different political activisms across invited and claimed spaces are paving the way for more marginalised people to become involved. Through that concurrent political activity as members of civil society organisations, engaged communities are using their collective power to make claims for their constitutional rights to participation, health and social justice.

In moving between invited and claimed spaces, they are building the capabilities to engage in higher level political challenges over socio-economic citizenship. In such ways,

the resources for meaningful political roles can extend beyond immediate community environs. This empowerment of community members suggests that new democratic procedures are evolving. In that process, the activities of some community members are having a significant impact on trial site community engagement, institutional sustainability and the strengthening of vaccine initiatives. In that process, those activities are changing research and scientific practice.

Ruger's (2007) three principles which provide the framework of these data chapters which address: changes in social norms; claims for valued health resources; and support for health agency, are useful in identifying the ways that access to health can be improved. However, this optimism needs to be weighed alongside the problems in context. I agree that there is a tendency for a neo-liberal "zeal for civil society" and that emphasis on community care betrays a "fetish for coping" (Marais, 2005). Miraftab (2004, p. 254) writes of the normative impulse behind "empowerment talk", with the term taken up and depoliticised by policy makers in a "posture of social upliftment" by engaging volunteer community labour to fulfil social and economic deficits. The presumption that civil society has the means to achieve socio-economic justice without political support is misguided in its estimation of the powers of those civil society activists and the ability of communities to cope with HIV/AIDS without that support over the medium to longer term. The government responsibility for supporting those shouldering the burdens of coping with HIV/AIDS needs material recognition.

This responds to arguments for "the openness and capacity of the state" in response to marginalised voices (Cornwall and Coelho, 2007, p. 23). With government support and improvements in HIV mainstreaming across provincial and local sectors, public health systems have a greater potential to become more effective. The connections being developed between vaccine initiatives and those health systems may stimulate improvements in access to health. Those changes may begin to arrest the spread of HIV/AIDS, already experienced in small measure by younger generations (Sishana et al. 2009, p. xvii), whose access to community engagement initiatives may have had some impact

on those rates of HIV infection and whose energies and enthusiasm for local health initiatives of this kind are building upon established forms of community engagement.

Recent governmental change and public pronouncements over HIV/AIDS policy change gives some indication that those material needs might begin to be addressed. Discussions around HIV and poverty are not as heavily imbued with political controversy. At the same time, the negative social norms which have constrained effective HIV/AIDS policy and practice have been shifting: not least due to the efforts of people working in their own communities. Community engagement in trial site HIV prevention activities is far from the ideals promoted and yet, still crucial in the development of sustainable local health initiatives of this kind. The influence of those initiatives may be more far-reaching than the geographical bounds of communities, to have a wider impact on global health governance.

CHAPTER 7

CONCLUSION

This research has sought answers to how health biotechnologies reach the communities in which they conduct HIV vaccine trials and how communities respond to these interventions. The rationale for the focus on community engagement in trial site activities was to identify the resources which communities find important in gaining access to health. This focus is important for two key reasons. Firstly, it recognises the significant role of civil society in health activism. Secondly, it sets this activism within the social, economic and political context which affects the fortunes those living in poor communities and on the local health initiatives which claim to support them.

In doing so, this work responds to the gaps in evidence of: the “software” of biotechnology interventions (Leach and Scoones, 2006) and their impact on poor people in the clinical research process (Chataway and Smith, 2006). It responds to the “paucity of data” on how communities deal with HIV/AIDS (UNRISD, 2009) and develops the growing literature on how involvement within such formal invited spaces (Cornwall, 2002) can be meaningful to participants. More specifically, it extends the literature on ‘good practice’ beyond the ethical remit to protect clinical trial participants, by exploring the wider benefits of engaging in trial site activity.

The primary research question asked: To what extent do communities play meaningful political roles in local health initiatives? This question sought evidence of the ways in which poor communities make claims for health. The theoretical framework generated understanding of local participation in health governance and the limitations on its impact due to higher levels of health governance.

In these South African contexts, the political controversy over the causes and consequences of HIV/AIDS has frustrated collective efforts to address the high prevalence

of HIV infection. Therefore, this activity has been framed in this thesis by wider health governance; with respect to governments, PPPs and GHPs at national and global levels. This focus on local health governance identifies the power relationships involved across those political arenas, and their impact on the agency of engaged communities as they seek access to health. The analysis of CABs in their liaison roles between researchers and communities reveals the ways that poor people seek social justice through health citizenship enacted in their daily lives.

This chapter begins with a summary of chapter themes, followed by a discussion of the key empirical findings and their theoretical and policy implications. It outlines some of the limitations of this research and new questions arising which reach beyond the boundaries of this study.

7.1 THE CHAPTERS

Chapter One set this research into context, by focusing on community engagement in HIV vaccine clinical trial sites in two urban South African settings within the wider national and global health governance arenas. The rationale was to assess the impact of those higher levels of health governance on local health initiatives and, correspondingly, to consider the influence of local health activism on health governance beyond trial site communities. This first chapter provided the background to the complex socio-political context where PPPs have been providing resources in a country struggling to cope with: the highest number of HIV infected people globally; one of the highest rates of inequality; a fragmented national health system; and a lack of political leadership in HIV/AIDS governance.

In Chapter Two, I set out the theoretical framework, beginning with the capability approach to social justice (Sen, 1999) by focusing on what communities are able to do in efforts to gain access to health. It considered that access in terms of the prevalent social norms and the valued health resources which influence community capabilities to achieve health

agency (Ruger, 2007). In doing so, it provided evidence of the characteristics which enhance the conversion of those resources into meaningful health choices (Sen, 1999). At the same time, it identified the limitations of Ruger's (2010a) conception of shared health governance, within those local environments and their wider socio-political contexts. Existing literature on community engagement, linked with concepts of invited and claimed spaces (Cornwall, 2002) identified the connections between them wherein communities are finding ways to develop shared health governance (Ruger, 2010a) from within and across trial site boundaries.

The concepts of explanatory and procedural governance (Yanacopulos, 2005) lent insight into the wider national and global health governance arenas which influence those liaison roles, and the daily process of health governance at community levels. The two concepts - explanatory and purposive - helped to tease out the detail of context and process to take account of the changing relationships between state and non-state actors involved, and health governance as it plays out in those different arenas. For example, the norms which have influenced HIV prevention programmes focusing on sexual behaviour have ignored the difficult circumstances in which poor communities live and which limit decision making over that behaviour. Decisions over trials in process cannot be made by CAB members if they do not have access to ongoing information from researchers. The external and internal pressures at community and institutional levels which influence community engagement and access to health are then revealed.

Allen's (2003) approach to power relationships was discussed for its capacity to explain that interplay of forces between different actors operating at those different levels of health governance. It was used to identify the constraints on the capabilities of communities to play meaningful political roles in that process from within invited spaces. At the same time, it identified where relations of power facilitate agency and socio-economic citizenship. The dimensions (Hardy and Leiba-O'Sullivan, 1998) and networks of power (Mann, 1986) gave further purchase on the institutional dynamics of the power relationships within the trial sites and across those boundaries into wider community

health activism, and through the vertical networks from local to global arenas where shifts in power relationships can occur with the flow of information, ideas and people across those networks.

Chapter Three set out the methodological approach which guided the qualitative research methods used in three successive phases of research over four and a half months between June 2007 and November 2008. The methodological approach afforded by "subtle realism" (Hammersley, 1992) set the range of perspectives on community engagement into the wider social reality. The intention was to test theory in practice and so the two urban trial sites were chosen to explore community engagement in established sites rather than to understand how to develop practice in new sites or those facing difficulties. I was fortunate to be accepted as a researcher after lengthy approval procedures. This suggests that ethics are taken very seriously in South Africa.

As discussed in Chapter Three, taking a case study approach may not reveal clear patterns or distinctions between them and no possibility of generalisations given the nature of qualitative research. However, theoretical conclusions might be drawn which fitted my purpose. In the event, a combination of method produced some of the rewarding data which Yin (2003) promised. The inductive and deductive approach allowed new questions and conceptual developments to form during data collection through observation, focus groups and semi-structured interviews, and unexpected events and issues gave new dimensions to the data, as did the extended ethical procedures which reveal the complex political research environment. Kabeer's (1999) conception of empowerment in terms of the resources, agency and achievements of those community members engaged in trial site activities gave a focus to data collection.

7.2 EMPIRICAL FINDINGS

This section reviews the research questions and the key findings to identify: how communities are engaged in the activities of the two clinical vaccine trial sites; how

communities influence that engagement process; and the wider contextual factors, within the localities and in the wider national and global health governance arena.

7.2.1 Reviewing the research questions

Main research question

'To what extent do communities play meaningful political roles in local health initiatives?' The following questions focus on each aspect of community engagement, to identify the constraints on health agency and evidence of political action:

Sub-questions

1. 'How do participants involved in trial site activities perceive community engagement and their roles in this engagement?' This question concerned the ways that different perceptions of community engagement of researchers, outreach staff and involved communities influenced their approach. It sought data on their motivations, expectations and experiences.
2. 'What resources are available and what resources do engaged communities bring to HIV vaccine clinical trial sites?' This question gave insight into how engaged communities use their individual and collective resources to play an active role in health governance and in gaining access to valued health needs.
3. 'What problems are being experienced during the process of community engagement and how are those problems being addressed?' This question gave focus to the physical, psychological and social aspects which inhibit effective participation. These encompass personal health problems, deficits in the resources available from within the health initiatives, and the wider social and political barriers limiting the kind of community engagement that is effective for researchers and of benefit to communities.
4. 'In what ways are those involved in community engagement developing the capacity to stimulate social change?' This question identified the support for agency which engaged communities use to gain access to health and to play roles

in the wider development of their communities. It revealed how they envision that development and how it might be achieved; both within those local environments and in the wider social and political arenas.

7.2.2 Key findings

The key findings from each data chapter as they relate to the sub-questions above are outlined here, beginning with health resources with respect to questions one and two, followed by findings on social norms on health arising from question three. The findings relating to question four, on agency and access to health, are discussed in the final part of this section.

Health resources

These findings relate to the value to engaged communities of health resources, as discussed in Chapter Five. Through analysis of the community engagement process, data confirmed the following points. Firstly, there are opportunities to use invited spaces to play meaningful political roles in clinical trial sites, by developing the capabilities to use valued health resources to broaden and deepen community engagement. However, not all CAB members have those capabilities. Secondly, the patchy nature of communications between researchers, CABs and communities throughout the clinical trial process in some cases contrasts with the ideal endorsed by advocates. Thirdly, the accountability of CABs to the range of communities within the trial sites continues to be a key problem. In particular, the representation of marginalised populations whose health needs are the greatest continues to challenge the ideals of community engagement exemplified by advocates.

In the two trial sites, data confirm that CAB members value the resources available. They value HIV/AIDS knowledge and opportunities to influence decisions over clinical research and they take pride in playing their chosen roles in relaying information to communities and researchers on crucial health concerns. Those with the capabilities to play those

roles to their satisfaction develop the kind of innovative strategies, discussed in Chapter Six, to encourage others in making decisions over health. In some cases, this extends to political activity across the trial site boundaries in health activism.

The less confident CAB members have difficulty in transmitting that knowledge, in contributing to decision making and in making claims for the resources which they need. Their diffidence limits deeper collective engagement between researchers, CABs and communities. It limits full understanding of community concerns over clinical research and efforts to engage others in influencing the research process. This is an important and unresolved ethical issue. Such difficulties in finding wider community representation are not easily conveyed to researchers whose primary focus is on fulfilling their clinical remit, despite their high degree of commitment to the people living in the communities where they work.

This focus on research priorities draws attention away from community engagement and accountability to CABs whose members need recognition for their work in order to sustain commitment and develop their roles. The Cape Town CAB members expressed a need for more regular feedback and ongoing contact with researchers throughout the clinical trial process. Where this is lacking, it may increase the high turnover of CAB members and contributes to the lack of community representation. The Sowetan CAB members were more concerned with difficulties in engaging the large and diverse range of communities which they serve. That concern was mirrored in Cape Town, but their problems were in engaging communities where the stigma of HIV/AIDS arose in conversations more frequently.

The fundamental problem of community engagement in such local health initiatives lies not only in maintaining community representatives, but also in developing a wider representative body which includes the most marginalised populations who are the most vulnerable to HIV infection. In both case studies, CAB members had difficulties in engaging others in their work. Such problems exist in other contexts, but some were

more context-specific. The vulnerability of excluded populations, whose greater risk of abuse and violence renders them 'hard-to-reach' in terms of HIV prevention and treatment, are the least likely to become engaged as CAB members. Despite the efforts of researchers to fulfil the clinical requirements of recruiting trial participants from those excluded populations, their potential to play meaningful political roles in trial site activities by using valued resources to promote health agency is severely constrained by multiple forms of social stigma and discrimination.

Social norms and health

Key findings here related to the ways that stigma and the confusion over HIV/AIDS generated by political controversy undermines collaborative efforts in HIV prevention, treatment and care. Consequently, as explained in Chapter Four, HIV prevention is a more complex matter than the dissemination of HIV/AIDS information. It requires a socio-cultural understanding of how people perceive HIV/AIDS and insight into the ways that political debate has influenced perceptions; both of which influence the ways that people respond to that information. This understanding facilitates locally informed challenges to negative social norms. In doing so, it supports community engagement in the diverse settings where local health initiatives operate.

Findings on health norms and the politics of AIDS provide an essential background to problems being experienced during community engagement. They give insight into the ways that the inter-related stigma and politics surrounding HIV/AIDS continue to influence social norms, even where scientific knowledge of HIV/AIDS is available. Some of those involved in community engagement activities felt betrayed by the government in power at the time, whose lack of support has hindered coherent health governance. They are frustrated by the stigmatising of those infected and affected by HIV/AIDS which makes people fear attracting attention by being engaged in trial site activities. This fear seals the future of those people in terms of health and other benefits. More generally, I found a reluctance to criticise government policy where historical allegiances continue to inhibit challenges.

Those engaged in trial site activities are deemed to be HIV positive through association. Given the high rates of HIV prevalence, many of those working in these capacities are HIV positive. Those assumptions can thwart attempts to engage communities, where priorities tend to be focused on survival rather than longer term threats to health and the avoidance of further stigmatising through association. Where that stigma is most prevalent, a complex process of decision making over disclosure of HIV status preoccupies outreach staff and CAB members so as to avoid social isolation. In heterogeneous communities where competition over resources is high, that stigma isolates the poorest and most marginalised people who are then excluded from any form of health activism. These are the contextual factors which influence health governance in poor communities. Those able to overcome personal and social challenges develop the capacity to generate social change by using available resources and health initiative support for their agency.

Agency and access to health

And so some community members are able to use their knowledge of HIV/AIDS and vaccine science gained through their capacities as health practitioners and CAB members. They use those resources in health activism across invited and claimed political spaces by building alliances with others during that process. Through these community engagement activities they develop innovative ways of communicating and debating HIV/AIDS and health issues. In this, CAB members achieve several goals: by challenging health norms to provoke shifts in understanding; by feeding back unresolved community concerns over clinical research; and by making claims to researchers for unmet resources to help them to play more meaningful political roles in the community engagement process.

Those who work in several political spaces across those loose boundaries, between invited and claimed arenas, are finding ways to address the health and related problems arising from the disease, with knowledge and experience in one arena informing the other. These are political acts which sustain morale and attend to the fine detail of local needs. Others work across those spaces to increase the potential for political engagement in

higher levels of health governance. These experiences reflect upon each other, making meaningful political roles in health initiatives more likely to develop, through community engagement and beyond into other communities and wider national and global arenas. Through that concurrent political activity invited spaces can be empowering.

In summary, these data support my argument that significant gains have been made in efforts to engage communities, some of whom are able to develop the means to achieve access to health which would not be available without those resources. Engaged communities do play meaningful political roles in local health initiatives. However, the degree of agency is related to: the individual characteristics which community members bring to CABs; the quality of trial site resources and their 'fit' with community needs; trial site political dynamics; and the wider historical, socio-economic and political context. Each of these factors has an impact on who is able to develop the individual and collective capabilities to influence health governance.

As argued, challenging negative social norms contributes to the ways in which communities play meaningful political roles in local health initiatives and within their communities: not least so as to include those most vulnerable to HIV infection. Networking generates wider political involvement in health governance beyond those immediate communities. That agency gives engaged community members the capabilities to build bridges between researchers and communities and between the government and those local health initiatives seeking recognition and financial support.

7.3 THEORETICAL IMPLICATIONS

The ways that findings have been informed by the theoretical framework and *vice versa* are presented here. Together, they represent my contribution to the understanding of how community engagement works in these particular clinical trial site environments, and the potential for communities to play meaningful political roles in that process. I begin with an outline of the theoretical framework which helps in understanding health governance in

the search for social justice and health citizenship by those engaged communities in these South African contexts.

7.3.1 Empirical and conceptual relationships

Key conceptual and empirical links, with key findings on social justice and health relating to community engagement in invited spaces are outlined here; supporting the literature on the crucial liaison roles between researchers and communities in terms of ethical practice and adding to this literature by exploring the potential for political activity arising from community engagement. This identifies the ways that engagement supports communities and describes the power relationships involved. This part of the discussion ends by explaining how communities find ways to use the opportunities to seek access to health and socio-economic citizenship.

The capability approach to health and social justice reveals how individual and collective capabilities are developed, and how Ruger's (2007) three elements necessary to achieve success in that endeavour can be achieved; by focusing on health quality and support for agency in difficult socio-economic and political environments. Providing HIV/AIDS information and knowledge helps to develop capabilities for decision making over health. Training opportunities develop the kind of capabilities needed to present that information to others, so as to stimulate debate and decision-making for health. In this respect, communities play meaningful political roles. At the same time, they fulfil commitments to the kind of shared health governance which Ruger (2010a) advocates.

Yet, that health governance does not provide sufficient explanation without considering aspects of power in terms of its relationships (Allen, 2003) and dimensions (Hardy and Leiba-O'Sullivan, 1998). The multiple accountabilities (Edwards and Hulme, 1996) of researchers to donors, to clinical research and to communities can strain capacities to respond to community engagement ideals. The ideals of community engagement are confounded by intermittent contact between researchers and CABs in some cases. This

suggests that CAB members may be placed by power (Allen, 2008) since their ability to exert influence on political relationships is circumscribed by the lack of direct contact with researchers which they seek and which Johansson and Hvinden (2009) find is valued in their research.

The high turnover of membership and limited representation of communities across the range of populations within diverse communities constrains capability building and opportunities for collective agency to develop across those communities. Here, having the capacity to remain engaged, or to become engaged, is constrained in two ways. Those who leave CABs are frustrated by the political dynamics and the lack of opportunity to pursue their goals. Those who are not engaged exclude themselves, or are excluded, through experiencing wider social and political constraints.

The concept of procedural governance has shown how norm and agenda setting influence policy formation and decision making over community engagement. It reveals policy priorities, such as funding community engagement, and the ways in which CAB issues are framed and steered. For example, the reasons for CAB dysfunction are interpreted in different ways depending on perspectives. This has repercussions on the ways that community engagement develops. Unresolved communication difficulties can lead to the withdrawal of support. The subsequent 'restructuring' of CABs may result in a more consensual body which may exclude those whose dissatisfaction is not expressed, or heeded. In that withdrawal, the power to play meaningful political roles in trial site activities may be less likely.

The capacity for local actors to play a role in negotiating different agendas in the health governance process and transform the policy-making discourse (Barnes et al. 2007) lends insight into problems and successes gained by communities in securing the valued health needs discussed by Ruger (2007). Evidence of opportunities for engaging in global health governance has shown how this can occur. Governance as an explanatory and procedural framework (Yanacopulos 2005) identified the changing relationships between

state and non-state actors in terms of health governance. More broadly, the dynamic relationships between state and non-state actors at higher levels of health governance influence that process. The degree of support for community agency from GHPs, PPPs and governments, and the capacity for shared health governance at these higher political levels has an impact on the capacity of local health initiatives to support that community agency.

These data suggest that there may be less room for manoeuvre in invited than in claimed spaces, and a greater potential for co-option into the dominant clinical research agenda to recruit trial participants. Yet, these invited spaces offer support for agency in the kind of acts of citizenship described by Isin (2008). Other acts may not challenge social norms around HIV/AIDS, but play a distinctive role in local voluntary HIV/AIDS care. These are the acts which Chazan (2008) describes. This more widespread 'survivalist' activity is a form of health citizenship which plays an equally distinctive and yet unrecognised role in addressing health inequalities.

Such forms of neighbourhood support by individuals and groups of people may not challenge health inequalities at higher political levels. Yet, I argue that they can be recognised as political in small but significant ways in sustaining morale and by supporting those who may not benefit from being engaged in local health initiatives. Those volunteers who work in both formal and informal capacities often work simultaneously in CABs so that each set of experiences inform the other and so capability building is symbiotic across those boundaries. Local experience of particular problems can be fed back into local health initiatives with the potential for those ideas to be exchanged across other networks. The agency developed through permeable boundaries between claimed and invited spaces (Cornwall, 2002) suggests that both spaces reflect on each other, so as to stimulate the direct dialogue and reconfigurations which Johansson and Hvinden (2009) claim to be possible. In such ways, community engagement can have a positive influence on the health of local communities and health governance more widely.

Ultimately, the power relationships involved prescribe the fortunes of those who develop the capabilities for agency and those who do not. The political dynamics of CABs determine whether or not new members feel encouraged to stay and develop their capabilities to fulfil their community engagement roles. A focus on the collective dynamics between actors raises points of conflict between CAB members. The kind of personal characteristics highlighted by Sen (1999) differentiates the capabilities of those who enjoy access to more powerful actors and who are more equipped than others to play a role in health governance, both within the immediate institutional boundaries and across them.

Drawing from conceptions of networking (Mann, 1986; Keck and Sikkink, 1998; Henry et al. 2004; Kahler, 2009) we can see how HIV/AIDS knowledge is spread to develop the means to prevent HIV infection in two ways: through the networking opportunities offered by the researchers, donors and AIDS vaccine initiatives; or created by CAB members via their connections within claimed spaces in other health and other political arenas. In using that information and in developing their ideas across health governance arenas which suit their particular socio-cultural contexts, their capacity for health activism is increased.

On the other hand, by identifying those who do not share in that health governance, the health injustices described by Ruger (2007) can be given attention. The multiple forms of stigma which limit the capacity for agency for MSM and 'foreigners', with their diverse health needs, confirms the value of looking at health inequalities in terms of variable health conditions and needs rather than seeking equal distribution of health resources (Ruger, 2007), since equal access to health does not guarantee a healthy life for those who suffer multiple disadvantage which equal distribution of resources may not address.

As argued, power relationships can be inhibiting, by "putting us in place" (Allen, 2008), to reveal the limits to Ruger's (2010) shared health governance. Alternatively, power can be an enabling force where claims for socio-economic citizenship can build on opportunities to influence health governance and improve access to health for poor communities with

diverse needs. These form the basis of claims for rights embedded in the South African constitution; including freedom from prejudice, so that victims can join others in health agency and the acts of citizenship (Isin, 2008) which CAB members use to challenge negative health and social norms.

7.3.2 Contribution to understanding

These data reveal some of the underlying processes of development which Hickey and Mohan (2005) have argued are a necessary element in understanding the conditions under which transformation may occur in these particular contexts. In doing so, this research contributes to limited evidence on: the social and political aspects of biotechnology initiatives; the invited political spaces wherein communities are engaged; and the political interactions between government, private and civil society arenas. This focus on how health is negotiated, the power relations involved and the potential of health citizenship responds to the theoretical gaps outlined in Chapter One. The research achieves this aim by contributing to the understanding of peoples' life-worlds and the realities of the political channels open to them; through analysis of participation "embedded in places which are contextual, but also interconnected", to provide "a more accountable form of participatory politics which is meaningful and with institutional purchase" (Mohan, 2007, p. 2).

By revealing aspects of those life-worlds, the research has provided evidence of the role of agency in generating new political spaces by those whose acts of citizenship challenge social norms, and those whose 'survivalist' caring work (Chazan, 2008) plays a significant role in supporting communities lacking material resources and in which community members engaged formally in local health initiatives work simultaneously. In doing so, the research contributes to understanding some of the complexities of the lives of people who are at the receiving end of global health policy; a gap identified by Seckinelgin (2008) in his critique of the medicalisation of AIDS.

This analysis of the software of science and technology innovations reveals the impact on communities and, alternatively, the impact of community engagement on science and technology governance agendas (Leach and Scoones, 2006). Understanding the role of PPPs in health governance contributes to the more widespread literature on state-society relations and accountabilities across those arenas. This analysis of community engagement beyond issues of ethical practice in clinical trials contributes to understanding the ways in which meaningful political roles in health governance can be achieved by communities. The limits to those political roles identify the particular difficulties which are specific to some institutional environments and those which are more general.

These data and the theoretical framework respond to calls for attention to participation within such arenas. As Jasanoff (2003, p. 227) suggests, equal benefits cannot be assumed and different kinds of engagement between "experts, decision makers and the public are required; reaching beyond formal mechanisms, to include public knowledge and skills to resolve common problems" during that process. Governance and power intertwined, to encompass both the constraining and enabling aspects of health governance across vertical and horizontal levels, helps to inform policy and practice. This has been an attempt to answer a call for a conception of the citizen as "somebody with a lifecycle, with a history … someone who knows things and has the capacity to make decisions" (Jasanoff, cited in Leach, Scoones and Wynne, 2006, p. 217).

This recognition of the ways that communities operate in their daily lives, as they use their agency in acts of citizenship (Isin, 2008) and in more humble daily caring roles, informs the literature on the socio-economic conditions under which poor people live and illustrated the innovative claims they make to address those inequalities. As explained, others who may not challenge social norms play a role in enacting citizenship in their daily acts of caring for those infected with HIV and dying of AIDS. They may not talk of HIV/ AIDS or TB as they care for others and so may not be recognised as provoking changes in consciousness, but in their caring roles they alleviate the isolation and suffering that people living with HIV or dying with AIDS experience.

These are the unrecognised actions which alleviate the daily impact of the difficult socio-economic conditions in which the majority of South Africans live. The social and political norms which reinforce women's caring roles leave them in vulnerable positions which exacerbate gender inequalities and disparities in health. And, as the number of orphans rises, the burden of care is becoming unsustainable without recognition and state support. However, in celebrating the endurance and ingenuity with which civil society finds ways of dealing with HIV/AIDS and other inequalities, there is a tendency to over-estimate the capacity of poor communities to address those inequalities and under-emphasise the role of the State in its responsibilities to support those activities, as Marais (2005) has pointed out.

Hence, this research provides important evidence of local health innovation, both in its formal and informal capacities, with specific lessons learned about the ways that communities use those formal and informal spaces to play meaningful political roles. At the same time, that information is offered to inform policy which recognises the structural limits to that agency and acknowledges the role of the State in supporting those initiatives.

7.4 POLICY AND PRACTICE IMPLICATIONS

This section discusses the above contributions to knowledge and understanding of claims made by people living in poor communities for valued health needs. It shows how that contribution informs health initiatives involved in HIV prevention and treatment, especially where rates of infection are still rising for vulnerable people. In addition, it benefits community engagement practice outlined below.

7.4.1 Contribution to policy and practice

This research confirms the need to recognise the socio-economic, political and historical contexts in which local health initiatives are situated. It identifies the role of social norms in knowledge and understanding of health problems. At the same time, it highlights the need to recognise the influence of power relationships as they facilitate or inhibit access to

health and health governance. The focus on developing capabilities to function reveals how communities identify valued health needs and use resources available to their advantage in seeking access to health.

The research identifies some of the gaps between the political spaces of global health governance and local health initiatives which hinder shared health governance across those divides. This awareness contributes to understanding what is involved in maintaining the sustainability of PPPs and the local health initiatives which they support. Further, it points to the significant role of the state in health governance and highlights the need for government support of such initiatives. In doing so, it alerts donors to the importance of funding community engagement to facilitate sustainable local health initiatives. At the same time, the research has identified the daily realities in which claims to health access are made and the wider political constraint on those ideals. These are the contexts in which the changing relationships between science and society, with influence passing back and forth between the people being engaged and those who are engaging communities in health governance and delivery.

Data on community engagement in local health initiatives facilitate practice in several ways. They highlight the importance in understanding perceptions of community engagement and the roles and responsibilities of CABs so that mutual goals can be achieved in HIV prevention and treatment, since contexts differ within countries and internationally. Given those distinctive contexts, the data suggest that there is no single 'best model' which facilitates this process. Appropriate innovations arise through collaboration in decision making over how this should be undertaken. This research endorses the calls of practitioners and community members for improved communications between local health initiatives and communities to those ends, identifying particular needs as well as the more general in their communication across local health initiative boundaries.

Communities need regular contact and the kind of recognition which enhances their skills for meaningful involvement in the health governance of communities. This is the distinctive feature of community engagement at its most ideal. It promotes active rather than reactive involvement in local health initiatives, with partners working together to design interventions which respond to those problems and, therefore, will have more purchase than those developed beyond those environs. For example, an intervention which does not take heed of the role of stigma in people's lives will not succeed however excellent the information about HIV/AIDS. In addition, this research endorses practitioner calls for improvements in communications between PPPs and public health systems, so as to avoid duplicating services already strained, and to challenge the unhelpful responses of public health workers to engaged community members as they attempt to engage others in local health initiatives. The waste of limited resources is then curtailed through greater communication between these different health arenas in a more collective approach to health governance.

7.5 LIMITATIONS OF THE STUDY

This section outlines some of the problems arising from data collection relating to access to the immediate clinical research environment. Civil unrest during the first data collection phase caused some disruption due to community members' preoccupation with significant crises in their midst. Other access problems arose due to the dissolution of the Cape Town vaccine CAB. Opportunities for interviews were dependent upon the other priorities of staff and CAB members. Each of those experiences point to the pressures under which staff and CAB members operate. Recognition of these pressures required respect and flexibility in order to acknowledge those difficulties and to meet the requirements of research. These realities provided essential data on both the problems and successes involved in community engagement.

7.5.1 Empirical limitations and strengths

Those realities lent insight into the daily difficulties faced by those involved and the innovative ways which they found to adapt to unforeseen events and other demands on

their time. “Making a plan” prefaced many deliberations over unexpected events. The civil unrest provoked the departure of many ‘foreigners’ from communities for their safety. Plans to visit communities during this exodus period were postponed until subsequent attempts at reconciliation had been made. This tension over the problem of ‘foreigners’ seeped into the research process, where my references to their predicament caused ambivalent responses during the research process and in less formal daily conversations. This ambivalence is an inherent consequence of living in such diverse communities, where conflict over resources and the traces a turbulent history continue to confound ideals of cohesive communities engaged in collaborative health governance.

Difficulties over access to the Cape Town vaccine CAB gave further insight into the impact of another crisis in the failed vaccine trial in 2007. Explanations differed over the reasons for that CAB dissolution and its connection with that crisis, during which time I was not granted access to meetings. Interviews with two of the remaining five CAB members proved to be useful. However, due to the chosen research boundaries, I was unable to interview the CAB members who had withdrawn their support and whose perspectives would have helped to unearth the detail of that event and their explanations for their departure.

Overall, most people working in trial site clinics were very busy. Staff and senior CAB members travel frequently to meetings with primary donors in the USA, to national conferences and other events to promote their work and to further their scientific research. The task of organising interviews, focus groups and the observation of meetings for data collection was instructive. Finding quiet places for interviews was difficult in busy overcrowded clinics. During interviews, phone calls, intrusions and noises from other rooms challenged our concentration. Such problems reinforce the daily experiences of working in such difficult environments. They provide a background to the socio-economic conditions which the majority of respondents experience as they seek access to health. Through this research, other questions have arisen which might be addressed, in

particular, by those more able to reach beyond the chosen research boundaries of this research.

7.6 FUTURE RESEARCH

Future research should include the following. An exploration of local health governance and community engagement needs to focus on: the interfaces between health initiatives and communities; the community members who develop the capabilities to function beyond the local arena into wider spheres of health governance; and longitudinal studies of community engagement to trace patterns of longer term change. In addition, the theoretical framework developed in this thesis will help to explain problems encountered in local health initiatives in terms of health governance and access to health. Each of these suggestions to inform policy and practice are dealt with below.

With regard to interactions between health initiatives and communities, useful data would arise from indigenous researchers best placed for this work, taking an ethnographic approach to elicit responses from those who choose not to represent their communities in local health initiatives; those who withdraw their support; and those who are not able to make choices of this kind. This would provide data on the reasons for those choices, or for the lack of choice, over engagement. A longer term commitment and knowledge of the key languages spoken would allow local researchers to blend into and interact with communities. The data arising from the monitoring and evaluation of such interactions would respond to deficits identified by my respondents and enhance community engagement practice. Longitudinal studies would trace the impact of these interactions between communities and health initiatives over time, to identify the ways in which community engagement is moving beyond its original remit to become a force for longer term development.

There will be value in exploring the biographies and narratives of those who develop the capabilities to do this work, to help to understand their success in engaging communities

and developing links between the invited and claimed spaces where they operate. Research into networks across those political spaces, will inform the civil society literature, to provide answers to questions as to how those political spaces are used and how this facilitates meaningful political agency. The detail of those linkages is of particular importance in developing understanding of the opportunities gained and political constraints involved in exchanging information and skills and in developing communication, with the impact on individual and collective empowerment. More research into the empirical value of concepts such as acts of citizenship will clarify unanswered questions about distinctions between those who perform such acts and others whose grassroots activism has value, but which may not break with habitus to challenge social norms.

Further, empirical work on access to health from a social justice perspective, as used in this research, will contribute to a deeper understanding of: how social norms prevent that access in different contexts; how those norms shift; and how power works to confound the ethical goals in shared health governance. By embedding research into socio-historical and political contexts shows how historical traces influence contemporary events, to broaden understanding of why those goals are confounded and how those problems can be overcome.

7.7 CONCLUSION

This research offers valuable data on how communities respond to local health initiatives as they seek access to health. It recognises the significance of the civil society role in engagement with biotechnology initiatives in resource poor communities. It provides important knowledge on the combined impact of the negative health norms and the politics of HIV/AIDS which increase health inequalities. Research into health and health access requires an understanding of the historical traces influencing contemporary development problems.

The need to ensure knowledge and understanding of HIV/AIDS, and to make closer connections between global policy and local initiatives, will remain whether or not an effective vaccine is discovered. Although patterns of HIV epidemics are not arbitrary, but reflected in prevailing socio-economic conditions and cultures, HIV prevention remains a key element in ongoing efforts for containment. As the epidemics mature, treatment goals will be difficult to meet and the burden of care will increase. Giving poor people access to health *via* scientific knowledge of HIV/AIDS and HIV prevention enhances capabilities to use opportunities for health.

I have argued for locally appropriate health initiatives, which build upon local socio-cultural understandings of HIV/AIDS to reach marginalised people, and which take an holistic approach to such health problems. In response to the research question, communities do play meaningful political roles in some cases. The realities of community engagement within the invited spaces of clinical trial sites reveal a complex picture, where dominant agendas can prevail over community concerns, to reproduce existing patterns of health governance. There are systemic institutional limits to making complaints and to shift the balance of power. Even so, the potential for change is revealed in the ways that engaged communities may challenge those dominant agendas through interrelationships within and across those institutional boundaries.

And so the future development of community engagement and health governance is not clear. This evidence does not suggest that all engaged communities are incorporated into the dominant agenda. A focus on the depoliticising aspects of interventions is important, but does not address the more challenging task of unpicking the nuances and ambiguities involved. Different motives and intentions for involvement in local health initiatives, and subsequent actions, conflict and coalesce at different times and in different ways in different contexts. The political subjectivities of those involved influence the process and outcomes of community engagement so that health governance is reproduced and reconfigured at different times and in different ways.

This research has shown the limits in taking a governance approach which lacks sufficient attention to the points of conflict between those whose commitments to mutual goals are undisputed, but whose priorities can differ due to wider accountabilities. The findings challenge perspectives which take little account of the acts of citizenship and everyday caring which need due recognition for their impact on health and development. In this, knowledge and power are intertwined, with understanding of HIV/AIDS and vaccine science increasing opportunities for negotiating, rather than reacting to, decisions over health strategies. Community level health governance has provided a focus on valued health needs. At the same time, it sheds light on the factors which enhance the potential for local participation and citizenship in health governance during that process.

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APPENDIX I

ETHICAL APPROVAL PROCEDURES

The following detail of five ethical approval applications gives some insight into the political sensitivities involved in South African research. I sought preliminary ethical approval from the Open University via the Human Participants and Materials Ethics Committee (HPMEC), to speak to my contacts in South Africa in 2007, prior to the full application before the two periods of fieldwork in 2008. Useful guidance and adjustments to the protocol for that fieldwork included an additional form with research information for research assistants which was used for the written acceptance of confidentially of data from transcribers.

South African access procedures

Approval for research beyond the immediate clinical trial site arenas was initially sought from SAAVI as the umbrella organisation for activities around vaccine development and community engagement. In particular, I was interested in their Community Involvement Project (CIP), called Masikhulisane (Let's work together). This research required permission from the South African MRC. This lengthy correspondence with SAAVI began in 2006 and continued during a visit to the SAAVI headquarters in Cape Town for an informal discussion with the SAAVI Acting Director in 2007. This contact continued, with sporadic response from SAAVI, until 2008 when my application for research with SAAVI was rejected. The reasons given were that the Masikhulisane project had been over-researched and that internal researchers were preferred. Meanwhile, the Socio-behavioural Research Group, academics based at the University of Stellenbosch, was disbanded following cessation of funding. An MRC based researcher continues with this social science research. This may be due to funding cuts or it may reflect that preference for less critical in-house research.

The rejection of my research protocol must be set into the context of critical governmental reviews of internal SAAVI governance, with subsequent loss of funding and operational

crisis[113]. This occurred amidst increasingly vocal criticism of the close government links with the MRC (Nattrass, 2007) and rising levels of civil society criticism of national AIDS governance. Consequently, my plans for further applications for research with SAAVI were abandoned. At the same time, the significance of the grassroots aspects of community engagement became a more compelling research focus set amidst this turbulent national health governance arena. And, having met trial site researchers and community members, confidence in my ability to do local research increased.

During the latter part of my field work, a request to attend a SAAVI National Forum for CABs was also rejected. The implications appear to be distinctly political, yet interviews and informal discussion suggested a more complex picture, where SAAVI support was valued. The SAAVI position appears to be guided by protection against researchers whose agendas might have a negative impact on the daily process of community engagement and the wider communities. It became clear that those motives are based on South African history and politics.

Trial site access procedures

The South African Human Sciences Research Council (HSRC) advised seeking access to the clinical trial sites from the PIs. Protocol approvals were granted from the relevant RECs from the Universities of Cape Town and Witwatersrand. In Cape Town the CABs were experiencing difficulties, hence their acceptance of my research protocol with my promise of a research report. My application was of interest to the REC which had been considering involving CAB members in their work.

This approval procedure would have been straightforward had the large vaccine trial of late 2007 proceeded as intended, but it failed, in the process drawing the attention of the trial site PI away from my application. It took some time for this procedure to be resumed and so my research was delayed until the following spring. By the time I arrived, the fallout was still being managed. Thus, another unexpected event with serious emotional

[113] These events are introduced in Chapter One and discussed in detail in Chapter Five.

and, in some cases, physical consequences had resulted in new dimension to my research.

The WITS university process during the UK summer of 2008 on my return to the UK involved two approval procedures; one with the university Medical Faculty REC and the other with the trial site team in Soweto. CAB members formed part of that team. No obligations to perform any research tasks were required in this case. However, I offered draft research reports to all participants should they be interested in my broad findings, both as a mark of respect for their research contribution and to check data reliability.

National access procedure

Unexpectedly, approval for national access to interviewees external to the trial sites was the most challenging part of the process. This required submission of a research protocol to the HSRC. Since permission to work with community members and trial site research staff was clearly stated as being sought from the local RECs responsible for trial site research approvals, this request was for access to interviews with approximately ten people including government ministers, academics and NGOs beyond those environs. However, the main focus of the HSRC questions on my protocol related to the trial site community members whom they sought to protect. I was asked to read literature on cultural aspects (Weijer and Emanuel, 2000, 1999; Barsdorf and Wassenaar, 2005; Tomlinson et al. 2006) and to revise my protocol accordingly before given permission to begin. They were concerned about my ability as a non-South African researcher to do research in such socially and culturally diverse contexts with vulnerable people. This application took several resubmissions but, in that process my understanding of socio-cultural issues developed. Guidance helped me to adapt my Soweto trial site research protocol and consent forms in the summer of 2008, before my return to complete the field work.

APPENDIX II

ID number:

INTERVIEW CONSENT FORM

Project title: Community engagement in South African HIV Vaccine Clinical trial sites
Name of researcher: Mary Upton
Institution: The Open University
Contact: Development Policy and Practice Group, The Open University, Milton Keynes, MK7 6AA, UK
Tel: +44 (0)1908 654634
Email: mary.upton@open.ac.uk
SA cell: 0765310720

Description of research project
Hello, I am a researcher from the Open University in the UK and this interview is part of a PhD research project funded by the Open University. My supervisors are Dr. Giles Mohan (http://dpp.open.ac.uk/people/mohan.htm) and Dr. Helen Yanacopulos (http://dpp.open.ac.uk/people/yanacopulos.htm). My aim is to understand how community engagement in HIV vaccine trial site activities works in this community. The purpose of this interview is to help me to understand the work that you do, how this helps to protect communities from HIV infection and how it can promote longer term community health and development. In this way, your expertise and insights will help us to find ways of making community engagement more effective. This will be of benefit to trial site communities in South Africa and in other countries where programmes for community engagement are being developed. In the longer term, it will help to protect people from HIV infection and promote community health and development.

Please understand that **your participation is entirely voluntary.** You are not being forced to take part in this interview. Your choice of whether to participate or not is yours alone. However, I would be grateful if you would like to share your thoughts. If you decide not to take part, you will not be affected in any way. If you agree, we will decide together when and where the interview will take place. The interview will take about 45 minutes, unless you decide that you do not wish to continue. If you do this, there will be no penalties and you will not be prejudiced in any way. If you prefer to use your own language, I will provide research assistance for language translation. If you decide to give your permission, I will record the interview and your words will be transcribed in full. There will be no way that your identity can be linked with the interview transcripts, but I will ask you for permission to explain your role and expertise.

The transcripts will remain confidential and kept separately from the consent forms. They will be stored in secure locations at the University where I am based while I am in South Africa and in my home University in the UK. No-one will have access to the consent forms apart from me. If translation is needed, only the research assistant will have access to those transcripts while working with me. The assistant has agreed in writing to keep the transcripts from anyone else's view. The original recordings and transcripts will be destroyed after three years.

The information will be analysed for this research project and may be used in research publications after that time. I am happy for you to have sight of a draft publication.

If you now decide to agree to this interview, please see the consent agreement details below:

I have been given information about the research project and the way in which my contribution to the project will be used and I agree to participate in this research project. I understand that:

- The nature of my participation is an interview.
- My participation is entirely voluntary and I understand that I can withdraw my consent at any time within the next 12 months. If I decide to withdraw my consent, this will be confirmed in writing and if I ask for any data collected to be destroyed, this request will be honoured.

Please tick as appropriate:

I give my permission for this interview to be digitally recorded.

Signature of participant …… …….. Date …….

I give my permission for the information that I am about to give to be used for research purposes (including research publications and reports) without my name, but showing my expertise.

I give my permission for the information I am about to give to be used for research purposes (including research publications and reports) without my name or my expertise included.

I understand that if I am unsure about anything regarding this research, or my part in it, I can contact Mary Upton at:

SA cell: 0765310720
Email: mary.upton@open.ac.uk
Phone: 0044 (0)1908 654634

If I feel that I have been harmed in any way by participating in this study, or if I wish to speak with someone else about any aspect of my participation, I can contact:

- The Human Sciences Research Council Ethics Line: Free Call 0800 212123
- Dr Giles Mohan, Mary's supervisor, at:

Development Policy and Practice Group
Chambers Building
The Open University
Walton Hall
Milton Keynes MK6 7AA, UK
Email: g.mohan@open.ac.uk

Signature of participant ……..Date ……

Title:……..
Organisation …….

I would like to see a copy of the draft report (please tick)

Signed researcher …… Date
…….

On behalf of The Open University

APPENDIX III

INTERVIEW SCHEDULE

'Community Engagement in South African HIV Vaccine trail sites'

- Semi-structured interviews
- Specific questions will be selected from this list depending on the particular interviewee(s)

Questions on community engagement

- What does community engagement mean to you?
- Who are the important people in community engagement and why?
- What are the key factors for successful community engagement?
- What are the key problems involved in community engagement and how do you try to solve them?
- What are the benefits of being involved in community engagement?
- What do we need to know to make community engagement more effective?
- What do you think the longer term aims of community engagement should be?

Questions on CABs

- What is the role of a Community Advisory Board?
- What are the key problems for CABs how have you tried to solve them?
- What kinds of support do you have in doing this work?
- What are the benefits of being involved in CABs, for the community and for you personally?
- How would you like to see the/your CAB developing and why?
- What do we need to know to make CABs more effective?
- What do you think the long term aims of CABs should be?

Questions on HIV/AIDS and vaccine science

- What types of information on HIV/AIDS and vaccine science are available for trial site communities?
- How do people engage with this information?
- Are there any problems in using this information?
- If there are, in what ways do you think they can be solved?