TOO POOR TO BE TREATED: BOTTOM-UP ADVOCACY BY HIV+ ACTIVISTS IN KHAYELITSHA AND LUSIKISIKI, SOUTH AFRICA

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Date: 16 February 2021

DECLARATION

I, Vuyiseka Dubula- Majola, declare that

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ii. This thesis has not been submitted for any degree or examination at any other university.

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[redacted] 15 **February 2021**

DEDICATION

This thesis is dedicated to all the fallen heroines and heroes who died fighting for access to AIDs medication in South Africa. In addition, to all the TAC and the NAPWA members who have contributed their insights and experience during my fieldwork.

To my family who provided tremendous assistance in the course of this study.

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KAFUSHANE NGOCWANINGO

Ukufezekiswa kwentuthuko ngokuvamileyo kuncike kwisithembiso sokuthi labo abathintekile bangabamba iqhaza ngendlela enohlonze nephusile ezinqubweni zokwenziwa kwezinqubomgomo kanye nasekuthathweni kwezinqumo. Kodwa-ke, kumashumi-nyaka edlule bekukuncane kakhulu noma-ke nje kungekho neze ukuvumelana phakathi kwezifundiswa mayelana nokuthi zisho ukuthini lezi zithembiso zenkululeko futhi yini inhloso yazo. Ngakho-ke, lolu cwaningo lufaka isandla ezimpendulweni zethiyori kanye nalezo eziphathekayo maqondana nokubamba iqhaza kweningi labantu ngaphansi kwesimo-ngqikithi esinezinhlelo zamandla ezibumba isimo okungenzeka ngaphansi kwaso intuthuko. Lolu cwaningo lusebenzise izindlela-kusebenza ezigxile ekutholeni izincazelo kanye nokuqonda okujulile (*qualitative approaches*) ngokusebenzisa izinhlolo-mbono ezijulile kanye nendlela-kucwaninga yokubukela nokuqaphela lokho okwenziwa ngababambiqhaza bocwaningo, lapho abahlinzeki bolwazi abangongoti bephendula umbuzo ongumongo wocwaningo: ukubukisisa nokuhlolisisa ngokujulile nhlangothi zonke ukuguquka okwenzekile kumasu namaqhinga ezishoshovu emkhankasweni wokweseka impi yokulwisana nengculazi kulandela ukuqaliswa kwezinqubo zokukhishwa nokusatshalaliswa kwemishanguzo yokudambisa ingculazi (I-ART) okuwuguquko oluqondene nabantu kanye nezinhlangano ezithintekile ngenxa yesandulela-ngculazi nengculazi eKhayelitsha kanye naseLusikisiki, ngaphansi kwesimo-ngqikithi sikazwelonke lapho ngowezi-2003 kwaba khona uguquko-simo lwamandla.

Lolu cwaningo lwathola ukuthi ukubamba iqhaza okuholwa ngumbuso kunabo ubundlovukayiphikiswa obuthile. Ukube ukuhlaziya kwezifundiswa ubushoshovu obunamandla bokugqugquzela impi yokulwisana nengculazi kwafinyelela esiphelweni ngowezi-2003, lokho bekuyosho ukungabi neze nomqondo ophusile. Kulelo qophelo, izishoshovu eKhayelitsha kanye naseLusikisiki esikhundleni sokuhoxa nokuhlehlela emuva zafaka ingcindezi ngokuhlanganyela, ngenhloso yokuphoqelela uhulumeni waseNingizmu Afrika ukuthi ahlinzeke ngemishanguzo yokudambisa ingculazi ukuze kusindiswe izimpilo zabantu. Ngesikhathi sokuqaliswa kwenqubomgomo, kungenzeka inciphe imibhikisho futhi kungenzeka eminye ithi ukumiswa kancane, kodwa-ke nakuba kunjalo lokho akusho neze ukuthi ngalokho izishoshovu kumele zihoxe noma zihlehlele emuva. Ukuhlinzekwa kwemishanguzo kwenzeka emazingeni ohulumeni basekhaya futhi lokho kwadinga ukuthi izishoshovu zivuselele kabusha izinhlaka zokubamba iqhaza ezabe sezifadalele ngokusebenzisa ukuqwashiswa komphakathi wonkana ukuze kuqinisekiswe ukutholakala kosizo lwezempilo oluhlinzekwa futhi lulawulwe ngokuhambisana

nezifiso zesiguli futhi sihlinzekwe ngolwazi ukuze sikwazi ukuqikelela impilo yaso. Ocwaningweni kuvele izinhlobo ezintsha zemikhakha yokubamba iqhaza ngokwehlukana kwayo kanye nezimo ezenza ukuthi zenzeke lezi zinhlobo zokuzibandakanya. Lokhu kwabandakanya nezinhlobo ezihlukile zokubamba iqhaza ngenkathi kuqaliswa ukusebenza kwenqubomgomo okuyinto ebonisa isibopho nokuzimisela kwezishoshovu ekuphoqeleleni umbuso ukuthi uhlinzeke ngezidingongqangi futhi lokhu kuyinto engaba nomthelela ekuqhubekeleni phambili nokungashabalali kwemibutho yezishoshovu kusuka manje kuya phambili. Izishoshovu zaguqula amasu namaqhinga azo kusuka ekuxhumaneni kwazo nombuso okujwayelekile lapho bezibonisa ulaka nethukuthelo yazo zaqoka ukusebenzisa indlela-kusebenza yamasu namaqhinga emkhakha-mbili ukuze lokho kuvumele ukuxhumana nombuso okuxubile okwenzeka emazingeni ahlukahlukene. Izishoshovu zenza imitholampilo yezempilo yaba yizizinda zokuphikisa nokubhikishela ukufakwa ngenkani kwezidingo eziqinile zezimvume-kugunyazwa kwemishanguzo yokudambisa ingculazi ezingatholakali neze kalula, ukuchithwa kwamandla ombuso agxile ezinqubweni eziyinkimbinkimbi futhi ezibambezelayo ekuqalisweni kokusebenza kwenqubomgomo ngokubeka imikhawulo nokulawula ukuhlinzekwa kwezidingongqangi. Izishoshovu zaqinisekisa futhi ukusimama nokuqhubekela phambili kokuxhumana kwazo nabasebenzi bakahulumeni ezifundazweni ngokusebenzisa abameli nomthetho kanye nemibhikisho yomphakathi wonkana njengezinyathelo-ngqo zokuphoqelela umbuso ukuthi uhlinzeke ngohlelo lokukhishwa kwemishanguzo yokudambisa ingculazi. Lokhu kuyabonisa ukuthi izinyathelo ezithathwa ngokuhlanganyela yizishoshovu emazingeni aphansi omphakathi zingawuphoqelela umbuso ukuthi uyivume induku yengcindezi evela emphakathini jikelele wenze lokho okufunwa ngumphakathi futhi kusenjalo ngakolunye uhlangothi nazo izishoshovu zibe ziyivuma eyokuhluleka nokungaphumeleli kweminye imizabalazo yazo njengalokhu kwabonakala ngokuqhubeka kwemikhawulo ebekiwe yokulawulwa kohlelo lokukhishwa kwemishanguzo. Imiphumela etholakale ocwaningweni ibonisa ukuthi imibutho yezishoshovu kumele iguqule amasu namaqhinga ayo ukuze kuvunyelwe ukuguqulwa kwezindlela-kusebenza ngokuthi kusetshenziswe amathuba avela ngenxa yokungqubuzana nobunhlakanhlaka obukhona ezinhlakeni zombuso ezihlukahlukene emazingeni ezifundazwe ukuze zikwazi ukufezekisa izinjongo zazo zokumela nokulwela izimfuno nezidingo zomphakathi. Ucwaningo luveza umbono-siphetho othi kunemikhawulo ecace bha enciphisa futhi ivimbele ukubamba iqhaza kwabantu ngoba phela izinsiza zemibutho yezishoshovu zingaba nomthelela emandleni nekhono lezishoshovu lokuqhubeka nokulwa kanye nokuzabalaza. Okuyinto ebonisayo ukuthi ukubamba iqhaza kuyinto eyinkimbinkimbi futhi okungeke kwathiwa noma kanjani izoholela ekufadalaleni kwemibutho yezishoshovu.

ABSTRACT

The attainment of development is often contingent on the promise that those affected can meaningfully participate in policy-making processes and decision making. However, over the past decades, there has been limited to no scholarly consensus about the meaning and purpose of these promises of emancipation. Therefore, this study contributes to theoretical and practical responses to popular participation within systems of power that shapes e condition through development occur. This study employed qualitative approaches using in-depth interviews with and participatory observation of key informants to answer the central research question: to critically examine the shift in AIDS activist advocacy tactics after the antiretroviral therapy (ARTT) rollout by people and social movements affected by HIV/AIDS in Khayelitsha and Lusikisiki, within a national context of dramatic changes in the balance of forces in 2003.

The study found that state-led participation has elements of tyranny. If scholarship analysis of popular AIDS activism ended in 2003, that would have been short-sighted. At that juncture, the activists in Khayelitsha and Lusikisiki, instead of retreating, stirred collective pressure to compel the South African government to deliver ART to save lives. During policy implementation, protest action may diminish during implementation of policy and some may fall in abeyance, which does not necessarily necessitate retreat. The ART rollout takes place at local levels, which then meant that activists had to revive dormant participatory structures through popular agency to democratised healthcare. Newer typologies of participation and the conditions that facilitated these forms of engagement emerged. These included the variants in participation during policy implementation, demonstrating activists' undertaking in forcing the state to deliver services, which had implications for the survival of their movements going forward. Activists shifted their tactics from traditional antagonistic engagements with the state to the use of a dual-tactical approach to allow for heterogeneous engagement with the state at various levels. Activists made health clinics sites of contestation and protesting against the imposition of unattainable ART accreditation, rejecting bureaucratic state power in policy implementation by rationing service delivery. Activists further sustained their engagement with provincial public officials by combining lawyering and popular protests, as direct action forced the state to release the ART rollout plan. This shows that grassroots activists' collective action can force the state to concede to popular pressure while losing other battles, as shown by the rationing of ART that continued. The findings suggest that movements ought to shift tactics, allowing for modifications in approaches and taking advantage of various

state ruptures at provincial levels to achieve their social movement goals. The study concluded that there are glaring limits to participation because movement resources can influence the ongoing ability of activists to continue fighting. That is, the practice of participation is complex and does not inherently amount to movement decline.

TABLE OF CONTENTS

ABBREVIATIONS

ACT UP	AIDS Coalition To Unleash Power
ABM	Abahlali baseMjondolo
AC	AIDS Consortium
AEC	Anti-Eviction Campaign
AIDS	Acquired immune deficiency syndrome
APF	Anti-Privatisation Forum
ALP	AIDS Law Project
ANC	African National Congress
APN	Asia Pacific Network of People Living with HIV
ART	Antiretroviral Treatment
ARVs	AntiRetroviral
AZT	Azidothymidine
BONELA	Botswana Network of Ethics, Law and HIV/AIDS
CAPRISA	Centre for AIDS Programme of Research in South Africa
CBO	Community Based Organisation
CIPC	Companies and Intellectual Property Commission
CMT	Community Media Trust
CCF	Concerned Citizens Forum
COSATU	Congress of South African Trade Unions
DDI	Didanosine
D4T	Stavudine
DAC	District AIDS Council
FDC	Fixed Dose Combination
GEAR	Growth Employment and Redistribution

GIPA	Greater Involvement of People Living with HIV/AIDS
GDP	Gross Domestic Product
GNP+	Global Network of People Living with HIV
GSP	Generalised System of Preferences
HIV	Human Immunodeficiency Virus Infection
HIVNET	HIV Network of Prevention Trials
IFPMA	International Federation of Pharmaceutical Manufacturers Association
IMSA	Innovative Medicines South Africa
IP	Intellectual Property
IPASA	Innovative Pharmaceutical Association of South Africa
IPR	Intellectual Property Rights
3TC	Lamivudine
LPM	Landless Peoples Movement
NAP	National AIDS Plan
NAPWA	National Alliance of People with AIDS
NDoH	National Department of Health
NEDLAC	National Economic Development and Labour Council
NVP	Nevirapine
NGOs	Non-Governmental Organisations
MCC	Medicines Control Council
MSF	Medicins Sans Frontières (Doctors without Borders)
MSM	Men who have Sex with Men

PAC	Provincial AIDS Council
PAIA	Promotion of Access to Information Act
PAISA	Pharmaceutical Industry Association of South Africa
PATAM	Pan African Treatment Access Movement
PEPFAR	Presidential Emergency Plan for AIDS Relief
PMA	Pharmaceutical Manufacturers Association
PhRMA	Pharmaceutical Research and Manufacturers of America
PFMA	Public Finance Management Act
PLHIV	People Living with HIV
PMA	Pharmaceutical Manufacturers Association
PMTCT	Prevention of Mother to Child HIV Transmission
RDP	Reconstruction and Development Planning
SA	South Africa
SANAC	South African National AIDS Council
SADC	Southern African Development Community
SANAC	South African National AIDS Council
SECTION27	Section27
SMAP	Social Movement Action Plan
TAC	Treatment Action Campaign
TL	Treatment Literacy
TLP	Treatment Literacy practitioners
TRIPS	Trade-Related Aspects of Intellectual Property Rights
UNAIDS	Joint United Nations Programme on HIV/AIDS

US	United States
USD	United States Dollar
USTR	United States Trade Representative
WHO	World Health Organisation
WTO	World Trade Organisation

CHAPTER ONE: INTRODUCTION

1. INTRODUCTION

The post-2003 period is characterised by AIDS activists' rebellion against the multinational pharmaceutical industry and the unilateral South African government's AIDS policy decisions. At the peak of their conflict, President Mbeki's' AIDS denialism fueled disconnections between state policy and AIDS activists. The state eventually conceded after a long period of adversarial, theatrical activist protest actions. AIDS activists claimed this policy victory; however, was not complemented with governments' willingness to smooth service delivery. Literature on participation suggests that affected poor people are often able to affect policy outcomes through engagement that is part of a wider radical political project in which activists secure citizenship rights for marginalised groups and engage with development as an underlying process of social change (Hickey & Giles, 2005). Attaining development is often dependent on the prominence of people's participation. Participation can be achieved if marginalised people meaningfully participate in policy-making processes and decision-making (Robins & von Lieres, 2008). The promise of emancipation through participation over the past decades has limited scholarly consensus about its meanings and purpose.

For activists, the primary measure of successful policy change should be whether they maintain collective power and agency as a force for effective implementation of new policy. However, the evolution of the TAC's advocacy strategies had been untested by scholars' post–ART policy implementation at a local level during the period that required constant vigilance. Holding government accountable for delivering services as promised is, however, contentious. It requires shifts in activists' advocacy strategies at various levels of government. The period of policy implementation provides insights into a social movement's evolution after a successful policy campaign.

2. RATIONALE

The rationale of the thesis is threefold. The first aim is to develop empirical perspectives on bottom-up participation in policy implementation in Khayelitsha and Lusikisiki in relation to the HIV/AIDS policy of the South African government.

The second is to explore typologies of participation from the bottom up, and the third aim is to understand movement evolution after its success. Both study sites reveal the impact of poor socio-economic conditions on the quality of life. It underscores the need for pro-poor development policy that addresses the needs of poor people, such as access to quality healthcare, social assistance, employment, housing, sanitation, water and electricity. Additionally, they both offer unique urban and rural perspectives, which contribute to the understanding of bottom-up policy advocacy and participation. Khayelitsha and Lusikisiki are also both important sites of AIDS treatment research and innovative collaborations between activists, communities, scientists and health professionals. The Lusikisiki ART programme was an expression of Mandela's political defiance of Mbeki's denialism. Therefore, a range of policy actors from the state, including social movements such as the TAC and the National Association of People Living with HIV/AIDS (NAPWA), health nongovernmental organizations such as Medicines Sans Frontiers (MSF), the SECTION27 (formerly AIDS Law Project), and leading politicians came together to engage around ART implementation in these sites. This thesis assesses the political changes in the balance of forces that occurred in South Africa, which led to AIDS treatment access breakthroughs (as well as policy implementation opportunities and challenges). Although the TAC did not have the same level of visibility and publicity during its participation in policy implementation as before the constitutional challenge, it nonetheless did continue its vigorously advocacy for the lives of poor people living with HIV through its new focus on effective ART implementation.

By studying the process of activists' ongoing participation after their initial success, we learn about movement evolution. The experience of AIDS activism in Khayelitsha and Lusikisiki provides important empirical insights into typologies of participation and movement evolutions. Scholars seem to suggest that movements can only undergo decline and institutionalisation after their initial success (della Porta and Diani, 2006), but a different possible trajectory can be discerned in the story of Khayelitsha and Lusikisiki.

1.2 RESEARCH PROBLEM AND KEY QUESTIONS

This research explores the ways in which AIDS activists had to adjust their advocacy strategies at the grassroots level to monitor government actions while it implemented the ART plan. These modifications in the strategies employed by activists included balancing movement actions and pressure directed at monitoring provincial governments as the primary locus for ART

implementation, while at the same time keeping the national government accountable. There were momentous engagements, both of an adversarial and collaborative nature, between AIDS activists and the South African government, during the ART rollout. These shifts in the advocacy strategies of activists after 2003 reveal new typologies of engagement and social movement evolution. The weaknesses of institutional spaces for participation at local levels gave rise to the movement and led to the formation of new participatory pathways in policymaking. Thus, the research hopes to contribute to the growing body of knowledge about participation within the realm of development studies. The bottom-up participation by AIDS activists in the context of the South African history of the AIDS conflict helps us to understand the nature of participation praxis from below.

To this end, the research pursues the following questions:

a) To critically examine the shift in AIDS activist advocacy tactics following the rollout of ARVs by people and social movements affected by HIV/AIDS in Khayelitsha and Lusikisiki, within a national context of dramatic changes in the balance of forces between 2004 and 2014, which led to AIDS treatment access breakthroughs. How did activists in Khayelitsha and Lusikisiki adjust their strategies and tactics following provision of ARVs in the public healthcare sector?

b) To examine new typologies of participation and engagement among activists during this time. What typologies of participation emerged during this period? What conditions shaped these typologies? How did the relationships between AIDS activists and policymakers shift?

c) To examine the evolution paths of social movements with reference to the TAC in light of these shifts. How did activists in Khayelitsha and Lusikisiki understand their participation between 2004 and 2014? What mechanisms or processes were present to facilitate engagements between communities/people living with AIDS and (local) government during this period? What impact did shifts in tactics and transforming participation typologies have on the TAC? How did activists in Khayelitsha and Lusikisiki understand the transformation? What are the implications of shifts in forms of participation for the survival of social movements? How do these shifts affect

bottom-up policy-making going forward in terms of democratising healthcare in South Africa?

1.3 THE TREATMENT ACTION CAMPAIGN

The Treatment Action Campaign (TAC) is a social movement that operates within the broader post- 1994 politics in South Africa. Goffman (1975), Snow (1986), and Benford (2000) define movement frames as active, dynamic, and evolving processes of meaning-making involving agency and contention. The TAC birth in 1998 coincided with the period where the impact of capitalist forces deepened. Particularly threats to basic service for the poor are adversely affected such as health, housing, water or electricity by government neoliberal policy positions. At the same time, the capitalists' power of multinational pharmaceutical companies consolidated its monopolies. Since the TACs formation in December 1998, it openly contests the affordability and accessibility of AIDS treatment for poor people living with HIV in South Africa. The TAC utilises a myriad of strategies such as public demonstrations, strategic litigation, social mobilisation and popular education to confront both the pharmaceutical industry and government, and innovatively articulate its demands within a human rights framework. The activists use of constitutionalism as a bridge to negotiate and confront the state policies. Framing the TAC demands within the human rights discourse was a strategic choice of the movement strategy while noting that legalism has its own limitations. The rights framework is a central theme of scholarship on new social movements.

For the TAC, the use of a human rights framework is a fundamental part of the movement's participation in policy processes. The TAC's human rights frame is built on the view that denying poor people lifesaving medicines is a contravention of both the South African constitution and universal human rights treaties guaranteeing rights to health, dignity, and life. As argued earlier, human rights and IPRs are fundamentally in conflict with each other (Hestermeyer, 2014). The TRIPS agreement represents the first conflict, and the second arises from the neglect of poor people's rights, leading to the antithetical relationship between TRIPS and human rights (Helfer, 2003). As a direct result of the TAC, the neoliberal capitalist state and the market faced public anger, as activists of the movement began to shift public discourse by framing its grievance around human rights discourse and biomedical discourse. The human

rights discourse shifted the narrative about access to ART as a human right, rather than a privilege or property right.

Framing AIDS treatment as a right place a constitutional obligation for the state and limits to private interests. The South African constitution section 27 (1996) says, "Everyone has the right to have access to health care services." Thus, the government has a constitutional duty to progressively improve healthcare access for everyone. The utilisation of South Africa's highest courts to adjudicate this claim was one of the TAC's strategies. Building on existing organisational foundations such as those of the gay rights movement, the TAC not only began to push for the rights of people living with AIDS, but also to engage the medical and political establishments in search of allies (Johnson, 2006). The AIDS activists' rights-based alignment discourse, which they use to frame their grievances and claims and to mould a collective identity, helps TAC to catalyse their struggles and to secure elite support and access to the state (Cousins, Dugard, Langford, & Madlingozi, 2013; Heywood, 2009) . The TAC is regarded as the global model for social movements using human rights frames to realise the promise of democratic citizenship, and the expected criticism from various scholars from the left is forthcoming. However, scholars such as Bond accuse activists of wasting time legitimising the constitution in courts for AIDS treatment knowing its futile outcome due to property rights (Patrick Bond, 2014b). He posits that the only progressive change is through explicit direct action. Similarly, Neocosmos (2009) agrees that rights-based movement demands are elitist and lead to passive movement ranks, proffessionalisation of NGOs, and demobilisation of movements and disempowerment of the masses. Further, Stahler-Sholk also argues against rights framing due to threats of co-optation and membership demobilisation if institutional participation is a means to an end (Stahler-Sholk, 2007).

On the other side, scholars such as Goldstone argue that it is given that institutional participation will lead to demobilisation, co-optation and political passivity. As alluded to in the case of Latin American movements, they fluidly move between institutional and non-institutional spaces to do their politics (Goldstone, 2004). The Neocosmos construction of a binary antagonism between state-centric movements and those that are not, by painting the non-state-centric movements as independent, emancipatory and "revolutionary" political approaches (Neocosmos ,2009) is challenged by Goldstone. In fact, the flaunting of confrontational politics through collective action outside the state machinery as the only progressive political strategy is proven otherwise by the TAC example. On the other hand, yes, the presence of government

power in the midst of civil society is inherently destructive, elitist and associated with political agendas and patronage. Neocosmos illustrates this point through the example of Abahlali baseMjondolo (AbM) the shack-dwellers movement (as working outside the state) and the TAC state -centric. He claims that the TAC is not anti-government and not radical enough, while painting the AbM as "revolutionary" and anti-state, with a flat organisational structure and less reliance on donor money. Gibson (2006) ; Neocosmos (2009) ; Johnson (2006) 's argument that the TAC's "over-reliance" on human rights discourse — together with its uncritical adoption of orthodox biomedical science discourse — had detrimental indirect and symbolic impacts on the movement and its members.

Given the receptive discursive and institutional context outlined in Chapter Two below and with regard to the goals of TAC, the AIDS activists deploy extra-institutional protest tactics including civil disobedience and sit-ins, as well as public demonstrations such as pickets and marches, to complement the institutional tactics such as parliamentary submissions, lobbying, media campaigns and litigation. The example of TAC's winning campaign to force government to provide ART to millions of South Africans is an example of how a myriad of strategies including litigation can yield movement success. The use of litigation strategy is not the panacea for all social justice problems but rather offers discursive and structural opportunities and tools to advocate for justice. The relationship between state practices and the praxis of social movements is dialectical and fluid; thus, the TAC's activist struggles take place across these institutional and non-institutional terrains (Steyn, 2012). The TAC's human rights frame resonates at all levels, in part because the TAC applies a combination of advocacy strategies including popular education, social mobilisation, and public protests, pursuing strategic litigation when exhaustion arising from protests sets in. The TAC's human rights frame and the myriad of advocacy strategies supporting it resonate with people living with HIV to interpret and express the idea of ART as a human right. However, litigation requires a few activists in the movement able to make demands within legal language (NeJaime, 2013). Thus, litigation, as a collective action strategy of the movement, potentially limited popular participation, because it required lawyers to represent activists' demands in court. However, since litigation utilised in combination with other strategies had potential to minimise, though not eradicate, elitism emerging within the movement.

This study shows the contrary to the above claims. After the 2003, policy gains the TAC used less courts but still managed to successfully contest the implementation of the ART rollout from a highly mobilised grassroots. Although the initial TAC founding members are from middle-class background "had working-class roots , the later leaders came from poor working class and mainly black African women members and formed majority movement card carriers," (Klugman, 2016). These activists mobilised the discourses of human rights and biomedicine to mobilise a grassroots constituency, to establish cross-class alliances, and ultimately to set up a social movement (Friedman & Mottiar, 2005). Therefore, it was not over-reliance on rights strategies that transformed the TAC into a professionalised quasi-NGO that has always been its character.

The TAC's biomedical discourse did not demobilise the movement. As demonstrated in Chapter Five, tinstead of demobilisation, the TAC organised in rural villages and townships after the ART policy victory with mass redistribution of the power of scientific knowledge from the elite to poor people living with HIV. In addition, central to the activists' success is the use of tactics such as branches as main community organising nuclei, and this is still the case. Furthermore, the backbone of the TAC's success lies in its popular education through a programme they call the treatment literacy programme (TLP). The TLP educated communities about the science of HIV/AIDS and its treatment as well as patients' rights to treatment. With this programme, TAC activists were able to demonstrate the efficacy of ARV treatment, counter stigma and mobilise grassroots support. As a result, the TAC deployed further advocacy strategies, such as popular rights education, social mobilisation, media and litigation. These approaches were combined in execution to contest drug company IP rules and, more broadly, to mobilise society to hold the state to account. For example, the media is a critical ally of the TAC, especially as the movement's rights discourse resonated with people making similar claims in other sectors. Social movements such as the TAC as spaces for popular participation are able to lead to an emancipatory praxis. The TAC's ART policy victory resulted in a change of the government's policy and the rollout of ART. In other words, the movement was able to successfully employ advocacy strategies to change the government's policy position, and to pressure pharmaceutical companies into dropping their prices.

Emancipation requires radical social revolution by poor people who understand their reality and are ready to act practically for transforming their socio-economic and political conditions. As shown in Chapter Two, the first battles were against the pharmaceutical companies, where

it was necessary to organize the revolutionary power of the poor to achieve social, economic and political change. There is outright public rejection of the false ideology illusion of capitalists' greed should be the norm. The AIDS treatment battle is fought and ultimately won (as discussed in detail in Chapter Three). Activists thereafter faced new challenges, due to the South African government's refusal to provide ART to poor people. Despite the government having fought alongside activists against Big Pharma in the 1997 Medicines Act lawsuit, state resistance to providing ART was decisive, as former President Thabo Mbeki maintained a stance often criticised as dogmatic AIDS denialism. Activists stirred their collective pressure to compel the South African government into delivering ART through the public sector health facilities for the benefit of poor people living with HIV and AIDS. Thus, the second part of this thesis describes the TAC's engagement with the South African state, and its advocacy strategies for ensuring the development of HIV treatment policy and delivery. It also recounts the increasing confrontation between the TAC and the national government around ART policy and provision, and it reflects on the process to develop an ART policy. There is a consensus that popular participation of poor people in policy development is fundamental in the democratic and constitutional building project of South Africa, more especially in the neoliberal context. This is because the authoritarian and capital interests tend to intentionally exclude the majority of poor people in policy decision-making. Thus, demands for popular participation have become critical in democratising the policy process that affects the populace. Likewise, Scholars (Mohan & Stokke, 2000) argue that participation in policy processes ought to be emancipatory; in other words, it should empower and facilitate people's capacity for direct influence in the policy process from the bottom up, thus challenging top-down development planning interventions. Participation connects different groups with various interests within the larger political, economic and global development context.

This thesis explores participation and social movement agency in the HIV/AIDS policy-making process in South Africa since the ART era. Most scholarly writings on participation and development are concerned with the democratic deficits and pitfalls of top-down development planning interventions(Cooke & Kothari, 2001; Cornwall, 2004). They examine the nature and degrees of bottom-up approaches to participation, as means for citizens to shape and influence policy from below. Many governments, especially in the developing world, are acknowledging the importance of citizen participation in development; for example, in South Africa, Section 152 of the constitution provides for the participation of communities and community organisations in the affairs of local government.

This thesis explores HIV/AIDS policy processes in South Africa through the lenses of participation and social movements. The use of the term participation is contested. This thesis approaches participation as praxis, which calls for analysing participation within a political and policy context of levels, forms, and spaces. The reality of participation is contrary to the acclaimed ideals of "democratic practices" (Cornwall, 2004). Thus, this study adopts a critical perspective on the praxis of participation in AIDS policy development. It questions the typologies of participation from below; using examples drawn from two case study sites after government approved the ART policy in 2003. A case study in this instance is for intensive study of a single unit of analysis for understanding a larger class of (similar) nature (Gerring, 2004).

Scholarly analysis on AIDS politics and social movements abounds. (Epstein, 1995) uses a political economic method to explore the nature of AIDS in Uganda and South Africa. In Fassin and Schneider (2002) analysis of the AIDS epidemic, before 1994, the failure to curb the epidemic is attributed to the government's aggressive pursuance of spatial, socio-economic and cultural segregation through its apartheid policy. (Fourie, 2006) political analysis of the management of the AIDS epidemic in South Africa, during the period 1982 to 2005, argues that public policy-making had gaps especially in the public sector, resulting in a number of mishandlings by the ANC-led government, which highlights critical lessons for policy-makers and other public health managers. Moreover, the post-apartheid South African political context shaped the development of the AIDS Policy. It engendered difficulties in implementation and in developing a comprehensive response to AIDS in a country undergoing restructuring at every level. (Schneider & Stein, 2001a) contend that the notion of "inadequate political will" explained the lack of progress and "quick-fix" actions. Further, (Schneider ,2002) argues that the AIDS world is partly defined by the emergence of a fatal disease that crosses many conventional social boundaries, involving a variety of actors and spawning local and global social movements . As argued by Butler (2005) there were two policy remedies, namely mobilisation of a biomedical paradigm, which focuses on societal mobilisation, political leadership and ART; and a nationalist ameliorative paradigm focusing on poverty, palliative care, traditional medicine, and nutrition. He further explores how public health sector institutions constrains access to biomedical interventions, while the ANC government puts up with protagonists of each policy paradigm (Butler ,2005). On the other hand, Schneider (2002)maintains that despite attempts to centralise decision-making on AIDS in the presidency, government itself is by no means united behind the president's positions on AIDS.

A degree of bureaucratic and political independence is evident from the increasing amount of resources being allocated for HIV and the decision by certain provincial governments to defy national policies on the use of antiretroviral drugs. Contestation within the state, although less visible, has thus significantly strengthened the position of non-governmental actors. AIDS policy under President Mbeki and his Health Minister, Manto Tshabalala Msimang, was characterized by hostility towards the use of ART in the public sector (Nattrass, 2008). In addition, the government's neoliberal macroeconomic policy: Growth, Employment and Redistribution (GEAR), had a pernicious effect on public social spending, including on HIV/AIDS (Walsh et al., 2008). The resource question is key to the ART rollout. (Nattrass & Geffen, 2003) argue that a full-scale ART rollout requires a significant fiscal commitment, and the extent and pace of the ART rollout would then be determined by operational issues, such as clinic readiness, rather than a priori financial considerations (Nattrass, 2004). Friedman & Mottiar (2005) study of the TAC underscores the role of social movements in policymaking. The advocacy strategies of the movement have implications for the ways in which democracy can yield greater social and economic equity. (Steinberg, 2011) explores stigma around HIV/AIDS and why people refuse to take ART through the story of Sizwe's fear, anxiety and shame towards the disease, the medicines and the cause of the illness, in the rural Eastern Cape. Activists' construction of a new, positive, HIV-positive identity and new meanings of the citizen-activist emerging from "near-death" experiences of AIDS, profound stigma and "social death" to create new forms of social activism enables AIDS activist commitment and grassroots mobilisation (Robins, 2006; 2005; 2010; 2004; Steven Robins & von Lieres, 2008). Powerful social movements can topple rule by international commercial interests and change government policy.

The emergence of the TAC and its success in leveraging "networks of influence" (which also included scientists, bureaucrats and politicians) contributed to the formation of a moral consensus on treatment access and the construction of an inclusive coalition that pursued policy change (Grebe, 2011). The TAC gave moral legitimacy to the international movement, which enabled it to effectively create new models of global health governance. The TAC had moral and credible leadership, that combined with their success in human rights–based litigation became effective in popularising the AIDS-related science (Mbali, 2013a).

Nevertheless, despite these advances in treatment and the TAC's drive to prevent new HIV infections, the problems are still vast, to the extent that many people still lack access to treatment, mainly because of the government's slow policy implementation (Padarath, and Friedman, 2008). Coalescing human rights advocacy with litigation and legal argument about the state's duties towards health does bring about tangible improvements (Heywood, 2005; 2004; 2009). The contribution of social movements, such as the TAC, assists in widening inclusive political spaces beyond policy-making (Jones, 2005). Active citizenship — political agency — is not necessarily conducive to a politics of emancipation; it merely enables the possibility of envisioning alternative modes of thought and political "possibilities" (Michael Neocosmos, 2009). (Tom Lodge, 2015) argues that the AIDS activists appear victorious in strengthening the South African government's HIV policy response. This stimulates participation between civil society and government in policy implementation, signifying that the state gained public support for its rollout over time. Thus, the political protests of activists entrenched political reforms and enhanced government constitutional checks.

1.4 SCHOLAR-ACTIVIST POSITION

This thesis is born out of my concern with social injustice, which emanate from my very own personal and political experiences of participation in AIDS policy processes in South Africa. I approach this research with the conviction that the issues I am investigating exist in a world where my assumptions and those of study participants can interdependently co-exist (Greene, 2014). My journey began with an HIV-positive diagnosis at the age of 22 years, during a period when ART was not available. Participation in the AIDS movement gave me a sense of citizen power in post-apartheid South Africa, without which AIDS treatment for ordinary people, like me, would not have been possible. I joined the TAC in 2001, during the social mobilisation of its campaign to prevent mother-to-child HIV transmission. Participation in the TAC as the movement of people living with HIV/AIDS contesting the power of multinational companies and the state was not an academic exercise. It was a matter of my life or death. Being told that you have HIV, while you are too poor to buy your life, was a death sentence. Later, in the process of the struggle, I came to believe that AIDS treatment access in my lifetime was a dream, because of the extent of government resistance. I have lived through watching hundreds of comrades die before my eyes. Most of us continued to fight for the future generations, but death lived with us. In the midst of those deaths, we mourned, organised and mobilised.

My first public event was the funeral of Sibongile Mazeka, a child who died of AIDS because her mother did not have access to a drug to prevent mother-to-child transmission. In those days, attending funerals was the norm, and we used them as political spaces to organise and mobilise communities. I knew very little about the politics of medicines and health, but through Treatment Literacy (a popular and rights education programme), we empowered ourselves with knowledge and used that power against the system. I led the TAC's Western Cape popular and rights education programme from 2002 to 2006. These years characterized the confrontational period when the state was dragging its feet in implementing the ART plan. I then rose through the ranks of the movement to the highest leadership position as its General Secretary, from 2007 to 2013. As one of the black African HIV-positive women activists in the TAC, my research undertaking is an attempt to fundamentally disrupt the continual privileging of some movement voices in knowledge production. Unequal power relations acutely affect social movements. As noted by Steyn (2016) that while social movements have a predominantly female social base, very few women are studying movements. Knowledge production in social movements is 'socially organised'. The silencing of some voices in some social movement accounts, especially those of black African women, means that the researcher decides whose version of the actuality of the movement is heard. By privileging the voices of some social movement actors and excluding others, the researcher may unwittingly reinforce unequal power relations within the movement (Haraway, 1997). In addition, amongst many obstacles to women's participation in development is the institutionalised male preference, which is embedded in the policy spaces and social movements.

> "We need strong voices of people living with HIV and it should not be Mark or Marcus that talks about these our policy issues. We need start skilling ourselves because we have our feet on the ground in this revolution,"(TAC009 Interview, 2015).

Furthermore, the racial cleavages between academics may at times have induced relations of dependency between white senior researchers, who cannot speak an indigenous language, and black junior researchers or research students, in terms of which the former usually feature as the first authors of research publications, while the latter are enlisted serving as data collectors. I have no doubt and illusion that tensions in my scholar-activist position will influence my inquiry into participation in the TAC after 2003. However, the scholar-activist tension is useful in the production of knowledge, as it allows for nuances in the studied phenomenon.

1.5 CHAPTER OUTLINE

This first chapter introduces the subject of the thesis, presents a brief background of the study, and highlights the rationale for pursuing this area of focus as described in the objectives and questions guiding the study. The rest of this thesis is organised into seven chapters, which are briefly described.

The second chapter presents the conceptual framework of the study and reviews the concepts that frame the research. The period after 2003 is of interest for the research. This chapter introduces the concept of participation and Social Movement Action Plan as frameworks through which the findings of this study interpretation, in order to understand bottom-up typologies of participation, critically explore typologies of participation among grassroots activists after 2003, when the AIDS policy context shifted in Lusikisiki and Khayelitsha. Further, it will explore the degrees of bottom-up participation, conditions that shaped these typologies of participation, and how the relationships between AIDS activists and policy-makers changed. It will also aim to ascertain whether these activists' tactical advocacy shifts tell us something about the evolution of social movements. This analytical approach for understanding and explaining the power of social movements for creating alternative forms of non-institutional participation provides a useful lens through which to interpret collective power and daily interactions with the state.

The third chapter examines the South African context with the aim of familiarizing the reader with participation in the context of AIDS policy. Chapter Three describes the AIDS policy and political context of South Africa from 1994, including the emergence of the AIDS movement for access and affordable medicines for people living with HIV and AIDS and its role in confronting pharmaceutical companies and their intellectual property claims. In addition, this chapter looks initial anemic government response to the AIDS epidemic. In doing this, I assess the civil society's response by recounting ways in which the administrative Government leadership transition from reconconciatory President Mandela to President Mbeki's adversarial engagements with civil society marked shifts in types of popular participation. This period faced increased rebellion from AIDS activists against unilateral state AIDS policy choices and decisions. At the peak of this conflict, President Mbeki's AIDS denialism fueled significant disconnections between state policy processes, the people and AIDS activists. Moving past a description of the key events of this story, it then explores this thesis' central questions about

the forms of popular participation in public policy development and implementation during those early years. Through the historical record of AIDS treatment activism, this chapter has demonstrated that there were shifts in activists' forms of participation in HIV/AIDS policy development as well as changes in advocacy strategies on the Treatment Action Campaign (TAC) to counter government policy on HIV.

The fourth chapter sets out the methodology applied in this study. It describes the process of selecting the sample using policy network analysis, as well as applying a social constructivist deductive qualitative research approach. The chapter outlines in-depth interviews and participant observation tools, sampling techniques, and the thematic approach taken to data analysis. The chapter also offers some insights into the quandaries and limitations of the research process from the scholar-activist's perspective.

Chapters Five, Six and Seven present the empirical results of this study, contributing to answering three research questions. Chapter Five discusses the advocacy tactics applied by grassroots activists, which shows the shifts from traditional antagonistic engagements with the state to the use of a dual-tactical approach. This includes using collaborative advocacy tactics such as treatment literacy as a form of popular education. Mobilisation created ART service demand and support for the ART rollout in the study sites. It demonstrates that the treatment literacy programme became a strategy that activists used to give rise to popular mass knowledge about the science of HIV and governance. It argues that the use of this tactic shifted the patient relations with the state because of increased knowledge and power of patients as they counter the health system elite and health administrators' authority. The grassroots activists applied treatment literacy to shift engagements with the dominant unequal relations entrenched in the health system where the health care workers and public administrators are seen as the experts and patients' passive receivers of care and non-experts. In turn, activists use treatment literacy as a tool to collaborate with the state using their pragmatic alliances with health providers as a way to have one foot inside the system. The activists remained inside the health system by offering health education to other patients and brokers of their own services. However, treatment literacy as a strategy may have created collaborative pathways for activists to work with the state, but it also has its own caveats. These include the fact that long-term involvement of activists in the ART sites can lead to co-option by adjusting their autonomous role to comply with the public sector procedures and roles. Over time, some grassroots activists were absorbed

into more service delivery than activism. Secondly, strategic solidarity within the public system by aligning with health workers struggles gained activists alliances. Thirdly, the pragmatic alliances expanded to public health administrations.

Chapter Six explains how the TAC altered its advocacy tactics in various ways when confronting the new implementation structural challenges. It suggests that the TAC Khayelitsha and Lusikisiki activists became more militant during ART service delivery to exert power in relation to their own conditions and on their own terms. The activists unrelenting engagement to negotiate and popular protests as direct action to force the state to release the ART rollout timetables.

The treatment timetables were critical for activists to mobilise in order to create demand for services and for monitoring service delivery. The TAC activists were reactive by occupying ART sites and protesting against the imposition of unattainable ART accreditation, showing that the bureaucratic power in policy implementation decisions led to rationing service delivery without engaging with those whom these procedures would negatively affect. Although the grassroots activists expressed direct collective action to force the state to concede on the rollout timetable at some point, on the other hand, the site accreditation rationing of care continued. The bottom-up activist participation changed the narrative from the perceived national character of the ART rollout, especially in relation to the centralised accreditation of ART sites to a contested provincial and local implementation. It is argued that the successful shifts in TAC advocacy tactics reshaped the perceived passive role of grassroots activists in implementation by transforming practices between health providers and patients and reviving the AIDS councils and clinic committees through popular agency. The TAC, with its strategic policy alliances, invented more participation spaces, resources for court cases, popular education, resources for protests and strategy advice about choices in the political struggle. Perhaps more importantly, it has thrived in providing support for networks of health care workers, community-based working class organisations and communities in Khayelitsha and Lusikisiki.

Chapter Seven examines the impact of activists' tactical advocacy shifts that led to grassroots typologies of participation for relations with policy makers between 2003-2015.

Chapter Eight covers what these typologies mean for the survival of social movements and policymaking going forward in terms of democratising healthcare in South Africa. This demonstrates how activists understood the transformation.

The final chapter - Chapter Nine, concludes the thesis with an analysis and summary of the findings against the study research questions. The answers to these questions assist in understanding the nature of the bottom-up participation by AIDS activists from Khayelitsha and Lusikisiki that followed the dramatic 2003 ART policy changes. This chapter also highlights the broader empirical and theoretical implications of the study and points to possible future research.

CHAPTER TWO: PARTICIPATION AND SOCIAL MOVEMENT THEORY

2.1 INTRODUCTION

This chapter hopes to assess critical emancipatory potentials of the participation and social movement theory in practice. Although theory is not always the driver of revolution, it can act as a stimulator of change through its interventional ideas for the poor about remaking their history. Certainly, the Marxist analysis for example is useful in understanding that the practice of participation and social movements will have to confront powerful multinational industries, repressive state machinery, and an ideological state geared to suppress those who threaten the hegemonic order, and this may manifest in various ways (Barker et al., 2013). Grounding the work of the AIDS activists in this way is critical as to how to utilise and apply theory in their movement strategies to counter the capitalist system and the state hegemony. Thus, emancipatory theory guides my orientation as a researcher to acknowledge that the world or social movements are not empty spaces waiting to be analysed. Thus, it is important to understand that theory it is entrenched in socio-economic and political life within which we understand society as a site of struggle. Emancipatory theory is a journey for independence and secure self-determination from supremacy, and freedom from conditions that distort understanding to deny humans the capacity to make their future through will and consciousness. Fanon (1972) content that the more people understand, the more vigilant they become, and more confident to they are deliberate and settle on their own course of action.

The analytical approach for understanding and explaining participation and social movements provides a useful lens through which to interpret collective power and daily interactions with the state and multinational companies. Prior to 2003, the national government and pharmaceutical companies were the primary target of activists' advocacy and, during the period of implementation, the focus had to shift towards local government. The AIDS activists' advocacy for antiretroviral therapy (ART) captured the imagination and hopes of poor people through their participation to push for policy changes in South Africa. Hence, the period after 2003 is of interest for the research, because the relationships and engagements between activists and the state fundamentally changed, as implementation occurred and participation became more complex and challenging at the level of the local.

Against this brief background, in this chapter we will critically explore typologies of participation among grassroots activists after 2003, when the AIDS policy context shifted in Lusikisiki and Khayelitsha. Further, I explore the degrees of bottom-up participation, conditions that shape these typologies of participation, and how the relationships between AIDS activists and policy-makers changed. To this end, the chapter is structured as follows: Section 2 undertakes an analysis of typologies of participation, 2.2 covers degrees of participation, section 2.3 covers levels of participation and its relational power, section 2.4 covers spaces, forms, and levels through which activists participated to shift policy power in decision making, section 2.5 covers sources and forms of power prevalent in the various spaces and levels. Section 2.6 reviews the alternative popular participation and 2.7 concludes the chapter.

2.2 TYPOLOGIES AND POWER OF PARTICIPATION

The literature offers diverse approaches and typologies of participation, especially if one seeks to influence policy decision-making. There are two notable approaches to participation, namely the sociological and political standpoints. The sociological approach is exemplified by the work of (Melucci, 1989), which defines participation broadly as a social process where a policy actor engages or acts to promote the interests and needs of marginalised people. Melucci definition falls short due to its silence on power, which is inherently present because of the elite forces, such as multinational companies, that also have high stakes in shaping global-or national level policy decisions. Similarly, the scholarly work of Arnstein's ladder of participation (S. Arnstein, 1969; Pretty, 1995; White, 1996) and on degrees and typologies of participation influenced development in the early years. This work has been criticised by Tritter as technicist and depoliticised, for the reason that participation inherently is a political process (Tritter, 2006). Additionally, Cooke & Kothari (2001)I also critique the early phase of participation in its construction of social power. They argue that participation is more than just deterministic placements of the state or multinational companies as the centre power at the top, thus rendering the poor as powerless at the bottom. Thus, it would be negligent to avoid power as one of the analytic foci in participation spaces, levels and forms, including in social movements. One of the assumptions underlying social movements is that they engage in politics inside and outside of the realm of the state and that, their members prefer independent political activism.

The political approach to participation is embodied in the work of Pateman (2014). Which explores uneven power relations between poor people, big business and the state as a critical basis to the limits of participation. For example, in the South African context, institutional participation can be a form of state power capture and can co-opt through the so-called partnerships with community-based organisations (CBOs) and nongovernmental organisations (NGOs) and government (Miraftab & Mcconnell, 2008), which are mainly due to unequal relations. In more recent history, scholars identified that power, participation, knowledge and action are inseparable (Cooke & Kothari, 2001; Gaventa & Cornwall, 2006, 2007; Hickey & Mohan, 2004; Ballard, 2008). Henceforth, one cannot probe participation without exploring how power negatively affects poor people when they participate, otherwise one cannot not grasp the full picture. Political scholar Carpentier (2016) further argues that participation is about balance of power, thus a site of political struggle to gain influence and control of policy decision-making processes. For that reason, participation in this thesis explores that spectre of the battle for policy control between powerful individuals/groups and those assumed to have less power (but in the end, everyone brings power into a space). Likewise, considering power allows recognition of sources of power beyond the state, to include movement members. Moreover, the research draws on different social movement scholarship (della Porta & Diani, 2006; Mcadam, Tarrow, & Tilly, 2003a, 2003b; Moyer, 1987; Della Porta & Diani, 2009) that recognizes the importance of collective action strategies and movement evolution to explain popular participation in policy development.

Examining participation through a power lens makes it possible to understand modes of domination and other forms of power that shape policy-making. Participation, as the interface between communities and the state, is a fluid and complex process. It includes participation through public protest (Gibson, 2006), and it interacts and overlaps with other concepts such as citizenship and governance (John Gaventa & Valderrama, 1999). As noted in Chapter One, participation and social movement action can no longer be explained only in class terms to advance capitalist societies (Buechler, 1995), it is also about deepening active citizenry and democracy. The power dynamics associated with institutional participation are particularly necessary to understand and explain the participation strategies of HIV/AIDS activists in Lusikisiki and Khayelitsha.

FIGURE 1: LADDER OF PARTICIPATION

Source: Arnstien, 1969

One of the earliest and best-known models of citizen participation is the ladder of participation conceptualised by (Arnstein, 1969), in which the levels of citizen participation shift by moving up the steps of the ladder (see above, figure 2). Much of this theoretical work on the ladder of participation, which differentiates levels of participation in terms of citizen power, tokenism and non-participation, is built on the Arnstein's model. Scholars such as Pretty (1995) in figure 2 and (White, 1996), distinguish between what drives those who participate and implementers of policy in upholding participation. The ladder of citizen participation begins with the lowest steps in the ladder portrayed as undesirable and passive. (Lukes, 2004) argues that people at the lowest level of the ladder are manipulated into thinking they are participating, while the agenda and decision-making power lies elsewhere on the top of the ladder. Further, contending the Arnstein ladder shows limited comprehension of power and domination, which is fundamentally contested by those who participate (Lukes, 2004). Hence, one must appreciate the varied interests and agendas, which are unavoidably contested. Without contestation, one wonders what sanitises and depoliticises such participation. It can only be tokenism disguised as information giving, and consultation does not shift decision-making power or control, as shown in the middle of the ladder, and is tantamount to no participation.

On the other hand, Carpentier (2016) debates that the ladder of participation in (figure 2) omits contingency, multiplicity and complexity of participation. Presenting participation as a staircase presents a crude categorical representation of typology with disregard of various interest groups' contestations of ideas, which may intensify over time. This means that the policy making process is not as stable as presented in the staircase. Moreover, typologies as presented by (S. Arnstein, 1969; Pretty, 1995; White, 1996) are incongruent with the realities of participation on the ground because as Lawrence (2006) also argues, participation is rarely a seamless process. Likewise, Cornwall (2008)adds that the ladder presents participation in a more standardised approach. The ladder confuses power with types/degrees of participation—that is, how much participation a movement is engaged in should reflect how much power a group ought to have. Hence, earlier scholars' such as (Arnstein, 1969; Pretty, 1995; White, 1996) writings have their use to the extent that they describe types of participation; however, they lack an analysis of the impact of power in the context of popular participation where there will be more transparency, accountability and deepening of democracy (Cornwall, 2008; Steven Robins & von Lieres, 2008). For example, (Young, 2002) defines democracy as a process of dialogue between citizens and public officials, whereby they offer ideas and criticise each other to find the best collective solutions to national challenges. Participation potentially holds hope to be a tool that citizens can utilise to reform public administration concerning the manner in which public services match with people's needs. Of course, Young's definition of democracy overlooks the reality of the practice of internal democracy within institutional state spaces and even in activists' spaces such as social movements. For example, the ability of movement members to resist and contest political intimidation from the behaviour of their own leaders. However, it cannot simply be assumed that the members of a movement would take action against coercive behaviour of the state and not that of their own leaders. As Lukes (2004) points out, it is very possible that the coercive or conflictual behaviour of those leaders who occupy positions of superiority and dominance within a movement may be left unchecked. Authority manifests as power over other people in policy relations, practices and policies that perpetuate marginalisation, exclusion and oppression. Unequal power balances are unrelenting, complex shifts in the nexus of the visible which manifest as power, hidden mechanisms of domination and effects of internalised oppression — and in order to engage with this complexity, we need to look beyond linear models of change. In fact, participation is a site of contestation and inequalities created by permeations of power between different actors (Gaventa, 2006b).

Moreover, it is not a given that groups that have power in the conventional sense will be able to exercise dominant power in the HIV/AIDS policy-making process without being challenged by AIDS activists (Cornwall, 2008). Other local scholars, such as (Ballard, 2008), argue that the emphasis when assessing people's participation should be on the extent to which policy processes involve people from start to finish. To add, (Mahlangu et al., 2017) argue that multisectoral policy-making enhances and intensifies policy debates. Multisectoral methods refer to deliberate collaboration among various stakeholder groups (e.g., government, civil society, and private sector) and sectors equally realise a policy outcome. When multiple sectors participate in policymaking, stakeholders can leverage knowledge, expertise, reach, and resources, benefiting from their joint and diverse strengths to produce better health outcomes. The more policy actors there are, and the more diverse their interests and agendas, the more broad-based and inclusive the process is. The multisectoralism of policy-making disperses power and control beyond the state, to marginalised people, giving them a better chance to influence policy development. Conversely, weaknesses in democracy can lead to insubstantial popular participation.

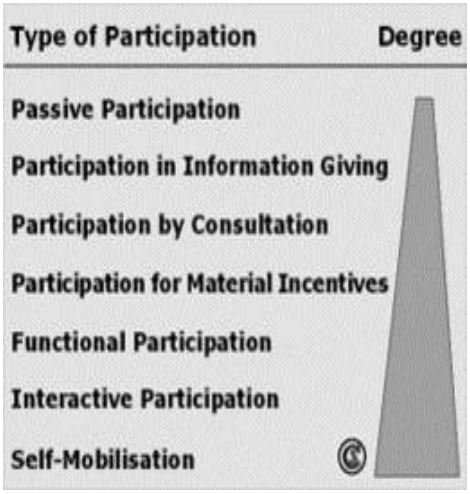
Significantly, scholarly work has criticised the practice and quality of participation at all levels, particularly at the grassroots (Cooke & Kothari, 2001; Cornwall, 2006; Penderis, 2012; Robins, 2005). Arguing for meaningful, bottom-up participation to promote agency and citizenry that can influence policy-making (Irvin & Stansbury, 2004)). Yet, there has been limited research on the impact of grassroots advocacy on HIV/AIDS policy-making (C. Campbell et al., 2005). The work of (Pretty, 1995)began to question the degrees of participation (Pretty, 1995), although it is limited in its application and relevance to date. Participation theory such as Cooke and Kothari (2001) critique the earlier theorists for evading analysis of the impact of power and politics in participation and therefore relegating poor people to a state of marginalisation. Freire anticipated these quandaries decades ago according to (Cooke & Kothari , 2001). The discourse on typologies of participation potentially can assist to identify conditions under which these forms of participation create emancipatory popular participation, entrench and/or reproduce existing power relations.

2.3 DEGREES OF PARTICIPATION

Pretty's model borrows some ideas from Arnstein (1969) ladder of participation, but it highlights degrees of participation, which include pragmatic activities to meet specific project objectives Pretty (1995) rather than broader participation for advancing transformation.

These degrees of participation proposed by Pretty (1995) focus more on how people participate in development programs or projects. As presented in figure 3, the top of the typology is passive participation, represented as manipulative with no control over policy decisions. Manipulation is pretense, by appointing people to committees that are unelected and have no power. The power elite make decisions prior to deliberations, and this type of participation involves unilateral announcements by the bureaucrats without any regard to people's reactions.

FIGURE 2: TYPES AND DEGREES OF PARTICIPATION



[Source: (Pretty, 1995)

For example, at the levels of information, consultation and participation for material incentives, participation is in name only, because these types of participation do not own decision-making. Sometimes people participate to gain access to spaces, resources, funding or other material incentives. Decisions taken in this context, however, are not meaningful forms of participation, because they orient project actions towards improving project efficiency, and those participating have no broader decision-making power. Pretty (1995) scale does anticipate, however, more productive types of participation.

As you move lower in Pretty's pyramid of typology of participation, the degrees shift from passive to interactive and functional forms of participation. Interactive and functional participation assume a more active, joint initiative and citizen control over decisions, but still within the context of participation as a means to achieve project goals. People's participation is a cost-cutting tool, with the outcome of reduced costs. Again, this form of participation may co-opt people into predetermined project goals, and being involved does not mean having influence. Given these degrees, applicability is narrow, because decisions and those participating have no broader decision-making power. Towards the bottom of the typology pyramid, Pretty (1995) lists self-mobilisation as a form of participation, in which participation is seen as a right, not just the means to achieve project goals. People participate in joint analysis, development of action plans, and formation or strengthening of local institutions.

On the other hand, White (1996) proposes four types and functions of participation, which include instrumental, representative, and transformative . Each form of participation presents as having a specific function, ranging from token to transformative. She conceptualises participation as a dynamic process that changes over time. The emphasis is on the political processes, which may potentially change patterns of policy-making. Instead of merely being concerned with degrees of participation, she questions how people are participating in a given process and believes that that is paramount. Critiques of Pretty (1995)'s degrees and White's forms of participation argue that nobody participates to check who is included and excluded. (Andrea Cornwall, 2008) argues that Pretty presents participation as a seamless process, as if it's not complicated, as if no power relations exist and ignoring that sometimes people self-exclude themselves for various reasons (Andrea Cornwall, 2008). For example, lack of confidence in the participatory process, stigma or fear of state retaliation can cause people to stay apart from the process. Moreover, scholars that are more contemporary, such as (Gaventa & Cornwall, 2006; Hickey & Mohan, 2004; Richard, 2008) contend that participation should be popular, political and contentious, and not merely project tokens. (Gaventa, 2006a) argues that implementation of policy is political, because implementation always involves a wide variety of interests and powers that want to control the process. Too often, models and practices of participation fail to engage critically with the politics of participation and contestation. Popular participation geared towards shifting power in policy implementation processes towards the control of the marginalised is key.

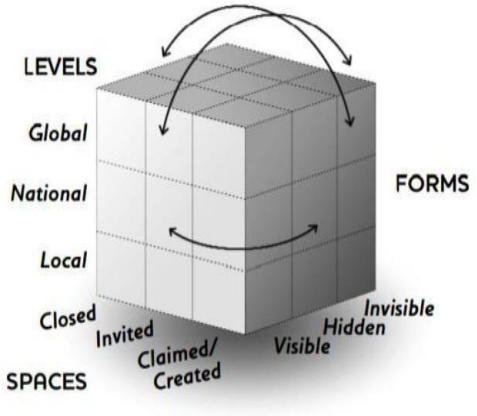
To better understand how participation and power intersect in this kind of context, (Gaventa, 2006) power analysis of participation offers a useful way to understand the levels, spaces and forms of power within spaces created for participation. The exercise of analysing sources of power has highlighted issues of legitimacy and accountability towards the communities on whose behalf they advocate. Power also refers to the capacity of activists and groups to build bridges, join forces, and/or build solidarity relationships to increase their chances of achieving movement goals (Gamson, 1961; McCarthy & Zald, 1977) . Strategic alliances are the coming together of individuals or groups who share ideological outlooks and experiences of struggle around common social conditions (Van Dyke & McCammon, 2010). The links can be formal or informal. Strategic alliances constitute a form of social power and a resource when groups are marginalised. In addition, these alliances are often embodied in advocacy coalitions as important aspect of success. Social movement groups, such as the Treatment Action Campaign (TAC), Doctors without Borders (MSF), and/or Section27, are more likely to face similar political threats and share resources (McCarthy & Zald, 1977; Van Dyke, 2003). However, even in the case of coalitions within movements, causes and shared goals have been found complicated if not mistaken (Obach, 2004; Staggenborg, 1986) . The most dominant sources of power are observable through mapping and analysis of powerful policy shakers and movers in any given context. For examples, the dominant policy actors are in a position to influence, connect, share knowledge, expertise, money and resources/infrastructure with each other, as well as form solidarity to protect and support each other through physical threats of violence from the state.

2.4 LEVELS OF PARTICIPATION AND ITS RELATIONAL POWER

Power in policy processes is everywhere, meaning that it is deep, subtly expressed in policy discourse, knowledge and scientific regimes of 'truth,' and may influence actors to use repressive state and multinational companies' apparatuses to maintain power (Foucault, 1980). Foucault's approach has been extensively used to appraise development discourses, scholarship and paradigms. Although Gaventa's power cube does not meet the Foucauldian deeper considerations of power, it provides a possibility for critical analysis and strategic action at the level of challenging or shaping policy discourse.

In this section, I attempt to give a descriptive account of levels for participation and relational power, and further review the role of the Greater Involvement of People Living with HIV/AIDS (GIPA) principle as a mechanism for inclusion of marginalised groups in policy process at all levels. Gaventa proposes a model through which to analyse power during a participation process by proposing that power shapes levels and spaces and forms participation (see Figure 3 below). This conceptual framework for power analysis provides a tool for activists to map types of power, levels and spaces so that they can strategize about how they plan to challenge power to bring about change. In his 'power cube,' he proposes examining the creation of different types of spaces, such as closed, invited and claimed spaces.

FIGURE 3: THE "POWER CUBE": THE LEVELS, SPACES AND FORMS OF POWER



[**Source**: Gaventa, 2005, Institute for Development Studies].

2.4.1 GLOBAL LEVEL

Policy debates occur at various levels, so it critical understand at which level and how participation in socio-economic and political power resides. Geopolitical processes such as globalisation and neoliberalism highlight the need for nations to address challenges related to increasing interconnectedness. Since the global-national-local powers influence or undermine levels for participation, it is important to recognise these levels and unpack how they shape participation. Increasingly there is integration for local-national global space into one community.

For example, global institutions such as The United Nations, the World Health Organisation (WHO), World Trade Organisations or the World Bank, to mention a few, reshape national policies and push forward legislative and fiscal reforms (Batliwala, 2002). In most cases the WHO and UNAIDS guide national AIDS policies and the AIDS treatment are regulated by the WTO, yet there is clarity about the democratic base for these institutions or their direct accountability to local citizens. To add, another complex layer to the levels for participation is the power of global donors such the World Bank, PEPFAR, Global, and they have become a dominant player in the local AIDS money politics. Perhaps we should rather view the levels for participation as interrelated (Gaventa, 2006b) and the impact of power affects all levels for those who participate in them.

Moreover, (Tarrow, 2005; Batliwala, 2002) amongst other scholars, warn that a balance must be sought between the local, national and global levels of advocacy, because power resides at all levels. Thus, Miraftab adds that the neoliberal ideological context poor people are used to legitimise non-inclusion policies so that the elite gain hegemonic power (Miraftab, 1997). Globally and domestically, neoliberal policies marked a transition from the left-Keynesian macroeconomic policy approach. While capitalistic power increasingly has become concentrated in global corporations, the responsibility for provision of basic services becomes more of a burden care on local communities with a high burden of care. By the 1980s and 1990s, participation increasingly adopted the tokenistic language prevalent in international aid, finance and development institutions, which in turn changed participation into a self-serving technical process rather than a political process to democratised development policy-making. During this period, the language of beneficiaries was introduced to describe those who were besieged by participatory development programmes and projects. Conceived in this way, participation is a technical exercise and sometimes a power game for controlling policy decisions. In fact, power plays a central role in the process of who is included and excluded from influencing policy.

The influence of neoliberal principles in participation theory has received critique from development scholars such as Williams (2004), who argues that, under neoliberalism, participation becomes a mere faceless (meaning without poor people's influence) structural adjustment tool to achieve cost-recovery in the context of governments' reduced role in development. For example, one of the activists interviewed argue;

> PEPFAR shifted its support from service delivery to technical assistance and now the National Department of Health is crowded by consultants, who actually have a lot of power through writing our policies, blurring the lines about who how civil society's inputs are considered. (MSF0066 Interview, 2015).

Likewise, Kavanagh , Dubula-Majola (2019) found their study that prospects for PEPFAR South Africa should include increasing service delivery support through community-based services. Further that, there is a need to pay attention to the multiple actors and the country policymaking system through which political priority is translated into programming. Therefore, as activists from MSF argue that the donors influence should not be greater that other actors. The presence of donor technical assistance, which then end up being their writers of policy, is indicative of their invisible power in policymaking. Sometimes, the presence of these consultants referred are there to push a particular interest and maintain hegemony of the status quo, in the Gramscian logic, requires reproduction of discourse by means of different channels to build and preserve social accord of the dominant power interests and structures that can be functional to the neoliberal world order.

Consequently, the manipulations call for neutralisation of any potential public unrest, protest or threats to its prevailing practice. The neoliberal influence on participation approaches and typologies has become the vehicle for depoliticisation of development through treating voices of the people affected as passive actors (Cooke & Kothari, 2001; White, 1996). Ironically, in the 1980s and 1990s, "participation" grew in such a manner that it is used to legitimise institutional development and new technical buzzwords. Furthermore, people turned into subjects of development largely seen as service users, as if they are customers in the development policy process. The language of customers is prevalent in commodities where one is seen as passive consumer rather than active agent of the service (Andrea Cornwall, 2002) , and they had no power in a politically stifled process, serving economic, institutional forms rubber-stamping for the mainstream. Participation, in the context of neoliberal development, failed to deliver transformations that end exclusion, injustice or unequal power relations. This type of participation is described as "domesticated", because it occurs within the framework of the oppressors and imposes itself on the oppressed, who internalise their oppression (Freire, 1998).

The oppressed are led to view their oppression as the natural order of things, rather than something that is socially constructed through power relations and therefore able to transform. This is contrary to the original mandate, where participation is comprehended as a project to counter hegemonic power and offer radical social transformation where the voices of the poor are taken seriously. By the end of the 1990s, scholars were raising sharp concerns about the challenges posed by mainstream participation and its failure to meaningfully engage poor people in development (Cooke & Kothari, 2001). Participation, therefore, helps us understand these systems of power that frame engagements between policy actors. These power dynamics exist between the state, citizens and the private sector, as well as within social movements themselves. Thus, in the emergence of social groups such as NGOs and social movements and other social change, actors' participation is critical to make new forms of contention towards unjust government policies (Cooke & Kothari, 2001). The young South African democracy confronts tension about its aspirations for greater participation and the global pressure to privatise and cut state budgets. For example, in South Africa the effects were visible post-1996, when the majority of poor people lost free basic services such as free electricity, healthcare or water due to cuts in public expenditures.

Hence, in the HIV policy space, the existence of transnational policy enables activists and movements (Sassen, 2008), to contest policies across borders. With transnational activism, activists in the North, and South activists for PEPFAR had to consider arrangements, which do not further endanger the lives of people who need care, and applied more pressure. For example, donors such as the US President's Emergency Plan for AIDS Relief (PEPFAR) as the leading foreign funding source in the AIDS response globally affect national government policy priorities, which led to support of the South African ART programme which has significantly scaled down (Kavanagh, Dubula-Majola, 2019). That sparked controversy after ending support for health worker salaries and moving a significant number of people on treatment from nongovernmental sites to public-sector facilities (Kavanagh, 2014). As (Tarrow, 2005) argues, transnational[1] activism builds on opportunities and resources provided by the availability of internet-based communication and mobilisation, allowing for wider spread and access to international spaces and places. He points out that this activism depends upon individuals

[1] Transnational as a term refers to the modern movements that operate in the era of globalisation and politics that increasingly go beyond borders.

moving cognitively and spatially outside of their origins, while continuing their close links to places, networks and opportunities in their domestic societies. The influence of local HIV/AIDS activism on local policy is understood through tracing its links to national and global popular collective actions.

2.4.2 GREATER INVOLVEMENT OF PEOPLE LIVING WITH HIV

"The Denver Declaration was the beginning of what many refer to as the patient response to HIV, in many instances it defined and reshaped patient involvement in their own healthcare," (Indep0083-Interview,2015).

The AIDS activists began to claim their voice and space by rejecting the labelling of "victims," which suggests defeat, and argue that they are only occasionally "patients," which in itself implies passivity, powerlessness, and reliance on the care of others (People with AIDS Advosory Committee, 1983). (Katz et al., 2013) affirms that the influence of the Denver Principles manifests itself in advocacy by PLHIV around the world, not only in the West but also in other countries such as Brazil, Senegal, Uganda, and the Philippines, to promote prevention and access to treatment, care and support for all. The greater involvement PLHIV emerged from support groups of dying and then led to broader AIDS Activist movement building from local to global. A number of such movements is the formation of the ACT UP in New York in 1987, a PLHIV advocacy group that, for example, inspired formation of the Treatment Action Campaign (TAC) in South Africa and has since persuaded governments and societies to change their responses to the HIV epidemic (Katz et al., 2013). The Denver Principles are instrumental in founding the National Association of People with AIDS (NAPWA) across the world.

The global legacy of the Denver Principles is the Paris Declaration which came out of the AIDs activists lobby during the Paris AIDS summit in 1994, where 42 governments acknowledged the GIPA principle (see figure 4) as a critical mechanism for effective and ethical involvement of PLHIV in national AIDS responses. In addition, a number of United Nations member countries' endorsements grew to 189 in 2001 and 192 by 2006. The Paris Declaration, referred hereinafter as GIPA, is a principle that calls on governments to commit to the notion of greater involvement of PLHIV for the realization of their rights, particularly the right to self-determination and participation in decision-making processes that affect their lives (UNAIDS,

2007). GIPA acknowledges the central role of PLHIV as part of the solution rather than the problem of HIV/AIDS. Furthermore, the Joint United Nations Programme on HIV/AIDS advocates for the adoption of GIPA and argues that PLHIV involvement in programme development and implementation and policy-making will improve the relevance, acceptability and effectiveness of programmes. The AIDS Alliance.org (2010) argues that the GIPA principle is a rights-based approach for AIDS programming and policy. It acknowledges the universal rights of PLHIV to self-determination and participation in decisions that affect their lives. In many ways, the principle of GIPA provides a blueprint for the greater participation of those most affected by HIV/AIDS in policy processes.

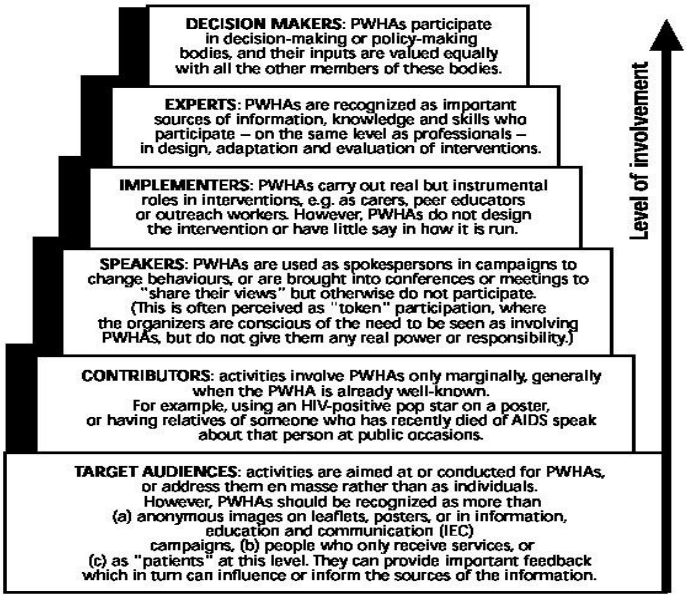
As such, it binds member states to a) stimulate the creation of supportive political, legal and social environments for the greater involvement of people PLHIV at all levels, b) rally the society, public and private sectors and PLHIV in a spirit of partnership, c) fully involve PLHIV in the development and implementation of public policies, and d) ensure that PLHIV enjoy the same level of protection regarding access to care, employment and education, freedom of movement, housing and social security (UNAIDS, 1999). The endorsement of GIPA through numerous follow up global, continental and regional agreements and declarations of commitment (see UNAIDS, 2007); and African Union Commission (AUC) and UNAIDS Declarations and commitments on HIV/AIDS is testament to its importance in response to HIV/AIDS. It suffices to note that close cooperation with PLHIV facilitates the achievement of a more effective HIV response at individual, organisational and community levels (UNAIDS (Joint United Nations Programme on HIV/AIDS), 2006).

"Nothing about Us without Us" (Charlton, 2012).

The use of the slogan "Nothing about Us without Us" is often used by PLHIV as a philosophy that acknowledges the agency of people, especially when engaging with systems and structures that oppress them. For Harris and Lewin, (1998), this slogan is common in the history of the disability rights movement's standpoint to discuss oppression of people with disabilities. Similarly, the slogan has been used in many movements including the AIDS movement to articulate their personal agency to be included because their personal suffering and voices matter, as they are often excluded in policy decisions that have to do with their lives. For example, people living with HIV in the 1980s, first voiced the idea that personal experiences should shape the AIDS response. To realise this greater involvement, the UNAIDS suggests a

model that describes how GIPA can be operationalised at a project or organisational level (see UNAIDS,1999), 'key material' From Principle to Practice). The model follows a similar hierarchical categorisation similar to Arnstein (1969) through a pyramid specifies the variety PLHIV roles at different levels of the organisation or project such as shown on Figure 5. These include programme planning and implementation, policy formulation, service delivery and programme evaluation. 152 As shown on Figure 5, the model represents GIPA as a hierarchy of involvement. The first strand is the lowest and less involving level where it depicts PLHIV as target audiences. The last strand is the highest level where PLHIV participate as decision makers who are able to influence and ultimately direct policy. For the UNAIDS and the Global Network of PLHIV (GN+), this level represents complete application of the GIPA principle. In between these two levels, PLHIV participate as contributors, speakers, implementers or experts. It is one of the tasks of this study to examine how and where PLHIV involved in the HIV response in South Africa get involved.

[FIGURE 4: A PYRAMID OF 'INVOLVEMENT' OF PLHIV]



[**Source**, UNAIDS, 1999)

On the other side, GIPA emerged in the era of the 1980s neoliberal context, in which ideas involving poor people are not presented with the aim of contesting the power of health authorities and their global health politics. The GIPA is meant to be achievable through increased engagement of PLHIV in policy development decisions, implementation and increased funding for organisations of PLHIV.

The political context of neoliberal language inspired a plethora of new "self-help" and "empowerment" activities through service-driven organisations. As some scholars (Nguyen, 2005) argue, global health programmes and spaces render people living with HIV/AIDS as bodies and objects of politics and often use terms such as "empowerment" and "participation" in order to constrain the scope for action. GIPA's focus tends to be more programmatic participation of patients in the delivery of care, and its underlying theory conflates this type of participation as active citizenry. This means the real GIPA project aspirations to be equal partners in their healthcare became a "deferred dream" and the power in the empowerment needed reform and new vision (Batliwala, 2007). It is yet to be seem if GIPA transformed the power relations between people living with HIV and health providers. The Global AIDS policy processes have evolved since the Denver conference of 1983 GIPA was both. The collective advocacy actions have redefined the meanings' participation in this era.

2.4.3 NATIONAL TO LOCAL

"To be effective in advocacy we need activists at district level to identify the implementation challenges and connect with national activists who are part of decision making," (ECAC004 Interview, 2015).

According to Section 152(e), an aim of local government is to promote the involvement of communities and community organisations in the matters of local government. Section 195(1) (e) states that "people's needs must be responded to, and the public must be encouraged to participate in policy-making." Section 17 establishes that "everyone has the right, peacefully and unarmed to assemble, to demonstrate, to picket and to present petitions,"(South African Constitutiont, 1996). A great deal of work in the area of decentralisation, for instance, discusses the dynamics of power between the locality and the nation state, while other literature argues for the importance of community based organisations as key locations for building power from below. In the context of South Africa, institutional participation often requires cooperation between local, provincial and national government, communities and the private sector under the democratic principles of co-governance and tolerating voices of dissent. The advent of democracy in South Africa catalysed space for policy dissent and opposition by creating institutional mechanisms for poor people to participate in policy processes beyond just elections.

The constitutional framework of 1996 articulates the importance of people's participation in governance and policy-making. The right of citizens to participate in decisions affecting them is constitutionally entrenched. Moreover, the Batho Pele (meaning people first) is a principle of public administration that was introduced the Department of Public Service and Administration in 1997 with the hope of inspiring a people-centred approach to service delivery. Participation had the potential to advance good governance in public health and HIV/AIDS service delivery. Instead, however, governance and policy participation have devolved and generated conflicts between the government and the people. At the local level, institutional policy participation suffers from a significant democratic deficit and lack of public accountability. In the light of ambitions for a more inclusive democracy, social groups have emerged through shared experiences of the state's failure to carry out its responsibilities.

Accompanying this South African legislative reform about participation was the expanded institutionalised forums (Heller, 2012) such as the AIDS councils as platforms for inclusion of marginalised people living with HIV to influence policy decisions and deepen democracy. (Cornwall, 2002) argues that statutory invited policy spaces are formal avenues for articulation, where dissent, confrontation, compromise and collaboration in policy demands can occur (Cornwall, 2004). Other scholars warn that institutional policy platforms for people to participate in democracy and its policy decisions have serious limitations (Ballard et al., 2006; Donatella della Porta & Diani, 2006; Krinsky & Crossley, 2014 ; Foweraker, 1995; Friedman & Mottiar, 2004; Lipton, 1993). Although the institutionalisation of AIDS policy participation was intended to democratise policy participation in South Africa Heller (2012) , particularly at the local government level, very little evidence points to its success. The power and politics between national and local government is worth noting, as these will come up in the findings chapter. The role of the government at the local level is reduced to a mechanism for service delivery, with reduced quality and scope for participation (Heller, 2012). This despite the fact that the Municipal Systems Act of 2000 (Section 16) mandates that lower levels of administrative governance should develop a participatory governance culture that creates and encourages conditions in which local people participate in all affairs related to service delivery. Increasingly, the Batho Pele (people first) ethos was reduced to rhetoric as the state became insulated and centralised (Donk, 2008) , making it difficult for ordinary people to influence policy decisions. Poor people thus resorted to the streets as alternative spaces for contesting this lack of open participation. Service delivery demonstrations escalated from 2005 onwards.

According to (Mottiar & Bond, 2012) , in 2010, more than 8000 Gatherings Act incidents were reported. Despite the number of protests, they argue that protesters remained isolated and disconnected from each other, limiting their prospects of political transformation. Local authorities' efforts to respond to local-level service delivery crises is hindered by the centralisation of policy processes, amongst other challenges. This has had a significant impact on local health authorities, who are stripped of decision-making powers and set up in a losing game against angry communities (Von Holdt & Murphy, 2007) . However, sometimes health bureaucrats at the grassroots level have the decision-making power concerning matters such as the pace of service delivery, resource prioritisation and infrastructure. Thus, the rise in service delivery protests and weak institutionalised platforms lay bare the distrust between state-led policy fora and the people. Social movements such as the TAC, AbM and others have emerged in opposition to state failure to address socioeconomic rights, basic service delivery, neoliberal policies and attempts at repression (R Ballard et al., 2006). On the other hand, Scholars (Rai, 2008) argue the public percieve local governance structures as frustratingly bureaucratic, complex and formal. Public officials interviewed seems share divergent views about participation. For example, One of the government officials interviewed for this research argues,

"The people who come to the SANAC meetings especially the at national and provincial levels, it's not clear who they represent and reporting back to," (NGovt0038 Interview, 2015).

This official question the legitimacy of those who participate and questions which constituency they represent. This occasional reception in government spaces where AIDS activists are sometimes received lukewarmly is very common. Public officials often criticise the deliberative policy-making process, saying that it lacks proper constituency representation as a way to keep certain voices out. On the contrary, some of the officials appreciate debate and contestation. "I learnt that in participation it is far much better to deal with the inconveniences due to a multiplicity of ideas, some of them misinformed rather than being in an environment where every contrary view is closed. This actually protects you as an official from making central decisions that will inevitably be contested by civil society,"(NGovt0027 Interview, 2015). Evidently, there are contradictions between those officials who value popular participation and others who do not.

In order to enhance participatory democracy, Section 19(2) of the Municipal Structures Act provides guidelines for the annual review of the needs of communities; as well of municipal processes for involving their citizens, together with their organisational capacity to deliver required services. Section 19(3) compels municipal councils to develop mechanisms to consult the community in performing their functions and exercising their powers. Local government has administrative and legislative power constitutionally recognised along with provincial and national government as a sphere of government, and has an entrenched though limited degree of autonomy.

2.5 SPACES, FORMS, LEVELS FOR PARTICIPATION

Space is a human construct with potential for emancipatory policy impact for poor people, rather than just a geographic object for means of control and domination of power. It is useful to understand the spaces dynamics, practice, and discourse relation to participation and development. As (Foucault, 1980) argues, that space is also a corridor of power and those who utilise such avenues should do so prepared to contest power . The concept of expressions of power has enabled activists to see power as something positive and negative that they also hold. Understanding how space, forms and levels for participation relate to expressions of power, we can borrow from the South African scholars Sinwell (2009) ;Miraftab & Wills (2005) who argue that institutional spaces are in the main organs of the state expression of their power. The two spaces: institutional and non-institutional, are not mutually exclusive, they often intersect and can take many forms and at various levels of participation. Thus, the power analysis is not only useful for understanding who exercises what kind of power, but also for drawing attention to the nature of relationships that give birth to or sustain certain power dynamics.

> AIDS activist leadership has limited professional skills and capacity to deal with health system challenges, for example the PLHIV sector representatives are out of depth and undermined by bureaucrats, thus we cannot hold them accountable,(ECAC004 Interview, 2015).

From the empirical results of this study, the AIDS activists share insights that public bureaucracy that values expertise and qualifications more than popular engagement from people who experience the poor policy implementation often controls institutionalised participation. Thus, the Greater Involvement of People Living with HIV/AIDS (GIPA) is not

fully internalised by all policy actors for its true meaning (NAPWA0050 interview, 2015). I contend that popular participation without people living with HIV/AIDS influencing policy is not meaningful and is tantamount to tokenism. To add, (Miraftab, 2003) shares her scholarly work on the housing policy and implementation process in South Africa, which lacks participation. In doing so, her study,

> Identifies the conceptual and operational shortcomings of the policy that impedes active participation of communities in housing processes and precludes any synergistic relationship between communities and other actors, (Miraftab, 2003).

As admitted by some of the public officials interviewed, "the problem is sometimes some government officials in order to justify excluding the TAC it's because you have people living with HIV on the table using NAPWA,"(Mail & Guardian, 2003). Therefore, you cannot say government is not sensitive to people living with HIV/AIDS.... So you inadvertedly are then playing organisations against each other (NGovt0027 Interview, 2015). The power cube (John Gaventa, 2006b) raises questions about how power influences, shapes and creates the norms of participations through rules of access, conditions of engagement and limitations that delineate who can do what or have a voice within those participatory spaces. Regarding state-led participation for example, in many instances' activists require an invitation to attend a meeting, must apply for a permit to protest or even get a court application to embark on litigation. All these examples illustrate government power used as a tactic to control access to closed spaces of participation. At a local example, the work of Sinwell (2009) in Alexandra, Johannesburg, demonstrates the point that ward committees are meant to be non- partisan yet, "the chair of the committee is the ward councillor (often a political party member) who has the final word on the agenda." This is visible power of officials setting meeting agendas, whose domination of policy debates is intentional to exclude those who are labelled as loud, militant, and difficult people or groups who do not speak the same bureaucratic language that elite social advocates have learned (Batliwala, 2002a).

The participation mechanisms such as consultation processes, AIDS council meetings, public meetings and forums often mean that government is engaging poor people to satisfy bureaucratic agenda to tick the box, and not engaging in meaningful participation. By blocking the activists' noise or disruption, the state is left unchecked, non-transparent and non-accountable.

Political hegemony in South Africa manifests itself through dominant voices of ANC Ministers in policy spaces, regardless of their poor attendance at meetings. When they are present, they take up too much space, time and are largely giving directions without question (Heller, 2001). Those included in the policy space, even the very people living with HIV, may consider such authoritarian behaviour as legitimate. Thus, the power analysis (Gaventa, 2006b) is not only valuable to understand who exercises what kind of power but it also places a spotlight on the nature of relationships' ability to produce or sustain power dynamics. Gaventa's framework is useful insofar as to understand what occurs in spaces. What is crucial is exposing how both invisible and hidden power operates. As some of the activists shared how hidden power can be felt too:

> We (activists in Lusikisiki) reported corruption done by a public health nurse selling government formula milk meant for positive mothers. We similarly testified about a false cure being sold (*Vukuphile*) at the door of the public clinic by the same nurse. In addition, we reported this to the provincial health officials but instead of investigating our allegations, they dismissed us like liars, undermined us, and denied all our allegations. We did our own resolve, by approaching the nurse, her that we know she sells government formula milk and false cure and we have evidence. After our intervention, she stopped selling both, (TAC0017 Interview, 2015).

This demonstration of state authority is normalised as a tactic to dismiss activists by doubting the credibility of their information or grievance. The power of authority such department of health officials wield is often felt but it is not always clear where it is coming from. It inculcates a sense of fear for authority, represses dissenting voices, and dismissive attitudes are often enacted. For example, one activist argues that "even though at times as people living with HIV we submit policy input one feels undermined by the Department of Health officials, because they would look at you and shake their heads like what do you know, you not a doctor, (TAC0079 Interview, 2015). I argue that the invisible power taps into the psychology of poor people especially PLHIV because they already have internalized stigma, limiting their agency and participation. I have personal experiences of being undermined on the basis that Im poor, woman, young and living with HIV – as if you do not know what you are talking about. This form of power is insidious as it shapes beliefs, perceptions and norms and legitimatises the unjust status quo.

The powerful elites reproduce ideologies through invisible power, thus maintaining their norms and vantage positions. In other words, it leads to the internalisation of the powerful elite semantics, values or policy shaping people's awareness and understanding of policies and their limitations to their policy claims. Invisible power is aimed at constraining poor people from realising their rights to make social justice claims and fight for them. This suggests that state-led spaces, such as the AIDS Councils, may be useful for advancing movement goals, but they can also limit progress in the very demands of the people. Activists challenge this form of power through various tactics such as Social change. Activists participate in this through lobbying, advocacy, and organising. This means that the praxis of participation is a site of struggle and it moves us beyond inclusion of marginalised people in institutional participation. The above literature concentrates on institutional spaces at the expense of non-institutional spaces. The subsequent discussion addresses the scholarship on popular participation through new social movements in South Africa, which emphasises the creation of non-institutional spaces for participation.

2.6 POPULAR SPACES OF PARTICIPATION

The emergence of new sites of popular participation can be traced in the work of social movements or the rise in social protests as alternative spaces of poor people's power in post-apartheid South Africa (Ran Greenstein, 2003; Snow et al., 2007). These scholars contend that social movements can be thought of as a means of collective action with some degree of organisation and continuity outside of institutional frameworks, established for the purpose of challenging and defending authority. Popular spaces are created by citizens, are organic and are sometimes held by issue-based movements. (Cornwall, 2002) describes claimed and created spaces as those that are independently invented by the marginalised. Other scholars discuss these spaces as 'third spaces' where social actors reject hegemonic space (the closed and invited spaces of formal participation) and create spaces for themselves. These spaces include petitions, walkouts, sit-ins, demonstrations and strikes (Coelho & Cornwall, 2007). Movements have emerged to contest policies that do not meet the basic socioeconomic rights and needs of the people, along with many other attempts to exclude people or silence dissent (Ballard, 2008). Social movements are spaces for deliberative, voluntary, collective action that create a critical mass to influence change as a block, made up of affiliated individuals or groups in relation to ideas and structures (Batliwala, 2011), and are at the forefront of re-awakening citizen imaginations in challenging exclusions in key government policy decisions.

Social movements organise activities, catalyse people, voice concerns, and orient them towards sustained actions and change. Another useful definition of social movement by della Porta & Diani (2006) is that social movements are informal, organised networks of political entities aiming to make a change, be it to policy, identity recognition or broad reforms of institutions and non-institutional powers. As (Tarrow, 1999) points out, social movements are collective contestations entrenched in shared determination, solidarities and vigorous activism with political opponents.

Moreover, movements are not necessarily immune from the exclusionary and undemocratic leadership tendencies often found in hierarchical political organizations and movements. Structured political organizations, movements, and unequal power relations shape the practice of internal democracy. Invited spaces are where participation is by invitation only. (Cornwall, 2002) argues that those who create such spaces frame invited spaces, and they infuse their power into the forms of interactions. The feminist literature (Batliwala, 2011; Hartsock, 1993) and Foucauldian literature draw our attention to power, domination, and subordination that can occur within popular spaces too. Power is a set of unequal relations permeating different (institutions) spaces including the government, prison, school, university, family, organisations and religion, at national, regional and local levels (Heller, 2012). In addition, just because social movements are invented the poor are insusceptible to dominant and oppressive tendencies. Male leaders lead most participation spaces and Foucault's power falls short in articulating a theory of power for women in a masculine and male dominated organisation (Bhattacharjya et al., 2013). As Foucault (1980) work indicates, the constant shifting ground in the struggle for control highlights that power permeates through levels and spaces and informs the patterns and practices of participation.

2.7 SOCIAL MOVEMENTS

Activists engage in conflict, negotiation and collaboration to achieve their demands. No single event or organisation in and of itself, however pivotal, constitutes a social movement. Collective action moves movements beyond their limits of direct, representational forms of participation in pursuit of policy reform and social change over time (Batliwala, 2011) . Social movements and NGOs as institutions can be vehicles for participation in development by opening up spaces for citizen engagement (Gaventa, 2006b).

When organised citizens take control of the direction of policy decisions, they will effect personal and community change (Heller, 2001).However, social movements and NGOs are not homogenous entities. Some groups do not aim to catalyse grassroots activism or active citizenship (Gaventa, 2002). Progressive social movements provide opportunities for enacting empowered forms of participation that are geared towards transformative or revolutionary change (Hickey & Mohan, 2005). According to (Morris & Mueller, 1992) , common characteristics of new social movements are categorised under four main criteria: goal orientation, forms, participation and values. Social movements are a necessary form of popular collective action for ensuring the meaningful inclusion of the majority of poor people who are excluded from social, political and economic policy participation. Some critics of social movements, such as (Neocosmos, 2009), contend that the civil society and social movement space is not a field of self-governance, but rather part of a hegemonic orientation towards state politics. He argues that civil society does not emancipate people but merely makes it possible to imagine alternatives. This argument suggests that a social group should be described as hegemonic if it also occupies leadership positions within a particular political sphere (Holub et al., 1996). Social movements, however, can also be a domain of political struggle and contestation over ideas and norms (Gramsci et al., 1971).

In addition, as Gramsci argues, hegemony is not always negative (as Neocosmos, 2009), but can be progressive if in alignment with how movements democratically seek consensus in society. Scholars such as Neocosmos (2009) claim that the citizenry is a myth, part of a bigger scheme of political passivity generated by neoliberalism. (Gramsci et al., 1971), though, argues that the evolution of progressive hegemonies can involve far greater degrees of state openness, democracy and consensus. Progressive hegemony is an attempt to build civic capacity to foresee various alternatives to norms of policy participation, and re-articulate their new ideas and visions. Neocosmos creates a binary opposition between a state-centric form and an independent form of popular politics called emancipatory politics (Steyn, 2012). The latter is criticised as anti-state politics, suggesting confrontational forms of collective action outside the political, institutional framework (Neocosmos, 2009). Social movements are not a homogenous group; there are distinct differences between movements, but one common thing is that under democracy, citizens should influence the design and decisions of policies and development. For example, the TAC is amongst the new social movements that have raised key health-policy opposition and have effectively employed a myriad of tactics to challenge the power of governments and the private sector in policy decisions.

Social movements have largely been characterised by collective actions constituted by individuals who share a common interest and identify with one another's struggles. They often seek to challenge power regarding its negative impact on the daily lives of the poor. In a Gramscian way, they counter hegemony at the level of policy development and make their power more visible in challenging the status quo. Social movements play a pivotal role in making and shaping social policy, making demands on the state based on socioeconomic rights. The rights-based approach to policy development unlocks the space for new alliances between social movements to demand accountability. This renewed interest in the interface between citizen and the state gives rise, in parallel, to an interest in participatory mechanisms and processes that can provide a means for more direct citizen engagement in enhancing the quality and scope of social provisioning, and can influence social policy. However, such patterns are not permanently fixed. Governments change, and political climates change more often and more abruptly. Social movements often need to follow up and sustain political gains and monitor the implementation process to ensure it reflects their policy outcome. However, sustaining meaningful participation that has a real effect on outcomes during implementation is a very complicated process. The measure of the TAC's victory is in not only policy changes but also effective state implementation that delivers medicines to save lives. The TAC activists sustained their ART advocacy during policy implementation because their victory depended on service delivery.

In the following chapter, I explore how the TAC's advocacy tactics shifted in response to the implementation challenges. It is debated here that social movement evolution and grassroots activists' participation in ART policy implementation is complex, with shifting trajectories influenced by external and internal movement forces. External factors (such as changes in policy) can enhance or inhibit the success of movement strategies. Political opportunities are not necessarily permanent, but rather fluid conditions. They open and close through historical, dynamic and iterative processes (Gaventa & McGee, 2010) . Social movements can develop and sustain themselves when they carefully identify and respond to political opportunities through the internal framing of demands, leadership, and creative advocacy strategies (R. Benford & Sociology, 2000) . This thesis shares insights into how activists creatively straddle operating outside of and against the state in some moments, and from within hegemonic state discourses and practices at others, to achieve their overall goals.

2.8 SOCIAL MOVEMENT ACTION PLAN

The work of Freire (1998) focuses on how the oppressed can liberate themselves from social oppression through popular agency. In Freire's view of participation, development is not attainable without the most vulnerable being part of the decision-making. Social movements mobilise citizens using unconventional oppositional forms of participation such as social mobilisation, protests, and litigation to pressure government for a more open policy-making process. Moyer (1987) put forward the eight stages of a social movement action plan (SMAP), as described in figure 6, which will be utilised where applicable to analyse the strategic advocacy methods TAC applied post-2003. This study reveals that policy participation and movement tactics in ART service delivery are not a linear process (see Figure 6 below). Social movement action plans undergo peaks and declines, which are observable in public mainly through shifts in protest activities. During policy implementation, the peaks of national, theatrical protest action can diminish. Some may perceive this as abeyance, but it does not mean retreat. Movements do not have to end or decline after their victory, but can continue to participate in policy implementation.

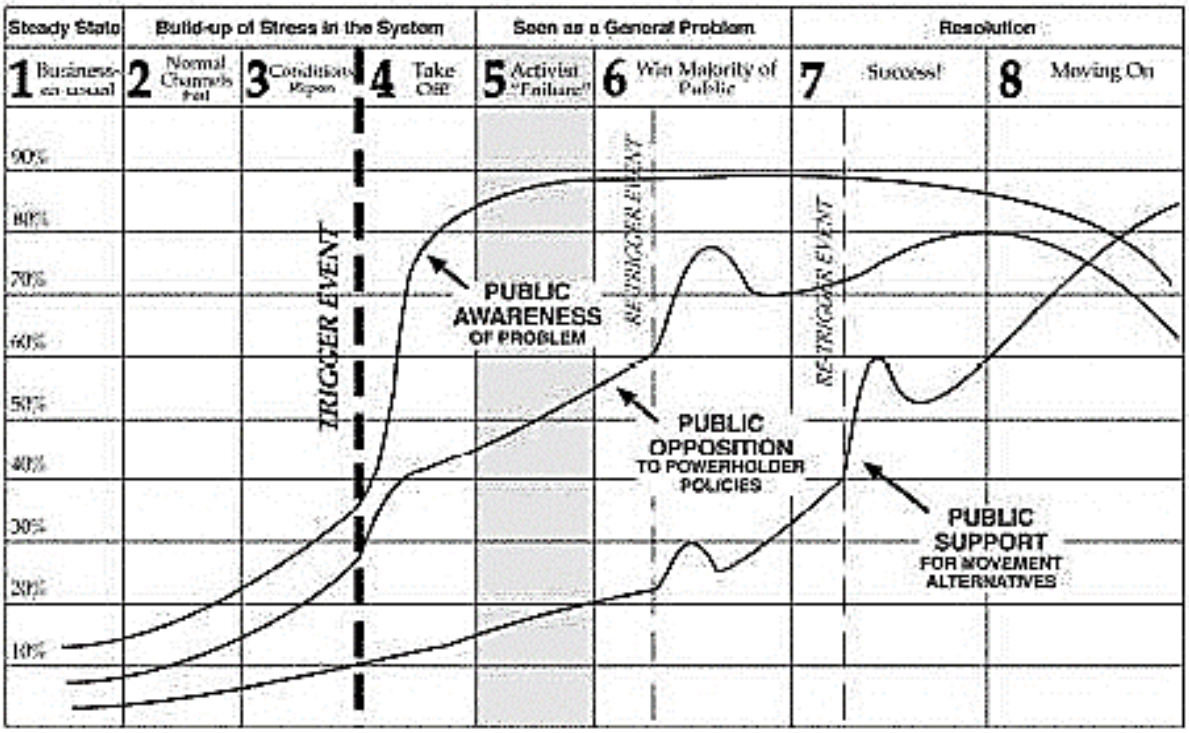
The social movement action plan assumes that social problems are caused by a concentration of political and economic power amongst a few elites for their own self-interest. Additionally, popular participation is one of the strategies to change societal conditions and establish a just, sustainable world for the majority of poor people. That means that political and economic power rests with the majority population; power-holders in any society can only rule as long as they have the consent of the people. The most important struggle between citizens and institutional power-holders revolves around determining whether society will be based on the power elite or the people-power model. Thus, without the ability of a social movement to contest power-holders that dominate current forms of HIV/AIDS policy participation, we would not have a policy in South Africa that reflects the needs and perspectives of those with less power. If social movements have a critical role to play, in what shape do social movement strategies and actions shift after a high-profile policy success? How do social movements enable meaningful engagement and achieve policy goals during the process of implementing policy wins? Many theories of social movement evolution end with the victory and then point to decline, or a shift to a new high-profile campaign. Decline is also influenced by the operation of power in a social movement.

The TAC's trajectory after they won their AIDS treatment campaign was not so clear-cut. AIDS activists needed to mobilise ongoing advocacy for ART policy implementation, which required the movement to adapt, exploit and generate renewed grassroots opportunities as well as pathways for new political action and activism. Grassroots AIDS activists' advocacy in the policy process, especially after a 'successful' campaign, can offer insights into bottom-up participation and movement evolution. New political opportunities are not permanent but mark a shift in political patterns, which may constrain or be a resource to contentious movement actors (McAdam et al., 2003b). I argue that the era after 2003 constituted a political opportunity for AIDS activists to push government to implement the national policy gains. However, implementation phases may not be as dramatic as earlier phases, but they are opportunities. It is then up to the movement that pushed for these shifts to create new action repertoires to mobilise and reactivate its members and supporters who may think the problem is over. Action repertoires are the different strategic tactics that are deployed by the collective actors while engaged in their contentious politics (Tilly, 2006). Further, Tilly (2006) argue that to understand how they emerge and how movements can make use of them, we must consider three things. (a) The openness in the polity and its effects on movement advocacy strategies; (b) The formal and informal structural aspects of political and policy openings and closures; and (c) The effects of different elements of political and policy opportunities on social movement outcomes. Considering these issues helps to predict shifts in the character, approach, and demands of activist policy advocacy demand over time and across institutional and non-institutional environments. One political opportunity created by the AIDS policy success was the opportunity for mass mobilisation of affected communities to connect policy intentions and implementation. The urgency of implementing ART was mounting, and the TAC activist leaders saw monitoring implementation as a continuation of their movement plan, but also as an opportunity to draw in richer engagement among its grassroots membership.

Moyer (1987) put forward that the social movement action plan, as shown below, provides some guidance in understanding the life of social movements. Social movements' real-life experiences do not fit neatly into the linear stages in this manner. Social movements are dynamic, and the SMAP merely serves as a theoretical model. Theory is also not a panacea, but it enables activists to better understand the nature of their actions, political opportunities, impediments, antagonistic opponents and supporters.

It is in this way that theory of social movements, even without being theory for social movements, may yet be valuable to social movements. The underlying issues in (Moyer, 1987) model are that there are mainly two contrasting models of power — that of the elite and people power. The power of the elite holds that society is organised in the form of powerful elites at the top and the relatively powerless mass populace at the bottom. The elites, through their dominant control of the state, institutions, laws, myths, traditions and social norms, serve their own interests, often to the disadvantage of the society.

FIGURE 5: SOCIAL MOVEMENT ACTION PLAN (SMAP



[**Source**: Moyer, 1987]

Social movements, after success, go through a decline — or the re-emergence of other social issues is the logical next step, as argued by (Moyer, 1987). Movements are driven and sustained by campaigns, which involve highly visible and contentious conflicts between policy actors. Moyer (1987) argues that social movements' action revolves around four phases although not in a linear fashion. The examples cited in this section are discussed in the findings Chapters Five, Six and Seven. The phases include section 4.2.1 The bureaucratic management phase is essentially the period when the state attempts to control what the public has access to in terms of policy and they deploy state bureaucracy to manage its propaganda.

This stage is characterised by stage one and two (see figure 6 above). In section 4.2.2. The crisis management phase is when policy problems that the state attempted to hide are not in the hands of social movements. Social movements then publicly animate the systemic and hidden injustices and expose the political elites. For instance, information about the behaviour and culpability of government ministers is often quite meagre until after a social movement has forced new information to light. This is revealed in stage three and four in the diagram above. In 4.2.3 inevitably, the social movement public demonstrations of state failures are exposed and there is heightened public awareness and public opposition of the state actions. This is exhibited in (figure 6 as phase five to six, and 4.2.4). Then there is broad-based public support which leads to movement success and policy win. After the policy is won the movement is meant to move on as shown by stages seven to eight. Moving on can mean demobilisation, death of a movement or transition to service delivery and policy implementation monitoring.

2.8.1 PHASE ONE: BUREAUCRATIC MANAGEMENT

The bureaucratic management phase is a strategy used by the state and other power-holders to prevent the issues raised by the social movement from becoming a public issue. This begins when policy conditions seem normal. This is achieved by keeping the policy problem out of the public's view of the world and thereby out of people's consciousness and keeping issues out of the public spotlight and off the society's agenda. For example, three months after the cabinet ART rollout announcement, the National Department of Health published its operational plan with incomplete sections, containing the ART rollout plan without timetables (referred to in the ART rollout plan as Annex A).The government ART operational plan proposed by the Department of Health included sections 135 and 136, which say, "The operational tasks are summarised in Annex A, which is a week-by-week schedule for the pre-implementation period with deliverables for each of the main focus areas. It further indicated that the detailed implementation plan, which follows as Annex A.2, sets out the tasks to be completed in each stage of the operational plan for each area of activity,"(Ministry of health South Africa, 2011). Power-holders maintain hegemony over information available to the public through the media.

The TAC activists, through cordial letters as their initial tactic to engage through negotiation first, urged government to publish the timetables. The AIDS activists with their allies ALP (known as Section 27 hereon) and MSF approached the National Department of Health in February 2004 requesting release of Annexure A. The activists were concerned that government centralisation of essential ART rollout plans would be tantamount to no real service delivery.

After ten months of letters from the TAC activists to the National Department of Health without progress on access to Annexure A timetables, the TAC attempted to engage government through legal action Annexure A Case no 215991/04) at the Pretoria High Court Silber (2008) and force it to publish these timetables. Activists claimed that the National Department of Health contravened the Constitutional rights of people to access crucial information according to the Promotion of Access to Information (PAIA) Act 2 of 2000 (Republic of South Africa, 2000). This act states that people can have access to any information held by government or anybody as part of an open and democratic society, which respects human dignity, equality and freedom as, articulated in the South African Constitution of 1996, section 36. AIDS activists argued it was a human rights violation to deny poor people living with HIV/AIDS information about when treatment would be available in their nearest clinics. The state's refusal to publicise the ART timetables triggered a new phase in TAC's tactics after the announcement of the ART plan. The trigger set off a movement and put the spotlight on the state's commitment to implement the ART policy, and the state's refusal sparked public outrage. The ART timetables trigger set off for the local activists a political opportunity to place the policy implementation challenges in the spotlight.

The focus was on the question about the state commitment to ART service delivery without a clear public plan that the activists could use to hold government accountable. The return to the courts offered the local TAC activists an opportunity to articulate ART rollout demands using the official/government avenues such as courts to force the state to offer transparency about the treatment plan timetables, which sparked public outrage. The state in its responding affidavit in September 2004 argued that any reference to Annexure A was an error, because there were no annexures. This is despite the ten months of earlier letters during which the state had sufficient time to point out this error (Cho, 2009; Heywood, 2009). The state denies that there is a problem and maintain unjust operational plan without timetables as promised and keep them hidden from the public by having a two-track system of official and operative policies. The operative policies are the government's actual policies, which are kept hidden from the public because they violate widely held values and therefore would upset most citizens. The state appeared to be involved in a resolution process during the court cases through new rhetoric such as claiming the timetable was an error.

2.8.2 PHASE TWO: CRISIS MANAGEMENT

Policy issues sometimes thrust particular government departments into the spotlight; more commonly, the problems that animate social movements are systemic and hidden, such that no responsible actor automatically comes to the fore. For instance, information about the behaviour and culpability of government ministers is often quite meagre until after a social movement has forced new information to light. For example, the National Department of Health imposed complex, high standards for sites to provide ART. Before a health facility could provide ART, they had to he inspected by a national government delegation to ensure compliance with the national accreditation requirements contained in Chapter Four, using the Service Point Assessment and Accreditation Guide in Annex IV (Ministry of health South Africa, 2015). The service point assessment accreditation is commonly referred to as site accreditation (see Chapters Six and Seven) which meant that dying patients could only access treatment through an accredited service site, and only health professionals who had undergone training and certification procedures to render the necessary ART services in accordance with the recommended treatment guidelines and protocols could treat them. Even though clinics in Lusikisiki and Khayelitsha were already initiating people on ART through MSF, with successful outcomes, they were instead subjected to the national government's bureaucratic assessment process that required on-site accreditation, swelling waiting lists across South Africa. The Lusikisiki ART programme was accredited a year after the announcement of the ART rollout plan. This resulted in an expensive and slow ART rollout model.

Activists linked this particular policy failure as intentional and indicative of the Minister of Heath's malicious compliance to movement demands and now delaying implementation was the state tactic to stall. The Minister of Health became the main actor which activists used to generate public information about these actors' practices and are crucial parts of what social movements do as part of their daily framing process (Benford & Snow, 2000). They make discernible and notable moments that reject the social order (Bartley & Child, 2014); some actions that perform an exogenous role are visible in social movement organising. The social movements in public articulate their claims and identify the government leader responsible by holding protest events, but also by developing capacities to attract media attention and collect new types of evidence. Construction of targets is bound up with repertoires of contention and configurations of power. Theorized by Tilly (2008) , repertoires of contention are repetitive sets of targets, tactics, and understandings of social change.

Theorists underscore that repertoires of contention are traditionally shaped by predominant patterns in the polity (Mueller & Tarrow, 1995) , but the following work of (Goodwin et al., 2007) as well as (Walker et al., 2008) concentrates largely on disparities in tactical repertoires in a given period. We seek to return attention to the co-evolution of repertoires of contention and forms of power by highlighting the production of targets, a subset of this larger process. There are two elements of that especially imperative for repertoires of contention and the construction of targets. First, forms of power in this instance include openness and spaces for advantage, which can be found in the contradictions of a multi-institutional social order (Armstrong & Bernstein, 2008). Second, both structural and cultural dimensions of power configurations shape the terrain that social movements navigate (Armstrong and Bernstein, 2008). We see structural dimensions as rooted in large-scale patterns of resource exchange, and cultural dimensions as based on symbolically potent images and discourses, although we recognize that the two may intersect and be mutually constitutive. Analysing the production of targets requires one to unpack the bases of material and symbolic power in different social fields (states and markets) and among different actors in the field. They then shift towards building up stress on the system and building movement energy, using a trigger through which public attention is directed to articulate their demands. After a policy becomes a public issue, the power-holders are forced to switch to a crisis management strategy. This may be done by attempting to vindicate unjust policies through first ignoring and discrediting the movement and denying the problem, explaining that their current policies are sufficient — and if necessary, repressing the movement. Power-holders may create trigger events to justify a new policy and get public consent and to overcome public opposition by destabilising the movement, making minor changes through reforms, compromises, and co-optation of opponents.

2.8.3 PHASE THREE: PUBLIC AWARENESS AND POPULAR OPPOSITION

Public awareness and popular opposition are impacted by the level of information available to the public about the problem as framed by the movement’s actions. This level of public awareness of the policy problem may represent the movement take-off stage, which sets the campaign high in the public discourse and media visibility from the trigger issue.

For example, the national government to their delay tactics to implementation through refusing to publish the treatment timetable, and then slowing the initiation of sick people onto to lifesaving treatment, the state resorted to active promotion diet-based approaches as a complement and poised them as an alternative to ART. The Minister and her allies, in the process discouraging the use of ARVs, promoted African vegetables, olive oil and other (expensive) immune system boosters vigorously (Cullinan & Thom, 2009; Geffen, 2010). The TAC deployed its movement local branch machinery to organise, educate and counter these forces by creating mass awareness and opposition to the state. As Gaventa & Cornwall (2006) argue, an informed, mobilised citizenry participates effectively through capacity built though popular education on rights. An informed, mobilised public can put pressure on the power-holders, and in consequence, the public administration takes steps to act in the best interests of the citizens and therefore transforms the relationships between the two. The movement campaign can then shift to the intensification of public policy discourse to change public opinion. Once the movement wins public opinion, it gains ground in shifting policy discourse, and the public relies on the movement as the provider of the policy alternatives. Through sustained pressure, the state will have no choice but to accede. Once policy reform occurs, then the movement is victorious. After the victory, the movement moves on and continues to monitor its gains and broadens its movement demands or goes through a decline.

2.8.4 PHASE FOUR: PUBLIC SUPPORT (2007)

This SMAP model will be employed, bearing this point in mind (Moyer, 1987). Successful campaigns depend on careful navigation to link international pressures with differing and constantly changing local and national contexts. Social mobilisation structures provide opportunities for the state, private sector-based reformers to generate change from within, and outside, just as political opportunity structures provide spaces for social actors to do so from without. Policy change on contentious issues requires controversial forms of mobilisation. Movements sometimes have the dynamism to reframe their demands, apply a broad range of strategies and adjust as the political and policy processes shift. Movement success can be understood in many different ways, in particular among the various actors in a broad-based campaign or social movement. Social movements, therefore, do not follow a rigid evolution and progression.

The TAC has gone through several stages, sometimes in a linear fashion and sometimes jumping over stages in the model. After government's public stance on ART policy changed, there was still residual resistance and denialism. Triggering events related to this resistance includes government's refusal to publish ART rollout timetables, the slow and complicated process of ART site accreditation and government has continued support for alternative therapeutic remedies. The lack of a robust state response catalysed the TAC activists' responses and helped to spark public attention to government inaction. It is often essential for the movement after what is considered a victory to sustain its frame so that its members and supporters are continuously engaged. The ongoing construction and reconstruction of meanings in collective action spaces is referred to as a frame (Snow et al., 2007). Therefore, frames are central to movement life and evolution. If there are political and policy shifts, frames sustain the movement's public relevance. This is because, as scholars such as (Tarrow, 1999) argue, frames ignite, dignify, animate and help the public to make sense of the movement's demands and shifting policies and political context. Therefore, framing influences the movement action plan and its action repertoire.

2.9 FRAMING POPULAR DEMANDS

One the important strategies that social movements utilise is framing their meaning to guide the public and followers about what the injustices are and make sense of the movement demands. Frames are not static: they evolve with the movement action plan. The use of frames dates back to the 1970s and 1980s, to scholars such as (Goffman, 1975; Benford, 2000; Gamson, 1990), who conceptualised framing as a process of active sense-making of something as it actively occurs or is being executed. It is a dynamic, evolving process, which implies people's agency and contention. It is within social movements frames are expressed to contest dominant frames. Therefore, the framing process is also central to understanding social movements' strategies and action, because, as scholars such as (Goffman, 1975) argue, frames are used to interpret, locate, identify and understand meanings within movements and their claims. In addition, (Meyer & Whittier, 1994) concur that framing processes are valuable to analyse movement claims and contested ideas. The existing literature suggests that there are a number of insights linked to the framing process, development and other overlapping processes that can be conceptualised as discursive, strategic, and contestations.

The main debates arise from two basic schools of thought. That of (Gamson, 1990) argues that frames help to understand meaning systems that people use to negotiate their way in political

contexts. The second school includes (Benford, 2000) who argue that framing helps not just by clarifying meaning but also by way of identifying social and political injustices, the parties responsible for causing them and possible solutions. They argue that movements offer tactics to solve problems and to motivate new members to be agents of change. Framing is a critical process through which people develop particular ideas about issues. It is fair to say that frames usually track trends on movement issues and have provided a way to link ideas and the social construction of ideas with organisational and political process factors. These studies, however, deal almost entirely with the cognitive components of frames, whereas emotional components are neglected.

Yet, powerful frames might be related to the values and the emotions that they contain; therefore, it might be argued that frames not only resonate cognitively but emotionally as well. Even though this study did not dive deep into the emotional meanings, culture are elements of framing within the movement but it is a vast research area to be explored. McAdam argues that framing is a process by which shared meanings can be created. He views these shared meanings as critical in mediating between opportunity, action and organisation. Emotion plays a role in communicating the feelings of both public anger and hope that their combined actions can improve their local situations (McAdam, McCarthy, and Zald, 1996). Ballard, Habib, Valodia, and Zuern (2006) point out that it is important for new social movement scholars to focus attention on the importance of subjective elements such as identity, meaning and emotion. The concept of framing processes, then, is use to describe the conscious efforts of movement leaders and their members to construct shared understandings and the underlying cultural resources, which they employ.

Tarrow argues that it is members' recognition of their common interests that translates the potential for a movement into action (Tarrow, 1999). While social movements adopt framing processes for their constituents and target audiences, the media play another role in re-framing and promoting the issues. Many potential recruits and supporters become aware of movements and their issues primarily through the movement's social mobilisation or the media. The role of personal, individual motivations as a resource in social mobilisation was not afforded much attention in resource mobilisation theories. People participate in movements for three main reasons: to influence social and political environments through demanding change; to build collective identities through searching for meaning; and to create platforms to express views

and feelings about grievances. It is important to note that the framing process is never an independent, static process.

The emphasis on collective identity rather limits the applicability of the theory in AIDS activism, since it is often based on alignments of purpose rather than the establishment of collective identities (Ballard et al., 2006). Often organisations, groups and individuals link up and act in a coordinated fashion merely strategically. This is not to deny that in some movements collective identities are fundamental. Evidently, collective identity formation is a key to movement emergence as was observed in the US from the 1960s and was still critical in the mobilisation of early AIDS activism (Grebe, 2011). Nonetheless, social movement theory does provide analytical tools that are useful in conceptualising the processes at the local level in movements, as long as we do not reduce the movements to these processes. At the same time, there is a place for political opportunities and processes in this study and its analysis. The activists in the TAC were successful in using strategies such as strategic litigation to force the South African government to fulfil its obligations to realise the right to health and to compel it to change its AIDS policy. This is an example of taking advantage of political opportunity presented by the South African constitutional democracy. Clearly, without the fundamental transformation of the state in the early 1990s, such a strategy could never have been successful, and in this sense, the state-centric political process model is perfectly applicable. However, the emergence and success of AIDS activism cannot be explained simply in these terms. Empirical studies of AIDS activism seem to confirm that a relatively small number of individuals can bring to bear the intergroup linkages that are critical to wide mobilisation, even if most movement participants rely on strong ties to mobilise friends and family. The activist movements that have been most successful at exploiting opportunities created by economic and political globalisation are those that themselves have a transnational character (Grebe, 2011).

2.10 BUILDING MOVEMENT SOCIAL POWER

Power, social relations, democracy and leadership are all central elements of different approaches to community organising. The central issue of social mobilisation is that through collective action the poor people become the powerholders that must win the hearts (sympathies), minds (public opinion), and active support of the great majority of the populace, which ultimately holds the power to either preserve the status quo or create change.

And here the role of movement culture and emotion for both external and internal movement resources and demise (Goodwin et al., 2007). In building social power, a movement utilises the emotional repertoires such as songs, to express demands, anger and joy, identity and culture to recruit member and supporters and for movement takeoff. Internally, the emotional framing can help us understand the dynamics of a movement. Building social power is a locomotive of social change through constituency building. I argue that from my experience, one cannot build social power without social mobilisation, which is means through with a movement recruits and wins popular support. Likewise, other scholars argue that mobilisation of the masses is an essential factor for the success of any social movement, and the idea of mobilisation is essentially derived from the general idea of participation (Campbell, 2014). According to (Niven, 2004), it is important that we distinguish political mobilisation within a social movement context from a voter turnout context, as the latter has a higher propensity and a lower risk factor compared to the earlier notion. The essence of mobilisation praxis posits that increased access to political information increases political popular participation within the particular contexts. This propagates the idea that increased political consciousness leads to more debates, critical analysis and collective action, which make mobilisation more effective. It is also necessary at this point to clarify that what is meant by mobilisation is not only the mobilisation of people, but also the overall mobilisation of resources required for the success of a given social movement.

Mobilisation means many things for different people, but for this thesis, it is the concept of mobilisation of people's time towards collective action, and resources such as knowledge, technology and financial resources to advance movement action plans. Social movements are collective actions in which the populace is alerted, educated, and mobilised, over years and decades, to challenge the powerholders and the whole society to redress social problems or grievances and restore critical social values. By involving the populace directly in the political process, social movements also foster the concept of government of, by, and for the people. The power of movements is directly proportional to the forcefulness with which the grassroots exert their discontent and demand change.

2.11 CONCLUSION

In sum, this chapter conceptually outlined the theoretical standpoint of the study by drawing on ladders of participation, degrees and typologies that describe prominent discourses in the field, particularly critical for the analysis of the bottom-up typologies of participation that emerged after 2003 in the HIV/AIDS policy context. It also applies social movement theory to interpret the shifts in bottom-up participation in advocacy by activists in Khayelitsha and Lusikisiki after 2003, which shaped the dramatic policy changes, during the distinctly different phase of policy implementation. I hope that this will provide insights into the evolution of the AIDS movement during the policy implementation period. Factors such as power analysis (forms, levels and space) of participation and the role of social movements in participation are underscored. It is my contention that bottom-up participation is a complex phenomenon with several determining factors. In addition, movement evolution does not follow a linear progression, but it can shift between various phases. The following chapter provides the socio-political context and historical background that fostered HIV/AIDS advocacy in policy spaces in South Africa.

CHAPTER THREE: AIDS RESPONSE 1994-2003: THE STATE, SOCIAL MOVEMENTS AND CITIZENS

3.1 INTRODUCTION

This chapter provides a literature review of the HIV/AIDS policy and public administration responses from 1994 to date. This review seeks to understand what drove the HIV/AIDS policy traction and the possible tension caused by the Trade-Related Aspects of Intellectual Property Rights (TRIPS) agreement about access to antiretroviral therapy (ART) and the AIDS movement's human rights framing of their claim for affordable medicines. Moreover, it highlights the forms of popular participation in those early years and recounts the administrative AIDS policy processes and transitions from President Nelson Mandela's conciliatory approach to participation to President Thabo Mbeki's antagonistic one, as well as the impact of the neoliberal fiscal policy framework on South African government choices in AIDS policy. During this period, the AIDS epidemic was transitioning from the asymptomatic 'silent epidemic' to a mature epidemic characterised by illness and death. This shift occurred about the same time as the South African dawn of democracy, as well as the rise of neoliberal policy frameworks and globalisation. One focus of activist energy during this period was pushback against the World Trade Organisation (WTO) and its TRIPS agreement. Shut out of critical trade negotiations, activists used alternative forms of participation to demand greater participation by poor people — especially people living with HIV (PLHIV) — in trade-related aspects that had an impact on their ability to access affordable medicines. At the same time, this period created opportunities for intensification in transnational activism, which created pathways for a global AIDS movement and solidarity. The AIDS movements from developed countries had begun earlier to advocate for access to AIDS treatment, led by United States groups like AIDS Coalition to Unleash Power (ACT UP), Health Global Access Project (Health GAP), Médecins Sans Frontières (MSF)-New York and others.

The administrative AIDS policy transition from Mandela to Mbeki's adversarial engagements with civil society marked shifts in types of popular participation. This period faced increased rebellion from AIDS activists against unilateral state AIDS policy choices and decisions. At the peak of this conflict, President Mbeki's AIDS denialism fueled significant disconnections between state policy processes, the people and AIDS activists.

This historical record of AIDS treatment activism [2] was also a personal journey for me, and retelling it in this chapter allows expression of my critical perspective about both healthcare advocacy and promotion of democracy, starting at the birth of the AIDS activist movement. Therefore, I use this examination to critically reflect on the forms of participation in HIV/AIDS policy development and advocacy strategies applied by the TAC activists prior to 2003.

3.2 BEGINNINGS OF AIDS ACTIVISM

In the first few years of post-apartheid South Africa, the AIDS epidemic transitioned from the asymptomatic "silent epidemic" to a mature epidemic characterised by illness and death. The concern that accompanied this transition generated activist momentum and political opportunity for a collective AIDS response. The first AIDS activist groups included the AIDS Consortium (AC), an umbrella organisation for community-based HIV/AIDS organisations. The AIDS Consortium, in turn, catalysed the formation of other important organisations and movements. Movements included the National Association of People Living with HIV and AIDS (NAPWA), founded to assert the voice of poor people living with HIV/AIDS, and organisations such as AIDS Law Project (ALP, now known as Section 27), a group of human rights lawyer activists who defended early HIV/AIDS discrimination cases for poor people who could not afford lawyers (Mbali, 2013a; Moyle, 2015). The development of the first National AIDS Plan (NAP) process seemed inclusive of groups representing people living with HIV such as the AC, the ALP and the NAPWA, with some form of participation. The NAPWA was another important organisation in these early days. Although it had some members who came from the gay and lesbian rights movements, its mandate was to mobilise the voices of poor people living with HIV in the HIV response in South Africa.

As Mbali (2013) argues, the development of the NAP involved subtle forms of exclusion, because the powerful role of those who had been in exile during apartheid (and were now political leaders) led to tensions and competition for power and control over the AIDS policymaking process). AIDS activists challenged forms of participation that included them as participants, yet barred from influencing the policy agenda setting and leadership in policy-

[2] AIDS activism in this study refers to HIV/AIDS policy actions using vigorous campaigning to bring about political or social change.

drafting processes was led by the state. For example, one of the interviewees recalls being present at the Lusaka conference;

> The AIDS movement at the time under the auspices of the AIDS Consortium rapidly contested lack of meaningful participation of PLHIV in the policy process. [They] marked the first group to criticise the conference status quo. (Indep006 Interview, 2015).

Consequently, two AIDS activists from NGOs and the people living with HIV/AIDS movement were included in the NACOSA conference programme as speakers. At this point, despite these tensions, the state and civil society organisations enjoyed close relations. The political opportunity that came with the 1994 defeat of the apartheid regime led to alliances between government and social movements. As (Heywood, 2005) points out, the ANC engaged effectively with NGOs such as the AC, the ALP and later, the NAPWA. In these early years, the NAP development mainly focused on prevention and protection of human rights as the anchor of the policy, because at the time, there was no AIDS treatment available. In 1996, however, triple therapy to treat AIDS, and Northern AIDS activists began advocating for its accessibility for the populations most in need.

In the process, Northern AIDS activists became an important set of transnational[3] AIDS policy actor networks. Key groups included health-related organisations like ACT UP, Health GAP, Doctors without Borders (MSF), Consumer Project on Technology and Oxfam — groups from developed countries that had already begun to advocate for access to AIDS treatment in the United States of America and elsewhere. International engagements between Southern and Northern AIDS activists first began during the early gay rights movements (Mbali, 2005). Network resources were critical in connecting local struggles to global struggles, and AIDS activism has proven that it works to create solidarity. These cross-border networks enabled critical knowledge exchanges about treatment access issues, advocacy strategies, networks, and opportunities for transnational activism, mobilising resources and coordinated action. Not long after the introduction of AZT, the NAPWA launched its treatment action campaign to begin to pressure pharmaceutical companies to make AZT available at affordable prices in South Africa. However, their advocacy strategies, which included confrontational tactics, became a source of internal contestation among AIDS activists in the organisation.

[3] *Transnational movement* is a term used to refer to modern movements that operate in the era of globalisation and increased international politics (Smith, 1997).

After a few months of the NAPWA's internal efforts to promote radical and confrontational advocacy strategies for the treatment access campaign, consensus among its members proved impossible. Some of the NAPWA activists, who were unhappy with a less confrontational and closer to government approach, argued, "We wanted to be a progressive, independent and mass-based movement," (see Mazibuko Jara interview in TAC History Archive, 2010) . Others wanted a more moderate approach. These internal tensions led to the creation of a splinter group, which became a movement of its own. Another TAC activist added, "The impetus behind the split between the TAC and the NAPWA was a principle issue about funding for the movement. We did not want to take money from drug companies or government, and we wanted poor black people living with HIV to lead the campaign for affordable AIDS treatment," (Zackie Achmat interview TAC History Archive, 2010) Building an independent movement that did not have financial associations with multinational companies or the state was to define the character of the TAC. The distance from drug companies and their money was congruent with the TAC's public efforts to challenge the moral values of drug companies to protect human rights.

Divisions arose around the longer-term AIDS treatment campaign strategies, in recognition of the fact that if successful pressure on drug companies led to lower prices, the focus would move to pushing the state to ensure access. However, some NAPWA members were reluctant to confront the state and preferred continuing its close alliance. This close relationship was not only political but also financial, with NAPWA depending on the new state for funding. Others saw confrontational advocacy tactics, and the need for independence, as inevitable and inseparable. Thus, Heywood (2005a), who was part of NAPWA at the time, argued that TAC broke away from NAPWA as an unapologetic independent advocacy movement for the right to health and life. The launch of the TAC as a social movement, independent from the NAPWA, was on International Human Rights Day, 10 December 1998. Although the TAC calls itself a movement, "The TAC did not begin as a grassroots movement; it started with a few middle-class people [who] had working-class roots. We knew we had to become a movement based in communities to have any integrity or we'd be just another NGO," (Siphokazi Mthathi |Interview in TAC History Archive, 2010). Without wasting time, they launched public protests against pharmaceutical companies by issuing a public call for a "Fast to Save Lives" on Human Rights Day in South Africa, 21 March 1999 to pressure the pharmaceutical sector and government to seriously address the need for equitable and affordable access to treatment and care for all people with HIV/AIDS.

The AIDS treatment activism sustained greater focus on treatment access, more confrontational advocacy strategies targeting pharmaceutical companies, and a human rights framework for the right to health for people living with HIV. The move away from a "prevention-focused" NAP was one of the TAC's advocacy demands. It worked towards a more robust policy response that included ART access. The involvement of groups like the NAPWA and the TAC opened the door for the participation of people living with HIV in policy debates around the AIDS response. Equally important, if not more so, however, were the initial legislative steps the South African government took in 1996 to ease intellectual property restrictions and make it more affordable for the state to provide treatment in South Africa. The Pharmaceutical Manufacturers Association (PMA) tried to block these moves by suing the South African government. The court battle that ensued is the focus of the first main section of this dissertation.

3.3 DECOMMODIFICATION OF AIDS TREATMENT

Despite substantial evidence about the effectiveness and potential affordability of ART emerging from wealthier countries (Heywood, 2004), such medicines were still inaccessible to the majority of poor people in developing countries. Azidothymidine (AZT) became available in the global market highly priced at USD 10,000 per patient per year (United Nations Development Programme, 2010), rendering it inaccessible and unaffordable for many poor people. In developed countries, access to ART has helped to turn AIDS into a manageable chronic health condition. The significance of this research is of academic importance, and personal experience is an important motivation for my health activism, my desire to transform and be part of this emancipatory resistance. The AIDS activists' struggle for access to ARVs was a class struggle, which required to be conquered by people living with HIV. A class struggle is a social, economic and political relations conflict often expressed in institutions of power. The activists rejected private interests in the form of maximum accumulation of profits above people's lives and demanded affordable medicines through breaking the dynamic capital expansion through monopoly and ever greening. Inherently, class as a process of multiple forms of resistance to exploitation or oppression (Barker et al., 2013). The agency of the people who, like me, are living with HIV are central to the making of our own history in rejecting the capitalist norms of health as a commodity and in that way constructing new democratic forms of power from below. For tens of millions of poor people such as myself, AIDS remained a death sentence before the 2003 period. Lack of access to medicines, especially antiretroviral treatment (ART), has been a key source of health inequity in post-apartheid South Africa.

"The cost of licensed pharmaceutical products amplified profits of international drug companies thereby escalating the public health challenges in South Africa in meeting its health policy goals," (Bond, 1999:766). Further, he raises concerns about the impact of globalisation in terms of the role of profit motives as an incentive in essential pharmaceutical products, and the depth of democracy in a country such as South Africa. The global market trend favours health as a commodity that creates precarious notions of health as a privilege rather than a public good and a right. Hence, AIDS activists as indicated above and the TAC succeeded in compelling multinational pharmaceutical companies and the South African government to improve HIV policy regarding access to lifesaving ARVs for people living with HIV and AIDS (Padarath & Friedman, 2008). In addition, the use of our personal lived experiences connects the personal and political. The expansion of capitalism expresses itself in what I experienced as a leader of the movement, which includes unpaid care work of poor women, sexism, racism, and wealth inequality. For the AIDS activists through their social movements mediating class struggle raises popular consciousness and hopes for emancipation. It was within the above-mentioned context that my personal diagnosis laid bare the politics of medicines, social injustice, and human rights violation.

In South Africa, like in many countries, poor people had to struggle to realize their human right to access affordable, lifesaving medicines, especially because people's right to access healthcare tends to be undermined by patent right. Santos (2015), argue that human rights discourse can be a powerful tool of resistance and emancipation if it's the hands of a radical movement that hopes to counter hegemonic neoliberalism(De Santos, 2009) .I as the scholar-activist am a human rights activist, subscribing to the definition that views rights as social instruments over the liberal conception of rights on the basis that the former encompasses redress of injustice. There are varying views about what human rights are, and the human rights academic literature ascertains that there are four human rights schools of thought. It suggests that there are natural scholars (Araral, 2013; Perry, 2000) who think of human rights as given. The deliberative scholars (Campbell, 2011; Derrida, 2003; Hannum & Ignatieff, 2006; Reyes, 2007) claim that human rights are political values that liberal societies choose to adopt; social movement scholars (Baxi, 2007; Stammers, 2009) are concerned with redress of injustice and that human rights claimants are often the less privileged, oppressed or those who advocate on behalf of others. The discourse scholars (Brown, 2004; Correa-Cabrera, 2018; MacIntyre, 1986; Mutua, 2013) claim that human rights exist only because people talk about them. Discourse scholars are convinced neither that human rights are given nor that they constitute the right

approach to address social justice, and they fear the domination of human rights (Dembour, 2010). Although human rights instruments such as the universal declaration of human rights (UDHR), especially article 25(1) (1948), guarantee, "everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control," (United Nations, 1948) , in the case of many there are no guarantees. On the other hand, the South African constitution (Government, 1996) goes as far as stating that citizens are rights bearers and the government carries the responsibility to fulfill these rights. The government is meant to make provisions for the realisation of rights as a duty bearer. However, the tension between nation-state and neoliberal globalization, which has translated into erosion of the power of states to guarantee rights *versus* transnational powers, including corporations (De Santos, 2009) . In the context of intellectual property rights (IPRS), the value of protecting human dignity and the common good collides with the commodification of life, placing profits above human need. The declaration itself is fuelling the conflict between health as a human right and patent rights, as article 17(1) states that "everyone has the right to own property," and this extends to medicines such as ARVs. Moreover, article 27 of the (United Nations, 1948) states that "(1) everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits. (2) everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author," (UDHR, 1948). Because of this the field of human rights is one in which change is clear because of its international legal respect and worldwide political currency (Barreto, 2014).

1.2 PATENT RIGHTS

Placing a high premium by enforcing and protecting patents is through TRIPS and has public health costs in developing countries. The patent regime also grants scientific innovation protection as a reward through the patent system. The patents provide the right to the manufacturer to prohibit any illegal manufacturing, selling, and importation for 20 years (Maskus, 2000) . The patent, thus, acts as an incentive for the invention. In addition, the patent license offers exclusive rights to the manufacturer to sell without competition.

The IP regime is, thus, exclusive, and it prevents others such as generic manufacturers from competing in the market (E Hoen et al., 2011). It means that in the case of medicines, you could have a lifesaving drug that is unavailable in a country while millions of people are dying, because the price of ART is too high and no cheaper generics are allowed because of the greed of the patent holder. As a result, the prices of HIV/AIDS medications are driven by monopolies, denying people and government the option to buy drugs from cheaper countries. ART transforms the life of a person living with HIV from facing an untreatable death sentence to managing a chronic disease and is hence hailed as one the most important scientific advances of the twentieth century. (Bourdieu & Nice, 1998) observe that neoliberal capital is a project that gives big business free rein through incentivising the inventors and in the process ignores other collective structures in a given country. In essence, the IP regime benefits the interests, power, and privileges of economic elites. The pharmaceutical companies tend to pursue their narrow business objectives at the expense of poor people's human right to health. High medicine prices have enabled drug monopolies to make huge profits from HIV/AIDS medication, mainly because of limited patent examination and regulation.

The IP regime needs strong regulations for patent examinations to prevent ever greening by pharmaceutical companies seeking the extension of patents. South Africa is well known for approving high volumes of patents on pharmaceuticals, which are estimated at 36,067 international patents compared to only 10% (4,064) domestic patents between 2005 and 2015 (J. Berger & Rens, 2018) . By contrast, Brazil, which conducts significant scrutiny in approving patents, has approved a mere 273 patents between 2003 and 2008 (Correa, 2011) . The South Africa's patent office does not examine whether patent application enforcement of national patent licenses are met, instead, the Companies and Intellectual Property Commission (CIPC) registers any patent based on whether the proper paperwork has been filed and the fees paid, not substantial review of its originality (Hill, 2014). The patent licenses influence medicines' affordability and related access for the majority of poor people in developing countries. Thus, health cannot be a commodity. Health is not an object or product that can be bought and sold for profit, in a marketplace. Turning health into a good or commodity brings little regard for the lives of the majority of poor people of the world. Commoditisation is unjust but also precarious as it frames access to healthcare as a privilege rather than a right. Human rights are internationally and domestically enforceable. Health in the context of IPRs has become a tradable and commodified good, resulting in the erosion of human rights. In addition, IPRs are reproducing health inequities, especially within capitalist countries.

The commodification of public goods, such as health, is a structural driver of inequities, such as race, class, and gender. IPRs come into conflict with human rights in countries where health is a basic right or a progressively realisable right. Hence, AIDS activists are interested in ensuring public and policy traction with respect to human rights, public health interests, and trade. There are inherent tensions in the discourse on health, commodities, and rights.

FIGURE 6: HEALTH GAP AND ACT UP ACTIVISTS IN NEW YOW YORK MARCH 2001

[Source: ACT UP, 2001]

When activists (figure 6) link the problem of unaffordable medicines to medical apartheid, they are essentially generating public awareness about the unjust practices of private interests over public interests. Globally, multinational pharmaceutical companies enjoy dramatic profits from sales of essential medicines. The "naming and shaming" of drug firms has grown into a key feature of many social movement repertoires (Krinsky & Crossley, 2014). Activists' naming of particular actors as responsible for injustice is fundamental in the policy process. On the other hand, the corporations' markets are in poor countries in the South, and their products accounted for 27% of the South African AIDS drug market in 1999 (Richwine, 1999) In most cases, the profits from multinational sales amount to more than the gross domestic product (GDP) of all of the twelve Southern African Development Community (SADC) countries. These multinationals often claim that developing countries are trying to steal their property.

Intellectual property rights derive from the WTO, which was established in 1994, with its mandate for trade negotiations. Essentially, WTO excluded poor people in their negotiations about fundamental trade matters, such as the intellectual property of medicines, amongst other issues. Further, in most cases, trade negotiations occurred in closed spaces without the voices of those whom these medicines should benefit. The AIDS response in South Africa needed to include access to AIDS medicines to treat the millions that were dying prematurely from AIDS. Nevertheless, the prices of ART at the time made them unaffordable and could have led to a fiscal crisis. AIDS treatment affordability and accessibility for the majority of poor people living with AIDS in the 1990s fundamentally shifted the notion of human rights and AIDS activists' participation in matters relating to medicines and patents. The implementation of the TRIPS agreement gained significant media attention, because it occurred at an important juncture in the HIV/AIDS era: the rise in HIV prevalence, the development of effective first-line AIDS treatment and the high cost of the drugs emerged simultaneously. Intellectual property rights and governments' unwillingness to use their legislative power to treat their populations stood in the way of people's access to lifesaving medicines such as antiretroviral treatment.

A year after the formation of the TAC, the South African government, under President Mandela, proposed the Medicines and Related Substances Control Act amendments (section 15C) and signed the amendments into law in December 1997. The act allowed the minister of health to declare conditions under which the supply of affordable treatment must be made available to protect the health of the public. This attempt by the South African government to improve legislative measures to allow for the progressive realisation of the right to access affordable medicines for the majority of poor people met opposition from pharmaceutical companies. At the time, the intention of these legislative reforms was related to all essential medicines, and AIDS treatment was not even part of the AIDS policy at the time. As a result, the Pharmaceutical Manufacturers Association (PMA), a collective consortium of 39 major pharmaceutical companies, filed a lawsuit in June 1997 against the South African government. The PMA challenged the constitutionality of the amended Medicines and Related Substances Control Act before the High Court of South Africa in February 1998 (case No 4183/98). The pharmaceutical companies' argument for the court action was that "parallel importation of drugs would undermine the ability of pharmaceutical companies to charge different prices in different parts of the world."

Moreover, they argued that a the pricing strategy permits wealthier countries to subsidise developing countries, and the drug companies still get profits they need for research, (Hoen et al., 2011). The pharmaceutical industry is in the business of producing ARVs and therefore sees patent rights as incentives for innovation. These companies claim ownership of lifesaving drugs, and whether others struggle to access those medicines or not is their main concern. The moral and human rights questions emerged. In an attempt to block the implementation of these amendments, the PMA took the South African government to court. An important development in the TAC's advocacy strategies was the decision to contest these questions of intellectual property (IP) and human rights, both within and beyond the formal institutional space, mainly through protests and petitions demanding affordable and accessible medicines. Below, I discuss a few examples to show how the TAC strategically used a myriad of advocacy tactics to participate in IP and AIDS policies around access to AIDS treatment. These tactics included litigation, protests, petitions, negotiation and social mobilisation.

Regarding the participation of the TAC in this policy matter, the organisation strategically joined an interesting case in support of the right of poor people living with HIV/AIDS to health. This TAC position on the lawsuit meant that they sided with the South African government. Amongst other actors with vested private interests was the United States government, which sided with drug companies to pressure the South African government, arguing that the amendments were equivalent to defying patent rights. This set-in motion the beginnings of AIDS treatment battles both locally and internationally. The TAC activists took the case as a political opportunity to grow their movement. Their application to join the South African government's side as friends of the court (amicus curiae)[4] in January 2000 was strategic (for a full account of the case, see (Mark Heywood, 2002). The TAC is founding amicus application sought for the court to recognise the following: the broad need for affordable medicines for all illnesses that affect the population in South Africa. The TAC argued that the extent of the HIV/AIDS epidemic was life-threatening in nature and that the efficacy of medicines used to treat opportunistic infections and the virus itself, and the rights of members of the TAC who lived with or were directly affected by HIV/AIDS, provided compelling examples of circumstances where some of the measures contemplated by the Act, specifically section 15C, 22F and 22G, are necessary so as to protect the health of the public.

[4] There was no formal collaboration between the TAC and the government, or even formal communication concerning this intervention.

Further, the TAC argued that people with HIV/AIDS, like all other people in South Africa, would benefit from the Act's primary aim, which was to ensure greater access to medicines that were not only of tested quality and efficacy but also more affordable. For people living with HIV, the need for affordable medicines is urgent and a fundamental human right advanced through the Bill of Rights. These rights include the rights to dignity, equality, and life, the right of access to health care services and the duty of the government to comply with international obligations. Additionally, the TAC's application brought public health interests to scale and drew attention to the impact that HIV/AIDS has on people living with HIV/AIDS, health care professionals who treat patients with HIV/AIDS, and the public interest in the treatment of HIV/AIDS (Mark Heywood, 2002). The TAC assembled a legal team, headed by the AIDS Law Project (now known as Section27) attorneys Anita Kleinsmidt, Teboho Motebele and Advocate Liesl Gerntholtz. Furthermore, counsel also included Matthew Chaskalson, senior counsel Gilbert Marcus, and advice from Advocate Daniel Alexandra and Advocate Jonathan Burger. "For the first time, the pharmaceutical industry will have to justify to South Africa and the world why their drug prices are so high and why the aggressive protection of patents when millions of people are dying, and cheaper drugs exist," (Mail&Guardian, 2001). However, admission as amicus curiae was dependent upon the consent of both the state and PMA. As anticipated, the "PMA declined TAC consent, thereby committing a tactical blunder as their refusal led to the trial within a trial (in limine) dispute to decide whether hearing the TAC's arguments add value by the court," (TAC008 Interview, 2015).

On 6 March 2001, the admission of TAC by the high court, which said, "people living with HIV/AIDS have a right to be heard in this case," was a small victory for the people. At the same time, while drug companies attacked the South African government both in court and in public rebukes, the TAC and its international allies intensified their insurgency against multinational companies. "The pharmaceutical companies have already delayed this case for three years. Every day's delay means no affordable medicines and more people dying," said Dr. Eric Goemaere, Head of Mission for MSF's programs in South Africa." (Afrol News, 2001). Activists framed the PMA actions as delaying implementation of the act and said that those delays would cause further premature AIDS-related deaths. In South Africa, activists launched public protests targeting the leading drug companies that were part of the lawsuit as well.

3.4 BATTLES IN COURT, TRADE POLICY AND PUBLIC OPINION

The presence of the activists, in this case, I argue expands notions of who can and should participate in IP-related matters. The exclusion of poor people and their movements in trade and IP negotiations forces citizens to participate through other avenues within the institutional participatory framework. The use of courts has become a popular space where activists make human rights claims and force other actors to come to the table to negotiate who otherwise would have ignored their public protests, actions and demands. However, movement participation in court cases needs to be narrow, technical and limited to only a few people. Trial arguments proceed in a highly technical fashion and require specialised skills to make effective arguments. To complement this important but narrow avenue for participation, and to shift the public discourse on the IP issues, the TAC also launched a media campaign and social mobilisation so that the public could be engaged in what was happening in the courts. The court case thus became one of the first policy opportunities for the TAC and activist allies in the United States to test their abilities to contest IP, to catalyse transnational solidarity and alliances, and to open up opportunities for mobilising both resources and expertise.

The TAC had the opportunity to emerge as a contender for AIDS treatment in the public eye, giving it energy and public attention. The court hearings lasted from February 1998 until November 2001. During this long period, poor people living with HIV/AIDS had no access to cheaper AIDS treatment. By late 1998 in South Africa, the price of the traditional first-line regimen of ARV medicines (zidovudine [AZT], lamivudine [3TC], nevirapine [NVP], didanosine [DDI], and stavudine [D4T]) was approximately R450 (US$64) per month (MSF, 2007). The South African government soon came under enormous pressure, however, from the US pharmaceutical industry, which enjoyed the support of the US government. The alliance between the US government and the drug company industry was instrumental in hounding developing countries to reform their IP laws to protect patent rights. For example, in May 1998, the South African government met with US government patent experts and congressional staff and attended a United States Trade Representative (USTR)-chaired US government interagency meeting attended by State Department officials. At this meeting, US government officials reiterated the US demand that South Africa comply with its international obligations to ensure adequate and effective protection to pharmaceutical patents.

The South African Health Minister Zuma pledged that it was not the South African government's intention to use Article 15(c) to abrogate patents or open the floodgates to parallel imports (Bond, 2003; Moyle, 2015). Nonetheless, the US Department of Commerce made an administrative decision to withhold preferential tariff treatment from certain South African exports in the early summer of 1998. While the US government pressured South Africa, other developing countries, like Brazil, with similar health challenges of high HIV/AIDS prevalence, began to manufacture generic ART. They used locally manufactured drugs in a market large enough to produce the economies of scale necessary to bring the cost of individual doses within an affordable range. However, developing countries that were at the forefront of providing ART began to experience the consequences of pharmaceutical patents on HIV/AIDS drugs.

In Thailand and Brazil, patents significantly limited the legal space to produce lower-cost generics, resulting in a heavy burden on public health budgets. The Brazilian government also came under pressure from the US government, being accused of violating TRIPS. In Thailand, government attempts to locally produce generic AIDS drugs did not go very far after the United States threatened to impose tariffs on their goods to the US. Thailand's intellectual property regime did not need to respect the higher IP standards required under the existing international standards, but US government pressure led the Thailand government to reform its patent law in February 1992 to comply with these demands. Around the same time, the USTR began an inquiry into India's intellectual property laws with specific interest to the Indian law's contempt for pharmaceutical product patent protection and its far-reaching involuntary licensing provisions. After India refused to accede to the US, President Bill Clinton partially suspended India's duty-free treatment under the Generalized System of Preferences, withdrawing about $80 million in benefits on exports. Thus, country-level activists' resistance had severe consequences both for governments and for people living with HIV/AIDS. However, unlike in Brazil, India or Thailand, in South Africa, the expanding pharmaceutical industry's entrenched patent law and the government lacked the capacity for local generic production of ARVs. The extent of the US government's involvement in the protection of patents was deeply problematic. For example, this speech by US trade representative to the US Congress in 1996 demonstrates this deep collusion between the US government and multinational pharmaceutical companies: "If the American firms are to take gain of the global demand for their products, rely on foreign governments to protect their valuable property rights." This public contention from Gore means that the AIDS crisis in developing countries had to be resolved within the IP framework, protecting the monopoly power of drug companies around the world.

3.5 ACTIVISTS PROTEST AGAINST BIG PHARMA

The TAC activists applied various advocacy strategies, such as meetings, pickets, marches, hunger strikes and patent breaking, to pressure pharmaceutical companies to drop the case. In TAC's launch statement in December 1998, it called for a fast on Human Rights Day, 21 March 1999, to "pressure the pharmaceutical sector and government to address the inequitable and unaffordable access to AIDS treatment for all people with HIV/AIDS."

FIGURE 7: TAC CAMPAIGN POSTER

[Source: TAC, 2000]

The TAC activists' initial protests targeted big drug companies, such as Glaxo Wellcome offices, which were in the big cities such as Johannesburg and Cape Town. Pharmaceutical companies that had offices in Cape Town and Johannesburg became easy targets for activists' pressure, because the TAC had just begun to grow its membership and support around the poor townships. One of the TAC's first actions was working with the NAPWA on the Fast to Save Lives campaign in front of Chris Hani Baragwanath Hospital (TAC History Archive, 2010) . This kind of performance of contentious politics connects the personal (body) to the political (economy), using fasting as a collective political tool during policy-making and political conflict. It relied on coverage in the media to communicate the movement's demands and garner public support for the personal sacrifice of people living with HIV/AIDS. The connection between their illnesses and the political economy of AIDS treatment struck a chord with the public. As (Tarrow, 1999) argues, hunger strikes demonstrate self-sacrifice, which conveys valuable symbolic meaning in nonviolent collective actions. The TAC's choice of symbolic tactics, like fasting or hunger strikes, is common in contentious politics (Beresford, 2004).

During this campaign, activists took to the streets of Braamfontein and Soweto, visiting clinics, hospitals, schools, shopping centres and bars, collecting 13,000 signatures demanding access to treatment (TAC History Archive, 2010). After that, the TAC activists rolled out some protests targeting drug companies and how the US government supports them. On July 5, 1999, the TAC held a protest outside the Consulate of the United States of America in Johannesburg. The picketing activists were calling for an end to US government interference with SA law making, and specifically questioned US government support for the litigation of the Applicants against the Amendment Act. On the 22 September 1999, another protest outside the offices of the first PMA Applicant handed over a memorandum to Ms. Maureen Kirkman, head of scientific and regulatory affairs at the PMA, demanding unconditional court case withdrawal as the basis for a negotiated settlement. Simultaneously, the TAC activists in Cape Town were also applying pressure to the Seventh Applicant and submitted a memorandum of demands to Mr. Ben Plumley and Ms. Vicki Ehrich. At the same time, the TAC activists applied pressure to drug companies that were meeting with government. For example, on 30 September 1999, the TAC activists met with the Minister of Health, Dr. Manto Tshabalala Msimang, and the Director General of Health, Dr. Ayanda Ntsaluba, emphasising the need for a rapid resolution of the court case.

The TAC activists' statement on September 13, 1999 demanded "unconditional withdrawal of the case." Because they knew that a statement was not enough to force PMA to pull out of the case, they applied more pressure on the streets. On November 30, 1999, the TAC activists met with the Chief Executive Officer of the First Applicant, PMA, Mrs. Miryeena Deeb, Ms. Maureen Kirkman of the PMA, and a representative from Abbott Laboratories. Again, the TAC requested the withdrawal of the court action and discussed the contested section 15C as per their earlier memorandum. Mrs. Deeb offered to return to the TAC activists before January 15, 2000, with what the PMA considered a suitable re-wording of Section 15C of the Medicines Act. At the same time, the TAC activists held a peaceful prayer vigil outside the PMA offices to commemorate those who had died of AIDS-related illnesses in 1999. As a result, six months later, in June of 2000, mediation between the TAC and the First Applicant and its members was due to take place in Johannesburg, facilitated by Justice Edwin Cameron and Dr. John Matjila. The PMA representatives, however, unilaterally withdrew from the agreed mediation process, without explanation. The mounting local and global pressure from the TAC activists and their allies in South Africa pushed the pharmaceutical companies into a corner publicly.

3.6 AIDS TREATMENT GLOBAL SOLIDARITY

The relentless aggression by the American government against South Africa's latest revisions to the Substance and Medicines Act attracted global attention. US AIDS activists made a political opportunity of the fact that US Vice President Al Gore was one of the presidential candidates in 2000. The activists' strategic alliance with the media occasionally leaked information, such as financial links between Al Gore and drug companies funding his presidential campaign, making it possible to accuse him of having double standards. They targeted Gore's public campaign, attempting to discredit his presidential candidacy. The activists' actions included holding public events where they shouted, "Gore's greed kills!" Ralph Nader, who was also running for US president at the time, openly attacked Gore for engaging in scandalous harassment tactics to prevent South Africa from implementing policies designed to expand access to HIV/AIDS drugs (Bond, 1999). Pressure mounted when 200 AIDS experts wrote a letter to Al Gore's office, echoing the concerns that AIDS activists had expressed to the US government in August 1999. At one point, activists even locked Al Gore out of his office. These events forced the US government to listen to activists, leading to a chain of noticeable shifts in US government and public discourse.

For example, US government invited activists to a meeting in the White House to discuss their concerns. President Clinton also assured the public that the US was committed to access to cheaper AIDS treatment during his speech at the Seattle WTO meetings. While the WTO held talks in Seattle, thousands of AIDS activists protested and disrupted the meeting proceedings, highlighting that trade policies must also consider sick people around the world. Transnational AIDS activism developed policy and political opportunities and resources afforded by access to electronic communication and mobilisation for a wider spread of campaign spaces internationally. Tarrow (2005) argues that transnational movements are successful only when they can link to global places, networks, and opportunities while maintaining their close ties to the domestic context. The AIDS movement is an example of a successful transnational movement. Both the Northern and Southern AIDS activists produced opportunities for collective action avenues, such as the PMA court case against the South African government, while political policy issues, which transpired around AIDS treatment access, created some. Locally, the TAC activists' advocacy strategies were evolving into more sophisticated, radical ways that were not new in South Africa. The activists introduced a defiance campaign against drug companies, which meant breaking the patents.

The campaign involved illegal importation of safe, effective and good-quality Dipluran generic medication as a public way to challenge the drug company Pfizer. The plan was to, upon arriving in the country, hand the medicines over to medical doctors within TAC networks to prescribe to poor patients with candidiasis in public health facilities. This tactic entailed an illegal importation of generic medicines from Thailand to defy the patent abuse by Pfizer. The planning of the patent breaking was highly secretive, very risky and required precision planning. After engaging with a few of the TAC supporters seeking help, Morne Visser, a local actor, agreed to support the TAC by taking part in the defiance campaign while he was in Thailand for a holiday. Upon his arrival back from Thailand on 13th January 2001, the TAC activists gathered at Cape Town International Airport to welcome the actor, who was bringing generic fluconazole for the public sector. In November 2001, the Medicines Control Council (MCC) granted these patients a conditional exemption for the use of the unregistered medicine, under Section 21 of the Medicines and Related Substances Control Act 101 of 1965.

Following the MCC success, about 1,500 people held an interfaith service and March on the 12 February 2001, to condemn Drug Company profiteering and to ask the government to produce generic antiretrovirals. This was a small, yet significant, victory for the TAC. Because of activists' pressure, Pfizer ended up donating its fluconazole to the state for two years. This was a victory for the people. However, people continued to die due to lack of access to fluconazole, as Pfizer's 'donation' had not reached the public sector hospitals. On July 9, 2000, during the Durban AIDS conference, the TAC and its allies organised a Global March for Access to HIV/AIDS treatments, which was attended by over 6,000 people. A memorandum was addressed to the South African government and the International Federation of Pharmaceutical Manufacturers Association (IFPMA) calling for an end to the litigation. The AIDS activists formed a strong coalition with the Congress of South African Trade Unions (COSATU), who were part of the delegation that handed the memorandum to the Minister of Health, Dr. Manto Tshabalala-Msimang, the Executive Director of the Joint United Nations Programme on AIDS (UNAIDS), Dr. Peter Piot, and the President-elect of the International AIDS Society, Dr. Stephano Vella. Moreover, AIDS activists globally continued to protest on March 5 2001 in New York City. Over 200 demonstrators joined ACT UP, Health GAP and other groups in the Global Treatment Access Campaign for a rally and March against multinational pharmaceutical company profiteering and patent abuse. The demonstration was a response to the call to action and request for solidarity from AIDS activists in South Africa. The response during the global day of action against Big Pharma shook the media airwaves.

Protests against AIDS drug companies held in 30 cities by 250 organisations across the world. These protests were in places such as Brazil, the Philippines, Thailand, Kenya, England, Germany and France. Activists carried pairs of shoes. At these protests, shoes were symbols conjured by the popular imagination, dumped outside the gates of drug company offices to signify lives lost because of the high price of medicines. At the same time, in South Africa, on 5 March 2001, the PMA court hearing took place in the Pretoria high court, and 5,000 AIDS activists marched to the high court. The local and global actions together were one of the first 21st century transnational coordinated AIDS actions ever seen. It looked like the world was rising to the AIDS movement entreaty, which Snow, Soule and Kriesi argue gave a collective voice to the concerns of people and was inherently oriented towards change (Snow et al., 2007). After long dialogues, the PMA's legal team announced to Judge Ngoepe on 19 April 2001 that the PMA unconditionally withdrew the case against the government and that all costs (except those of the TAC) would be borne by the applicants (PMA). A three-year legal battle had dissolved. Although the withdrawal was not legally binding, implementation of Section 15(C) of the act provided mechanisms for the state to bring cheap medicines into the country. The TAC's presence in the court case was a strategic moment, and this achievement gave it a public boost to keep pushing the boundaries of power. The balance of power was shifting, and the TAC activists were becoming pundits in AIDS treatment advocacy. Activists celebrated a victory. The TAC activists' presence in court exploded into struggle songs, while the PMA and its legal team left the room with their tails between their legs. This case undoubtedly had an impact on South Africa and the Doha Ministerial Conference in November 2001.

The outcomes of the Doha negotiations on TRIPS recognised that "each developing country has the right to use TRIPS flexibilities to protect the public health of its populations against pressure by multinational companies' reading of trade laws."[5] AIDS activist attention now turned to the South African government. The collaborative engagements between government and the TAC activists on the PMA case proved beneficial for both parties. The next phase, however, shows how the TAC and government began to drift apart and become adversarial when the TAC began to make demands on the state to develop and implement new AIDS policies for treatment access.

[5] DOHA Declaration on the TRIPS Agreement and Public Health, Ministerial Conference, Fourth Session, (WT/MIN (01)/DEC/W/2)

The Doha outcomes did not stop Big Pharma for the continued attempts to interfere with developing countries' attempts to improve access to essential medicines. Without ongoing activists' vigilance in the late 90s gains will be lost. For example, in 2014 the front page of the Mail and Guardian January 17, quotes the South African (SA) Minister of Health, Dr. Aaron Motsoaledi, who accused the Pharmaceutical Industry Association of South Africa (PAISA) of genocide (De Wet, 2017). A leaked document exposed the Innovative Pharmaceutical Association of South Africa (IPASA), a trade association of 26 multinational pharmaceutical companies plot to stall the South African government's intellectual property (IP) policy reform (Azrak, 2014). According to the Treatment Action Campaign and its allies (TAC, 2014), the Department of Trade and Industry organised a meeting in August 2011 to obtain comments from external stakeholders who wished to influence the IP policy, but representatives of civil society were not invited to this meeting.

The pharmaceutical industry and the vigilant global treatment movement were aware of the implications that SA actions had on patent laws related to the availability of affordable medicines in low- and middle-income countries. South Africa's revised IP policy met fierce opposition from the industry, even though the planned reforms were within the realm of the World Trade Organization's TRIPS agreement (Hill & Hupe, 2014) . The PAISA plotting strategy document mentioned financial resources invested in the accomplishment of the plot (monetary value of USD 600,000). The financing a local organisation in South Africa by the Pharmaceutical Research and Manufacturers of America (PhRMA), with the intention of hire politicians promote the objectives of PhRMA while rejecting the IP policy reform agenda. Of course, the PAISA distanced itself from the "PharmaGate" saga as soon as it became public knowledge (Beaumont, 2014) in extract (figure 1) of the leaked email is below.

FIGURE 8: DELAY THE INTELLECTUAL PROPERTY POLICY FINALISATION

From: Azrak, Michael [mailto:michael_azrak@merck.com]
Sent: 10 January 2014 12:18 PM
To: Mavundla, Gauta P; pierre.bosch@alcon.com; steenkamp_morne@allergan.com; COLLEEN PURDY (colleen.purdy@amgen.com); karl.friberg@astrazeneca.com; frans.labuschagne@bayer.com; Andrew.eve@boehringer-ingelheim.com; Andrew.Bird@bms.com; Barry Wren (barry.wren@covidien.com); Jenny Wright (jenny.wright@galderma.com); Anne Gillman (anne.gillman@ge.com); kventer@its.jnj.com; ann-marie@lilly.com; Darryl.Langford@merckgroup.com; Dougy Kevan (dkevan@norgine.co.za); Luciano Marques; TKED (TIMOTHY KEDIJANG); Louw, Hendrik J; 'Daniel, Brian (Brian.Daniel@pfizer.com)'; burcak.memisoglu@roche.com; JohnA.Fagan@sanofi.com; Steve Speller (steve.speller@za.netgrs.com); john.norman@takeda.com; Val Beaumont; Shakira Ramlakhan
Cc: Hawkins, Lyn; Carew, Louise; shanti.naidoo@alcon.com; Mthembu_Thabelwa@Allergan.com; mazuba.mwale@astrazeneca.com; vasinthie_moodley@baxter.com; monica.martin@bayer.com; sue.taylor@boehringer-ingelheim.com; Christine.Jacobsz@bms.com; alina.mokhali@covidien.com; Ilne.woller@galderma.com; vhughes@its.jnj.com; kateres@lilly.com; kbirkholtz@merck.co.za; Brownlee, Michele; CMokwele@norgine.com; caurrider.longwe@novartis.com; ntnd@novonordisk.com; dede.boughey@pfizer.com; michelle.maher@roche.com; Chantal.Davies@sanofi.com; desree.murgatroyd@za.netgrs.com; lori.harding@takeda.com
Subject: FW: ACTION REQUIRED: Agreement to proceed with Stage 1of IP Campaign- DUE by January 15

Dear Colleagues,

I hope you and your families had the opportunity to enjoy some well-earned rest over the holiday season. I look forward to working with you as we build a stronger IPASA in 2014.

I wanted to provide each of you with an update of where we stand with our work regarding the proposed IP Policy and to gain your agreement on the path ahead. To date it appears that the IP Policy has not been submitted to cabinet for endorsement, therefore we need to continue our activities to ensure we bring more balance into the IP debate.

As we agreed at the last Board meeting in December, we have moved ahead in identifying a high calibre consultancy group to work with us. The group selected is Public Affairs Engagement (PAE), a Washington DC based team led by former US Ambassador James Glassman. This group was selected after a detailed process, where we received proposals from a number of agencies both Local and International. The final selection was carried out in consultation with PhRMA. As part of this work PAE will contract with a local Public Affairs/Lobby team to ensure we have 'constant in country support'. It's currently proposed that Abdul Waheed Patel of ETHICORE (CT based) may be the local partner, but this will be confirmed after Stage 1 of the campaign.

The attached file outlines the proposed campaign in detail. You will notice that we will be staging this campaign. Stage 1 is to commence from January 17 – February 15 and Stage 2 from February 15 through to June 15. The detailed activities under stage 1 in the proposal are merely summarised, IPASA and PhRMA will hold the consultants to the indicated deliverables per a comprehensive project plan and SLA.

Key Objectives of the Campaign:
The overall campaign is aimed at delaying the finalization of the IP policy by the Cabinet until after the 2014 election. Delay will provide time to develop a third stage of the campaign: establishing a strong, comprehensive IP policy and, at the same time, a new strategic approach to health care policy in South Africa, supported by the Vision 2025 study.

Key elements of the Campaign
Mobilize voices inside and outside South Africa to send the message that the proposed IP policy threatens continued investment and thus economic and social well-being. This mobilization will occur through an energetic campaign, which will feel like a political campaign. With well-constructed and supported activities t

The theme/message of the Campaign:
A comprehensive IP policy is needed, but if South Africa rushes into the policy offered by the Department of Trade and Industry, it will be doing great damage to the country and helping competitors such as Nigeria. Moreover, patents do not impede access to medicines; industry stands ready to be a partner with South Africa in finding sustainable healthcare solutions. It is now time for cool heads to prevail. Slow down and devise a better policy.

Investment:
The total investment for this 5 month campaign will be circa US$450K. PhRMA will contribute $350K & IPASA will contribute $100K. In addition, IPASA will be responsible for the remainder of IP activities in 2014, with a reserve of $150K for any additional activities. So in total we will invest approx. $600K in IP related activities in 2014. Our IPASA contribution will be R2.5m (slightly less to what we were agreed to invest at the December Board meeting).

I'm confident that this positive, forward thinking and proactive campaign is what we need to bring balance back into the entire discussion around IP and access to medicines. PAE have worked successfully with PhRMA in other countries with an established track record.

What we need from you:

1) Please **discuss and gain agreement from your above country**/Global HQs on our planned approach. We do not want a situation where above country teams have not been informed and they delay our progress by asking to be brought up to speed. I'm counting on each of you to have detailed discussions with your above country teams. If you need further clarity on any item of our strategy Val/Shakira or myself are at your disposal.
2) **Please revert by COB next Wednesday January 15**, if you or your above country teams have any concerns or reservations activating Stage 1 of the campaign (January 15 – February 15). We can gain agreement on Stage 2 activation at the next IPASA board meeting on February 5. If I do not receive a response from you, then we will assume you and your Global organisations are in agreement with moving ahead with Stage 1.

I'm sure you can sense my urgency; however, we have been successful to date as we have maintained our momentum. We can't afford to wait until February to get this campaign moving. The first four weeks will be critical in setting the foundations for a very successful outcome.

Please let me know if you have any questions or comments.

Kind regards,
Michael

Michael Azrak
Managing Director
MSD Southern & East Africa

[Source: MSD leaked email, 2014]

The TAC General Secretary Vuyiseka Dubula made the following statement:

> The Treatment Action Campaign is outraged over what appears to be a covert and well-funded plan from the foreign pharmaceutical industry to delay an essential law reform process in South Africa. It takes us back to the turn of the century when 39 pharmaceutical companies took President Nelson Mandela and the South African government to court to try to stop legislative reform to improve South Africa's ability to access affordable life-saving medicines. Now, just weeks after his death, foreign pharmaceutical companies are coordinating another major attack on this right. We call for the urgent finalisation and release of the Department of Trade and Industry's long-awaited Intellectual Property Policy. Any further delays are unacceptable and will have far-reaching impact on the provision of public health. We will not allow foreign industry to derail this national process, especially in such a secret and underhanded way. The TAC fought before and we will fight again now to protect the Constitutional rights of all people in South Africa," (TAC, 2014).

When civil society received a leaked version of the draft policy, it was clear that multinational pharmaceutical industry associations were being consulted by the state before the public. This occurs in the context of forceful global restricting of production undermining developing countries' public health interests. For example, in the extract in figure 1, the Innovative Medicines South Africa (IMSA) represents big multinational pharmaceutical companies who as a block outlined their opposition to the reforms promoting access to medicine through their comments on the official policy draft. In May 2012, a draft of an IP reform document was leaked to civil society, and the document already contained extensive comments from the pharmaceutical industry, thus revealing that that industry is consulted prior to the involvement of civil society. This special privilege to comment to a public policy prior to the majority of the poor people who the IP policy will affect was not easily granted. Holloway's contention is that the state does not operate in vacuity but rather is knitted in global social and trade snares in the era of globalising capitalism at its centre (Holloway, 2005). Lack of access to medicines, especially antiretroviral treatment (ART), has been a key source of health inequity in post-apartheid South Africa. "The cost of licensed pharmaceutical products amplified profits of international drug companies thereby escalating the public health challenges in South Africa in meeting its health policy goals," (Bond, 1999:766).

Further, he raises concerns about the impact of globalisation in terms of the role of profit motives as an incentive in essential pharmaceutical products, and the depth of democracy in a country such as South Africa. The global market trend favours health as a commodity that creates precarious notions of health as a privilege rather than a public good and a right. Hence, AIDS activists as indicated above and the TAC succeeded in compelling multinational pharmaceutical companies and the South African government to improve HIV policy regarding access to lifesaving ARVs for people living with HIV and AIDS (Padarath and Friedman, 2008). One of those health challenges facing South Africa is HIV, which has exacerbated the country's prolonged public health burden. The adult population living with HIV estimate is 7.5 million, and high HIV incidences estimated at 1,000 new infections daily (Stats SA, 2018) pose major challenges far beyond health.

In the late 1990s, the cost of AIDS treatment ranged in price from USD 7,944 to USD 20,224 per person per year (Perez-Casas et al., 2001), preventing any significant progress in the AIDS response without affordable ART for poor people living with HIV and AIDS. My introduction to the politics of HIV and its treatment began with my journey of taking an HIV test at the Green Point community health facility on April 5, 2001. At 22 years old, I was naive and unassuming about the implications of a positive HIV diagnosis. The test outcomes showed a severely compromised immune system, with a CD4 count of 215 mL (per millilitre of blood), making my body prone to opportunistic infections such as tuberculosis. If I lived in a developed country or had money, I would have qualified to be initiated on ART as soon as possible. To add to my dismay was learning that there was no treatment in public health facilities, which left me mentally, emotionally, and physically vulnerable. Access to AIDS treatment was the only thing standing between my life and death. Consequently, the poor population of people from disadvantaged communities such as the townships and rural villages of South Africa organised themselves and resisted the government's neoliberal HIV policy (Cousins et al., 2013), which was imposed through unaffordable and inaccessible medicines in many poor countries, including South Africa, India, and Thailand.

3.7 GOVERNMENT AIDS RESPONSE

3.7.1 GENERALISED HIV EPIDEMIC: NEW CHALLENGES FOR PARTICIPATION

HIV, like any other epidemic, is not just about health. It is a socially, economically and politically contested terrain. Every epidemic determines who is vulnerable, what should be done to respond, and how decisions about the policy response are made. In the case of South Africa, the changing character of the epidemic and who it has affected shifts who is included and excluded from AIDS policy development. AIDS policy-making in South Africa emerged as a more centralised response to AIDS. While some civil society groups were included in policy processes, they failed to transform AIDS policy into an inclusive and effective policy. Epidemics link people to governments and democracy. HIV in South Africa presented new challenges for popular participation. The interaction between the AIDS epidemic and governance is deep and problematic. Thus, the AIDS response requires the mobilisation of institutions and power. This section describes the character of the epidemic and the new questions about participation that arose from it.

The AIDS epidemic initially emerged in South Africa as a concentrated epidemic, but it had a somewhat different trajectory from that of Northern developed countries. Concentrated epidemics are restricted to certain subgroups of the general population. Thus, the early signs that announced that there was an AIDS problem here began with men who have sex with men (MSM) in the early 80s. The HIV prevalence thought to be concentrated amongst white gay men, after the initial discovery of the two gay men believed to have recently travelled to the United States, revealing a concentrated epidemic similar to that of the US. However, these cases began to pick up speed in the late 80s (N Geffen, 2010) . In Johannesburg's gay community early reports suggested steep increases in infections (Lawson, 2008). During this phase, there was barely any policy participation of people living with HIV in any state responses. Three years after the first cases were found, the apartheid government established the AIDS Advisory Group (AAG), made up of white men, to drive the AIDS strategy, with no trace of the most vulnerable in the policy decision-making. As a result, the apartheid government response was a centralised administrative AIDS unit made up of bureaucrats to promote awareness in gay communities.

A demonstration of the state's lack of inclusion in its AIDS approach was the introduction of regulations to quarantine people living with HIV/AIDS (for a 14-day mandatory and then indefinite isolation) as their attempt to control the epidemic. While this was the state response, the prevalence increased to about 120,000 living with HIV (McNeil, 2015) by 1990. At this point, those affected by the disease were in the main excluded from meaningful participation in policy development processes. The AIDS epidemic transition shifted the situation from a concentrated to a generalised epidemic (Karim & Karim, 2002). Evidence from early community surveys showed new HIV cases amongst sex workers, people with haemophilia, and mineworkers. Events took a sharp turn discovery of cases of HIV amongst people with haemophilia and commercial sex workers in stored specimens from community-based research from as early as 1987. Further, three cases of Malawian mineworkers with HIV were also identified around 1985-86. The first two cases, in rural heterosexual women in the former Transvaal, were reported in pointing to a growing generalised epidemic beyond just key populations. South Africa was experiencing a new wave of the HIV epidemic, which was no longer just amongst specific sub-populations upon (Karim and Karim, 2002). Traces of an emerging generalised epidemic were picking up speed. To date, the HIV/AIDS epidemic has continued to spread, with heterosexual transmission accounting for 90% of the reported cases in the southern parts of Africa.

These new cases connected the dots between the socioeconomic structural determinants of HIV, which influenced the gender, age, and migration-related distribution of the South African HIV epidemic. As the early HIV epidemic trends from rural Hlabisa communities in KwaZulu-Natal indicate, HIV prevalence increased from 4.2% in 1992 to 34.0% in 1999 amongst women attending prenatal care age (Karim & Karim, 2002). In addition, while rapid spokes in HIV infections amongst teenage girls, they remained low in teen boys of the same age, indicating a feminised epidemic. The apartheid government had no incentive to mobilise public resources to address HIV/AIDS vigorously ((Fourie, 2006) . There was profound neglect of poor people's health needs. Without a doubt, the dawn of democracy in 1992 brought public euphoria that inspired new energy for meaningful policy participation, but these were unmet hopes in the HIV response. By 2003, (UNAIDS (Joint United Nations Programme on HIV/AIDS), 2006) reported that women were severely affected in their prime years (from age 15 to 49), accounting for almost 5.1 million of those living with HIV/AIDS. The antenatal surveys also confirmed the extent of HIV, with 24% of women testing HIV positive.

Population-based surveys from the Human Sciences Research Council (HSRC) expanded the data on HIV prevalence and behaviours associated with the spread since 2002. This affirmed the evolution of the epidemic to a more generalised character that required diversification in the conception of who was affected and most at risk and, thus, who needed to be included in AIDS policy-making. The epidemiological evidence showed that it was poor women who were most at risk. The connections with HIV/AIDS, poverty, and social inequality added a layer of exclusion for those who needed to participate in policy development. This raises important issues about how to include the most affected in AIDS policy processes. At a global level, people living with HIV were beginning to position themselves within the AIDS response and came together in 1994 to agree on principles of their participation, signing the Greater Involvement of People Living with HIV and AIDS Declaration (GIPA).

GIPA is envisaged as one of the fundamental commitments to shift towards participation of PLHIV in service delivery processes that affect their lives (Cain et al., 2014) as argued in Chapter One, the participation of poor people in policy developments became popular in the 70s, within a particular period of globalisation. With neoliberal economic policy development came with patronising forms of participation further promoted cost-shrinkage mechanisms using social groups of poor people to deliver services that had historically been part of the state's role (Cornwall & Gaventa, 2000). For example, the growth in HIV/AIDS organisations that provide services not necessarily interested in politicising their participation in policy development is a challenge. Scholars in East and Southern African countries such as ((Birdsall & Kelly, 2007) argue that there has been significant growth in HIV/AIDS civil society since the early 1990s, reaching a peak between 1996 and 2004, the same period of reduced state accountability. This growth indicates a problem in the state responsibility for the AIDS response; it also shows a growing AIDS burden that falls squarely on the shoulders of community-based organisations. This represents the failure of the neoliberal foreign development approach in grasping the long-term complexities of developing country government bureaucratic and political arrangements. This, in turn, affects popular participation in AIDS policy developments.

3.8 MANDELA'S AIDS RESPONSE: 1994-1998

The Mandela administration brought much-needed optimism for building participatory policy processes in which the poor and most affected could influence the AIDS response. In the post-1994 era, popular participation was seen as part of the democratic transition (Heller, 2012) with the Constitution protecting supreme human rights values. Law brought optimism for newly revived prospects for the poor to influence policy developments. Democracy entails governance between the state and its populace as a condition for popular participation in policy and politics in the terms and purposes of the people. To that end, the participation of AIDS activists and their social movements in the AIDS policy-making process serves not just as an ideal but is a necessity for deepening democracy.

The first phase of Mandela's administrative AIDS response began with promising opportunities for these collaborative engagements with AIDS activists, but I argue that these relations could not bring significant change in the AIDS epidemic and affected people during policy implementation of the first NAP. A combination of weak state accountability and civil society engagement hampered meaningful participation during the development of the NAP. Consequently, the state made a series of unilateral policy errors, such as the Sarafina II scandal and Virodene saga, which led to the breakdown of trust between the state and civil society. Before South Africa could deliver on its full democratic potential, the impact of AIDS on the public health system, society, micro-macro economy and political processes needed an emergency response in the post-1994 era.

3.8.1 CONTEXT FOR THE NATIONAL AIDS PLAN

The pre-1994 context had strong networks of anti-apartheid activists in the AIDS NGOs, AIDS researchers and health workers who were keen to help the newly elected ANC government. The political and policy atmosphere was conducive to AIDS policy participation, and the new government was open to collaboration. Some, as a consultative, inclusive, human rights-centred framework for policymaking (Nattrass, 2004), hailed the Mandela administration. At the same time, the impact of AIDS was felt by those on the frontline of the response such an AIDS activists and healthcare workers, who had expectations for a speedy process to develop and implement an AIDS plan. In addition, the dawn of the new democracy brought the human rights approach as an anchor of all its social policy approaches.

The articulation of rights-bearers, obligations and responsibilities for upholding these rights through the Constitution (1996) demonstrated this human rights framework. There was no doubt that there was a need to ensure that social policy took the human rights framework as central. The requisite for an urgent response to AIDS was predictable before the democratic dispensation in South Africa. Therefore, the NAP was part of the policies developed by the ANC government in waiting as it prepared for governing South Africa. Moreover, the ANC health activists such as Stein, Susser, Tshabalala-Msimang, and Dlamini-Zuma who served on the Health Committee for Southern Africa amongst other committees while in exile led the process of the NAP(Lawson, 2008). During this period, there was no ideal institutional policy participation for the majority of poor people in South Africa. The NAP development process became one of the priorities for the ANC government, to create space for a multisectoral policy development process as a foundation in the new democratic dispensation. The National AIDS Committee for South Africa was one of the first attempts to bring together diverse groups of people and organisations to mobilise policy consensus to shape the AIDS response in South Africa. The AIDS policy discourse, however, faced anti-imperialist critique and skepticism of a Northern-driven diagnosis of the problem or biomedical responses. The AIDS crisis narrative and the democratic transition in South Africa permitted some level of political distrust. The South African historical and political upheavals contributed to residual distrust around the science of AIDS, sparked by the debates around the association between HIV and AIDS. Questions about the cause, transmission and necessary response to HIV were highly politicised.

The late onset of AIDS in South Africa, where few cases were recorded in the 1980s and were among white homosexual men and Malawian migrant miners, was, incidentally, a potent argument against those who would reject the existence of an HIV pathogen (Marks, 2002). Some within the circles of the ANC in exile publicly denounced the conventional scientific claims about AIDS in black communities as racial stereotyping. Earlier assertions by the apartheid government regarding the racial profiling of the AIDS epidemic as, first, a “white gay men’s disease” and later a “black women’s disease” increased scrutiny of AIDS discourses in general. The narrative origins of the virus follow suspicion about the colonial “masters’” involvement in the possible spread of the AIDS and its discourse to further undermine Africans. Moreover, some of the assertions that AIDS originates from the African continent intersect with racist prejudices against black people.

The existence of alternative and contradictory hypotheses about the origins of HIV further complicated matters. There were early reports that AIDS originated in West Africa in the 1930s. Others claim that it originated from the United States in the 1960s. Others claimed that the cases in Congo fueled the perception that AIDS originated from Africa. While others claimed that, it originated from the Norwegian sailors in the 1970s. Doubts about the origins of HIV traced to the ANC's journal, Sechaba,[6] in two articles on HIV/AIDS. In those articles, Nxumalo, writing under the name 'Mzala' (Mzala, 1988) drew from some of the East German scientists that seemed to suggest that HIV was imported into Africa through an American military conspiracy. Nxumalo also argued that the vast majority of HIV testing resulted in false positives (Lodge, 2003). Denialism was not simply a problem of Mbeki's, but a reflection of views from the dissident cohort within the African National Congress. Their posture was one of nationalist defiance, denunciation of racism and defiance of imperial power. South Africa faced multiple challenges, and HIV/AIDS competed for attention within the social reconstruction and development agenda of the country. From the political angle, HIV/AIDS and ART were viewed as Western imperial ideologies to control Africa. Thus, the South African political leaders' pursuit of independent "solutions" sounded appealing to some political quarters. Perhaps taking inspiration from the great words of Fanon that Africa must craft its tools and wage a relentless battle against any form of imperialism, (Fanon, 1972) AIDS may have been classified as such:

> AIDS has fallen victim to the same process of bedevilled health under capitalism, where medical facts are often over-dramatised for the sake of making huge profits for the drugs industry, (Mzala, 1988:22-31).

Further, Mzala is arguing here that the narrative that AIDS is a public threat is an attempt to shift the new South African democratic society into a "middleman" role for global capital, thereby disrupting the project of liberation. However, there were inconsistent assertions in these claims across all socioeconomic policies of the ANC, making it almost hypocritical and selective in its rebuke of global capital. Nevertheless, the subsequent adoption of the neoliberal economic policy is similar to acting like the "foreman of big capital." AIDS policy, like many social policies, has become the victim of globalisation, which came with capitalism. Therefore, consistency in policy approaches is crucial so as not to apply selective rebuke and hypocrisy.

[6] Sechaba was an ANC monthly journal and magazine before liberation.

However, Mzala's views were not shared by many of the South African scientists and antiapartheid activists like Zena Stein, Mervyn Susser and Malegapuru Makgoba, who were amongst the first to recognise the impact of AIDS,"(Karim & Karim, 2002) from their early exposure in the United Kingdom and United States. Stein, Susser and Makgoba were amongst those who spoke out, together with the global community of science, to unequivocally establish a peer-reviewed causality of HIV and AIDS. HIV/AIDS had begun to cause a real public health threat (Van der Vliet, 2004).

3.8.2 DEVELOPING THE NATIONAL AIDS PLAN

The ANC approach to AIDS policy-making during the Mandela administration was said to be conciliatory, consensual and bottom-up and took a populist, participatory direction with broad stakeholder inclusion in the process (Fourie, 2006). The NAP signalled a new political environment, euphoria and spirit of solidarity brought by the dawn of democracy. The conference in Lusaka to develop the NAP was attended by 450 delegates from diverse (102) organisations of various sectors. This includes political parties, trade unions, civil society, and the private business sector funded by the European Economic Community (EEC) through the Kagiso Trust (Lawson, 2008 ; Mbali, 2013b; Moyle, 2015). Political activists and civil society activists brought insights and experiences from both South Africa and exile (European and other African countries). Notably, the conference occurred during the heightened enthusiasm of the pre-democratic period, and thus political activists from exile took control of the processes.

The Maputo conference thought that it was a power game for political elites. There were elements of centralised power within the ANC (which were not new), and they permeated this space. This created tensions with local political activists and civil society activists. As argued by some who participated in the National AIDS Coordinating Committee of South Africa (NACOSA) processes, the "Maputo conference was more about power and NACOSA became the internal movement where the exiles took control of the space," (Indep006 Interview, 2015). Meanwhile, GIPA emphasised greater involvement of PLHIV, meaning that national AIDS councils had to include PLHIV representatives to show visibility and voice to people who were mainly affected. Within the participation literature, it is debated as to which people to include and exclude. As (Lawson, 2008) argues, a group or person's gain is equal to another's loss. Thus, direct vs collective popular participation is unachievable as imagined in the GIPA.

Participation of PLHIV is often unattainable because the default mode of operation is that the elite control policy processes, including the vision and technical writing processes; the PLHIV were merely involved in the programmatic areas of policy-making. During the NAP development process, people living with HIV/AIDS such as Peter Busse and Shaun Mellors expressed that although they were invited to the NAP conference, they "felt excluded in key decision-making". Some of the officials expressed that the speeches of people living with HIV at the conference were pushing an HIV-positive self-pity and gay politics narrative in the wrong conference. Fleming's views were that AIDS activists were being diverted from bigger issues (Lawson, 2008). The AIDS activists clearly did not embrace this tokenistic role and instead organised their collective voices through their organisations and pioneered a social and human rights response to HIV/AIDS. Their advocacy strategies, however, tended to be collaborative relations with the government-in-waiting. For example, the launch of the HIV/AIDS and Human Rights Charter (AIDS Consortium, 1992) which was designed by the non-state actors, was endorsed by the ANC. The ability of social movements and civil society organizations to hold the state to account was compromised, since they were often not truly independent actors but were instead too closely aligned with the ruling party.

This conference strongly recognised a human rights foundation for the formation of the NACOSA, marking the first inclusive, broad-based, and multi-sectoral AIDS policy-making body(Fourie, 2006). Following the political negotiations and elections, a culture that demanded participation had emerged. However, despite the fact that HIV/AIDS policy actors collectively understood the epidemic growth as a unique crisis requiring multi-sectoral coordination, government leadership of health policy-making was often the norm. At the inception of President Mandela's administration, there was wide support for the national HIV policy framework and some level of institutionalisation of policymaking. The NAP process was not without a cost. For example, the NAP was estimated to be R256.77 million, which is ten times the HIV/AIDS budget and the staffing needs at the time (Mbali, 2013b). The NAP became an approved government AIDS policy in October the same year. AIDS activists' participation, however, was by invitation and limited to being faces of the anti-stigma interventions. The NAP was also heavily focused on prevention, reducing social impact and mobilising all stakeholders at all levels towards an effective NAP.

At the time when the NAP was developed and approved, there were barely any institutional mechanisms for participation at local levels to monitor implementation. In fact, some scholars argue that the NAP implementation was almost fully loaded on the government to effectively implement, with very little oversight from other sectors besides the state. The belief that the ANC government was going to solve all problems was soon disappointed, when the NAP struggled to get off the ground. Thus, it is argued that for people living with HIV/AIDS, participation in the NAP was tantamount to functional participation (Buccus & Hicks, 2007), in which the only intent is to increase programme efficiency and effectiveness. Although it seems that there was no obvious malicious intent by the ANC government to limit participation, it is also the responsibility of social groups such as the NAPWA to monitor government. Some of this centralisation of AIDS policy making was also the result of global understandings of best practice for national AIDS responses. High-level global institutions viewed state involvement as crucial to provide political leadership in the AIDS response. Hence, the emphasis on the location of the AIDS programming in the presidency. In South Africa, HIV/AIDS became one of the presidency-led programmes, competing with other pressing programmes such as reconstruction and development. The government also took a cue from President Museveni of Uganda's precedent of being hailed and often cited as an example of political commitment through a high-level personal willingness to make AIDS a central issue of government. This role included resource mobilisation and fast-track implementation. Hence, political commitment became a key ingredient crucial in HIV/AIDS policy-making at all levels of governance. However, political will did not automatically eliminate policy implementation difficulties experienced by the government. Political will assumes that political leaders such as Mandela are enough for policy change. Scholars argue that strong government with good institutional capacity as well as political will make a strong state (Reich, 1995).

Political will is acknowledged as a necessary policy enabler in developing countries, but not the only ingredient (Grindle & Thomas, 1991). In the AIDS policy process, political will is critical to its success in the Ugandan AIDS response. So, even in South Africa, political will by the Mandela administration was seen as a way to move the AIDS plan faster. Nevertheless, this did not yield the intended results. "The first time President Mandela spoke about AIDS at all was in February 1997, nearly three years after he took office. Also, he did not even speak on AIDS when he was in South Africa," (Edwin Cameron quoted by Breslow, 2013) .

Political rhetoric alone could not solve all the policy implementation challenges at the provincial level. Implementation needs more than strong political leadership. The promise of NAP began its descent into failure with its silence on the use of ART and deficiencies in its implementation. As a result, HIV prevalence rose from 1.8% in 1994 to 10.1% by 1999 (Wouters et al., 2012). Many scholars point out that NAP overstated the capacity of the public health system to deliver on its promises (Schneider et al., 2006). Additionally, the location of the NAP within the Department of Health rather than a multisectoral effort was a blunder (Wouters et al., 2010). Policy implementation requires a vibrant civil society that will hold government accountable for the services it provides. Some of the challenges with the NAP implementation process lay with provinces that had limited power over weak district health structures that, in turn, had barely any relationships with nongovernmental networks (Schneider & Stein, 2001b) . Such a policy context is bound to result in power struggles between government coordination and decentralisation of the NAP and civil society's involvement. One of the most common reasons given for the difficulties in implementing AIDS policy in South Africa is "lack of political commitment".

However, the more involved politicians are in policy implementation, the more other dilemmas emerge, such as the problem of wanting to control implementation. The politicians could mobilise the much-needed resources for NAP implementation, but in the process, the involvement of politicians also created a favourable funding environment for other social movements such as the NAPWA, resulting in numerous problems such as AIDS "scandals" like Sarafina II. As a result, the Mandela administration made damning blunders in their first phase of implementation of the NAP, in search of quick and locally brewed solutions. The AIDS policy environment also radically shifted within two years of the NAP implementation, affecting its prioritisation. The effects of the 1996 neoliberal economic policy that the South African government embraced shifted our fiscal space into conservatism. This manifested in the famous new government policy of the Growth, Employment and Redistribution Programme (McIntyre & Gilson, 2002), which marked a transition from the Left-Keynesian macroeconomic policy approach. This shift had significant impact on the poor due to less public expenditure on public policies.

This was met by rebellion of the poor through organisations such as the Anti-Privatisation Forum (APF), the Landless Peoples Movement (LPM), the Anti-Eviction Campaign (AEC), the Concerned Citizens Forum (CCF) and Alexandra Renewal Project (ARP) (Luke Sinwell, 2009a). The policy shift characterised the early years of democracy and disinflation, privatisation and cuts in public expenditures, which affected the implementation of the AIDS plan. Implementation of the AIDS plan initially relied on increased public spending, something that shifted significantly under the new GEAR policy. The negative impact of the macroeconomic policy framework on implementation of the AIDS plan, and its targets became inevitable. As a result, pressure for budget cuts placed on all aspects of public sector service provision (McIntyre & Gilson, 2002) became the norm. The state defended its actions as necessary in ensuring macroeconomic stability for investment, growth and redistribution (Cleary et al., 2004) by prioritising limiting the social spending within the stringent government budget and those actions that negatively affected health spending as well. Thus, private investment, and consequently the privatisation of health care, was favoured over redistribution and social spending, which had a dramatic impact on the health sector. Under the GEAR austerity programme, real government social spending declined by 1% per year (Walle et al., 2010). Nonetheless, some attempts were made to create an inter-ministerial committee on AIDS, forcing all national ministries and government departments to formulate policy on AIDS. We learned later, however, that these structures do not always yield the intended results and sometimes tend to obstruct progress.

3.8.3 GOOD POLICY ON PAPER, NO IMPLEMENTATION

The first four years after 1994 were marred by conflict, apparent lack of progress, and a breakdown of trust and co-operation, both within government and between government and NGOs (Schneider & Stein, 2001b) . The location of the AIDS programme was within the health department. By redefining HIV/AIDS as solely a public health problem, the policy response ignored social, economic and behavioural factors that drive the spread of HIV and its consequences (Marais, 2001) points out those attempts to merge the medical and socio-political paradigms were unsuccessful. Equally important, the NAP also fell into the hands of the Ministry of Health, which brought its politics and a reluctance to consult with the community. Moreover, positioning the plan within the Ministry of Health contradicted initial multi-sectoral, consultative and inclusive aspirations.

The posture of the leadership on the plan was skewed towards health, overestimating the internal capacity of the state to implement such a complex, multisectoral plan. This blunder undermined the ability to frame AIDS as a developmental and human rights concern and later was said to undercut the subsequent implementation of the plan (Fourie, 2006). The AIDS plan was assigned as a central responsibility of national government, as the leader, funder and implementer. This was counter to a South African quasi-federal system, which articulates concurrent competencies and powers between all levels of government. The one national government is responsible for policy development, while the nine provincial governments are responsible for policy implementation. Thus, the responsibility for implementation of most public functions, such as the AIDS programmes, lies at a provincial level, not national. Moreover, the ANC government was new and had limited provincial capacity to implement the NAP. This is where the NAP was very optimistic with its implementation goals, goals it fell short on because it did not take into consideration the many challenges of transition from the old apartheid government to the new democratic government. AIDS activists were accommodated in the AIDS policy implementation through pragmatic elements such as being "AIDS ambassadors." Through the NAPWA efforts and collaborations with the Department of Health, DoH created 12 positions for AIDS activists to be AIDS ambassadors[7] (Indep0087, 2015) . The NAPWA also led the public anti-stigma campaigns, with an intention to visualise the silent and degrading effects of the AIDS epidemic and humanise those it affected. This provided symbolic participation in the response and very limited influence in the decision-making and direction of the NAP.

Other NGOs linked to the NACOSA became service providers for interventions such as counselling, testing and education and awareness programmes. This arrangement made it more difficult for civil society to maintain its independent monitoring voice and hold the state to account for the pace of NAP implementation. Although democratisation of AIDS policy-making was flawed, it laid foundation for building inclusive policy making. In practice, though, the NAP lacked a multisectoral approach and high-level political leadership. HIV/AIDS was originally positioned as not only a health condition but also as a social issue which requires political and medical response.

[7] AIDS ambassadors were HIV-positive people who were open about their status and played a role of being public faces of AIDS in order to encourage openness and visibility and challenge stigma.

The making of the early forms of AIDS exceptionalism by verticalising emerged and making AIDS a special deadly virus that needed high-level political commitments through the presidential-led programmes. Nevertheless, this became mere rhetoric; AIDS did not appear to be a priority for President Mandela in the early years of the new democracy. Accordingly, the implementation process revealed a noticeable disconnect between the intentions and the reality of policy, consequently preventing the NAP from achieving its goals (Mcintyre & Klugman, 2003). Challenges with the NAP implementation soon emerged in the form of blunders, as Schneider and Stein argue, such that the ensuing period of the good policy was harmed by interference from senior politicians. (Nyamukachi, 2004) defines political interference as when a department's political heads instruct accounting officers to take decisions, which are in breach of legislative, and policy rules. More often than not, it involves certain individual's appointment in certain strategic positions. This was later revealed in the NAP review conducted in 1997 (South African Government, 2000). The findings of the review identified challenges such as the lack of a multisectoral implementation approach and heavy reliance on the Department of Health as the sole driver of implementation, limiting broad-based reach and impact. However,(Schneider & Stein, 2001a) argue that the national AIDS plan review paid limited attention to analysing the NAP policy and the political environment that led to poor implementation . This included lack of political will from Mandela's leadership on AIDS, which had an impact on the success of implementing the NAP. As (Nattrass, 2007) points out, it took Mandela's administration almost three years to make a first major statement against AIDS.

3.9 FAILING INSTITUTIONAL PARTICIPATION

Although the Mandela administration is viewed as inclusive, with a multisectoral plan, it failed to implement the AIDS policy. Afterwards, a series of scandals further discredited government actions, including the Sarafina II and Virodene sagas. The Sarafina saga came about after the Ministry of Health awarded an R14 million contract in a non-transparent manner to Mbongeni Ngema Sarafina II (a musical theatre). The size of the contract finally became public knowledge through the media after six months, causing an outcry from all non-state sectors against the lack of consultation (Lodge, 1998). The matter also became an issue in parliament among opposition parties, and the Office of the Public Protector launched an investigation. In addition, the public protector found widespread administrative and tender irregularities (Protector, 1996).

Consequently, the public protector recommended termination of the Sarafina II contract. There were no consequences for the minister, who had an oversight role in this major contract. All that the Mandela Administration's 1996 review alluded to was a reflection that the Sarafina II saga as one of the ANC's key AIDS mistakes of the year (Schneider & Stein, 2001b). The Sarafina saga was not the last mistake, though, as the Virodene incident hit the airwaves soon afterwards. As Ndebele (2011:61-64) , "There was this sense that this drug would offset the perception of Africans as substandard and less capable, all eyes were upon the ANC and expectations were high, so the ANC was driven by the need to show the world that African can do it and Virodene was the redemption. The Virodene saga of February 1997 began after a Cabinet press statement about the development of a South African treatment for AIDS. This claim for a newly found cure came from a group of researchers from the University of Pretoria that approached the minister of health for funding for a breakthrough treatment; they scored an audience with Cabinet. The drug, known as Virodene (actually, an organic solvent), was tested in a few volunteers living with HIV/AIDS, deceptively but with some success.

However, a later enquiry into Virodene by an independent panel of scientific experts revealed that this study had not passed basic biological and animal testing. Both the university ethics committee and the Medicines Control Council turned down applications for further testing in humans. Once again, a controversial media fight ensued. This earned government a fair share of criticism from the medical professional bodies as well as HIV activists (Geffen and Cameron, 2009). The state's unwillingness to receive advice, and an extensive account of the saga, are detailed by (Myburg, 2007) . There was a substantial public outcry from people with AIDS and the medical profession. The AIDS policy environment had become an open ground for corruption, wasteful expenditure, disorganised state action and weak state accountability. The government through the Inter-Ministerial Committee (IMC) in 1997 led the first post-1994 institutionalised participation process. This method of participation came as a recommendation from the NAP's review and shown to work in other countries such as Uganda. The IMC, however, tended to be heavily government-focused and involved barely any popular participation. The presidency was seen as a crucial enabler and leader of the AIDS response in providing high-level political will. The IMC used a highly centralised and top-down policy-making process, with limited popular participation. The IMC was the first high-level structure established to oversee the state's response to the HIV/AIDS policy at a time when HIV/AIDS was growing at an alarming rate.

Thus, increasingly, the exclusion of people living with HIV/AIDS from decision-making about a policy that affected their lives. A shift in participation had to occur in the late 90s towards inclusion of PLHIV in programs but were not engaged at policy levels. The first contestations around the inclusion of ART came through the main AIDS movements such as the NAPWA established in 1992. The NAPWA reached an agreement that a treatment campaign was necessary to complement the "openness and acceptance" campaign. As (Heywood, 2005a) argues, the treatment campaign was launched as an unapologetic advocacy campaign for the right to health and life. The TAC broke away from the NAPWA in 1998 to advocate for affordable and accessible AIDS treatment for all people living with HIV. These movements had some form of duality in approaches, with inherent contradictions and cruel splits. NAPWA continued with its collaborative engagement with the state, giving an impression of working from within the state corridors of power to shift policy. At this point, the TAC worked with less collaboration and more adversarial engagements with government, indicating this distrust of relying on one approach. Radical approaches were meant to shift the state ART public policy discourse away from paternalistic HIV policy approaches and towards a more human rights–oriented approach. The TAC and the NAPWA's relationship were further strained in the process.

TAC raised global public awareness about the human right of poor people living with HIV to access lifesaving medicines. As discussed in the Introduction, TAC used the PMA court case as an opportunity for activists to argue for the need for cheaper medicines for poor people living with HIV/AIDS. The struggle for AIDS treatment involved both local and global forces. AIDS activists' participation and advocacy have become prominent features in the scholarly literature of political science, sociology and development studies. Moreover, with a society such as South Africa, that has an apartheid history, popular participation in policy processes has become a fundamental concern. By the end of Mandela's term, the state was under enormous public pressure for service delivery, and the state had already become hostile to popular participation (Lodge, 2003). President Mbeki marked the transition between collegial partnership and conflict with government (Heywood, 2005). The relations between government and the AIDS movement around AIDS treatment policy became much worse during his tenure. The perceived alliance between the state and civil society during Mandela's administration was soon to end under President Mbeki.

3.10 MBEKI'S AIDS RESPONSE: 1999-2003

In 1999, new HIV infections reached 600,000, and 24.8% of pregnant women were living with HIV/AIDS (Karim & Karim, 2002). Furthermore, the heterosexual HIV epidemic has had a distinctive character, with catastrophic transmission patterns, no sign of a saturation plateau, and predominance in women at a younger age. The President Mbeki administration had an opportunity to shift state engagements with AIDS activists during the development of the new AIDS Strategic Plan of 2000-2005. This process was less consultative than the NAP process. Although, rhetorically, Mbeki framed this period as an era of partnership against HIV/AIDS, his actions were contrary to this intent. For example, his opening speech at the Durban International AIDS Conference focused on his concern with the cause of AIDS. Activists later described President Mbeki as a denialist because of his public doubts about the scientific link between HIV and AIDS (Geffen, 2010).

The TAC's actions at the Durban AIDS conference in 2000 also provided a moment to solidify its demands in the international audience, and drew battle lines between the TAC and the state. The eleven-year-old and HIV-positive Nkosi Johnson and the HIV-positive judge Edwin Cameron followed President Mbeki's opening speech, which questioned the cause of AIDS. The result was nothing short of fire and oil. Nkosi got HIV from his parents, who did not have access to prevention of mother-to-child transmission (PMTCT); he died later that year. Mbeki's speech defined his later approach to AIDS. The Durban AIDS conference provided the AIDS movement with an opportunity to draw its battle lines and issue marching orders to its members. The presence of the global media spotlight fueled the solidarity of HIV activists and the support of scientists, health professionals and some sympathetic politicians and public officials. President Mbeki's speech at the AIDS conference was a defining moment for the government's adversarial policy engagement with AIDS activists.

3.10.1 THE STATE AS THE FOCUS OF ACTIVIST GRIEVANCES AND DEMANDS

"Change does not come from government; it comes from grassroots to government," (TAC0015 Interview, 2015)

The state became the activists' focal point for the expression of its grievances during President Mbeki's administration; the AIDS policy environment became more hostile because of the engagements with TAC activists. Under President Mbeki's leadership, with the government is questioning of HIV/AIDS science and actively obstructing the use of ART in the public sector (Geffen, 2010; Nattrass, 2007), AIDS became the political issue of the early 2000s. The South African government did not take advantage of the legislative frameworks that would have allowed it to purchase more affordable medication; instead, it made various excuses for not providing treatment access. The state's philosophical aspiration of an African problem manifested itself in the questioning of the science of HIV and Western treatment approaches. Questions of affordability did not hold much weight, as the prices of AIDS medication were dropping fast. The AIDS activists had begun challenging the state AIDS policy on the use of ART for those already positive for HIV.

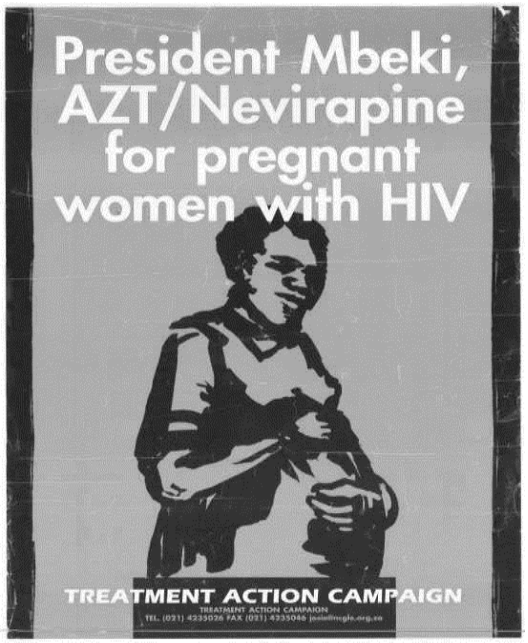
3.10.2 TAC'S FIRST COURT ACTION AGAINST THE SOUTH AFRICAN GOVERNMENT

As earlier argued, the TAC is a rights-based movement that frames its grievances and claims by employing human rights discourse. It uses the constitution and courts as institutional avenues to hold the state to fulfill its obligations. However, the TAC deploys its tactics beyond institutions, with public demonstrations, social mobilisation and civil disobedience, demonstrating its dual strategies in engaging other powerholders (Friedman & Mottiar, 2005). So lawyering is included amongst the myriad of strategies at their disposal. The courts are opportunities for social movements to articulate their claims; constitutions offer resonant frames for a movement's members. Thus, AIDS activists approach the court to construct meaning and life within a constitution that otherwise would be meaningless if not tested. The courts are institutional avenues for movements to articulate their demands and vision and to force government to engage (NeJaime, 2013).

> As you know when the first trials on Nevirapine for MTCT programme was the first antiretrovirals to be considered, at that time government had concerns with knowing very little about these new drugs and side effects. So, Department of Health decided to do small pilot sites and that is when the TAC went to court against us, (NGovt0038-Interview, 2015).

The TAC launched its first court case against the South African government using its human rights frame to make a constitutional claim. The movement argued against the state's failure to fulfil its constitutional duty for the rights of women to access reproductive health care as enshrined in section 27 (1) of the South African constitution (South African Constitution, 1996). The scientific evidence from the Thailand Perinatal HIV Network of Prevention Trials (HIVNET 012) demonstrates the efficacious and safe use of AZT short-course therapy to reduce vertical transmission of HIV from mother to child by 50%(Karim & Karim, 2002) . This scientific breakthrough became an activist tool to demand that the South African government use this evidence to demonstrate its commitment to the struggle of access to ART. This provided an opportunity for the South African government to respond to its HIV crisis in pregnant women. Some of the TAC activists argued that "Minister Dlamini-Zuma's initial reaction to PMTCT was positive, but her attitude shifted when the TAC activists made demands," (TAC008 Interview, 2015). The relationships from then onwards were confrontational.

FIGURE 9: TAC POSTER



[Source: TAC, 2001]

There was no shortage of help from civil society. According to MSF, an international medical humanitarian organisation, their "experience from other parts of Africa such as Kenya on their programmes of vertical transmission of HIV from mother to child, had an internal dialogue about the possible expansion of their PMTCT experience to South African poor resource settings," (MSF0028 Interview, 2015). In 1999, they approached the National Department of Health, where they met with two senior government officials to offer their help in exploring a PMTCT collaboration with Alexander Township, Gauteng. The state response stunned the MSF team, who were asked to go against science and offer a PMTCT intervention that did not use ART Darder & McGregor & Devine, 2014) .There has never been an effective non-ARV-based PMTCT intervention, but this was indicative of internal government politics around the science of ARVs and HIV. Compelling government to introduce a new policy intervention, such as a PMTCT programme, also requires fiscal investment in health infrastructure and human resources that might otherwise not be in place. Most importantly, in early 1999, Zuma claimed that budget shortfalls is due to pressure to cut their public expenditure and comply to the structural adjustment of gross domestic product ratio 9% in1994 to 3% by 1999, thus I argue that the state failure to provide of AZT to pregnant HIV-positive was just seen a mere collateral damage. Nearly 30,000 lives would have been saved with universal provision of AZT for pregnant women, at the cost of about US$13 million per year (Bond, 1999). It makes matters worse; the reduced ART prices could have helped the government but the official government statements from Parks Mankahlana (the presidential spokesperson in 2000) continued to feed the public a narrative of cost. He argues that "the HIV-positive mother is going to die and that HIV-negative child will be an orphan. That child must be brought up. Who is going to bring the child up? It is the state, the state. That is resources, you see, that provision of PMTCT to sick, pregnant, HIV-positive women its cost is beyond just the ARVs but a great a burden for the state welfare services to bear (Roux, 2000). The state argued that it was not affordable to save babies whose mothers were going to die anyway and leave them as orphans. A generation of AIDS orphans and child-headed households resulted (Cullinan & Thom, 2009).

Balancing the government fiscal constraints and the duty to protect the right to health for the population is critical. The introduction of PMTCT is a net gain for poor people and public health that goes beyond the direct benefit received by the people in need of treatment. This formed a basis for the TAC's legal action against the state's failure to provide PMTCT.

The TAC activists approached the courts to challenge the state over its refusal to provide single dose NVP to HIV-positive pregnant women. It argued, further, that the government should be ordered to make PMTCT available in all public health facilities. Anything short of this, the TAC argued, was a violation of the right to healthcare and therefore unconstitutional. The federal government arrangement between national and provincial government worked to the advantage of the movement. Whilst the national government rejected use of ART in preventing mother to child transmission of HIV, the Western Cape government went ahead to consider the HIVNET 012 trial results as a basis to explore piloting two PMTCT sites in Khayelitsha (Hodes & Naimak, 2011), and the partnership began (Abdullah, 2004). Khayelitsha, a semi-urban township on the outskirts of Cape Town with a high HIV prevalence, was an ideal place for MSF to provide support. "The Western Cape government at first resisted, fearing poor uptake of PMTCT by communities (WCDoH001Interview, 2015).

During this period, HIV prevalence in Khayelitsha had reached 15% and was increasing to 30% by 2002 (MSF, 2009). Furthermore, three out of ten pregnant women attending public health clinics in South Africa were HIV positive; this represents approximately 280,000 women each year. The TAC PMTCT campaign gave hope to many young black women who found themselves diagnosed with HIV while pregnant (TAC0039 Interview, 2015) but were not offered any HIV prevention interventions. Similarly, the campaign also offered courage to children who had a chance to escape HIV infection. The constitutional framework offers the poor some institutional judicial recourse and resolution when the state does not deliver on its duties. However, activists approach courts knowing their decisions will not be enforced or implemented (NeJaime, 2013) without social movements' vigilance. Participation of poor people in policy is articulated in the constitution. It is within this context that activists make use of all institutional participation avenues to offer space to the government to explain its policy decision and negotiation. Three of South Africa's nine provinces broke ranks with government policy and initiated their PMTCT programmes. I argue that this demonstrates that the state is not a homogenous unit, rather parts that can be taken advantage of by activists to advance their cause. Moreover, I contend that activist took advantage of the various political differences adds more to the ruptures of the state. The Inter-party conflict sometimes advances the government ruptures and to the advantage of movements or demise. For instance, there have been clear attempts by the ANC to undermine local government in the DA-controlled city of Cape Town.

For example, the MSF Khayelitsha and DA-led Western Cape provincial government partnership began its PMTCT programme in 1999 and expanded across the province. TAC activists demanded expansion of PMTCT sites. When the Khayelitsha subdistrict of the City of Cape Town disobeyed the National government and rolled out ARVs in the Western Cape it was a demonstration of those concurrent powers' dynamic at play. And political parties undermined each other all the time (Cameron, 2014) to score popular votes or opinion. Similarly, other provinces, such as ANC-led Gauteng and KwaZulu Natal, also followed suite to break ranks with the national government. In the case of the Gauteng Premier it shows that even within one political party cracks again showing that there is no homogeneity as many thinks.

> In the minister's view, the Gauteng premier's announcement is, therefore, in breach of that resolution as well as the earlier Minmec (a forum of Ministers and MECs) decisions setting out the envisaged roll-out programme based on the experiences and lessons learnt from the agreed upon research sites. Tshabalala-Msimang's statement contradicted words from her Director-General, Ayanda Ntsaluba, who said Gauteng's decision was in line with national protocols. Jo-Anne Collinge, a spokesperson for the department of health, said she was not sure whether Ntsaluba had checked his statement with the minister before releasing it (News, 2002.).

A province such as Gauteng could exercise its constitutional power that governs concurrent powers to implement the ART policy regardless of the National Minister of health's blessings. In this case, the power dynamics were in favour of the poor we were waiting for life saving medication. The two provinces went ahead in implementing PMTCT programmes in 2001, without awaiting the court ruling. The national government applied political pressure to the three provinces not to provide PMTCT services. This is indicative that ffederalism is contested the extent to which PMTCT had become a political issue, rather than about providing access to lifesaving treatment. Federalism also serves developmental goals by allowing policies and programmes to be tailored to the specific needs and preferences of particular regions, and may increase transparency and accountability; again by bringing officialdom closer to the people they serve.These provinces demonstrated that government insistence that there was no capacity to introduce PMTCT services in the public sector was not true. The above examples I argue show that federalism serves popular participation by forcing these ruptures in governments in attempt introducing checks and balances that may minimize opportunities for majority tyranny.

However, six out of nine provinces complied rigidly with the government position and did not exercise their constitutional prerogative powers, to the extent of closing down non-government organisations that were providing single-dose Nevirapine to pregnant women (Heywood, 2002). The TAC, in July 2001, sent a letter of demand to the court, and a month later, on 21 August, a court case was filed[8,9] in the Gauteng North High Court. The TAC enjoyed the official support of various key policy actors, such as COSATU, Institute for Democracy in South Africa, former President Mandela, Cotlands Baby Sanctuary, Community Law Centre, the Centre for AIDS Programme of Research in South Africa (CAPRISA), Children's Rights Centre, and other experts such as MSF, Dr. Haroon Salome, and Prof Helen Schneider, Prof Nicola Nattrass, and Dr Jerry Coovadia, demanded government provision of nevirapine to pregnant women to prevent mother-to-child transmission (Heywood, 2004).

Some scholars (Albertyn & Meer, 2008) and other feminists criticised the TAC for its focus on the baby and not women's reproductive health rights. This was viewed as a compromise of women's agency during the PMTCT campaign (see a full account of this in (Mbali, 2013b). As one of the women leaders in the TAC movement, I argue that the PMTCT campaign was never seen as a universal remedy to solve all injustices, but as a short-term tactical solution, a step to universal access to ART for all. By November 26, 2001, the case was argued in court, with government responding that nevirapine was unaffordable, non-efficacious, and unsafe, posing the public health risk of HIV drug resistance for women living with HIV. The outcomes of the court case were positive for the AIDS movement: On 14 December 2001, the Gauteng high court made a resounding judgment in favour of the TAC. The state declared its court appeal to the Constitutional Court, despite the fact the TAC got an interim relief for the state to implement whilst pending the court processes.

[8] TAC founding affidavit filed on 21 August 2001 at Pretoria High Court (RTF) (ASCII Text).

[9] Affidavit by Nurse Stella Dubazana, of Cotlands Hospice. TAC's Affidavit by Siphokazi Mthathi (Text). Robin Wood replying affidavit on nevirapine (Word Document) (Text). Helen Schneider affidavit responding to the state's defence of operational complexity (Word Document) (Text). Hermann Reuter affidavit responding to Nono Simelela allegations about the Khayelitsha PMTCT programme (Word Document) (Text). Prof. N. Nattrass affidavit replying to the affidavit of Dr. Ntsaluba (Word Document) (Text). Allan Colm affidavit concerning the Eastern Cape Health Department's work on combating HIV/AIDS, and the resources available to it. Prof. Cooper affidavit in reply to Dr. Ntsaluba. Quarraisha Abdool Karim reply to Makeable.

The PMTCT programme was then onwards implemented by a court judgement rather than being the practice and evidence-based medicine (Heywood, 2002). The state should provide NVP to doctors in the public sector, who prescribe it after voluntary counselling and testing have been offered. The 2001 judgement was an interim measure, while the case went to the Constitutional Court. The government reluctantly implemented an NVP regimen in May 2001 at two pilot sites in each of the nine provinces, once NVP had been reviewed and registered (after long delays) by the Medicines Control Council (Heywood, 2002). The planned pilot sites were meant to two years, and at a later stage government will decide on a universal rollout. With only 18 sites providing PMTCT across the entire country, the majority of pregnant women in South Africa were excluded from PMTCT programmes. The TAC began its monitoring of the PMTCT rollout and the activist's vigilance exposed challenges with implementation, such as uneven and political opposition to the rollout. Mpumalanga province had only 53% coverage of PMTCT after seven years. Thus, the TAC activists filed a contempt of court application in Mpumalanga. Provincial Executive Member for Health in Mpumalanga, Sibongile Manana, was a loyalist to Tshabalala-Msimang. She took it upon herself to go to the extent of firing doctors who questioned the state on PMTCT policy. Accusing doctors of exploiting black women as guinea pigs to test unsafe AIDS drugs, she continued to terrorise and evict health professionals from the Greater Nelspruit Rape Intervention project who provided ART for rape survivors. The TAC filed a contempt of court application against the Mpumalanga MEC for health and minister of health, which TAC won (Altenroxel, 2002).

Intense pushback continued through the state from the Medical Control Council (MCC), which also began to play games in support of the government's NVP toxicity discourse. The MCC threatened to de-register it on the grounds of toxicity. Evidence was overwhelming from expert allies of the TAC against the MCC evaluation of NVP safety data. When the toxicity argument was not successful, it then became a matter of affordability. Eventually, after two years, the PMTCT pilot sites were evaluated. Hospitals were prevented from using antiretroviral drugs, including nevirapine, a much cheaper alternative to AZT, even for treating rape survivors. Healthcare workers were treated with hostility by the state for their refusal to follow the minister of health's orders not to provide ART. Instead of expansion, the state unilaterally suspended all PMTCT sites, claiming that they had limited effects, since they targeted HIV-positive pregnant women instead of HIV-negative people. The official government statements argued that affordability was the main reason for the suspension.

The TAC and its allies went back to the court to seek an execution order based on irreparable harm, and government appealed this to the Constitutional Court. On April 4, 2002, the matter was heard. This was almost a year and an estimated 100,000 infant infections after the TAC had initiated legal proceedings. The court outcome was in favour of the TAC and dismissed the state judgement appeal. In the end, after many months of court battles, the Constitutional Court judgment compelled the South African government to provide mother-to-child transmission prevention.[10] The TAC activists' participation in the AIDS policy discourse continued and was instrumental in expanding the boundaries of AIDS treatment access for the poor. For HIV-positive pregnant women, the Constitutional Court ruling put the responsibility of their access to AIDS treatment on government(Levy et al., 2005) . Through the PMTCT case, I argue that the TAC activists' participation showed the movement's influence on policy through the courts (a first of its kind) post-apartheid. The scope of participation for ordinary TAC members in courts, however, was limited to being a witness in court or participating in broader mobilisation outside the court. Furthermore, the TAC was slowly approaching a peak in its AIDS treatment access campaign, because PMTCT introduced the drugs in the public health system.

The TAC's advocacy action in this PMTCT case also provided the movement with insight into the complexities of service delivery monitoring, policy implementation and problematic political influence into policy. Going forward, for the TAC activists, victory was needed both in courts and on the street to pressure the government to implement PMTCT guidelines based on international scientific developments and provide the budget required to implement them adequately. Furthermore, the strategic alliances built from strong local associations with expert scientists and lawyers, and the strong presence emerging at the grassroots through social mobilisation strategies to bring women to the movement (F Venter, 2012). This brought a major boost to the movement and grew its imagination about what was possible going forward.

[10] Supporting Affidavits: Affidavit of Second Applicant: Haroon Saloojee (Save Our Babies) (ASCII Text). Affidavit of Second Applicant: Cati Vawda (Children's Rights Centre) (ASCII Text). Affidavit on Epidemiology by Quarraisha Abdool Karim (RTF) (ASCII Text). Affidavit on Medical Science by Robin Wood (RTF Format) (ASCII Text). Affidavit on Economics by Nicola Nattrass (RTF) (ASCII Text). Affidavit on Price of Nevirapine by Chloe Hardy (ASCII Text). Personal Affidavit by Bongiwe Mkhutyukelwa (ASCII Text). Personal Affidavit by Busisiwe Maqungo (ASCII Text). Personal Affidavit by SH (ASCII Text). Personal Affidavit by Tshidi Mahlonoko (ASCII Text). Personal Affidavit by Vivienne Mathebula (ACII Text).

The PMTCT case provided the foundation for the TAC to make further demands for an ART treatment plan. The ruling party and government, however, deepened its defiance. The activists faced criticism, as some (Beresford, 2004) argued that activists such as myself and others were mere poor, ignorant township residents (referring to the black African leaders) in the midst old lefties and marathon runners, (referring to the non -black Africans). These claims assumed that activists are passive actors in politics and the policy space and therefore do not have agency and knowledge to act against the injustices they face—and these claims were far from the truth. No doubt, the TAC's public face was predominantly white, middle-class men, such as Nathan Geffen and Mark Heywood. But, the TAC leaders whom scholars and the media tend not to see included comrades such as Siphokazi Mthathi, Mandla Majola, Linda Mafu, Pholokgolo Ramothwala and many others. This combination of grassroots involvement and middle-class leadership and visibility was an ongoing challenge in the TAC and many movements in South Africa, and are thus not unique to the TAC. The state's resistance to TAC demands was observed in the Mbeki (2001) speech at Fort Hare University where He expresses discomfort with the presence of the TAC activists in the policy space.

> People who consider AIDS movement leaders are protesting in the streets, carrying a placard with their demands. Because (we) the poor are germ carriers and human beings of a lower order that cannot subject its passions to reason, the poor must unavoidably adopt strange ideas, to save immoral and diseased people from perishing from the self-inflicted disease " (Mbeki, 2001).

President Mbeki not only blamed those who contested AIDS ideas but also ridiculed people living with HIV/AIDS as blindly led to foreign ideas of how to solve this problem. Mbeki argued the TAC leaders were driven by racism. President Mbeki was later described as a classic denialist. (Geffen, 2010) argued that Mbeki promoted one or more of the three denialist views about the causal link between HIV and AIDS. Denialism is a process whereby a person refuses to admit the truth of a concept or proposition that is supported by the majority of scientific or historical evidence. This process employs some or all of five characteristic elements, which include belief that something is not true due to disapproval of scientific evidence; believing in fake experts; selectivity in use of insignificant data against dominant consensus; creation of impossible expectations of what research can achieve; and conspiracy theory, misrepresentation and logical fallacies.

As such, Mbeki's submission to the AIDS debate was that people are dying of poverty-related illnesses such as tuberculosis (TB), rather than a virus. Some (Presidency0062-Interview, 2015) who expressed dissent to. (Geffen, 2010) 's view that Mbeki was a total denialist argue, "He points out that Mbeki was not a total denialist but argues for other explanations to the causes of the disease which cannot be proved in the laboratory. Further, Mbeki's earlier reception of Virodene provides that window that he did believe in conventional medicine." The NAPWA added its voice in accusing the TAC of promoting a hidden "anti-government" and "racist" (anti-Black) agenda and officially distanced itself from the TAC. This was unsurprising from NAPWA, which was widely perceived by the informed public as a close ally of government in the fight against the TAC and ART. The NAPWA during the PMTCT campaign period was still enjoying state funding and had chosen collaborative engagements with the government. These public tensions between the TAC and the NAPWA divided people living with HIV and polarised AIDS policy into opposite sides. This marked the beginnings of the TAC, the NAPWA and government's shift from collaboration to confrontation.

3.9 SUSTAINING AIDS ADVOCACY MOMENTUM

Shortly after the publication of a new government HIV/AIDS strategy plan of 2000-2005, President Mbeki framed it as a new era of "partnership against HIV/AIDS," though his actions were contrary to that. His announcement of the formation of a Presidential AIDS Advisory Panel, inviting leading "dissident scientists" such as David Rasnick to review the "hypothesis" that HIV caused AIDS, stunned the country. Further, he claimed that the Sub-Saharan HIV epidemic was an exaggerated status of the disease in the late 90s and, in particular, in 2001, he publically referred to the insulting theory that AIDS originated in Africa. The AIDS advisory panel to produce a 13-page dossier with conflicting assessments amongst its members, at the cost of R2.5 million, while the state argued ART was still not affordable (News24, 2001).

The continued exclusion of the TAC and its allies from the formal forums such as South African National AIDS Council (SANAC) was also deeply problematic and scholars (Schneider, 2002) argue that the exclusion of a number of key organisations such as TAC, the AIDS Consortium and major medical researchers was indicative of the rise in totalitarian policy-making. Likewise, (Heywood, 2005) adds that government AIDS denialism was central in blocking the formation of a democratic national AIDS policy coordination. This created political opportunity for those actors excluded from participating by other means.

Hence, activists invented alternative spaces to influence AIDS policy independent of state approval. The national government's reluctance to engage with the TAC activists escalated through various forms. The hostile political and policy environment escalated under President Mbeki and his Health Ministry, and in response, the TAC activists also ratcheted up their pressure based on the momentum TAC had built up from the 2002 court victory. AIDS treatment activism had momentum, but it was clear that the normal tactics of protests, negotiation and courts alone were not going to be sufficient for success.

3.9.1 AIDS POLICY DEVELOPMENT CONTROLLED BY THE STATE CENTRE

Along with the new AIDS plan, new institutional participation mechanisms were established. The South African National AIDS Council (SANAC) launched in January 2000 with the aim to broaden civil society participation at all levels, replacing IMC on AIDS, led by the Ministry of Health. The SANAC became the institutional platform for multisectoral HIV/AIDS policymaking where government, the people, and private sector were meant to contest, shape and influence policy issues. With the assistance of the UNAIDS, guidelines were established for the HIV/AIDS action framework for policy formulation, coordination of the AIDS response and resource mobilisation within one broad-based multisectoral plan, coordinating authority and a unified country-level monitoring and evaluation framework (UNAIDS, 2002). However, national government continued its reluctance to engage with the TAC activists who were in opposition to state AIDS policy.

While the SANAC was meant to be a multisectoral vehicle for popular participation because of its central location within the Office of the Presidency (Hongoro, Mturi, and Kembo, 2008), it soon became a space for divide and rule, and the opposition was not welcomed. As (England, 2006) argued, centralisation of the SANAC in the state executive office led to co-optation and manipulation and captured the groups involved rather than resulting in the intended executive accountability. During the TAC's PMTCT campaign, the SANAC played no prominent role to counter the state policy position. In this context, institutionalisation and independence of civil society seem more antithetical than complementary, despite the fact that the location of the SANAC at the presidency meant to protect its independence from the national DoH. The hierarchy of power remained, and the leadership remained in the government, with the chairperson being the deputy president of the country.

The inclusion of certain marginalised groups was enforceable through donor requirements, like those of the Global Fund to Fight AIDS, Tuberculosis and Malaria (UNAIDS, 2005), that country-coordinating mechanisms should involve PLHIV in all HIV/AIDS policy decisions and responses. However, this alone was not able to achieve meaningful popular participation. AIDS activists' participation in policy was important beyond just being around the table to check efficient use of donor money; it was mainly to hold government accountable for the entire policy-making process, including resource allocation and responsible spending. However, as limited as it is to rely on donor enforcement for compliance with the inclusion of people living with HIV in a country's AIDS coordinating mechanism, it certainly does create some room for inclusion. The SANAC model of participation was then decentralised in provinces, which ended up with variations of Provincial AIDS Councils. This, at least, allowed for a real test of the quasi-federal governance system during moments when the national government's resistance to ART allowed provinces to break ranks. As described in the Introduction, KwaZulu-Natal, Western Cape and Gauteng represented examples of provincial defiance against a national policy position during the PMTCT case in 1999 and 2000.

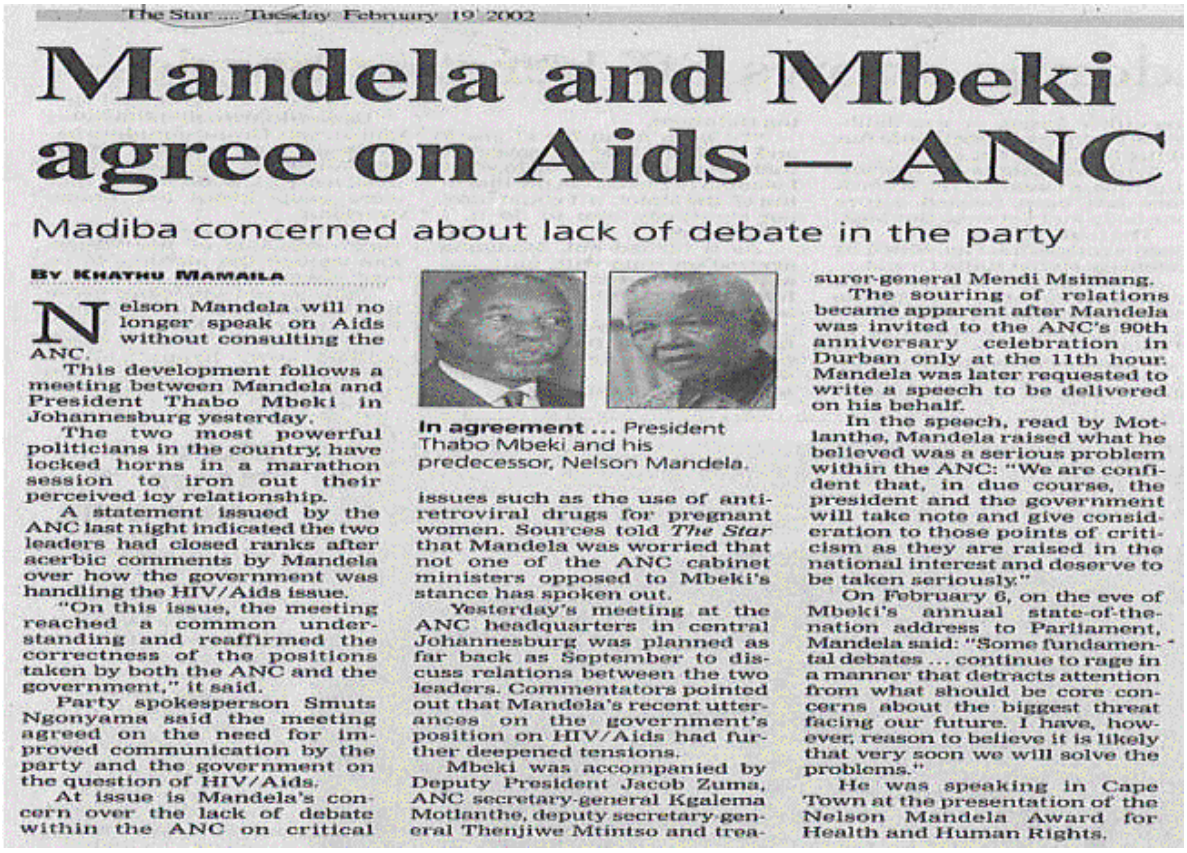
Again, the partnership between MSF and the Western Cape government allowed for the introduction of ART in the public health sector against the national government's instruction. There were three dedicated ART treatment sites in Khayelitsha, where this writer was amongst thousands who migrated from surrounding townships in search of ART. Later, these sites also provided post-exposure prophylaxis for rape survivors and workers who had experienced occupational health accidents (MSF, 2009). The Global Fund and donations from MSF funded these, because at the time, there were no ART budget allocations from the Treasury (Hodes & Naimak, 2011). The Western Cape Province was one of the TAC strongholds by 2000, especially in Khayelitsha, and through their strong alliance with MSF. Similarly, in the ANC-led Eastern Cape Province, the Nelson Mandela Foundation independently approached the provincial government to provide ART in Lusikisiki without the endorsement of the national government. Although the Eastern Cape government largely remained unsupportive of ART, the "Mandela factor" played a role in getting the ART pilot site going. As a result, the Lusikisiki HIV/AIDS programme initiated in late 2002 as a collaboration between MSF, the DoH and the TAC, with financial support from the Nelson Mandela Foundation.

It was one of the first HIV/AIDS programmes in South Africa providing ARV treatment in a rural area and based upon principles of decentralised health care, task shifting and community mobilisation and involvement. By this time, the relationship between the TAC activists and government had hardened. Mandela further defied the official ANC stance by visiting the MSF ART clinic in Nolungile (Site C), Khayelitsha in 2002. As well as showing personal support to the TAC campaign, he paid a visit to the sick TAC leader Zackie Achmat, the TAC's chairperson at the time. Achmat had made a public stance and political statement, refusing to start antiretroviral medication at the time when his health was at its lowest point, until the state made ART readily and freely available to everyone.

3.9.2 ANC SPLITS OVER AIDS TREATMENT

The TAC's pressure on AIDS policy led to divisions in parliament, with members of parliament such as Barbara Hogan, Pregaluxmi (Pregs) Govender, and Andrew Feinstein breaking ranks. As Govender recalls, she could no longer sit and watch but organised within the women's committee, and so did Hogan (Govender, 2007). Similarly, the Sisulu family symbolically demonstrated their solidarity in the AIDS struggle through public disclosure of Rosabella Sisulu's AIDS-related death. Former president Mandela also followed by publicly disclosing his son Makgatho Mandela's AIDS-related death. This symbolic stance demonstrated to the public that their leaders are infected and affected, regardless of President Mbeki's reluctance to acknowledge their pain. In addition, there was support from other key leaders, such as Archbishop Desmond Tutu, Archbishop Dungan and Winnie Madikizela-Mandela. Opposition political party leaders such as Patricia DeLille, United Nations Special Envoy for Africa Stephen Lewis, US Senator Barack Obama, Dr. Peter Piot of UNAIDS, and international singer Annie Lennox pledged solidarity with the TAC demands. When Nelson Mandela expressed his uneasiness at the ANC National Executive Meeting over the government's refusal to support the rollout of nevirapine (Dugger, 2008). As one of the government officials interviewed said "Mandela's proposed interventions were not welcomed by the government leadership to the extent that President Mbeki later requested guidance on how to handle interference from former state presidents," (NGovt0057 Interview, 2015).

FIGURE 10: MANDELA, MBEKI, AND THE AIDS DEBATE



The Star ... Tuesday February 19 2002

Mandela and Mbeki agree on Aids – ANC

Madiba concerned about lack of debate in the party

BY KHATHU MAMAILA

Nelson Mandela will no longer speak on Aids without consulting the ANC.

This development follows a meeting between Mandela and President Thabo Mbeki in Johannesburg yesterday.

The two most powerful politicians in the country, have locked horns in a marathon session to iron out their perceived icy relationship.

A statement issued by the ANC last night indicated the two leaders had closed ranks after acerbic comments by Mandela over how the government was handling the HIV/Aids issue.

"On this issue, the meeting reached a common understanding and reaffirmed the correctness of the positions taken by both the ANC and the government," it said.

Party spokesperson Smuts Ngonyama said the meeting agreed on the need for improved communication by the party and the government on the question of HIV/Aids.

At issue is Mandela's concern over the lack of debate within the ANC on critical issues such as the use of anti-retroviral drugs for pregnant women. Sources told *The Star* that Mandela was worried that not one of the ANC cabinet ministers opposed to Mbeki's stance has spoken out.

In agreement ... President Thabo Mbeki and his predecessor, Nelson Mandela.

Yesterday's meeting at the ANC headquarters in central Johannesburg was planned as far back as September to discuss relations between the two leaders. Commentators pointed out that Mandela's recent utterances on the government's position on HIV/Aids had further deepened tensions.

Mbeki was accompanied by Deputy President Jacob Zuma, ANC secretary-general Kgalema Motlanthe, deputy secretary-general Thenjiwe Mtintso and treasurer-general Mendi Msimang.

The souring of relations became apparent after Mandela was invited to the ANC's 90th anniversary celebration in Durban only at the 11th hour. Mandela was later requested to write a speech to be delivered on his behalf.

In the speech, read by Motlanthe, Mandela raised what he believed was a serious problem within the ANC: "We are confident that, in due course, the president and the government will take note and give consideration to those points of criticism as they are raised in the national interest and deserve to be taken seriously."

On February 6, on the eve of Mbeki's annual state-of-the-nation address to Parliament, Mandela said: "Some fundamental debates ... continue to rage in a manner that detracts attention from what should be core concerns about the biggest threat facing our future. I have, however, reason to believe it is likely that very soon we will solve the problems."

He was speaking in Cape Town at the presentation of the Nelson Mandela Award for Health and Human Rights.

[SOURCE: THE STAR, 2002]

Mandela's participation in the AIDS debate publicly displayed the ANC and government's divisions on the ART policy issue. However, Mbeki supporters such as Thami Mazwai also lashed out at Mandela publicly in a City Press article titled, "Leave Mbeki to Rule!" referring to former president Nelson Mandela's intervention in the HIV/AIDS issue and several other issues concerning the government. They suggested that it was insensitive to and undermining of Mbeki's government. This assertion not only silenced dissent but also muted public debate on a matter that killed thousands of poor people. Mazwai's concern was not with the matter itself, but about protecting President Mbeki. Even within the corridors of parliament and the media, as Pregaluxmi 'Pregs' Govender recalls in her book, the TAC was labelled a pharmaceutical company agent. She further argues that AIDS treatment policy divided parliament. She could no longer sit and watch, but rather organised within the women's committee. Parliament as another avenue for popular participation was even harder to influence over the AIDS treatment plan. Govender recalls that Barbara Hogan, Pregs and Andrew Feinstein were amongst those that were being lobbied by the TAC to act within their capacities (Govender, 2007). The corridors of parliament had to toe the party line on AIDS policy matters.

However, members of parliament such as Govender argued that the manner in which the state demonised the TAC in parliament as a pharmaceutical company agent just because they fought for access to medicines created divisions within parliament. The relationship between Mbeki and some of the members of the cabinet who were supporters of the TAC or even opposed to Mbeki's views also revealed similar antagonisms. Therefore, AIDS divided parliament. As Govender argues, she and other members of parliament could no longer sit and watch but began to organise other voices within parliament committees (Govender, 2007). As a result, due to the lack of progress in getting the government to commit to a national ART plan, the TAC escalated its resistance. It launched a civil disobedience campaign, attempting to be more confrontational and force its participation in AIDS policy. After attempts to engage through negotiation and public protests, the TAC targeted the minister of health and Minister of Trade and Industry Alec Erwin, by laying criminal charges of culpable homicide for the premature AIDS deaths that occurred under their watch.

3.11 TAC LAUNCHES CIVIL DISOBEDIENCE

During the TAC's 2002 national treatment preparedness meeting in Durban, a new strategy of nonviolent civil disobedience debate escalates the TAC demands. This heated as I recall, with some of the activists worried about the upcoming election and what this would mean for the ANC support within the movement. After long hours of arguments, consensus by majority agreed that the ANC government had left the AIDS activist with choice but to increase resistance. The nonviolent civil disobedience was founded on breaking the law (disobeying) for a good cause. Civil disobedience is an act of protest that takes deliberate, rational, conscious unlawful action in the public space (Chong, 2001). For nonviolent civil disobedience to be impactful, the TAC relied on the moral and human rights framing of its struggle for access to treatment (Friedman and Mottiar, 2005). For the TAC activists, the struggle for access to ART had reached a stage where normal routes of resistance were yielding very little change. Thus, their choice of action included making noise (such as blowing whistles) and disruption of speeches by those ministers and the president responsible for bringing change. Activists accused the ministers of health and trade and industry[11] of culpable homicide and demanded

[11] The pills I take twice a day since 2004 are a reminder of how leaders can sell their people out — how they can commit genocide and go unpunished — how building poor people's power is the only way we trust, instead of being taken for a ride by politicians. The pills are a beautiful memory, as well as a painful reminder, of evil politics. One would have thought that we would

that they be arrested. These strategies-required activists to pledge written consent within the movement to be prepared to be arrested or even die. The TAC's lawyer supporters were ready, however, to support the movement in case there were any arrests. The TAC's launch of nonviolent civil disobedience was a shift from its traditional advocacy strategies. The TAC had reached a critical mass in social mobilisation; had experience in successful litigation, media campaigns, and strategic transnational and national alliances; and began a massive rollout of popular education.

Some of the TAC allies were not supportive of this move. Amongst those opposed were COSATU, which argued that the current ANC-led government was democratically elected and that civil disobedience should only be used against illegitimate states. The COSATU's view is on civil disobedience means breaking unjust laws, mainly against illegitimate governments. Therefore, decided that as it reaffirmed full support for the TAC it distanced itself from the civil disobedience campaign (Heywood, 2005). The COSATU stance of opposing civil disobedience and rather facilitate negotiations with the government through the National Economic, Development and Labour Council (NEDLAC), where on 28 June 2002; on the agenda was the HIV/AIDS treatment plan where the government negotiators blatantly refused as expected. The other parties of NEDLAC agreed to the plan but only government refused to sign an agreement with the NEDLAC, the TAC organised one of its landmark national marches to parliament in February 2003. This march attracted an estimated 20,000-multisectoral supporters across the country. Movement actions were shifting at the same time as the growth of the movement. The question of the state adopting the TAC demands on the AIDS treatment plan felt like a matter of when rather than if. Public opinion on the AIDS treatment plan had shifted, and this affected the ANC. By this time, the state's handling of the AIDS saga had become a serious liability for the ANC. With looming general elections, Deputy President Zuma on behalf of the ANC party not government was delegated to negotiate with activists to withdraw their civil disobedience on the condition that the ANC commit to a treatment plan. The government later committed to the TAC demands, and activists suspended their civil disobedience. I argue that the popular power is what forced the state to concede and agree to the ART plan. However, this concession does not guarantee actual implementation as discussed in chapter 5 and 6 later.

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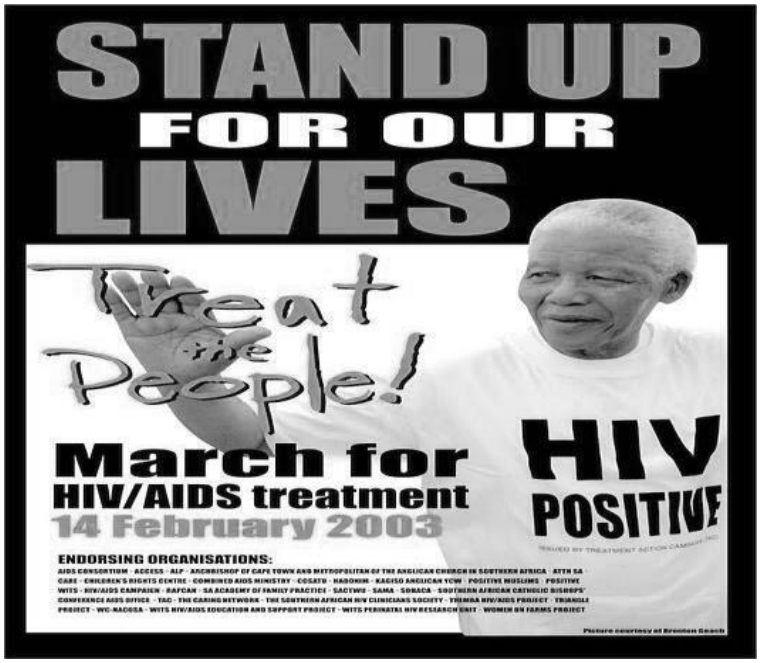
learn from the past to avoid repeats of bad mistakes. People living with HIV, mothers, fathers, and children died under Mbeki's leadership. Our deaths became a common norm as our leaders moved on with their lives.

While the Activist applied pressure to the state, they also challenged the pharmaceutical companies and launched a case with the Competition Commission (Hazel Tau and others vs. GlaxoSmithKline [GSK] and Boehringer Ingelheim [BI]), accusing them of exorbitant pricing to the point of unaffordability. The companies entered into negotiations with the TAC, and a settlement was reached in December 2003, which stated that both companies were guilty and therefore must allow generic ART manufacturers to enter the South African and other sub-Saharan African markets to compete, thereby allowing the state to purchase the best cheap medicines (Matthew, 2011). A combination of the TAC's 2002 civil disobedience led to the state entering into negotiations with TAC through the leadership of Deputy President Zuma. The landmark national march to parliament, which attracted between 10,000 and 20,000 people and the poster below (figure 11) demonstrated the support of political leaders such as Mandela.

FIGURE 11: POSTER FOR NATIONAL MARCH



[Source: Eric Miller/TAC, 2003]

The internal ANC factions, combined with the Cabinet conducting its internal ART affordability study, an upcoming election, and the negotiations between the TAC and Deputy President Zuma (NGovt0057 Interview, 2015), resulted in a dramatic turn of events when the Cabinet announced an AIDS treatment plan in late 2003.

That same year, the TAC's successful competition case against GlaxoSmithKline and BI resulted in a number of drug companies agreeing to provide licenses to generic manufacturers. This action led to a drop in the price of a yearly first-line treatment for AIDS from US$10,439 per person in 2000 to US$182 by May 2005 (Nattrass & Geffen, 2005), adding to activists' victories. It was clear that the moment of a national ART plan had arrived. In August 2003, the Cabinet made a dramatic U-turn by instructing the minister of health to develop a comprehensive HIV care and treatment plan for the public sector. The minister of health was given three months to present a plan by November 2003. This move signals the new dawn in HIV policy-making in the country. It is this era, and the forms of political activism that emerged from it, that are the focus of this thesis. In the end, the proximity of civil society to the state in the initial phases of the AIDS response left the state less accountable for its anemic policy implementation. At the same time, the new democratic dispensation post-1994 led to an initially inclusive policy-making process, in which attempts to be inclusive seemed fair but not adequate for meaningful participation during implementation. The second phase under Mbeki, when the state was in the spotlight for implementing an AIDS plan and faced enormous opposition from the TAC, exposed other possible forms of popular participation in public policy development and implementation during those early years. The weaknesses of the institutional participation structures such as the SANAC that were controlled by the state led to increased popular participation through alternative forms. These included protests, negotiation through new avenues such as the NEDLAC, litigation and civil disobedience.

Further, the centralisation of policy processes allowed for a build-up of residual popular resistance within the state both at national and provincial levels. At the same time, provinces that went ahead with implementation of ART without national government approval tested the federal arrangements. These are key contextual factors when considering the new challenges, the TAC faced during implementation after 2003. A movement that fails to re-evaluate its role after a successful campaign is likely to experience a breakdown in public relevance, membership decrease and general decline. The TAC had to readjust its strategies to suit the needs of advocacy and tools to engage with policy implementation and state accountability at the local level. The activists boosted their organisational support towards ART policy implementation, which then required yet again new forms of bottom-up participation. This meant that the TAC branches had to work closely with public health facilities because implementation needs to be inclusive of participation at the provincial level.

The provincial focused activist pressure meant activists dispersed its organising capacity towards supporting nine provinces that are diverse. The different service delivery models dramatically influenced the outcomes. In addition, implementation is a highly technical exercise, and now activists had to understand systems of service delivery, which could be a demobilising factor for popular participation. In most cases, a functioning public health system was critical in the effective and efficient rollout of ART. The TAC had to come up with new strategies for participation that addressed both ART services provision but also the broader health system if it wanted to ensure quality treatment and care for those living with HIV. These issues are the subject of the rest of the thesis. The following chapter discusses the research methods used in gathering the insights and experiences of AIDS activists and their social movement participation in AIDS policy processes after 2003.

In sum, the administrative AIDS policy transition from Mandela to Mbeki's adversarial engagements with civil society marked shifts in types of popular participation. This period faced increased rebellion from AIDS activists against unilateral state AIDS policy choices and decisions. At the peak of this conflict, President Mbeki's AIDS denialism fueled significant disconnections between state policy processes, the people and AIDS activists. Through historical records of AIDS treatment activism this chapter has demonstrated that there were shifts in activists' forms of participation in HIV/AIDS policy development as well as changes in advocacy strategies on the Treatment Action Campaign (TAC) to counter government policy on HIV.

CHAPTER FOUR: METHODS

4.1 INTRODUCTION

This chapter examines the methodology applied in this study. It describes the process of selecting the sample using policy network analysis and the social constructivist deductive qualitative research approach applied to the process. The chapter outlines the data collection tools, sampling techniques and thematic approach to data analysis. The chapter also offers some insights into the quandaries and limitations in the research process from the scholar/activist's positionality perspective.

This chapter describes this project's research methods as well as how its methods were informed by my position as an activist scholar. The focus of the thesis was on the meanings activists attached to their advocacy, their worldviews, their interpretation of key events, their tactics and strategies, and the social and political alliances they made as part of their effort to influence antiretroviral therapy (ART) policy. This required in-depth interviews, participatory observation, HIV/AIDS policy network analysis and a review of key HIV/AIDS policy documents and policy events for the period. These multiple methodological approaches enabled robust triangulation of the data, in turn enabling a nuanced investigation of typologies, degrees of participation, social movement tactical evolutions, political opportunities and framing strategies. The primary timeline covered by this study is 2003 to 2015. Dramatic shifts in HIV/AIDS politics and policy began in August 2003, at a time when AIDS activism had been happening at a furious pace and included civil disobedience, media and community mobilisation, campaigns and litigation (Heywood, 2009; Dubula and Heywood 2012).

After August 2003, however, AIDS activism began to develop in new directions, ones that captured much less scholarly interest than prior periods of more dramatic national-level conflict. The central focus of this study is the evolution of the Treatment Action Campaign (TAC)'s AIDS activism in the key case study sites—Khayelitsha and Lusikisiki—in the years after 2003, after the TAC's most celebrated successes. My approach is that of an activist scholar who was involved in the events being described. There were moments when I realised that the understandings and experiences of HIV activists, NGO leaders and government leaders were radically different from what I thought they were. I can never know the full impact of my identity as a young, Xhosa-speaking, black African woman living with HIV/AIDS from the TAC background on this study.

4.2 ACTIVIST/SCHOLAR POSITIONED OBJECTIVITY

The ART victory for TAC was not just a political agenda; they were personal gains for their constituents. This research is born out of the need to reflect on the years of intense ART policy contestation by AIDS activists (I amongst them) and their social movements in South Africa. That knowledge is vital to social action—as to individual ethics—has long been recognized. Thinkers have been doers (contrary to stereotype). Moreover, reflection on successes, failures, and unexpected consequences of social action has been a vital source of new understanding (Bond et al., 2018). Yet activist scholarship often seems an unusual or surprising idea. It is not widely taught in textbooks. Tenure committees are unsure how to think about it. Why should this be so? Three reasons seem especially influential: (1) modern science (and modern epistemology more generally) has developed an ideal of knowledge based on detached, objective observation; (2) the university has come to contain a much larger proportion of scholarship than in the past (though perhaps not as big a proportion as academics believe), and thus scholarship is more contained with "academic" agendas and career structures; and (3) activism is widely understood as directly expressive of individual interests, or emotions, or ethical commitments rather than of a broader, more reflective, and more intellectually informed perspective on social issues. The earlier period of ruthless betrayal of people living with HIV and AIDS questioned the ideals of constitutional human rights, participation and deepening of democracy. That period has already been subject to significant documentation and analysis, but the second phase of policy implementation warrants equal consideration. It is worth noting that my many years as an AIDS activist provide access to the in-depth lived experience of the South African policy-making processes.

4.2.1 CLASS AND GENDER CRITIQUE

As one of the black African HIV-positive women activists in the TAC, my research undertaking is an attempt to fundamentally disrupt the continual privileging of some movement voices in knowledge production. Unequal power relations acutely affect social movements. I have no doubt that tensions in my scholar-activist position will influence my inquiry into participation in the TAC after 2003. However, the scholar-activist tension is useful in the production of knowledge, as it allows for nuances in the studied phenomenon. Activist social scientists strove to maintain connections with broader publics and practical work on social issues. Activist scholarship is not simply the 'application' of previously accumulated knowledge.

The scholar-activist is a different breed, concerned with things further than just seminal opinion and opening up knowledge systems, but also with rethinking and enacting social justice. First, activist scholarship—like a variety of practical engagements—is part of the process of forming, testing, and improving knowledge. Science is, after all, in large part a process of learning from errors, not just a process of accumulating truths. Commitment to social action in pursuit of social change is one of the sources for a commitment to social science. Activist scholarship is a matter of critique, not just advocacy. Activist scholarship is obvious but worth restating: the world is in considerable need of improvement, and improvement comes in large part by means of social movements, struggles, and campaigns to change public agendas, not merely by the provision of technical expertise to those already in power. Activist scholarship can help movements have more success in improving the world. Activist scholarship is one way to make social science useful but we are not martyrs. We are activists because of the joy political work gives us, because even when we fail, working to make our society kinder, fairer, more just, gives a satisfaction like no other, because the comrades we find in the effort are friends like no other, and also because our activist efforts illuminate our social and political world in ways that scholarship alone never can. Nevertheless, activist scholarship can also make social science better, providing occasions for new knowledge creation, challenges to received wisdom, and new ways of thinking.

4.3 QUALITATIVE QUANDARIES

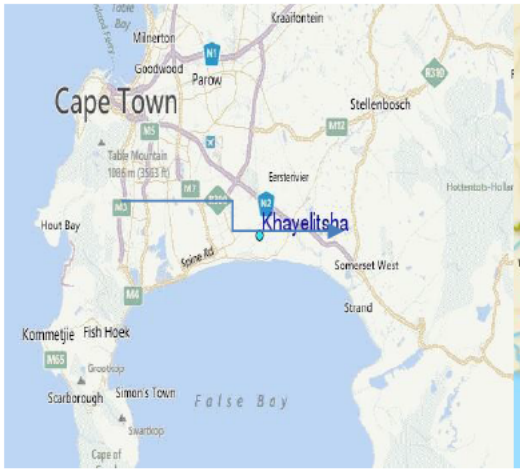
Commitments to activist scholarship can leave one feeling torn, stretched too thin, and resentful, especially toward the larger academic community, whose reaction generally ranges from indifference to outright hostility. However, insider and outsider position are not static, but a process of becoming. The rest of this chapter reviews this study's methodological approach and reflects on these questions of my positionality and activism.

4.4 STUDY SITES

To understand shifts in social movement advocacy strategies, it was appropriate to use qualitative research methods. Qualitative data achieve several goals, including understanding the meanings and insights of participants, the role of key policy events, situations and actions in which they were involved, and how particular contexts shaped participants' actions and experiences of social movement activism. I focus on the two health sub-districts as sites for this

study. Khayelitsha and Lusikisiki have played a pivotal role in ART policy and AIDS activism. Both locations have a history of AIDS activism, dating back to late 90s in Khayelitsha and 2000s in Lusikisiki. As a result, there are deep-rooted experiences with and a culture of AIDS activism among people living with HIV/AIDS in these areas. Below (figure 11 and 12) are maps of both locations.

FIGURE 12: KHAYELITSHA TOWNSHIP MAP **FIGURE 13: LUSIKISIKI TOWN MAP**



[Source: City of Cape Town]

[Source: Ingquza Municipality]

4.4.1 KHAYELITSHA

The name Khayelitsha originates from a deceitful description of this community as a "new home" (in isiXhosa) for black South Africans who were forcibly removed to the area in the 1980s (Kinkead-Weekes, 1992) .This settlement reflects the apartheid government's approach of racial segregation, using Khayelitsha as 1,070 hectares of dumping ground for up to 120 000 (at the time) poor black African people who were considered refugees in their own country. Its location on the margins of Cape Town, 30 kilometres from its economic hub, affirms the spatially and racially divided nature of the city. After the pass laws were abolished in 1986, Cape Town experienced fast in-migration of people mainly from the Eastern Cape Province. Khayelitsha was among the townships that sustained rapid growth, forcing the city to clear land to make way for new homes in the form of RDP houses.

To date, Khayelitsha is a sub-district within the City of Cape Town Metropole under the Western Cape government administration. It is estimated to be the second largest semi-urban township in South Africa, with a population of between 500 000 and over one million residents (Garone et al., 2017). This represents a significant proportion of the rest of the city's population. Khayelitsha is largely overcrowded, with 64% of its 22 subdivisions made up of informal housing with lack of clean running tap water, electricity, sanitation and roads. The area continues to expand annually. The City of Cape Town estimates that 10 000 new "shacks" are erected each year. Moreover, according to the City of Cape Town's economic report (2014), inter-country and provincial migration, as well as urbanisation, drive poor people to cities in search of opportunities such as employment, education and healthcare (state of Cape Town 2014) .

In Khayelitsha, 54% of the residents were unemployed in 2011, compared to the rest of Western Cape Province, which has an average of 29% unemployment (Seekings, 2013). Further, MSF (MSF, 2009) argue that by 2011 Khayelitsha had the largest numbers of people living in informal settlements, which in turn correlates with high rates of HIV and tuberculosis (TB) infection. I argue that these health challenges are a result of social fragmentation due to urban transition, poor policy implementation, and poor socioeconomic conditions. HIV/AIDS and TB are some of the major health challenges facing the area, with an estimated 33.4% of Khayelitsha pregnant women living with HIV/AIDS and 70% of people living with HIV/AIDS having TB at the same time (MSF, 2009). HIV/AIDS has remained the leading cause of under-five child mortality, while for the 14- to 19 years old age groups, homicide accounts for almost half (48.6%) of mortality (Groenewald et al., 2008). This increases the demand for health care services, including the availability of medicines, human resources and health facilities, among other needs. To date, the area has about ten primary health clinics, three Midwife Obstetric Units (MoUs), two youth clinics, two male clinics and one district hospital, all within a 30-minute drive.

4.4.2 LUSIKISIKI

The name Lusikisiki originates from the onomatopoeic meaning of the sounds of reeds rustling in the wind at nearby rivers and wetlands. The town is a former military camp, established in 1894(South African history online, undated) .

To date, it is a recognised town under the Eastern Cape government and local health municipality of Ingquza in the former Transkei (Oliver Tambo District Municipality) authority. Its populace is relatively small—279 795 people (Statistics South Africa, 2018b) who are scattered across the surrounding rural villages. Most villages are under the dual administration of the local municipality and traditional leadership. However, since 2000, the roles of the municipal council and traditional leadership have tended to overlap, with boundaries for traditional leaders becoming vaguer and allowing them less constitutional power (Rugege, 2003). Because of democratisation, all governance is subject to contestation, as opposed to the practice of traditional, unopposed leadership. This creates different dynamics for activist work in such areas. Lusikisiki has a high unemployment rate of 66%, compared to the rest of the Eastern Cape Province, which has an average unemployment rate of 53% (Statistics, 1998). HIV/AIDS has severely affected Lusikisiki, with 29% of its pregnant women living with HIV/AIDS (Bedelu et al., 2007) , and this situation remains to date. Access to essential health services remains one of the biggest challenges due to the road infrastructure among other problems, with only one provincial hospital surrounded by twelve primary health care clinics (Beresford, 2004) to serve the rural population.

Both Lusikisiki and Khayelitsha reveal the urban/rural divide in terms of access to health services and the poor socioeconomic development to address inequity in health care, social assistance, employment, housing, sanitation, water and electricity. The gaps in the provinces' health spending arise from the Treasury's bias toward income rich provinces such as the Western Cape, Gauteng and KwaZulu-Natal, the historical inequalities in public health capacity appear to be more important determinants of inequalities in health care financial allocations (Stuckler et al., 2011) . This inequality trap has enduring effect on both the health service delivery due to resource shortage. Thus, both offer sites unique urban and rural perspectives, which serve to contribute to the understanding of bottom-up policy advocacy and participation. Equally, Khayelitsha and Lusikisiki both became sites of AIDS treatment research and innovative collaborations between activists, communities, scientists and health professionals. Additionally, the Lusikisiki ART programme existed because of Mandela's political defiance of Mbeki's HIV denialism. Therefore, a range of policy actors from the state, social movements such as the TAC, the National Association of People Living with HIV/AIDS (NAPWA), a civil society organisation such Doctors Without Borders (MSF), Section27 (formerly AIDS Law Project) and politicians engaged around ART implementation in these sites.

There were initial doubts about whether AIDS activism in rural areas would pick up speed in a way similar to that seen in urban townships. The third trigger was when government dragged its feet in the ART rollout, with its efforts to prioritise prevention over treatment in public health discourse and its embrace of "alternative" forms of treatment for HIV. For example, (Robins, 2004) argues that it is yet to be seen to what extent the TAC and MSF's export of urban AIDS treatment activism (from Khayelitsha) to poor, rural former homelands would be possible, where AIDS myths, tribalism, and patriarchy were key drivers of the AIDS epidemic. Nonetheless, Lusikisiki became a site of active contestation. These sites thus both offer unique windows into the TAC activists' continued contestation of ART policy implementation at the grassroots post-2003.

4.5 DATA COLLECTION METHODS

Primary data collection methods such as interviews, participant observation and secondary document reviews were the suitable tools for soliciting insights into the experiences of AIDS activists and their social movements. This study used several data collection methods and sources to garner primary and secondary data. These methods included policy network analysis to identify key informants, participatory observation, in-depth interviews, and document reviews of sources found in online research, speeches, emails, newsletters, and organisational data from the South African National AIDS Council (SANAC), the Department of Health, the TAC reports, the NAPWA reports, the MSF reports, the Section27 reports as well as newspapers. After conducting a policy network analysis of major actors in ART advocacy, key informants were identified using purposive sampling strategy. This sampling tactic effectively allows selection of appropriate participants who hold key insights for the study. Purposive sampling aimed for two principles in this study: (a) selecting participants who are knowledgeable about the topic under study as well as allowing for continuation of new interviews until saturation was reached, thus achieving completeness; and (b) convergence and divergence of interpretations and meanings, thus allowing for a wide range of experiences to be articulated and interpretations to be challenged. The main objective was to focus sample selection based on particular characteristics of the population of interest (Taherdoost, 2016) and those best able to answer the questions of this study. Purposive sampling allows one to select policy actors who are actively involved specifically in ART policy advocacy, not generally in HIV/AIDS policy. Inherently, purposive sampling creates an inevitable positive sampling bias, due to the targeted selection of knowledgeable informants best suited to answer

the study question. This bias, however, contributes to the strength, efficiency and quality of data collection(Marshall, 1996) , because data is drawn from expert research participants.

4.4.1 POLICY NETWORK ANALYSIS

Policy network analysis involves the mapping of network interactions and power sharing between local, provincial and national policy actors. The map helps to identify the actors who shape and influence policy developments and implementation. This can be done through observing formal and informal clusters amongst policy actors (Peterson, 2003) through participatory observation, in-depth interviews and analysis of written scholarly and grey literature. This study utilised an existing list of AIDS and ART policy actors within the South African National AIDS Council, combined with a literature review of the most-mentioned ART policy actors, their alliances and their links to AIDS activists and social movements involved in AIDS treatment advocacy in Khayelitsha and Lusikisiki during the period under study.

It was apparent in some instances that some important alliance partners did not appear on the SANAC list of 18 sectors' HIV/AIDS policy actors. This was confirmed during participatory observations and interviews. Without mapping the broad policy network, selection of participants would have been difficult and open to researcher bias. Networks are important in social science research. They provide insights into who the main players are. (Borzel, 1998) posit these as relatively stable relationships that tend to be non-hierarchical and symbiotic, linking various policy actors, who share common policy interests and exchange information, define policy networks. Thus, networking is also a resource mobilisation tactic between two or more actors (Ruming, 2009); together with being spaces for technical and financial resource sharing, as no actor alone has enough resources to unilaterally influence policy decision-making. Networks capture various formal and informal relations amongst a complex set of diverse policy actors, which can be perceived to be organised entities that reflect some institutional organisation. This is true about the SANAC policy actors, because policy actors are organised by sectors, reflecting institutional arrangements. There are various types of policy networks, as (Rhodes & Marshal, 1992) explains. They range from highly integrated to lose networks of policy actors who form networks or associations based on their common policy concerns. Hence, the SANAC list was inadequate on its own to utilise as a basis for key informant selection. Moreover, policy networks exist outside of the formal, institutional,

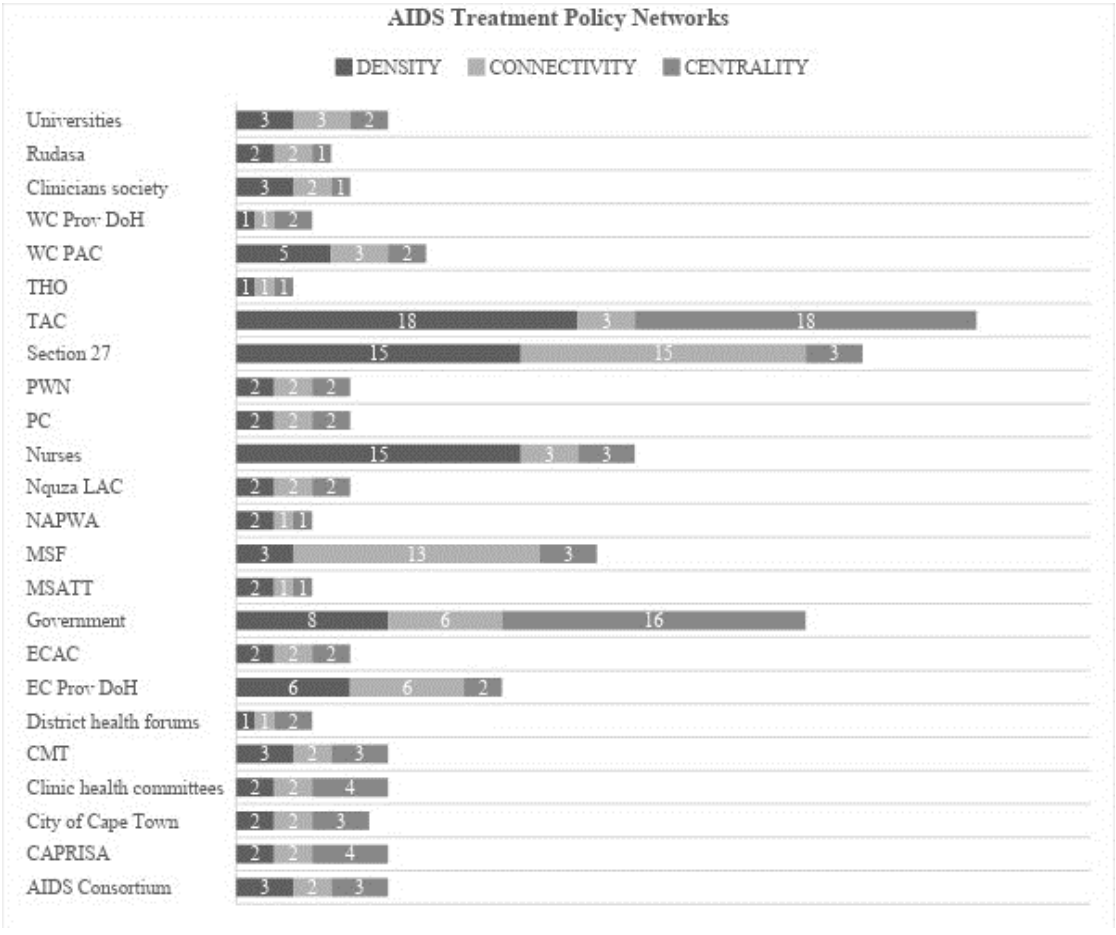
participatory spaces as well. Thus, identification of other ART policy networks in the non-institutional platforms was critical. These popular spaces include the following:

- Joint Civil Society ARV Monitoring Forum
- Joint Civil Society Budget Monitoring Forum
- Joint Civil Society Stop Stock-outs Forum

Networks are interdependent, because their interactions frame their policy discourses and narratives. These popular spaces, I argue they act as policy networks with close relationships emerging out of organizations and individuals with frequent contact with one another in particular policy areas. Engagements between actors are in themselves sites of collaborations and contestation. Hence, alliances amongst policy actors are indispensable to achieve a policy and political change (Henry & Dietz, 2011) . Accordingly, there are various types of policy networks, ranging from policy communities, professional networks, intergovernmental networks, and issue networks. Comparing their linkages to Khayelitsha and Lusikisiki and the organisations that have those associations with potential participants, I considered one or more of the following criteria: density, connectivity and centrality. In the first place, density here refers to the degree of policy actors' closeness, communication (such as emails or joint press statements) and interaction between them. Concentration is critical to distinguish networks' points of intense interaction. Critical mass in policy networks is a source of information, influence and power. The denser the linkages around a certain policy actor, the greater the information flow and influence to and from those linked to the densest node. A densely interconnected network with many consensual coalitions might produce better policy shifts than a network in which actors do not collaborate powerfully and contest over deviating policy agendas. Policy networks replicate the processes of brokering and providing direction among policy actors (Peterson, 2003). Equally significant, connectivity is essential when analysing policy networks. Connectivity is the extent to which policy actors have common shared interests, which means their similarity and tendency to be in policy coalitions. Coalitions play a crucial role in information dissemination and consolidation of policy positions and demands. This has the power to influence change, more than those actors with no allies do. This affects collective power and popularity.

Likewise, centrality in policy networks relates to the number of associations between actors, the frequency of information exchange, the flow of resources amongst them, the flow of technical expertise and knowledge, and the tendency to be innovative and increase social cohesion. The centrality of the actors is determined by the position in the structure being analysed. Centrality can lead to increased power and dominance. If power is distributed among two or more equally strong coalitions representing different views of the policy problem and offering possible solutions, there is a high probability that coalitions mutually block policy decision-making processes. Below, figure 14 presents the data from the literature review, media report, and organisational press statements as well as from key informants. Organisations, rather than individuals present the policy actors below in figure 13, because participation is through representation. These networks were then compared according to their closeness, linkages, relations and engagements with each other and with Khayelitsha and Lusikisiki TAC activists, as they are the sites of investigation.

FIGURE 14: AIDS TREATMENT POLICY NETWORKS



[Source: Dubula-Majola, 2015]

Most social groups and government departments had a large density, which means the number of connections observed within the networks divided by the number of possible connections (Carrington et al., 2005). The following networks had regular communications, interactions and joint public actions with the HIV activists in Khayelitsha and Lusikisiki. The TAC, nurses, Section27 (formerly known as AIDS Law Project), National Department of Health, Eastern Cape Provincial Department of Health, and the Western Cape Provincial Department of Health were the top six in the proportion of group ties associated with the most policy actors. In the case of TAC and the government, there were high density and centrality observations. This means that they had a large number of policy actors linked to them forming networks (or alliances). Again, observations of Section27 and Medicines Sans Frontiers (MSF) with the highest number of direct and indirect relations indicated the critical in-between pathways in policy engagements. Both organisations provided key support and resources such as legal advice, medical evidence and, to some extent, financial support to other organisations and movements. For example, Section27 attorneys are usually the TAC lawyers as well. While the MSF is made up of medical experts with experiences in working within health facilities across Africa, it also served as a resource within the AIDS movement.

Figure 14 above shows that the TAC, Section27 and government had the highest number of AIDS policy networks and actors associated with them. Since the focus of analysis is ART policy actors, it not surprising that the most policy actors were aligned to the above organisations, but centrality is not necessarily related to connectivity. This is so because connectivity is more specific, but does not speak to the importance of the policy actor in the network. Indeed, as we observe, the government had high centrality but low connectivity (see above). This can also have meant that if you remove the government in the ART policy network, then the consequences were not determined by connectivity but by the fact that it links with different parts of the network. Notably, policy network analysis was useful to establish relations between national policy actors and their associations and linkages with the grassroots AIDS movement, by observing formal and informal clusters among grassroots policy actors. Having such a diverse set of participants, including activists from social movements and those not associated with movements, government, politicians, NGO leaders and academics involved in HIV/AIDS policy, affords the opportunity to crosscheck information and provide a sense of the complexity of the South African AIDS movement.

From the list of 24 institutional policy actors above, purposive sampling was the most useful way of selecting key informants who had insights and experiences needed to answer the research question. From these, 70 key informants were selected, made up of all genders, ages above 18 years old, and roles. This approach is informed by the nature of the research topic, which entails relying on participants' insights into policy processes and willingness to share those insights. Deliberate inclusion of such key informants improved the strength, efficiency and quality of the data collected, as knowledge was drawn from competent informants. From this sample, primary data was collected through participatory observation and in-depth interviews.

4.5.2 PARTICIPATORY OBSERVATION

Participatory observation as a data collection method is not new in social sciences, including social movement research and anthropological studies, where researchers immerse themselves in a situation, while at the same time recording what is being observed as part of the data collection method. This approach has been applied in several studies to explore actions of people in public spaces (Angrosino, 2005; Low, 2000; Southwell & Clark, 2007; Wallace, 2005). This data collection technique was employed in this study because of its appropriateness to qualitative research conducted by researchers who are practitioners or activists. The investigator's goal was not detachment from the policy space. I argue that as a scholar/ activist immersion offer opportunities to learn/unlearn from experiences of others and is thus viewed as an integral part of the analysis that provides the researcher with new vantage points for surprises through making the strange familiar and the familiar strange. I observed actors' attempts to influence policy and used these observations as a backdrop for my interviews, which were conducted later, and in-between observations.

The participatory observation was used at four events to gain insights into the policy environment of the key informants. These included national policy meetings, social movement meetings, and local and national protests. There were one meeting in Khayelitsha and three meetings with national policy actors. Of utmost importance in this approach was an attempt not to display their narratives objectively, because human beings are not machines. In fact, subjectivity was incorporated by engaging with participants in the field. Implicit in this approach is the acknowledgement that my role as the researcher in the inquiry process does not

aim to reintroduce the self in social research. The goal here was not to be taking a distant view of data, because there is no one truth, but multiple realities within a particular context. Moreover, the process of knowledge production was a product of experiences from both the participants and the researcher. This approach is therefore at odds with positivist, reductionist notions of science. As such, it centres on challenging the status quo and applying data collection methods in a particular manner congruent with principles of emancipation. I was interested in the kinds of nuances and insights that surround policy-networking spaces. This includes key informants in their places of work, homes, meetings and recreational sites. Although these were mainly semi-structured participant observations, I used the interview questions as a conceptual guide throughout the process of systematic noting and recording of events, behaviours, and settings.

4.5.3 IN-DEPTH INTERVIEWS

In the end, a total of 74 key informants' interviews were conducted. The extra four interviews were through referrals, with people who were deemed critical informants by other informants. Interviews allowed free conversations and sharing of experiences, so that the research shifted into an environment similar to that in which participants' experiences occur from (Coghlan & Brydon-Miller, 2014). All the interviews were semi-structured, with open-ended questions, using an interview guide. Although ethical protocols required using codes in place of the real names of participants, some of the participants were already well-known AIDS activists, senior politicians, and senior public officials. They agreed to be interviewed with names kept anonymous, even though some found this unnecessary. The above provides only a glimpse of the richness of the data collected and analysed. Having such a diverse set of participants afforded an opportunity to crosscheck information and provides a sense of the complexity of Khayelitsha and Lusikisiki within the national context. To make interviewing an interactive experience, I brought my role into the research relationship by answering participants' questions, sharing knowledge and experience, and giving support when asked (Knapik, 2006). One does not need to be either an insider or an outsider to do this.

Despite creating an environment conducive for participants to express themselves freely, it did not make the process of interviewing any easier. Each participant had their preferred way of answering questions—varying from those who preferred to tell their story to others who preferred guiding questions.

A list of the participants that indicates who was invited to participate in the study based on the list received from the SANAC and those who agreed to be interviewed. No real names were used, and each participant had an allocated code. In total, 74 became the actual interviews conducted, of whom 62% were AIDS activists from the TAC, the NAPWA, and independent activists not affiliated with social movements. Of the 46 activists interviewed, 28 (60%) were from the grassroots (Khayelitsha and Lusikisiki). The other key informants were from the government, across all levels; eight (10%) were public administration officials and politicians. From civil society, there were four (5%) from MSF, three (4%) from Section27, two (2%) from SANAC, two (2%) nurses from Khayelitsha and Lusikisiki, one nurse (1%) from the City of Cape Town, one (1%) member of the Positive Women's Network, and one person (1%) from Community Media Trust. The overall breakdown of gender representation in the sample was as follows: 31 (41%) of the participants were women, 41 (59%) were men and two (2%) were LGBTIQ people. It is particularly telling that most of the women leaders who participated in policy spaces now participate less because of prioritization of time and financial resources. Fewer women now participate in the policy process through formal structures. As (Gorna, 2014) shares in her essay, she was told by one of the Western Cape Provincial Health officials that they (women living with HIV) no longer have a cause to fight at the moment—they don't even come to the meetings anymore, they were always there and they had a complaint. Now we are waiting for them to have a cause again. Most women activists are juggling many roles, which include care burdens both at home and in society, leadership, and unpaid domestic work. Moreover, institutional participation is not always a priority when social movements face multiple challenges with overstretched human and financial resources.

I as a scholar/activist position had advantages and limitations. As anticipated, it created a much friendlier interaction. Nonetheless, I would not conclude that it made the environment more natural wwithout being sure what natural is in a research context, I do not think this is ever possible. There were clear judgment issues present from both the researcher and the participants under study. It uses a collaborative mode of knowledge production that draws out the vast information of the protagonists themselves, to put this in horizontal dialogue with the scholars' distinctive perspective and to keep the resulting creative tension intact as an experience-based challenge to conventional academic wisdom. Most feminist theorists would acknowledge a primary intellectual debt to women's struggles against patriarchy and sexism.

I contend that the connections between knowledge production, patriarchy and capitalism are all interrelated systems dominance which often activists are shy to call it out within movements. The view that feminism is less important than class or even divisive of class is still argued by Marxists and has risen as a backlash against postmodernism arguing the primacy of class(Ledwith, 2009), for example, draws attention to the complex ways that global capitalism simultaneously cleaves divisions of poverty and wealth within and between countries and uses individualism as a smokescreen for its necessary illusion of progress, giving legitimacy to this juxtaposition of extremes of wealth and poverty. Black militancy has taken the lead for years in efforts to destabilize and discredit "blame-the-victim" explanations for persisting racial hierarchy, debates that subsequently have played out in strictly academic realms. Theories emerged first in the context of political struggles against attempts to prioritize one of people's multiple axes of oppression, a practice that inevitably deprives the others of attention and importance. Gramsci developed his theory of hegemony and political subjectivity through efforts to address the bitter contradictions of Italian workers' consciousness and practice under the ascendant influence of fascism. While it is frustrating that the activist origins of theoretical innovation are so often ignored, the basic assertion is hardly controversial: social contradictions and political struggles are generative sources of knowledge. Regarding the epistemological divide between the researcher and the researched, there is no distinction between the researcher and the researched subject; all are involved in the research, dialogue, action, reflection, and further action (Berger, 2015). Knowledges are produced in multiple locations. One of the main approaches explored in this thesis is the walking a path the alternative epistemological situated knowledge divide. Hegemony is knowledge production is a powerful mental order of global science. Thus, feminist critiques have rejected the view on science as objective and value-free (Haraway, 1997).

4.6.1 POSITIONED OBJECTIVITY

During my fieldwork, it was clear that my research encounters were influenced by power between participants and myself. These arose from the various roles and status I hold such as race, gender, movement affiliation and social status (being openly HIV-positive). Defining relationship with key informants in the process of data collection based on some features what mark me as either a researcher or activists to those I was interviewing.

For example, pparticipants in reality could not separate my activists and researcher roles; for example, one said "I know, but it's hard to separate you, Vuyiseka the activist from the student,"

(NGovt0038 Interview, 2015). Others expected the communication to remain casual as was the case of an activist who said, “Your interview invite is rather too formal, comrade, and makes some feel unprepared for this interview,” (MSF0046 Interview, 2015). Moreover, as one participant remarked, this was seen as rather uncharacteristic of an activist, and some participants had assumed the researcher remains with the activists’ identity and struggled with the dual activist/scholar role. Some participants expressed challenges about my new role and how they should view it. These dilemmas revolve around the constant tension of positionality and its related power.

I too went through similar challenges in how to remain with both identities, and each posed its ethical quandaries. The very conditions of activist research place the scholar in an advantageous position to develop a deep, multifaceted, and complex understanding of the topic under study. Familiarity of the researcher with the research participants and their social setting allowed the researcher to approach individuals as almost equal peers rather than subjects of a study. Most participants were happy to be interviewed and often more than willing to offer a comfortable environment for recording the interview. However, some groups found it difficult to trust me because of my association with the TAC. Invitations to participants were through emails, whatsapp messaging, telephone calls, and participants found my communication more formal than usual.

4.6.2 ACQUAINTANCE BETWEEN RESEARCHER AND PARTICIPANT

“Feel a bit overwhelmed by questions, but will spend some time thinking because, at my age, often forgot far too much,” (WCGovt001-Interview, 2015).

During interviews, I used the tactic of starting with a disclaimer, indicating that although I may have been involved or would be aware of certain things, it would be best if the participants could answer the questions as if I did not know the issues. An interview guide was prepared to serve as a scope for the interviews. All interviewees were given options regarding whether I would conduct the interviews over the telephone, face-to-face or by requesting written responses to questions. The majority, 65 out of 74, chose face-to-face, six chose email, and four out of 74 chose telephone interviews. Most of the interviews were conducted in Khayelitsha, Lusikisiki, Gauteng, Cape Town and Durban, in isiXhosa and English. In all, I visited four of the South African provinces. Semi-structured interviews are not meant to be interrogation

sessions; hence, the researcher does not need to be asking a series of questions to which participants are expected to respond with great accuracy all the time. The purpose of semi-structured, interactive interviews in this research was to have a guided but open-ended conversation. At times, some interviewees had anxiety around remembering the detail of historical events. Some participants asked for the interview questions to be sent in advance to prepare for the interview.

I still got deferring responses, such as, "So I think SANAC helped a lot. But I must also say that more recently the relationship is not as harmonious and I'm not telling you anything you don't know," (NGovt0038-Interview, 2015). Furthermore, some participants would say, "Correct me if I am wrong,"(NGovt0057 Interview, 2015) or "as one will recall." Even when tactically trying to circumvent these deferring statements from participants they still occur. The questions asked in the interviews were open-ended. I started the interview by asking participants questions that allow participants to share their stories of interest. The first question was how they became involved in HIV/AIDS policy developments in South Africa. This question was the one that most participants answered with a feeling of starting with ease, and that affirmed that I was interested in their story. Participants did not just start out sharing intimate details of their lives; they constructed their story as they began to trust me, irrespective of my insider positionality. I then used their story to ask questions to follow up, without going back too much to the guide, but still in keeping with what I needed to find out. In cases where some participants wanted me to relate my story, I answered them with ease but without taking too much time. Many researchers work to reduce status differences in interviews by sharing information about their own lives and why they have an interest in the research.

For those who chose to respond to the main question through a narrative rather than question and answer format, notes were taken sparingly to allow more eye contact and gestures of interest in the story. This allowed the conversation to flow in a non-hierarchical manner, so that the researcher was not in charge of how the narrative is told. Using the tape-recorder assisted greatly during these interviews. As alluded to earlier, face-to-face interviews were the most preferred interview approach to obtain people's narratives and opinions about their experiences. Access to participants was not an issue; in fact, I had more people interested in participating than could be accommodated in the study. It was easy to access participants at all levels. However, interviews were not without their challenges, such as unavailability due to numerous

priorities, which led to several postponements. This was especially the case for those key informants who held leadership positions and postponed due to sudden commitments that emerged on the day of the interview. Despite participants' busy lives, and sometimes taking two or three deferments to get to the interview, in the end, they all materialised. Once the interviews were in process, even those who were nervous felt that they could express themselves. It is their memory and their experiences that matter. Two other challenges were noted during the fieldwork: cultural identity alignment and the access to participant.

4.6.3 CULTURAL IDENTITY ALIGNMENT

The cultural identity alignment refers to the view that insider researchers might be perceived with limited objectivity about their community of membership. Those who relate to the researcher as part of their group can be ambivalent in narrating their stories fully, due to the assumption that they are speaking to one of their members who should know the details. This heightened level of positive and negative uncertainty can be detrimental to data collection and analysis processes. At least I admit commitment to work on the faultlines.

4.5.4 ACCESS TO PARTICIPANTS.

It is often assumed that being an insider means easy access to a participant's life (Berger, 2015; Bourke, 2014), especially when compared to outsider researchers. True as it may be, easy access does not mean good data emerges. Good, reliable data comes from interviews where participants do not reserve certain information due to uncertainty. The advantage of being an activist doing research meant that I could access participants more swiftly, which has been referred to as expediency of access, but this also meant that more follow-up questioning was needed to get to the important details. The underlying ambivalence in the narratives shared by both those associated with my social identity and those not indicated that the associational stigma attached to certain researchers could both facilitate and constrain the practice of qualitative research. The association participants attached to the researcher did not diminish during the process of fieldwork. For example, some local activists were hard to locate on the day of the interview, even with prior arrangements. These are people with busy schedules and much more important matters to deal with, and my interviews were not at the top of their priority lists. I understood this, as too often activists are inundated with interview requests, and the researcher expects them to always honour the time and place of the agreed-upon interview.

AIDS activists deal with unpredictable social events, so the researcher must understand the drill. I understood that the best way was to follow them in the field, where it was easier to catch them. However, it was challenging to conduct an audible interview where there was possibly too much noise or too much traffic to conduct an interview. This reflexivity required careful consideration of the consequences of the interactions with those being investigated (England 1994: 82). Making it critical to the conduct of fieldwork in a manner that is considerate of participants competing pressures.

In some instances, the research is expected to support participants with the transport costs to the venue of their choice for the interview. Incurring participants' transport costs is something that one has to plan for in cases where participants' plans change. The place of the interview shifts all the time when dealing with busy activists; they have work to do, and therefore it was reasonable to expect that the research should go where they are. Unplanned costs incurred, and the duration of time spent with a participant could not be predicted. These factors affected the duration of interviews, as some participants tended to first debrief about some of the challenges they were dealing with in the present before they could settle down for the interview. I dealt with this not just for community activists but also for senior government officials as well. There was a situation in which one participant got three chances for the interview, and the participants used two out of the three interviews to just debrief. Even the third time, the interview was incomplete. The insider researcher may become privy to confidential information about certain participants and the institution under study; this can also have a negative effect on relationships.

4.6.4 THE IMPORTANCE OF SPACE, RESOURCES AND TIME DURING INTERVIEW PROCESS

The environment in which the participants allowed their narrative to be shared involved not just their physical, but also their mental space. For instance, one of the participants (TAC0030 Interview, 2015), who is a senior TAC leader, was interviewed in his small office which he shared with four other people. This was indicative of the physical space within which social movements operate. He also postponed our interview once due to other pressing priorities, and when it eventually happened the second time, it was full of issues that he was dealing with. Thus, the state of mind of activists does influence the story they choose to share with you, regardless of your pre-planned interview guide. The fact that he physically looked exhausted

triggered a dilemma in my head as to whether I should continue with the interview or not. Even after offering another appointment, he insisted that we go ahead now, as he might not have another chance, "so let us soldier on, comrade," (TAC0030 Interview, 2015). Once the interview began, his energy resurfaced, and we completed the interview. There were similar dynamics in an interview with a public official (Presidency0080 Interview, 2015) in the Cape Town parliamentary offices. The offices are typical government style, big and well furnished—in fact, a bit intimidating. They offer tea and biscuits to guests. Although this environment seemed neat and organised, the same challenges regarding availability, fatigue and distraction with multiple priorities emerged. I had to figure out the best way to move ahead with my data collection while being considerate of the participant's situation. Again, in this case, it was a second appointment (the first one was cancelled by the participant due to other commitments at short notice). Even when I finally got this chance, we ran out of time due to a general discussion prior to the interview. Interesting stories emerged as he walked me to the parliament gates to see me out, but these were unfortunately off the record.

4.7 SECONDARY DATA SOURCES

The period under study requires that researchers take both a historical and ongoing policy perspective. Written documents entail specialised content, and a careful, analytical approach can reveal important aspects of those who produced them. I examined ongoing accounts of socio-political and policy processes in newspapers, publications, policy documents, social movement archives and events from the period dating back to 2003. The use of secondary data sources also included social movements' reports, minutes, emails, speeches, news and digital archives. Written material such as email messages, books, newspapers, novels, music or non-written forms such as pictures, political speeches or struggle songs of a particular period in their policy advocacy can become part of data collection and the analysis method. Additionally, communication messages and symbols are unique and, therefore, differ from observable events or interviews and reveal properties of those who produce them (Krippendorff, 2012).

The study also used official sources such as publications of the South African National AIDS Council, Department of Health, and Human Sciences Research Council. This study has an advantage in speaking with people who were and are active in AIDS treatment politics and who were able to give a historical account of AIDS activism, social movements in policy advocacy

since 2003, and perspectives on policy processes. This approach avoids the methodological flaws of exclusively relying on official sources, which often produce politically biased data.
The I collected diverse views from indigenous and grassroots people, rather than only gathering the understandings of leadership. Social movement research sometimes tends to privilege the interpretations of leaders, who can also obscure and contradict (Steyn, 2016: 115) the views of grassroots members. I also worked to avoid the media sensationalisation and scholarly romanticisation of social movement news, which tends to focus mostly on national spectacular events and episodes. Both social movements and NGOs played a pivotal role in the HIV/AIDS struggle for access to ART policy and politics. The TAC and the NAPWA were hybrid social movements, as they were positioned as membership-based organisations with sustained campaigns for human rights and social justice while at the same time having features of NGOs. MSF and Section27 are not social movements but NGOs located in the wider struggle for social justice. This study has the advantage of speaking with people who are active participants in policy processes—the phenomena under study. Secondary sources complement the primary data gathered in the study. This provides a balanced view of policy advocacy from the perspective of everyday HIV activists and those responsible for policy implementation. Combining in-depth interviews and participatory observation with secondary data yielded qualitatively rich data for addressing the research question of this study. This methodological thoroughness allowed a nuanced investigation of factors such as government administration style, political structure, citizen policy participation type, political opportunity and framing tactics. It also offered insights into the socio-political space epitomised in South Africa and illuminated the trajectory of policy advocacy in Khayelitsha and Lusikisiki.

4.8 DATA ANALYSIS: CRITICAL DISCOURSE ANALYSIS USING NVIVO

Qualitative data analysis methods provide insights into and a rich analysis of the fine-grained experiences of AIDS activists and their social movements. NVivo qualitative data management software was used to allow data management and coding, allowing ideas and issues to unify to build themes(Edwards-jones & Edwards-jones, 2017). It also eased the process of interrogating and probing the data. My approach to qualitative data analysis accommodated various types of data including interview transcripts, documents, pictures, videos and audio records, all of which were coded; codes were collected into categories until the categories developed into broader meaning and themes categories enabling a conceptual plan to emerge (Zamawe, 2015).

Data from interviews were transcribed and captured in NVivo, after which they were coded. A thematic analysis approach was taken to identify basic, organising and global themes (Vaismoradi et al., 2013) . The conceptual framework described above was used, as well as the coding frame, which arose from the text, participatory observations and policy network analysis. Themes were identified to describe commonalities and divergences in meanings, narratives and insights of the key informant's experiences of policy processes, events, situations and actions they were involved with or engaged in. This allowed for the identification of unanticipated occurrences, influences, understanding and progression by which events and actions took place, thereby creating underlying contributory circumstances. This offered opportunities to understand underlying issues beyond just descriptions and explanations The literature review and analysis of spoken and written policy and movement narrative perspectives of AIDS activists allowed for analysis of shifts in HIV/AIDS policy advocacy discourse and established the dominant arguments of the reformers' and non-reformers' discourses, policy discourse collaborations, and their meanings for AIDS activists and their movements. This too allowed for connections between micro, meso, and macro levels as well as local to global activist policy interactions. It was critical in this study to understand the origins, influences, and means and sites of discourse engagement at the local level and how connections are made in the three spheres where AIDS treatment activism actions occur. This analytical approach assumed a dialectical connection between particular discursive practices and the specifics of actions (including situations, institutional frames and social structures) in which they were embedded. The situational, institutional and social settings were both shaped by and shaped discourses, political processes and actions. In other words, discourses as linguistic, social practices were seen as constituting non-discursive and discursive social practices and, at the same time, as being constituted by them. Discourse, as distinctly explained by Foucault refers ways of knowledge production, social practices, forms of bias and power relations. Thus, the discourses shape meaning in movements, in engagements in the policy arena as sites of contestation of ideas.

Research is not part and parcel of knowledge so the iterative research process which includes researcher reflexivity in ensuring connections between the research question, literature, participant recruitment, data collection and data analysis. Investigation and data analysis occurred concurrently to allow innovation and reflexivity (Nagar et al., 2007).In addition,

reflexivity is strategy to visibilise knowledge power relations and surrender situated impartiality position of the researcher (Rose, 1997:305).

This helped in recognising saturation levels and adjustments needed to achieve reliability and validity to ensure rigour. This research is premised upon the ideas that (a) social research should include a diversity of social experiences, and (b) that research methods should not reproduce the acts of oppression upon communities or people. In other words, research methods as a process of knowledge production should aim to emancipate or contribute towards a non-oppressive relational engagement between researchers and society. Hence, the researcher in this study applied social research methods that could improve or contribute to emancipation. The key was that the manner in which the investigation was conducted could contribute towards the emancipation of humankind not just through the findings, but also though the methods of investigation. Traditional or positivist approaches to science require the researchers to distance themselves from their research and participants. This approach was challenged in this study. Such an approach potentially created a false notion that reality is constructed only from a distance, thereby securing the researcher's position as the "expert" rather than an active knowledge co-producer in the study (Gaventa & Cornwall, 2007). Leveling the playing field in this approach was a conscious and political act on the part of the researcher. Social science should embody knowledge production that is reflective, engaging rather than detached, and aims not only for objectivity (Charles, 2008)

That is, it should be geared towards understanding and mitigating power relations in research that may serve to oppress particular groups within society. This study, therefore, took a conscious position on the privileged position of the researcher, as well as not being pretentiously objective towards this research. This research was embedded in emancipatory research principles about the lives and experiences of people who have historically been marginalised. Building on previous feminist research (Brooks, 2016; Flowers et al., n.d.) and disability research (Barnes, 2001), it suggests that the emancipatory research paradigm is based on reciprocity (which means that I had to give something as well extract knowledge) and that the participant also stands to gain from participation and get some form of empowerment (Adshead & Dubula, 2016). It is within this context that in the designing of the research agenda, I gathered some of the participants in a workshop to understand their research needs after the research was completed. Presentation of the findings to the same community was of utmost

importance. Allowing participants to take the opportunity to define research agendas that (potentially) affect their lives was important.

Within the emancipatory framework, ‘the researched’ can be involved in the research: from its initial planning to its execution and monitoring, and even to commenting on the results. Thus, I did not embrace notions of neutrality but rather a more active participant-observer relationship that was reflective while immersed in the investigation. This was so due to my 18 years of involvement in HIV/AIDS activism in South Africa. However, my approach to data analysis embraced a more critical and reflective approach and involved more distance from the data. This was premised upon my concerns about the power I had in the research and its effects in the data analysis processes. In this study, critical means being able as a researcher to distance oneself from your data analysis process while at the same time being embedded in the socio-political context within which data were collected.

CHAPTER FIVE: SHIFTING ACTIVIST STRATEGIES AND TACTICS

5.1 INTRODUCTION

"Without monitoring the state during the ART rollout, one could have a situation where the state was left to decide the pace of service delivery,"(Presidency0080 Interview, 2015) .

The state itself claims to value popular participation, monitoring, and accountability by non-state actors. The notion of participation by grassroots activists in policy implementation is not very common in social movements. Movements tend to be preoccupied with visioning, not service delivery. The role of the TAC during the ART rollout is an interesting story about the typologies of grassroots advocacy during policy implementation and demonstrates that movements evolve. Within the context of ART policy implementation and participation, the concepts of 'politicisation' and 'depoliticisation' have become popular (Beveridge, 2012), (Burnham, 2001; Kuzemko, 2013; Wood & Flinders, 2014) .This resonates with the problem of critically analysing "anti-politics". These concepts have sparked recent "interest" among political science scholars (Foster et al., 2014) remind us that depoliticisation is emerging as one of the most important devices used by the neoliberal project to undermine popular power in participation as well as critical for understanding contemporary patterns of governance.

Politicisation is a reflection of the power dynamics in a society, and in the case of public policy, different actors engage one another in an attempt to secure their respective interests. The final public policy outcome will reflect the relative balance of forces in that society at a specific time. Reflecting on the term politicisation the Treatment Action Campaign and the South African government are being utilised as the two key protagonists in the politicisation of the ART rollout in South Africa, exemplifying different understandings of the nature of activist advocacy tactics in responding to service delivery in South Africa. The literature (Madlingozi, 2013; Mbali, 2003, 2013b; N Nattrass, 2007; Michael Neocosmos, 2009; Vandormael, 2007) describes the TAC as the most influential AIDS organisation that compelled the state to change its ART policy stance in South Africa (Nauta, 2011). While this chapter focuses on the TAC activists' tactics of advocacy for policy implementation by the government, this politicized the HIV/AIDS service delivery in South Africa without implying that they were no other players in this politicisation.

This case implies how the TAC shifted its strategies in engaging with government at local level within a national context of the politicisation of HIV/AIDS during this era. Participation and social movement theory are the main two conceptual frameworks applied in order to interpret the data gathered during the course of the study about bottom-up activists' advocacy after the introduction of ART policy. The purpose of this chapter is to answer objective one, which is to understand the shift in AIDS activist advocacy tactics following the rollout of ARVs. This chapter applies Moyer's (1987) social movement plan to interpret the ways in which activists' advocacy strategies shifted after the ART implementation era. Movements sustained their collective actions through campaigns that were highly visible at local and national levels, using various advocacy tools to maintain their movement frames in the public domain. Activists' participation in policy implementation takes various stages, forms and shapes, from attending AIDS council meetings, public meetings, protests, litigation, social mobilisation, popular education, and picketing to advocacy, and these interactions overlap. This chapter positions participation as praxis: in other words, participation is an act of engagement, application, exercise, realisation and practicing of ideas.

Freire (1970) in Pedagogy of the Oppressed defines the term praxis as critical thought and action towards the structures to be transformed. He argues that through praxis, the oppressed can gain a critical consciousness about their own conditions of struggle for liberation. This suggests that praxis is more than just practice or implementation, but that it develops to a level where everyone concerned knows exactly how to respond to the particular issues involved. Therefore, praxis calls for seeing TAC's participation within a political and policy context, using examples drawn from two case study sites after the government approved the ART policy in 2003. A case study in this instance, as explained in Chapter two, is for intensive study of a distinct unit of inquiry for the purpose of understanding a larger class of (related) environments (Gerring, 2004). The interface between activists and the state is broadly defined within the concept of participation (Ginsborg, 2005). As such, the structure of this chapter presents information in a way that explores the praxis of participation as it appears to both activists and government during ART policy implementation.

The scholarly writing thus far attempts to demonstrate that participation is one amongst several critical factors in the success of implementation. In addition, there is a critique of grassroots practices and meanings of participation during policy implementation that the policy outcomes should reflect the original intent. Policy formulation and implementation are not detached from the socioeconomic and political context in which they take place. The social, political, and economic contexts influence what policies are developed and whether and how those policies are put into practice (Grindle and Thomas, 1991). Social and political contexts can provide both opportunities and constraints for effective policy implementation (Palumbo and Calista, 1990). These forces exist at multiple levels of policy spaces, as discussed in Chapter Two (e.g., international, national, local), and their impacts shift over time.

This is the first of four chapters that present the analysis in which activists' bottom-up policy advocacy shifts after the AIDS treatment victory in Khayelitsha and Lusikisiki within a national context. The three Chapters (Five, Six and Seven) are the findings chapters that aim to contribute to answering the main questions of this thesis and critically examine how the AIDS activist advocacy tactics shifted following the rollout of ARVs by people and social movements affected by HIV/AIDS in Khayelitsha and Lusikisiki. What impact did shifts in tactics and transforming participation typologies have on the TAC? How did activists in Khayelitsha and Lusikisiki understand the transformation? Changes in activists' tactics are observed within a national context of dramatic changes in the balance of forces between 2004 and 2014, which led to AIDS treatment access breakthroughs (as well as challenges). Section 5.3 discusses the advocacy tactics grassroots activists applied, which shows the shifts from traditional antagonistic engagements with the state to the use of a dual-tactical approach and impact on the local membership. This includes using collaborative advocacy tactics such as (5.4) treatment literacy as a form of popular education, (5.4.3) mobilisation to create ART service demand, and support for the ART rollout in the study sites. It demonstrates that the treatment literacy programme became a strategy that activists used to give rise to popular mass knowledge about the science of HIV and governance. It argues that the use of this tactic shifted the patient relations with the state, because of the increased knowledge and power of patients as they countered the health system elite and health administrators' authority.

The grassroots activists applied treatment literacy tactically to shift the dominant unequal relations entrenched in the health system, where the health care workers and public administrators perceived as the experts and patients observed as passive receivers of care and non-experts. In turn, activists used treatment literacy as tool to collaborate with the state, using their pragmatic alliances with health providers as a way to have one foot inside the system. The activists remained inside the health system by offering health education to other patients and negotiated where possible for service delivery from within. However, while treatment literacy as a strategy may have created collaborative pathways for activists to work with the state, it also has its own caveats. These include the possibility that the long-term involvement of activists in the ART sites could lead to cooptation by adjusting their autonomous role to comply with the public-sector procedures and roles. Over time, some grassroots activists were absorbed into more service delivery than activism. Nevertheless, there are strengths as well, such as strategically building solidarity within the system through aligning with health workers and engaging in pragmatic alliances with public administrations.

5.2 ONE ANTIRETROVIRAL ROLLOUT SITE PER DISTRICT

> Within a year, at least one antiretroviral (ART) rollout site in every health district across the country, and progressively one service point in every local municipality within five years, (Government Communications, 2003).

Often, policies are redefined and interpreted throughout the service delivery phase as shown about with the government announcement, and this is where they the realities of implementation on the ground begun (Alesch and Petak, 2001). The Cabinet statement announced (GCIS, 2003) that only one site would provide ART per district, which meant that some would have access and others not. Government further planned to reach all health facilities and municipalities within a five-year period. This was a huge shift in the state policy. It occurred under the President Mbeki administration, and it is predictable that there would be a residue of denialism in provinces. This indicates a political structural and power shift at least at the national government level. The real significance of this policy shift lies in the ambit of provincial government where implementation occurs. Of course, when the government announced its ART implementation intentions, which shifted the movement's public focus from traditional adversarial policy advocacy, it attracted the heightened media attention.

The public attention to the announcement may go both ways in that it may normalise the public discourse indicating that the state has listened to movement demands. On the other hand, the activist reframes the state ART policy announcement as its victory and immediately transitions their advocacy pressure towards service delivery to avoid the diminishing and demobilisation effects that comes with "victory". Service delivery shifts public spotlight from national government to local. The official government policy announcement turned out to be a fictitious commitment given that they later dragged their feet to implement their own policy, as discussed in Chapter six.

Policy implementation refers to a process of breaking down the policy intentions into program activities, identification of delivery platforms, human and financial resources needed, and monitoring and evaluation of policy outcomes. The true policy victory is realised during its implementation—not in public statements, but in operational plans and budgets. This sounds straightforward to many, yet scholars argue that (Schneider, 2002) policy implementation is one of the weakest policy development processes in South Africa. It can be quite complex, but understanding the nature of policy implementation is important because international experience shows that policies, once adopted, are not always implemented as envisioned and do not necessarily achieve intended results. O'Toole (2004) points out that during implementation the policy process involves public administrators who give a more expressed meaning of policy intentions through their actions and behaviours (O'Toole, 2004). Policies often are interpreted throughout the implementation process as they confront the realities on the ground (Alesch and Petak, 2002). Scholars define implementation in many ways, but the one that resonates refers to implementation as policy models that assist to find out what and how policy should be implemented, be it interventions to respond to a specific problem or the type of practices best suited for intervening based on specific local contexts. Implementation is, therefore, an ongoing iterative process of interaction between the state and the communities to act on a given approved policy by setting service delivery as well as taking actions to achieve these goals. The concern with implementation is the fundamental failure to translate policy intentions into service delivery to meet the demands of the public. Implementation is a process that involves a relationship between the public and the state, and accountability is fundamental to those engagements.

The power of accountability resides in the public through using participation as a means to hold the lower echelons of the state such as the street-level bureaucrats accountable. Grassroots activists have a right to question and be informed and thus enforce accountability on governments (Mulgan, 2000). This is important to this thesis, as the social movement way of holding government to account is embedded in representative democracy (Taylor, 2007). Policy implementation is a distinct stage in the policy development process, one that focuses on how a national policy commitment translates to service delivery at lower levels of government (Lester and Goggin, 1998). Accountability is a social relationship in which an actor feels an obligation to explain and to justify government conduct to some significant other (Bovens, 2007). Bovens argues that for government accountability, there need to be various types of accountability, which include political and administrative accountability when it comes to implementation (Bovens, 2007). Soon after government announced the roolout plan, the activists too made a statement calling its members to be ready to monitor and support the implementation.

> The challenges ahead for all of us are to ensure that the plan is implemented as speedily as possible and to mobilise our communities around counselling, testing and understanding how treatment works, (TAC statement cited in AfricaFocus, 2003).

If communities believe that government has the political will to implement policies and actually follow through with its promises, the state may get public support and win political trust (Chanley et al., 2000). In this case, the policy shifts came about because activists forced public traction on the problem of access to ART and the state being able to deliver. The period of policy implementation provides insights into a social movement's evolution after a successful policy campaign. Thus, the second part of this thesis critically assesses the grassroots popular participation advocacy strategies for ensuring ART policy delivery in Khayelitsha and Lusikisiki. It also recounts the contradictions of activists' advocacy strategies including collaborations and confrontations with the state during the ART policy implementation. There is a consensus that participation of marginalised people in policy development is fundamental. Mohan and Stokke (2000) point out that participation in policy processes ought to facilitate marginalised people's capacity for direct influence in the policy process from bottom-up. Different factors influence the conditions in bottom-up activists' participation in policy implementation, such as the content of the policy, the nature of the policy process, the actors

involved in the process, and the context in which the policy is designed and implemented. Thus, after 2003, policy implementation concerned how governments would put the ART policy into effect. The policy adoption is one of the critical milestones in the policy development lifecycle. The adoption of ART policy marks an achievement but more importantly indicates a continuation of the policy development process to make sure that access to affordable ART for poor people becomes a reality beyond just adoption. The South African government announced its plans to roll out AIDS treatment to every municipality across the country within certain timeframes. The government delays in implementation created political opportunity of the movement actions to continue to enjoy some media attention for their local advocacy. The TAC shifted its advocacy tactics in Khayelitsha and Lusikisiki to facilitate conditions for activists' engagement with ART service delivery in five ways. In section 5.3, I discuss use of a dual tactical (collaboration/confrontational) approach to counter state ART service delivery. In section 5.4, the rise of popular power using the TAC's treatment literacy is an example of the shifted advocacy engagements from below. Section 5.5 shows how activists' tactics had distributive policy impact in the ART service demand creation. Lastly, in section 5.6 I demonstrate how activists' strategies begun to build bridges between patients, service providers and policymakers.

5.3 THE TACTICAL APPROACH TO COUNTER STATE ART SERVICE DELIVERY

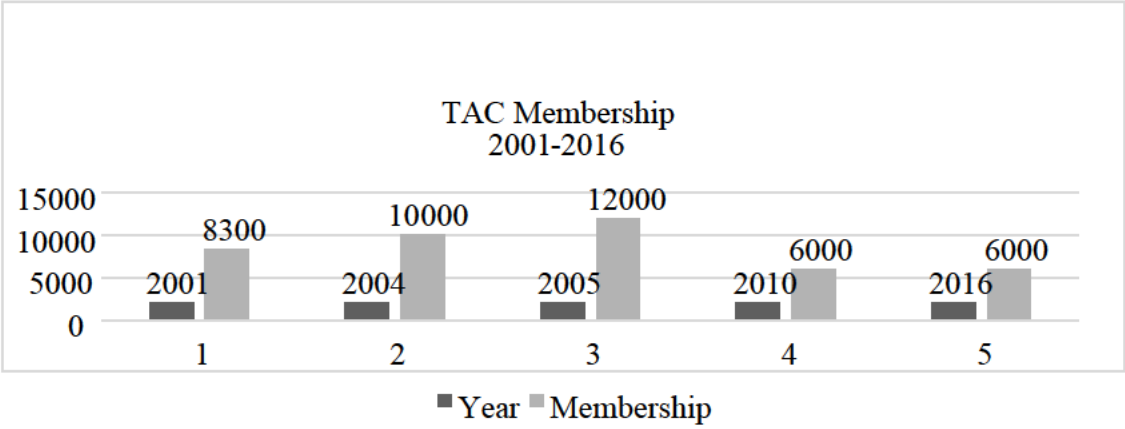
"TAC's primary mission after 2003 was mobilising people who need ART; creating demands to services, while monitoring roll-out in local clinics," (TAC008 Interview, 2015).

The announcement above points out the measured shift in TAC's focus in warranting that the people should drive the ART policy implementation. TAC's purposeful and collective attempt to influence and shape implementation of ART policy was clear; their pursuit of the rights of people living with HIV/AIDS to access ART continued but the frame evolved. They issued a statement targeting their members and supporters, framing their shifting focus into local organising, demand creation and monitoring of the ART rollout. Even during implementation, the grassroots activists adopted direct and instrumental advocacy tactics to ensure that they shaped the direction and the pace of the ART rollout. The framing tactic was for grassroots activists to develop a particular orientation and conceptualisation of ART access and how they wanted to influence and participate in implementation. The TAC's choice of recourse to prime

the public used both institutional and non-institutional forms of popular participation; we know this because in their statement they express a clear intent to organise and create demand for services, as well as to monitor the ART rollout making sure that the majority of poor people are included in the ART rollout plan post-2003 in the public health system that refused them access before 2003.

The monitoring role frames the outsider, independent role of the TAC movement action plan to sustain its watchdog role in ensuring that the policy they pushed for meets their expectations. No doubt, the TAC had the infrastructure to receive the call from the movement leadership because of the presence of its active branch membership across six of the nine South African provinces. However, the new shift required resources to support local activists in their effort to hold government accountable for implementation. The TAC's grassroots membership are unpaid volunteers who work regularly—daily and weekly—in their local communities. The branches are meant to be where the pulse and soul of the movement resides, and a place where leaders take mandate from and are accountable to its members. Their socially assembled assessment of membership that is an active presence around the local health clinics created human and social capital as well as political sites of local contestation. The strength of TAC's grassroots legitimacy lies in the strong branches (Klugman, 2016). The TAC compelled its organisational resources through its local branches and membership to support and monitor the ART rollout, which then required yet again new forms of bottom-up participation. The assigning of a monitoring frame means that relevant service delivery events and conditions intended to mobilise potential members and supporters to garner public support and/or disarm antagonists (Benford & Snow, 2000).

FIGURE 15: TAC MEMBERSHIP 2001-2016



[TAC, 2004 ; 2009 ; 2010; Klugman, 2016]

5.3.1 SHRINKING LOCAL SUPPORT

According to various sources within the TAC, the membership fluctuates between 6,000 and 12,000 across the country, with Khayelitsha and Lusikisiki accounting for a large membership resembling a mass movement. The trajectory of membership (in figure 15 above) follows the peak of the TAC struggle for access to ART. Noting that in 2003, the activists achieved their highest peak in social mobilisation and membership if one looks at in terms of large crowds. However, during implementation, there was decline in the large crowds and the movement was left with groups due to many factors.

> "I think it is hard for TAC because there are no clear battle lines with (MSF0066 Interview, 2015).

As the MSF activist argue that because of the dispersed activist's advocacy the battles line was not one but many in various provinces. This was hard and confusing for members at the grassroots level and affected their morale.

The second reason for the fluctuation in social movements like TAC is the challenge of sustainability of its local operations due to shrinking funding. As projected by TAC by mid-2008, which was the year of the international financial recession, TAC faced major funding cuts (Khumalo et al., 2009). At the time, I had just been the General Secretary for a few months. I remember vividly the horrible feeling of retrenching my fellow comrades including hundreds of the community educators and organisers and closing down of provincial offices. TAC was

once one of the most loved and funded movements by donors in South Africa (Boulle & Avafia, 2005). From 2008 to 2012, the TAC went through its first internal restructuring which came with shifting focus from provincial wide mobilisation to 'model districts' as part of the public health paradigm in which interventions are tested in specific places and if they work, they then get rolled out nationally. The TAC's work in these districts strengthened its participation service delivery, however, the members in branches that were outside model districts felt unsupported and membership dropped radically (Klugman, 2016). Some of the members argued that the dissolution of support outside the chosen districts led to the loss of TAC radicalism, and solidarity.

"The problem is you get funding who dictate what should be done with their money," (TAC0030 interview, 2015c). he TAC founder leaders were moving on and the organisation needed to be developing a new institutional culture; it found itself answerable for "deliverables" against which it had received funds (Klugman, 2016).

"We are chained by funding agreements; as a result, we spend too [much] time dealing with donors rather than organising,"(Section27 0058 Interview, 2015). Therefore, some activists argue that the reduction of TAC work into small unit will be felt at grassroots. The "Reduction TAC to model districts is a 'demobilisation' that may eventually kill off the organisation," (TAC History Archive, 2010) . As the one of the comrades argue above that the reduction of TAC work in model districts will affect the morale of the movement. This shift as argued by TAC and Section27 activists above is due to resources that forces a shift to focus in one district in per province. TAC has members and branches outside of the 'model districts' and in other provinces which were left unsure of how they will be supported. One of its principles that makes the TAC set apart from the rest of movements is that they chose not to accept South African government, US government or big pharmaceutical companies funding. This limited the TAC funding pool to a small pool of international donors and kept it under constant pressure to diversify its funding base to include local corporate and individual donations. The situation has not improved; in 2015, TAC was facing a severe financial crisis – one that is more serious than any previous financial crisis. This means there is not enough money available to continue operations at the current level. It is very unlikely that we will be able to raise the funds to continue with the staff numbers we have today and the activities carried out. The demobilisation affected the broadening of TAC's mandate to include improving the quality of the public health system so that it can deliver a sustainable ART rollout. "Downsizing was the most difficult and

painful process for the leadership, we had to retrench organisers and educators who are breadwinners," (TAC History Archive, 2010). Further, by 2014, at the time of this research the TAC face yet another downsizing of its local offices that were critical in supporting branches. Other activists argue that the TAC's fast growth in the early 2000's during the initial ART rollout phase will cost the organisation members on the ground (TAC History Archive, 2010) . The TAC is a victim of its own success, in that it has been so successful in its access to treatment campaign that members now expect the organisation to start addressing the broader socioeconomic needs of its members.

> We need to find resources from within our own movements, both nationally and internationally, to fund social justice activism, breaking our dependence on donor governments. The reliance on donor funding has been both a blessing and a curse. While it has provided the resources to tackle important issues, it has also made civil society organisations vulnerable to the accusation that they are imposing foreign ideas and agendas on local populations," (Extract from Dubula's talk at (Centre for Civil Society, 2014).

A year later, in 2015 the Health e-news reported that after several attempts to support fundraising effort of the TAC the Stephen Lewis Foundation, a Canadian non-profit, made a 14 million pledge at a press conference, which I attended. These funds helped the TAC to continue to save it from closing its doors, but will not save jobs already on the cutting (Lopez-Gonzalez, 2015). Activists in model districts such as Khayelitsha and Lusikisiki had to keep contesting implementation. The activists' advocacy continued, committed to monitoring the state and promoting accountability during implementation (Bhuyan, Jorgensen, & Sharma, 2010) . One of the strengths and demise of TAC is its ability to straddle between collaborative and confrontational advocacy strategies to counter the government ART rollout. As stated earlier, the evidence in this section suggests that the manner in which the ART rollout at the grassroots led to a proliferation of popular mobilisation and education to support, monitor and counter the rollout in the study sites is incontrovertible. The activists' vigilance on service delivery standards, equity and quality of policy implementation becomes essential. The impact of HIV/AIDS has led to the emergence of a new layer of social groupings such as NGOs or social movements that monitor and advocate for effective state policy implementation. Advocacy is popular participation that seeks to influence and shape policy processes and decisions. Monitoring the state implementation became the focus of building and mobilising grassroots members to participation in collective action. It is common for social movement evolution to

involve reframing of policy problems or continuing to frame remaining unjust conditions. The TAC articulated mechanisms by which members could focus their collectives using the local health clinics as sites of organising, contestation, and the reconstruction of patient-provider relations.

Additionally, the TAC monitoring frames performed a transformative shift from national to local attention and the activists' engagements with the state, as in the reconfiguration of aspects of local advocacy actions around routine grievances of injustices and mobilisation around those at the local level. Grassroots activists are agentic and adopted a contentious collective frame embedded in everyday practice related to the experiences of people's access to ART.

Framing processes are critical in grassroots advocacy to highlight their movement concerns, demands and the government target for their actions (Carragee & Roefs, 2004) .Thus, the TAC frame articulation connected the local events, people's experiences, and the participation of the grassroots in implementation in a relatively integrated manner. On the other hand, framing is not just an abstract process devoid of political and social influence hence the participation of activists in policy implementation began to deconstruct the distribution of power to reduce state hegemony, as discussed later in this chapter. The sections below discuss the various collaborating advocacy strategies applied during the rollout; evidencing shifts in the types of participation at local levels. This discussion includes a focus on the TAC's mass education campaign, social mobilisation techniques and application of consistent pressure at local health facilities by monitoring the pace of the ART rollout in Khayelitsha and Lusikisiki.

Collaborative strategies secured inside access to the state, which includes working with frontline health care workers, and confrontation where the state was not delivering. These tactics involve using treatment literacy and building alliances within the system through strategic alliances with health care workers and public officials. I divide the dual tactical approach into two major categories for analytical purposes. First, activists applied collaborative advocacy tactics to support and monitor ART rollout in the study sites using the popular education programme known as treatment literacy. The use of treatment literacy to collaborate with the state was a way to have one foot inside the system. The activists remained inside the health system by offering health education to other patients along with their own services. Second, activists used confrontational tactics to contest and monitor ART policy

implementation in the study areas. I contend that the grassroots activists applied strategic litigation to challenge the state's lack of transparency about its ART rollout timetable.

5.4 RISE OF POPULAR POWER: LESSONS FROM TAC'S TREATMENT LITERACY

Before working with TAC, I knew very little about the politics of medicines and health, but through Treatment Literacy (a popular and rights education programme), we empowered ourselves with knowledge and used that power against the system. It is through this that I learned that the theory/practice dichotomy is disrupted when ordinary people empower themselves and their communities through production of knowledge and use that knowledge to reflect on their socio-political conditions through action (Freire, 1970) . Freire's political view of knowledge is a prime source of inspiration. He argues that consciontisation in the form of political awakening through popular education is pivotal to activist's critical consciousness of their struggle. Therefore, he suggests that the only way that the oppressed could practice freedom and, more importantly, accomplish change is through political awakening. This was an emancipatory and liberatory pedagogy aimed at rejecting the 'fear of freedom' through discourse and contention as tools of learning and acting on one's own condition. From (Kluttz & Walter, 2018) we learn that there are various schools of conceptual thought about movements and learning spaces. This includes the sociology of social movements are spaces for identity through which individuals and the collective engage in intellectual praxis and (Holford, 1995) (Kilgore, 1999) we acquire new identities, construct new knowledge and take action for social change. Learning in social movements is an evolutionary, messy process, taking place in a social and political context where people in a particular locality may invest time in this consciousness process. The Marx view is that social movements are about the emancipation of the working class by the working class, which alludes to the active radical participation of the poor in their rebellion (Barker et al., 2013). Freirean and feminist scholars (Butterwick & Elfert, 2015; Clover, 2010; Irving & English, 2011) understand conscientisation, transformative learning and educative-activism to happen across these various oppressions and associated social movements. (Gouin, 2016) adds that social movement learning includes the understanding of the intersectionality of oppressions even inside the very sites of transformation (which means the social movements are not immune).

"The treatment literacy uniqueness is that it empowers its member so that they are able to participate in policy making spaces with ability and confidence to articulate themselves," (TAC005 Interview, 2015).

It is not strange for a social movement to build capacity of its members but the treatment literacy program served three purposes being a political school for activists' critical conscientiousness and serves as a space for testing political ideas and politicisation of health and HIV policy. In Section 2, I discuss how activists co-created simplified and popularised of medical knowledge. In section 3, I argue that popular education had direct benefit for movement members and patients' consciousness building.

In section four, I discuss how the TAC's popular education builds grassroots movement power. Moreover, the treatment literacy program serves a pragmatic advocacy tool, which shapes four types of grassroots outcomes in the ART rollout. Other outcomes included in section 4 are distributive effects of activists' advocacy in the health system and policy, such as shifting relations and creation of a new social contract between providers and patients, and in section 5 the systemic effects in terms of ART service demand creation for collective gain for the wider society of people who need access to lifesaving treatment (Amenta & Young, 1999). Despite a growing body of research on advocacy's outcomes, only direct benefits have been systematically studied empirically.

5.4.1 CO-PRODUCTION AND DISTRIBUTION OF MEDICAL KNOWLEDGE

"People were interested in the treatment literacy because it's popular education element which interrogates the science, politics and actions to achieve access to healthcare," (TAC008 Interview, 2015).

The treatment literacy is a form of popular education that the movement used to lay a strong pedagogical element to its strategies to build agency in order to shift apolitical nature of engagement between state and the poor. Popular education became a strategy that activists used to (a) give rise to popular mass knowledge about the science of HIV and governance. I demonstrate in this section that the use of this tactic shifted the (b) patient relations with the state because of increased knowledge and power of patients as they counter the health system's elite and health administrators' authority. The authoritative role of health care workers and

public officials as the health system elite slowly diminishes as the public's influence and knowledge over their ART service delivery increases (Piven, 2008).

The grassroots activists applied treatment literacy tactically to shift engagements with the dominant unequal relations entrenched in the health system where the health care workers and public administrators are seen as the experts and patients as passive receivers of care and not experts. The health system has an inherent hierarchy through its medical professional establishment of ranks and authority along the lines of expertise. The implementation process is complex, and the unpredictable health facility level requires activist bargaining advocacy tactics and negotiation tactics at different levels rather than as a seamless sequence of movement advocacy action. This has led to activists' recognition of the importance of engaging with the state using different approaches, because the state is not one monolithic machine with which one can use a one-size-fits-all approach. For activists, the approach to health care workers was one of offering help to win then over and build alliances with them. Activists' efforts to sustain their public influence meant that they had to create and strengthen strategic coalitions for the new challenges at the local level. One of the TAC's most strategic alliances was with the MSF. This strategy meant building solidarity within the system through aligning with health workers. The TAC uses popular education programmes to collaborate with government in offering knowledge about the science of health, HIV and governance to shape people living with HIV's levels of awareness. Patients organised themselves through the TAC to be part of a group, so if there were any cases of abuse of power by the health system, the group acted on behalf of the individual if the individual did not feel empowered or safe enough to address their issues. This is evidence from testimony from activists:

> We received several complaints from patients about the Site B day hospital pharmacy and we tried to engage with hospital management about the staff attitudes and long pharmacy queues, (TAC0015 Interview, 2015).

The presence of TAC in clinic spaces developed into activists brokering with the health system with frontline health providers on the quality of care—and new types of relationships with health care providers and policy-makers (Robins, 2005) emerged. I argue that at times, activists had to engage confrontationally where negotiation yielded no results and change. The power relations between them were uneven, but activists used knowledge as their tool to engage with evidence against the health system. As (Gaede, 2016)argues that health professionals too can

be street level bureaucrats because they get to make decisions at facility level and can ration care based on available resource. However, activists in Khayelitsha and Lusikisiki begun to shift and challenge the power of health professionals.

“The TAC has influenced the new patient-centred approach to HIV services - by improving the patient relationship between doctor,” (MSF0059-Interview, 2015).

The MSF activists worked closely with TAC activists on the ground in communities, which increased forms of power and participation during the ART rollout. The two organisations joined forces to increase their chances of success in monitoring the implementation of the ART plan.

The MSF was largely made up of medical health professionals with HIV treatment experience in service delivery, and these alliances fostered activists’ presence in the public health clinics already offering popular education to support group members and partnering with MSF to train HIV/AIDS counsellors and nurses. In this sense, the TAC and MSF performed an expert service-delivery role that does not have any express political agenda. These sorts of alliances also lay the foundation for knowledge sharing and breaking hierarchies of access to medical knowledge through popular approaches, leading to unique and pragmatic alliances between activists and healthcare workers (Steinberg, 2011). Regardless, local activism provided opportunities for new forms of collaboration between patients and health professionals to act in solidarity rather than in opposition. The local branches in poor townships and villages became platforms for rights education, local activism and advocacy focusing on monitoring access to health and HIV/AIDS services and inducing government accountability at all levels. Treatment literacy was a tool to build public consciousness, and it led to the growth of the TAC at the local level with broad-based movement alliances, in turn creating a critical mass for its demands for a faster rollout beyond just Khayelitsha and Lusikisiki.

In Lusikisiki, local branch policy participation was also critical in holding local health authorities to account for the services they provided. There were often delays in getting children on ART, as the ordering system did not allow for a buffer stock of pediatric ARVs (Bedelu et al., 2007; Garone et al., 2017) . For example, when there were drug supply challenges, the TAC activists developed a drug-monitoring tool and reported out-of-stock drugs to people at management level. The TAC advocacy model is based on active citizenry where the unequal

relations between users and providers of ART services are reformed (Mfecane, 2011). Thus, the focus is on building new kinds of social contracts between activists and their health providers through treatment literacy. In Lusikisiki, for example, AIDS activists and MSF provided evidence that the state model of ART service delivery was expensive and unsustainable because of its high dependence on scarce public doctors. It exposed the suboptimal numbers of doctors in Lusikisiki, which at the time was fourteen times below the national average.

Combined with 37% of the nurses' posts being vacant in the Eastern Cape (Bedelu et al., 2007), this begs the question of who was going to initiate people on ART if there were no human resources. The MSF also used its experience from the Khayelitsha ART programme to demonstrate that nurse-driven ART management supported by a large pool of non-professional lay workers (including introducing innovative adherence programmes) in a community health facility was feasible with the same quality of care for patients (Wouters et al., 2012). This was an advocacy tactic to counter the state's claims of a lack of human resources.

In this new phase, the TAC, along with its traditional allies in the international humanitarian organisations such as MSF, developed strong patient-health provider coalitions in both study areas that shifted the ART policy implementation forward. "TAC has the ability to get the doctors and the nurses behind them, there are hundreds doctors and nurses who became AIDS activists that is quite an unusual phenomenon," (SANAC003 Interview, 2015). The partnerships amongst NGOs and social movements on their own created new social power that could challenge government policy implementation. At the local level, opportunities for collaboration were created through activists offering to support and monitor implementation using treatment literacy to raise awareness about the plight of the people, provide support to local health facilities and gain credibility with local health workers. They were therefore not just radical activists but activists who could improve implementation. In so doing, the TAC enables the movement of marginalised people to participate as active citizens in their health. The contention over ART implementation at the local level facilitated new kinds of bottom-up alternative participation pathways and consequently began to shift the balance of power at local levels. Social movement actions during the ART policy implementation provided activists with a sense of social power and active citizenry through participation.

The MSF and the TAC share ideological congruence around the use of ART as a pivotal intervention to save lives. They both have struggled around the common social conditions. The MSF instituted innovative models of care in limited-resource settings, which is critical in sustainable health approaches. However, these coalitions between patients and health providers were not without challenges. Social movements in opposition to the state are more likely to face similar political threats. Therefore, strategic alliances by groups who share similar marginalisation such as TAC, Section27 and MSF tend to form coalitions and stand to gain policy success. Implementation meant that TAC at grassroots should extend its alliances and introduce other allies to participate in various guidelines, supply chains, ART stock-outs monitoring and representation at various SANAC structures to increase its influence.

Another example of the alliance between activists and health care professionals went broader than just service delivery issues and included solidarity with healthcare professionals in their struggles with conditions of employment that had a negative impact on service delivery. For example, in 2004, the TAC in Lusikisiki challenged the Department of Health over the poor housing conditions of student nurses in St. Elizabeth Hospital (the only hospital in town). These nurses lived in tents frequently destroyed by the wind, while providing essential healthcare services. These unique alliances are not very common between patients and health providers.
Moreover, the activists used evidence on the levels of human resources in Lusikisiki to expose even more problematic health governance matters such as lack of delegated powers to the local Department of Health to make decisions. They were responsible for employing staff in the clinics, but they did not have the power to create positions without approval from higher levels of government. The Ministry of Health had no clear human resource and infrastructure plan or budget, which should have accompanied the ART rollout plan (TAC, 2007a). So, the “Batho Pele” (people first) service in practice was reduced to rhetoric as the state became insulated and centralised (Donk, 2008) , making it difficult for ordinary people to influence policy decisions. About 60 Khayelitsha nurses were dismissed for participating in the strike, since they were essential service public sector workers (TAC, 2007b). further, their dismissal without alternative human resource plans to close the health provision gap, however, compromised service delivery for patients in the community. The TAC and five patients who were TAC activists took the Western Cape and national governments to court for dismissing these workers.

The TAC activists provided three important affidavits from Dr. Srinivasan Govender, a senior physician in Khayelitsha, Dr. Goemaere, head of MSF South Africa and Sr. Mantangana, a chief nurse at Ubuntu clinic Site B Day Hospital. They demonstrated the irreparable harm caused to patient care and service provision by the dismissal of 60 nurses. Judge Desai ruled that their dismissal without any measures to address the resulting staff shortages and patients' needs infringed upon patient rights protected in Sections 27 and 28 of the Constitution. He ordered the government to restore the health services in Khayelitsha. The judge also ordered the government to pay the TAC's costs for the court application. The five patients who were applicants in the case demonstrated the power of patient agency in not accepting poor service delivery and taking steps such as using courts to challenge the state. However, the use of litigation as a confrontation tactic to force the state to deliver on its constitutional obligations had its limitations.

In this case, the court could not order the state to reinstate those dismissed nurses but could only order it to restore the services (Government, 2007). The TAC was instrumental in highlighting local level healthcare challenges, which affected the rollout.

> The Nolungile (known as Site C) clinic where an HIV doctor works half-days, leaving patients desperately unattended. We raised complaints that were not addressed; we then escalated our actions to protest outside the hospital and as a result, the clinic got a new full-time doctor, (TAC0010 Interview, 2015).

The idea of poor people, especially living with HIV, making a claim that those essential medicines such as ARVs should be available in all rural or poor township primary health facilities or demanding that a doctor arrive on time was without precedent. Participation of grassroots activists inside the health system allowed advantage and a shift from being just passive beneficiaries of ART services into advocacy that could hold the state accountable through new forms of governance that involve more regular and direct engagement. Activists use negotiation and bargaining first to allow health facility managers to respond, and if there is no improvement in their demands, they escalate to protest to enable citizens to express their concerns more directly to those with the power to influence the service delivery process in the health facility. Then opportunities for more engaged patients in their care opens up for enhanced state accountability and responsiveness. The traditional ways of upholding accountability such as elections, public meetings or the media are not always sufficient in giving people a sense of

ongoing influence and control in health governance (Gaventa & Valderrama, 1999). Popular participation builds civic confidence and capacity to articulate the grievance, ideas and visions.

5.4.2 DIRECT BENEFIT FOR MOVEMENT MEMBERS AND PATIENTS

> I learnt about my rights, how to use the constitution to hold government accountable and not to fear confronting and engaging politicians about poor service in health facilities, (TAC0079 Interview, 2015).

As said by the activist below that learning about rights and how to use it to hold government accountable. The TAC treatment literacy help to shift understanding of the science, treatment, side effects, and guidelines so that the patient can be more active in their healthcare and demand their rights when not available to them, (Treatment Action Campaign, 2008). (Freire, 1970) defines the notion of literacy as a process of consciousness awakening that facilitates transformation. As (Cornwall & Gaventa, 2000) argue, an informed, mobilised citizenry participates effectively through capacity built though popular education on their rights. In addition, a knowledgeable, organised public can put pressure on the public administrators, and as a result, government will take steps to act in the best interests of the citizens. The grassroots movement membership consciousness as shown above creates counter-hegemonic knowledge arising from below, constructing and building power within excluded and marginalised groups. "I learnt to so much about politics, race through TAC about my own privilege , a lot of people at TAC saw me as this science expert but I actually learnt a hell of a lot of science," (TAC005 Interview, 2015). For Freire, literacy makes sense if people begin to talk about the social condition in the world, their position and their encounter of consciousness. The TAC became the first AIDS activist organisation to pioneer the concept and practice of HIV Treatment Literacy in a developing country (Heywood, 2009). Most of the grassroots activists interviewed for this study indicated that their entry to HIV policy participation and politics was through their personal HIV-positive status.

"Before the ART rollout announcement, we said ourselves as people living with HIV that we are waiting for our death," (TAC0042 interview, 2015)

Members joined the TAC primarily desperate for help and later found a political home. Most of the activists at the grassroots were in need of health information about their condition and access to treatment. Most activists joined the TAC with fear, isolation, stigma, despair and anger arising from their HIV diagnosis. Central to their primary experience of TAC was the emancipating practice of activists learning about the science of health, politics, governance and human rights brought by the treatment literacy process. Treatment literacy also gave people living with HIV public voice and visibility during a period when HIV was highly stigmatised and seen as a silent disease. The thrust of the TAC's struggle had been on citizens' rights to health care and broader national questions relating to scientific authority and expertise.

Hence, treatment literacy functions as TAC's grassroots advocacy tactic of popular education, often common in social movements for the purposes of conscientisation and transformation that can result in collective action for social change (Grenier, 2019). Social movements are spaces for learning that can lead to social and political transformation because they not only analyse society but also put forward new alternatives to knowledge generation and social action (Kluttz & Walter, 2018).

"We must credit TAC for the massive treatment education rollouts at the grassroots level for people living with HIV/AIDS,"(NAPWA0049 Interview, 2015). Even the opponents from NAPWA argue above that the TAC popular education increased their health science knowledge and therefore their power to counter the health system elite and health administrators' authority. For example, the trainings were held in a non-traditional manner-turning people living with HIV/AIDS into AIDS science experts. Popular participation is a key to resolving current social injustices because political and economic power rests with the majority population. The example, the TAC cadres in Khayelitsha were trained as trainers to support branches to reach as many people as possible with education while they encouraged local people to participate in their health facilities, clinic committees, hospital boards as well as the communities. Therefore, popular education promotes participation because the more knowledgeable poor people living with HIV/AIDS are, the more likely they are to participate in policy matters that concern their lives and their communities.

"People living with HIV don't only talk about their needs, they talk about the needs of others," (TAC0076 Interview, 2015).The popular education connects the individual activists (micro level) to learning new health, science, political and rights knowledge through which

understanding is directed to gain new critical knowledge about the HIV issues, policy actors and relations of power in the health system that its members are willing to apply through participation. Treatment literacy creates awareness that people living with HIV are agentive rather than passive receivers of health services. Treatment literacy without it we would not have been able to empower people living with HIV, to be able to take that and challenge their lives. The strategic recruitment of members in workshops and training further conscientised community members, created demand for ART, and visibilised and politicised ART implementation from local clinics, thereby forcing change from below.

5.4.3 POPULAR EDUCATION BUILDS GRASSROOTS POWER

> The TAC treatment literacy program is unique in the manner which it empowers members; enabling them to occupy policy making spaces with ability and confidence to articulate themselves,(TAC005 Interview, 2015).

Treatment literacy is a movement mobilisation tool to build public power. Activists have the power to contest or reject health system practices that marginalise people and challenge the practices of power by health professional workers and health authorities. Health professionals are the agents of the (dominant in most cases) "system of power" and tend to be reputed as the experts of scientific truth and knowledge (Foucault, 1980). The TAC treatment literacy approach disrupted the norm that health professionals with unlimited power drive health services over patients. The treatment literacy tool shifted the production and dissemination of medical knowledge (Epstein, 2008; Shim et al., 2003) and increased the prominence of lay expertise . "As an ordinary citizen on the ground, I did not know what ways I could use the constitution to make government accountable. I had fear of confronting and engaging politicians. In the treatment literacy workshops I learnt and gained a lot confidence in my own voice, how to claim my rights and to demand service delivery on our own health facilities by challenging doctors," (TAC0079 Interview, 2015). Popular education challenges hegemony at cultural and discursive entrenched in the health system and the grassroots activists utilised it to develop alternative understanding of contemporary reality.

The activists' investment in popular education increased the prominence of non-health professionals, which is known as lay expertise (Epstein, 1995), and instinctively made it seem probable that citizen knowledge and citizenry are central to policy participation. Therefore,

activists transformed the relationships between the two because power in the ART policy processes also belongs to the poor who are the users of health services and their families, and made it so that they too have agency, which is a fundamental theme in Foucault's conception of power. It is Foucault's (1980) contention that the masses no longer need the intellectual, meaning the elite within movements to speak for them, as they are certainly capable of expressing themselves. Activists at the grassroots used this tactic to shift engagements from the unequal relations where the health care workers and public administrators were seen as the experts and patients as non-experts.

The "Treatment literacy is political because it's about popular education using science to achieve political change in the health system: The political leadership who builds knowledge on politics; the science leadership who politically builds knowledge on science and medicine," (TAC008 Interview, 2015). The TAC activists in Lusikisiki and Khayelitsha disputed this notion of passive actors with no role or interest in policy implementation. In support, the redefining of 'expertise' both reveals the tangled relations of power and the assertion of legitimate demands to knowledge by those on the receiving end of policies (Cornwall, 2004). As such, they provide a means by which the 'policy implementation space' is remodelled and created popular expression of alternative power relations in the health system. Popular education is a vital element of the broad effort to empower social movements' members and followers. In essence, it is a strategy to challenge and build counter hegemony from grassroots up.

5.5 DISTRIBUTIVE POLICY SHIFTS AND ART SERVICE DEMAND CREATION

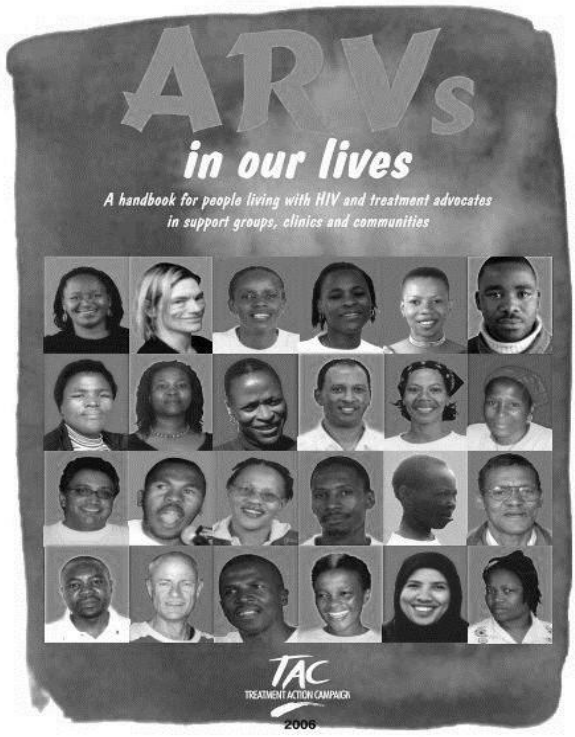
"The TAC's primary mission after 2003 focused on mobilising people who need ART to create demands to medicines while monitoring roll-out in local clinics," (TAC008 interview, 2015).

The TAC activists used their treatment literacy strategy to create demand for HIV services through collaborative tactics at the local level. The notion of demand creation derives mainly from marketing studies and is defined as a process of increasing the demand for a product or service using marketing techniques, typically applied to unsought products that have little demand because it is unknown to customers. In the context of ART implementation, the public had little knowledge about AIDS treatment; therefore, the TAC activists in Khayelitsha and

Lusikisiki had to create awareness and education, and mobilise people to create the demand for ART services in the minds of those who need medication. The grassroots activists create demand for ART by using treatment literacy as a strategy to educate people living with HIV and their families about the science of health and medicines and the challenges people face without access to medication. The popular education strategy became a powerful frame at the grassroots, which brought together people with shared health challenges to engage about what kind of service they should be receiving comparable to the status quo. Moreover, activists conducted community workshops as daily events of creating grassroots oppositional consciousness in order to animate by demanding access to local clinics.

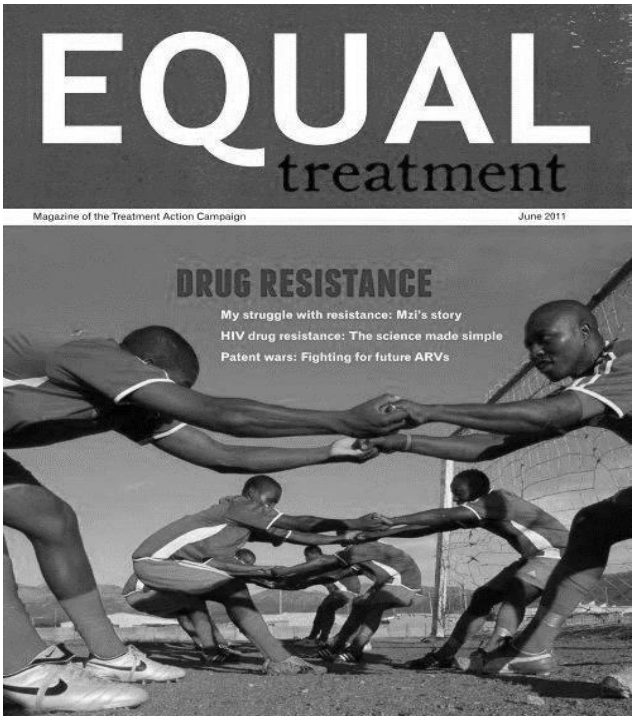
The TAC organises treatment literacy workshops for activists, some with very little formal schooling. In the TAC, increasing knowledge implies awareness of societal power structures and how these affect public health and personal health and this in turn enables activism and change. Monitoring the ART rollout meant monitoring the supply of ART access within health facilities, and it appears to be the movement's tactical choice to operate outside and inside the health system. The local health facilities became contested participatory space - known to scholars as political space, where poor people pursue to exert their power and influence (Cornwall, 2004). Thus, at the grassroots level, the activists mobilised people living with HIV/AIDS to create demand for the services while monitoring government supply. The mass involvement of poor people in policy implementation was not a usual activity in the public healthcare sector, especially in Khayelitsha and Lusikisiki. The treatment literacy built into these workshops created demand for ART services and placed pressure on the health system to respond to the needs of patients while building social power that potentially reconfigured the public health system in practice.

FIGURE 16: TAC BOOKLET



[Source: TAC, 2006]

FIGURE 17: TAC NEWSLETTER



[Source: TAC, 2011]

Treatment literacy as a mobilisation tool involved a series of educational materials (see above figure 16 and 17) such as songs, posters, and booklets developed for mass education. The activists in Khayelitsha and Lusikisiki achieved ART service demand creation by rolling out popular education, which invigorated the public to demand the services they deserve, thus creating the necessary pressure for service delivery. “TAC gave me training on treatment literacy it was the most achievement and the community started taking TAC very serious and they gave TAC support,” (TAC0016 Interview, 2015) . Treatment literacy programmes became a strategy that activists used to give rise to popular mass knowledge about the science of HIV and governance.

> The treatment literacy was always a way for the TAC to mobilise communities through trainings and workshops empowering the communities to stand up for their own health issues, (TAC009 Interview, 2015)(TAC009 interview, 2015).

Increased political consciousness leads to more debates, critical analysis and collective action, which makes mobilisation more effective. The significant of mobilisation is beyond just to organise people, it is also about catalyse popular participation of those who are marginalised and excluded from policy processes (Niven, 2004). The AIDS activists needed to mobilise ongoing advocacy for ART policy implementation, which required the movement to adapt, exploit, and generate renewed grassroots opportunities as well as pathways for new political action and activism. As discussed in chapter six that the mobilisation was not just included increasing popular participation in local AIDS structures for transparency and accountability. The grassroots AIDS activists' advocacy in the policy process, especially after a successful campaign, offer insights into bottom-up participation and movement evolution.

"No other organisations provided this level of ART education and people living with HIV in the country," (MSF0066 interview, 2015). As the MSF activist argue that the mass popular education rollout reached many organisations and their partnership with Community Media Trust (Siyayinqoba! Beat It!) they mass produced popular educational material and videos. Moreover, TAC organised community-based workshops to build an oppositional ideology (Hodes et al., 2010).

The HIV in Our Lives booklet series covered critical topics of interest to people with HIV/AIDS and translated posters into local languages, distributed widely across all provinces and to the other neighbouring countries through a regional network called the Pan African Treatment Access Movement (PATAM) organisations. As the MSF activists indicates, "The internationalisation of the TAC across Africa like Kenya, in Malawi, in Mozambique connects MSF and TAC beyond South Africa," (MSF0066 Interview, 2015). The movement material disseminated was mainly through the media agencies such as the Sowetan, Mail and Guardian, and City Vision newspapers. The movement workshops created spaces for shared lived experiences, emotions and shared meanings. Small groups of people living with HIV reflected together upon the immediate conditions of their lives in this unconventional learning practice.

5.6 ALLIANCES BETWEEN PATIENTS, HEALTH CARE WORKERS AND PUBLIC ADMINISTRATORS

> Being in the clinic doing treatment literacy does not mean making friends with nurses who abuse patients; we as activists need to maintain our distance without being rude,(TAC0022 Interview, 2015).

The TAC activist interviewed above allude to the fact that they utilised their treatment literacy as a tactic for collaborative engagement with the state allowed for achieving benefits in shifting structures, systems and policy implementation decision-making at local level. Applying strategic alliances with health providers and public administrators was a way to have one foot inside the system. The activists remained inside the health system by offering health education to other patients and brokers of their own services. The local health clinics also became sites where people living with HIV found movement solidarity and affirmation of expressive collective identities. This dual strategy as explicitly stated in the TAC statement (above) is that the activist roles will be that of insider/outsider through supporting the state ART plan and mobilising for services, while putting pressure on the state through demand creation and monitoring of service delivery. Additionally, activists participate through advocacy in the policy process as a form of governing matters that concern their lives. Often governance requires democracy and political tolerance of voices of dissent. As Della Porta (2013) understands it, participation is democracy through constructing deliberative and open policy contentious spaces. The grassroots activists continued to monitoring of policy implementation in order to guard their movement action gains does not go unchallenged by the public officials. The example below demonstrates the complex encounters between activists and public health officials.

> In a meeting with the provincial and district health managers, we (two TAC Lusikisiki women) brought forward a case of formula milk and traditional medication (*Vukuphile*) that was being sold at the clinic by the same nurse. The response we got was ‘where did we did, we see that? Formula milk has never been sold at the clinic and by the way who are you?’ My response was ‘I did say I’m from TAC a community care worker,’ but the way we were undermine and disbelieved us as if we are creating a story. We left that meeting and approached the Lusikisiki sub-district health to resolve the matter, then we

> went to the nurse and we told her that we know she sells the formula milk and we have evidence, that's when she stopped selling the milk. TAC have capacitated us to deal with these situations, (TAC0017-Interview, 2015).

One of the TAC activists' from Lusikisiki argue that even when they bring the data about corruption the clinics, which negatively effect on services and they are undermined. Undermined with intention to discredit their reports because the activists were not naming that one of the culprits is one the government workers. This vigilant activists' advocacy which does not give even in the presence of adversity such the above example promotes accountability by holding policy-makers and implementers accountable during implementation (Bhuyan, Jorgensen, Sharma, et al., 2010). Advocacy in this case is popular participation that seeks to influence and shape the government to investigate corruption in the clinic, as well as that the officials needed to be aware that activists are watching. This is active and which is informed with facts to meaningfully engage to make and influence state policy decisions (Andrea Cornwall, 2002) (Coelho & Cornwall, 2007).

The state is not a homogenous entity; some parts of it pull again activists demands such the example above where the activists found malpractice and reports but the state refuses to believe the fact. Whereas other parts pull towards activists calls for change in the example below, when the Gauteng province broke rank from national to rollout ART it was because of activists' public pressure.

"Dr. Gwen Ramokgopa was one of the few that broke ranks; she persistently maintained readiness of the Gauteng province in rolling out ART rollout and eventually went ahead without the approval of National Department of Health," (Presidency interview, 2015b).

Demonstrating the important role of leadership in the AIDS response, Premier Mbhazima Shilowa and MEC Gwen Ramokgopa led the charge by announcing the ART rollout on 1 April 2004. The bureaucrats such as Premier Shilowa and Nomonde Xundu add to the advantages of perpetuity and stability in the public administration, and they became potential movement allies. Ministers come and go, but the basic work of civil servants does not change simply because the minister is gone. The period of ART rollout shows the dynamic evolution even in the relations between public administrators and activists. The grassroots activists and public officials at the local level maintained their dual strategy of collaborating where possible. There were

dissonances and convergences, which will be discussed below, owing to a confluence of factors, including network of implementation structures, national-provincial political conflicts, and administrative reforms that shape how policy ideas are translated.

Public administrators are presumed to have separate powers from the partisan politics, which then allows them to engage in government rather than political party lines. Administrators are often the face of implementation that interact both with other governmental officials such as the legislators, the political executive, other inter-governmental administrators and with representatives of social groups such as social movements. Similarly, the Homeless People's Alliance used this similar approach of being patient with the state where there is openness to negotiation that which is referred to as 'bureaucratic intimacy' in order to achieve the delivery of housing (Khan & Pieterse, 2004). In reality, the role of administrators and political officials are not always clearly separable from the ways party politics influence policy implementation. Officials often carry with them a continuing commitment to the cause of particular interests, and pressure groups may function in quasi-official capacities. Legitimacy and its probable influences on policy will vary considerably as a function of the type of actor involved as well as a function of the type of agency activity involved—two dimensions of political activities by public administrators.

For administrators, this presumed separation of administration and politics allows them to engage in politics (organizational rather than partisan) without the bother of being held accountable politically for the outcomes of their actions (Hughes, 2012). Hence, the role of public administrators is not to be underestimated, but is essential during implementation for translating policy goals into an operational costed service-delivery plan. For example, the public administrators are the main bureaucrats involved in making key decisions about how policies implementation occurs. As discussed later in the chapter, the public administrators, local health authorities and health care workers play a fundamental role in the developing and imposing public bureaucracies that may dominate how the actual policy implementation. Lower echelons of the state may do what they think they can do rather than what they should do or even want to do. This level of government is not always involved in policy intention but are critical for implementation planning and execution. "The ability of a national Minister to follow through to influence with authority the provincial level implementation is very limited without strong

support from the President," (NGovt0057 Interview, 2015) . Interestingly, however, the conflict between bureaucracy and interest groups has been sufficiently ameliorated in most societies so that the two sets of organizations are able to not only coexist but also even to cooperate effectively. The power or lack of national level influencing provincial implementation exposes that implementation is not just contested by outsiders but within the state itself. There seem to be unclear powers between national and provincial governments due to political party influences. For a minister to need intervention to the highest order of the state seems to suggest that if a particular province did not deliver services as expected by the national government, the minister of health feels powerless.

I assert that through the concurrent power arrangement between these two levels of the state, what seems to interfere are the political loyalties and alliances, and I will make this point clearly in the next chapter. For the grassroots activists this means that it is critical to understand the levels and forms of power underlying the local implementation and, clearly, the national government had invisible and visible power over the ART rollout. The local level advocacy had to take into account some focus on national level pressure because of the strong residual influence that the minister of health had in provincial-level implementation. For provinces such as the Western Cape not under the ANC-led government, defiance may seem easier than in other provinces. The Western Cape government went against national government and met with TAC Khayelitsha activists to discuss implementation in favour of the TAC demands.

These earlier experiences gained from MSF's ART pilot programmes in Khayelitsha gave the TAC activists in Khayelitsha and Lusikisiki an advantage in understanding how ART could work in the public health system. Many thought that this was possible because the province was under the Democratic Alliance rule; but, surprisingly, when the ANC-led Gauteng Province broke ranks from its political party and went ahead to roll out ART ahead of the national full support, this created political opportunities for activists to collaborate with public officials where conducive conditions allowed. Similarly, in the ANC-led Eastern Cape Province, the Nelson Mandela Foundation independently approached the provincial government to provide ART in Lusikisiki without the endorsement of the national government. Although the Eastern Cape provincial government largely remained unsupportive of ART implementation, the "President Mandela factor" played a role in getting the ART pilot site at Lusikisiki going. As a result, the Lusikisiki ART programme was initiated in late 2002 as a collaboration between MSF, the Provincial Department of Health (PDoH) and the TAC, with financial support from

the Nelson Mandela Foundation (NMF). It was one of the first HIV/AIDS programmes in South Africa providing ART in a rural area based upon principles of decentralised health care, task shifting and community mobilisation and involvement. The provincial administrators that chose to comply with national government were Mpumalanga, Northern Cape, and the greater Eastern Cape, with the exception of Lusikisiki and North West. Policy intention and criteria application are within bureaucratic discretion to preserve but it also meant that the public administrators might revise policy priorities during implementation if activists are not vigilant. Many scholars (Giugni et al., 1999) assume that social movements hardly ever change political institutions and that they can do so only when crises make institutions vulnerable. Further, suggesting that social movements face a fundamental quandary: the choice between demanding short-term policy changes and long-term institutional changes.

The activists used their presence in the health facility to offer health education while remaining independent. Treatment literacy created collaborative pathways for activists to work with the state but created its own caveats. In the long-term, activists experienced co-optation and ended up adjusting their activist roles to comply with the state accreditation process for community health workers. The World Health Organization (WHO) proposed task shifting and the training of community health workers as core ideas in its AIDS and health workforce plan (WHO, 2006). The massive training of community-based workers was identified as a quick win for achieving the sustainable development goals (UN News Centre, 2015).

Over time, some grassroots activists were absorbed into more service delivery than activism. However, there was no real commitment to absorb community health care workers into the government workforce. Lack of human resources for health has been an ongoing crisis in South Africa—even the Reconstruction and Development Plan (RDP) excluded support to community care workers (CHWs).

5.7. CONCLUSION

In sum, concurrent with the application of collaborative activists' advocacy tactics in engaging with local health facilities, the activists also applied confrontational tactics targeting provincial and national government to counter the residual state denialism that was hampering implementation. As will be demonstrated in the next chapter, activists at the grassroots utilised confrontational advocacy tactics such as strategies using public protests, strategic litigation and

social mobilisation to maintain their distance (outsider) from the state as they monitored service delivery. Activists in Khayelitsha and Lusikisiki challenged the government's use of bureaucratic tactics to undermine ART implementation. Given the long history of antagonistic AIDS politics and tensions between the state and the TAC, activists were wary about engagement with the government during implementation. In this chapter, I have demonstrated that the shifts in advocacy in Khayelitsha and Lusikisiki were tactical and shaped by the various governments' lack of political commitment, which consequently triggered a dual participation (confrontation and collaboration). The activists considered the implementation phase as a natural progression for their movement action by drawing on their grassroots membership to monitor service delivery. As illustrated above, collaborative advocacy strategies were applied to shift engagements from the unequal relations in health care where health professionals, not patients, are seen as the experts. The strategic use of treatment literacy as a movement popular education and mobilisation tool gave rise to popular mass knowledge about the science of HIV and governance. This demonstrated the increased patient knowledge and power to counter the health system elite and health administrators' authority. The chapter shows that grassroots activists used popular education to collaborate and to monitor the state as a way to maintain insider access and outside watchdog roles in engaging with the health facility level of the health system.

The activists remained inside the health system by offering health education to other patients and brokers of their own services while using the same tool outside the system to create demand for ART implementation. In the long term, strategic alliances and solidarity between patients and health workers emerged, as well as pragmatic alliance engagements with public administrations at lower levels of government. However, we also learned in this chapter that treatment literacy as a strategy can have unintended caveats, especially when working within the corridors of state power, such as co-opted government culture of accreditation and absorbing activists into more service delivery than activism. In chapter 6, I interrogate the mechanisms or processes present in facilitate engagements between communities/people living with AIDS and (local) government during this period. What impact did shifts in tactics and transforming participation typologies have on the TAC? How did activists in Khayelitsha and Lusikisiki understand the transformation? Lastly, Chapter Seven asks what are the implications of shifts in forms of participation for the survival of social movements? How do these shifts affect bottom-up policy-making going forward in terms of democratising healthcare in South Africa?

CHAPTER SIX: EVOLVING SOCIAL MOVEMENT TACTICS : THE TAC DURING THE ARV ROLLOUT

6.1 INTRODUCTION

"The official policy from government said yes to ARVS but in practice it was a no because they made sure that they were putting all these barriers,"(MSF0028 Interview, 2015).

As a new social movement, the TAC has been the vanguard in opposing ANC-led government HIV/AIDS policies in relation to access to affordable ART in the public health sector for poor people living with HIV, which has brought about antagonistic relations between the two. The TAC has a reputation of being both cooperative and confrontation in its direct actions towards the state and multinational companies and expresses its collective power through popular education, mass mobilisation, direct public protests and legal advocacy in the courts (Friedman & Mottiar, 2004). The TAC's movement politics suggest that Khayelitsha and Lusikisiki grassroots activists are in better positions to provide more nuanced knowledge about the bottom-up participation typologies and movement evolutions beyond the 2003 ART policy victory. During policy implementation, the peaks of national, theatrical protest action may diminish. Some may perceive this as abeyance, but it does not mean retreat. Movements do not have to end or decline after their victory but can continue to participate in policy implementation.

New political opportunities in the form of the government ART plan are not a permanent shift but mark a political pattern that may constrain or be a resource for contentious movement actors (Tarrow, 2005). I argue that the era after 2003 constitutes a minor political opportunity for AIDS activists, because the state commitment to implementation was made with reservations. It took the same activists to drive government to deliver on its promise of ART. We learn in this chapter that activists' advocacy tactics shifted from confrontation to countering the destructive national political influence in local implementation. Hence the two locations offer this chapter insight for scholarly analysis for the purpose of understanding bottom-up participation from two analogous sites of struggle (Gerring, 2004). This chapter explains how the TAC altered its advocacy tactics in various ways when confronting the new implementation structural challenges.

It suggests that the TAC Khayelitsha and Lusikisiki activists became more militant during ART service delivery to exert power in relation to their own conditions and on their own terms. The TAC sustained its engagement with provincial public officials by combining lawyering to bargaining and popular protests as direct action to force the state to release the ART rollout timetables. The "Government was not totally open about treatment timetable and targets, no one knew that so we had to fight Manto Shabalala for the rollout," (TAC009 Interview, 2015).

> The ART rollout was announced, but with no timetable how is government going to implement it. From this it's clear they did not want us to know they were planning the slowest service delivery ever, (Section27 0055 interview, 2015)

As the TAC and Section27 activists argue that the state maliciously announces the ART policy but without a details implementation plan. This meant that activists had to engage adversarial with the state to compel it to release the rollout plan. The treatment timetables were critical for activists to mobilise to create demand for services and for monitoring service delivery. The TAC activists were reactive by occupying ART sites and protesting against the imposition of unattainable ART accreditation, showing that the bureaucratic power in policy implementation decisions led to rationing service delivery without engaging with those whom these procedures would negatively affect. Although the grassroots activists expressed direct collective action to force the state to concede on the rollout timetable at some point, on the other hand, the site accreditation rationing of care continued. In the meantime, while the state dragged its feet on the ART rollout and the TAC used popular protests, the state created a parallel discourse discrediting ART use and actively promoted natural remedies as treatment for HIV, causing public doubts and confusion. The bottom-up activist advocacy tactics shifted the national ART policy with its centralised ART site accreditation and made it a locally contested issue thus creating pressure in the system from below.

I argue that TAC, with its strategic policy alliances, invented more participation spaces, resources for court cases, popular education, resources for protests and strategy advice about choices in the political struggle. Perhaps more importantly, it has thrived in providing support for networks of health care workers, community-based working class organisations and communities in Khayelitsha and Lusikisiki. The TAC contributed to the expansion of the popular democratisation of the health system. The ART rollout era generated extensive public debates, galvanising social movement opposition and sometimes forcing the state into a defence

reaction (Jones, 2005; Ranchod, 2007). This chapter will continue from where Chapter Five left off in examining the shifts in TAC's advocacy tactics during the ART rollout and whether they tell us something about the bottom-up participation and movement evolution in Khayelitsha and Lusikisiki. This chapter focuses on the combative advocacy that the TAC applied to drive the ART rollout, and I argue that the TAC at grassroots provides alternative typologies of participation. The grassroots activists' tactics were flexible enough to endure the shifts in political processes over time, still straddling between the confines of cooperative relations with the state. Limiting demand making to one mode of interaction with the state may constrain the ability of organisations to influence policy (Ranchod, 2007). Therefore, the TAC's influence diminishes when the state shifts its leadership to one that is receptive to the movement demands.

6.2 BOTTOM-UP TYPOLOGIES OF PARTICIPATION DURING ART IMPLEMENTATION

"If the government does not deliver on our demands for a faster rollout, then they should expect confrontation through marches and sit-ins," (TAC0010 Interview, 2015).

If poor activists experience prolonged unmet expectations, trust erodes. As found in this study, the consistent theme that emerged from the key informants is that, despite the significant changes in government in South Africa, political trust is declining. "Activists lived and experienced state betrayal for over a decade and so relations will have reservation for any Health Minister," (NGovt0057 Interview, 2015). Political trust is a complex concept — political convictions seem to shape the activists' propensity to oppose government policies, based on past experiences of engagement with government that inform the degrees and types of current and future participation. Political trust is necessary for the sincerity of the government and its policies. Political trust then is present in policy spaces and where there is contested participation. Hence, where government has consistently betrayed the trust of its people over time, suspicion and lack of trust become a permanent feature of policy and political engagements. The ongoing construction and reconstruction of meanings in collective action spaces is referred to as a frame (Snow et al., 2007) , and frames are central to movement life and its evolution. This is because, as such scholars (Tarrow, 1999) argue, frames ignite, dignify, animate and help the public to make sense of the movement demands and the shifting policy and political context.

Activists' expressed doubts about government commitment made activists need to keep their confrontational tactics such as protests to mobilise public support and advance the movement's agenda by exerting influence on political elites. The role of public administrators is key in the implementation policies, because of their interface with the public. These bureaucrats have a high margin of decision-making about service delivery and resource allocation (Hupe & Hill, 2007; Lipsky, 1979; May & Winter, 2007) (Lipsky, 1979). Moreover, at clinic level I argue that doctors especially in rural Lusikisiki make a lot of decisions and they too are part of the state bureaurocracy (Gaede, 2016). During implementation, the state was the primary target of grassroots grievances and mobilisation, and even though there was no willingness at the national level to engage, local levels had political opportunities. Political opportunity theorists have long recognized the importance of divided elites for the capacity of movements to influence policy makers (McAdam et al., 1996). The combination of impetus behind the movement's use of non-disruptive tactics broker chances for state concession to their demands without confrontation. The use of negotiation is together with action repertoires depending on the state's response (openness to negotiation) to its demands after negotiation (Heywood, 2009). Considering this helps to envision shifts in activists' advocacy tactics over time. (Gamson, 1990) argued that movements employing disruptive techniques are more able to draw attention to their goals, impose costs on political incumbents, and ultimately achieve their goals than movements using non-disruptive techniques (Tarrow, 1999). Social movements, therefore, do not follow a rigid evolution and progression, as proposed by many participation scholars.

The TAC has gone through several stages, sometimes in a linear fashion and sometimes jumping over stages in the model. After government's public stance on ART policy changed, there was still residual resistance and denialism. Triggering events related to this resistance includes government's refusal to publish ART rollout timetables, the slow and complicated process of ART site accreditation, and government's continued support for alternative therapeutic remedies. The lack of a robust state response catalysed the TAC activists' responses and helped to spark public attention to government inaction. It is essential for the movement after its considered victory to sustain its frame to keep members and supporters continuously engaged in the discourse.

6.3.1 RESORTING TO NEGOTIATION IN COURTS

> Use participation platforms to push the TAC Khayelitsha agenda, but the AIDS councils belong to government— the streets are our vehicle to influence policy changes, (TAC0010 Interview, 2015).

The grassroots activists participate in the local institutional participatory spaces to shape and influence the policy implementation process to achieve their movement goals. As the activists in Khayelitsha argue that, they keep their confrontational tactics as well in cases where they cannot achieve their demands inside the boardroom. Often local activists employ less institutionalised tactics such as rallies, demonstrations, and litigation. Institutional tactics are used in the spaces of participation by invitation. As alluded to by the activist interviewee above, among the tactical methods utilised are both institutional and non-institutional. However, it is imperative to note that using the institutional and non-institutional is restricted because activists are there by state invitation. This is in contrast to non-institutional antagonistic forms of collective action efforts in social movements spaces invented by activists. Thus, even TAC activists can be insider actors as well as utilise their outsider advocacy tactics, because there is no deterministic link claimed concerning an actor's institutional location and the tactics that actor is likely to employ. Although the state-centric focus of the TAC as a social movement has attracted criticism (Goodwin & Jasper, 2019; Snow et al., 2007; Young, 2002) , the state as the central target remained, although the TAC kept up its pressure targeting the multinational companies as well. Similar to Chapter Five, this analysis views both institutional and non-institutional activists' advocacy tactics as more of a continuum than a dichotomy. I place the advocacy tactics in this analysis along a range of non-institutional tactics including sit-ins, pickets, demonstrations, rallies, symbolic displays, lawyering and civil disobedience. In the present analysis, I examine only some of these that were most commonly used after the policy shifts in 2003.

"We urge government to release the full treatment plan so that civil society can study its details and assist with its implementation,"(AfricaFocus, 2003).

The ART treatment timetables were critical both for activists to mobilise to create demand for services and for monitoring service delivery as figure 18 above demonstrates. ART rollout timetables are critical for people to anticipate service delivery and hold the state to account. The state wished to maintain the unjust policies by keeping certain information hidden from the public by offering a two-track information system through the official and operative policies.

FIGURE 18: TAC ACTIVIST DEMONSTRATION

Source TAC, 2004: photo of TAC AIDS activists marching

Within three months after the cabinet announcement, the National Department of Health published its operational plan with incomplete sections, containing the ART rollout plan without timetables (referred to in the ART rollout plan as Annex A). According to the (Ministry of health South Africa, 2015). The ART plan included sections 135 and 136, which say, "the operational plans are summarised in Annex A, which is a week-by-week schedule for the pre-implementation period with deliverables for each of the main focus areas. Further, indicated that the detailed implementation plan, which follows as Annex A.2, sets out the tasks to be completed in each stage of the operational plan for each area of activity,".

The operative policy information that seemed to be the government's actual policy was kept hidden from the public because it violated widely held values and therefore would upset most citizens. The official policies are fictitious policies given to the public.

Bureaucratic management is a strategy often used by government to prevent the issue raised by a social movement from becoming a public issue (Moyer, 1987). The state bureaucratic management manifests when policy conditions seem normal and is achieved by keeping the policy problem out of the public's view of the world and thereby out of people's consciousness and keeping issues out of the public spotlight and off society's agenda. The goal is to maintain hegemony of information available to the public through the media. The state denies that the problem exists and creates "societal myths," which define the problem for the public as exactly the opposite of reality. State-sponsored fear in the general population is created so that they will unquestioningly support whatever policies the powerholders take.

When the public is not aware of ART implementation targets and timelines, it is impossible to hold government accountable. ART target information was critical for AIDS activists, because they could use such information to hold the state to account against its targets. Public awareness and popular opposition are based on the level of information available to the public about the problem as framed by the movement's actions. This level of public awareness of the policy problem may represent the movement take-off stage, which sets the campaign high in the public discourse and media visibility from the trigger issue. These conditions fostered the nature of confrontation and suspicion about the state's commitment to the rollout. This served to heighten activists' vigilance in the implementation and reflected doubts amongst various public health officials as well. The ART timetables trigger set off for the local activists a political opportunity to place the policy implementation challenges in the spotlight. The focus was on the question about the state commitment to ART service delivery without a clear public plan that the activists could use to hold government accountable. The return to the courts offered the local TAC activists an opportunity to articulate ART rollout demands using the official/government avenues such as courts to force the state to offer transparency about the treatment plan timetables, which sparked public outrage.

The TAC activists, through cordial letters as their initial tactic to engage through negotiation first, urged government to publish the timetables. The AIDS activists with their allies ALP (known as Section 27 hereon) and MSF approached the National Department of Health in February 2004 requesting release of Annexure A. The activists were concerned that government centralisation of essential ART rollout plans would be tantamount to no real service delivery.

After ten months of letters from the TAC activists to the National Department of Health without progress on access to Annexure A timetables, the TAC attempted to engage government through legal action (Annexure A Case no 215991/04) at the Pretoria High Court (Silber, 2008) and force it to publish these timetables. Activists claimed that the National Department of Health contravened the Constitutional rights of people to access crucial information according to the Promotion of Access to Information (PAIA) Act 2 of 2000 (Republic of South Africa, 2000). This act states that people can have access to any information held by government or anybody as part of an open and democratic society, which respects human dignity, equality and freedom as, articulated in the South African Constitution of 1996, section 36. AIDS activists argued it was a human rights violation to deny poor people living with HIV/AIDS information about when treatment would be available in their nearest clinics. The state's refusal to publicise the ART timetables triggered a new phase in TAC's tactics after the announcement of the ART plan. The trigger set off a movement and put the spotlight on the state's commitment to implement the ART policy, and the state's refusal sparked public outrage. The state in its responding affidavit in September 2004 argued that any reference to Annexure A was an error, because there were no annexures. This is despite the ten months of earlier letters during which the state had sufficient time to point out this error (Cho, 2009; Mark Heywood, 2009). The return to the courts offered the TAC an opportunity to articulate its demands through official avenues and force the state to listen and respond.

The court actions served as important fields for mobilisation, battleground, confrontation and contestation (NeJaime, 2013) but they were limited in their ability to enforce judgments without organised communities to demand change. Every court appearance that the TAC made was accompanied by mass mobilisation and protests outside the courts (see figure 13) to display mass support for the movement. If anything, government actions promoted a revival of TAC's public support as people realised the importance of following through to ensure delivery of policy concessions as promised. Grassroots activists used confrontational advocacy tactics to compel the government to disclose the ART rollout timetable. The closed spaces are sometimes where decision-making involves only those authorised and there is clear intention to exclude others. They are spaces where activists take action for greater transparency and accountability. For example, activists may use legal provisions to access certain policy documents kept secret from the public by government to avoid accountability for service delivery.

The court battles did not last long because the government defiantly professed that there were no treatment timetables. Judge Ranchod (Pretoria high court) handed down a ruling in November 2004. The court found that the Minister of Health was contravening Section 195 of the constitution that states that the public administration be governed by democratic values and principles entrenched in the constitution, which includes high standards of professional ethics, accountability and transparency that extend to all organs of the state (Silber, 2008) .Further, the judge noted the Minister of Health's failure to take corrective measures for the insertion of any reference to Annexure A in a public document. The fact that she was aware for several months about the activists' requests for the Annexure meant she was fully aware that they did not exist and yet she did not act. The court found this to be unconstitutional conduct. The court ordered the Minister of Health to pay punitive costs to cover the TAC attorneys for misleading the public (Silber, 2008). As (Friedman & Mottiar, 2004) note, the relationships between the TAC and government quickly deteriorated after the first legal battles during the implementation phase. This continuation of adversarial engagement of the state exposed the malicious intentions of the state and the extent of its abuse of power. The TAC's grassroots advocacy strategies maintained a balance of confrontation and collaborative approaches, from social mobilisation to work with the state in local health facilities, to engaging the state on the streets, in courts and international arenas.

The TAC activists considered this victory their first blow in developing new political opportunities in the post-2003 era. (Bond, 2014a) accuses activists of wasting time legitimising the constitution in courts for AIDS treatment knowing its futile outcome due to property rights. He poses that the only way to achieve progressive change is through explicit direct action. In addition, (Neocosmos, 2009) argues that rights-based framing of movement demands is elitist and leads to passive citizenship in the movement's ranks. Further, (Stahler-Sholk, 2007) argues that rights framing brings threats of movement co-optation and membership demobilisation if institutional participation is a means to an end. It is not certain that institutional participation will lead to demobilization, co-optation and political passivity. Their rights-based alignment discourse, which they use to frame their grievances and claims and to mould a collective identity, helps the TAC to catalyse their struggles and to secure elite support and access to the state (Cousins et al., 2013).

> The Department of Health maliciously conformed to the AIDS treatment rollout. It took another four years of antagonistic AIDS response before real progress was made,(Section27 0055 Interview, 2015).

The national Minister of Health's steadfast abuse of power to delay and undermine ART implementation led her further away from possible constructive engagements with AIDS activists at the national level. The sluggish ART rollout consistently troubled the relationship between government and AIDS activists. For the TAC, when advocating for provision of ART in the public healthcare sector in Khayelitsha and Lusikisiki, the movement had to readjust its strategies to suit the needs of activists' engaging with policy implementation and state accountability at the local level, which can cause conflict. Activists vividly recollect the ART plan announcement day, when the policy changes became a new potential avenue to foster improved engagements with the state. "Activists have lived and experienced a decade of state betrayal, and so the relations will always be challenging for any Health Minister,"(NGovt0057 Interview, 2015). Other government officials such as above acknowledged the activists' mistrust of the state's commitment to deliver a quality ART rollout is the disease, it might be part of the cure as well, through applying a myriad of measures for demanding transparency. This is what other scholars refer to as counter-democracy or counter-power to compensate for the erosion of government trust by organising doubt. The government response to activists exposed a lack of desire to engage positively with activists after the ART policy change.

6.3.2 Activists defied government 'Death by Delay'

The next period demonstrated yet again the necessity for antagonistic advocacy tactics including public protests and sit-ins to contest the imposition of unattainable ART accreditation standards, which showed the bureaucratic abuse of power in policy implementation decisions that led to rationing service delivery without engaging with those whom these procedures would negatively affect. The government's lack of political commitment triggered grassroots activists' contestation using a dual (confrontation and collaboration with the state) tactical approach for the success of ART implementation.

> It was heart-breaking what people were being forced to sit through…These screening procedures people had to answer HIV knowledge tests. If you admitted to drink alcohol,

smoker or you did not know all the answers then committee sent you back and say well come back next week because you did not study properly. It became a way to reinforce the power of local health elites, (TAC0085-Interview, 2015).

FIGURE 19: TAC PROTEST AGAINST ART SITE ACCREDITATION IN KHAYELITSHA

[Source: TAC archives, 2005]

"The state used a stringent accreditation process, which by design excluded most of the primary health care clinics in Khayelitsha and Lusikisiki, including those where MSF had been providing ART for over two years. Activists in Lusikisiki argued that the state undermined poor illiterate people. 'They are not educated, how are they going to understand the treatment?' We as the movement had to make sure that people were treatment literate prepared patients, even at night, because we were worried that when the accreditation team come we must be ready," (TAC0017-Interview, 2015). The National Department of Health imposed complex, high standards for sites to provide ART. Before a health facility could provide ART, they had to he inspected by a national government delegation to ensure compliance with the national accreditation requirements contained in Chapter Four, using the Service Point Assessment and Accreditation Guide in Annex IV (Ministry of health South Africa, 2003).

"In the local clinics government had set up a panel of selection committees to interrogate this poor people," (TAC0085-Interview, 2015). This meant that dying patients could only access treatment through an accredited service site, and only health professionals who had undergone training and certification procedures to render the necessary ART services in accordance with the recommended treatment guidelines and protocols could treat them. These service delivery conditions triggered the public crisis, activists linked this particular policy failure as intentional and indicative of the Minister of Heath's malicious compliance to movement demands, and now delaying implementation was the state tactic to stall. Government claimed that the accreditation procedures would ensure that the facilities provided quality antiretroviral treatment and observed the highest standards of care. In addition, extensive training and certification of health professionals would be carried out on an ongoing basis to support this treatment programme (Ministry of health South Africa, 2003). This meant that achieving the expected health force for sites to be accredited meant that the ART delivery model outlined in the Operational Plan would thus require 2,000 doctors and 4,000 nurses. (Van Damme et al., 2008) estimate that in 2003 when the ART rollout began, South Africa had 7,645 medical doctors in the public sector (out of 30,000 doctors in all sectors) to service 80% of the population. This would mean that one quarter of all South African doctors in the public sector would have to dedicate their entire time to ART delivery. Thus, achieving the ART target in South Africa would require a drastic reorganisation of the health sector, with important consequences for human resources for health (Wouters et al., 2010). The HIV prevalence caused a huge human resource strain, with large numbers of people needing ART in an already frail public health system. It is estimated that four doctors per 1,000 of the population falls well above the WHO 'critical' benchmark of 2.5 health workers per 1,000 (Ashmore, 2013; WHO, 2006).

In practice, this means that some communities have no doctor, which severely hampers universal access to ART, even if onerous accreditation requirements were not a concern. Scholars (Lehmann et al., 2008) contend that the South African health system was noticeably more fragile than two decades before. Hence, innovative changes such as redistribution of tasks among health workforce teams from doctors to nurses and from nurses to lay health workers would be key to relieve this urgent need for health personnel (Lehmann et al., 2008 ; MSF, 2007; Callaghan et al., 2010); Task shifting, however, was not something that the National Department of Health's accreditation requirements made much space for, with dire consequences.

Even though clinics in Lusikisiki and Khayelitsha were already initiating people on ART through MSF, with successful outcomes, they were instead subjected to the national government's bureaucratic assessment process that required on-site accreditation, swelling waiting lists across South Africa. The Lusikisiki ART programme was accredited a year after the announcement of the ART rollout plan. This resulted in an expensive and slow ART rollout model. This model of ART rollout made medicines inaccessible to the majority of poor people, who lived far from central hospitals. "There were significant systemic failures in local health administration and our ART delivery platforms," (NGovt0027 Interview, 2015). According to (Osewe & Pillay, 2016) the accreditation process was based on the reasoning that evaluation of ART facilities was necessary to ensure sufficient and skilled staff were available to deal with the complexity of administering ARV drugs safely and effectively. However, the state failed to arrange the periodic reaccreditation or regular inspections. Although some public officials argued that these ART accreditation standards were meant to safeguard patients' lives (Simelela & Venter, 2014) , these so-called safeguards created massive backlogs and deadly waiting lists. Consequently, 50 people were dying while waiting each month (Joint Civil Society monitoring and evaluation forum , 2004; Ndlovu & Daswa, 2008).

In 2005, the Eastern Cape Province had only 20,000 people on ART instead of 24,000. The ANC-led Eastern Cape Province had only 20,294, against the 25,000 target (Ndlovu & Daswa, 2006). Another example: in one health facility in KwaZulu-Natal in 2009 there were 400 patients on the waiting list, 100 of which had a CD4 count of less than 100. TAC called a citywide march on 16 July 2009 to protest against inadequate health services for people living with HIV. Public protests escalated to an 80-person night vigil on 15 July 2009 outside the hospital (Section27 Report, 2009). In defense of government, the KwaZulu Natal Province's MEC for Health, Sibongiseni Dhlomo begun to aggressively, investigate the TAC allegations, which includes visiting the hospitals, as well as holding public meeting in the offered roving microphones to anyone who wanted to speak or ask questions, in front of the press to throw his weight around. The fact is that across the country most provinces were falling behind the national target, which means many people were dying waiting. The long "AIDS death queue" exposed the bureaucratisation and consequent restriction of access to ART implementation, and the activists contested this with confrontation.

As argued above, the activists in Khayelitsha and Lusikisiki applied brokering tactics including letters and meetings as well as antagonistic advocacy tactics including public protests, sit-ins and litigation to contest the lack of government transparency concerning the ART treatment timetables. The timetables contained detailed plans and deadlines, which constituted critical information for the grassroots activists for popular education, mobilisation to create demand for ART services, and for monitoring service delivery. As result of the TAC's drive, the ART rollout began in 2004 in the public health sector (Nattrass, 2007).

FIGURE 20: TAC ACTIVISTS PROTEST AGAINST ART WAITING LIST IN QUEENSTOWN

[Source: BlackAIDS.org]

> "He (Queenstown Hospital superintendent) ordered the police to shoot and beat sick people. As results, many suffered from injuries from the rubber bullets and police batons," (TAC0018 Interview, 2015).

The Eastern Cape Department of Health issued a memorandum in December 2004, stating that there would be no new initiations of patients on ART until further notice. Frontier Hospital received this memorandum while they were already under pressure from grassroots AIDS activists. Frontier Hospital was the only accredited ART site for the entire Chris Hani District, and it unilaterally decided to initiate only ten people on ART(The New Humanitarian, 2005).

When poor people challenged state decisions, they often met hostile and repressive state responses. These protests, however, often turned violent. In one case, a meeting that had been arranged between the people and a local hospital superintendent to submit the people's demands for ART turned into open conflict. The Queenstown Hospital superintendent's refusal to meet grassroots activists demonstrated the arrogance of public officials who seemed to believe that they did not have to account for their policy decisions. Instead of accounting to the people, this kind of pushback from local and provincial government officials sparked public outrage locally and globally. Grassroots TAC activists from the Eastern Cape held spontaneous peaceful protests against the slow pace of ART initiation and demanded accountability for the continued deaths.

"We did not expect the Queenstown police to shoot at us for demanding a faster roll-out," (TAC008 Interview, 2015).

The TAC's advocacy strategy was to show the public that ART implementation was getting worse rather than improving. Waves of localised protests to demand a faster ART plan rollout soon began to take shape as a form of resistance to the National Department of Health's constant lack of attention to ART delivery. The ART site accreditation is a public administrative function that became a focus of contention, and the implementation of these site accreditations was an indication of state deployment of bureaucratic power (Lipsky, 2010). The imposition of unattainable ART accreditation shows bureaucratic power in policy implementation decisions that led to rationing service delivery without engaging with those whom these procedures would negatively affect. For the reason that patients waited for too long because of the bureaucratic process of accreditation, it had to be ended in 2009 in favour of devolution of responsibility from clinicians to nurse practitioners, and the setting of targets. This strategy ensured that all public health facilities were equipped with the capacity to provide ART (Osewe & Pillay, 2016). Activists coordinated their policy implementation action across multiple levels of government and policy issues (O'toole, 2004) because accountability was centrally a challenge at local levels. Hence, social movements need to follow up on their policy gains and monitor the implementation process to ensure it reflects their movement's aspired policy outcome. The measure of the TAC's victory is in not only policy changes but also effective state implementation that delivers medicines to save lives. AIDS activists needed to mobilise ongoing advocacy for ART policy implementation, which required the movement to adapt, exploit, and generate renewed grassroots opportunities as well as pathways for new political

action and activism. Over time, it became apparent that part of the implementation challenge was budget and expenditures of provincial governments.

The current coalition needed to create a node with specialists in budget monitoring and health system specialists. Then, the civil society budget expenditure-monitoring forum (discussed in Chapter Seven) was created to inform the JSCMF of emerging implementation challenges from a budget angle.

6.3.2 COUNTERING THE RESIDUAL DENIALISM

> "The national Minister of Health celebrated her loyalists such as Mpumalanga Department of Health for dismissing doctors who initiated ART in the public sector ," (NGovt0057 Interview, 2015).

The grassroots challenged the state-sponsored alternative policy discourse to discredit the official policy, which led to the Minister of Health championing use of natural remedies that led to public conflict, casting public doubts on ART. The more the state became openly against the use of ART; the more the local activists applied their confrontational strategies using public demonstrations to contest the residual denialism in provincial implementation plans. The activists considered the implementation phase as a natural progression for their movement action through drawing on their grassroots membership to monitor service delivery. The third trigger was when government dragged its feet in the ART rollout in its efforts to prioritise prevention over treatment in public health discourse and its embrace of alternative forms of treatment for HIV. In spite of the ostensible policy change in 2003, Minister Manto Tshabalala Msimang unwaveringly insisted that most public expenditure should be directed at prevention, not AIDS treatment (Nattrass, 2004).

In addition, the Minister of Health also offered contradictory and confusing policy messages that highlighted patients' right to choice between using ART and other complementary treatments (Butler, 2005) to sabotage the ART programme. These government actions sparked further public protests. The public fights between the state and HIV activists continued into the late 2005/early 2006 period over the Minister's promotion of alternative HIV remedies for an extensive account of this period (Geffen, 2010). Matthias Rath is a wealthy German industrialist who denounced ARV treatment and instead marketed his vitamin pills as therapy for HIV/AIDS through setting up clinics in Khayelitsha as alternative care (TAC, 2008). In response, TAC

activists in Khayelitsha clinics became the eyes and ears for the movement within the health system. Although some thought that sending in people to Rath's clinics was collaborating with government, this approach proved to be effective, because we saw first-hand the impact of Rath and the confusion caused by the Minister of Health.

> "There was quite a lot of residual denialism in provinces represented by Peggy Nkonyeni and Sibongile Manana and loyalty left for Manto at national level such as Thami Mseleku," (NGovt0057 Interview, 2015).

There were a number of challenges at the onset of the rollout of ARVs in South Africa, which suggested a continuing lack of political will. When a government is compelled to adopt a policy position against its will, opponents in the government may choose to undermine this victory through sluggish policy implementation. government commitment to this new policy would not be found in press statements and policy papers, but rather in the ensuing ineffective implementation at the local level to deliver lifesaving medicines to poor people (Nattrass, 2004). The activists' focus on using the state residual denialism to build up stress from below and to ignite movement energy, using a trigger through which public attention is directed to articulate their demands. After a policy becomes a public issue, the power-holders are forced to switch to a crisis management strategy. This may be done by attempting to vindicate unjust policies through first ignoring and discrediting the movement and denying the problem, explaining that their current policies are sufficient and, if necessary, repressing the movement. Power-holders may create trigger events to justify a new policy and get public consent and to overcome public opposition by destabilising the movement, making minor changes through reforms, compromises, and co-optation of opponents (Moyer, 1987). The national and provincial governments political will and commitment is argued in this section as critical to the success of implementation. Public administration scholars (Peters & Peters, 2018) point out that politicization of the civil service manifest in three ways including their involvement in political decision-making, defining policy priorities and implementation. As argued above that the activists shared during the interviews that the provincial administrators had more power to block the implementation than anticipated. Thus, these TAC activists felt constrained to influence the state from the inside and opted to work outside the bounds of institutional politics to achieve their movement goals.

(Piven and Cloward, 1977) are proponents of the view that the way to know if protests work is by observing the unruly effects on the state. The "public discontent drives public traction and visibility, and that public pressure leads to change," (Presidency0080 Interview, 2015).

As might be expected, influence from pressure groups of this type is not the normal pattern of policy-making. Such influences tend to be indicative of some rather fundamental failures of the policy-making system in satisfying the demands of one or more sectors of the society. Since 2004, an unprecedented wave of popular protests has surged across the country, and Alexander, (2010) calls it the revolt of the poor against poor service delivery and socioeconomic exclusion. Further, (Booysen, 2009) adds that these protests had dual répertoires, proposing that they are "service delivery protests," and the actions are mainly occurring at the grassroots "and the trigger seems to come from failures of national government to fulfil their duties including housing, land, jobs and, I would argue, health too," (Booysen, 2009). As (D. Powell, 2009) argues, local government faces pressure, because it is the state sphere that is closest to people and should deliver services as per national promises. Thus, South Africa has seen an upsurge in protests after the one-sided growth observed after the implementation of the neoliberal macro-economic and micro-development policies post-1994 (Patrick Bond & Mottiar, 2013).

6.3.3 BIOMEDICINE VS COMPLIMENTARY MEDICINES

> So, we [TAC activists] went undercover to investigate Rath operations in Khayelitsha. Some of us went to the Rath clinics and his agents disguised as potential 'patients,' which is how we caught them, (TAC0015 Interview, 2015).

Activists saw this as government and Rath's attempts to confuse people who were desperate for an AIDS cure. At the time, the national government actively promoted diet-based approaches as a complement and poised them as an alternative to ART. The Minister and her allies, in the process discouraging the use of ARVs, promoted African vegetables, olive oil and other (expensive) immune system boosters vigorously (Cullinan & Thom, 2009) Geffen, 2010) . The AIDS dissident faction in the ruling party developed alliances with non-state organisations, including captured movements of people living with HIV such as the NAPWA, which disseminated alternative views on HIV/AIDS (TAC008 Interview, 2015) .As one of the interviewees argues: "There was vegetables, vitamins vs ART street war sponsored by former Director General Thami Mseleku, President Mbeki and Tshabalala-Msimang," (TAC008 Interview, 2015). The TAC activists viewed these barriers as evidence of residual state

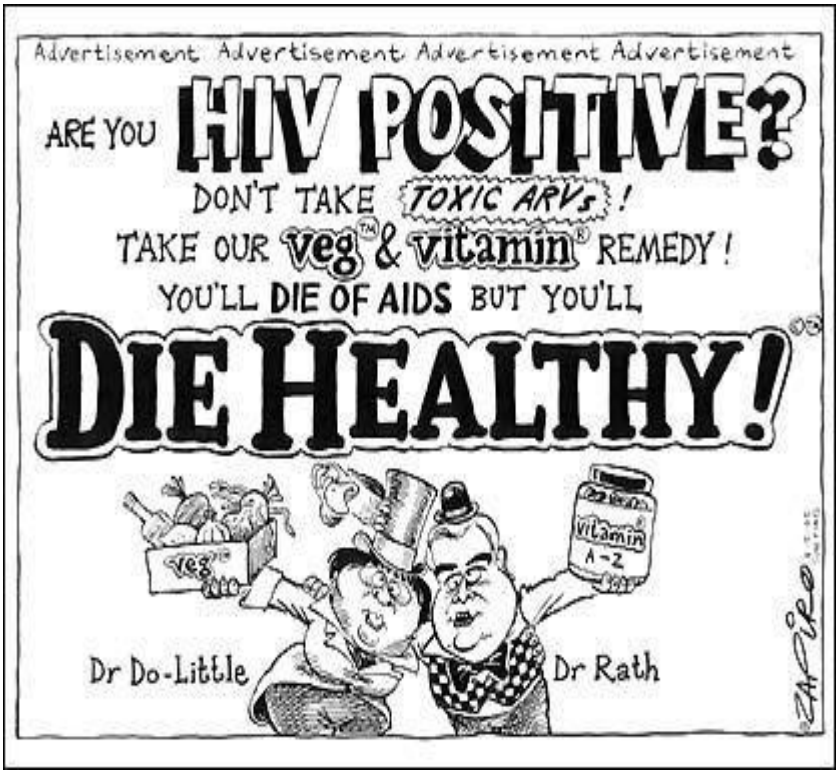
denialism, and in 2004-08, they continued to publicise their difficulties in accessing ART. The more closed the political and policy space, the greater the levels of public confrontation between the government and the people. Government's active obstruction of the use of ART while promoting alternative therapies attracted quacks and opportunists like Rath and his supporters. TAC activists resorted to their confrontational direct protests and lawyering to counter the Minister of Health's confusion. Without reaching a critical mass of popular education and mobilisation, the TAC activists in Khayelitsha and Lusikisiki would have struggled to counter the fear-mongering messages coming from the state, such as "AZT kills." "We were able to convince people in clinics to be vigilant and dispute the myths that the Minister of Health Manto was spreading," (TAC0010 Interview, 2015) . in addition, TAC activist argue that "the NAPWA, Rath, SANCO, ANCYL and the state were united in an attempt to discredit ART and TAC," (TAC005 Interview, 2015). "AIDS activist, Zackie Achmat, is HIV positive and is outspoken in his criticism of NAPWA. The TAC Khayelitsha had branches in most areas in Khayelitsha, and HIV/AIDS and treatment education was the movement's backbone and part of the branch life," (TAC005 Interview, 2015). Consequently, to demystify the confusion around denial narratives, the "TAC activists deployed their local branch educators in the main areas of the community, including those who were linked to support groups and clinics," (TAC0049 interview, 2015). The Rath Foundation had set up an unethical clinical research site in Khayelitsha, and this was viewed by local TAC activists as "aiming to undermine the ARV rollout and that it was left to us to convince people about ARVs, and to prove that ARVs save lives,"(TAC009 Interview, 2015).

The close connection between Rath and senior political leaders gave him political protection as he recruited in townships such as Khayelitsha, working with the South African National Civics Organisation (SANCO). The SANCO is supposedly representing organised local civic and street committees. Even though civic organisations were vibrant against apartheid in coordinating the political resistance at the grassroots, now they are just spaces with entrenched patronage. The Rath Foundation promoted its vitamin and micronutrient supplements as an alternative discourse to the toxic state-provided ARVs and the big drug company interests behind them. Additionally, the endorsement by the Minister of Health fundamentally plays into the discourse of denialism, appealing to the public's distrust of science and big business as well as backlash against scientific authority. Whereas in 2003, the MCC was quick to act against complaints about Hadebe's cure '*umbimbi*', the opposite has been the case with regard to the

Rath Health Foundation. Despite a series of complaints by the TAC and others, the state against Rath and many others took no official action.

There were various versions of other alternative remedies advertised as a cure for AIDS, such as, in KwaZulu-Natal, the famous u*Bhejane* and Tina van Der Maas's false cure, amongst many that the Medical Control Council received complaints from TAC (Geffen, 2010). The Traditional Healers Organization has sided with the Rath Health Foundation in its legal battles with the TAC, and there have been several marches by traditional healers in support of Tshabalala-Msimang (Geffen, 2010; Nattrass, 2008) . Further, the tension between TAC and NAPWA is well known, as discussed in Chapter Two, and they were different movements that utilised dissimilar strategies to shape and influence policy. The shadow of AIDS denialist politics created mistrust that led to further adversarial engagement between TAC activists and the state. That exclusion gave an advantage for the TAC activists to re-articulate ideas for independent people-driven policy implementation outside of the institutional channels of SANAC. The non-existence of institutional AIDS policy forms at the local level was critical as well. The TAC emerged as an alternative grassroots activist space of participation to force government transparency and accountability.

FIGURE 21: MINISTER OF HEALTH RATH CARTOON



[Source: Zapiro, 2005]

"TAC fought with Dr Rath and his people in the streets of Khayelitsha and the courts of Cape Town," (TAC0010 Interview, 2015).

Confrontational engagements can be a resource for social movements, because they get the public engaged. Cultivating public sympathy mobilises potential members' emotions, attracting bystanders and media (Jasper and Owens, 2014). The TAC, together with the South African Medical Association, filed court papers in November 2005 against the Minister of Health, Matthias Rath and several other AIDS denialists. At the time of the TAC court submission in August 2007, this case had yet to be heard (Nattrass, 2008). The TAC and MSF in Khayelitsha took Rath and the Minister of Health to court, arguing that deaths would result if people who had been taking the drugs stopped taking them in favour of the vitamin supplement (see figure 20 above). The activists and their allies gave evidence that some people had died for this reason. In June 2007, the campaign won a ruling from the South African High Court that the Dr. Rath Foundation study of vitamins for HIV positive patients was an illegal trial and had to be stopped. The court also censured the South African government for failing to clamp down on unlicensed remedies. Dr. Rath has said that he will appeal against the judgment. The TAC activists intensified their fight and used the World AIDS Conference in Toronto in 2006 as a battleground where the TAC publicly challenged the South African government's continued denialism as evidenced by the Minister of Health's exhibition display of nutritional remedies for HIV (Alluri, 2010). The Toronto AIDS conference in 2006 was a site of contestation and activists' confrontation of the state officials who attended the conference, along with collaboration and transnational activism. The TAC mobilisation connected the local struggles for access to ART with other activists beyond borders. International and domestic pressures from a growing civil society movement expressed heavy criticism of the then–health minister's stance that nutritional choices could benefit people with HIV (Osewe & Y Pillay, 2016).

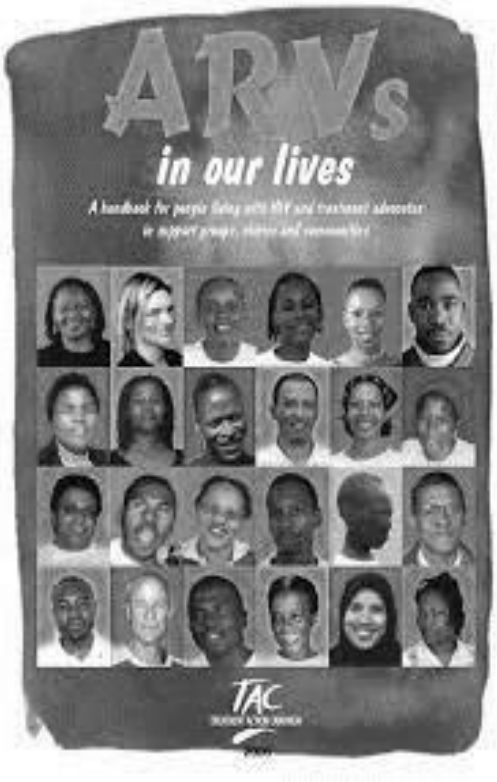
6.3.4 SYMBOLIC CELEBRATIONS OF ART PATIENTS

"We celebrated the ART milestones, like when Khayelitsha reached 1,000 people on treatment, to show our opponents that people are alive," (MSF0066 Interview, 2015).

FIGURE 22: MSF KHAYELITSHA MURAL PAINTING

[Source: MSF, 2004]

FIGURE 23: TAC TREATMENT LITERACY BOOKLET

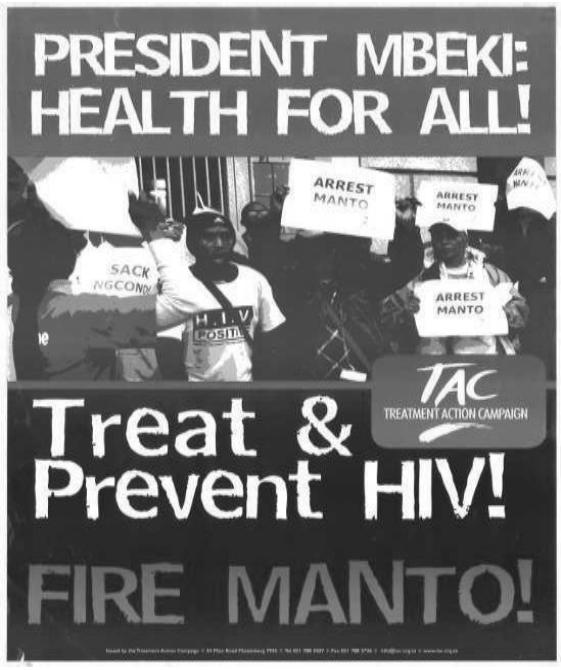


[Source: TAC, 2006]

To demystify the fear created by government, TAC and MSF began to hold symbolic celebrations and dedicated mural paintings in busy streets (see figure 21 and 22 above). The TAC also scaled up its treatment literacy material using real faces of people alive and well on ART. This demystification targeted both the public to disrupt the state discourse and confusion about ART and patients on ART doubt potency of treatment. According to (Cloward, C & Piven, 1977) , poor people only attain concessions when they disrupt activities valued by elites through riots, sit-down strikes, and other aggressive activities. They have to frighten and not just inconvenience their targets. In a way, the activists were transforming their frustration with government into a positive accomplishment that applies far beyond the individuals taking treatment but also to the general public (Jasper, 2014; Spencer & Walby, 2013). Activists strategize about what to do to stimulate movement participants and targets and diffuse opponents.

6.3.7 CIVIL DISOBEDIENCE

FIGURE 24: TAC CIVIL DISOBEDIENCE POSTER AGAINST MINISTER OF HEALTH



[TAC poster during their 'fire Manto' campaign, 2007]

FIGURE 25: TAC PROTEST

[Source: TAC Archives]

Policy issues sometimes thrust particular government departments into the spotlight, but more commonly, the problems that animate social movements are systemic and hidden, such that no responsible actor automatically comes to the fore. For instance, information about the behaviour and culpability of government ministers is often quite meagre until after a social movement has forced new information to light. Linking a particular policy failure to government ministers or actors generates public information about these actors' practices and is a crucial part of what social movements do as part of their daily framing process (Benford & Snow, 2000; Powell & DiMaggio, 2012). They make visible and memorable moments that delegitimize the existing social order. Social movements publicly articulate their claims and identify the government leader responsible by holding protest events, but also by developing capacities to attract media attention and gather new types of information. The construction of targets connects repertoires of contention and configurations of power (Bartley & Child, 2014). Tilly, (2006) theorised that repertoires of contention are repetitive sets of targets, tactics, and understandings of social

change which are traditionally shaped by predominant patterns in the polity (Mueller & Tarrow, 1995) .

attention to the co-evolution of repertoires of contention and forms of power by highlighting the production of targets, a subset of this larger process. There are two elements of that especially imperative for repertoires of contention and the construction of targets. Analysing the production of targets requires one to unpack the bases of material and symbolic power in different social fields (states and markets) and among different actors in the field (particular firms in a market). Activists then shift towards building stress to the system and building movement energy, using a trigger through which public attention is directed to articulate their demands. After a policy becomes a public issue, the power-holders are forced to switch to a crisis management strategy by vindicating unjust policies through ignoring, discrediting, and denying the problem, explaining that their current policies are sufficient and, if necessary, repressing the movement. Power-holders can create a trigger event to justify a new policy and to get public consent, and overcome public opposition by destabilising, making minor changes through reforms, compromises, and co-optation of opponents. Social movement organisations publicly articulate grievances and identify responsible parties not only by holding protest events, but also by attract media attention (Rohlinger, 2013) . The activists created advocacy posters such as those charging the Minister of Health as an inexcusable culprit in policy implementation. Information about the behaviour and culpability of a government minister forces the public to see her in a new light.

For instance, one poster had in large print, “Arrest Manto,” an expression that is normally used to refer to criminals (figure 23 and 24 above). This allowed citizens to identify her as an enemy of poor people. Furthermore, they made visible and memorable moments that delegitimised the existing government order. The activists’ tactic on the posters is to link the two ministers to criminality and negligence, which represent inaction to stop the “600 deaths daily,” and this produces public information about these politicians’ practices, which is a crucial part of what social movements do. As (Benford & Snow, 2000) argue, social movements frame everyday practices as problematic and promote particular diagnoses of the problem. As theorised by (Tilly, 2006), activists construct targets for their action repertoires for contention about the particular policy. They use these constructed targets such as government ministers as their focus for their demands and organise their movement’s theatrical actions to depict their anger.

Theorists stress that repertoires of contention are traditionally explicit and moulded progressively by main patterns of state policy (Tarrow, 1999). Government leaders such as the Minister of Health in South Africa sponsored the activists through their policy inaction. The reputational hierarchies in state systems such as the ministries responsible for the policies the movement is contesting create points of advantage for activists. As argued, social movements respond to particular structures of power. “The local and national health officials were highly demoralised after Manto, imagine the national department of health had only one deputy director general in 2008, good had left,” (NGovt0057 Interview, 2015). In 2008, the ANC recalled Mbeki and Tshabalala-Msimang. Activists viewed this as a watershed moment. AIDS activists began collaborating with her Deputy Minister MadlalaRoutledge and Deputy President Mlambo-Ngcuka on the development of a new NSP as well as the restructuring of SANAC (see Chapter Seven). In the process, the TAC had demonstrated that the presence of political elites, and state capacity and apparatus for repression or co-optation,(Goodwin & Jasper, 2019; McAdam et al., 1996); were not always necessarily a barrier but could also represent an opportunity for activists’ engagement.

In sum, grassroots activists altered their advocacy tactics in various ways when confronting the new implementation’s structural challenges. “We occupied police stations around the country, and in Cape Town we were 200 members that got arrested. In Durban there was a violent confrontation with the police using tear gas to dispersed our members,” (TAC008 Interview, 2015). This suggests that the TAC Khayelitsha and Lusikisiki activists became more militant during the ART service delivery to exert TAC’s power on its own conditions and terms. The TAC activists were reactive by occupying ART sites and protesting against the imposition of unattainable ART accreditation, which showed the bureaucratic power in policy implementation decisions that led to rationing service delivery without engaging with those whom these procedures would negatively affect. Although the grassroots activists expressed direct collective action to force the state to concede about the rollout timetable at some point, on the other hand the site accreditation rationing of care continued.

FIGURE 26: PROTEST

[Source: TAC, 2006]

In the meantime, the state created a parallel discourse discrediting ART use and actively promoted natural remedies causing public doubts, confusion and death of people (figure 25). The invented bottom-up participation tactics shifted the state practices in provinces, such as the perceived national character of the ART rollout, especially in relation to the centralised accreditation of ART sites. Reviving the AIDS councils and clinic committees through popular agency. The TAC, with its strategic policy alliances, invented more participation spaces, resources for court cases, popular education, resources for protests and strategy advice about the political struggle. Perhaps more importantly, it has thrived in providing support for networks of health care workers, community-based working class organisations and communities in Khayelitsha and Lusikisiki. The TAC contributed to the expansion of the popular democratisation of the health system. During policy implementation, the TAC movement action had peaks of local theatrical protest action, which demonstrate continued influence and participation in ART in service delivery. The political opportunities that came with the government ART plan were a resource to contentious movement actors (Tarrow, 2005) to drive implementation. Above I demonstrate that the period after 2003 constituted a minor political

opportunity to AIDS activists, because there was no state commitment to implementation of ART. It took the same activists to drive government to deliver on its promise of ART.

We learn in this chapter that activists' advocacy tactics shifted to confrontation to counter the destructive national political influence in local implementation. The Khayelitsha and Lusikisiki sites show that grassroots participation in the health services has expanded the scope for public administration to be more socially accountable. This kind of accountability functions through a national network of civil society with strong links with grassroots organisations focused on patient activism and support (Lodge, 2015). TAC strategically applied its advocacy tactics to pressure government. Direct popular participation in policy through formal institutional channels through litigation leveraged action, and the civil disobedience campaign forced government to change its pace of rollout. Although the direct protests against site accreditations and court rulings (the Annex A case e and Rath case) did not quickly lead to direct change in the general policy implementation at the time, they are widely considered as one of the reasons for universal access to ART in South Africa (London & Schneider, 2012). Additionally, the strategic alliances with other civil society organizations, including the Southern African HIV Clinicians Society and Médecins Sans Frontières, facilitated a broader social response and a united front against the government's intractability (Venter, 2012). The change of guard during the 2008 election (more precisely, Mbeki's resignation) provided the catalytic shift in overcoming political resistance to ART. It is because of TAC activists and their allies' continued advocacy, vigilance and contestation that South Africa can boast to have the largest ART programme in the world, with 3.4 million people estimated to be taking antiretrovirals by 2018. ART services are available in most primary healthcare facilities countrywide. Expansion of ART access was projected to reach 4 million people by 2019. In the next chapter, I unpack the impact of activists' advocacy tactical shifts that led to grassroots typologies of participation for relations with policy makers and activists. This is to share some light into what the types of participation mean for the survival of social movements and policymaking going forward in terms of democratising healthcare in South Africa.

CHAPTER SEVEN: EMERGING TYPOLOGIES OF PARTICIPATION

7.1 INTRODUCTION

“During the administration of denialists, the TAC could not sit around the same table with government, but now we are able to and even in other forums like SANAC,” (TAC0030 Interview, 2015) .

The state exclusion of the TAC activists and its allies under the Mbeki administration involuntarily played into the hands of movements to even out the unequal institutional participation. The activists’ creation of alternative policy discourse narratives discredited the state-sponsored public doubts over biomedical solutions to HIV/AIDS. The state narrative promoted natural remedies, which caused public confusion. The use of coercive advocacy tactics is theatrical in nature and tend to raise public awareness and create political targets for the movement. Both tactics used the media for external projection of the movement's power and built the movement's own internal movement propaganda through newsletters, media advocates and television programmes. While public policy in South Africa praises the virtues of participation (and may even make it a legislative framework), evidence suggests that state opposition to popular participation is often an obstacle for successful policy (Crawford et al., 2002) . Grassroots activists’ advocacy patterns of popular participation reflect the sum total of the forces of power in AIDS policy processes, those working to maintain the status quo, and those seeking to reshape it. If uneven participation is a present and persistent concern across various modes of participation in South Africa, then inclusion is clearly significant and can only be the right thing to do in democratic institutions. The activists also used institutional engagement through the courts to push for recognition and influence over state policy, which expanded the forms of expressions of power by citizens over the state. Activists’ infiltration of formal participation spaces activated the interface between communities and government and exposed its limitations. The establishment of AIDS councils as advisory bodies not as a juristic entity deem it hard to hold its leadership accountable. SANAC structures are bound to be insufficient in the long term to address health service challenges as shown in the example of the ART rollout. This is mainly because the state is “a player and a referee” and if we are to leave these institutional spaces without oppositional social movements to hold them accountable inside and outside then they are not fit for purpose. (Hongoro et al., 2008) argue that AIDS councils are not a panacea for AIDS policy participation. In fact, we have learned through the

TAC activists that local people choose to invent their own alternative spaces where they have control and power to influence policy on their own terms. The role of the government at the local level had been reduced to a mechanism for service delivery, with reduced quality and scope for participation (Heller, 2012). The ostensible commitment to participatory governance can be a political dividend for public officials to give themselves distinctive public identities as champions for the cause of open and accountable government. Within state bureaucracies, activists recruit allies who play a crucial role in creating and resourcing spaces for change from within, and as such become supporters for social movements and civil society. For example, the "Eastern Cape government was clearly committed to ART rollout, the Minister of Health lobbied within government for change of provincial leadership and a new MEC Dyantyi and new Head of Department deployed from National Ministry Dr Mbhengashe came in. I knew to have TAC Eastern Cape as partners, I had to make changes and sent signal of my commitment,"(NGovt007 interview, 2015).

On the other hand, in South Africa there is no Act with Parliament oversight, which begs the question about its accountable measures to the cabinet. Furthermore, there is no single parliament document that articulates SANAC's mandate. Instead, capture of the AIDS council mandate is in several documents, each with a slight variation. For example, the SANAC Trust, the only legal entity since 2002, is responsible for SANAC business (National HIV AIDS and TB Unit, 2005). Yet, there are no AIDS council Trusts at local levels, which points to inconsistencies. Further, since its establishment, the SANAC Secretariat has been relying on financial and administrative support from the Department of Health, just recently establishing itself as an independent institution. There is no clarity regarding roles and responsibilities between the Office of the Deputy President, the SANAC Secretariat, and the Department of Public Service and Administration (key HIV/AIDS coordinating divisions). Only as recently as 2012, a joint parliamentary committee of HIV/AIDS was established after several lobbying actions by civil society (Chiguvare, 2015). However, the disbandment of this committee two years after without any public explanation left civil society in astonishment.

When civil society (Civil Society Group,2015) applied pressure, they were ignored and the matter died down. This raises questions of accountability with SANAC. The creation of the AIDS councils came with aspirations to decentralise participation and create similar structures at provincial and lower levels. At lower levels, the process of developing provincial strategic plans was not as extensive as at the national level.

Nor did it allow much space for local activists, who were in any case suspicious of the state. Nonetheless, with the founding of the SANAC also soon came the subsequent 'establishment' of Provincial AIDS Councils (PACs), the District AIDS Councils (DAC), the Local AIDS Councils (LACs) and even the Ward AIDS Committees (WACs) in some municipalities. This move evoked some optimism among grassroots people, since local government was also meant to be developing into a fully-fledged sphere of governance by 2000 (Kanyane, 2014). Local governance was said to be the centre of the practice of participation and democracy (Parnell, 2002). Likewise, stamping out unequal participation requires activists and communities' participation in policy decision-making processes that affect their lives. Understanding this is a pertinent crisis in development because it tells us something about democratic and institutional decay.

Exclusion in policymaking includes events that may be particularly associated with development that disregard marginalised voices and subsets of a population. Legislation in South Africa provides for a myriad of avenues for participation, such as municipal planning, budgeting, service delivery, and performance evaluation. A variety of structures serve this goal (Integrated Development Planning Forums, ward committees, and service delivery improvement forums). Of course, institutional or invited spaces such as ward committees are full of partisan politics and sometimes participation is through alignment to certain party politics. The current legislation and policy process formal spaces are largely shaped and owned by the state. At a local government level, these include local elections, ward meetings, council meetings, and public forums. As Cornwall, (2002) also adds, invited spaces are created government and may hold limits to what activists can achieve. Despite these government machinery avenues for participation, communities seem to express their exclusion through their own invented means such as protests. The protests have increased in number and frequency in post-1994 South Africa. For example, between 2007 and 2010, the average number of protests per month was 9 in 2007, 10 in 2008, 19 in 2009, and 16 in 2010 (Powell, 2012). The activists' combination of protest and bargaining policy advocacy tactics within the policy institutional arena was part of their rational movement action plan. Through the participation and social movement theory, we learn that activists' engagement with government transforms popular participation from below.

Having discussed the activists' advocacy tactics shifted to challenge government ART rollout in Chapter Six, I will now demonstrate the impact of activists' tactical shifts in facilitating new typologies of participation and their implications for reforming grassroots engagement with public administration. As I indicated in Chapter Two, the analysis of the findings is grounded in a popular participation perspective and social movement action plan. As noted in the previous chapters, participation is fluid and movements evolve. The findings presented in this chapter demonstrate how the TAC activists' advocacy actions are premised on the principle that the state alone, especially the national Department of Health, is unable to develop and implement a successful National Strategic Plan (NSP) against HIV/AIDS without the people who are most affected by such policy. It shows the fundamental need for a people-centred policy development beyond formulation, but also in the subsequent implementation (Fourie, 2006).We also learn from insights and experiences of those who struggled and actively participated in policymaking processes after the ART policy victory. The policy processes that facilitate engagements between communities, people living with AIDS and government during these period share ideas about the TAC in terms of continued influencing AIDS policy in South Africa during service delivery.

Against this background, in section 7.2 I present the main impact of activists' advocacy tactical shifts that led to grassroots typologies of participation for relations with policy makers between 2003 and 2015. In section 7.2, I discuss the impact of activists' engagements to challenge the clinic committees. In section 7.3 I demonstrate how the activists understood their participation transformation. In addition, in section 7.4 I will explore what these participation typologies mean for the survival of social movements and how policymaking is going forward in terms of democratising healthcare in South Africa. In section 7.5, I summarize the main points.

7.2 IMPACT OF SHIFTING BOTTOM-UP PARTICIPATION FOR ACTIVISTS AND POLICYMAKERS

7.2 CHANGING THE PRACTICE OF GIPA

"People living with HIV were paraded to disclose publicly their HIV status without real influence in policy decisions," (NAPWA0050 interview, 2015).

Activists living with HIV seem to be aware that, occasionally, public administrators use them for tokenistic purposes. They refer to their experiences as random posturing, which constitutes a mere cosmetic pretence that their participation has no influence or power (Pretty, 1995) . This type of participation demonstrates tokenistic legitimacy through placing people living with HIV/AIDS in visible positions rather than meaningful participation, as they did not influence shifts to the state policy before and after 2003. Nominal power sharing between state and non-state policy actors has limitations for grassroots people who need to exercise agency to influence policy development processes. The GIPA principle proposes that people living with HIV activate their involvement from the bottom of the pyramid of power yet envisioned being contributors, speakers, implementers, and eventually experts and decision-makers, progressively shifting towards the top of the pyramid (see figure 5). The NAPWA's initial efforts to implement GIPA-informed collaborations with the Department of Health reflected this idea about entering at the bottom.

A study (Stephens, 2004) evaluating the GIPA in Benin, Brazil, Cambodia, South Africa and Ukraine and the degree to which PLHIV participated in the national HIV/AIDS strategic framework design and planning (Stephens, 2004). The study established that while all countries had appreciation for the GIPA the degrees of their involvement differed from one country to another with Brazil having been able to achieve consistent involvement in national HIV/AIDS strategy and South Africa placing emphasis on participation of PLHIV in its HIV/AIDS and STD Strategic Plan (Stephens, 2004). South Africa is one of the countries where the UN piloted GIPA and developed the GIPA Workplace Model. The model saw placement of PLHIV in government departments, key parastatals as well as corporate and NGO workplaces where they set up and review workplace policies and programmes among others (Stephens, 2004); (Simon-Meyer and Odallo, 2002). An evaluation of this model found that PLHIV "can add value to workplace HIV/AIDS programmes in a way that is relevant, effective, efficient, sustainable and ethical (Simon-Meyer and Odallo, 2002). Therefore, the study concluded that the GIPA implementation in the Asia-Pacific region ranges from tokenistic to genuine partnership and empowerment. Similarly, due to fear of HIV/AIDS-related stigma and its various consequences, tension exists when individuals contemplate to disclose their positive status for the purposes of involvement.

This is compounded by one's right to confidentiality and personal considerations regarding how and when to diagnose and disclose (Stephens, 2004) Retaining PLHIV is also another challenge to GIPA. Through GIPA, PLHIV gain skills, self-esteem, and start making impact on their communities. However, many have fall sick and die, and a wealth of expertise gets lost (Morolake et al., 2009). Stigma is another form of soft repression that is present in policy spaces which acts to impair collective identity, where connection with the group of people living with HIV is a source of discredit and devaluation because that is how public administrators and the public view the group as a whole (Davenport & Johnston, 2018). Most activists joined the TAC with fear, isolation, stigma, despair and anger arising from their HIV diagnosis. The treatment literacy also gave people living with HIV public voice and visibility during a period when HIV was highly stigmatised and seen as a silent disease. The thrust of the TAC's struggle had been on citizens' rights to health care and broader national questions relating to scientific authority and expertise. Hence, treatment literacy functions as TAC's grassroots advocacy tactic of popular education, often common in social movements for the purposes of conscientisation and transformation that can result in collective action for social change (Grenier, 2019). Popular education connects the individual activists (micro level) to learning new health, science, political and rights knowledge, through which they understand new critical knowledge about the HIV issues, policy actors and relations of power in the health system that its members are willing to apply through participation. Social movements can lead to social and political transformation because they not only analyse society but also put forward new alternatives for knowledge generation and social action (Kluttz & Walter, 2018) .

7.3 ACTIVISTS ALLIANCES WITH HEALTH PROVIDERS

"Even when we conflicted with the government, the Deputy President Mlambo-Ngcuka came to address our 2008 Congress, symbolically building bridges," (TAC0016-Interview, 2015).

A conciliatory phase began, which represented a period of rebuilding relationships with the state, a move the TAC framed as trying to get the government to do what it is supposed to do while not seeking friendships (Treatment Action Campaign, 2008). Politicians and senior bureaucrats who can be lobbied to be champions of change within bureaucracies play a crucial role in creating and resourcing spaces for change, and as such become allies for social movements and civil society (Amenta, Caren, Chiarello, and Su, 2010b).

The importance of activists contesting the power of street-level bureaucrats is critical, as they are the implementers of policy on the frontlines. often frontline workers such as hospital managers, nurses and doctors in health facilities represent hidden power; as seen in Chapter 6 (figure 4), these health officials have a certain degree of power and discretion in policy implementation decision making. Discretion gives freedom to public administrators to determine the quantity and quality of policy choices (Tummers, 2012). Nevertheless, discretion cannot always be seen in a negative view; likewise, it can be applied to adapt policy implementation needs to suit local community needs. Of course, willingness of frontline health workers to use positive discretion depends on whether they have been delegated decision-making authority (Meier and O'Toole, 2002). The new types of advocacy encompass contesting the power of frontline public health workers in the local clinics using bargaining, where most people had to interface with frontline health care bureaucrats.

The TAC's ongoing advocacy after the ART rollout in the local health facilities expanded local sites of participation for grassroots activists to shape and influence implementation. Bottom-up typology of participation is the unique, deliberate and contestation acts by local activists to spotlight unfavourable policies in order to engage government as well as to expand the scope of influence and conflict. The repertoire of popular participation is expanding rapidly to include health facilities, AIDS councils and clinic committees. Institutional participation is invited (Keeley and Scoones, 2014) in bureaucratic spaces led by public administrators, especially the Mayors, Premiers, Ministers of Health and the Deputy Presidency. Activists' participation in formalised policy spaces should, then, be part of their movement strategy. The TAC activists' participation in SANAC is through internal movement election and mandate; so, they, in turn, must be accountable to the people, because participation is elixir of life for democracy. The newly gained activist power became a resource that led to breakthroughs in the AIDS policymaking space regardless of the state's dominance. The TAC activists recognised that sources of power reside at different levels (national, provincial and local) and beyond the state. The site of struggle means that it is a fluid and non-static process with multisectoral layers, and is complex and has contingency. The activists' strategic alliances in SANAC, provincial through PAC and local levels through the DACs, MSATTs and the clinic committees opened new horizons for popular participation and openness in health governance.

The presence of TAC in all the levels of policymaking reminds us that at every level activist can shape policy. As indicated below in Gaventa's power cube (figure 4) power shapes participation at every level, from the national to the local, to the very micro. The new typology of participation we learn from Khayelitsha and Lusikisiki is that activists' advocacy tactics evolved to counter the state's slow ART service delivery. Activists' collective actions included disruption, negotiation, protests and litigation as their exercise of power and control over policy affecting them. Their use of popular protests as direct action to gain access to policy decision making about the treatment timetables and countering the imposition of unattainable ART accreditation forced the state to concede and release the ART rollout timetables and abandon the ART site accreditation, which would have otherwise led to rationing service delivery. Resistance is an exercise of power. (Carpentier & Dahlgren, 2014) underscore the importance of sustained activist participation during ART implementation as an act of balancing power, reconstructing the sites of political struggle to gain influence and control of policy decision-making processes. Hence, I argue that communities should create their own spaces through which to assert their agency and influence in policy processes. Thus, activists extended their sites of popular participation through protests and contentious activism.

7.4 ACTIVIST TAKE OVER AIDS COUNCILS

Policy spaces have potential for political opportunities where citizens and policymakers come together and interact, which has the potential to be transformative engagements (Young, 2002). Moreover, space, in policy processes, can be a democratic process in which citizens can engage to claim citizenship and influence and affect governance processes (Coelho & Cornwall, 2007; Andrea Cornwall, 2002). The AIDS councils continue to be under the state command and authority through the bureaucrats and government-appointed experts setting the predetermined agenda. The Presidency office is viewed as a high-level government leadership enabler of political will in the AIDS response. Typically, social groups who claim to have national footprint are invited to represent their constituency in the policymaking processes. From my activist experience of participating in policy making at both national local levels these representation arrangements are not clear in how it is applied at local level. The AIDS council needed reform so that they could be more inclusive of affected voices. The policy-making processes through SANAC has to reflect power views of all actors, which then brought the politics on the table. The TAC shifted the balance of power in the AIDS council by bringing its allies and pushed for a sit in the leadership. For example, in this new political change period,

collaborative engagements between activists and government became possible because activists created them through the new National Strategic Plan (NSP) on HIV/AIDS and STIs in 2007–2011. In the end, it turned out that the real leaders of the National Strategic Plan development in the AIDS council were, in fact, the TAC more than the government. "The real leaders of the National Strategic Plan development in SANAC were TAC more than government, and brought all its networks into the committees of SANAC to do the guidelines, the children guidelines, the treatment guidelines. Government had very limited expertise at the national level," (MSF0028 Interview, 2015). The activists' domination may shift the people's non-compliance with the status quo and place the state into subordination. Dominance is a sign of visible power to gain influence and control over policy decision making. "TAC was central to the SANAC revival — with Mark Heywood as the deputy chairperson and leader of civil society," (SANAC003 Interview, 2015).

The restructuring of the SANAC included the Deputy President appointment as the chairperson of the SANAC. However, some public officials argue, "SANAC restructuring resulted in government and civil sector working together in the AIDS response. The reform of SANAC offer civil society what they want in terms of control in decision-making. In addition, the leadership of civil society through the co-chair offer influence" (NGovt0040-Interview, 2015). The TAC activists worked hard to gain power in the official terrain of formal policy engagement by, for example, assuming leadership positions in the AIDS council. "The TAC dominance in the policy ART discourse and in SANAC led to perceptions that they have taken over the Department of Health" (NGovt007 interview, 2015).

Particularly in the Department of Health, which dominates together with other members of government such as the AIDS councils, there is limited space for unorganised social and civil groups to have a strong voice. Popular participation in state-dominated spaces is a strategic choice by activists in pursuit of their social movement goals. Institutional policy spaces can offer options for movements to negotiate with the state (Tarrow, 1999) while simultaneous confrontational tactics are applied.

> MSF was included in a number of task teams and policymaking groups to influence how the rollout would happen from below. As well as, advised at the WHO level

> because of the local specific experiences. People know what is in the guidelines they implement (MSF0066 Interview, 2015).

The NSP development process covering all nine provinces and in each province two days allowed for more participation of grassroots people. Over and above that, the MSF and TAC activists made sure that one of their own was on the NSP writing teams and the subsequent implementation task teams. TAC brought to bear all of its networks, expertise and allies into the committees of the AIDS council to develop the prevention, treatment and paediatric guidelines. For example, the NSP has treatment targets to reduce the impact of the epidemic by extending access to appropriate treatment, care and support to 80% of people diagnosed with HIV (Wouters et al., 2010). The ability of activists to scrutinise activities of government institutions is crucial and fundamental to any democratic policy making, as well as essential to build trust and confidence of populace in the policy-making process. The TAC activists were also wary of bureaucrats trapping them in countless NSP negotiations. From the National Strategic Plan to the restructuring of SANAC, the work gained pace following the International AIDS Conference, with an assessment of the previous National Strategic Plan undertaken in August (SANAC). From this point, leading HIV/AIDS activists worked closely with the Department of Health until the finalisation of the new National Strategic plan 2007-2011, which was a product of many months of consultation with communities. The SANAC reconvened a newer national deliberative participation structure where the nomination of the TAC activist Mark Heywood to serve as deputy secretary of SANAC the following month (SANAC) was seen as leadership reform and victory to TAC activists.

I argue that it is a direct impact of TAC and its allies that reform and change has arrived which otherwise would not have happened in the absence of the movement's actions. With this framework and after a consultation process of more than six months, the NSP was finalized in partnership with civil society and several other stakeholders (Wouters et al., 2010). Of course, evidence from consultation exercises suggests that the deep scepticism expressed by citizens about their capacity to affect the decision-making process is often justified. Yet, the TAC made sure that the consultations in provinces were organised by collaborating with activists to make sure the right people and voices participated. This internal epistemic community had to become experts on the science of health, HIV/AIDS, rights and politics so that it could talk confidently to government and other stakeholders (Vandormael, 2007). Then, after 2006, the TAC became

part of the AIDS council during implementation to shape the new National Strategic Plan on AIDS/TB and STIs, helping to set targets and identify mechanisms to reach them. Where authorities are interested in fighting AIDS, the TAC is present in participatory governance forums. Where they are not, it is not. The key variable is not participation in formal processes but the extent of its influence and the willingness of authorities to engage with it. At most, participation in forums may enable it to consolidate gains, not to make them. By actively reforming the AIDS council governance structure to ensure better oversight of the implementation of the new NSP, success seemed possible.

Hence, for the TAC, the post-2003 institutional reform opened up space for the movement to pursue its agenda. This reform is a political opportunity for the movement to create their own spaces for institutionalised policy systems. The reform of SANAC and the NSP development processes were moments of political opportunity where activists and policymakers came together and interacted with a potential to be transformative engagements (Young, 2002).The TAC activists' dominance in a government space meant that they could shape policy, especially the National Strategic Plan (NSP) from 2007 to 2011. The government leadership concur that:

> "SANAC is the best thing that happened to us in South Africa, because it brings civil society and government into this structure as equals, whereas other forms of engagement would already happen at a level that also brings into it power relations" (Presidency0062 Interview, 2015).

7.5 REVIVAL OF LOCAL AIDS COUNCILS

"At the local level, the majority of AIDS councils are non-functioning, with exceptions of a few," (SANAC003 Interview, 2015).

Despite the optimism surrounding the participatory framework, the local activists struggled to win basic policy decisions and processes around service delivery. This has resulted in challenges, namely that the lack of institutional capacity at the grassroots meant that local people's participation is not sustainable, nor taken seriously by local government, and thus local people resort to using other means to influence policy. Hence, given these challenges, often local government officials are accountable to their political leaders and parties rather than the citizens who are at the receiving end of poor service delivery (Booysen, 2012). The TAC

activists made investments in reforming the AIDS councils; they had to strengthen local institutions so that the NSP implementation could be coordinated in order to succeed (Spotlight, 2012). Where there was activist pressure, those AIDS councils at least held their meetings. In response to activist pressure for inclusion government tends to increasing the size of the council which then bloats the structure. This is similar to local structures such as ward committees where members increased from 10 to 30 in response to protests for inclusion in development. I argue that in agreement to increasing representative but at the same time numbers do not translate to meaningful participation. What matters are that the decision taken favorable to the activists demands.

"We had to rebuild and revive local AIDs structures in most provinces because they were non-functional"(Section27 0058 Interview, 2015).

The Activists in their attempt to democratize and politicize implementation of ART had to revive non-functioning local participation structures. As alluded to by the Section27 activist that it also became the role of activist to build local accountability for the rollout. This mean that the devolution of institutional governance as envisaged does not guarantee meaningful participation of poor people and improved service delivery (Richard, 2008). Defunct institutional structure such as the AIDS council and their lack of a clear mandate, poor coordination, uneven representation of civil society and government sectors, resource shortages at local levels, and lack of accountability for those participating, therefore, no oversight implementation thus hampered the ART rollout. Another example, the activists interviewed below alluded to the challenge of capacity to engage in the councils. This supports my argument that it no use to increase numbers of participants if they do not have the skills and the mandate to push for movement agenda.

> In OR Tambo district we pressured the AIDs council to reform and also build capacity of the members both government and civil society so that the structure can deliver for what it is set to do (TAC008 Interview, 2015).

The AIDS councils are struggling for much-needed support, especially at provincial, district and local levels, because they are largely weak and failing to implement the AIDS plans (Mahlangu et al., 2017) . Due to the scope of institutional participation and the close proximity

of the department of health, the separation of powers for accountability was critical. This means that the historical executive authority of the AIDS council under the command of the Department of Health is not ideal, because how can activists hold them accountable if they are the authority in the space? Thus, the Presidency, Premiers, and Mayors became custodians of government leadership on AIDS. However, even this model by its nature came with its own challenges, because not all leaders were able to take leadership on AIDS. For example, one of the observations made during this study is that most Mayors and Premiers delegate this responsibility to the HIV coordinators in the municipal offices or the department of health officials in provinces. In general, the AIDS councils at local levels were not functioning; the activists focused their attention on reconstructing these spaces. Likewise,(Friedman & Mottiar, 2004) also argue that formal forums would not have been able to exercise the degree of pressure required to win the change. TAC's presence in participatory governance forums is a consequence of its influence, not a cause. This finding is similar to what other scholars (Mahlangu et al., 2017) have also found, that the AIDS councils at all levels, with a few exceptions, are weak and struggle to perform their mandate.

Even some government officials agree that the AIDS council is not always the space for popular participation but for resource competition. "The AIDS councils are useful for competing for resources, 'talk shops' for government and civil society, not for popular participation" (NGovt0040-Interview, 2015) . The quality of participation is compromised not just in the local councils, but also in the top structure such as SANAC. Being in the highest structure does not signify transformative power just by having open access to AIDS council spaces with limited discursive opportunities to control the decision-making. Power remains among the elite because they dominate, and that brings chances of co-optation and resource competition. The most dominant sources of power that have been observed by mapping and analysing powerful actors in in this context have been position, political influence, connection, knowledge, expertise, money and resources/infrastructure.

"Being a direct beneficiary of government funding limits movement advocacy effectiveness; as we have seen in the NAPWA, they could not bite the hand that it feeds " (TAC0085-Interview, 2015). As activists TAC and SANAC officials argue that accepting state funding negatively affects the movement's autonomy. On the other hand, the NAPWA activists were amongst those working closely with the Department of Health and had a presence in the AIDS council since

its inception. The NAPWA's funding relationship with the government made them protagonists in AIDS battles, aligned with the government's ART position. Some organisations that are state-funded are not in a good position to criticise the slow service delivery. Whether this was an intentional act of "divide and rule" by the government to pit movements against each other to divert public attention from the real policy issues is discussed later.

"The power of money and what it does [makes] you forget about what brought you to the AIDS council," (SANAC002 Interview, 2015).

Even though NAPWA activists were involved in the AIDS councils, they did not apply pressure, because they were operating within the corridors of power, and its policy discourse engulfed them. Financial autonomy safeguards movements from being absorbed by the trappings of state power. Activists turn into autocrats and slowly become aloof from grassroots policy challenges. Thus, spaces with donors and government officials limit poor people's exercise of power and agency, because participation becomes a functional exercise that does not shift the balance of power. The activities of some participating NGOs can serve to support the power (or hegemony) of the state, as seen in the past with the NAPWA example. A clearly visible trend today is the establishment of parallel organisations, as governments form or control their own CSOs, sometimes called GONGOs (government organised non-governmental organisations), in order to undermine, discredit, and divert funding away from the legitimate CSO sector. These organisations aim at promoting and protecting government interests. Resources seem to be powerful forces in formal participation spaces at national levels, which may shape the limitations in what movements can achieve in these spaces if the priority of other actors is competing for resources rather than influencing policy decision making. Movements work within limits of resources — especially economic, political and communications resources. Social groups quite naturally compete for space and resources. Hence, you find that not all actors are interested in policy development but are there for proximity to state power and resources. There is evidently a clash of values between diverse policy actors with unequal resources, and access to power inevitably complicates the AIDS councils. The exercise of analysing sources of power in this research has highlighted issues of autonomy of social groupings when participating and state accountability towards the communities. Accountability for public services is understood to be part of the health governance apparatus necessary to ensure service delivery works for people. Therefore, contestation is central to how civil society contributes to development, because of the scope it creates to recognise, voice, and demand accountability.

Formal structures such as AIDS councils at local levels, in turn, become vehicles for political patronage, resulting in mimetic participation. “SANAC is the only organised HIV/AIDS policy space for participation – it has its limitations, with civil society spending too much time talking to themselves without government attending most meetings,” (SANAC003 Interview, 2015). The national and provincial governments are not doing enough to support the development of municipalities to play a meaningful role, but they further weaken local governments by placing additional service delivery targets and demands on them (Atkinson, 2003). Notwithstanding the impact of HIV/AIDS in municipalities, financial resources and technical capacity restrict many. Most municipalities receive a small budget to hold World AIDS Day, but very few receive any funding to support local structures for participation. Engaging citizens has resource implications, both in terms of organising engagement and the potential restructuring of administrative procedures and working practices to accommodate participation. For example, in the 2014/15 financial year, the AIDS council at the national level spent R3 million on governance and civil society coordination (SANAC Trust Report, 2015), while the majority of municipalities do not have budgets for AIDS council meetings. Where there are AIDS policy participation structures in existence and with resources, there are often no clear roles or procedures for participation. So, despite these democratic dispensations, meaningful participation of poor people in policy development remains weak at the grassroots (Heller, 2012) .

“TAC must take power back to the people and be visible at local clinics,” (TAC0030 Interview, 2015).This activist’s interview alludes to the need for activists take back power to the grassroots and a visible alternative force to hold health facilities accountable. This is to counter the perceived and experienced lack of community voices in decision-making and therefore move towards deepening democracy in health governance at grassroots level. Even though the intention is to democratize local clinics, it is evident in the study that it is harder for the poor to navigate the promise of participation and the reality of tokenism. This shifts the locus of activists’ advocacy pressure from primarily national towards pressure to local health officials as the main interface between communities and government. The local clinic as a site of contestation challenges the privilege of the medical profession and health professionals as the sole power holders in decision-making in health facilities. Power and participation in health governance are inseparable. Similarly, (Foucault, 1980) also wrote that medicine can assume an important place in the health system and is part of the government machinery of power.

Hence, the recognition of power as a form of inhibitor if not a barrier to the visibility of activists' influence in the local clinics is clear from the activists interviewed. There are no relations of power without activists' resistance. In a Gramscian way, they counter hegemony at the level of policy development, and make their power more visible in challenging the status quo. Activists' public visibility brings heightened peaks in social mobilisation periods, which go together with media coverage, which enlivens grassroots activists. Without this, disengagement from movement activities is to be expected.

7.6 NEW ADMINISTRATIVE PHASE: HOGAN AND MOTSOALEDI

"The new political leadership priority was to shift the international public attention away from Mbeki's denialism," (NGovt0057 Interview, 2015). In the past activists were excluded from the AIDS council by government, but that did not stop the TAC and its allies from winning the policy change. Their exclusion fueled their popular participation outside of government-controlled policymaking – the activists compelled the stat to a more energetic response all through the external AIDS council pressure by TAC and a variety of allies. The TAC is a good example of a movement of people living with HIV that was initially delegitimised within the AIDS council but, because of its persistence and organising capacity, was ultimately recognised by the state and drawn into formal engagements with the state (Mathoho, Greenberg, and Benit-Gbaffou, 2010). Participating in the AIDS council offered a platform for dialogue while activists continued to utilise other tactics outside these formal structures, such as protest and litigation. Well-resourced organisations acting tactically can take unpopular policy positions against the government and stick to their principles while still being able to continue relating to government. "TAC's participation in AIDS councils allowed working with Minister Hogan, which has never happened under Minister Tshabalala-Msimang," (Independent0074, 2015). Another visible indication of change is the revival of political administrative policy environment that created new political opportunities for activists to engage with the state. The new national administrative leadership represented by a new Health Minister, Barbara Hogan, brought the much-needed urgency to the epidemic response but met with provincial political crisis. The shift in the ANC political leadership patterns after 2007 shows that the changes may constrain or be a resource to contentious movement actors such as the TAC (Mcadam et al., 2003a). Minister Hogan was only in the position for six months before general elections, after which she was replaced another new minister Aaron Motsoaledi to the Ministry of Health.

"When Minister Barbara Hogan was appointed in Health, it was a shock because the was an outspoken supporter of the TAC" (TAC008 Interview, 2015). The TAC activists argue that they did not expect to have a Minister is considered one of their own. This was a clear political shift toward change and conceding to activist pressure. Nevertheless, activists' ongoing vigilance is more critical regardless of political changes. "We appointed Barbara Hogan because we needed an administrative surgical overall; change the health approach and attitude. This gained even more momentum with the appointment of Minister Motsoaledi, and the Director General, which made it more possible to have a more responsive attitude in the department," (Presidency0062 Interview, 2015). Even though the Presidency politicians argue that this was a swift move towards a better responsive administration, during this period the rollout was still very slow, even in Khayelitsha, with accumulating waiting lists, delayed ART initiation at CD4 count of 50, lay counsellors not paid, countrywide condom shortages and turning people away from HIV testing (TAC, 2007a). This is the paradox of the state's professed ART policy intentions, which showed yet again the gap between the promise and implementation that had continued (Schneider et al., 2008).

(Tarrow, 1999) is instructive here. His exposition of political opportunity structure theory suggests that the state's response to the causes of action of the new movements shapes the extent to which they operate autonomously. "Now with the Minister speaking very nicely the whole cause has been recuperating in the political environment and in political terms. Where you never know what is promise and reality. It was a difficult period for TAC definitely," (MSF0028 Interview, 2015). For example, some activists were weary of the new environment: many become a double-edged sword for the movement. "I think we are in honeymoon because the previous minister Manto did not want to engage with us and now new minister is open to work with us. The boardroom does not stop us from going to the streets," (TAC0012 Interview, 2015).

> "Public can be confused why is the TAC marching while its leaders have platforms such as AIDS councils to engage," (MSF0028 Interview, 2015). Other activists from MSF were worried about the public confusion created by the insider/outsider advocacy approaches.

"We had to work beyond and against the state because there are always elements government is the health provider of public goods, the constitutional duty bearer but at the time we know

that they are captured by certain capital interest," (Independent0087 Interview, 2015). Although the activists' initial reaction to the political shifts after 2008 were uncertain, they did offer a conciliatory relationship, which was largely at national not local levels of government.

> HIV activists have lived and experienced a decade of state betrayal, and so the relations will always be vigilant of any Health Minister, (NGovt0057 Interview, 2015).

The TAC's experience in engaging with national government shaped the choices of their strategies during service delivery. The use of both conflict and negotiation or collaboration allowed the movement to move beyond their ART success to policy implementation and counter the state in order to guide their struggle gains. The use of a dual repertoire of protest and collaboration is within the realm of contentious politics. The activists utilise protests and negotiation as complementary tactics applied in different arenas, where institutional structures and power relations offer chances to advance movement goals. At the grassroots, activists optimise their chances for service delivery, whether it is for national government policy development or local health facilities to deliver services.

For activists to vent their anger, they use public demonstrations and at the same time collaborate with the state at the clinic level. The state is not a homogenous unit; it is likely that activists remain in antagonism and negotiation with national government and forge progress at local levels. Hence, the targets for activists' conflict during policy implementation shifts from primarily national government to local levels of public administration where services ought to be delivered. The TAC at the grassroots did not merely attract the attention of the Mbeki administration, which was, after all, aware of the slow pace of the ART rollout.

> Motsoaledi appointment sustained Hogan's momentum and more. He escalated the ART implementation and engaged with parliament closely to remove all barriers to service delivery, (NGovt0038-Interview, 2015).

Rather, the movement created disruptions in the norms that all was well with government implementation, forcing government to enter decisively into the contentious discourse. Activists continued to use tactics that ranged from the confrontational to collaborative engagements. The activists sustained their engagement with local public officials through bargaining and through combining lawyers' efforts and collaboration to test the state's willingness to come to mutual agreement.

> I allowed Mark to go and do a fact-finding mission in Eastern Cape but in the end I do not like what he did. He called a press conference to disclose his findings even after my attempt to negotiate, but he insisted. I thought we were partners to help your members who are not getting medication, and after this relations drifted to antagonism between me and the TAC, (NGovt007 interview, 2015).

This suggests that activists were open to reasonable diplomatic engagement with public administrators at the facility level; and where it was not possible, confrontation was an option. The use of bargaining tactics such as negotiation and litigation as collaborative forms of participation may yield minimal outcomes. Hence, the TAC maintained its aggressive tactics such as protests to expand the scope of conflict in exposing the failure of state policy, in order to exacerbate the government's frustration and to show the public that the status quo could not hold. The use of trigger events dramatises the movement demands through protests to amplify activists' local actions and to stir public outrage; these become a movement resource to enhance policy influence and decision-making. The state, as indicated in the above quote, tried to bargain with activists to keep certain failures out of media and public attention but failed.

7.7 DISTRUST OF INSTITUTIONAL SPACES

"The so-called government relationship weakens the movement because we end up nursing the relations not the community needs and organisational plans," (TAC0023 Interview, 2015).

Political and policy opportunities are fluid, short-lived and far from permanent. The threat of co-option and demobilisation for social movements is real when entering institutions (Stahler-Sholk, 2007) ; thus, both authors point out to institutional participation can dilute the mass character of a social movement, especially when its social base is made up of largely poor. Thus, some scholars who are against institutions (Castells, 1983) regard institutionalisation as negative and argue that it leads to loss of radicalism, collective identity, and solidarity. "When you are led by leaders who [are] aloof from movement struggle at the grassroots level, they fall prey to co-option, diminished relevance and weakening the movement they represent," (TAC0010 Interview, 2015). Political systems such as institutionalisation have both negative and political opportunities and the case of the TAC illustrates this paradox. As much as the AIDS policy development process (NSP) offered a new pathway to power and influence in the policymaking process, the activists remained suspicious of neutralisation and being caught up

in technical processes. “It is precarious to entangle activists in all the National Strategic Planning processes where the bureaucrats learn to speak our language,”(TAC, 2007a). Activists took a rational, careful approach to engage in a both antagonistic and collaborative to influence implementation. Activists were wary of state co-optation. In institutional designs such as the AIDS councils where power lies so heavily in the hands of public authorities, the potential for manipulation and co-optation of citizens is high. As pointed out by (Stahler-Sholk, 2007) , the threat of cooptation for social movements is real when entering institutional participation, but it is not inevitable. Indeed, the creation of new procedures such as the NSP development processes and institutional arenas can be seen as a means of co-opting movement elites and demobilising the grassroots (if activists are naive, they may not notice the deception in government spaces) (Cloward & Piven, 1977) .

“After we got reports about the Free State ARV moratorium, we tried to reach out to Minister Hogan without any success; we then wrote legal letters for the record. After the letter, we received a call from the Minister to meet us in parliament where she told us she is offended by our intervention. We could not sit back saying we now cannot do anything, our hands were tied because our friend is the Minister,” (Section27 0055 Interview, 2015) . Henceforward, the TAC’s intent to take over the SANAC agenda was clear in its national meeting minutes, that activists must note the state’s apparent language and tone used in the NSP development and the need for activists to set their own independent tone for the NSP target with no compromises. This shows that formal structures such as SANAC have their usefulness for activists to counter the policy narratives and achieve movement goals, but that activists are also aware of the limitations of what these spaces cannot offer. Thus, social movements such as the TAC do not just enter into institutionalised spaces intuitively; they strategize and plan their participation. The relationship between state practices and the praxis of the NSMs is dialectical and fluid; thus, the struggles of the new movements take place across institutional and non-institutional spaces regardless of the political opportunity within the structure in which they operate (Steyn, 2012).

The TAC activists framed co-optation differently, but acknowledged that the “public may get confused and may not see the importance of TAC marching while its leaders have platforms such as AIDS councils to engage,” (TAC0017 Interview, 2015). Cooptation in this study refers to the movement loss of its autonomy from government, because it is not absolute.

Independence from government is critical for a movement to pursue its goals with legitimacy and ability to oppose government when necessary. Of course, over time, the "TAC struggled with transition under an open government administration – our public visibility was reduced as well as funding prospects," (SANAC003 Interview, 2015). As the TAC shifted strategy to cooperation, the public perceived that it was going through a decline, and so did some of its members. On the other hand, "you get funding from the funders who will dictate how its funds must being used, you can only do certain things with their money," (TAC0010 Interview, 2015). The TAC and Section27 articulates the careful and rational thoughts in movement decisions with full understanding of the state's possible co-optive elements. Thus, social movement participation in AIDS policy processes was a strategic use of institutionalisation linked to their advocacy agenda rather than just participation as the main target. Early literature on social movement tends to equate institutionalisation to automatic co-optation (Cloward & Piven, 1977). AIDS activists such as Mark Heywood representing civil society participation in the NSP writing process, along with government officials, a UNAIDS official, and researchers, did not result in cooption but the contrary. Therefore, conventional institutional participation can be a complementary approach. Reforming policy should be the goal, rather than getting institutions right. This is the reason social movements and NGOs must always be wary of tactics that seek to co-opt and discourage social movement confrontational tactics towards unproductive normalisation. When government fails to co-opt social movements and NGOs, it usually labels them irrelevant distractions. Institutionalisation and independence seem antithetical, not complementary. The AIDS movement used the official terrains of formal policy engagement to achieve its goals. Hence, autonomy can only be partially achieved, and since the new movements are heterogeneous, the extent to which they operate autonomously from the state will differ from time to time.

7.3 HOW DID ACTIVISTS APPRECIATE THIS TRANSFORMATION?

For TAC activists' institutional spaces are sites of struggle for the balance of power and for activists to gain influence in policy and control of decision-making processes. The practice of participation in Khayelitsha and Lusikisiki is about deepening active citizenry and health governance as part of the democratic project. Contemporary development thinking tends to assume that open, participatory spaces for various actors will protect basic civil and political rights and contribute to inclusive development processes that are equitable across all groups in society in ways that meet social justice imperatives and are sustainable over time and the

available resources. Social movements are particularly important in facilitating a process in which nobody left behind from participation in policy developments that concern their lives. There are two ways activists appreciated their advocacy approach to transformation. Through working within and outside the state in section 7.3.1, I demonstrate how activists democratise healthcare, thereby empowering patients and communities. Section 7.3.2 reveals how activists challenged the micropolitics of clinics. Section 7.3.3 shows activists building a social contract. In addition, section 7.4 reveals that activist's advocacy alliances build social power during implementation, as well as revealing examples of activist advocacy tactics outside the state to build a culture of transparency and accountability through monitoring ART supply chain, service delivery and provincial budget allocations.

7.3.1 ACTIVISTS DEMOCRATIZING HEALTHCARE IN SOUTH AFRICA?

"People were interested in treatment literacy because it's about popular education and science to achieve access to healthcare," (TAC008 Interview, 2015).

When communities are well-informed on health issues, their active participation in a transparent system can serve to hold service providers and government officials accountable for their actions (Laverack & Labonte, 2000) . Participation in health governance is a right enshrined in the South African constitution, the (Act, 2004; Republic of South Africa, 2000). Participation in development is as central to achieving the human rights of poor people in accessing health services. If we take this South African rights approach to participation, one can assume that participation is not just by invitation but forms an integral part of human rights and the democratisation of public healthcare. The confluence of development and a democratisation agenda brought poor people to a place central to governance. In South Africa, the term, "health governance structures" is used to refer to clinic committees, community health forums, hospital boards and district health councils. Popular participation should take place in a number of enclaves, free from institutional power – including that of social movements themselves.

7.8 MICROPOLITICS OF CLINIC COMMITTEES

"Clinic committee are gatekeepers; [they do] not really engage with the problems people are facing," (NGovt0057 Interview, 2015).

The clinic committees are the primary point of call to engage the health system, because of their proximity to communities. Institutional participation is an important feature of South Africa's public health system, which essentially should occur at the facility level. In other words, from the perspective of activists, the spaces for participation are beyond just the AIDS council but include health governance avenues. The structures, such as clinic committees, hospital boards and district health councils are envisioned as platforms for popular voice expression at a local and district level. Clinic committees are examples of invited spaces, because who gets to participate has to be vetted by the health administrators, and they infuse their power in such spaces. In most clinic committees, the responsibility for convening the clinic meetings currently rests with the clinic professional nurse in charge of the clinic (Padarath & Friedman, 2008) . Facility managers and ward councillors tend to take ownership of the clinic committee and consequently limit the mandate of the committee. (Tshoose, 2015) adds that local government officials often act as gatekeepers and controllers rather than allies with communities to have greater voice and control over service delivery priorities and resource allocation.

Clinic committees, hospital boards and district health councils should act as a link between communities and health services and should provide a conduit for the health needs and represent aspirations of the community at various local, district, provincial and national levels. These bureaucrats are responsible for many of the local-level policy implementation applications such as who gets invitations to participate, program eligibility, allocation of service delivery packages, and imposing rules. As (May & Winter, 2007) argues, public health officials and health care workers act as street-level bureaucrats with power to apply discretion and influence over policy implementation. Hence, very often the health administrators tend to choose their loyalists to be the chairpersons who act as gatekeepers to dominate and suppress those who contest their power. (Qwabe & Mdaka, 2011) suggest that local government officials are often unwilling to share decision-making powers with communities and ignore input from councilors. Depoliticisation in this thesis generally refers to a set of tactics, tools and processes that place the political character of decision making at one remove and reduce the capacity for collective agency. There are clearly existing clinic committees in the two provinces that the study focused on. For example, in the Eastern Cape in 2003, there were 57 clinic committees, with a noticeable increase to 73 by 2008. Western Cape Province seems to be have fewer: 28 in 2003 and 48 by 2008 (Padarath & Friedman, 2008). Both show a quantifiable upsurge of clinic committees, which may be due to the expressed political commitment to health governance in the National

Health Act. The act delegates the function of committees to provincial mandate to articulate the terms of references for these committees. In this context, the TAC often takes the role of building the understanding of community representatives regarding their roles, about the responsibilities of clinics and about patients' rights. The functionality is a different matter than counting the number of committees. For example, in Lusikisiki, activists argue, "there are no guidelines on how the clinic committees should function," (TAC0017-Interview, 2015)(TAC0017 interview, 2015). Clinic committees, in many health facilities where they exist, have no resources and rarely fulfill their intended roles and are therefore not active.

Even though the NHA also recognises the importance of these clinic committees, it does not elaborate on the functions and power of these committees, ascribing this to provincial legislation. The National Health Act (Act, 2004) states that each clinic or community health centre or a group thereof must have a health committee and at least include a government councillor, a community member from the facility's target area and the head of that facility (Act, 2004). Contrary to the aspirations of the AIDS councils model, which makes provision for formally constituted, multisectoral representation in the delivery of healthcare, this was not the reality of many poor people. While the participation of poor people in the health system is necessary and an important feature of the public health system at various levels, it has been yet another failed attempt to connect people and the state. For clinic committees to work effectively there has to be a shared understanding between clinic staff, community representatives and political leadership as to their roles in promoting primary health care. Neither financial resources nor process guidelines are provided by government to facilitate effective participation of community members (Padarath & Friedman, 2008). The facility managers often do not have clearly defined roles and clarity on the importance of health committees (Haricharan, 2013). Even though it seems the role of committees is stipulated in the Draft Paper on Health Governance Structures, the clinic committees generally lack clarity of roles.

The draft paper specified that a clinic committee be meant to provide advice and play an advocacy role for the communities they represent. This role does not include decision-making powers, oversight, transparency, and accountability, which seem to be fundamental in making sure that community members are not just there for menial roles. When activists have no decision-making power and no oversight in making sure that the clinic is transparent and accountable, then this is not transformative participation, because there is no deepening of democracy without internal clinic committee democracy. The public officials in the clinic are

given free power to make unilateral decisions. The role of members is limited to efficiency of the clinic under the tokenistic mask of being advisers; manipulating them into thinking they are included in the power sharing, while in reality they are domesticated in a false partnership that occurs within the power and authority of clinic manager. Thus, activists' role is sometimes reduced to rubber-stamping, pragmatic functions such as managing complaints, and campaigning for their respective clinics.

The 2003 Facilities Survey found that while 59% of clinics reported having clinic committees, only 35% were functional and had met recently (Padarath & Friedman, 2008).This situation by 2019 had not improved, according to (Spotlight, 2019) only four provinces, namely Eastern Cape, KwaZulu-Natal, Western Cape and Free State, were able to pass the provincial legislative regulation on clinic committees. Clinic committees remain weak as a policy opportunity for activists to build alternative power for people to force change. Dysfunctional participatory institutions lead communities to adopt other modes of expression such as protests to have their policy demands heard. Instead, "People living with HIV used to be highly involved in clinic committee meetings around issues of clinic services and ART services, but over time our participation has dropped," (TAC0079 Interview, 2015). As a result, committee members can find themselves assisting in administrative tokenistic roles such as managing clinic queues, cleaning, or helping to volunteer in managing complaints, as opposed to meaningful engagement. Thus, strategic advocacy also depends on activists' agency inside and outside the state structures to lever pressure for change (Ruiz, 2004). Hence, the TAC targeted clinics and entered as allies in brokering with the health system with frontline health providers on the quality of care—and new types of relationships with health care providers and policy-makers (Robins , 2005) emerged. "Being in the clinic doing treatment literacy does not mean making friends with nurses who abuse patients; we as activists need to maintain our distance without being rude," (TAC0022 Interview, 2015).

Of course, the power relations between them were uneven, but activists used knowledge as their tool to engage with evidence against the health system. "TAC activists who work at clinics are taken as spies from TAC, so whatever happens they are always careful when a person from TAC is there, we are not all like that as educators people who can stand their grounds," (TAC0022 Interview, 2015). Regardless, local activism provided opportunities for new forms of collaboration between patients and health professionals to act in solidarity rather than in

opposition only. The local branches in poor townships and villages became platforms for rights education, local activism, and advocacy focusing on monitoring access to health and HIV/AIDS services and inducing government accountability at all levels. The TAC advocacy model is based on active citizenry, where the unequal relations between users and providers of ART services are reformed (Mfecane, 2011). Thus, the focus is on building new kinds of social contracts between activists and their health providers through treatment literacy

7.9 CREATING A SOCIAL CONTRACT

> I joined the TAC in 2002, at [that] time I did not know much about HIV, but I joined a local branch where people knew so much about HIV and health issues, and that information did not only help me, but TAC helped my community, (TAC0039 Interview, 2015).

This was an emancipatory and liberatory pedagogy aimed at rejecting the fear of freedom through discourse and contention as tools of learning and acting on one's own condition.

The treatment literacy programme empowers patients and communities with the science of health and HIV, rights and governance for effective participation. For the TAC activists in Khayelitsha, it was important to master the technical procedures related to ART implementation as a mobilising and empowering tool for the grassroots populace to counter the unjust pace of implementation. Even though the TAC activists operated with an insider/outsider advocacy strategy, they managed to maintain their autonomy to a certain extent and remained accountable to the people below. Only then can meaningful participation of the poor have equal power to determine policy decision outcomes, as alluded to by (Arnstein, 1969) as citizen control. Opportunities for popular participation in the processes of policy in South Africa have expanded through the introduction of AIDS councils, yet in some ways they have also contracted, since they are under-funded and there is no real commitment on the ground for their legitimate functionality so that they are fit for their intended purpose.

"The TAC has influenced the new patient-centred approach to HIV services - by improving the patient relationship [with their] doctor," (MSF0059-Interview, 2015).Raising grassroots consciousness had direct benefits for TAC members living with HIV/AIDS. It also had distributive effects on activists' advocacy in the health system and policy, such as by shifting relations and the creation of a new social contract between providers and patients, and systemic effects in terms of ART service demand creation for collective gain for the wider society of

people who need access to lifesaving treatment. The use of treatment literacy became a strategy that activists used to give rise to popular mass knowledge about the science of HIV and governance. Activists' presence in the clinics to collaborate and monitor health service delivery transformed the relations of power in the health facilities. This advocacy tactic shifted the patient relations with the state, because of the increased knowledge and power of patients as they countered the health system elite and health administrators' authority.

Thus, activists build power to exercise their free will in policymaking and use treatment literacy as an advocacy and activist consciousness-building tool. This shaped four types of grassroots outcomes of using treatment literacy for collaboration during the ART rollout. Informed and mobilised citizenry have the capacity to participate and influence policy decisions. The AIDS activists began to claim their voice and space by rejecting the passive, powerless patient narrative. The GIPA principle relies on knowledgeable activists, use of unconventional advocacy tactics and collective action to make it meaningful. The visibility of activists at the grassroots contesting the ART rollout delegitimised the notion that patients are powerless. This is another way TAC has contributed to the expansion of popular participation and democratisation of the health system.

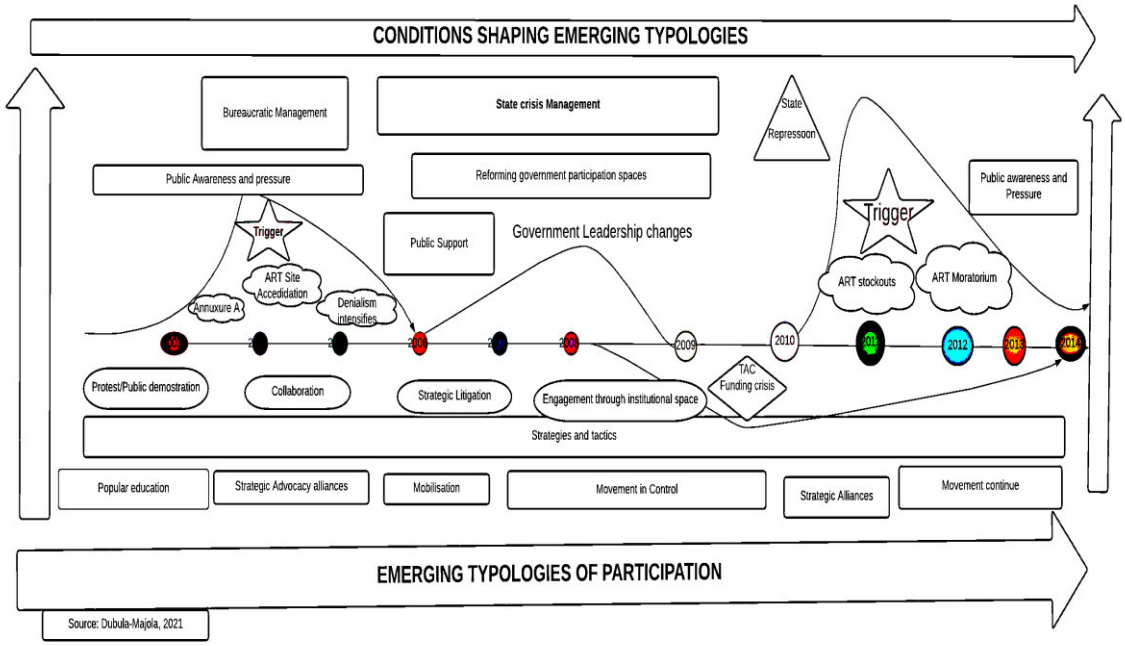
CHAPTER EIGHT: POPULAR PARTICIPATION

> We had meetings with membership to debate embarking on and risks associated with nonviolent civil disobedience, we accepted the consequences and we then occupied police stations around the country, (TAC008 Interview, 2015).

Organisations such as the TAC contribute to the creation of alternative policy spaces for grassroots participation, separate both from governing institutions and from organizations devoted to production or reproduction, in which consequential deliberation over public affairs takes place – as well as sometimes contributing to transfers of power over states. Public space and transfers of power then supposedly promote democracy, at least under some conditions. The TAC, with its strategic policy alliances, invented more participation spaces, resources for court cases, popular education, and resources for protests and strategy advice about choices in the political struggle. Perhaps more importantly, it has thrived in providing support for networks of health care workers, community-based working class organisations, and communities in Khayelitsha and Lusikisiki. The TAC contributed to the expansion of the popular democratisation of the health system. What do these typologies mean for the survival of social movements and policymaking going forward in terms of democratising healthcare in South Africa? To demonstrate how activists understood their transformation. There are four ways activists appreciated their advocacy approach transformation through engaging outside the corridors of state power. In section 7.4.1, I demonstrate how activists reveal that activist's advocacy alliances build social power during implementation. Section 7.4.2 illustrates activist advocacy tactics to build a culture of transparency and accountability through examples of monitoring ART supply chain, service delivery and provincial budget allocations.

Figure 24 below shows in a graphic display of the emerging typologies popular participation and the conditions of these forms of engagement as they emerged. I provided variants of participation and movement advocacy plans in Khayelitsha and Lusikisiki for furtherance of movement represented by the TAC. This section aims to share the advocacy coalition based on the premise that in understanding the process of policy, who shapes and influences ART policy implementation after 2003. As well as, interaction between policy actors from different organisations in terms whom shapes, influence or follow other in the policy decisions (Jenkins-Smith et al,.1994) in ART policy implementation area.

FIGURE 24 EMERGING POPULAR TYPOLOGIES OF PARTICIPATION



8.1 STRATEGIC ADVOCACY COALITIONS

Different organisations can come together as a coalition with think-alike organisations (Weible & Ingold, 2018) and are a source of social power hence activists' insights in how they utilised them during the ART policy implementation.

> I like the way TAC brought in experts, it would be doctors working in the field, it would be doctors administering treatment, it would be scientists that would be working with academics,"(TAC009 Interview, 2015).

The TAC activists had capacity to build grassroots networks to build bridges of service delivery solidarity in order to increase their chances of achieving their advocacy goals. The movement has entrenched policy networks in the AIDS sector, which intensify the influence of collective action and sustain contention against powerful opponents such as government or pharmaceutical companies. Strategic alliances constitute a form of social power and a resource when groups are marginalised; in addition, these alliances are often embodied in coalitions that are an important aspect associated with greater levels of success (WGamson, 1990; Van Dyke, 2003).The strategic mobilising consensus of the TAC through building service delivery alliances became critical in coordinating monitoring activities after the ART rollout. The TAC,

with its strategic alliances, invented more participation spaces, resources for court cases, popular education, resources for protests, and strategy advice about the options for political struggle. Policy actors become part of coalitions in different ways as movement supporters, activists or experts, not through membership, but rather informal associations and shared beliefs. “I think that MSF gained much more from TAC than the other way around. In addition, I think simply the offices and things is just practicalities like MSF has more resources and TAC Khayelitsha and Lusikisiki struggled for money. Nevertheless, I think MSF could have never had the success story of Khayelitsha without TAC. TAC was fundamental in that,” (MSF0046 interview, 2015) . Alliances require time availability, skills, resources and believing in the cause. As Van Dyke and McCammon (2010) also argue, coalition is the coming together of individuals or groups who share ideological outlooks and experiences of struggle around common social conditions . Coalitions are not just apolitical harmonious spaces but they too have their own internal precarious tensions.

> My dream was to have a TAC branch next to each clinic across the country. To have legitimacy because those nurses they will not just let a troublemaker enter into the clinic. To have legitimacy they needed to trade access to information with service provision. Only if they [activists] were really familiar with the clinic the clinic would let them in and give them access and management board of the clinic,(MSF0028 Interview, 2015).

For example, some of the MSF activists argue that some of the Tac activists used to joke that “Where there is MSF it is where TAC is; where there is TAC, the MSF is not,” (MSF0028 Interview, 2015). For the TAC activists, for whom the implementation of ART policy is about life and death, their personal is political and they want to be the main actors who shape and influence strategies and decision-making in the coalition. The TAC activists had the capacity to build bridges, join forces, and/or build solidarity relationships to increase their chances of achieving their movement goals (Weible & Ingold, 2018). The critical role of alliances in the praxis of participation is apparent in the power of the connections the local TAC activists had at national and international levels. These alliances came together because of shared policy values and local and personal proximity to the TAC. They utilised the popular modes of advocacy to force concessions from government from below to invent alternative participation spaces, resources for court cases, popular education, resources for protests, and strategy. Perhaps more importantly, these alliances have thrived in providing support for networks of health care workers, community-based working class organisations, and communities in

Khayelitsha and Lusikisiki. The role of powerful alliances within the state and outside the state remains one of the TAC's grassroots strengths.

The TAC contributed to the expansion of popular democratisation of the health system. This advocacy tactic transformed patient relations with the state, because of the increased knowledge and power of patients as they countered the health system elite and health administrators' authority. Bottom-up participation tactics shifted the state practices in provinces and the perceived national character of the ART rollout, especially in relation to site accreditation contestation. Changes in the TAC's advocacy tactics reshaped the perceived passive role of grassroots activists in implementation by transforming practices between health providers and patients, as well reviving the AIDS councils and clinic committees through popular agency. The activists' advocacy created distributions of generated social power within poor communities to access popular participation in service delivery. The movement's investment in building grassroots activists as claimants in the ART rollout relied heavily on invented (non-institutionalised) forms of participation with the state and opponents (Tarrow, 1999). Below are examples of movement-invented popular spaces through strategic advocacy coalitions to shape and influence government ART implementation and hold the state accountable.

8.2 LOCAL HEALTH ACCOUNTABILITY AND TRANSPARENCY

> One of our branch members was given D4T (ARV medicine) because it was on stock the correct medication was out of stock. The clinic refused to give the patient the correct medication and w staged sit-in... there was no advance plan for the protest and by the time the TAC [Lusikisiki] office heard about it we were already in the sit-in and no one wanted to leave. Some of the branch members were there, like Nzali, Thandeka, Sizwe, Nozibele and other new members of the branch, (TAC0073 Interview, 2015).

The traditional ways of upholding accountability such as elections, public meetings, or the media are not always sufficient in giving people a sense of ongoing influence and control in health governance (John Gaventa & Valderrama, 1999) . One of the activists interviewed argue that a move away from radical advocacy strategies to paper-based and boardroom activism means less confrontational [action], which is predominantly what TAC is known for,"(TAC0010 Interview, 2015) . Thus, social movements such as the TAC do not just enter into institutionalised spaces intuitively; they strategize and plan their participation. The grassroots activists continue to monitor policy implementation in order to guard their movement

action gains. Activists' advocacy promotes accountability by holding policy-makers and implementers accountable during implementation (Bhuyan, Jorgensen, Sharma, et al., 2010).

At the local level, however, the TAC activists engaged with more confrontation, collaboration and demonstrative service delivery to drive implementation. After 2009, though, there were political and policy shifts in ART policy implementation favourable to the TAC demands. As demonstrated in Chapters Five and Six, direct protests against government ART site accreditations and court rulings (Annex A case and Rath case) did not quickly lead to direct change in general policy implementation at the time. They are widely considered to be one of the reasons for universal access to ART in South Africa (Osewe & Pillay, 2016).

The confrontation tactics such as protests and litigation were positively correlated with successes in three measures of success (treatment timetable, pushing back on accreditation, successfully winning the court case against Rath) and gained the TAC and its allies status as legitimate claimants about ART policy implementation, while reframing the discourse to obtain new gains for the movement's goals. Implementation meant that at the grassroots level the TAC decided it should extend its alliances and introduce other allies to participate in various guidelines, supply chains, stock-outs monitoring and representation at various SANAC structures to increase its influence. Social movement groups, such as the TAC, MSF, and/or Section27, are more likely to face similar political threats and share resources(McCarthy & Zald, 1977; Nella Van Dyke, 2003) . Perhaps more importantly, the alliances have thrived in providing support for networks of health care workers, community-based working class organisations, and communities in Khayelitsha and Lusikisiki. However, even in the case of coalitions within movements, where causes and goals are ostensibly shared, this assumption has been found complicated (Obach, 2004; S Staggenborg, 1986). The change of guard during the 2008 election (more precisely, Mbeki's resignation) provided the catalytic shift in overcoming political resistance to ART.

8.3 CIVIL SOCIETY MONITORING FORUM

"We are seen as spies in government clinics – some nurses and doctors behave better when they see us…" (TAC0022 Interview, 2015).

As argued before, the true policy victory is realised during its implementation—not in public statements, but in operational plans and budgets. On the other hand, the activists reframed the state ART policy announcement as its victory and immediately found areas to problematize in the policy implementation to avoid the diminishing and demobilisation effects that come with so-called "victory" that can eventually shift the public spotlight, especially in the media, away from the movement agenda. The official government policy announcement turned out to be a fictitious commitment, given that they later dragged their feet to implement their own policy. TAC set out to monitor the ART rollout, making sure that the majority of poor people could access ART services in the public health system that refused them access before 2003. The monitoring role frames the outsider, independent role of the TAC movement action plan to sustain its watchdog role in ensuring that the policy they pushed for meets their expectations.

The TAC had the infrastructure to receive the call from the movement leadership because of the presence of its active branch membership across six of the nine South African provinces. The contention over ART implementation at the local level facilitated new kinds of bottom-up alternative participation pathways and consequently began to shift the balance of power at local levels. The necessity for activists to monitor the ART rollout led to the creation of new popular participation spaces and coalitions.

The JCSMF became an independent creation of activists as an organic, fluid alliance association of civil society organisations, research institutes, health workers, private sector and government officials who have a direct interest in the implementation of the ART plan. The founders included the TAC, ALP, Health Systems Trust (HST), Centre for Health Policy (CHP), AIDS Budget Unit at the Institute for Democracy in South Africa (IDASA), Open Democracy Advice Centre (ODAC), UCT School of Public Health and Family Medicine, Public Service Accountability Monitor (PSAM) and MSF. This was nothing short of a ferment in terms of collective ideas from activists who represented patients, health providers, health system researchers and other key NGOs and institutions of higher learning who came together for a holistic understanding of monitoring the ART rollout. The coalition linked urban and rural experts and activists, and they applied power to the state in relation to its pace of the ART rollout and the ART site accreditation process, which were supposedly the key elements of ART policy implementation. The continued pressure and oversight over the state ART policy implementation was critical, hence the formation of the JCSMF in 2004 ((Moyle, 2015;TAC, 2005). The government guidelines and indicators to monitor progress made in relation to the

ARV rollout plan are meant to be public, but this was not always the case. For activists, monitoring involves access to information and assessing budgets, targets and the human capacity to roll out ART. Some of the provincial departments did not provide this information for public consumption. Provinces needed to report how they spent their ARV allocations to be able to identify unmet needs or surpluses to be utilised for other HIV and AIDS interventions. Access to information is key to participation principles, otherwise accountability becomes a futile exercise without transparency. State openness determines the extent to which citizens participate in public processes and service delivery. The JCSMF carried out its independent ART policy monitoring and assessment of the implementation based on patient targets as per the treatment timetables. The power and resource-sharing capacities of a mutual-support coalition were evident. The forum included provincial officials participating, but there was no national official actively engaging, even though they were invited. The JCSMF is an example of an independently created space by activists and spaces emerge out of common concerns of poor people as a result of popular mobilisation which Cornwall (2004) coined as democratic spaces.

"TAC became involved not only in Khayelitsha, in many of the other ART sites where we rolled ART out to, and became the grassroots-led implementation and people were involved in all other sites across the province too," (WCGovt001-Interview, 2015).

Social movements need to follow up on their policy gains to monitor and ensure that service delivery reflects the policy outcome they seek. As the Western Cape Government official argues that the activists began to spread across the province to measure victory through monitoring implementation. I remember vividly driving my second hand Volkswagen Chico golf car to the outskirts of Western Cape delivering guidelines, holding training workshops with health care workers getting them ready for the rollout and support groups because the victor that delivers no medicine to save lives is no victory at all. AIDS activists needed to mobilise ongoing advocacy for ART policy implementation, which required the movement to adapt, exploit, and generate renewed grassroots opportunities as well as pathways for new political action and activism. Activists coordinated their policy implementation action across multiple levels of government and policy issues (Meier & O'Toole, 2002) because accountability is centrally a challenge at local levels. As part of the JCSMF document review done for this research, I came across some work done by activists to influence budget allocation and hold local government

to be transparent on their HIV spending ART medication tender processes. Although none of the interview activists mentions this during the interviews, it is important work worth noting. So, in section 7.4. 3.1 I show how the activists advocated and challenged HIV budgeting. In section 7.4. 3.2 I show activists' involvement in shaping the direction of the ART medication tender through negotiating with the state.

8.4 BUDGET EXPENDITURE FORUM

At provincial level, growth in overall budgets for health service delivery in the provinces in 2003/04 was evidence with projected increasing trajectory from R33.1 billion in 2002/03 to R36.9 billion in 2003/04 (Hikey & Guthrie, 2003). Over time, it became apparent that part of the implementation challenge was budget and expenditures of provincial governments. Then, the civil society budget expenditure-monitoring forum established to inform the JSCMF of emerging implementation challenges from a budget angle. For example, local government officials had no political will to address HIV/AIDS at local level, some calling it a soft issue — no transparency about AIDS budgets, and with no one [being held] to account.

The current coalition needed to create a node with specialists in budget monitoring and health system specialists. The (Budget And Exenditure Monitoring Forum, 2009) reported that due to lack of ART rollout monitoring and evidence for the budget allocated to provinces, they observed manifestations of critical cracks in the ART programme, such as austerity measures applied by provinces in the form of moratoriums, waiting lists and essential drug stock-outs. The austerity measures have become a permanent feature of the state ART implementation and it is not tolerable. The public administrators working in these institutions mediate particular social movement demands through both formal and informal channels and frequently ally themselves with movement representatives in order to increase the amount of public resources available in the policy areas over which they have authority. They tend to have frequent contacts with representatives of the social movements involved in their areas. A number of local activists contend that there is limited political commitment to respond to HIV/AIDS because it is not considered an important challenge by local government. Most communities do not have easy access to budget and expenditure reports for their local government on an ongoing basis. This is in addition to the fact that without knowledge about the budget, it is not possible to monitor government spending. Budgets are a good indicator to track policy commitments through resource allocations to service delivery.

Given the unfavourable economic policies concerning increased public spending, one would assume that this would have an impact on the ART implementation on the ground. Moratoriums, long waiting lists and stock-outs have become an unacceptable norm of the government ART programme. There is poor monitoring, and the budgets are not evidence-based (Ndlovu and Daswa, 2008). Even so, activists create public awareness and opposition to the budget challenges as they affect implementation. This level of public awareness of the policy problems did not lead to movement take-off but helped the movement to frame the challenges for the public through the media. The letter below describes several concerns about the impact of provincial budgeting practices on the rights of people to have access to health care services. Several government austerity measures resulted in budget-related decisions that are in clear violation of the Constitution, the National Health Act (NHA) and the Public Finance Management Act (PFMA). One of the impacts of these decisions was the moratorium on the initiation of new patients onto antiretroviral (ARV) treatment, and some provinces were more affected than others were. For example, activists exposed the Free State provincial government for their decision to halt ART initiation to dying patients in November 2008 through to March 2009. The Southern African Clinicians Society estimates that we lost at least 30 lives per day due to the moratorium, not taking into account other essential health services cutbacks.

(Extract from BEMF letter to Minister of Health and Minister of Finance in 2009)

> "We therefore are distressed that at the Free State Health Summit that was held from 16-17 July, representatives of the Free State Department of Health announced that, due to financial constraints, it is expected that a new moratorium on initiating patients onto ARV treatment would be implemented in September 2009, unless additional funds were made available from National Treasury. We have received several reports, which, anecdotally, reveal that the health system is under considerable strain because of insufficient financial resources and administrative competency. We also note that, while we understand that the flawed implementation of the occupation specific dispensation for nurses (OSD) has significantly contributed to over-expenditures in provincial health department budgets, these over-expenditures should not significantly impact programmes funded primarily through conditional grant allocations, such as HIV treatment and prevention programmes," (Budget And Exenditure Monitoring Forum, 2009).

Despite increasing HIV/AIDS budgets, the spending of such allocated funds has been slow (Ndlovu & Daswa, 2008). In some provinces, in fact, the allocated funds have not been fully spent South African financial year runs from April to March. Thus, the year 2004/05 refers to the financial year that goes from April 2004 until March 2005(Goals et al., 2011). University of Cape Town's increasing challenge for HIV/AIDS policies in South Africa seems to lie in utilising these newly available funds for the effective implementation of programs. South African provinces, which are responsible for implementing health programs, have experienced increasing spending pressures, which are likely to continue in the near future. There is a danger, however, that pressures to spend public HIV/AIDS funds quickly may compromise their efficient utilisation and the achievement of optimal outcomes. The OSD crisis emphasises the need for the public release of the Integrated Support Team (IST) reports on the financial and administrative management capacity of the DoH and provincial health departments. Commissioned by Barbara Hogan during her tenure as Minister of Health in 2008/9, the IST reports have yet to be made public(Barron et al., 2009). A leaked copy of the Free State report reveals startling findings about the lack of cohesion between policy and budgets, poor monitoring and evaluation, challenges to the sustainability of the ARV treatment programme, and a host of other financial management problems. The TAC's campaign for resources for health to meet NSP targets and monitoring of health budgets is a good start, but why has the TAC not taken the lead in mobilising for quality public health services?

8.4.1 ART TENDER

Another way activist' monitored government commitment to expand ART is by monitoring the ARV tender closely. In 2010, the ARV tender was expiring, and activists advocated for drugs to be included in the tender and provided evidence for prices. This would enable the state to purchase ARV medicines at globally competitive prices. The ARV tender processes became another obstacle for the program, because they took too long to finalise and were not flexible enough to procure the best drug solutions. The WCDoH established a parallel ARV pharmaceutical service, independent from the one used for all other drugs, which was considered effective in the short term, as it enabled tight management and fast delivery of ARVs (Budget And Exenditure Monitoring Forum, 2009). The forum sent a letter of demand to the Minister of Health regarding the issuing of compulsory licenses for the manufacture of Efavirenz. Therefore, activists' constant engagement ensured that the government have

flexibility to allow companies to submit tender bids concerning medicines that have yet to be registered for use in South Africa but for which applications for registration have already been made to the Medicines Control Council (MCC). On the other hand, activists continue to engage with drug companies to reduce price through the Fixthepatentlaws campaign. This campaign was not fully explored in this chapter but I will add more discussion in a possible book, which will follow this dissertation.

In 2012, the TAC found out that the ARV tender did not include the latest fixed-dose combination (FDC) that would enable a reduced pill burden to patients and arranged a meeting with Dr Anban Pillay, Head of Pricing, Procurement Unit, at the National Department of Health. Mr Pillay informed TAC that FDCs would be included in the 2013-2014 tender. One of the TAC's concerns, however, was a clause in the tender that specified that FCDs would only be procured if they were cheaper than the sum of the single components. At the time, FDCs in South Africa were still more expensive than the single components on the tender. After further discussions between the TAC General Secretary and Anban Pillay, the TAC got confirmation from Mr Pillay that the FDCs would be procured, despite the specific clause. Finally, on 29 November, the results of the tender were announced and the TAC sent out a press statement welcoming the announcement that government will procure FDCs for use in the public sector. The NDOH further announced that the rollout of FDCs would start in April 2013 according to a phased plan and full coverage would be reached by November 2013. The TAC has since embarked on a national education drive to inform people who are on HIV treatment about the changes in their medication. Brochures were developed in English, isiZulu, xiTsonga, seSotho and isiXhosa and are being distributed to clinics, adherence groups, community centres and TAC branches. The HIV Clinicians Society has agreed to print extra copies and distribute them with their quarterly journal and nursing magazine to about 2,000 doctors nationwide. The NDOH approached TAC in early 2013 to collaborate on a national education drive. Once the roll-out of the FDCs were announced, however, the relevant department remained silent and appeared to be no longer interested in a joint education drive. The TAC had sent a high-resolution copy of the FDC brochure to Helecine Zeeman and Anban Pillay. The brochures were produced under a Creative Commons license and can therefore be freely reproduced and distributed by the NDOH or any other interested party. While TAC members were distributing the brochures and educating patients on the upcoming change in their medication, TAC members were also monitoring clinics and pharmacies for stock-outs.

8.4.2 STOP STOCK-OUTS CAMPAIGN

> The issue of drug stock out, it is not like we are denying it but things did not add up, is it us [national] or is it the provinces? I called pharmaceutical companies. We spent 6 hours with them and it was clear that many of them are giving problems, (NGovt007 interview, 2015) .

The ART implementation process is complex, and the unpredictable health facility level requires activist bargaining advocacy tactics and negotiation tactics at different levels rather than as a seamless sequence of movement advocacy action. This has led to activists' recognition of the importance of engaging with the state using different approaches, because the state is not one monolithic machine with which one can use a one-size-fits-all approach. For activists, the approach to health care workers was one of offering help to win them over and build alliances with them. Monitoring the state implementation became the focus of building and mobilising grassroots members to participate in collective action. For example, when there were drug supply challenges, the TAC activists developed a drug-monitoring tool and reported out-of-stock drugs to people at management level (see figure 26 below). I argue that it is not strange for social movements to evolve and this involves its framing about the unjust conditions. The TAC articulated mechanisms by which members could focus their collectives using the local health clinics as sites of organising, contestation, and the reconstruction of patient-provider relations. They worked to create channels of access to policymakers and form alliances. This organizational continuity means that the experiences of early-riser movements are both resources and constraints for those that follow (McAdam et al., 1996).

> "The TAC and Section27 investigation in the Eastern Cape expose flaws in the provincial drug procurement system, whereby medical depots staff keep inadequate stock levels in order to create a crisis in the supply chain system. The was a clause in the tender prescription that in times of crisis such as drug stock shortages the provincial government can bypass tender procedures," (NGovt007 interview, 2015).

At the start of 2012, antiretroviral stock-outs of one of the first-line adult therapy drugs, tenofovir (TDF), became a major problem. Stock-outs were driven by poor coordination between the role-players and meant that large numbers of patients had the drug substituted with more toxic but more widely available drugs (F Venter, 2012) . Antiretroviral stock-outs

emerged as a major threat to the programme at this time. The sheer scale of manufacture and tight margins, reliance on international sources for active pharmaceutical ingredients, and intense competition between drug companies meant that manufacturing processes were susceptible to disruption if anything went wrong. Poor provincial ART forecasting added further stress to manufacturing capacity and timelines. The right to health cannot be realised without functioning public health care facilities and properly implemented programmes. It cannot be realised without available, trained medical personnel providing and dispensing essential medical services and medicines. When essential medicine supply is inadequately provided, the adverse effects on communities and particularly vulnerable groups are clear.

> TAC brought a woman who cried in public as if I'm now killing people, about how she took her child to clinic she could not find vaccine, you know when things show on TV they show a completely discouraging image because I'm feeling that the TAC is seeking to show me as an incompetent Minister, (NGovt007 interview, 2015).

The stock-outs were the result of some provincial and national planning challenges. The provincial departments often do not plan their medication stock levels adequately or pay suppliers on time. The provincial medical depots are also often dysfunctional. There were some efforts by the Minister of Health in 2012 to reform the medical depot system towards centralisation. This move was to avoid expiring stock, to have suppliers directly delivering to health facilities, and to have central hospital take over their medication purchases. Although the depots were never centralised, the national department of health has taken more responsibility and power over ARV procurement. The TAC activists engaged actively around the stock-outs challenge. Grassroots collaboration between the TAC activists in Lusikisiki and the state in the Eastern Cape stock-outs crisis in 2012, in fact, saved thousands of lives. There was some hope that 'fixed-dose combinations' (FDC) of ARVs would help reduce stock-outs, but just months into the national FDC roll out, shortages were already being reported.

FIGURE 25: TAC PROTESTS AGAINST ART STOCK OUTS

[**Source**: TAC, 2010]

The stock-outs crisis became public knowledge after the TAC exposed the Eastern Cape administration dismissing about 30 medical depot workers in the Mthatha depot who had engaged in an unprotected strike in 2012. The Mthatha medical depot handles medical stocks worth between R40 million to R50 million per month (Medecincs Sans Frontieres et al., 2013). The Mthatha Medical Depot supplies medical items to over 300 health facilities in the OR Tambo district (North of Eastern of Eastern Cape) which covers a third of the Eastern Cape population. The TAC Lusikisiki and MSF mediated during a crisis of medicines shortages and entered into an agreement to prevent unnecessary deaths that would have occurred without their emergency intervention. Some local activists argued, "This depot had always performed sub-optimally due to a history of corruption and mismanagement. The Department of Health had been investigating these issues but to no avail," (TAC0017 Interview, 2015). The unpredictable nature of the drug supply in the Mthatha region was not only expensive but also meant that drugs often expired before they reached rural clinics, impacting individual patients further and leading to excess mortality rates in the province (Médecins Sans Frontières, Section 27, Rural Health Advocacy Project, and Treatment Action Campaign, 2013).

In September 2012, the depot workers went on strike, leaving the depot in crisis. Approaching the December long holidays patients were sent home without any medication. The TAC

Lusikisiki activists debated a response and options included instigating litigation, but by the time the case would be heard in court, thousands of people would have died. As activists argued, "We wanted to lodge an urgent court case, but with December approaching, affecting the timing of the case, [the] hearing would be in the following year, and by then thousands of people would have died. So, we decided to temporarily assist the government," (TAC0018 Interview, 2015). Activists were also concerned that intervening against the strike might undermine the strikers' cause and their broader political struggle. "An excruciating decision was eventually reached that no other option was viable and that the TAC should view this mobilisation as a temporary measure," (TAC0017 Interview, 2015). The TAC and its allies formed a coalition called the 'Stop Stock-Outs' campaign, to monitor the supply chain and develop independent stock-out intelligence across the provinces. The TAC Lusikisiki activists and MSF negotiated with the Eastern Cape government to resolve this new issue, but without success. The Eastern Cape government refused the TAC Lusikisiki support, and so the TAC approached the National Minister of Health Motsoaledi, who agreed without hesitation.

Ten TAC local activists, along with medical staff from MSF, volunteered to set up a rescue team that was then sent to the medical depot for three months. The TAC local branch members went to the clinics to assist in off-loading trucks and went door-to-door asking people to return to the clinic for their medication. Those at the depot created a stock-out monitoring system (liaising with those on the ground), established a hotline for clinics and people to call in to, and publicised the hotline and ensured patients were recalled to fetch their medication (Medecins Sans Frontieres et al., 2013). While all this was happening, the provincial department went to the media accusing MSF and TAC of misleading the world and claiming that no single clinic reported stock-outs and that this was a fabricated crisis. The same year as the intervention in September 2012, roughly 5,494 people living with HIV (of these, 561 were children) in OR Tambo district missed at least a dose of ARVs a day due to treatment stock-outs (Medecincs Sans Frontieres et al., 2013). In response, the TAC Lusikisiki activists advocated in rural clinics, ordering medicines and improving supply systems by enabling each clinic to order directly through an individualised code rather than the centralised system, which relied on St Elizabeth Hospital to order for all Lusikisiki clinics. However, stock-outs continued to plague village clinics.

> We are tired of stock-outs of medicines – in village clinic, we held a sit-in demanding that the health staff should make a plan to give people their medication; otherwise, we the patients are not leaving the premises, (TAC0017 Interview, 2015).

The TAC activists in these village clinics held a civil disobedience demonstration several times due to patients being sent away without medication. One of the local activists who led this demonstration explained, "We held sit-ins at the clinic demanding that the health staff must make a plan and that patients were not leaving the premises without ARVs," (TAC0017-Interview, 2015). The TAC and MSF mediated for three months until the crisis stabilised and handed over a report to the government with their analysis of the problem, with key recommendations and early warning interventions to prevent unnecessary deaths that could have occurred without their emergency intervention. Local public health officials rely on centralised power, where Donk (2008) bureaucrats in provincial offices make policy decisions.

As a result, poor people resorted to alternative means of participation, including taking over core functions of the health service when they failed, as a way of contesting policy designs and decisions. Some public officials argued, "The process of activists' simplification of policy processes and looking for villains instead of calling it a bad political patch. Its consequences were that even the individuals who were good in that political space and wanted to do the right thing is that there were significant systemic failures in our system of public administration and our delivery platforms," (NGovt0027 Interview, 2015). When the TAC and Section27 activists released their report (Section27, 2013), this report caused a commotion in Parliament and the media. Minister Motsoaledi appointed a team to investigate and verify activists claims. Soon after, the Minister announced several mitigation interventions, and Eastern Cape Provincial Health reshuffled and MEC Gqobana did not return to this position after the 2014 elections. With these successes, and with high-profile events such as President Zuma himself publicly undergoing an AIDS test, government leadership's support for an effective ART programme was no longer in doubt. Moreover, real improvements were starting to be seen. There were only 490 ARV treatment sites in February 2010. At this point, only 55% of adults and 36% of children who were eligible for ART were receiving it (Simelela & Venter, 2014). By the end of 2012, this number had increased to 3,000 facilities, which were well equipped to initiate ARV treatment. It is estimated that 1.7 million people were on ARVs in 2012, compared to approximately 920,000 in 2009, an approximate 75% increase in just two years. The rate of

mother-to-child HIV transmission at six weeks decreased from 8% in 2008 to 3.5% in 2010 and down to 2.7% in 2011. Further, by 2012, the government paid a significantly reduced price for ART, estimated at 53% less than before (equivalent to two-year fiscal savings) (Trust, 2015). These successes did not mean, however, that all was well between the TAC and the state. The implementation of the policy phase was not as theatrical as before 2003, but there were many dispersed triggers for action, sometimes happening at the same time. This period became the period of "quiet showdown," where the state saw that it could not maintain slow AIDS implementation, bringing drastic shifts in line with the demands of activists. The state tended to encourage institutionalisation only if it considered it politically necessary to avoid disruption of the normal political process and social order. Social movements contributed to social and political change so long as they maintained relative autonomy from the state.

This need for a match between state capacity and social movement vitality indicates an outcome—when power imbalances arise, the power relationship between the social movement and the state is not always zero-sum but can be negative- or positive-sum. Two further examples demonstrate these dynamics. In the wake of the stock-out campaign in the Eastern Cape, the TAC and Section27 together with 19 other civil society organisations established the Eastern Cape Health Crisis Coalition (ECHCC), which began bringing more health system challenges to the fore. One of their letters to the Eastern Cape Provincial Department of Health and the South African Human Rights Commission, dated 20 May 2014, demanded a public meeting and an inquiry into the emergency transport crisis. Some public officials argued, however, that the: "Polarised policy issues are unconstructive, for example, the Section27 position in the Eastern Cape Health Crisis seems to be about points [of] weakness without solution, and that is a dangerous activist to make media good news," (NGovt0027 Interview, 2015). Similarly, in Khayelitsha, a similar process was taking place. The TAC challenged human resource shortages in the Site C Day Hospital, where the HIV doctor only worked for half a day daily, leaving patients desperately unattended. "Upon receiving complaints about this situation, we addressed them with the hospital management through a meeting to demand improved services, including a full-time doctor. After we saw no progress, we then organised a protest outside the hospital with key demands, and as a result, the clinic got a new full-time doctor" (TAC0010 interview, 2015). Such activities made people trust that the movement was taking their issues seriously. This was participation not through institutionalised structures but through alternative pathways which were sometimes more effective than formal platforms.

"During the implementation there is no clear 'enemy'—instead, we have seven provinces that look different from each other," (MSF0028 Interview, 2015).

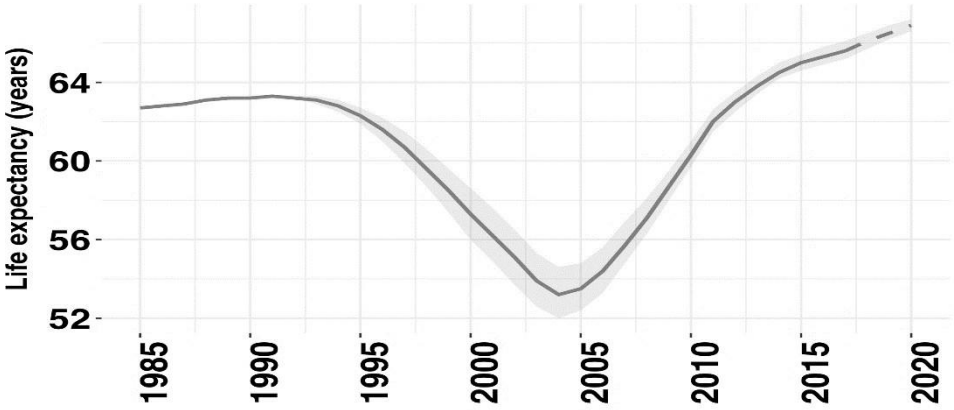
During the period prior to 2003, the focus of activists' advocacy in the main was directed to the national government as the "enemy." Service delivery battles had no definite battlegrounds, and the new struggle had to be targeting various fronts. The locus of activists' attention and advocacy shifted to local implementation, which meant keeping an eye on national government while scaling up movement actions at the grassroots level. With implementation, there were nine different provincial governments to engage with activists. The policy implementation context of South Africa is that of nine provinces, meaning translating the national policy intentions at multiple service delivery platforms at local levels. The TAC's collective national strength dispersed into nine provinces, while at the same time maintaining focus at the national level, because the same Minister who refused to provide ART was still in power. Activists had to mobilise the nine provinces, compared to before when they focused their pressure on the national government. The assertion from the above quote indicates that activists understand that policy implementation is complex and full of challenges related to the multiple administrations at the local level.

The Stop Stock-Outs Project (SSP) is a consortium of six civil society organisations dedicated to assisting the thousands of people whose lives are threatened by the chronic shortages of essential medicines and children's vaccines in South Africa. The project was established in 2013, following the Mthatha depot crisis in the Eastern Cape in 2013 (Medecincs Sans Frontieres et al., 2013). The TAC, Section 27, MSF, the Rural Health Advocacy Project (RHAP), Roads, and the Southern African HIV Clinician Society, who recognised that monitoring drug stock-outs and shortages of essential medicines in primary health care facilities was a national priority, initiated the project. Consortium members provide expert advice, technical support and advocacy to reduce stock-outs across the country through community engagement, a case management database (hotline reporting and hot spotting) and a telephone survey to review the state of healthcare and medicine stock-outs in national health facilities in district and sub-district hospital and clinics. The SSP monitors the availability of all essential primary health care (PHC) medicines and children's vaccines through the following: implementing capacity building and community engagement activities and training with

community structures through the SSP hotline. In addition to developing a case management database: All reports of drug stock-outs or shortages are added to the case management database, allowing SSP to track which provinces, districts and sub-districts are experiencing stock-outs of which drugs.

Moreover, they conduct an annual survey of public health facilities across all nine provinces to monitor stock-outs and shortages. It is because of the TAC activists' and its allies' continued advocacy, vigilance and contestation that South Africa boasts to have the largest ART programme in the world, with 3.4 million people estimated to be taking antiretrovirals by 2018. ART services are available in most primary healthcare facilities countrywide. Expansion of access to treatment has started to affect AIDS mortality, with the proportion of overall deaths that are related to AIDS decreasing between 2006 and 2011.

FIGURE 26: SOUTH AFRICAN LIFE EXPECTANCY, 2018]



[Source: Statistics South Africa]

This graph shows life expectancy at birth in South Africa. It shows a dramatic drop to 53.2 as the HIV epidemic grew to its peak in 2004. The impressive increases since have been recognised globally as the result of ARV provision by the state (see Figure 17). This graph also

makes it clear that notable escalations in the years of life gained are only a relatively modest improvement on pre-HIV levels. Life expectancy in 1994 was 62 and 25 years later in 2019, projected to be 66.5. Estimates of life expectancy indicate an increase from a low of 54 years in 2005 to 60 years in 2011. Social movements such as the TAC have emerged in opposition to the state's failure to address socioeconomic rights, basic service delivery and attempts at repression (Ballard et al., 2006). In addition, as (Ferguson, 1994) contends, spaces are corridors of power that must be taken into consideration by citizens who utilise such avenues. Power in policy processes is everywhere, meaning that is deeply embedded in subtly expressed policy discourse, knowledge, and scientific regimes of 'truth' and it may influence actors to use repressive state and multinational companies' apparatuses to maintain power (Foucault, 1980; Freire, 1970). Foucault's approach is extensively applied to appraise development discourses, scholarship and paradigms. Although Gaventa (2006b)'s power cube does not meet the Foucauldian deeper considerations of power, it provides a possibility for critical analysis and strategic action at the level of challenging or shaping policy discourse. Further he proposes a power-tube analyses to identify levels, spaces and forms of participation and the related power (see Figure 3). Gaventa's conceptual framework for power analysis provides a tool for activists to map types of power, levels and spaces to strategise about how they plan to challenge power to bring about change. In his 'power cube,' he proposes examining the creation of different types of spaces, such as closed, invited and claimed spaces.

7.5 SURVIVAL OF SOCIAL MOVEMENTS?

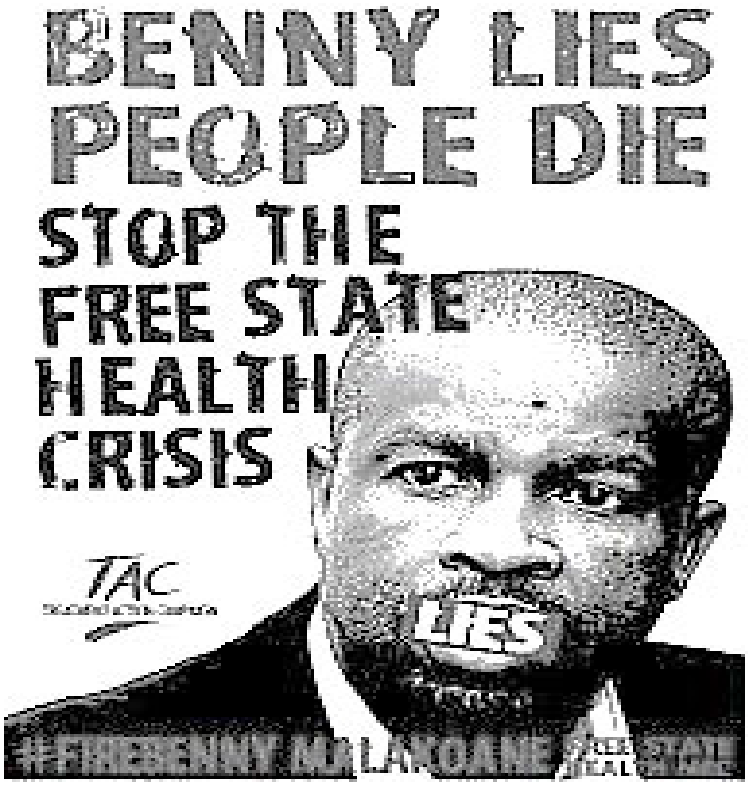
As demonstrated in this chapter, the changes in policy environment affected the TAC advocacy tactics in the long term. The TAC trajectories from 2003 to 2015 shows that the linear movement action plan presented by (Moyer, 1987) is applicable to a certain extent. The TAC clearly adjusted its advocacy tactics to counter government poor policy implementation, which then meant that the movement membership grew. On one side the activists argue that "we [activists] are not angry anymore because of the positive responses from government after lately," (TAC0048 Interview, 2015). On the other hand, the Ministry of Health too is worried about his relationship with the TAC "I am concerned. I'm feeling that the TAC is now starting to see me as an enemy and I have been trying to establish why, because I thought we were friends ever since Mark left SANAC as a chairperson," (NGovt007 interview, 2015).

After 2008, when the state conceded its power and changed its leadership to allow for policy changes and faster ART rollout, this affected TAC tactics in the long term to more collaborative and sporadic confrontations as opposed to their traditional confrontation and negotiation. When protest declines (and with it, resources of militancy), movement organizations tend to survive by institutionalising their structure: they look for money, either by building a mass paper membership, selling products to a sympathetic public, or looking for public monies, in particular in the third-sector economy. These changes have been interpreted as institutionalisation of movement organizations, with ideological moderation, specialized identities, and the fading away of disruptive protest. This evolution produces critical effects and discourages participation from below. There are four ways activists appreciated their advocacy approach transformation through engaging outside the corridors of state power. In section 7.5.1, I demonstrate how TAC grappled with the survival overtime. In section 7.5.2 I illustrate how political crisis colluded with provincial inability to deliver the ART services within a functioning healthcare system. In 7.5.3 I cover how TAC overtime faces diminishing visibility. In 7.5.4 I show how they faced global dwindling funding which affected the movement morale and size.

8.5 REPRESSION AND DE-LEGITIMISATION

> The TAC activists' steady pressure to the Free State provincial officials led to the state seeing us as a threat, and now they play divide and rule within some of civil society organisations to get rid of us, (TAC0030 Interview, 2015).

FIGURE 27: TAC POSTER CALLING FOR MEC MOLOKOANE TO BE FIRED



[Source: TAC, 2015/16]

We need to understand the distinct relationship concerning relations between political repression and activist dissent itself as a political creep into public administration, for example when government divides those who opposed and those in agreement with their political discourse. "After the TAC, Section27 and others released a report '*death and dying'*(Section27, 2013), the MEC of health went public and claimed that TAC activists are counter revolutionists. Further, that "we [TAC] are discrediting the ANC leadership in Free State by undermining Premier Magashule, you go to the Eastern Cape they are doing the same to MEC Gqobana" (TAC0010 Interview, 2015). "Some public health administrators argue that Provinces, some of the things they are doing are the wrong things.

It is not the lack of capacity. If you look at the spending in some of provinces, you will see they are underspending so it is not a lack of money. It's sometimes a lack of will and the right people in the right places," (NGovt0038-Interview, 2015). While the national politicians argue that "no Minister is supposed to fire the MEC but TAC believed I must fire Benny (see figure 27 above) and I said they have to confront the premier of Free State, they must make noise with

the premier not me, the premier appeared publicly and said Benny is going nowhere,"(NGovt007 interview, 2015). The ANC in the Free State province retaliated to protect the MEC and called for the TAC to be deregistered. This is tantamount to a clampdown on any dissenting voices using the authoritarian language of deregistration because vetting organisational registrations is within the power of the state machinery. The provincial political leadership experienced insecurity because their power is contested power and their way to try to regain control is through repression tactics. Below (Figure 28) is a feature of shrinking space where political leaders sponsor smear campaigns against movements or activists to undermine independent actors who are holding public officials accountable. The ultimate aim of activists repression from the Free State is to make sure that no more visible dissent come after this tactic is applied (Davenport , Johnston, 2018).

FIGURE 28: MARCH AGAINST TAC

[Source: ANC Free State, 2015]

If you speak truth to power trying to hold politicians accountable you will be identified or labelled as counter revolutionary, and in that process, they are turning a blind eye on the health challenges taking place on the ground. For example, ANCYL marched to

> TAC offices demanding that TAC should be deregistered and accuse us of being used by western countries, (TAC0030 Interview, 2015).

In figure 28, the poster portrays the Free State premier as one of the two prominent political figures in front, and the MEC of Health who is the target of the activists' pressure is hiding behind the Premier while shaking his reprimanding posture using his index finger. This is intimidation at its best, and soon after the poster was published, the ANC Youth League leader of Free State published a Facebook chat stating that the gloves were off against the TAC – practically declaring war. It has long been clear that the gatekeepers of mainstream political spaces have simultaneously co-opted and instrumentalised key civil society organizations in SANAC while pushing activists that are more radical into a shadow realm where they face de-legitimization, threats, and excessive control – with the precise aim of countering their appeal. Recent scholars' attention has gone into understating how the civic space may shrink due to the collusion of the various forces of hegemony.

"In South Africa we're slowly moving back towards a Ministry of Health that does not tolerate criticism. That's always dangerous," (MSF0066 Interview, 2015). The shrinking space for movements and activists can be understood because of the forceful construction of tyrannical approaches and political struggle, which includes ways in which movements respond to these methods to reclaim their popular political space, and the impact that the activists' responses have on how the state relates to the movements. Within the civil society, shrinking space means limitations to popular politics to operate fairly with governments without perceptions as a political threat to state authority. Accordingly, if the state perceives movements as threats to their political power, they can discredit and weaken movements' political space, affect their funding prospects and challenge the value of their work to manipulate the public in order to decrease trust in civil society. Most movements such as the TAC continue to apply popular pressure regardless of the threats from the state.

8.6 DIMINISHING VISIBILITY

> The TAC internally battled with transitioning from adversarial to open engagements with political leaders, because it affected its adored public visibility, and funding prospects diminished, (SANAC003 Interview, 2015).

This transitional stage posed dilemmas within the TAC, in part because of the movement's public visibility and reduced media opportunities. It is very difficult to sustain high levels of spectacular and public support energy during policy implementation. Decline or perception of failure or success occurs when the movement has less public visibility. Courting the new minister was an important political opportunity to push for faster ART rollout. However, this move proved confusing to those participating in alternative spaces. As the national political environment shifted towards positive engagement at national level, while new implementation challenges created adversarial engagement with activists. I have argued that shifting political processes occurred when the TAC protest actions and events were frequent enough to cause massive societal and political instability and intense enough to be noticed and to represent a threat. However, visibility is not realised through moderate institutional participation, and this may fragment the movement, as it does not achieve the heightened connection with members and the public that protests do. Without this, disengagement from movement activities is more likely to occur, and the balance of power shifts towards the state. The absence of movement prioritisation on building visible social mobilisation has an impact on grassroots participation in policy processes. Social movements can sometimes be significant actors in the policy process: identifying social problems; pressing for particular solutions; pressuring institutional actors for action; and strengthening the bargaining position of institutional allies. Movements, visible and active, can improve the policy prospects of their constituencies, largely by mobilising them, and policy victories can lead to subsequent mobilisation. The second wave of activists' mobilisation reflects the influence of a broad and diverse social movement, and provides a notable contrast with the policy processes of the 2000s.

The TAC survives the decline of its national popular mobilisation after the ART victory. The uncertainty of the 2007 political shifts had an impact on the activist national prominence and visibility. The local visibility where implementation occurs became the new priority for activists. As a result, the political opportunity, which came with the government ART plan, became a movement resource for constant contentious grassroots collective action (Diani & McAdam, 2003) . This may result in social movement national solidarity decline (Meyer, 2003). The movement continuity rarely happens in the same publicised theatrical manner as the movement adapts to pursue more specific implementation goals, with spill-over effects in forging new advocacy alliances. We can begin to see how the TAC might miss opportunities by looking at the processes of movement decline and abeyance (Meyer, 2003). Activists redirected their efforts to more promising political venues in ART policy implementation,

following a long-established conflict with government. "In South Africa, I feel we [activists] we don't have our finger on the pulse compared to before we used to have very frequent discussions with TAC,"(MSF0028 Interview, 2015) . Success and political change came with some loss of movement visibility at national level, but the policy battles at the provincial and local levels remained difficult as argued in Chapters Five and Six. For example, some activists argue that they are community responsive and "As TAC we saw a need for TAC to participate fully in support of xenophobia for example, also some of the donors were able to come back to TAC and say you were not able to send a report and you have failed in doing so. Also at local level our comrades whenever there is a problem on the ground whether there's funding for that particular thing, we jump for it and not focus on core business, hence we must partner with other organisations so that we can refer some issues," (TAC0030 Interview, 2015). Another example of this community responsiveness tension and maintaining what others call core business: "A young girl was raped and the community asked the support of TAC to protest. Now the community is talking saying if it was not for TAC they would not be able to fight and win the case, the offender ended up arrested," (TAC0067 Interview, 2015). Unfortunately, some of the advocacy coalition's partners were lost along the way because the TAC's focus became more on advocacy for a quality healthcare system that could deliver ART services.

8.7 CONCLUSION

In sum, public policy in South Africa praises the virtues of participation (and may even make it a legislative framework), but evidence suggests that state opposition to popular participation is often an obstacle for successful policy (Crawford et al., 2002). The findings presented in this chapter demonstrate how the TAC activists' advocacy actions are premised on the principle that the state alone, especially the national Department of Health, is unable to develop and implement a successful National Strategic Plan (NSP) against HIV/AIDS without the people who are most affected by such policy. The TAC monitoring frames performed a transformative shift from national to local attention, and the activists began engagements with the state, as in the reconfiguration of aspects of local advocacy actions around routine grievances of injustices and mobilisation around those at the local level.

But formal participation relies on the existence of functional and decisive local spaces as well as organised, affected people in its efforts to enhance empowered participatory processes, to assess opportunities created for civic engagement in the fight against HIV/AIDS (Mantzaris &

Ngcobo, 2007). Through the participation theory and movement action plan, we learn about the transformation of activists' engagement with government from below. The final public policy outcome reflects the relative balance of forces in South Africa after 2003, when the ART rollout would have been unachievable at a speedy pace without the activists' politicisation of service delivery in Khayelitsha and Lusikisiki.

CHAPTER NINE: CONCLUSION

9.1 INTRODCTION

Literature suggests that historically, policy participation has inherent deficits in shifting power and control over developmental processes towards popular participation by poor and marginalised people. As demonstrated in Chapters Five and Six respectively, personal accounts of grassroots activists shed light on diverse flaws and paradoxes in the practices of participation from grassroots activists, particularly those from marginalised communities. The aggressive battle between AIDS activists, the South African government, and multinational pharmaceutical companies became a key feature demonstrating how extensive capital interests tended to have more privileges over policy processes that affected a majority of the poor. In this case, the state had a constitutional duty to progressively provide the cheapest available medicines for poor people who depended on government for healthcare services. In reality, the multinational companies made it very hard even for willing governments to provide ART because of the affordability issue. Furthermore, the role of the state and its institutional participation spaces is evolving significantly due to globalisation and transnational economic and political forces. To date, state institutions, the markets, and social movements represent the contested contextual landscape of policy development.

Grassroots social movement action plans evolve faster than theory, as each day presents its own political opportunities and challenges. Participation in grassroots policy implementation is complicated, technical, mundane and challenging, as it involves more than just policy change. The introduction of a new policy creates a greater need for grassroots participation, but this also tests a movement's imagination and limits. My experiential, personal and subjectivity are intimately linked to the basis upon which I know something to be true or not, as well as inform the choices of methods and tools for data collection I applied. This research is born out of the need to reflect on the years of intense ART policy contestation by AIDS activists (I amongst them) and their social movements in South Africa. The earlier period of ruthless betrayal of people living with HIV and AIDS questioned the ideals of constitutional human rights, participation and deepening of democracy. That period has already been subject to significant documentation and analysis, but the second phase of policy implementation warrants equal consideration. It is worth noting that my many years as an AIDS activist provides access to the in-depth lived experience of the South African policymaking processes.

The period before 2003 featured high rebellion from AIDS activists against unilateral state AIDS policy choices and decisions. At the peak of this conflict, President Mbeki's AIDS denialism fueled significant disconnections between state policy processes, the people and AIDS activists. After the antiretroviral therapy (ART) victory, peaks of national, theatrical protest action did not accompany policy implementation. Some may perceive this as abeyance, but it does not mean retreat. As indicated in Chapter One, two propositions undergird the thesis. One is that the existing literature had limited insight into bottom-up participation and movement evolution lacks accounts of the ways in which AIDS activists' advocacy shifted tactics to counter government policy implementation after the ART victory, although recently several volumes have engaged the issue of participation more seriously. The activists reframed the state ART policy announcement as their victory and immediately found areas to problematise in the policy implementation to avoid the diminishing and demobilising effects that come with so-called 'victory' that can eventually shift the public spotlight, especially in the media, away from the movement agenda. The official government policy announcement turned out to be a fictitious commitment, given that they later dragged their feet to implement their own policy, as discussed in Chapter Six.

For activists, the primary measure of successful policy change should be whether they maintain collective power and agency as a force for effective implementation of new policy. However, the evolution of the TAC's advocacy strategies had not been tested by scholars' post–ART policy implementation at a local level during the period that required constant vigilance. Holding government accountable for delivering services as promised is, however, contentious. It requires shifts in activists' advocacy strategies at various levels of government. The period of policy implementation provides insights into a social movement's evolution after a successful policy campaign. The post-apartheid South African political context shaped the development of the AIDS Policy. It engendered difficulties in implementation and in developing a comprehensive response to AIDS in a country undergoing restructuring at every level (Schneider & Stein, 2001a). Contestation within the state, although less visible, has thus significantly strengthened the position of non-governmental actors.

The AIDS policymaking under President Mbeki and his Health Minister, Manto Tshabalala Msimang, was characterised by hostility towards the use of ART in the public sector (Nattrass, 2008). The position taken in the thesis is that both the practice of participation and movement

actions produce and sustain collective actions beyond policy victories. While the South African literature has clearly provided an important starting point from which to understand the government's top-down practices of participation in development, much of it has focused on the prospects of decentralised participation in the lower echelons or invited participatory spaces. It takes a one-sided and deterministic approach by ignoring the potential for agents acting outside of the politics of invited spaces to influence participatory and even development outcomes.

The underlying argument presented here is that the era after 2003 constitutes a minor political opportunity for AIDS activists, because the commitment to implementation was made with state reservations. It took the same activists to drive government to deliver on its promise of ART. The TAC altered its advocacy tactics in various ways when confronting the new implementation's structural challenges. The typologies of bottom-up participation and movement action plan tactics shifted the state health service delivery practices in provinces and the perceived national character of the ART rollout, especially in relation to the centralised accreditation of ART sites where contestation was not given. The TAC advocacy tactics reshaped the perceived passive role of grassroots activists in implementation by transforming practices between health providers and patients and reviving the AIDS councils and clinic committees through popular agency. This approach reveals specific aspects of participatory processes, which may provide building blocks for the future construction of a transformative health governance defined from below through popular agency. It may simultaneously unveil the processes through which activists and movements can be captured by hegemonic development and policy agendas, thereby rendering participatory spaces tyrannical. Applying this approach in Khayelitsha and Lusikisiki, this thesis has sought to explain the shift in AIDS activist and advocacy tactics following the rollout of ARVs by people and social movements affected by HIV/AIDS in Khayelitsha and Lusikisiki, within a national context of dramatic changes in the balance of forces between 2004 and 2014, which led to AIDS treatment access breakthroughs. It also explored the implications of these policy shifts for activists' advocacy strategies during the ART rollout and their impact in transforming the TAC.

While this study concludes that the TAC shifted from traditional antagonistic engagements to a dual-tactical approach with the state, this had strong elements of grassroots contention, and the

analysis of activist advocacy beyond the ART victory would be short sighted if it stopped here. One of the primary arguments made here is that participation in policy implementation processes are always in flux and cannot easily be predetermined. In Khayelitsha and Lusikisiki, these prominent features have been brought into popular contestation by the fact that popular participatory spaces in Khayelitsha and Lusikisiki have challenged the AIDS council relevance and trajectory in creating spaces for popular voices. This chapter concluded that the activist and advocacy tactics after the ART victory had implications in shifting bottom-up policy-making going forward in terms of democratising healthcare and the survival of social movements. This analytical approach for understanding and explaining the typologies of participation and social movement action plans provides a useful lens through which to interpret collective power and daily interactions with the state. Applying this approach in Khayelitsha and Lusikisiki, this thesis has sought to explain the activists' advocacy tactics and typologies of participation. While this study has concluded that the AIDS council, an invited participatory space, has strong elements of tyranny, the analysis of participation in development in the TAC would be short sighted if it stopped here.

In the first chapter, I contextualise the research problem by situating Khayelitsha and Lusikisiki in the policy participation crossroads of South Africa, despite participation hailed as a salient component in the attainment of development. Over the past few decades, a virtually universal consensus has emerged amongst conservatives, liberals and radicals alike, that development cannot occur without participation. I argue that the political changes in the balance of forces that occurred in South Africa, which led to AIDS treatment access breakthroughs, are nothing new in South Africa and pose a relatively negligible threat to the state's poor service delivery and pharma's corporate existence. No AIDS policy crisis fundamentally challenged the precarious health policy implementation in South Africa as the rise of AIDS activists' pressure in Khayelitsha and Lusikisiki since 2003 did.(Lodge, 2003) argues that the political protests of activists entrenched political reforms and enhanced government constitutional checks. The AIDS treatment movement demonstrates shifts in activists' forms of participation in HIV/AIDS policy development, as well as changes in advocacy strategies adopted by the Treatment Action Campaign to counter the government's insufficient policy on HIV post- apartheid.

I contend that despite the impressive array of studies on the Treatment Action Campaign, social movement scholarship has yet to examine the Khayelitsha and Lusikisiki bottom-up advocacy

that catalysed grassroots participation in ART service delivery and other civil society groups. I traced this academic oversight to the fact that the adoption of policy by government often has demobilisation effects on social movements. At that juncture, the TAC activists — instead of retreating — stirred their collective pressure to compel the South African government into delivering ART through the public sector health facilities for the benefit of poor people living with HIV and AIDS. Thus, the second part of this thesis describes the TAC's engagement with the South African state, and its advocacy strategies for ensuring the development of HIV treatment policy and delivery. It also recounts the increasing confrontation between the TAC and the national government around ART policy and provision, and it reflects on the process to develop an ART policy. The bottom-up participation by AIDS activists in the context of the South African history of the AIDS conflict helps us better understand the nature of participation praxis from below. I accentuate the significance of this study by stating the need to embed the ongoing praxis of popular participation from the grassroots in the wider social movement literature and development scholarship.

Against the above background, the remaining sections of the chapter will explore the theoretical implications of the research findings and suggest a new intellectual praxis for research on social movements. Accordingly, section 9.2 distills from the findings the most important implications for theory. Section 9.3 puts forward entry points for a discussion on a new intellectual praxis and crystalizes the main arguments emanating from the research findings, suggesting that the philosophy and practice of participation and social movement advocacy actions, which have been neglected by scholars, provide a useful framework with which to understand the potential for participation in development to enable agents to control development on their own terms. The way in which the TAC employs power over the development process with protests and collaboration distinguishes it from other movements; if its advocacy tactics are harnessed more carefully, it could hold transformative potential in the long term. The final section, 9.4, concludes the chapter.

9.2 EXAMINING THE THEORETICAL IMPLICATIONS OF THE RESEARCH FINDINGS

The findings of this study raise critical questions about the praxis of bottom-up participation after a successful movement advocacy campaign for policy change. The final public policy outcome reflects the relative balance of forces in South Africa after 2003, because the ART

rollout would not have been achieved at a speedy pace without the activists' politicisation of service delivery in Khayelitsha and Lusikisiki. Adoption of an ART policy marks an achievement but more importantly indicates a continuation of the policy development process to make sure that access to affordable ART for poor people becomes a reality beyond just adoption. The TAC is amongst the new social movements that have effectively employed a myriad of tactics to challenge the power of governments during service delivery. The AIDS activists' advocacy for ART captured the imagination and hopes of poor people through their participation to push for policy changes in South Africa. Hence, the period after 2003 is of interest for the research, because the relationships and engagements between activists and the state fundamentally changed, as implementation occurred and participation became more complex and challenging at the local level.

In Chapter Two, we learned that popular participation for grassroots activists after the 2003 ART success was both an act of deliberative governance value and a right for social inclusion. In the literature, it is generally assumed that movements go through an abeyance after a successful campaign, but evidence from this study challenges the participation scholars to empirically establish whether a movement necessarily declines during policy implementation. During policy implementation, the peaks of national, theatrical protest action may diminish. Some may perceive this as abeyance, but it does not mean retreat. Movements do not have to end or decline after their victory but can continue to participate in policy implementation. This is particularly important to note, because service delivery takes place at local levels — as opposed to the period before implementation, when the national government is the centre of movement actions and it not simply given that the typologies of participation should remain the same. The findings suggest that the movement ought to shift its tactics to allow for differences in approaches to the different provincial implementation platforms with various political opportunities. That is, the practice of participation is more complex and does not inherently amount to movement decline.

If we go according to the findings of the research on AIDS activists in Khayelitsha and Lusikisiki, it cannot be simply assumed that all movements will continue with the same advocacy tactics, with adversarial tactics as the only form of engaging government during implementation. These tactical changes included confrontation, bargaining and persuasion to impact policy implementation. The use of various forms of advocacy tactics has allowed the TAC continuity and the ability to sustain their independent participation and public presence.

Furthermore, after the 2003 policy victory, the TAC continued to utilise courts and contested successfully the implementation of the ART rollout from highly mobilised grassroots organising and negotiation. (Lodge, 2015) argues that the AIDS activists appear victorious in strengthening the South African government's HIV policy response. Through social mobilisation, they created ART service demand and support for the ART rollout in the study sites. The TAC altered its advocacy tactics, which became militant during the ART service delivery exerting its soacial power to shape policy implementation. For example, the activists' advocacy tactics were in response to the government's lack of will to roll out ART. A chance to shift implementation priorities from below meant that activists had to engage with the state using both institutionalised and non-institutional forms of participation (as both insider and outsider). In response to the failure of the government's mechanisms to influence policy, the AIDS activists created a culture of resistance against top down government policy interventions, which remains embedded along with patronage and tokenistic means.

The TAC altered its advocacy tactics in various ways when confronting the new implementation and its structural challenges. This suggests that the TAC Khayelitsha and Lusikisiki activists became more militant during ART service delivery to exert power in relation to their own conditions and on their own terms. Key changes in decision-making, regarding policies or specific development interventions, do not occur in a black box and rarely are made without being contested. Rather, these decisions are negotiated by society over time. Because the act of decision-making by government officials or other authorities is socially constructed, various agents along the political spectrum can therefore transform it. This thesis reconfirms the salience of agency. Activists applied pressure from within in order to take control of policy decision-making. The locus of activists' participation shifts from primarily protests targeting national government to local health officials as the main interface between communities and government.

The local clinic as a site of contestation challenges the privilege of the medical profession and health professionals as the sole power holders in decision-making in health facilities. Power and participation in health governance are inseparable. In other words, we cannot take for granted the presence of asymmetrical power nested in institutionalised participation, which governs the engagements between activists and public administrators in state corridors. Formal policy spaces, by nature of being institutionalised, can arguably be useful for bargaining, but they constrain popular agency and have limited effects in deepening popular participation.

Institutional participation often requires cooperation between different parts of government, the people and the private sector under the democratic principles of co-governance and tolerating voices of dissent. Institutional spaces can also be spaces where organs of the state express their power (Cornwall, 2004), counterbalancing the power of citizen participation. Participation in Khayelitsha and Lusikisiki goes beyond the tyranny approach to participation in development, since agents' question, actively resist, and at times transform top-down processes of decision-making into ones that are redefined from the bottom up. Unlike Arnstein and Pretty's typologies, which are incongruent with the realities of participation, it is shown in the TAC case that participation is rarely a seamless process but rather fluid and complex. Henceforth, as (Steyn, 2012) points out, the relationship between state practices and the praxis of social movements is dialectical and fluid; thus, the TAC's activist struggles take place across institutional and non-institutional terrain. While the AIDS council spaces offer development practices to the TAC, they dos not seriously offer alternative development policies. It testifies to a people's desire and ability to control important aspects of their lives and, indeed, to some extent control their own destinies.

As such, Khayelitsha and Lusikisiki undeniably are challenging places to implement the ART rollout without the people themselves. The TAC activists defied the assumption that the South African public health system is the way it is and cannot be reformed. Thus, the movement had a relatively small use of the formal participation such as the AIDS Council as a collective bargaining platform for the ART implementation. The invented bottom-up participation tactics shifted the state practices in provinces and the perceived national character of the ART rollout, especially in relation to the centralised accreditation of ART sites where contestation was not given.

The findings thus confound the theoretical claims outlined in Chapter Two about the novelty of participation, as they suggest that participation is about balance of power, therefore participation is inherently a site of political struggle to gain influence and control of policy decision-making processes. This means that the conflicting relations between powerful individuals/groups and those with less power are brought into power participation spaces. Public policy in South Africa praises the virtues of participation (and may even make it a legislative framework), but evidence suggests that state opposition to popular participation is often an obstacle for successful policy (Crawford et al., 2002). The findings presented in this

chapter demonstrate how the TAC activists' advocacy actions were premised on the principle that the state alone, especially the national Department of Health, was unable to develop and implement a successful National Strategic Plan against HIV/AIDS without the people who are most affected by such policy.

Accordingly, the participation discourse celebrates the South African constitutional framework, which places importance on popular participation in governance and policymaking, to the tune of making articulating participation a right of citizens and influencing the policy decisions affecting them a constitutionally entrenched right. Hence, the findings suggest in Chapters Five, Six, Seven and Eight that after the ART success, the TAC advocacy tactics focused on routine access to the polity through institutional participation in order to reshape and influence policy directly in the boardrooms. In addition, TAC sought to debunk the perception that grassroots activists are passive influencers of policy implementation. They did this through transforming practices between health providers and patients and reviving the AIDS councils and clinic committees through popular agency. Conversely, this tactic drifted the TAC in Khayelitsha and Lusikisiki away from more disruptive approaches such as protests. Activists took this rational decision knowing that the limitations of institutional participation included having little independent impact on policy implementation changes on the ground. On the other hand, grassroots activists utilised formal participation as their space for bargaining as a form of mechanism for influence. However, the findings suggest that grassroots activists are not defenseless with a shortage of extra-institutional strategies to mitigate the risks of institutional participation. In Chapter eight, the activists applied cautionary measures to curb cooptation within the movement. Within the movement, the membership in SANAC decided which representatives of the movements must account to the movement and cannot make unilateral decisions. This also limits the boardroom private bilateral meetings between the movement leaders and government.

The literature celebrates social movements as the institute of autonomous, alternative, popular participation spaces. The emergence of new sites of popular participation can be traced in the work of social movements or the rise in social protests as alternative spaces of poor people’s power in post-apartheid South Africa (Greenstein, 2003). Social movements mobilise lower echelons of citizens using unconventional, oppositional forms of participation, such as social

mobilisation, protests, and litigation to pressure government for a more open policy-making process. There is, therefore, a serious need to understand the alternatives that exist to these institutional mechanisms and the extent to which they hold the possibility for bringing about, and sustaining, transformation. The contention over ART implementation at the local level facilitated new kinds of bottom-up alternative participation pathways and consequently began to shift the balance of power at local levels. The implementation process is complex, and the unpredictable health-facility level required activists to use bargaining advocacy tactics and negotiation tactics at different levels, rather than as a seamless sequence of movement advocacy action. This has led to activists' recognition of the importance of engaging with the state using different approaches, because the state is not one monolithic machine with which one can use a one-size-fits-all approach. For activists, the approach to health care workers was one of offering help, to win them over and build alliances with them.

The most recent literature on participation in South Africa shows that the government's invented mechanisms intended for participation, such as AIDS councils, clinic committees, or ward committees do not fulfil its intended purpose (Sinwell, 2009) . The analysis of the TAC I argue concurs with this conclusion and extends the analysis by suggesting that the state approach to participation as practiced through the AIDS councils and clinic committees has strong elements of tyranny. However, just labelling participatory processes as merely tyrannical ignores the potential for people to influence the development process through their own agency. While available literature on participation no doubt provides a starting point to help explain the typologies of participation in development, it is arguably short sighted. Through sustained theoretical reflection and empirical analysis of the interface between local government and social movements over time, this thesis has confirmed that this approach to the study of participation in development does not adequately reflect how agents influence development processes. Activists are not passive pawns of top-down service delivery, but active agents who can transform policy implementation processes — even though they may appear, initially, to have little chance at influencing these processes. This has been illustrated in Chapters Five to Seven in this thesis, demonstrating activists' varying degrees of success at influencing the ART rollout practices in their favour. The aim of discussion in this section was not to refute the typologies of participation based on limited cases of analysis, but rather to question existing claims about the practices.

9.3 SOCIAL MOVEMENT ACTIONS AND EVOLUTION

Though this new approach did bring clear policy gains for the movement, it confused members at the grassroots level and affected the movement's morale. There were real concerns about loss of radicalism, collective identity, and solidarity (Castells, 1983), resulting in social movement decline (Tarrow, 1983). Movement continuity rarely happens in the same publicised theatrical manner as the movement adapts to pursue more specific implementation goals, with spill-over effects in forging new advocacy alliances (Meyer, 2003). The activists' collective actions after 2003 shifted the focus from merely national government towards also building up stress on the public health system from below to deliver services. This shift helped to build movement energy and reduce the effects of post-campaign demobilisation. The movement used triggers through which public attention was directed to articulate its demands. After a policy becomes a public issue, the power-holders are forced to switch to a crisis-management strategy.

9.4 MOVEMENT ACTION PLAN

The findings draw attention to the blind spots of the social movement action plan (SMAP). They suggest that social movement action plans undergo peaks and declines, which are observable to the public mainly through shifts in protest activities. Accordingly, as noted in Chapter Two, while it is generally assumed that social movements' action plans revolve around four phases, the case of the TAC suggests a non-linear evolution. In fact, contrary to the SMAP postulate in Chapter Two, the movement action plan is influenced and aided by political processes, mobilisations of grassroots members, and its precipitated demobilisation as discussed in chapter eight. There are clear benefits of the SMAP in relation to some of its stages, such as the bureaucratic management phase, crisis-management phase, and public awareness and opposition phase as being dominant in the TAC movement action plan. The official policies are fictitious policies given to the public. Bureaucratic management is a strategy often used by government to prevent the issue raised by a social movement from becoming a public issue. This begins when policy conditions seem normal and is achieved by keeping the policy problem out of the public's view of the world and thereby out of people's consciousness and keeping issues out of the public spotlight and off society's agenda. The goal is to maintain hegemony of the information available to the public through the media. The state denies that the problem exists and creates "societal myths," which define the problem for the public as exactly the opposite of reality. State-sponsored fear in the general population is created so that they will

unquestioningly support whatever policies the powerholders take. When the public is not aware of ART implementation targets and timelines, it is impossible to hold government accountable. ART target information was critical for AIDS activists, because they could use such information to hold the state to account against its targets. Public awareness and popular opposition are based on the level of information available to the public about the problem as framed by the movement's actions. This level of public awareness of the policy problem may represent the movement take-off stage, which sets the campaign high in the public discourse and creates media visibility from the trigger issue.

These conditions fostered the nature of confrontation and suspicion about the state's commitment to the rollout. This served to heighten activists' vigilance in the implementation and reflected doubts amongst various public health officials as well. The ART timetables trigger set off a political opportunity for the local activists to place the policy-implementation challenges in the spotlight. The focus was on the question about the state commitment to ART service delivery without a clear public plan that the activists could use to hold government accountable. The return to the courts offered the local TAC activists an opportunity to articulate ART rollout demands, using the official/government avenues such as courts to force the state to offer transparency about the treatment plan timetables, which sparked public outrage. The trigger set off a movement and put the spotlight on the state's commitment to implement the ART policy and the state's refusal to publicise the ART timetables. This trigger was created by the powerholders — not the movement.

Every court appearance the TAC made was accompanied by mass mobilisation and protests outside the courts to display mass support for the movement. If anything, government actions promoted a revival of TAC's public support as people realised the importance of following through to make sure policy concessions were delivered as promised.

The TAC monitoring frames performed a transformative shift from national to local attention and the activists' engagements with the state, as in the reconfiguration of aspects of local advocacy actions around routine grievances of injustices and mobilisation around those at the local level. Grassroots activists are agentic and adopted a contentious collective frame embedded in everyday practice related to the experiences of people's access to ART. Waves of localised protests to demand a faster ART plan rollout soon began to take shape as a form of resistance to the National Department of Health's constant lack of attention to ART delivery.

ART site accreditation is a public administrative function that became a focus of contention, and the implementation of these site accreditations was an indication of state deployment of bureaucratic power. The government response to activists exposed a lack of desire to engage positively with activists after the ART policy change.

Furthermore, the findings indicate that the experiences of grassroots activists do not fit neatly into the SMAP. They suggest that political opportunities as seen in 2008 are not permanent, but mark a shift in political patterns. The measure of the TAC's victory is in not only policy changes, but also effective state implementation that delivers medicines to save lives. AIDS activists needed to mobilise ongoing advocacy for ART policy implementation, which required the movement to adapt, exploit, and generate renewed grassroots opportunities as well as pathways for new political action and activism. It is not uncommon that social movement evolution involves reframing of policy problems or continuing to frame remaining unjust conditions. There are two elements of that which are especially imperative for repertoires of contention and the construction of targets, in which activists link particular policy failures to government ministers and actors. This generates public information about these actors' practices and is a crucial part of what social movements do. However, where there are nine provinces implementing a plan, which minister to do you put the spotlight on? This required activists to unpack the bases of symbolic power that these ministers had.

The treatment timetables were critical for activists to mobilise to create demand for services and for monitoring service delivery. Although the grassroots activists carried out direct collective action to force the state to concede on the rollout timetable at some point; on the other hand, the site accreditation and rationing of care continued. Therefore, the TAC had to sustain its engagement with provincial public officials.

To gain public support and awareness about implementation challenges, the TAC activists reacted by occupying ART sites and protesting against the imposition of unattainable ART accreditation, showing that the bureaucratic power in policy-implementation decisions led to rationing service delivery without engaging with those whom these procedures would negatively affect. The state dragged its feet on the ART rollout, and the TAC used popular protests. The bottom-up participation tactics shifted the state practices in the provinces, and as such, the perceived national character of the ART rollout, especially in relation to the centralised accreditation of ART sites where contestation was not given. The TAC, with its

strategic policy alliances, invented more participation spaces, resources for court cases, popular education, resources for protests, and strategy advice about choices in the political struggle. Perhaps more importantly, it has thrived in providing support for networks of health care workers, community-based working class organisations and communities in

Khayelitsha and Lusikisiki. Regarding the notion of policy networks to illustrate the complex web of policymaking and the interrelationships between different state and non-state actors, in some instances, the interactions may be highly contentious, with non-state actor networks pressing the state to shift its position. Activists stirred their collective pressure to compel the South African government into delivering ART through the public-sector health facilities for the benefit of poor people living with HIV and AIDS. This stimulates participation between civil society and government in policy implementation, signifying that the state gained public support for its rollout over time. Thus, the political protests of activists entrenched political reforms and enhanced government constitutional checks.

Movements use grassroots membership, which is largely constituted by unpaid volunteers, to hold government to account. The strength of activist organizations lies less in numbers and more in assets such as strong leadership, evidence-backed positions, good media relations, a network of strategic alliances with other groups, the ability to use multiple strategies, organizational structures, and sufficient independent financial resources (Laverack, 2012).
Grassroots movements—i.e., movements of, for, and by people most directly affected by the consequences of public policies—are emerging as global movements and forming structures to sustain their movements. They are challenging the rights of non-grassroots organizations to lead and represent them, especially in the public policy arena, at both national and international levels.

9.5 DEMOCRATISATION OF THE PUBLIC HEALTH SYSTEM

As much as public policy in South Africa praises the virtues of participation (and may even make it a legislative framework), evidence suggests that state opposition to popular participation is often an obstacle for successful policy. The TAC activists' advocacy actions are premised on the principle that the state alone, especially the national Department of Health, is unable to develop and implement a successful National Strategic Plan against HIV/AIDS

without the people who are most affected by such policy. The grassroots activists' collective demands are grounded in localised actions of accountability, rallying popular mobilisation on shared experiences of the poor with lack of service delivery. Therefore, the local health clinics also became sites where people living with HIV found movement solidarity and affirmation of expressive collective identities. The TAC articulates mechanisms by which members could focus their collectives using the local health clinics as sites of organising, contestation, and the reconstruction of patient-provider relations. The activist use of popular education tactics for mass empowerment gave rise to popular consciousness about the politics of health and governance. Popular education became a vital element of the local activist movement to empower and mobilise its membership and supporters. In essence, this facilitated popular counter state hegemony from the grassroots.

In addition, this shifted patient relations with the state because of the increased knowledge and power of patients as they countered the health system elite and health administrators' authority. The use of popular education had transformative effects for movement members. The movement achieved mass redistribution of the power of scientific knowledge from the elite to poor people living with HIV. Central to the activists' success was the use of tactics such as branches as a main community organising nucleus, and it still is. I argue that participation in policy processes ought to be emancipatory; in other words, it should empower and facilitate people's capacity for direct influence on the policy process from the bottom up, thus challenging top-down development planning interventions. For activists, the primary measure of their success in policy change is maintaining their collective power and agency as a force for implementation.

The grassroots activists applied treatment literacy tactically to shift engagements where there were dominant, unequal relations entrenched in the health system. In these relations, the health care workers and public administrators were seen as the experts, and patients were seen as passive receivers of care and non-experts. In turn, activists used treatment literacy as a tool for participation in development and empowerment of target groups of poor people (Mohan and Stokke, 2000). The activists remained inside the health system by offering health education to other patients as well as their own services. However, treatment literacy as a strategy may have created collaborative pathways for activists to work with the state, but it also has its own caveats. These include the reality that long-term involvement of activists in the ART sites can

lead to co-optation by adjusting their autonomous role to comply with the public sector procedures and roles. Over time, some grassroots activists were absorbed into more service delivery than activism. Scholars argue that this is decline, which in this case we may see as the loss of national visibility and public arousing strategies, and which comes naturally with the implementation itself that is largely invisible, caused atrophy to some parts of the movement's activities. Movements cannot engage in broad-based mobilization forever; decline and fragmentation are likely inevitable. However, just as successful mobilisation is a combination of agency and environment, so is decline and abeyance. Choices that activists make about claims and tactics, albeit not in circumstances they themselves choose, affect the trajectory of a movement, its unity, and its prospects for subsequent success. If organizers work to maintain a public face, they can minimize periods of decline and fragmentation, and protect some victories.

The TAC contributed to the expansion of popular democratisation of the health system. The contribution of social movements, such as the TAC, assists in widening inclusive political spaces beyond policy-making (Jones, 2005). This has been illustrated by the four invented spaces discussed in this thesis, which have had varying degrees of success at influencing the policy implementation practices in the movement's favour. Each invented space attempted to engage within and beyond the invited space such as AIDS councils, as well as with local government officials and clinic structures, but usually with only limited success.

9.6 SITUATED KNOWLEDGES, RESEARCH AND ACTIVISM

This study, contributes to knowledge about scholar-activists conducting research in their movement as an offering of concrete research experiences no just ethnography. Yes, theory and practice are not always in harmony in the daily life of activists. Advocacy is a living act in constantly unpredictable political environments. There were productive tensions I encountered which are discussed in chapter four. Thus, as a scholar-activist your methods have embedded reflexivity to help not lose sight of our embodied positions within fields of power that can affect the production of knowledge.

It is my orientation and personal experiences of systematic marginalisation of women voice in knowledge production in AIDS movement that led to me embarking on this journey in foreground women's experiences participation in scholarship. Our lives and perspectives in fieldwork were at fore because they have consistently been left out of scientific studies where men's constitution in the AIDS movement were supposed to encampusing all our movement experiences (Gilbert 1994: 90, Moss 2002: 3). It also not just by default those women's insights had to be at the centre, it is because the hold majority position in the TAC membership of working-class township youth and unemployed African women and HIV positive like me. Therefore, they represent those marginalised by an unjust health system and often excluded from participation in politics by their own communities based on their status. Without women activists in Khayelitsha and Lusikisiki who contested the government ART rollout and led in the shifting movement advocacy strategies after 2003, it would be short-sighted if this study missed to document their contribution. As discussed by Mottiar and Dubula, that women activists roles proved to be fundamental in shifting consciousness and building the movement despite the social and cultural identities imposed on them The idea of 'giving voice to' women and their personal lived experiences as women activists myself is an important part of the political agenda of feminism, social justice and emancipation.

In the later part of this thesis I grappled a lot with creep of distant research and proximate myself in the research. This inherent tension and contradiction to my beliefs that I can be a transparent reflective scholar-activist was harder that I imagined. The locating of the researcher in a detached position outside power, and the view on power as something knowable turns scholar-activists' demand for transparent reflexivity into a 'goddess trick' that is no better or different from the 'god trick' of positivist science (Rose 1997: 311). "However, the researched must be placed in a different position from the researcher since they are separate and different from her. Differences between researcher and researched are imagined as distances in this landscape of power," (Rose 1997: 312). My positionality of holding both identities of researcher and researched remained in my thoughts about who has 'more or less power each time I want to assert my voice. The (constant) difference between researcher and participants is understood as distance, which is an effect of the material and analytic power of the researcher.

9.7 CONCLUSION

This chapter explored the implications of the research findings for participation and social movement theories, and it put forward entry points for a discussion that should be broached on participation praxis and social movement research (mainly based on existing research on poor people's movements in South Africa). In addition, it made recommendations for future research. This project signposts the need to advance and sharpen the theory and analysis of participation. We need to rebuild our definitions and theories of participation, because the term has become so loosely used in current discourse as to become almost devoid of meaning. A nuanced approach is employed by putting socio-political and historical conjectures, ruptures, trajectories and flows into consideration. Bottom-up participation, in particular, cannot be extricated from the definition of advocacy and democracy. This study also demonstrates that Khayelitsha and Lusikisiki are places of transformation and hope for a better world to come. This highlights a key aspect of transformative approaches to participation, securing the participation of marginalised groups. However, a closer analysis of the literature on transformative approaches to participation when applied to this situation suggests limitations that these movements hold for reaching transformation, since none of them seek to engage with immanent development, that is, development as an underlying process of social change.

Similarly, this suggests that when the state fails to meet the basic needs of its citizens, it is inadvertently asking the people to engage in collective action — for better or worse. This study thus shows the need for scholars to go beyond policy victory and attempt to gain an understanding of the implementation from below through the lens of the actors involved.

This study also signifies the critical role played by popular participation during policy implementation. In Chapters Five and Seven, the TAC shifts its advocacy tactics in various ways when confronting the new implementation's structural challenges. It suggests that the TAC Khayelitsha and Lusikisiki activists became more militant during ART service delivery, in order to exert power in relation to their own conditions and on their own terms. They reshaped the perceived passive role of grassroots activists in implementation by transforming practices between health providers and patients. The grassroots activists' tactics were flexible enough to endure the shifts in political processes over time, still straddling between the confines of cooperative relations with the state. Therefore, in the context of Khayelitsha and Lusikisiki, state created participation spaces such as AIDS councils and clinic committees deemed non-

functional or non-existent for its intended purpose. In addition, activists created new extra-institutional spaces constituting the quintessence of rationality of grassroots advocacy action. Activists create an alternate opportunity structure to climb the conventional participation "ladder", attain socially just policies, and service delivery. As I argue in chapter Eight, several activists have endeared themselves to the people of their communities through the social services they render. Despite having reservations about the AIDS councils, the activists' engagements are crucial to shaping AIDS policy in their provinces. This research provides an empirical example drawn from a country democracy and how that liminality both enabled and disenabled various repertoires of protest. It accentuates the theoretical currency of the political process paradigm, particularly the notion of contentious politics. It reinforces the relevance of the framing perspective. This study is a testament to the relevance of master frames such as the injustice frame, environmental justice frame, return to democracy frame, and human rights and minority rights frames.

In conclusion, this thesis brings together an analysis and summary of the findings against the study research questions. The answers to these questions assist in understanding the nature of the bottom-up participation by AIDS activists from Khayelitsha and Lusikisiki that followed the dramatic 2003 ART policy changes. This chapter also highlights the broader empirical and theoretical implications of the study and points to possible future research. This is a contribution to the disciplines of development studies, political economy, public health literature, sociology, political science, and social movements, among others.

9.7 AREAS FOR FUTURE STUDY

There are several areas for further investigation. First, a longitudinal study of movement members participating in the ongoing policy implementation in Khayelitsha and Lusikisiki will help to assess the success of the TAC contribution in health governance over time. This is particularly relevant as a way of understanding future trajectories of grassroots participation in service delivery. Secondly, considering the important role of women in social movements, particularly in AIDS policy development, I believe that this topic calls for a more directed study on women's contributions to development. Finally, a cross-regional comparison between TAC and groups like ARASA, BONELA and Nigeria Treatment Access Movement will provide fascinating academic material. A comparison between these and TAC's advocacy tactics in

policy implementation may reveal nuances in typologies of participation and movement evolution from other contexts where a human rights legislative framework is limited.

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ADDENDUM A: ETHICAL CLEARANCE

UNIVERSITY OF KWAZULU-NATAL
INYUVESI YAKWAZULU-NATALI

09 December 2014

Mrs Vuyiseka Dubula-Majola (213572908)
School of Built Environment & Development Studies
Howard College Campus

Dear Mrs Dubula-Majola,

Protocol reference number: HSS/1148/014D
Project title: "Too poor to be treated": Bottom-up advocacy by HIV+ activists in Khayelitsha and Lusikisiki, South Africa

Full Approval Notification – Committee Reviewed Protocol

This letter serves to notify you that your response received on 24 November 2014 to our letter of 12 November 2014 was reviewed by the Humanities & Social Sciences Research Ethics Committee, has now been granted **Full Approval.**

Any alterations to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. Please quote the above reference number for all queries relating to this study.

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

The ethical clearance certificate is only valid for a period of 3 years from the date of issue. Thereafter Recertification must be applied for on an annual basis.

Best wishes for the successful completion of your research protocol

Yours faithfully

[redacted]

.....
Dr S Singh (Chair)

/ms

cc Supervisors: Professor Patrick Bond and Dr Shauna Mottiar
cc Academic Leader Research: Professor MP Sithole
cc School Administrators: Ms Meera Dalthaman

Humanities & Social Sciences Research Ethics Committee
Dr Shenuka Singh (Chair)
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban 4000
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Website: www.ukzn.ac.za

ADDENDUM B: CONSENT FORM

Informed Consent Form

My name is **Vuyiseka Dubula-Majola (student number 213 572 908**). I am completing a PhD on Public administration and politics and investigating participation in policy development and implementation by HIV/ activists: a bottom-up perspective from Khayelitsha and Lusikisiki.

The Objectives of the study are:

1. To critically examine participation in policy development and implementation by people and social movements affected by HIV/AIDS in Khayelitsha and Lusikisiki, within a national context of dramatic changes in the balance of forces between 2004-2014, which led to AIDS treatment access breakthroughs (and setbacks).

2. To critically evaluate the impact of participation in policy and implementation on subsequent, more nuanced policy development and also on participants, especially advocacy-oriented social movements.

My supervisor is Prof Patrick Bond and co-supervisor Dr Shauna Mottiar at the Centre for Civil Society, School of Built Environment and Development Studies, University of KwaZuluNatal. Should you have any questions you can contact my supervisors Prof Bond at pbond@mail.ngo.za and Dr Mottiar at Mottiar@ukzn.ac.za. You can also contact the University of KwaZulu-Natal's Research Office: Tel: +27 31 260 8350, Email:

snymanm@ukzn.ac.za

You have been identified through a process called purposive sampling which selects people with special insights in the topic area. You will be required to participate in an interview which will take between January-April 2015. The interviews will be conducted in Khayelitsha, Pretoria, Johannesburg, Lusikisiki and East London. The interview will take between 45 – 60 minutes and will be conducted mostly in English and Xhosa. You may stop the interview and continue again at your convenience. The interviews will be recorded and if you are uncomfortable about this please indicate and the recorder will be switched off.

There are no financial or any other material benefits of participating. However, you will be reimbursed for your travel expenses.

All data collected will be kept in a locked cupboard and only I will have access to the keys.

I will refer you to some of these organisations listed below, at your convenience should you require future support and management:

1. AIDS Consortium 011 403 0265
2. Hiv911: http://www.hiv911.org.za
3. Lifeline South Africa Tel: (+27 11) 715-2000 or (switchboard cell): 082-231-0805
4. Aids Training, Information and Counselling Centre (ATICC): tel 021 763 5320/1/2/3
5. National Association of People Living with HIV/Aids (Napwa): tel 021 424 1106
6. Treatment Action Campaign (TAC): 021 422 1700
7. Section27: 011 356 4100
8. SA Human Rights Commission (SAHRC): tel 011 484 8300
9. Khethimpilo 0861 543 844
10. Doctors Without Borders (MSF): 011 403 4440

At the end of this research the data will be destroyed and a research report published. I will also present the findings at a workshop.

If you wish to contact me or have any questions my contact is: Vuyiseka Dubula-Majola, email address: dubulav@gmail.com mobile number: 082 763 3005 or 076 492 6216

Thank you for agreeing to take part in this study and the researcher would like to emphasize that:

a) Your participation is entirely voluntary;
b) All real names will be replaced by codes to ensure confidentiality and anonymity;
c) You are free to refuse to answer any question;
d) You are free to withdraw at any time without providing reasons and this will not disadvantage you in anyway.

I ---------- (Full names of participation) hereby confirm that I understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

I understand that I am at liberty to withdraw from the project at any time, should I so desire.

Additional consent, where applicable I
hereby provide consent to:

Audio-record my interview/ interview	YES	NO
Use of events photographs (organisational)	YES	NO

SIGNATURE OF PARTICIPANT DATE

Write your address below if you wish to receive a copy of the research report

ADDENDUM C: INTERVIEW GUIDE

1. HIV ACTIVISTS, SOCIAL MOVEMENTS AND NGOS

- Please share your journey about how you became involved in policy processes
- Please share your views and experiences about bottom-up advocacy by HIV activists, what kind of advocacy should they be involved?
- What role should NGOs and social movements play in supporting activist's participation in policy design, implementation when necessary and advocacy?
- Please share your experiences about the period after 2003 HIV policy shifts, did this affect your role as HIV activists and your movements and in what way?
    - Are there examples of HIV/AIDS policy development influenced by participation of HIV activists, especially social movements such as TAC and NAPWA, and how did a changing policy context affect these organisations?
- Considering the policy changes what in your view and experiences should be or has been the mandate of the AIDS councils?
    - In your view does it fulfil this mandate? If yes how, if no why do you think so?
    - Who sets the agenda of SANAC and why? Please give an example where you felt that you contributed to the agenda setting.
    - Are people living with HIV/AIDS seen as critical policy actors at various levels of policy development? Please share an example (*some examples HIV testing policy, Treatment Guidelines, CHW policy, stock-outs etc.*) that demonstrates your impact in HIV/AIDS policy development and implementation in South Africa. What platforms are there for people living with HIV/AIDS to participate other than SANAC?
- Can you remember how you forged coalitions with other movements and how did that help or set your policy goals? Which organisations did you see as on the opposite side from you and why?
- What are the views your identity as an HIV activist *both* as an individual and as members of a social movement? o Can you recall how if there have been any changes in this identity and what brought that change about?

- Did you experience any HIV related stigma and discrimination while participating in policy making and implementation? If yes how did that experience impact on your identity construction; or your degree of participation?

2. NATIONAL, PROVINCIAL AND LOCAL POLICY ACTORS

- Can you recall the 2003 ART announcement and what did it mean for public administration o Are there any shift that emerged in relations and connection between public administration and HIV activists post 2003?
    - How did these shifts occur? positive or negative?
- In your view what remains to be the role of AIDS councils post ART 2003 as compared to before ART period o What do you think should the mandate of the AIDS councils's during this period? Is this the case and why do you this it is or it is not?
    - Who sets the agenda of these AIDS councils and why?
    - What in your view should membership of AIDS councils be based on especially post 2003 ART victory? Is there still a need for inclusion or not of people living with HIV/AIDS? And Why
    - In your view what should be the role of NGOs and social movements post ART victory in 2003? Are there any examples of how this being currently done or can be done?
    - Are there any examples of bottom-up policy advocacy by HIV activists from Khayelitsha and Lusikisiki? (*question only for provincial and local health officials*)
- In your view what are the successes, gaps and structural challenges that remain to be addressed?

What do you think are biggest major HIV/AIDs policy development and implementation challenges facing South Africa today? What do you think should be done? And what is the role of local – provincial – national – international HIV activists and government in that?

ADDENDUM D: LIST OF INTERVIEWS

1	WCgovt001-Interview	WC Government- Health
2	SANAC002-Interview	SANAC
3	SANAC003-Interview	SANAC
4	ECAC004-Interview	ECAC
5	TAC005-Interview	TAC
6	Independent006-Interview	INDEPENDENT ACTIVIST
7	NGovt007-Interview	National Government
8	TAC008-Interview	TAC
9	TAC009-Interview	TAC
10	TAC0010-Interview	TAC
11	HCW0011-Interview	Health Care Worker
12	TAC0012-Interview	TAC
13	TAC0013-Interview	TAC
14	TAC0014-Interview	ACTIVIST – interview incomplete
15	TAC0015-Interview	TAC
16	TAC-0016-Interview	TAC
17	TAC-0017-Interview	TAC
18	TAC0018-Interview	TAC
19	TAC-0019-Interview	Interview incomplete
20	TAC-0020-Interview	Interview incomplete
21	TAC-0021-Interview	Interview incomplete

22	TAC0022-Interview	TAC
23	TAC0023-Interview	TAC
24	TAC0024-Interview	TAC
25	ECDoH0025-Interview	EC Government interview incomplete
26	NGovt0026-Interview	National Government
27	NGovy0027-Interview	National Government
28	MSF0028-Interview	MSF
29	TAC0029-Interview	Interview incomplete
30	TAC0030-Interview	TAC
31	NAPWA0031-Interview	Interview incomplete
32	TAC-0032-Interview	Interview incomplete
33	TAC0033-Interview	Interview incomplete
34	TAC0034-Interview	Interview incomplete
35	TAC0035-Interview	Interview incomplete
36	TAC0036-Interview	TAC
37	TAC-0037-Interview	TAC
38	NGovt0038-Interview	National Government
40	NAPWA0039-Interview	Interview incomplete
41	NGovt0040-interview	National Government
42	TAC-0041-Interview	Interview incomplete
43	TAC0042-Interview	TAC
44	NAPWA0043-Interview	NAPWA

45	NAPWA0044-Interview	Interview incomplete
46	NAPWA0045-Interview	Interview incomplete
47	MSF-0046-Interview	MSF
48	TAC0047-Interview	TAC
49	TAC0048-Interview	TAC
50	TAC0049-Interview	TAC
51	PWN0050-Interview	Interview incomplete
52	HCW0051-Interview	Health Care Worker
53	PWN0052-Interview	Interview incomplete
54	TAC0053-Interview	Interview incomplete
55	TAC0054-Interview	TAC
5	Section27 0055-Interview	SECTION27
56	Indep0056-Interview	ACTIVIST
57	NGovt057-Interview	National government
58	MSF0058-interview	MSF
59	MSF0059-Interview	MSF
60	TAC-0060-Interview	TAC
61	HCW-0061-Interview	Health Care Worker
62	Presidency0062-Interview	Presidency
63	NAPWA0063-Interview	TAC
64	TAC0064-Interview	TAC
65	TAC0065-Interview	TAC
66	MSF0066-Interview	MSF

67	TAC0067-Interview	TAC
68	TAC0068-Interview	TAC
69	TAC 0069-Interview	TAC
70	TAC 0070-Interview	TAC
71	TAC 0071-Interview	TAC
72	TAC 0072-Interview	TAC
73	TAC0073-Interview	TAC
74	Indpendent0074-Interview	INDEPENDENT ACTIVIST
75	TAC 0075-Interview	TAC
76	TAC0076-Interview	TAC
77	TAC0077-Interview	ACTIVIST
78	Indep0078-Interview	INDEPENDENT ACTIVIST
79	TAC0079-Interview	TAC
80	Presidency0080-Interview	Presidency
81	TAC0081-Interview	Interview incomplete
82	TAC0082-Interview	Interview incomplete
83	Indep0083-Interview	INDEPENDENT ACTIVIST
84	TAC0085-Interview	TAC
85	TAC 0086-Interview	TAC
86	CAPRISA0087 interview	CAPRISA