WOMEN’S ACCESS TO NEVIRAPINE TO PREVENT MOTHER-TO-CHILD TRANSMISSION OF HIV: A CASE STUDY OF POLICY DEVELOPMENT IN SOUTH AFRICA

by

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A thesis submitted in conformity with the requirements for the degree of Master of Science
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ABSTRACT

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South Africa (SA) houses the greatest number of HIV+ people in the world. Studies suggest that the second leading mode of transmission, via mother-to-child (MTCT), could be reduced by 50% through a prevention program using a two-dose Nevirapine regimen. The SA Government initially stalled full rollout of such a program, opting for an 18-site pilot program instead. In response, an advocacy group, the Treatment Action Campaign (TAC) successfully challenged and overturned the government’s policy in court.

Purpose: To understand both the policy process that initially rejected and then brought about a nation-wide Nevirapine-centered MTCT prevention program, and the related perspectives of the TAC and other stakeholders, including physicians. Methods: Mixed methods including qualitative interviews with 21 policy stakeholders. Results: Multiple factors influenced policy development including divisions within government, leadership styles, government-civil society relationships, policy-related barriers, and activist pressure. This case was also characterized by subversion of formal policy by physicians.
This project had ambitious goals, and required input and support from a number of “experts”, not to mention a number of ethics review boards. Thus the project relied on the contributions of many individuals for success. With respect to the “experts”, who provided hours of their time giving feedback, pointing me in the right direction, and helping me to clarify my thoughts, I was fortunate to have worked with some of the most distinguished scholars in a variety of fields. James Orbinski helped me sort out the initial focus and approach for this study. His insights have proved invaluable.

My committee members, Terry Sullivan, Bev Chalmers and Richard Lee all provided unique advice. Terry – thank you for clarifying the world of policy, it can be a scary place. Bev – your ability to integrate social and biological aspects of health in a meaningful way will be remembered as I move into more clinical settings in my education. Professor Lee – thank you for opening my eyes to the world of anthropology and for many great experiences along the way.

Solomon Benatar, who acted as my South African field supervisor, was an indispensable source of knowledge. Dr. Benatar – thanks for having the confidence to support me, and this project. It is an honour to be associated with an academic and physician of your caliber.

Peri Ballantyne was my supervisor. There is no way to express my gratitude for the unfailing help, guidance and support she provided. Peri – your enthusiasm in opening my eyes to new areas, in constantly seeking to improve my learning experience and in supporting my ideas for this project have motivated me to persevere in the face of
obstacles. My thoughts and ideas have matured through the two-years of discussion, collaboration and learning that I have experienced under your mentorship. Thank you!

I also extend my gratitude to the Canadian International Development Agency (CIDA), the body that funded this project, as well as the Canadian Bureau for International Education (CBIE), who administered the funding.

In addition to the “experts” who spent hours consulting on this project, my family has been a source of ongoing love and support throughout the past two-years. Mom and Dad – thank you for always encouraging my adventures even when you didn’t want to, and for instilling in me the confidence to seize opportunities, big and small. Mom, I also thank you for the days and days you spent assisting with interview transcriptions. I might still be transcribing had it not been for your help. Steve – this thesis would not exist without your unconditional love and encouragement; thank you for always believing in me. Thank you for your patience in living through weeks of thesis writing with me (and for 3-months without me). Thank you for your help proofreading and for your figure-making expertise. More importantly, thank you for reminding me that there is more to life than a thesis!

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In recognition of the plight of many people living with HIV/AIDS globally, many of whom live without access to treatment (including many in South Africa), I would like to open with a story of one man’s experience. This story reminds us, in a highly political
world, that real people – people with families, hopes, dreams and aspirations – both reap the rewards and, in this case, suffer the consequences of policy outcomes.

More than 42 million people live with HIV/AIDS, with the vast majority living in low- or middle-income countries, and over 29 million living in sub-Saharan Africa (UNAIDS 2002a). Fewer than 4% of people in need of antiretroviral treatment in low- and middle-income countries were receiving these drugs at the end of 2001 (UNAIDS 2002a). Further, less than 10% of people with HIV/AIDS have access to palliative care or treatment for opportunistic infections (UNAIDS 2002a).

Mzokhona Malevu’s story explains what this disease is like for many of the people who suffer from AIDS and live in poverty, with no access to treatment and limited access to other medical care. His story is told in words and pictures in Gideon Mendel’s book, *A Broken Landscape* (Mendel, ActionAid (Organization), and Network Photographers 2001). Mzokhona’s family lives in a squatter camp in Enseleni Township, near Durban, South Africa, having lost their home during political violence in 1992. Mzokhona lived with his mother, father, 7 siblings and his 11 nieces and nephews – 21 in total, and shared a room with 7 of his nieces and nephews. His father does piecework on construction sites when jobs are available, and his mother is a maid for whites in Richard’s Bay. As Mzokhona recounted before his death:

> Sometimes we do not have enough food to go round. My father usually bathes me early in the morning before he goes to work, but since recently we have had to pay for water which he collects at the communal taps. It is 60 cents a bucket. Now even some water for washing can be a problem. (Mendel, ActionAid (Organization), and Network Photographers 2001:74)

Mzokhona further explained:

> I was given some drugs, which made me feel much better, but I cannot afford them now. I have heard that in overseas countries the government provides drugs
and food free for people with AIDS, but here in South Africa there is nothing now. At the clinic they often say there is nothing they can do. You must go home. It is not fair. People overseas can get better from the good drugs they are given, while we in South Africa have to die. (Mendel, ActionAid (Organization), and Network Photographers 2001:74)

Mzokhona died at age 29, not long after this interview was given. As you read this thesis, remember that the lives of people like Mzokhona can be altered for better or for worse, by the policy choices made in South Africa.
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On March 9, 2000 Justice Edwin Cameron, Acting Justice of the Constitutional Court of South Africa, made the following statement during his address at the Gala Dinner of the Second National Conference for People Living with HIV/AIDS, held under the auspices of the International AIDS Conference in Durban, South Africa in 2000:

...the fourth, and final matter for concern about current government policy... concerns the provision of anti-retroviral medication to pregnant mothers and their infants. It is correct, as has been emphasized, that there are many questions in the AIDS epidemic that are still unanswered. There are many things that we do not know about the virus, about the human body, and about human society and human behaviour in it. Nevertheless, there are many things that we have in fact learnt about AIDS, and about ourselves in how we respond to AIDS. Since 1994, very detailed and careful scientific and medical studies have been done on how to reduce the risk that a mother with HIV will transmit it to her baby during or after birth. The overwhelming scientific consensus is that effective anti-retroviral medication can be made available in a developing country to reduce transmission. Every month in our country, approximately five thousand babies are born with HIV. Medicines exist that, now, can reduce this figure by half. Economists have done detailed studies that show that this medication can be made available cheaply and affordably. Their studies have also shown that, from a purely economic point of view, it is better to save young babies from getting HIV than to let them fall sick and die of AIDS, and that intervention will save the country money. In brutal terms, it is cheaper to have a healthy orphan than a sick, dying orphan. So overwhelming is the medical, scientific and economic consensus on these points, that many people find it almost impossible to understand why our government is still delaying the immediate implementation of programs to prevent mother to child transmission of HIV. (Cameron 2000)

The thesis that follows develops an analysis of why Justice Cameron’s argument, supported by physicians and activists throughout the country, was on its own, not enough to persuade the South African Government to implement a comprehensive, nation-wide program to prevent the transmission of HIV from mother to baby.
1.1 INTRODUCING THE PROBLEM

1.1.1 Statement of Research Problem

Justice Cameron’s comments identify some of the brutal realities of AIDS in South Africa, and the related failure of government to develop a broad-access policy for the prevention of mother-to-child transmission of HIV (PMTCT). The following case study examines the development of PMTCT policy using the antiretroviral drug Nevirapine. The intent of this study is to understand the policy process that initially rejected and then eventually brought about a nation-wide Nevirapine-centered PMTCT program. This study further explores the role that local treatment advocates, namely the Treatment Action Campaign, and practicing physicians played in influencing the South African Government’s national policy.

1.1.2 A Brief Description of the Case

HIV/AIDS has ravaged South Africa. Current estimates indicate that every year over 70,000 children are born with HIV due to mother-to-child HIV transmission (MTCT) (Treatment Action Campaign 2001b). In response to this unsettling state of affairs compounded by a lack of access to treatment, in December 1998 the Treatment Action Campaign (TAC) was founded. The initial campaign of this treatment advocacy group put pressure the South African Government to implement a program whereby all HIV+ pregnant mothers could access drug interventions to prevent transmission to their babies (Treatment Action Campaign 2001a).
In January 2001, in the face of concentrated pressure, applied most vocally by the TAC, the Department of Health announced that they would begin an 18-site PMTCT pilot project (kaisernetwork.org 2001; Smith 2001). The Department’s program included the provision of the antiretroviral drug, Nevirapine, as well as milk formula¹ (Smith 2001). As mentioned by Justice Cameron, two doses of the drug Nevirapine, one to the labouring mother and one to the baby after birth, reduce the rate of MTCT by 50%.

However, by restricting the pilot project to only 18 sites, access to this important drug by citizens with HIV varied widely. For example, doctors working in the public health care system, outside of the designated sites, were precluded from prescribing Nevirapine, even when medically indicated and where the necessary support services for administration of the drug were available. Yet, women with private insurance, who received care outside of the public system, could access Nevirapine with a prescription from their physician.

Health activists, led by the TAC, have taken issue with this strategy involving a limited-access program, as Nevirapine is considered a life-saving medication. Most South Africans cannot afford access to private health care (Treatment Action Campaign 2001b). Thus, the TAC and its partners claimed that the government’s policy discriminated against the poor, which in the South African context amounted to discrimination on grounds of race as well. The TAC also argued that the government was threatening their citizen’s constitutional rights to health (Treatment Action Campaign. 2001b). Eventually taking their claim to the courts in August 2001, the TAC used the

¹ Transmission of HIV from mother-to-child can occur in pregnancy, labour and through breast milk. The initial strategy used to prevent breast milk transmission was to replace it with formula feed. This approach has been recently challenged due to the cost, cultural inappropriateness, and health concerns associated with formula feeding. These issues will be elaborated on in more depth in Chapter 2.
liberal\(^2\) South African constitution to argue their case (Treatment Action Campaign 2001b). After a series of decisions and appeals, in July 2002 the Constitutional Court of South Africa upheld the TAC’s position, and charged the South African National Government with the responsibility of expanding access to PMTCT using Nevirapine to all those in need of it.

\[\text{1.2 INTRODUCING THE STUDY}\]

\[\text{1.2.1 Reflexivity and Thinking About the Problem}\]

In this study, a qualitative case study approach (Creswell 1998) is taken to understand the policy process as it related to PMTCT in South Africa. Qualitative research, like other types of research, requires that choices be made by the researcher; in qualitative research these choices include everything from the selection of the topic of study and mode of inquiry, to decisions regarding recruitment, the interpretation of information and its selective presentation in final reports. Value is added to the research data when it is made clear how and why these choices were made, therefore qualitative research encourages reflexivity (Berg 2001; Stake 1995). Reflexivity entails identifying researcher biases and making them clear to readers. However these biases are not always obvious to the researcher herself. Therefore introducing the background of the researcher will help readers to participate in the evaluation of potential biases. Thus, throughout this thesis I attempt to be as clear as possible on how choices and decisions were made in the

\(^{2}\) Because the current South African constitution was tabled in light of the travesties, human rights violations, and inequities experienced during Apartheid, it is thought to be the most progressive and liberal constitution in the world in terms of the rights it aspires to secure for the people of South Africa.
research process and indicate my own biases where I feel they exist. I begin in this section by outlining my perspective on the HIV/AIDS and PMTCT issue at the outset of the research process.

Introducing the Researcher

Prior to beginning this study I had some understanding of the HIV/AIDS epidemic and some of the common themes associated with it, for example, stigma. Yet, upon embarking on the research process I believe I became indoctrinated into what I will call “the orthodoxy of AIDS”, that is the common line of thinking held by a majority of AIDS researchers and propagated at events like International AIDS Conferences. For example, at the 2002 International AIDS Conference in Barcelona, the central message was for access to treatment, that is to say, access to primarily long-term, life-sustaining antiretroviral drugs for people in the developing world. Developing countries, in particular those in sub-Saharan Africa, have been hardest hit by the AIDS pandemic, yet have the most restricted access to these much needed medicines for a multitude of reasons including patents, prices, and governments’ failure to act. This does not exclude other important factors like infrastructure and capacity, however the message delivered at Barcelona was that these barriers (infrastructure, capacity, and the like) could be overcome by the goodwill of pharmaceutical companies and the dedication of governments in both developed and developing nations. The argument for treatment access is a highly political one: failure to institutionalize treatment in poor countries

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3 Stigma originated as a term used by the Greeks to refer to “bodily signs designed to expose something unusual and bad about the moral status of the signifier” (Goffman 1963). Stigma, as it relates to HIV/AIDS, is pervasive; as this disease is to a great extent sexually transmitted its victims are often viewed as culpable for acquiring the virus, which left untreated results in death in a matter of years.
results in continued AIDS-related denial, silence and stigma by maintaining HIV-infection as a death sentence. Having attended the 2002 Barcelona Conference, and through my preliminary research, I have been persuaded by the TAC’s argument for treatment, which is based on the moral position that access to life-saving treatment is a human right. Arguments of this nature have been so persuasive that I have shifted the focus of my student activist career, by being involved in the inaugural campaign of a national student AIDS activist coalition in Canada. Nevertheless I have attempted to keep an open mind with respect to my own research and have been interested to learn why the TAC’s argument may not be viable. To this end, it is prudent to recognize that, as with any political issue, there are a variety of perspectives involved. While my perspective, which directed the research, has been identified, the points of view that are not adequately addressed in this thesis should also be noted.

Multiple Perspectives and the PMTCT Problem: Identifying the Overarching Paradigm Influencing this Research

Justice Cameron’s comments are perhaps an appropriate introduction to this thesis as they represent the dominant perspective addressed here: treatment works, based on well-established science, and therefore it should be accessible to all as a matter of fulfilling every human’s right to health. This standpoint prioritizes Western, scientific-positivist medicine, and accordingly, excludes some other epistemologies, like traditional African conceptions of health and illness (Chalmers 1990). While the Western biomedical perspective has been the basis for the TAC’s argument against the government in this case, it clearly does not represent the views of all those affected by South African policies. Moreover, an individual’s right to health, like all human rights
dogma, may not be universally applicable in that it places too much emphasis on the autonomous individual (Howard 1995; Tangwa 2000). That is, the concept of “human rights”, as spelled out in United Nations (UN) sanctioned documents, isn’t necessarily appropriate in cultures where communalism is a key organizing principle, such as in many African cultures (Chalmers 1990:4). Nevertheless, the South African constitution is thought to be the most liberal in the world, in terms of the individual human rights it aspires to guarantee. I bring up these differing perspectives here because the interplay between them is not addressed adequately in this thesis, particularly since many of the participants interviewed for this research propagate a Western viewpoint which gives primacy to the self-governing individual, subscribes to scientific thought and accepts conventional medical interventions. Because distinct African ideas about health, illness, and healing, as well community, as compared to individuality, are underrepresented in this work, it is essential that their existence be acknowledged. Recognition of the different belief systems that underlie this case is crucial, precisely because the dominance of Western thought pervades this work, as it is pervasive on the global stage.

1.2.2 Purpose

In order to address the complexities of access to essential HIV/AIDS medicines in the developing world from a national, government policy perspective, this research involves the exploration of the politics of drug access in South Africa, focusing specifically on the prevention of mother-to-child transmission of HIV using Nevirapine. This focus is centered on the brief description of the events precipitating current government PMTCT policy, from January 2001-July 2002 (discussed above). However,
these events are situated within PMTCT policy generally, as well as broader AIDS policy. Therefore, the research aims to explicate the policy process that has led to piecemeal, incremental drug access to Nevirapine for PMTCT, making reference to the underlying context of both PMTCT policy at-large, and the broader response to AIDS in South Africa. Furthermore, the research attempts to identify historical, political, social and cultural legacies and beliefs in South Africa that have influenced the current policy environment. Finally, I examine the ideologies, agendas, methods of advocacy and outcomes of the Treatment Action Campaign and other treatment proponents, as well as the perspective of health care providers, throughout this policy process. My analysis is informed by the relevant literature that predates my fieldwork, but is based primarily on information extracted from qualitative interviews with key informants (policy stakeholders) conducted in South Africa, and supplemented with data obtained through participant observation at XIV International AIDS Conference in Barcelona, and via my participation on an intellectual property and health internet listserv.

1.2.3 Objectives

There are five objectives of this study: two primary objectives, two secondary objectives and a post-study objective regarding dissemination of the research.

Primary Objectives

A. To describe the policy process that brought about the decision by the current South African Government to implement pilot programs to prevent MTCT using Nevirapine. This objective aims to describe the rationale behind the decision that specifically rejects more comprehensive access/universal accessibility.
B. To explore the events subsequent to the implementation of pilot programs that have resulted in continued pressure on the government to implement a more comprehensive program.

Secondary Objectives

C. To evaluate the ideologies, agendas, and activities of health activist groups, including the Treatment Action Campaign, and similar social movements, focusing on the strategies used and outcomes relevant to the Nevirapine-based PMTCT policy process.

D. To understand the perspectives of health care providers from both inside and outside relevant activist groups, as they relate to the Nevirapine-based PMTCT policy process, and particularly as they relate to the actual delivery of care to patients.

Ongoing Objective

E. To disseminate the research widely; including to all research participants and major policy stakeholders both within and outside of South Africa.

1.3 CHAPTER SUMMARY

This thesis continues in five subsequent chapters. Chapter 2 reviews the relevant literature, Chapter 3 explains the methods for the study, Chapter 4 and 5 present results, and Chapter 6 presents the discussion.
Chapter 2 sets the stage for this research by providing a broad review of the literature. It places Nevirapine PMTCT policy within the global struggle for access to medicines, and considers technical information related to Nevirapine, including the costs associated with a Nevirapine-based PMTCT program. This chapter also explores the impact of Apartheid on health services in South Africa and the current government’s obligations for health care based on the Constitution. Finally, the development of AIDS policy in South Africa, within which the Nevirapine PMTCT policy process is situated, is reviewed.

Chapter 3 describes the methodology used in this research: a qualitative case study. The general epistemology of the three broad approaches that informed this study are discussed; these are case study research, ethnography and the Advocacy Coalition Framework (for understanding policy change). Next, the research process is described chronologically, and the multiple sources of data for this study are noted.

Chapters 4 and 5 present the results based on these multiple sources, but focused primarily on qualitative interview data with 21 policy stakeholders. These chapters represent what was learned about the case during this study, in line with research objectives. Chapter 4 presents a detailed discussion of the government’s role in Nevirapine policy, placed in the context of the broader response to AIDS, and Chapter 5 explores the ideologies, views and activities of civil society actors who responded to the government’s limited-access Nevirapine policy. Chapter 4 attempts to address objectives A and B, and does so by highlighting a number of themes identified by participants as helpful in understanding PMTCT policy development. These include political and bureaucratic distinctions within government as well as provincial and national
governmental divisions. With respect to historical factors, themes also address early inaction by government, and a number of important policy events that were identified as preemptive to the PMTCT response. Political and social factors are noted, including concerns of intra-governmental loyalty, and styles of leadership. Lastly, practical themes (like implementation barriers) are addressed. Chapter 5 speaks to objective C and D, and is focused on describing the roles, perspectives and motivations of the TAC and physicians/researchers in the PMTCT policy process.

Chapter 6 presents a discussion of the findings, and integrates these with some relevant literature and theory. The Advocacy Coalition Framework is among the literature referred to here.
CHAPTER 2: LITERATURE REVIEW

As this research was of an exploratory nature, potential issues of interest or concern in the PMTCT policy process were not known a priori, therefore the review of the literature that follows is broad, including reference to a number of areas that informed this study.

In general, PMTCT policy in South Africa is situated within the broader problem of HIV/AIDS; globally, sub-Saharan Africa is most affected by the HIV/AIDS epidemic, and South Africa is one of the most severely affected nations. Because PMTCT policy has centered on access to medicines to prevent transmission of HIV from mother to child, it is also situated within the international struggle for access to essential medicines, primarily for people living in developing countries. These issues, including reference to the scientific evidence behind Nevirapine as well as its cost in a PMTCT program, are addressed in Section 2.1.

More specifically, PMTCT policy is located within the politics of access to health care in South Africa. That is, PMTCT has become part of the political wranglings of the post-Apartheid African Nation Congress (ANC) Government which tabled a constitution aspiring to equal access to health care, in response to the institutionalized inequalities in access during Apartheid. The legacy of Apartheid on health care and the health-related constitutional obligations of the current government are examined in Section 2.2.

Finally, this study is informed by the limited number of research and opinion papers that have examined PMTCT policy and it’s development in South Africa. In addition, I have drawn on earlier articles that examine AIDS policy more broadly, as well
as relying on recent portrayals and explanations of South African PMTCT policy from electronic and media sources. These writings on PMTCT policy in South Africa leave a number of questions unanswered or inadequately answered - this research attempts to address a few of these. Thus, Section 2.3 reviews this literature and situates the current study.

2.1 AIDS, MOTHER-TO-CHILD TRANSMISSION AND ACCESS TO MEDICINES

International players have deliberated over approaches to the HIV/AIDS epidemic, constructing a selective discourse around which responses have been articulated. Players include media-savvy international activists who use a morally grounded and rights-based approach to lobby against pharmaceutical companies’ high drug prices and argue for the primacy of public health over patents (Booker 2001; Cameron 2002; ‘t Hoen 2003; Winestock 2001). In contrast, the pharmaceutical companies’ arguments favour the protection of existing patent regulations that allow them the opportunity for sizable profits; they concede occasional drug donations or price concessions, effectually portraying them as good-will ambassadors, caring for the unfortunate who are afflicted with HIV (Cherry 2000; Winestock 2001). Next are national governments, who decide on policy for their own countries, and in this way are actors on both the international stage as well as on an intra-national level. With respect to the former, the main area of contention in dealing with HIV/AIDS pertains primarily to
foreign aid policy. The issue here relates to whether developed countries are paying enough attention to the growing HIV/AIDS epidemic, most prevalent in developing nations, and specifically whether they are paying out enough to fund initiatives to slow down the epidemic (Harris 2001; Lee 2002; Weissman 2001). The activities of and relations among these international players are overarched and to some degree structured by bodies like the United Nations (UN)⁴, the World Health Organization (WHO), the World Trade Organization (WTO), and the World Bank through schemes like the UN-initiated Global Fund for AIDS, TB, and Malaria (Weissman 2001) and via international accords, like the WTO’s Trade Related Aspects of Intellectual Property Rights Agreement (TRIPS) (Cameron 2002; Quick 2003; ‘t Hoen 2003; Winestock 2001).

At an intra-national level, HIV/AIDS issues are equally controversial. However, here debate pertaining to government policy is primarily focused on how HIV/AIDS is addressed within nations; access to health care, the protection of citizens against discrimination, and the development of AIDS education and prevention programs are some of the issues at hand. These debates are normally staged between national governments and local non-governmental organizations (NGOs), advocacy groups and/or other members of civil society who have a vested interest in HIV/AIDS policy (Cameron 2002). In the developing world these national-level activities are also influenced by the large international organizations mentioned above⁵, as well as by more powerful nations,

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⁴ The United Nations also has its own “Joint United Nations Programme on HIV/AIDS”, called UNAIDS. UNAIDS is run in collaboration with the WHO, World Bank and other UN agencies, like the United Nations Children’s Fund (UNICEF).

⁵ For example, through World Bank supported Structural Adjustment Programs (SAPs), financial aid for developing countries was often tied to neoliberal conditions that included limiting government expenditure, especially on items not considered essential for economic growth, like social programs (Hewitt 2000). Consequently SAPs have been highly criticized for counterproductive outcomes; moreover, the debt accrued from any type of loan/aid program, including SAPs, often results in debt-servicing that constrains...
especially in terms of the financial aid developing countries receive and the attached conditions. Ironically, people living with HIV/AIDS, the group directly impacted by AIDS policies and activities, with minor exception\(^6\), have little influence in ongoing international debates. Instead it is assumed, inline with Western schools of thought on medicine and human rights, that it is morally unconscionable to limit access to these lifesaving drugs to only the privileged few (Andrews 2001; Cameron 2002).

Policy for the prevention of mother-to-child transmission (PMTCT) in South Africa is, as it sounds, a national-level policy (involving both federal and provincial governments). Therefore, in this continuum of varied actors, the focus of this research is limited to the South African government and civil society actors who have shaped the development of PMTCT policy. However, the other actors named above are referred to insofar as they have influenced PMTCT policy in South Africa.

2.1.1 The HIV/AIDS Epidemic in South Africa and Implications for PMTCT

South Africa is home to the greatest number of HIV-positive people, compared to any other country in the world (UNAIDS 2002b:190). The prevalence rate in the adult population is 20.1\%, however, the disease burden in women is disproportionately greater than in men (Gilbert and Walker 2002), with 2.7 million adult women infected, and 2 million men infected (UNAIDS 2002b:190). Biologically, women are more vulnerable to HIV (UNAIDS 2000); in Southern Africa women are socially vulnerable as well due to much of developing economies’ resources, diverting them from national-level programs (Benatar 2001; Hewitt 2000).

\(^6\) Zackie Achmat, the leader of the Treatment Action Campaign in South Africa is the immediately obvious example of a person living with HIV/AIDS who has had his voice heard in the international milieu. This however, is the exception rather than the rule.
their lack of control in sexual decision making\(^7\). Prevalence tends to be greater in poorer, mainly black areas. Prevalence rates at antenatal clinics in South Africa range from 8.7% to 36.2% depending on where the clinic is located (Adler 1999; UNAIDS 2002b). The implications for an epidemic of this magnitude are far reaching: it exacerbates the problems of poverty, homelessness and illiteracy, as well as having a potentially profound impact on the economy (some say the South African economy will contract by at least 20% by 2010) (Andrews 2001).

Next only to transmission via heterosexual intercourse, mother-to-child transmission (MTCT) is the leading mode of HIV spread (UNAIDS 1998), accounting for 70,000 babies being born HIV+ in South Africa each year (Treatment Action Campaign 2001b). Thus, more than 6% of the 1.1 million births in the country each year (UNICEF 2002) give rise to an HIV+ child. At the end of 2001 there were 250,000 children (aged 0-14) living with HIV/AIDS in South Africa (UNAIDS 2002b); this is indicative of the fact that these children die early, representing somewhere between 26,000 and 48,000 deaths per year (UNAIDS 2002b). Thirty-five to 59% of HIV+ African children die by their second birthday (Dabis and Ekpini 2002); data from Uganda and South Africa show 91% mortality by age eight (Soderlund, Zwi, Kinghorn, and Gray 1999). These disturbing figures are primarily due to HIV infection (life expectancy for uninfected children is 66 years (Soderlund, Zwi, Kinghorn, and Gray 1999)), because access to life-sustaining antiretroviral drugs is non-existent in the public health care sector of most African countries, although factors like poor nutrition and minimal access to basic health care services certainly contribute to these troubling statistics.

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\(^7\) Women’s lack of power is related to both the “relative economic, personal and social vulnerability of women” and “the cultural assumptions about relations between men and women and the subordinate status of women” (Akeroyd 1997:23).
Given this sizable problem, the considerations around how to reduce MTCT have weighty implications for reducing not only the virility of the virus, but for reducing the suffering of babies and for staving off the annihilation of the South African population. Options for reducing MTCT will be discussed next, as well as the potential for their safe, sustainable, equitable, and culturally appropriate implementation in South Africa.

2.1.2 Current PMTCT Strategies

UNICEF claims that access to antiretroviral drugs during pregnancy in conjunction with education, counseling, antenatal care, improved labour care, and postnatal support can reduce MTCT by 50% (UNICEF 2003). A number of review articles examine PMTCT strategies and their applicability in developing countries; the following summary of relevant approaches is based on these evaluations (Coovadia and Coutsoudis 2000; De Cock, Fowler, Mercier, de Vincenzi, Saba, Hoff, Alnwick, Rogers, and Shaffer 2000; McIntyre 2002). While elective caesarean sections, which aim to prevent fetal contact with maternal blood, can reduce transmission rates, they are not yet a feasible option in most resource poor settings (Coovadia and Coutsoudis 2000; De Cock, Fowler, Mercier, de Vincenzi, Saba, Hoff, Alnwick, Rogers, and Shaffer 2000; McIntyre 2002). Furthermore, transmission can occur through breast milk, therefore PMTCT strategies must consider how HIV+ mothers should handle infant feeding. While formula feed prevents contact with infected breast milk it is costly and often culturally inappropriate. Experts continue to debate the relative merits of breast milk versus milk formula products, particularly in environments where resources are constrained (Coovadia and Coutsoudis 2000; De Cock, Fowler, Mercier, de Vincenzi,
Saba, Hoff, Alnwick, Rogers, and Shaffer 2000; McIntyre 2002). Recent studies have indicated that the risk associated with exclusive breastfeeding early in babies’ lives (in the first 3 months), carries no greater risk of HIV transmission than does formula feeding (Coutsoudis, Pillay, Spooner, Kuhn, and Coovadia 1999). Further, it is important to recognize that in most rural environments in South Africa there is a favourable attitude towards breast feeding infants, and to do so is the socially accepted norm (Chalmers 1990); therefore, besides the disadvantage of cost, bottle feeding often identifies women as being HIV+, and subjects them to the stigma that still surrounds this condition (Goldin 1994).

**Antiretroviral Drugs and PMTCT**

In 1994, the landmark ACTG 076 trial established that antiretroviral drugs could be used to prevent MTCT (Connor, Sperling, Gelber, Kiselev, Scott, O'Sullivan, VanDyke, Bey, Shearer, Jacobson, and et al. 1994). A number of trials using various drugs and regimens have since been conducted, and some of these have implications for PMTCT in developing countries as they are simpler and/or cheaper than the ACTG 076 regimen (Guay, Musoke, Fleming, Bagenda, Allen, Nakabiito, Sherman, Bakaki, Ducar, Deseyve, Emel, Mirochnick, Fowler, Mofenson, Miotti, Dransfield, Bray, Mmiro, and Jackson 1999; Lange 2001; Shaffer, Chuachoowong, Mock, Bhadrakom, Siriwasin, Young, Chotpitayasunondh, Chearskul, Roongpisuthipong, Chinayon, Karon, Mastro, and Simonds 1999). Of the more recent studies with antiretroviral drugs for MTCT interruption, the HIVNET 012 regimen, which uses the drug Nevirapine (Guay, Musoke, Fleming, Bagenda, Allen, Nakabiito, Sherman, Bakaki, Ducar, Deseyve, Emel,
Mirochnick, Fowler, Mofenson, Miotti, Dransfield, Bray, Mmiro, and Jackson 1999), is currently favoured in resource constrained settings “in terms of feasibility, adherence and cost” as it only requires one dose given to mothers while in labour, and a second dose given to babies within 72 hours of delivery, compared to other regimens which require multiple doses to mothers and/or babies (McIntyre 2002). The efficacy of the HIVNET 012 Nevirapine regimen is approximately 50% in that it reduces the natural rate of MTCT (with no intervention) from approximately 30% to 15%8. A later trial conducted within South Africa further confirmed the safety and efficacy of short-course antiretroviral regimens, including the HIVNET 012 protocol, in reducing MTCT among populations in developing countries (Moodley, Moodley, Coovadia, Gray, McIntyre, Hofmyer, Nikodem, Hall, Gigliotti, Robinson, Boshoff, and Sullivan 2003). While the HIVNET 012 Nevirapine regimen (hereafter referred to as PMTCT using Nevirapine) is more amenable to the financial as well as infrastructure- and capacity-related constraints that exist in developing nations, it does not necessarily follow that Nevirapine is therefore a viable option for these countries. The following section will examine the costs associated with the introduction of a comprehensive PMTCT program involving Nevirapine and explore the feasibility of such a program in South Africa in particular.

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8 Because Nevirapine was approved for clinical trials after other proven MTCT interventions were established, namely using the drug AZT, it has not been used in a MTCT study vs. a placebo as it would be unethical (McIntyre 2003). Therefore the efficacy of Nevirapine is extrapolated from the results of the HIVNET 012 study which compared it to AZT (Guay, Musoke, Fleming, Bagenda, Allen, Nakabiito, Sherman, Bakaki, Ducar, Deseyve, Emel, Mirochnick, Fowler, Mofenson, Miotti, Dransfield, Bray, Mmiro, and Jackson 1999), from other clinical trials with AZT, like ACTG 076 (Connor, Sperling, Gelber, Kiselev, Scott, O'Sullivan, VanDyke, Bey, Shearer, Jacobson, et al. 1994), the short-course AZT CDC-Thai trial (Shaffer, Chuachooowong, Mock, Bhadrakom, Siriwasin, Young, Chotpitayasunondh, Chearskul, Roongpisuthipong, Chinayon, Karon, Mastro, and Simonds 1999), and from historical transmission rates (McIntyre 2003).
2.1.3 The Cost of PMTCT and the Implications for Nevirapine Provision in South Africa

Presently antiretrovirals are becoming much cheaper and therefore accessible to developing countries (Cameron 2002). This is in part due to the public pressure and persuasive dialogue employed by groups like Médecins Sans Frontières (MSF) and other international activist groups, whose activities were alluded to above (Cameron 2002). This pressure, among other things beyond the scope of this research, has resulted in the WTO endorsement of an interpretation of the TRIPS Agreement that protects public health over patents (Winestock 2001), and in some pharmaceutical companies agreeing to lower prices or develop donation programs to make drugs more accessible to lower income countries (Cherry 2000). To this end, the manufacturers of Nevirapine, Boehringer Ingelheim, have offered to provide the drug for free for five-years in most developing countries for use in PMTCT programs; though uptake by governments has been slow (Anonymous 2001).

Boehringer Ingelheim’s offer has put public pressure on governments to provide access to Nevirapine to HIV+ pregnant mothers, particularly when no prior strategy for PMTCT was in place, as in the case of South Africa (Skordis and Nattrass 2002). However, that acceptance of Boehringer Ingelheim’s offer has been unhurried is indicative of the reality that providing access to these medicines on the ground is much more complicated than simply handing out pills, and that costs of delivery extend beyond the costs of the drug alone.

A 1999 study, carried out prior to the establishment of the HIVNET 012 protocol as a safe and effective option, assessed the cost-effectiveness of various PMTCT
strategies in South Africa (Soderlund, Zwi, Kinghorn, and Gray 1999). This study concluded that implementing a short-course AZT-based program (using the CDC-Thai regimen) was likely to be cost saving, relative to the costs of having no PMTCT intervention. It is estimated that the cost of such a program, established nation-wide, would be R100 million annually, or 0.5% of South Africa’s annual public health budget (Soderlund, Zwi, Kinghorn, and Gray 1999). However, subsequent commentary highlights that a program of this nature, requiring immediate resources, would necessitate the closure or cessation of existing services, based on South Africa’s current macroeconomic policies (Benatar 2001:361). Furthermore, Benatar notes the difficulty of such a policy decision, particularly in light of the significant reductions in the provision of tertiary health services, that are currently being imposed in the public health care system (Benatar 2001:361). Moreover, Benatar expands on the “complications” alluded to above, that make the creation of an comprehensive PMTCT program more difficult than simply the procurement and provision of a drug.

Valid obstacles to the immediate introduction of a comprehensive HIV transmission prevention program thus include constraints on resources and their maldistribution; an inadequate health care infrastructure in the country to ensure widespread success of a program to reduce vertical transmission; inability to stop breast-feeding as part of a prevention programme; concern about potential adverse effects of (anti)retroviral drug therapy in a poor and nutritionally vulnerable population; paucity of knowledge of the long-term implications of such a programme; and concern about the possibility of promoting drug resistance. (Benatar 2001:362)

In addition to these “valid obstacles” Benatar notes that “there are other less obvious pressures” that may come into play when intensely drug-focused interventions are being considered (Benatar 2001:362). These more obscure pressures include a concern about the drug industry’s motives in lower-income countries, “especially against the backdrop
of vehement interference by powerful nations and multinational drug companies in attempts by poor countries to import generic drugs to lower excessively high drug costs” (Benatar 2001:362-3). Another less apparent concern for developing countries is the extent to which a drug-based, “purely biomedical approach deflects attention from broader considerations affecting health,” like women’s education and empowerment (Benatar 2001:363-5). Due to the broad range of adverse forces, among them social and economic, which propagate the HIV/AIDS pandemic, solutions must extend beyond just the medical realm (Benatar 2001).

Though few would argue with these insights, the pressure on the South African government to initiate antiretroviral programs, and specifically a nation-wide PMTCT program, has been fervent. The details of this pressure will be described below. However, two other analyses, which reflect in part this pressure, are pertinent to include here. First is a commentary by Andrews, which summarizes a number of requirements that must be met to ensure access to medicines in South Africa, but goes on to advocate for immediate provision of antiretrovirals despite these: “It is obvious that the first step along the road to making this plan a reality lies in the provision of inexpensive, effective and sustained sources of antiretrovirals and other agents. The concept of infrastructure to use such medications cannot be realized without access to learning about them first hand” (Andrews 2001:386). While Andrews discusses the South African Government’s pre-2001 amendments to the Medicines Act, which make use of mechanisms under the TRIPS Agreement to enhance access to these drugs more readily; these changes have yet to be enacted in accessing antiretrovirals.

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9 In his discussion of ways in which the South African Government could gain access to HIV/AIDS medicines more cheaply, Andrews highlights mechanisms under TRIPS, and points out legislation that was
A second article by Skordis and Nattrass builds on Andrews’ argument, also stressing the urgent need for antiretrovirals in South Africa (Skordis and Nattrass 2002). Skordis and Nattrass are more critical of government to this end, noting “the government’s failure to act appropriately” in terms of PMTCT programs (Skordis and Nattrass 2002:406). Their research provides an economic analysis of the feasibility of providing antiretroviral drugs for PMTCT in the public sector in South Africa (Skordis and Nattrass 2002). Making use of Boehringer Ingelheim’s offer of free Nevirapine in their analysis, the authors compare the cost of doing nothing to combat MTCT, with the cost of providing AZT (with breastfeeding, therefore not accounting for the cost of providing infant formula) and the cost of providing Nevirapine (also with breastfeeding). As represented in their title “Paying to waste lives”, the paper concludes that Nevirapine is the cheaper of the two options per life saved, and argues that because the cost of providing MTCT prevention is less than the cost of doing nothing, that PMTCT is affordable in South Africa (Skordis and Nattrass 2002:405). The cost of doing nothing includes the government’s provision of hospital-based palliative care to HIV+ babies; thus Skodis and Nattrass’ estimate is not a true reflection of reality, as many babies are never brought to hospital, and the cost savings associated with using Nevirapine may be an overestimate. In contrast, the authors surmise that Nevirapine provision may be even passed by the government to this end, but later challenged. The Medicines and Related Substances Control Act (Act 90 of 1997) was signed into law by Nelson Mandela to ensure that all South Africans had “access to health care services” as one of their constitutional rights; in response to the current global economic environment, the Government amended the Act to allow for provisions set out by TRIPS to be used to this end. However, the international Pharmaceutical Manufacturers Association (PMA), who represents the major research-based pharmaceutical companies, challenged the amendments to this law in court only three months later. At issue was a clause in the Act that dealt with the concept of parallel importation; the PMA (and European Union and USA) held that this clause was actually in violation of TRIPS (Andrews 2001). The case was later dropped, perhaps because of the enormous negative public pressure the Treatment Action Campaign and others applied to the PMA, which was quickly picked up and publicized by international media.
more cost-effective than they predict because their model excluded the costs associated with guardians’ missed work time to care for their HIV+ babies, costs related to transport to hospital, and those implicit in the provision of medicines to treat opportunistic infections associated with HIV\(^{10}\) (Skordis and Nattrass 2002:418). Ultimately this study estimates the cost of a Nevirapine-based PMTCT program as being between 0.18% and 0.27% of the government’s total budget of approximately $30 billion US annually (Skordis and Nattrass 2002). While this estimate includes the hospital costs for children who are born HIV+ irrespective of the program, neither milk formula feed costs, nor the costs of new infrastructure and any additional training required to implement such a program are accounted for (Skordis and Nattrass 2002). The costs associated with these omissions could be very significant, and are likely to outweigh drug costs when a two-dose Nevirapine regimen is used (even if the drug were purchased rather than donated); however, the value of the omitted costs remains unclear.

Thus the literature reflects varying opinions on exactly how feasible it would be for South Africa to establish a comprehensive PMTCT program. Some of the potential barriers to the establishment of such a program, referred to here, are better understood in the context of the post-Apartheid health care system in South Africa, explored in the next section.

\(^{10}\) Ironically, many of the medicines useful in treating opportunistic infections, characteristic to HIV, but which can occur in other circumstances as well, are provided in the public health care system.
2.2 HEALTH CARE AND HEALTH POLICY IN SOUTH AFRICA

2.2.1 Health Care Under Apartheid

Portrayals of South African PMTCT policy in the literature (discussed below) often present its development as a governmental failure. Further, the Treatment Action Campaign’s eventual lawsuit against the government made reference to economic and racial equity in arguing for wider access to Nevirapine. Consequently, it is reasonable to include in the literature review an examination of health care under Apartheid. The effects of over four decades of white minority-rule continue to pervade all aspects of life, including public health, in this fledgling democracy. The discussion that follows provides the context in which PMTCT policy development is situated, that is, within South Africa’s unique post-Apartheid environment.

Health care policy in South Africa has been in flux since before Apartheid began in 1948. The then emergent issues of private versus public health care as well as issues of equity in health still remain prominent health care concerns today (Benatar 1997). The health care legacy of Apartheid includes a strong and well-funded private health care system and a fragmented and desperately under-funded public health care system; in addition, divisions exist within the public sector in terms of the level of service provision in rural areas compared to urban locales (Benatar 1986; Benatar 1990; Benatar 1991; Benatar 1997; Chalmers 1990; De Beer 1984). The current status of health care services in South Africa can be better understood by examining the development of the these services under Apartheid.

Health Services During Apartheid
During Apartheid there were wide disparities in access to health care resources (De Beer 1984). Because of the government’s policies of racial exclusion during Apartheid, blacks were relegated to their bantustans, or African homelands; this was true even for those who lived in urban centers and had never set foot in their respective “homelands” (De Beer 1984). Conditions in the homelands were desperate: overcrowding limited land for agriculture, resulting in a less than subsistence level of food production, and malnutrition; high unemployment led to a collapse of the family structure due to economically-necessitated migration to find work; and there was a prevalence of infectious diseases such as TB, which flourished in this environment (De Beer 1984). Ill health was propagated by these unfavourable social conditions, and health care services in these areas were less than sufficient (Benatar 1991; De Beer 1984). The health care services in the homelands were public, administered primarily by the bantustan bureaucracies. Because the “homeland governments” had no significant source of revenue they relied entirely on the central government in Pretoria for funding (De Beer 1984:58). Because of a shortage of funds however, the medical infrastructure in the homelands was entirely inadequate: for example, the community medicine-based aim of developing primary health care clinics, rather than hospital-based curative services, was achieved only in part, as in one area where 18 such clinics were proposed and only five built after five years (De Beer 1984). The hospitals that did exist in the homelands often served 30 to 40 villages or population groups that were spread over a wide area, yet these facilities only had three or four functional ambulances. Given the erratic nature of existent public transportation, patients often had to walk long distances
to receive treatment (Chalmers 1990; De Beer 1984). This resulted in many poor blacks having very limited access to often second-rate public health care services.

To get a sense for the kinds of inequities that existed between the primarily white and well-off urban populations and the mainly black and impoverished rural populations, consider that in 1986 Johannesburg and Cape Town contained 11% of the population, three of the seven South African medical schools, and 40% of the country’s doctors; while rural areas, which were home to 50% of the population, were serviced by only 5.5% of practicing doctors (Benatar 1986). Put another way, in 1981 the number of available doctors per person, by racial group was as follows; 1:330 Whites, 1:730 Indians, 1:12,000 Coloured and 1:91,000 Blacks (Seedat and International Defence and Aid Fund 1984). Although both the public and private health care infrastructure was and is relatively well developed in the cities mentioned (many facilities are comparable to their Western world counterparts), access due to geographical proximity was not easy for the majority of poor blacks. However, if rural patients were formally referred to more advanced urban health care services then government would often sponsor the payment of their travel costs (Benatar 1986).

It should be noted that access to private health care was, and is restricted to only those who can afford to pay for it out of pocket or who have medical aid coverage, usually through their employer. These are not realistic options for the vast majority of poor South Africans, who are large-in-part black (Benatar 1991). In 1987, 78% of whites had private health coverage, though only 4% of blacks were covered (Benatar 1991). Disparities in access to private care are compounded by an inequitable distribution of resources: in 1987, 80% of the population was serviced by the public health care sector,
though expenditures in this sector accounted for only 53% of all money spent on health
(2.7% of GNP) (Benatar 1991).

Post-Apartheid Reform

In the face of Apartheid’s legacy of discrimination and inequality, since the first
democratic elections in 1994, governments have been struggling to build a public health
care system that can equitably meet the needs of all the citizens of South Africa (Benatar
1997). The national government has endeavored to reduce large disparities in health and
health care between blacks and whites through the advent of a new National Health Plan
for South Africa, developed by the post-Apartheid ruling party, the African Nation
Congress (ANC). The Plan, founded on the basis of equity and the right to health,
emphasized primary health care services; a comprehensive, equitable, and integrated
National Health System; and the necessity for political will, accountability and
community participation, as well as the maintenance of social and economic justice
(African National Congress, UNICEF, and World Health Organization 1994). While the
tenets of the Plan, and the specific rights to health it aimed to secure (which are explored
in Section 2.2.2) are laudable, it should be recognized that in light of the disparities
institutionalized during Apartheid, as well as the massive restructuring of the post-
Apartheid government, these would be difficult to achieve. Because, during Apartheid,
funds were primarily directed to the creation of hospital-based curative services, rather
than a system focused on primary care, the ANC’s goals, outlined in the new Plan,
required significant reorganization of resources. Nevertheless, the aim of stressing
primary care is appropriate given that such a system would better cope with the health
care needs of the majority of South Africans, who are relatively poor and live in rural areas with little health care infrastructure (Benatar 1997). Moreover, the past inability of South Africa’s health care system to meet the primary care needs of its citizens is likely a contributing factor to the prevalence of AIDS, which increased 14-fold between 1990 and 1995 (Benatar 1997).

Although the Apartheid regime has been abolished for some years now, its legacy still remains, not only in the realm of health care, but also in every other facet of society. Rural South Africans continue to have poor access to health care, and wealthy urban dwellers have access to private health care that ranks among the best in the world (Benatar 1997).

A Caveat

It should be clarified that the groups impacted during Apartheid and now in the post-Apartheid era are not only divided between black and white. A statistic noted above regarding the number of physicians per person during Apartheid also included figures for the Indian and Coloured populations. The figures for these two groups fell between those for Blacks and Whites, indicating that during Apartheid these groups were not as poor off as the Black population, though not nearly as well off as the White population. It is the plight of the Coloured population, those worse off of these two intermediate groups, that I would like to draw attention to here. The Coloured population, or people of mixed race, “are descendents of European colonists, Malay and Indonesian slaves, and Khoi and San bushmen and other African tribes, proof that the races have mingled on the tip of Africa for more than 300 years” (Polgreen 2003). Many Blacks and Coloureds feel that the
post-Apartheid period has not lived up to their expectations, or demonstrated an improvement of the quality of their lives (Polgreen 2003). A recent article from the New York Times, takes up this issue in reference to the coloured population. This article provides some insight into the unique concerns of this group (Polgreen 2003), as this research does not deal with their interests independent of the interests of those unable to afford private health care or medicines in South Africa.

Briefly, the article recounts the telling experience of one Mr. Khan, a Coloured man living in a township outside of Cape Town built by the Apartheid Government. Mr. Khan recalls the day in 1994 when a representative from the ANC came looking for votes in South Africa’s first democratic elections.

… the man said that in the new South Africa people of mixed race, known here under Apartheid as Coloureds, would be full equal citizens. To someone like Mr. Khan, who had lived only as a second-class citizen, derided as the progeny of forbidden racial mixing, uprooted from his neighborhood in Cape Town as a little boy and sent to live in a distant ghetto to make room for white people, it was a powerful message. (Polgreen 2003)

However, nearly 10 years after he first heard this message, Mr. Khan is still unemployed, as he was during Apartheid.

“In the old system we weren’t white enough,” Mr. Khan said. “Now we aren’t black enough. It is still Coloured people who are stuck in the middle, and no one cares about us. I’m not a racist, and I fought in the struggle against Apartheid. But we have to admit that under white rule, we had a better life – less crime, more welfare, better schools and doctors… Black people have jobs because of affirmative action… White people had everything anyway. But we lost the little bit we had. It isn’t fair.” (Polgreen 2003)

Mr. Khan’s story reveals the complex nature of achieving equity in South Africa – a difficult task in any country, but compounded in South Africa by the Apartheid-enforced divisions among different racial groups. Given this complexity, I turn to the challenge of developing appropriate birthing care in the post-Apartheid era.
Implications for Birthing Practices

Among black South Africans, particularly those in rural areas, it is common to make use of African expertise at birth, for example through the assistance of elders in the family or a traditional birth attendant (Chalmers 1990). This is in contrast to both the high-technology, medicalized services that are provided to women at birth in hospitals (especially private hospitals), and the sometimes biomedical approaches used in Midwife Obstetric Units (MOUs) and community-based clinics, which typically employ physicians and nurses, as well as midwives. The range of settings available to women for peri-natal care reflect the distribution of resources and infrastructure fashioned during Apartheid: “As with many aspects of Western health care services, those related to childbirth appear to be inadequate to meet the needs of all African women. Those living in outlying areas probably experience the most difficulty in obtaining adequate medical care” (Chalmers 1990). While access to Western biomedical services varied, culturally based values related to health varied as well, with implication for the desirability of utilizing Western services even when available. Among black Africans, traditional conceptions of health and illness¹¹ are held by many, while the Western biomedical perspective on health and health services is predominant in more developed areas (Chalmers 1990). These varied values, and delivery settings have implications for the conceptualization of health care, for the delivery of drugs, and for other biomedical interventions during labour; this in turn has relevance for implementation of the ANC

¹¹ This area of study is too detailed to explore here; for further information on traditional African conceptions of health and illness see the following references: African Birth: Childbirth in Cultural Transition (Chalmers 1990), "Disease Etiologies in Non-Western Medical Systems" (Forster 1998), and Boiling Energy: Community Healing Among the Kalahari !Kung (Katz 1982).
Government’s new (1994) National Health Plan and their constitutional obligations for providing health care services post-Apartheid.

2.2.2 The New Government and Constitution: New Health Care Obligations

After a lengthy struggle against Apartheid, South Africa’s first democratic elections were held in 1994, culminating in the country’s peaceful and negotiated transition to democracy (Benatar 1997). The struggle against Apartheid had involved many civil society interest groups coming together against white minority rule, and eventually working with the F. W. de Klerk Government to abolish the regime. Leaders in the resistance movement included the ANC, the Congress of South African Trade Unions (COSATU) and the South African Communist Party, who together formed the Tripartite Alliance (African National Congress. 1999; Congress of South African Trade Unions 1985). Moreover, the ANC was allied with the United Democratic Front (UDF), an inclusive civil society group that brought together the voices of actors within “the oppressed masses” (United Democratic Front. 1983).

In 1989, de Klerk was elected as President and began calling for a non-racist South Africa and for negotiations about the country's future. He lifted the ban on the ANC (which was established in 1960, 12 years after white minority domination began) and released Nelson Mandela from prison in 1990 (African National Congress. 1999). In 1994 the ANC was elected and Mandela became South Africa’s new President. There was “jubilation” within the country; South Africans and indeed, citizens around the world were inspired by the achievements made in the peaceful demise of Apartheid (Benatar 1997). The country’s new leaders recognized the need to enshrine not only universal
civil and political rights, but also social and economic rights, in order to overcome the inequities that had been institutionalized during more than four decades of racially segregated policies. To this end, South Africa’s Constitution, officially adopted in 1996, is thought to be the most liberal in the world.

Health Care and the Constitution

The Constitution outlines the government’s obligations in providing health care and indicates the individual rights it aspires to guarantee with respect to health, and the responsibilities of both the central (national) government as well as the provincial governments in creating and implementing health policy. With respect to the latter, the following duties are assigned to the national health authority, the Department of Health:

- formulating health policy and legislation,
- formulating norms and standards for health care,
- ensuring appropriate utilization of health resources,
- coordinating information systems and monitoring national health goals,
- regulating the public and private health care sectors,
- ensuring access to cost-effective and appropriate health commodities at all levels, &
- liaising with health departments in other countries and international agencies;

The following duties are the responsibility of each of the nine provincial Health Departments:

- providing and/or rendering health services,
- formulating and implementing provincial health policy, standards and legislation,
- the planning and management of a provincial health information system,
- researching health services rendered in the province to ensure efficiency and quality,
- controlling the quality of all health services and facilities,
- screening applications for licensing and the inspection of private health facilities,
- co-ordinating the funding and financial management of district health authorities,
- effective consulting on health matters at community level, &
- ensuring that delegated functions are performed.

(South African Government 2001)
The significant overlap in the responsibilities of the national and provincial governments has created an environment where policy formulation falls within the jurisdiction of both levels of government. Thus, it is difficult to determine who has ultimate policy-making power or responsibility in the implementation of nation-wide prerogatives within each province. This gives the provinces the space to interpret and selectively adhere to certain national policy objectives, inadvertently creating fragmentation in health care and mimicking the disjointed approach during Apartheid. Similarly, the reliance of “homeland governments” on the central government for funding during Apartheid is also reflected in the current system. Interestingly, since there are no provincial taxes, the country’s public health care system is funded entirely from federal taxes (Benatar 1997). Thus, the national government does retain control over funding as well as official legislation, as indicated above (Benatar 1997). It is not clear however what interest the national government has in enforcing this legislation or what mechanisms it has available for this purpose.

Despite this uncertainty, the provincial and the central governments share the responsibility of providing health care. In the Treatment Action Campaign’s case against the South African Government for national PMTCT roll-out, the national ANC Government, as well as all nine provincial governments are named. The duties of government and rights of citizens, as enshrined in the Constitution and other government-supported documents, formed the basis for the TAC’s case. This case is described in more detail below. Besides making the argument that the government’s policy created inequalities that discriminated along economic, and consequently racial lines, the TAC also claimed that the government’s PMTCT pilot-program policy, which restricted
widely access to Nevirapine, constituted “a profound threat to the fundamental rights of South Africans to:

- access to health care services, including reproductive health care (section 27);
- basic health care services for children (section 28(1)(c));
- life (section 11);
- human dignity (section 10);
- equality (section 9); and
- psychological integrity, including the right to make decisions regarding reproduction (section 12(2)(a)).”

(Treatment Action Campaign 2001c)

In addition, the TAC cited the following government documents that make reference to government obligations with respect to health care, as well as its duties and governing values.

By Government Notice 657, Government Gazette 15817 of 1 July 1994 the Government decreed that pregnant women and children under the age of 6 years were entitled to free health services rendered at State health care facilities. The free health services are defined to include “the rendering of all available health services ... including the rendering of free health services to pregnant women for conditions that are not related to the pregnancy.”

Section 7(3) of the Constitution places a duty on the State to “respect, protect, promote and fulfill the rights in the Bill of Rights.” Section 237 of the Constitution requires that “all constitutional obligations must be performed diligently and without delay.”

Section 195 of the Constitution requires, inter alia, that public administration must be governed by the democratic values and principles enshrined in the Constitution including the principle that a high standard of professional ethics must be promoted and maintained. It also requires that people's needs must be responded to and that services be provided impartially, fairly, equitably and without bias.

(Treatment Action Campaign 2001c)

This summary of the responsibilities of government and the “division of labour” with respect to both policy-making and implementation, provides the basic technical information that informs the policy environment discussed below. The discussion below highlights the importance of both this technical legal information, as well as
medical/scientific knowledge, discussed earlier in this chapter, which contributed to the development of current MTCT interventions.

2.3 NEVIRAPINE POLICY DEVELOPMENT IN SOUTH AFRICA

Prior to commencing my fieldwork for this study, in September 2002, there were very few academic articles exploring South Africa’s PMTCT policy, particularly as it has been most recently debated, with reference to Nevirapine. There is a reasonably developed body of literature that examines AZT policy, making specific reference to its usefulness in PMTCT, which began to make headlines beginning around 1998. However, this literature only gave passing mention to Nevirapine. Although Nevirapine had been available in South Africa since 1996 for long-term antiretroviral therapy, it was only released in 1999 in a suspension formula for babies and children (though the suspension was not registered with the Medicine Control Council (MCC) in South Africa until March 2001\(^\text{12}\)). At the same time, the results of the HIVNET 012 study were being released (Guay, Musoke, Fleming, Bagenda, Allen, Nakabiito, Sherman, Bakaki, Ducar, Deseyve, Emel, Mirochnick, Fowler, Mofenson, Miotti, Dransfield, Bray, Mmiro, and Jackson 1999). This study demonstrated Nevirapine’s effectiveness in reducing MTCT with only two doses: a tablet to mothers in labour and the suspension to newborn babies. With the advent of this new regimen, which was simpler and cheaper than the previously

\(^{12}\) Registration with the Medicine Control Council (MCC), equivalent to the Food and Drug Administration (FDA) in the US, occurred later, as it is dependent on bureaucratic processes involved with the review of a new drug or indication (Medicine Control Council 2002); although some described the lag as an “inordinate delay” implying that the process was purposefully delayed (Jones 2002), this has not been substantiated.
established protocols using AZT, PMTCT policy debates shifted to focus on Nevirapine-centred programs. Another important event advanced discussions about Nevirapine and PMTCT: in July 2000 the manufacturers of Nevirapine offered to donate the drug to developing nations, including South Africa, to help reduce HIV transmission from mother to baby (Cherry 2000).

While the object of the present study is Nevirapine-based PMTCT policy development, this process can only be understood in light of both AIDS policy in general, and the PMTCT discussions around AZT that preceded it. Drawing on the above technical information and background on health care in South Africa, this section provides the context within which Nevirapine PMTCT policy is situated and outlines developments, with respect to this policy, until July 2002.

Because the literature on Nevirapine policy in particular was not extensive, this review makes use of earlier articles related to AIDS policy, as well as media sources and websites for more current information about Nevirapine developments.

Before launching into the discussion of the complex policy environment that frames the case of interest, the following figure provides a chronology of key events that are relevant to Nevirapine-focused PMTCT policy. The events outlined here are included either as background information (i.e. the first case of AIDS in South Africa) or because the authors whose work is reviewed below (Section 2.3.1) have identified them as being significant to Nevirapine policy development.
Figure A. A Chronology of Key Events Significant to Nevirapine Policy Development until July 2002

<table>
<thead>
<tr>
<th>DATE</th>
<th>EVENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1984</td>
<td>The first case of AIDS is reported in South Africa.</td>
</tr>
<tr>
<td>1990</td>
<td>The ANC meets in Maputo. Those recently returned from exile, who had witnessed the devastation of AIDS in other countries, warn of the disease’s potential to undermine national reconstruction; the Maputo Statement is drafted which indicates the need for HIV prevention in South Africa (Stein 1990).</td>
</tr>
<tr>
<td>27 April 1994</td>
<td>South Africa's interim constitution is entered and the first democratic elections are held; the African National Congress’s (ANC) Nelson Mandela becomes President.</td>
</tr>
<tr>
<td>1994</td>
<td>NACOSA’s AIDS Plan is handed over to Mandela’s Government; the plan is adopted and resources are mobilized to establish the country’s AIDS Programme.</td>
</tr>
<tr>
<td>November 1994</td>
<td>AZT is established as an effective therapy in reducing mother-to-child transmission of HIV (ACTG 076) (Connor et al. 1994), though drug costs are prohibitive to lower income countries (Cameron 2002).</td>
</tr>
<tr>
<td>December 1994</td>
<td>A National AIDS Programme Director is appointed; the director is positioned within the Department of Health, despite the NACOSA Plan’s suggestion that the AIDS Programme be inter-sectoral.</td>
</tr>
<tr>
<td>1995 - 1996</td>
<td>Sarafina II, a musical about AIDS prevention commissioned by the Ministry of Health, is publicly criticized due to a lack of transparency; the initiative is later cancelled.</td>
</tr>
<tr>
<td>May 1996</td>
<td>The new South African Constitution is officially adopted.</td>
</tr>
<tr>
<td>July 1996</td>
<td>At the Vancouver International AIDS Conference UNAIDS announces the start of a new study (PETRA); the study will test shorter term AZT regimes for PMTCT, and will have two sites in South Africa: Baragwanath Hospital (University of Witswatersrand, Johannesburg) and King Edward Hospital (University of Natal, Durban) (Lange 2001).</td>
</tr>
<tr>
<td>1997</td>
<td>Virodene, recognized later to be a toxic substance containing industrial solvent, is touted as a South African cure to AIDS; government officials pressure the Medicine Control Council in South Africa to approve human trials for Virodene.</td>
</tr>
<tr>
<td>1997</td>
<td>The AIDS Law Project (ALP), a group from which TAC later spawns, publishes a Code of Best Practices for HIV in Pregnancy; this document states that women should be given the option of antiretroviral therapy for PMTCT (AIDS Law Project. 1997).</td>
</tr>
</tbody>
</table>


- **Spring 1998**  
  A short-course AZT regime for PMTCT is established (CDC-Thai) which requires fewer doses of the drug and is therefore less expensive than the established ACTG076 protocol (Shaffer et al. 1999); to activists this represents the first drug intervention for AIDS that is within the financial reach of the South African Government.

- **1998**  
  Maternity wards prepare for a five-site PMTCT pilot program using AZT (planned by a Task Team under the Gauteng Provincial Department of Health).

- **Fall 1998**  
  The prevention focused Presidential Partnership Against AIDS is formed; on the same day Nkosazana Dlamini Zuma, then Minister of Health, withdraws national government sponsorship of the five-site PMTCT pilot, citing cost of the program as a barrier (a leaked document indicated that the government’s Interministerial Committee supported this decision and would reconsider if new information related to cost-effective interventions, appropriate for South Africa, became available with the results of the South African arm of the PETRA study).

- **10 December 1998**  
  The Treatment Action Campaign (TAC) is founded; TAC calls on Minister Zuma and Finance Minister Trevor Manuel to meet immediately with the National Association for People Living with HIV/AIDS (NAPWA) and HIV/AIDS NGOs to plan for resources to introduce free AZT to HIV+ pregnant mothers.

- **January 1999**  
  The Western Cape province’s Department of Health begins the first PMTCT pilot site nationally in Khayelitsha, using AZT; this program, conceptualized by former ANC Provincial Minister of Health, Ebrahim Rasool, was now being carried out by the new Minister, Peter Marais of the New National Party.

- **March 1999**  
  TAC continues to pressure Minister Zuma on the PMTCT issue, then on March 24 Zuma is reported by the Cape Times as saying that the high cost of the drugs makes the program unaffordable, she continues that “if you want to fight for affordable treatment then I will be with you all the way”; TAC subsequently initiates a campaign against AZT-manufacturer, Glaxo-Wellcome, urging them to make the drug more affordable.

- **May 1999**  
  A new study (SAINT) is initiated in South Africa, that aims to compare regimes from the PETRA study with a modified HIVNET regime (based on the HIVNET 012 study using Nevirapine being conducted simultaneously in Uganda); 11 public hospitals are chosen to participate in this study (Moodley et al. 2003).

- **2 June 1999**  
  Mandela’s successor as leader of the ANC, Thabo Mbeki, is elected as President in South Africa’s second democratic election; Manto Tshabalala-Msimang is later appointed as Minister of Health while Nkosazana Dlamini Zuma assumes the position of Minister of Foreign Affairs.

- **October 1999**  
  A Nevirapine regime for PMTCT is established (HIVNET 012) which is even cheaper and simpler than the CDC-Thai course of therapy using AZT (Guay et al. 1999).

- **1999 - 2000**  
  Questions about the toxicity of AZT emerge from the national government, later the President states the need to re-examine the link between HIV and AIDS; both these positions reflect the views of so-called AIDS dissidents (a group of actors, including American scientists, who challenge the orthodoxy of AIDS and claim that AZT causes AIDS).
January 2000  The South African National AIDS Council (SANAC) is established by the Presidency; significantly, this council excludes key medical researchers and AIDS NGO representatives.

March 2000  Mbeki announces the President’s AIDS Advisory panel, composed of both “orthodox” AIDS scientists as well as AIDS dissidents; the goal of the panel is to reconcile the “science” behind AIDS in order to develop an effective South African anti-AIDS strategy.

July 2000  Boehringer Ingelheim announces that they will provide Nevirapine free of charge for a period of five years for the prevention of mother-to-child transmission of HIV-1 in developing nations (Cherry 2000).

9-14 July 2000  South Africa hosts the XIII International AIDS Conference in Durban; President Mbeki’s recent questioning of the causal link between HIV and AIDS is highly criticized.


January 2001  The Western Cape province (ruled by the New National Party) announces province-wide PMTCT rollout using Nevirapine.

Early 2001  The Pharmaceutical Manufacturer’s Association (PMA) launches a case against South African Government for alleged infringement on intellectual property rights under the TRIPS Agreement (based on changes to the South African Medicines Act aimed at making drugs more accessible); the South African Government, local NGOs, TAC and international activists come together in protest of the lawsuit, the suit is withdrawn in April 2001 and the unified front of these actors collapses.

March 2001  Nevirapine is approved for use in preventing mother-to-child transmission by the MCC in South Africa, based in part on the HIVNET 012 study results (Medicine Control Council 2002); the tablet form had previously been approved for long term antiretroviral therapy.

May - November 2001  The 18 national PMTCT pilot sites are established.

August 2001  TAC files a lawsuit against the government to mandate the provision of Nevirapine to all medically indicated pregnant women in South Africa.

December 2001  The Pretoria High Court’s Judge Botha rules in favour of TAC; the South African Government appeals this ruling to the Constitutional Court on the basis that the courts do not have jurisdiction in deciding on policy matters.

January 2002  KwaZulu Natal province (ruled by an ANC-Inkatha Freedom Party coalition government) announces that it will make Nevirapine available in all public health facilities in the province (kaisernetwork.org 2002h).

February 2002  Gauteng province (ANC ruled) announces province-wide expansion of PMTCT (kaisernetwork.org 2002n).

March 2002  TAC applies for, and is granted, a Temporary Execution Order by the Pretoria High Court to force the government to roll out Nevirapine nationally while the Constitutional Court appeal is waiting to be heard; the government appeals the Execution Order.

April 2002  The government’s Execution Order appeal is denied by the courts.
The Constitutional Court unanimously rejects all the government’s contentions and upholds the Pretoria High Court’s December 2001 ruling (kaisernetwork.org 2002b; Sidley 2002).

The creation of this figure relied primarily on the following references, which are discussed in more detail below: an attempt by an American-educated journalist to better understand South Africa’s peculiar AIDS policies (Epstein 2000); a historically situated summary of the country’s response to AIDS, written by a South African who authors a weekly AIDS information service (van der Vliet 2001); two articles by a South African scholar based at the University of Witwatersrand’s Centre for Health Policy in Johannesburg (Schneider and Stein 2001; Schneider 2002); and lastly, a collection of articles that chronicle recent TAC activities in court and with respect to Nevirapine access (Jones 2001; Jones 2002; Treatment Action Campaign 2001a; UN Integrated Regional Information Network 2003).

2.3.1 Nevirapine, PMTCT, and AIDS Policy Development in South Africa

An Overview of AIDS Policy: Insights from an Outsider

Chronologically, one of the first major articles that makes more than a passing reference to PMTCT policy in South Africa is Helen Epstein’s work: “The Mystery of AIDS in South Africa” (Epstein 2000). This essay is a journalistic piece that goes into great depth about the country’s HIV/AIDS policies, and is written based on Epstein’s three-week journey to South Africa to learn about the epidemic. Epstein opens by describing how she came to be concerned with this issue:

I became particularly interested in the AIDS crisis in South Africa last winter (1999/2000), when I heard that President Thabo Mbeki had begun to solicit the opinions of a murky group of California scientists and activists who believe that
AIDS is caused not by HIV but by a vague collection of factors including malnutrition, chemical pollution, recreational drugs, and by the very pharmaceutical drugs that are used to treat the diseases. These “AIDS dissidents” may not agree among themselves about what the cause of AIDS actually is, but most seem to believe that the tens of thousands of scientists who work on HIV and AIDS are, largely unwittingly, part of a vast conspiracy cooked up by the pharmaceutical industry to justify the market in anti-AIDS drugs, such as AZT, worth billions of dollars a year. (Epstein 2000:2)

Based on information gleaned in her travels, Epstein sees Mbeki’s questioning of the causal link between HIV and AIDS, likely the most well-known incident in the whole of the country’s AIDS response, as revealing in reference to the more recent “failure” of the government to provide MTCT interventions.

The interest that Mbeki has taken in the AIDS dissidents is more than an intellectual diversion. It is contributing to a public health disaster by distracting the Health Ministry and other official institutions from addressing the epidemic, and by failing to prevent HIV infection in South African children. (Epstein 2000:2)

Epstein is unclear about what motivated the government to act in such an unpopular way, given the availability and demonstrated effectiveness of the drug AZT in interrupting mother-to-child transmission (it had already been used in many Western countries and was recommended for this purpose by the WHO). Furthermore, a newer drug, Nevirapine, that was cheaper and easier to use, had been shown to be effective, but was still undergoing further trials in South Africa (Epstein 2000:3,16). While now questioning the reasons for the government’s association with AIDS dissidents, as well as its failure to save the lives of babies, due to what media had portrayed as an inclination towards “pseudo-science”, Epstein finds that PMTCT policy had been characterized by contradictions since 1998, before Nevirapine had been established as a MTCT intervention:
In 1998, a number of maternity wards in South Africa’s public hospitals were also getting ready to establish pilot projects to see how feasible it would be to offer AZT to every South African HIV-positive mother-to-be, no matter how poor. Almost immediately, then Minister of Health Nkosazana Zuma suspended public funds for these projects, because, she said, even these short courses of AZT were too costly. (Epstein 2000:3)

In response to this, Epstein suggests that “AIDS activists and doctors mounted protests” but the government held it’s ground (Epstein 2000:3). Later, once Mbeki had taken a greater interest in the AIDS dissidence line, “he stated in an address to Parliament that AZT was not only expensive, it was also alleged to be toxic, or so he had learned from some of the AIDS dissidents’ websites. AZT would not, therefore, be administered to pregnant women attending public hospitals until it had been thoroughly investigated” (Epstein 2000:3).

Epstein sees the government’s anti-AZT policy as aligning with its broader response to AIDS which has also caused confusion, specifically surrounding the motives of government. She highlights the National AIDS Directorate’s failure to spend 40% of its budget in 1999/2000, and the government’s appointment of a National AIDS Council (SANAC) early on in 2000, that excluded many of South Africa’s leading HIV/AIDS scientists but included an athlete, TV producer and two traditional healers, as “other evidence (that) suggested that the government’s response to AIDS was incoherent and disorganized” (Epstein 2000:5). Epstein’s detective work, seeking explanation for South Africa’s seemingly unusual AIDS policies, takes her back in time once again; she uncovers information about a drug trial in Kalafong that may have gone wrong, however, the details she provides on this are inconclusive. Nevertheless, in this discussion she relates the “highly unusual move” made by then Deputy President Mbeki and Health Minister Zuma in 1997 when they invited two South African researchers with a supposed
cure for AIDS to address Cabinet, and then pressured the Medicine Control Council (MCC), the South African equivalent of the Food and Drug Administration (FDA) in the US, to approve human research trials using this so-called cure (Epstein 2000:11). Virodene, as it was called, was later found to contain industrial chemicals, and its ability to benefit AIDS patients is thought to be “very unlikely” (Epstein 2000:11). Epstein mentions that the African Nation Congress (ANC), the political party that Mbeki and Zuma represent, may have had a financial interest in Virodene, however this is not clearly demonstrated in her paper (Epstein 2000:12).

Finally, Epstein closes, somewhat inconclusively, by stating that the government continues to argue that providing women with AZT to prevent MTCT is “too expensive and the drugs are toxic” (Epstein 2000:16). She claims that Mbeki’s critics maintain “the drugs are not too expensive, and that their prices are falling anyway, and that they are very unlikely to be toxic in the short doses used to prevent infection during childbirth” (Epstein 2000:16). Epstein then looks to the upcoming July 2000 International AIDS Conference in Durban as a potential forum for clarification, and notes that the government has “quietly approved” public pilot projects using the cheaper drug, Nevirapine, and that if the results of ongoing studies with Nevirapine are convincing to the MCC, these projects could be implemented (at that time the drug had not been approved by the MCC for use in PMTCT in South Africa; it was later approved in March 2001) (Epstein 2000:16).
Situating AIDS Policy Historically

Another very comprehensive article, this one on AIDS policy both during Apartheid and beyond, was published approximately six months after Epstein’s review. “AIDS: Losing the New Struggle” by Virginia van der Vliet, gives an insightful historical perspective into the development of AIDS policy in South Africa as well as chronicling the mounting opposition between the South African Government and orthodox AIDS scientists and activists in the country, centred around Mbeki’s questioning of the link between HIV and AIDS (van der Vliet 2001).

In her effort to understand the controversial development of South Africa’s AIDS Program, van der Vliet suggests that looking at the responses to the epidemic under Apartheid helps to explain the problem of AIDS as we see it today. First, because of the “racially differentiated nature of the epidemic” it has been more difficult to deal with: “the fact that it is sexually transmitted and that HIV is believed to have origins in Africa have, on one hand, fueled racist stereotypes, discrimination, and Afro-pessimism, and on the other, prompted anger, denial and genocidal conspiracy theories” (van der Vliet 2001:153). She reports that some members of the white Apartheid Government were pleased when it was recognized that because of the prevalence of poverty in black areas and the resultant migrant labour system the epidemic would affect blacks more than whites. One MP reportedly said “if AIDS stops black population growth it would be like Father Christmas” (van der Vliet 2001:156). The problem of dealing with AIDS under Apartheid was further compounded by the “unprecedented political turmoil and violence, with blacks bent on overthrowing the government by making the country ‘ungovernable’” that characterized the 1980s (van der Vliet 2001:154). Van der Vliet
contends that “whatever fragile social fabric had survived the Apartheid years was torn apart by the politics of the 1980s” (van der Vliet 2001:154). Moreover, because of this state of affairs, any kind of program that attempted to provide AIDS education was seen as the white government’s exertion of control over blacks and their sexuality, and was thus “met with suspicion and hostility” (van der Vliet 2001:155). “While AIDS is inevitably politicized, the superheated political climate between 1984 and 1994 ensured that people of all ideological persuasions interpreted, manipulated or ignored it to suit their own political agenda” (van der Vliet 2001:155). She suggests this was exemplified in that many black militants, up until at least 1993, believed that AIDS was a government fabrication designed to strengthen the government’s “genocidal” family planning program and reduce population growth in the black population by promoting condoms. Likewise, black adolescents thought AIDS was “a joke”, one 1990 survey reported that 90% of these youth said they would never use a condom (van der Vliet 2001:155,159).

In the late 1980s anti-Apartheid NGO groups, such as COSATU, became involved in the struggle against AIDS, yet their efforts were limited (van der Vliet 2001). Even after 1990 when the Maputo Statement was drafted by the ANC and a number of other NGO collaborators, such as the UDF, COSATU and the National Medical and Dental Association, “the seeming inertia of the ANC and COSATU (to act on this statement) was puzzling” (van der Vliet 2001:158). One explanation that van der Vliet forwards is “that responses were slow because programs could not be imposed from the top, but needed to be developed through the cumbersome participatory style of community decision-making that had evolved in the internal anti-Apartheid movement” (van der Vliet 2001:159). Temporally, the inclusive and participatory NACOSA process
follows; through the involvement of all the major civil society players, including scientists and AIDS organizations, a comprehensive and intensive AIDS strategy was produced and presented to the new government in 1994. However, NACOSA’s contributors were dismayed when major recommendations from the plan, such as the need for the AIDS Program to be multisectoral, as opposed to being led exclusively by the Department of Health, were not followed (van der Vliet 2001).

Another setback in the implementation of the NACOSA plan was the “intrusion” of the WHO’s Global Program on AIDS (GPA), which the Director of the Centre for the Study of AIDS at the University of Pretoria, Mary Crewe, criticized for using “an ‘African approach,’ as if the continent were a homogeneous whole” (van der Vliet 2001:161, cited in). The GPA emphasized a different set of priorities than the NACOSA plan had and it therefore “shook the confidence of local groups and blurred the responsibility for implementation” (van der Vliet 2001:162). Van der Vliet provides a concise summary of the resultant impact of these uncoordinated efforts to reduce AIDS in South Africa as of 1996:

In a political situation still on the boil, one could hardly expect to find programs working as they might in a stable democracy with a nonpartisan, trained, and experienced bureaucracy. By 1996 the AIDS Plan was in serious difficulties. Two years into its implementation, not only had HIV prevalence climbed from 7.6 percent in 1994 to 14.2 percent in 1996, but the ideal of “South Africa United Against AIDS” had not been realized. At all levels, there was discord and disarray. (van der Vliet 2001:162)

This sentiment was confirmed by the head of the Department of Health’s National HIV/AIDS Program at the time, who pointed out in 1997 that a major deficiency in South Africa’s strategy against AIDS was that the war against AIDS was being waged exclusively by the Minister and Department of Health, while general political
commitment to fighting AIDS within the rest of government was weak (van der Vliet 2001:162).

Van der Vliet argues that the “credibility” of the government’s AIDS strategy was further reduced “by a series of scandals and blunders” (van der Vliet 2001:162). The first of these was “Sarafina II”, a play on HIV prevention that was commissioned by the Health Department in 1995. The controversy around Sarafina II stemmed from the exorbitant budget (R14.2 million, approximately $3 million CDN) and an unfair tendering process (van der Vliet 2001:162). Civil society actors were persuasive in their opinion that this AIDS money could be more effectively spent elsewhere, and the play was later cancelled. The damage had been done however: this was confirmed in a 1996 NACOSA statement to Parliament. “Sarafina II has done immense damage to individuals and organizations active in the AIDS field. The process was not transparent and this has resulted in a rift between the Department of Health, NACOSA and the NGOs, as well as public derision about and hostility to HIV/AIDS work and programmes” (cited in van der Vliet 2001:163).

The Virodene scandal that followed, described previously by Epstein, where a toxic industrial solvent was supported as a cure to AIDS by then Deputy President Mbeki and Health Minister Zuma, caused further separation among South African AIDS actors. “Like Sarafina II, Virodene succeeded in dividing those who should have been united in the fight against AIDS” (van der Vliet 2001:164).

A further observation that also may have set back the AIDS response in South Africa, was the lack of leadership with respect to AIDS by former President Nelson Mandela. Van der Vliet comments that “Mandela had never made AIDS a priority” and
that he failed to participate in the AIDS program (van der Vliet 2001:165). Van der Vliet again cites Crewe, from the University of Pretoria, who elaborates on Mandela’s absence from the program, which “undermined the whole exercise” (van der Vliet 2001:165, cited in). “Why should the skeptical nation take AIDS seriously when the President doesn’t?” and “Why did he fail the nation?” Crewe asks (van der Vliet 2001:165, cited in). Van der Vliet suggests that it may have been because he was uncomfortable talking about AIDS, concerned he would offend people with language that was too forthright in reference to sex (van der Vliet 2001:165). Nevertheless, the Presidential Partnership Against AIDS was formed in 1998 under Mandela, in an attempt to “revitalize South Africa’s flagging program” (van der Vliet 2001:166). On the same day however, then Health Minster Zuma announced the withdrawal of national funding for an AZT-centered PMTCT pilot program, stating that the program was too expensive. This further characterized AIDS policy as contradictory and incoherent.

Van der Vliet continues her discussion of the controversy around AZT, highlighting the new drug Nevirapine as being a better option for PMTCT because it involves a simpler regimen (van der Vliet 2001:166). She also refers to the 2002 Skordis and Nattrass study, mentioned above, that demonstrates the cost-effectiveness of both Nevirapine and AZT, stating that “the case for antiretrovirals seemed clear” (van der Vliet 2001:166). She then points out Zuma’s continued opposition to providing AZT, and adds that the Health Minister defended this view by noting that “the government’s priority was prevention” (van der Vliet 2001:167). Critics were then “quick to point out (that) the prevention of MTCT was the object of using AZT, but Zuma was adamant” (van der Vliet 2001:167, author’s emphasis). Even after AZT’s manufacturer, Glaxo-
Wellcome (now Glaxo-SmithKline), drastically reduced the price of the drug (primarily due to pressure from the TAC), the government still refused to change its position, indicating that the costs of providing testing, counseling and formula feed, as well as those associated with technical support for the program, were still too much (van der Vliet 2001:167).

Van der Vliet then elaborates on the response to government by activists and physicians, alluded to previously by Epstein. Van der Vliet, mentions a letter to government written by James McIntyre and Glenda Gray, directors of the Perinatal HIV Research Unit at Chris Hani Baragwanath Hospital in Soweto. This letter indicated their concern with the government’s policy and their inflexibility in discussing the issue. McIntyre and Gray also noted that the government’s policy contravened South Africa’s guarantee of free maternity treatment and free medical treatment for children under six, which had typically covered even “expensive hospital procedures” (van der Vliet 2001:167, cited in). At this point international actors were also indicating their dismay with South Africa’s policies, as researchers from abroad threatened to boycott the International AIDS Conference, to be held in Durban in July 2000. Furthermore, the Western Cape, which was not governed by the ANC and “therefore was more independent of pressure from the centre” went ahead and began PMTCT pilot projects using AZT, in contravention of the central (national) government’s policy (van der Vliet 2001:167).

Opposing the picture she has painted up to this point, focused on the government’s resistance to drug-based PMTCT programs, van der Vliet notes the hope for access to drug interventions that was instilled in the electorate when a new health
minister took office. In 1999, when the second democratic elections were held in South Africa and Mbeki became president, a new Health Minister was named: Dr. Manto Tshabalala-Msimang. The new Minister “appeared more approachable” than Zuma, and early on in her tenure she traveled to Uganda, where Nevirapine was being used for PMTCT in a successful campaign to bring that country’s epidemic under control (van der Vliet 2001). Upon returning to South Africa, the new Minister was enthusiastic. “We came back as a South African delegation absolutely inspired, absolutely motivated. If Uganda can do it, so can South Africa. We have fought many battles. We can’t be defeated by a virus” (cited in van der Vliet 2001:168).

Van der Vliet continues to elaborate on the development of AIDS policy from 1999 until just after the Durban AIDS Conference in 2000 making no mention of any further positive developments as far as PMTCT policy is concerned (van der Vliet 2001). Shortly after the 1999 elections, a number of events followed which instead distanced the government from the development of an approach to PMTCT that was acceptable to scientists, doctors and activists: discourses of toxicity and AIDS dissidence emerged from the President’s office; SANAC was established, excluding major South African AIDS players; and an AIDS Advisory Panel, including both AIDS dissidents and orthodox thinkers, was created by the President in an attempt to establish where the “real” truth lies with respect to the cause of AIDS (van der Vliet 2001).

Van der Vliet brings in the President’s personality in attempting to understand the government’s tactics. She quotes a letter that Mbeki sent in early 2000 to British Prime Minister Blair and US President Clinton explaining his position in his own words. In his correspondence, Mbeki says that because HIV is primarily transmitted homosexually in
the West, but in Africa the epidemic spreads mainly via heterosexual intercourse, that it is a “uniquely African catastrophe” and therefore “a simple superimposition of Western experience on African reality would be absurd and illogical” (van der Vliet 2001:172).

While Mbeki’s rationale for engaging the AIDS dissidents may have been sound, his actions were highly criticized, particularly in the international media. The controversy heightened as South Africa came closer to hosting the XIII International AIDS Conference in Durban. “In their efforts to retain acceptability with their global peers” the conference chairperson, a South African scientist, Hoosen Coovadia, and his colleagues wrote an article portraying the issue as “false Africanism versus scientific globalism” (van der Vliet 2001:173). The authors refer to the idea of an African renaissance, demanding African solutions to African problems - a positive notion that has been taken to an unacceptable extreme by Mbeki when it came to HIV/AIDS. Mbeki’s push for an African solution is thought to stem partly from his distrust of the Western pharmaceutical industry. Although not an unjustified position, the government’s view in the respect was seen as extreme. In a statement released by the head of communications for the President’s office this suspicion was made explicit:

The tragedy is that HIV/AIDS is not going to succumb to the machinations of the profiteering pharmaceutical companies and their propagandists. Like the marauders of the military industrial complex who propagated fear to increase their profits, the profit-takers who are benefiting from the scourge of HIV/AIDS will disappear to the affluent beaches of the world to enjoy wealth accumulated from a human kind ravaged by a dreaded disease. (cited in van der Vliet 2001)

Despite making the connection between Mbeki’s questioning of AIDS and AZT and his distrust of Western biomedically-based pharmaceutical companies, many questions remain unanswered when it comes to why AIDS policy in South Africa played out in this controversial way. Some insight can be gained here by using a more political lens to
view policy development: this lens attempts to identify the various interests of stakeholders as well as the structures that both impede and facilitate policy implementation.

Understanding the Political Context and Actors

Helen Schneider, Director of the Centre for Health Policy at the University of Witwatersrand in Johannesburg, builds on the work of both Epstein and van der Vliet by taking a policy-studies approach in her two more recent publications. The first is focused on the implementation of AIDS policy post-Apartheid. In it she outlines some reasons for the difficulty experienced in AIDS policy implementation and provides recommendations for overcoming these difficulties. She highlights the roles for not only government, but also non-governmental actors (Schneider and Stein 2001). In the second, Schneider explores the politics of AIDS policy in South Africa and provides a summary of the agendas and activities of what she identifies as the three main grouping of actors involved in AIDS policy: government, activists and health scientists (Schneider 2002). She details the political interests of these three groups and thus helps to explain some of their actions in contemporary AIDS policy contestation in South Africa.

First, Schneider explores AIDS policy implementation since 1994 which “has been characterized by a lack of progress and a breakdown of trust and cooperation, both within government and between government and NGOs” (Schneider and Stein 2001:723). Prior to 1994 the AIDS world was made up of a strong network that included NGOs, researchers, sympathetic health workers, and the anti-Apartheid political groups (Schneider and Stein 2001:723). As exemplified by the inclusive NACOSA process
initiated in 1992, the expectation was that the new government would work together with
these actors to “lead a high-profile and comprehensive response to AIDS” (Schneider and
Stein 2001:723). Yet, as detailed previously, even some years later this goal had not been
achieved. To this end, Schneider explains some conditions that have impacted the
implementation of AIDS policy.

Initially Schneider sets the stage by making special mention of the peculiarities of
South Africa: South Africa is a middle income country that differs from most of its
continental neighbors in its ability to independently fund a universally accessible
“package” of AIDS prevention care and support, including antiretroviral therapy to
prevent MTCT. However despite its income level, South Africa fairs consistently poorer
on social access and outcome indicators than other comparable countries, due to the
enormous inequities that remain as the legacy of Apartheid rule (Schneider and Stein

With this in mind, Schneider contends that the following conditions inhibited the
implementation of “an ambitious programme through a weak, inherited administration…
derunning restructuring at every level” (Schneider and Stein 2001:724). First, the return
of exiled ANC members in 1990 brought together two differing styles of leadership
within the party. ANC members residing in South Africa during Apartheid had “an open
and responsive style of political leadership that resulted from an internal tradition of mass
political mobilization” (Schneider and Stein 2001:724). In contrast, ANC members
living in exile took “an authoritarian approach to leadership necessitated by the military
and underground struggle waged in exile for many years” (Schneider and Stein
2001:724). The two styles have since been apparent in the dealings of the current ANC
government. With respect to AIDS policy however, Schneider pinpoints the latter style as a contributor to the events of Sarafina II and Virodene; “scandals (that were) precipitated by (the) centralized actions of politicians” (Schneider and Stein 2001:727).

Second, the protection of civil servant jobs for the five years following 1994 meant “many managers in responsible positions lacked basic skills such as planning, budgeting and evaluation” (Schneider and Stein 2001:724). Finally, because of the post-Apartheid establishment of a quasi-federal political system, the “roles, responsibilities and relationships” between the spheres of government (national and provincial) are “mixed and complex” (Schneider and Stein 2001:726). Schneider notes that “stronger provinces resent national interference and the weaker provinces would like to abdicate responsibility to the national level” (Schneider and Stein 2001:726). The broad results of these three conditions were that the “AIDS Programme infrastructure post-1994 was… placed within a narrow health and biomedical framework and staffed mostly from the old civil service” and that the “essential tenets of the AIDS Plan, in particular the non-discriminatory aspects started to become diluted or lost” (Schneider and Stein 2001:726). Ultimately the AIDS plan was fundamentally flawed “in that it over-estimated the implementation capacity of the new government during a transition period” (Schneider and Stein 2001:726).

In response to past failures Schneider elaborates on the need for leadership among government and non-governmental actors in overcoming implementation obstacles. However, given the capacity issues just discussed, the concept of “political will” as an explanation for AIDS policy failure is deemed inadequate because it “assumes that decisions of political leaders are both necessary and sufficient for political change”
(Schneider and Stein 2001, cited in). Rather Schneider suggests that “the real problem underlying AIDS implementation failure in South Africa appears to lie less in the degree of political concern than in the quality of this concern; less in the lack of political commitment than in the inappropriateness of more centralist and authoritarian styles of leadership in facilitating the response to AIDS” (Schneider and Stein 2001:728, author’s emphasis). To this end she recommends that “an expanded, multi-sectoral response to AIDS is crucially dependent on mobilizing and co-ordinating civil society institutions” such as NGOs and activist groups who can work with government (Schneider and Stein 2001:728).

If the government bureaucracy is a weak player, it should also be feasible for credible political leaders to harness the considerable energies available outside of the formal government AIDS programme. However, to achieve this requires a particular kind of enabling leadership, which is very different to the notion of leadership as control that had tended to characterize the national government response to AIDS. (Schneider and Stein 2001:729)

Schneider’s recommendations are well taken, as it is precisely this controlling, authoritarian style of leadership as well as the inability of civil society actors and government to define a common strategy that are likely contributors to what she describes in her second article as the “vicious cycle of growing alienation between key members of the state and non-governmental actors” (Schneider 2002:150). For example, in the early post-Apartheid period the obstacles to implementation were generally not recognized by AIDS activists; one representative of this group who participated in a 1997 systematic review of the response to AIDS said, “Until I participated in the review and visited provinces, I never understood what a district health system was, or the incredible difficulties of amalgamating five bureaucracies into one province, or what a rural health service looked like” (cited in Schneider and Stein 2001:727). Making sense of the
disconnect between government and civil society actors, apparent in many of the policy issues explored by Epstein and van der Vliet, and characterized by Schneider as a “vicious cycle”, requires a deeper understanding of these actors’ motivations, and interests of the groups they were associated with.

Schneider’s second paper helps to clarify the interests of the three groupings of actors whom she has identified as key players in AIDS policy: the government, medical researchers and activists (Schneider 2002). Introducing the connections among these actors, Schneider elaborates on what may have motivated Mbeki’s inquiries into the link between HIV and AIDS: “While President Mbeki’s statements questioning conventional views on the causes of AIDS may seem bizarre to many, these statements have a much clearer logic when seen as part of an ongoing struggle between various players in South Africa” (Schneider 2002:145). Schneider begins her explanation of this “struggle” by noting, “interventions by the Ministry of Health and the presidency appear increasingly determined by the dynamics of response and counter-response within the AIDS field itself” (Schneider 2002:150). Here Schneider implies that the actions of these high level government actors, namely the Minister of Health and the President, seemed at times reactive to the resistance applied by civil society. The motivation and background for this resistance will be discussed in more detail below, in connection with the actors who led the “counter-response” to government, while the substantive events characterizing this struggle have been introduced previously by Epstein and van der Vliet.

First, in an attempt to explain the government’s actions, in particular the controversial views of the President about the cause of AIDS, Schneider legitimizes these views with supporting external evidence. For example, she remarks that President
Mbeki’s aim in establishing his AIDS Advisory Panel composed of orthodox scientists and dissidents “correctly point(ed) to a real lack of explanations for the pattern of the HIV pandemic, particularly in Southern Africa” (Schneider 2002:150). She substantiates this by citing a recent study that failed to account for differential HIV rates in cities versus rural areas, and by noting that dominant public health models have been inadequate in addressing the social and structural issues that underlie HIV transmission (Schneider 2002:151). To this end, Schneider expands her reasoning, drawing on the state’s justifiable “antipathy to the perceived imperialism of global norms” and “intellectual critique of scientific certainty and control” (Schneider 2002:151). This attitude and approach is legitimate from the perspective that the AIDS epidemic is characterized very differently in the Western world compared to Africa\(^\text{13}\) and that “science does not have enough answers to deal with this question”\(^\text{14}\) (of how to control HIV/AIDS) (Schneider 2002). Moreover, she surmises that Mbeki’s views were also founded in “a critique of the political economy of biomedical research” since “scientists and activists calling for antiretroviral treatment have… been projected as playing into the hands of the profit-making multi-national pharmaceutical industry” while “dissidents have been hailed as revolutionary” in the US and then in South Africa (Schneider 2002:152). Schneider accounts for the Virodene incident as a championing of an African renaissance (Schneider 2002:151), as introduced in the discussion of van der Vliet’s article above.

\(^{13}\) HIV risk groups in the West have been generalized as gay men and IV drug users, whereas in Africa heterosexual transmission accounts for the majority of new infections.

\(^{14}\) This quote is from an interview given by President Mbeki which points out the US Government’s issuance of new guidelines for antiretroviral use which were “radically different to what had been the practice before”, thus raising fundamentally that “science does not have enough answers to deal with this question” (of how to control HIV/AIDS) (Schneider 2002:151).
In contrast to what has been perceived as a “bizarre” response to AIDS nationally, especially by the President, Schneider explains that globally the South African Government’s “contribution and presence has been the prototype of mainstream international approaches to HIV” through its support of many major AIDS initiatives led by the UN and others (Schneider 2002:152). She also points out that there has been a degree of independence from the presidency, both within the national bureaucracy and among the provincial governments, in that actors in these bodies have gone ahead with conventional anti-AIDS strategies despite the President’s unconventional stance (Schneider 2002:153-4). Schneider resolves however, that while the President’s response to the disease could be viewed as denial of the country’s severe AIDS problem, her observations support an alternative explanation:

Equally plausible is that the conflict around AIDS, in the context of an emerging post-Apartheid state, represents a battle between certain state and non-state actors to define who has the right to speak about AIDS, to determine the response to AIDS, and even to define the problem itself. Ultimately it can be seen as an attempt on the part of the political leaders to establish who will legitimately be accepted as civil society partners with the new state and the extent to which non-state actors can define government policy. High level state interventions in the AIDS field have thus perhaps less to do with the differences in the content of policy than with a discomfort, and at times exclusion of, social movements that express certain styles of activism and that fall outside of the immediate networks of political patronage and influence within the Tripartite Alliance. (Schneider 2002:153)

Schneider’s theory then also relies on an understanding of the activities of non-state actors as protagonists in this conflict. In this respect she identifies the major players as belonging to either activist groupings or the medical research community. According to Schneider, these groups are linked to “a range of other actors” like clinicians, NGOs and policy researchers, as well as having “numerous international connections”

15 Recall that the Tripartite Alliance, formed in resistance to the Apartheid Government, includes the ANC, COSATU and the South African Communist Party.
This description gives the impression of a unified network or coalition of AIDS actors both within South Africa and globally. Looking specifically at the research community, she explicitly defines this group as “basic and public health scientists at academic institutions – the Medical Research Council and universities (predominantly in the metropolitan areas of Durban, Johannesburg and Cape Town)” (Schneider 2002:155, author’s inclusion in round brackets). She claims that this group “has and is playing a crucial role in research (both nationally and internationally) around mother-to-child transmission of HIV and AIDS vaccines” (Schneider 2002:155, author’s inclusion in round brackets). Based on the well-established research tradition that exists in South Africa the “local research infrastructure is able to access large amounts of international funds available for AIDS research, and even to play a role in shaping global research agendas” (Schneider 2002:159). The approach of the scientific community in influencing AIDS policy has been characterized by “ideal and somewhat triumphalist notions of the role of science” as well as “a human rights perspective on public health” (Schneider 2002:160). Many of the scientists involved in AIDS research “emerged from the progressive health movement of the 1980s” and thus links to “activist fields have been shaped by common historical affiliations with the mass democratic movement and have further been consolidated by common participation in local and international forums such as NACOSA and AIDS conferences” (Schneider 2002:159).

With respect to the “activist fields” Schneider defines this group’s membership as “consisting of a number of organizations and alliances” (Schneider 2002:154). Similar to the research community, the activist grouping has been “strongly influenced by a legal/human rights presence in the field” (Schneider 2002:154). Schneider connects the
emergence of AIDS advocacy in South Africa to “the mobilization of an AIDS
movement in the late 1980s in the US and other industrialized societies (which) in many
ways set the scene for AIDS activism in South Africa” (Schneider 2002:155). She goes
on to situate the appearance of AIDS activism in the West and its connection to activism
in the developing world:

Until the mid-1990’s when ‘HAART’ – highly active (triple) antiretroviral
therapy – became widely available in industrialized societies, AIDS was as much
a death sentence for a white middle class gay man in New York or Cape Town as
for a black working class woman in Kampala or Johannesburg. This unusual
commonality of experience, at both the individual and community level, has facilitated bonds
and forms of action across numerous of the classic social divides. (Schneider
2002:155)

In the First World, because HIV was most prevalent among gay men, the materialization
of AIDS activism relied strongly on “traditions of gay identity politics and mobilization”
(Schneider 2002:155). This social movement was dominated by white middle-class men
and was associated with intellectuals, artists and professionals, giving it the power and
credibility needed to impact scientific and political AIDS debates (Schneider 2002:155).

One of the formal groups that formed within this environment was ACT-UP (AIDS
Coalition to Unleash Power) based in New York and San Francisco (Schneider 2002:155-56).
ACT-UP and others “forced changes at many levels: in the conduct of scientific
trials, the approval of drugs and in the representation of AIDS activist as equal partners in
scientific forums” including the International AIDS Conferences (Schneider 2002:156).
A primary focus of AIDS activists in the West has always been access to drugs due to a
reluctance to see people living with HIV/AIDS as victims (Schneider 2002:156).

Schneider elaborates on how achievements in the West influenced actors in South Africa:

16 “Extremely high rates of HIV infection (similar to that being found in Southern Africa) were documented
in the gay communities of San Francisco and New York in the 1980s” (Schneider 2002:164).
The readiness of NGOs in South Africa to provide an open and early challenge to the new government around Sarafina II, local demonstrations against drug companies, the ‘illegal’ importation of fluconazole by the TAC\textsuperscript{17}, and the focus of activism on treatment all reflect what was learnt and understood about AIDS activism from the North. AIDS in South Africa has thus been a beneficiary of ‘social movement spill-over’ in the same way that the AIDS movement benefited from prior mobilization around gay struggles. (Schneider 2002:156)

Nevertheless, she notes that “AIDS activism in South Africa cannot be seen as a simple reflection of movements elsewhere” (Schneider 2002:157). Rather, Schneider maintains that AIDS mobilization in South Africa has roots in the mass democratic movement against Apartheid in the 1980s and 1990s, “giving it a wider social base and a need to frame AIDS struggles within broader political and economic struggles” (Schneider 2002:157).

Within South Africa, AIDS activism has “evolved in two strands” (Schneider 2002:157). The first, which includes many members of the medical research community described above, “is rooted in the anti-Apartheid health sector organizations, which addressed AIDS as an extension of their other activities” (Schneider 2002:157). This group has been involved in the drafting of the Maputo Statement, as participants in the NACOSA process, and in specific projects, such as a large national community mobilization project initiated by the National Progressive Primary Health Care Network (NPPHCN). While this strand includes primarily health sector actors, it has previously rejected a narrow biomedical approach to AIDS, recognizing the need for broader sociopolitical change as well (Schneider 2002:157). “The second strand of activism emerged from a legal and human rights base (and was) also established around the time

\textsuperscript{17} One of the activities of the Treatment Action Campaign (TAC) has been to import generic fluconazole, a drug used to treat opportunistic infections that often affect people living with HIV/AIDS. The intent of TAC actions has been to make this drug more accessible to people in South Africa (Treatment Action Campaign 2000).
of political transition in South Africa” (Schneider 2002:157). This strand is comprised of the AIDS Consortium, “a well established networking and information dissemination NGO, formed in 1992” (Schneider 2002:154); the AIDS Law Project (ALP), based at the University of Witwatersrand’s Centre for Applied Legal Studies (AIDS Law Project. 2002); the National Association of People Living with HIV/AIDS (NAPWA); and the TAC (Schneider 2002:157). These groups’ activities have been focused on legal and social equality and have included advocating for gay rights, as well as autonomy and confidentiality, as they are linked to broader social and economic rights (Schneider 2002:157). Schneider highlights that within this group, the TAC “is currently the most high profile contemporary expression of an AIDS social movement in South Africa” (Schneider 2002:158). While the TAC is similar to AIDS activists groups in the West, in its refusal to see AIDS as a death sentence by advocating for access to treatment, it is also formally linked to some of these groups (Schneider 2002:158). For example, the TAC has liased with MSF, Ralph Nader’s Consumer Project on Technology (CPTech), ACT UP, Health GAP and others in the global struggle for access to AIDS treatment, particularly in poorer nations (Schneider 2002:158). This international coalition building has benefited from the use of email listservs as well as international forums, like the International AIDS Conferences, held biannually (Schneider 2002). Additionally, the TAC has formed intra-national alliances, including with COSATU (a former member of the Tripartite Alliance with the ANC) and with other actors who oppose “the government’s macroeconomic policies of fiscal restraint and privatization” (Schneider 2002). While the TAC primarily focuses on access to treatment, they have also been connected to “broader anti-poverty demands” (Schneider 2002:158).
Therefore, according to Schneider, there are numerous actors who influence AIDS policy in South Africa. In summary, these actors include the government, made up of high-level national officials like President Mbeki and the Minister of Health, national bureaucrats, the provincial governments and others. There are medical researchers who have made strides in AIDS research and to this end have advocated for the benefits that medical science can offer to AIDS patients. There are activists: the first strand includes those with a background in the health sector, including some of the medical research community; the second strand includes those with a legal/human rights perspective, whose foundations are in the gay rights movement, among others. Medical researchers, as well as both strands of activists have international collaborators and have used their involvement in the anti-Apartheid struggle as an asset, employing strategies learned in the 1980s and 1990s in the more recent AIDS struggle. Of the non-state actors involved in AIDS, the TAC has been the most prominent (Schneider 2002). Moreover, the TAC has actually led the resistance against the government’s limited access PMTCT-Nevirapine policy. The remainder of this section will look specifically at the TAC’s activities as related to this resistance, setting the stage for the current study.

**The Treatment Action Campaign, Court Action and PMTCT Policy**

Given the vastness of the AIDS pandemic in South Africa, the Treatment Action Campaign (TAC) was established on December 10, 1998, International Human Rights Day, to advocate for greater access to HIV treatments for all South Africans (Treatment Action Campaign 2002). TAC’s specific objectives are “1) to ensure access to affordable and quality treatments for people with HIV/AIDS, 2) to prevent and eliminate new HIV
infections, (and) 3) to improve the affordability and quality of health-care access for all” (Treatment Action Campaign 2002). TAC was founded by Zackie Achmat, the group’s current Chairperson. Achmat is HIV+ himself, and although he could access treatment, he refuses to do so until all South Africans have public access to HIV/AIDS medicines (Thom 2000). This type of personal sacrifice made in the interest of others has helped to raise public awareness and support for treatment advocacy.

TAC’s founding campaign was for access to antiretroviral drugs for PMTCT (Treatment Action Campaign 2001a). At that time, TAC’s call was for AZT; Nevirapine was not indicated for PMTCT yet. Since that time TAC has continued to push relentlessly for PMTCT interventions and access to long-term antiretrovirals, among other national and international campaigns in support of their objectives (Schneider 2002; Treatment Action Campaign 2001a). Since its inception TAC has both opposed and worked with government while advocating for treatment for people living with HIV in South Africa (Treatment Action Campaign 2001a). One notable example of the latter was in early 2001 when the PMA launched their case against the South African Government for so-called infringements to the TRIPS Agreement. “The TAC, trade unions and the government seemed united against the ‘Goliath’ of drug company might” (Jones 2002), however this was not to be long-lived. Once the case was dropped because of “massive international and local opposition” this coalition of government with TAC and others dissipated (Jones 2001; Jones 2002). This was manifested in the next court case of significance to treatment access in South Africa, which pitted the TAC against government.
The “vicious cycle” or ongoing contestation around AIDS policy had an established history by now, as detailed previously, based on the work of Epstein, van der Vliet and Schneider (Epstein 2000; Schneider and Stein 2001; Schneider 2002; van der Vliet 2001). Their work outlines many of the important events that have characterized AIDS policy development in South Africa from the pre-1994 period until the middle of 2000. The resultant policy environment had been highly influenced by the “bizarre” views of the President about the link between HIV and AIDS, and subsequently the toxicity of antiretrovirals (Schneider and Stein 2001; Schneider 2002). With respect to drugs for PMTCT, a number of arguments explaining why these were not currently viable in South Africa had emerged from the national government: toxicity, cost of drugs, cost of milk formula, and cost of new infrastructure and training associated with a new program have formed the basis for these explanations (Epstein 2000; Schneider and Stein 2001; Schneider 2002; van der Vliet 2001). In 1999, the Minister of Health indicated in a speech, “that AZT was too expensive, and Nevirapine, although cost-effective, (was) not registered for use in MTCT programs” (Gerntholtz 2002). In July 2000, the pressure for access to treatment heightened, when drug company Boehringer Ingelheim offered five years of free Nevirapine to developing countries for PMTCT (Cherry 2000). As early as August 2000 the Health Minister had initiated discussions about a national PMTCT pilot program using Nevirapine (Baleta 2000; Gerntholtz 2002). However, it wasn’t until January of 2001 that the pilot program was formally announced; it would be launched at 18 sites, two per province, and would include Nevirapine as well as 6 months of free infant formula (kaisernetwork.org 2001; Smith 2001). The intent of the program was to assess operational issues in the delivery of antiretroviral drugs (Gerntholtz 2002). The
commencement of the pilot programs was dependent on the registration of Nevirapine by the MCC, however, at the time of this announcement Nevirapine had not been registered, after what some have called an “inordinate delay” (Jones 2001). By April 2001 the drug was registered (Medicine Control Council 2002) and the pilot projects were underway in the latter half of 2001.

While pushing for access to treatment, the TAC had been critical of a limited-access pilot program for PMTCT. “We want programmes implemented on a phased basis… at facilities where it’s possible,” stated Mark Heywood, the spokesperson for the TAC (Baleta 2000). This indicated the focus of the TAC, to get treatment to as many people as possible, as soon as possible. The TAC’s insurgence climaxed in August of 2001 when it launched a court case against the government claiming that the government’s failure to provide Nevirapine to all HIV+ pregnant mothers “constituted a violation of the rights of access to health care, equality, life, dignity, reproductive choice, and the rights of children” (Gerntholtz 2002:21). Further, TAC argued that “the failure amounted to a violation of the duties of public officials and a violation of the rights of pregnant women and children below the age years to have access to free health services” (Gerntholtz 2002:21).

In their case, the TAC, and the other applicants, physician Haroon Saloojee and the Children’s Rights Centre, named the following respondents: the National Minister of Health as well as all nine provincial Members of the Executive Committee (MEC) for Health (the MEC for Health is the provincial equivalent to the Minister of Health) (Treatment Action Campaign 2001b). The TAC’s founding affidavit is a lengthy document that first outlines “the issues” of “whether the Respondents are entitled to
refuse to make Nevirapine (a registered drug) available to pregnant women who have HIV and who give birth in the public sector” and “whether the Respondents are obliged, as a matter of law, to implement and set and clear timeframes for a national programme to prevent mother-to-child transmission” (Treatment Action Campaign 2001b). The founding affidavit also lays the groundwork for their case, including a description of the magnitude of the HIV problem in South Africa, and in particular that 70 000 babies are infected with HIV due to MTCT each year (according to government estimates) (Treatment Action Campaign 2001b). It points out that Nevirapine is a registered drug (Medicine Control Council 2002), which has been shown to effectively reduce MTCT in a number of studies (Guay, Musoke, Fleming, Bagenda, Allen, Nakabiito, Sherman, Bakaki, Ducar, Deseyve, Emel, Mirochnick, Fowler, Mofenson, Miotti, Dransfield, Bray, Mmiro, and Jackson 1999; Moodley, Moodley, Coovadia, Gray, McIntyre, Hofmyer, Nikodem, Hall, Gigliotti, Robinson, Boshoff, and Sullivan 2003) and offered for free for five years by Boehringer Ingelheim (Treatment Action Campaign 2001b). The affidavit also notes that there is a minimal risk of antiretroviral resistance when using the Nevirapine MTCT protocol (this is an ongoing concern with short term antiretroviral use); that Nevirapine is effective in reducing MTCT both with or without breastfeeding; and that the World Health Organization’s recommends that Nevirapine is a safe, effective and simple regimen for widespread use in South Africa (Treatment Action Campaign 2001b). Further, the affidavit brings up the concern that the government’s pilot policy makes Nevirapine universally available in the private sector, while it is limited to only 18 sites in the public sector (Treatment Action Campaign 2001b). It follows with a summary of the attitude of health care professionals, many of whom would like to be able
to make Nevirapine available to their patients for MTCT; and a critique of the approach of government, including an “arbitrary” choice of sites (Treatment Action Campaign 2001c), as well as other items to support their case (Treatment Action Campaign 2001b).

In short, the following arguments founded on this background information, formed the basis for the TAC’s case. First, because the pilot project was restricted to only 18 sites, doctors working in the public health care system, but not at designated sites, were precluded from prescribing Nevirapine, even when medically indicated and where the necessary support services were available; conversely, privately insured women, who access care in the private sector, could purchase Nevirapine with a prescription from their physician. “The rest of the patients who are forced to use the public health care system by reason of poverty or geographical location are denied access to medication which offers real hope of reducing the risk of mother-to-child transmission of HIV and thereby saving the lives of their children” (Treatment Action Campaign 2001c:section 1.5). This inequality led TAC to argue that:

The real possibility of life for the many thousands of children born to HIV+ mothers is thus made dependent on two factors: First, the extent to which they are able to afford treatment in the private sector. Second, the random and arbitrary designation of a limited number of sites per province in the public health care system at which it is permissible for doctors to dispense the drug. It is this irrational and arbitrary policy which is the subject matter of the present application. (Treatment Action Campaign 2001c:section 1.8)

TAC continued that this “irrational and arbitrary” policy adopted by government, “creates an untenable inequality which discriminates against the poor. Inevitably this amounts to discrimination on grounds of race as well” (Treatment Action Campaign 2001c).

The TAC’s case also addressed the following contentions related to government obligations as well as commitments to uphold rights, as outlined in the Constitution
(Treatment Action Campaign 2001c). First, TAC argued that current policy violated the government’s commitment to the provision of free health care to pregnant women and children under 6 years, as well as to “the rendering of all available health services… including the rendering of free health services to pregnant women for conditions that are not related to pregnancy” (Treatment Action Campaign 2001c). Moreover, TAC claimed that the government’s policy threatened the “fundamental rights of South Africans” to access to health care, including for reproductive health; basic health care for children; life; human dignity; equality; and psychological integrity, including the right to make decisions regarding reproduction (Treatment Action Campaign 2001c).

In addition, TAC’s case makes reference to the unique example of the Western Cape. In November 2001, the TAC replied to the response from the Department of Health to their initial claim made in August (Treatment Action Campaign 2001c). In this document, TAC formally states that their August concerns have been resolved as far as the Western Cape province is concerned.

The Western Cape stands out in marked contrast to the other provinces. It has a substantial and expanding program to make Nevirapine available throughout the province. By 30 June 2002, it is estimated that 90% of the HIV infected mothers in the province will have been reached by the programme. By March 2003, it is anticipated that coverage will approach 100%. The applicants have settled their dispute with the Western Cape, but the example of the Western Cape conclusively demonstrates the feasibility of making Nevirapine accessible to all in the public health system. (Treatment Action Campaign 2001c:section 1.6).

The government’s response to the case hinged on the argument that “it had taken all reasonable steps, within its available resources, to achieve the progressive realization of health care, including reproductive health care” (Gerntholtz 2002). This level of detail provides an adequate overview of the legal case between the TAC and government, as it
informs this study; therefore the legal intricacies of the government’s position as well as
the TAC’s reply will not be explored further.

    TAC’s position was supported by Judge Botha of the Pretoria High Court in
December 2001. The decision stated that the limited nature of the pilot program “is not
reasonable and that it is an unjustifiable barrier to the progressive realization of the right
to health care” (Gerntholtz 2002). Thus, the government was ordered to make
Nevirapine available outside the pilot sites (Gerntholtz 2002). However, this decision
was then appealed by government, on the grounds that the court’s do not have
jurisdiction in deciding on matters of policy (Gerntholtz 2002). At the same time TAC
launched an application to the courts to compel government to carry out the initial
decision while waiting for the government’s appeal to be heard by the Constitutional
Court (Gerntholtz 2002). These applications were heard in March 2002, and TAC’s
Execution Order was granted during the delay (Gerntholtz 2002). In what had now
become a long string of appeals, the Execution Order was also appealed by government
(UN Integrated Regional Information Network 2003).

    Interestingly between late January and mid-February of 2002, the KwaZula Natal
and Gauteng provincial governments announced that they, like the Western Cape, would
rollout widespread access to PMTCT programs in their provinces. At this time this was
considered to be in defiance of National Policy as the case had not been closed by the
Constitutional Court (kaisernetwork.org 2002h; kaisernetwork.org 2002n). Showing
further resistance in February 2002, the media noted that despite previously refraining
from doing so, former President Mandela had criticized the Mbeki Government’s
“lackluster” response to AIDS for the second time that month (kaisernetwork.org 2002n).
Moreover, that same month the “Interim Findings on the National PMTCT Pilot Sites” were released. The main conclusions of this report were: “There are no good reasons for delaying a phased expansion of PMTCT services in all provinces. The pilot sites have already generated a lot of useful and important lessons that can now be put to use” (McCoy 2002:iv).

In April 2002 the government’s appeal of the Execution Order was denied (UN Integrated Regional Information Network 2003). TAC continued to apply pressure to government, and now committed to monitoring progress, with the threat of further litigation if the government did not adhere to the Execution Order (Beresford 2002).

Finally, in July 2002, the Constitutional Court released its ruling that the Pretoria High Court’s December 2001 decision was to be upheld (Sidley 2002). As Chief Justice Arthur Chaskalson explained, “Government is ordered without delay to remove the restrictions that prevent Nevirapine from being made available for the purpose of reducing the risk of mother-to-child transmission of HIV at public hospitals that are not research and training sites” (cited in kaisernetwork.org 2002b).

2.3.2 Questions Left Unanswered: The Niche for this Study

These previous writings on PMTCT policy in South Africa leave a number of questions unanswered or inadequately answered; I attempt to address a few of these in the current study. Although Epstein, van der Vliet and Schneider all provide some useful insights into the AIDS policy process in South Africa, they do not factor Nevirapine-based PMTCT policy development into their analyses (Epstein 2000; Schneider and Stein

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18 There is no conclusive data yet on the actual impact of the Nevirapine PMTCT program. Obstacles to the collection of this data include difficulties in follow-up and the reliance on either imperfect or expensive test procedures to determine the HIV status of babies (McCoy, Besser, Visser, and Doherty 2002).
2001; Schneider 2002; van der Vliet 2001). Therefore, in my research I have attempted to understand the policy process and rationale that influenced the government to initiate Nevirapine delivery on a limited-access, pilot project basis only. I further sought to understand the continued pressure on government that led to an expanded program, including through the court case described above. The goal was to provide new insights from the perspective of policy stakeholders in South Africa; I hoped to learn what was not apparent from the media coverage of high-level government officials, that is, I hoped to learn about the perspective of stakeholders, who cope with the government’s PMTCT policy on a daily basis: clinicians, activists, bureaucratic government officials, NGO representatives, and others. In particular, my aim was to explore the ideologies, agendas and activities of the Treatment Action Campaign and other relevant health activist groups, as well as the perspective of physicians throughout the Nevirapine-PMTCT policy process. Again this objective was intended to help me articulate a deeper analysis of the issues and perspectives of these groups than was available from excerpts from high-level TAC representatives or prominent physicians, portrayed in the media.
CHAPTER 3: METHODOLOGY

The current research is based on a qualitative, case study approach. The rationale and background for this approach is discussed here in Section 3.1. This section introduces other approaches that informed this study: ethnography, a methodology used in qualitative research and the Advocacy Coalition Framework, a lens through which policy development can be understood. These varied approaches inform the mode of inquiry for this study and the relevant background for each is provided in this section.

Section 3.2 moves temporally through the research process, describing each of the five phases. Here, the rationale is provided for each step in the process, based on the approached discussed in Section 3.1. Finally, Section 3.3 discusses ethical issues and limitations related to the current study.

3.1 EPISTEMOLOGICAL INSIGHTS

Qualitative research has roots in both sociology and anthropology (Vidich 2000). Although it has been widely used, it is still compared to and distinguished from quantitative methods, which are more pervasive, even in the social sciences (Berg 2001:2). Qualitative research is used to gain a “greater depth of understanding” about an issue or topic of interest, and involves a set of strategies unique from the measurement-focused approaches of quantitative studies (Berg 2001:2). Denzin and Lincoln, who have written widely on qualitative research, define it in the following way:
Qualitative research is multimethod in focus, involving an interpretive, naturalistic approach to subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, personal experience, introspective, life story, interview, observational, historical, interactional, and visual texts – that describe routine and problematic moments and meaning in individuals’ lives. (Denzin and Lincoln 1994:2)

Creswell, who writes about various approaches within qualitative research, summarizes it this way:

Writers agree that one undertakes qualitative research in a natural setting where the researcher is an instrument of data collection who gathers words or pictures, analyzes them inductively19, focuses on the meaning of participants, and describes a process that is expressive and persuasive in language. (Creswell 1998:14)

With this general understanding of qualitative inquiry, case study research and ethnography are discussed next. In addition, the Advocacy Coalition Framework is introduced and its utility for this research explored.

### 3.1.1 Case Study Research

The case study approach is chosen for a variety of reasons. The following section outlines some of the features of case study research and explains why this is a rational approach for this study. In Creswell’s comparison of five qualitative traditions, he recommends that a case study approach20 be used “to examine a ‘case,’ bounded in time or place” (Creswell 1998:40). The “case” itself can be “a program, an event, an activity, or individuals” (Creswell 1998:61). This is an appropriate approach then for the study of

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19 Inductive analysis implies the application of inductive, rather than deductive reasoning. Inductive arguments are knowledge expanding, in that their conclusions contain more information than included in the premises of the argument; however, this feature also means that the truth of a conclusion is not guaranteed (Giere 1984). “Thus the very nature of scientific reasoning introduces a real and unavoidable possibility of error into the scientific process” (Giere 1984:45).

20 Note that case studies can be both qualitative and quantitative in nature (Stake 2000; Yin 2003).
Nevirapine policy development in South Africa; a process that formally began in January 2001 (though it roots go back to a much earlier time, as discussed in Chapter 2), and came to a court-ordered end in July 2002\textsuperscript{21}. A case study can have multiple sites, or take place at a single location (Creswell 1998:61). This case study is a “multi-site study” (Creswell 1998:61); because it looks at a national policy, it draws on the experiences and perspectives of stakeholders across the country, namely in Cape Town, Durban and Johannesburg and their surrounding areas, it is further informed by the views of interested parties from around the world.

“The Case” of Interest for this Study

It is pertinent to note here that the case in question is the Nevirapine-based PMTCT policy process in South Africa, that generally took place between January 2001 and July 2002, and NOT the court case launched against government by the TAC, described above. This study focuses on the negotiated policy process that took place, and how actors in this process made their interests known and how some of them got their agendas met. The court case is therefore a part of the broader case of interest studied here. From this point on, reference to the “case” implies the case of study, and not the court case (which will be herein referred to as the “court case”).

\textsuperscript{21} Creswell notes that “some case studies may not have clean beginning and ending points, and the researcher will need to work with contrived boundaries” (Creswell 1998:64). That is precisely the predicament with this particular case. Although Nevirapine policy development can be bounded temporally from January 2001-July 2002, this temporal limit cannot be strictly adhered to, as participants indicated events prior to this that were seen as significant to this particular case, and made mention of subsequent ongoing developments that also provide insight into the case in question.
Applying a Case Study Approach

According to Creswell’s description above, almost any program, event, activity, or individual can form the basis for a case study (Creswell 1998:61). However, there are many other approaches to social research (Yin 2003); so why choose a case study? Yin, in his writing on case study research explains that, “in general, case studies are the preferred strategy when ‘how’ or ‘why’ questions are being posed, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real-life context” (Yin 2003:1). The Nevirapine PMTCT policy process in South Africa is clearly a modern-day event within a real-life context; further the basis for this study is a desire to better understand the ‘how’ and ‘why’ of this process. The goals of the project are to describe the process and understand why the government initially rejected a universal access program. Moreover, the research attempts to explore how activists and physicians were involved in mandating a more comprehensive program, and why they were motivated to do so (i.e. by understanding and evaluating their ideologies and perspectives).

Another reason for choosing a case study approach is that it is an effective way to include multiple disciplinary perspectives. “Case study research holds a long, distinguished history across many disciplines”, including anthropology and sociology (Creswell 1998:62), and political science (Yin 2003:1). It is therefore an appropriate mode of inquiry for this research, which makes use of perspectives from sociology, anthropology, policy studies, medicine and women’s health studies in an attempt to understand the intricacies of the case of interest.
A case study requires that the researcher “have contextual material to describe the setting for the case” and “have a wide array of information about the case to provide an in-depth picture of it” (Creswell 1998:39). “The context of the case involves situating the case within its setting, which may be a physical setting or the social, historical, and/or economic setting for the case” (Creswell 1998:61). Part of this information, especially the contextual material, is contained in Chapter 2, while more detail about the case itself is provided in the results chapters (4 and 5). Moreover, “a wide array of data collection procedures” or reliance on “multiple sources of information” are characteristic of case study research (Creswell 1998:39,61). Using multiple sources of data is a way of achieving “redundancy of data gathering” (Stake 2000:443). This is desirable, and is common in qualitative research as a means of “reduc(ing) the likelihood of misinterpretation” (Stake 2000:443). This technique is generally referred to as “triangulation”, meaning that the researcher uses “multiple perceptions to clarify meaning, verifying the repeatability of an observation or interpretation” (Stake 2000:443). The current study used academic, as well as journalistic and media text sources to describe the case context. It also made use of participant observation (through my presence at the International AIDS Conference in Barcelona), qualitative interviews (involving 21 different policy stakeholders in South Africa), and “virtual dialogue” (gleaned from an intellectual property and health listserv), as sources for data.

Another feature of case study research is that it can be “instrumental”, when researchers have “a need for general understanding, and feel that we may get insight into the question by studying a particular case” (Stake 1995:3). However, a case study can also be “intrinsic”, when “we are interested in it, not because by studying we learn about
other cases or about some general problem, but because we need to learn about that particular case” (Stake 1995:3). While this case may give insight into the general problem of access to medicines, and perhaps even strategies that could be used in countries other than South Africa, in this struggle, it is by and large an “intrinsic” case study. That is, because of South Africa’s distinctive post-Apartheid context, and because of the exceptionality of the case itself (for example, the fundamental role played by a well-organized, law-savvy, activist group), this research was undertaken to examine the unique features of this particular case.

Because some have deemed case study research as “not a methodological choice but a choice of what is to be studied” (Stake 2000:435), it is implied to be a topic-related choice. Based on the justification provided above, which explains why the case of interest (topic) is an appropriate focus for case study research, this may already be obvious. Most texts do not define a single methodological approach to case study research, thus, there are multiple methods which can be applied in case study research (Stake 2000:435). Thus, the researcher must decide how information will be gathered.

3.1.2 Ethnography

Merriam describes an “ethnographic case study” as one methodological approach to case study research (Merriam 1988:23).

An ethnographic case study… is more than an intensive, holistic description and analysis of a social unit or phenomenon. It is a sociocultural analysis of the unit of study. Concern with the cultural context is what sets this type of study apart from other qualitative research. (Merriam 1988:23)

Given the focus of this research of the Nevirapine PMTCT policy process and its attempt to identify historical, political, social and cultural legacies and beliefs in South Africa that
have influenced the current policy environment, this sociocultural form of analysis is appropriate. Of course, the ethnographic case study, is a case study informed by the traditionally anthropological method of ethnography (Merriam 1988:23). Ethnography has been widely defined and redefined, as it has transformed from an approach used by anthropologists to study human society and culture, to a form of research used in many social science disciplines. The following descriptions represent this transition and further elucidate just what ethnography is.

Ethnography is a set of methods used to collect data, and it is the written record that is the product of using ethnographic techniques. Ethnographic techniques are the strategies researchers use to collect data about the social order, setting, or situation being investigated. Common techniques of data gathering are interviewing, documentary analysis, life history, investigator diaries, and participant observation. Just using those techniques, however, does not necessarily produce an ethnography in the second sense of the word. An ethnography is a sociocultural interpretation of the data. As analytic descriptions or reconstructions of participants’ symbolic meanings and patterns of social interactions, “ethnographies recreate for the reader the shared beliefs, practices, artifacts, folk knowledge, and behaviours of some group of people.” (Merriam 1988:23)

Merriam’s description, from 1988, indicates the earlier, mainly social and cultural focus of ethnography, which has now been expanded; however she is accurate in the range of techniques she ascribes to ethnographies. Recall that this particular study uses interviewing and participant observation. Further, Merriam emphasizes the analysis of data as critical: the aim is to represent what participants said as clearly as possible, and place this data within its social and cultural context. A more contemporary description of ethnography provides insight into the broadened nature of this method beyond anthropology and the study of culture.

Ethnography involves an ongoing attempt to place specific encounters, events, and understandings into a fuller, more meaningful context. It is not simply the production of new information or research data, but rather the way in which such
information or data are transformed into a written or visual form. As a result, it combines research design, fieldwork, and various methods of inquiry to produce historically, politically, and personally situated accounts, descriptions, interpretations, and representations of human lives. (Tedlock 2000:455)

This study then drew on both the methods of inquiry as well as analytical techniques characteristic to ethnography, to place an understanding of the Nevirapine PMTCT policy process within the “more meaningful context” of the participants’ (policy stakeholders) lives. The specifics of these approaches will be described below in Section 3.2.

Reflexivity

One other important aspect of most qualitative research, and of ethnography in particular, is “a reflective concern on the part of the researcher”, also called reflexivity (Berg 2001:139). “This reflexive characteristic implies the researcher understands that he or she is part of the social world(s) that he or she investigates” (Berg 2001:139).

Reflexivity requires that the researcher be self-conscious, aware of his or her own influence in knowledge production. Stake explains the need for reflexivity in qualitative research by comparing it to quantitative approaches:

All research depends on interpretation, but with standard quantitative designs there is an effort to limit the role of personal interpretation for that period between the time the research design is set and the time that data are collected and analyzed statistically – sometimes thought of as a ‘value free’ period. Standard qualitative designs call for the persons most responsible for the interpretations to be in the field, making observations, exercising subjective judgment, analyzing and synthesizing, all the while realizing their own consciousness. (Stake 1995:41).

Reflexivity is an exercise that helps ensure that data, through analysis, is represented truthfully. “Recognizing good sources of data” and assessing the robustness of one’s interpretations requires “sensitivity and skepticism”; “this expertise comes largely
through reflective practice” (Stake 1995:50). This reflexive practice includes an “internal dialogue that repeatedly examines what the researcher knows and how the researcher came to know this” (Berg 2001:139, author’s emphasis). Thus, as mentioned initially, the reflective process involves first being aware of one’s influence in the research and therefore in the knowledge created. Then, as Stake alludes to here, this thought process should then be extended to an internal evaluation of where data came from, how it was interpreted, and whether the interpretation is a true representation of the data.

3.1.3 The Advocacy Coalition Framework: A Theoretical Approach to Studying Policy Change

Because this study centered around a policy process, ways of looking at policy development were of concern. There are many different types of policy research, and it is commonly defined in this way:

A policy research effort begins with a social problem, such as malnutrition, poverty or inflation, evolves through a research process whereby alternative policy actions for alleviating the problem are developed, and communicates these alternatives to the policymakers. (Majchrzak 1984:13)

This definition implies that policy research is undertaken to inform policymakers by providing a careful analysis of policy options. This is not the aim of this research. Ham and Hill differentiate between two types of policy analysis: “analysis of policy and analysis for policy” (Ham and Hill 1993:4). They indicate that the former is “an academic activity concerned primarily with advancing understanding,” while the latter is, as described above, “an applied activity concerned mainly with contributing to the solution of social problems” (Ham and Hill 1993:4). This research takes the former, “academic” approach to policy analysis. It examines an ongoing policy process, to
understand how specific groups’ activities as well as values and beliefs are influential in policy change, and how these are founded in historical, social, political, cultural and economic milieus. One approach that seemed suited for analysis of this particular policy process was the Advocacy Coalition Framework (ACF). The ACF proposes a theory for the policy development process, specifically when multiple actors are involved, and their alliances fall outside traditional boundaries (Jenkins-Smith and Sabatier 1993). For example, divisions might be typically be made between government and a particular activist grouping; the ACF promotes the concept of a coalition that challenges these divisions, by allowing sympathetic member of government to be grouped with activists, when they share similar beliefs (Jenkins-Smith and Sabatier 1993). In this way the ACF proposes a theory for how policy is developed and specifies a qualitative (as well as a separate quantitative) approach for testing this theory. Because this research was of an exploratory nature, the imposition of theory early on was seen as limiting. Therefore in an attempt to be open to what participants said, and the ways in which they characterized policy development, this ACF methodology was not used. However, the theory it presents did inform this study, by presenting one way in which policy development could be conceptualized. It is helpful to summarize the ACF here, as it does provide some insight into how to make sense of policy processes, and its usefulness in explaining this particular policy process is discussed in Chapter 6.

The Role of Theory in this Research

Before launching into a detailed explanation of this theoretical approach, it is important to note that case study research can employ theory in different ways (Creswell
“Social science theories might be absent from the study, with a focus on a description of the case and its issues” (Creswell 1998:87; Stake 1995). Theory can be introduced early on and “used to guide the study in an explanatory way” (Creswell 1998:87; Yin 2003). It can also be brought in at the end of a study to make sense of the research findings (Creswell 1998). It is this final approach that best describes the role of theory in this study. However, as I became aware of writings about the ACF early on in the research process, I introduce it here because my readings of this theory did thus inform the study, especially by giving insight into the complex process of policy change. Nevertheless, an Advocacy Coalition Framework for analysis was not imposed on the methodology. Instead, this theory and others that have relevance to the findings will be addressed in Chapter 6 (which develops a discussion of the findings).

Introducing the Advocacy Coalition Framework

The ACF is a tool to analyze policy change. The framework rests on a few basic premises. The first premise relates to time, and states that understanding the processes of policy change requires a time perspective of a decade or more (Jenkins-Smith and Sabatier 1993). The second premise highlights the uniqueness of the ACF: “the most useful aggregate unit of analysis for understanding policy change is the policy subsystem, that is, those actors from a variety of public and private organizations who are actively concerned with a policy problem or issue” (Jenkins-Smith and Sabatier 1993:16). Within a subsystem, actors are grouped into coalitions based on their beliefs, specifically as they relate to policy. This emphasis on belief systems is a hallmark of the ACF and is also what allows the framework to move beyond grouping actors based on predetermined
governmental structures, like specific administrative agencies or legislative committees. The transcendence of preexisting organizational boundaries means that each coalition can be composed of actors from a variety of sectors, for example, actors from government, civil society, media, and academia could compose a coalition given that they share core beliefs that pertain to the policy problem. Within a policy subsystem there may be one or a number of coalitions. The third premise is that policy subsystems will normally involve actors from all levels of government, for example, local, provincial and national governments (Jenkins-Smith and Sabatier 1993). The fourth and final premise is that:

Public policies and programs incorporate implicit theories about how to achieve their objectives and thus can be conceptualized in much the same way as belief systems. They involve value priorities, perceptions of important causal relationships, perceptions of world states (including the magnitude of the problem), perceptions of the efficacy of policy instruments, and so on. This ability to map beliefs and policies on the same ‘canvas’ provides a vehicle for assessing the influence of various actors over time, particularly the role of technical information (beliefs) on policy change. (Jenkins-Smith and Sabatier 1993:17)

Thus, from an ACF perspective, policy development is conceptualized as a reflection of the beliefs and values that are held by those actors who are influential in policy change.

Figure B depicts a general overview of the ACF. The boxes on the left show two sets of exogenous variables. Of particular note is that the extent to which resources are limited, based on the distribution of natural resources and/or changes in socioeconomic conditions, directly impacts the policy change process. Where resources are more constrained, policy decisions are typically more drawn out, as many more compromises need to be made among coalitions and government to accommodate the competing interests of each group for scarce resources. The right side of the figure shows the policy subsystem – there are two competing coalitions, A and B, as well as a sovereign body,
and policy brokers. Each of the coalitions as well as the policy brokers (i.e. technical experts and government consultants) attempt to inform the sovereign body. This body is typically government, but could also include other authorities with policy-making influence such as the courts. Note that within any given subsystem there may be one or many competing coalitions.

Figure B. An Overview of the Advocacy Coalition Framework

(Jenkins-Smith and Sabatier 1993:18)
Policy-Oriented Belief Systems

The concept of belief systems in the ACF has three basic points of departure. As described by Sabatier & Jenkins-Smith (Jenkins-Smith and Sabatier 1993), these three concepts include, first, Ajzen and Fishbein’s “theory of reasoned action” (Ajzen and Fishbein 1980). This theory effectively states “actors will weigh alternate courses of action in terms of their contribution to a set of goals, but in which the preferences of reference groups (such as members of one’s coalition) are accorded a more prominent role” (Jenkins-Smith and Sabatier 1993:30). The second concept is that “rationality is limited rather than perfect” (Jenkins-Smith and Sabatier 1993:30). Thus, decisions by actors, either as coalition members or government officials, do not and will not always be based on reason alone or make rational sense. Finally, “because subsystems are composed of policy elites rather than members of the general public, there are strong grounds for assuming that most actors will have relatively complex and internally consistent belief systems in the policy areas of interest to them” (Jenkins-Smith and Sabatier 1993:30).

Moving from these concepts, it is hypothesized that policy elites’ belief systems will be structured as follows: deep or normative core beliefs, these are part of an actor’s basic personal philosophy, apply to all policy areas, and are very resistant to change; near core or more policy-focused beliefs, these are fundamental policy-related positions concerning the basic strategies for achieving deep or core beliefs and are difficult yet possible to change; and secondary beliefs, these relate to policy instruments to achieve deep or core beliefs, are specific to a specific policy area, and are moderately easy to
change (Jenkins-Smith and Sabatier 1993). Illustrative examples of these three levels of beliefs are shown in Figure C.

**Figure C. Illustrative Examples of the Structural Components of Belief Systems in the Advocacy Coalition Framework**

<table>
<thead>
<tr>
<th>Illustrative components</th>
<th>Deep/normative core beliefs</th>
<th>Near core/policy-focused beliefs</th>
<th>Secondary beliefs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Relative priority of various ultimate values, i.e. freedom, security, power, knowledge, health, love, beauty, etc.</td>
<td>Proper scope of governmental vs. market activity.</td>
<td>Information concerning program performance, the seriousness of the problem, etc.</td>
</tr>
</tbody>
</table>

(adapted from Jenkins-Smith and Sabatier 1993:31)

**Policy-Oriented Learning**

A final characteristic of the ACF is its focus on “policy-oriented learning” or the lasting role technical information and expertise has in developing policy (Jenkins-Smith and Sabatier 1993). As the interplay among coalitions, or between a coalition and government, within a policy subsystem aims to promote each group’s policy-related beliefs, new technical information is brought into the policy environment to support these beliefs (Jenkins-Smith and Sabatier 1993). The entrée of new technical information, either to provide evidence that substantiates a group’s beliefs, or to inform policy instruments, allows for learning to occur. Thus, because a coalition has used its resources to make relevant policy-related knowledge or information public, the government has the opportunity to learn from and use this information in their policy decision-making process. Further, this information can be used to inform future policy. Thus, policy-
oriented learning occurs when new information, brought to bare in the policy change process, is incorporated into one’s belief system and applied in policy decisions.

Thus the ACF provides some key characteristics of policy development, including a focus on coalitions, beliefs and learning. The discussion of how these might be applied to this research will be limited to Chapter 6. However, this theory informed my thinking about policy and perhaps influenced my analysis: this warranted its inclusion here as well as the later discussion of its relevance to this research. A description of the research process as informed by case study research and ethnography is developed below. This development of the research plan did not rely on the ACF as a methodology, though to some degree, it did influence my thinking about how to study policy change (i.e. the inclusion of a variety of actors influential in policy to learn where, if at all, coalitions existed).

3.2 RESEARCH PLAN

The following chart sets out the timeline for this study relative to the case of interest. As previously noted the case is roughly set between two events: the January 2001 announcement by the National Government that PMTCT pilots using Nevirapine would be established and the July 2002 Constitutional Court decision that mandated national rollout of the pilot programs. This does not imply that proceedings before and after these events are unimportant; in fact, one aim of the research is to establish how the
Nevirapine policy process came about in light of historical developments. Furthermore, the relevant events after July 2002 are discussed in the results section.

Figure D. The Research Timeline and Policy Development in South Africa

<table>
<thead>
<tr>
<th>SELECTED POLICY EVENTS</th>
<th>DATE</th>
<th>RESEARCH EVENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>The National Government announces an 18-site Nevirapine-based PMTCT pilot project</td>
<td>January 2001</td>
<td>n/a</td>
</tr>
<tr>
<td>Nevirapine is approved for PMTCT by the MCC in South Africa</td>
<td>March 2001</td>
<td>n/a</td>
</tr>
<tr>
<td>The establishment of the 18 national PMTCT pilot sites begins</td>
<td>May 2001</td>
<td>n/a</td>
</tr>
<tr>
<td>TAC files lawsuit against the Government</td>
<td>August 2001</td>
<td>n/a</td>
</tr>
<tr>
<td>The establishment of the 18 national PMTCT pilot sites is completed</td>
<td>November 2001</td>
<td>n/a</td>
</tr>
<tr>
<td>The Pretoria High Court rules in favour of the TAC; the South African Government appeals this ruling to the Constitutional Court</td>
<td>December 2001</td>
<td>Phase 1a/2a: Literature review and background research for the study begins</td>
</tr>
<tr>
<td></td>
<td></td>
<td>--Phase 1b: The process of establishing contacts in South Africa begins</td>
</tr>
<tr>
<td>The TAC applies for, and is granted, a Temporary Execution Order by the court to force government roll out of Nevirapine nationally; the Government appeals the Execution Order</td>
<td>March 2002</td>
<td>A research plan is drawn up</td>
</tr>
<tr>
<td>The Government’s Execution Order appeal is denied by the court</td>
<td>April 2002</td>
<td></td>
</tr>
<tr>
<td>The Constitutional Court rejects the Government’s initial appeal, the Pretoria High Court’s December ruling is upheld</td>
<td>July 2002</td>
<td>Phase 2b: Participant observation at the Barcelona International AIDS Conference</td>
</tr>
<tr>
<td>(Subsequent policy events will be discussed in the Results)</td>
<td>August 2002</td>
<td>--Phase 4a: Interpretation, and some analysis begins</td>
</tr>
<tr>
<td></td>
<td></td>
<td>--Phase 2c: Subscription to IP-health (intellectual property and health) listserv begins</td>
</tr>
</tbody>
</table>
The research timeline shown here outlines part of the five phased research plan. Each phase of the plan is discussed in more detail below. The aim(s) of each phase is/are bulleted below the section title, and reflect the research objectives.

### 3.2.1 Phase 1: The Literature Review and Making Contact

- To review the existing literature and establish primary contacts in South Africa.

**Phase 1a: Literature Review**

Beginning in December of 2001 literature was gathered to inform the direction of the research. Based on over three months of literature searching, following media
coverage of the court case, and reviewing potential methodologies, a preliminary research strategy was put together. Moreover, the case that this research would explore was identified. The goal of the literature review was to frame the problem of drug access and access to health care in South Africa in a historical, political, economic and social context, making specific reference to policy and equity impacts due to the legacy of Apartheid. Further, the literature review attempted to give some background on PMTCT policy development, particularly with respect to the policy involving Nevirapine. The types of sources drawn on in this phase included academic journal articles, media sources, and websites. These became a few of the “multiple sources” of data that Creswell recommends for case study research (Creswell 1998), particularly since following the development of this literature became an ongoing process in this research, as described in Phase 2a. Qualitative interviews, participant observation and listserv membership provided other sources of data, and will be described in more detail below.

Phase 1b: Establishing Contacts

At the same time, a number of academics and activists who had a known interest in the case (as expressed through the literature22) were identified. These individuals were targeted to both give feedback on the topic of study and preliminary research plan, and also to help to refer me on to others who might participate in qualitative interviews, the primary mode of data collection for this study. Five people were contacted by email for further information about Nevirapine PMTCT policy in South Africa. Two of these five contacts were maintained: one became the South African advisor for this study, who was...

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22 For example, people were identified because they had published an article related to Nevirapine-PMTCT policy, or because they had been identified in the media as being associated with the policy (i.e. through a published comment).
not interviewed as part of the research, while the other was a research participant, and
gave an interview during the field work (Phase 3). Attempts to make contact with the
three other individuals were unsuccessful. All were unresponsive after a series of at least
three attempts (by email). The two contacts that were maintained referred me on to other
people living in South Africa, deemed by them to have an interest or association with
Nevirapine PMTCT policy development. Once ethics approval was granted (see Section
3.3 for more details regarding this), I continued to make contact with potential interview
participants. This continued both prior to, and throughout the field work, as I asked all
participants to refer me on to others who they felt could contribute to the study. The
composition of the participant group as well as the recruitment procedures are discussed
next. All participant recruitment was considered part of Phase 1b. (The interviews
themselves were part of Phase 3, and the rationale for using this approach as well as an
explanation of the interview procedures in discussed in that section.)

Participants

Based on the literature reviewed in Chapter 2, it is clear that a number of people play
a role in shaping policy. AIDS policy development was characterized by the contribution
of three groups in particular, as identified by Schneider: government, activists and
physicians (Schneider 2002). Therefore, the objectives for this research were to learn
more about Nevirapine PMTCT policy development from these perspectives, and also
from others who could be identified as stakeholders. Many of the accounts of AIDS
policy development in South Africa come from media portrayals or academic
commentaries, therefore the goal of the interviews was to learn about Nevirapine policy
from “the horse’s mouth”. That is, to learn from those people who dealt with this policy in their everyday lives, rather than those who were providing second-hand commentary or detailed analysis. Based on the literature and discussions with advisors, the following list of potential stakeholders was agreed upon:

- Government Officials
- Media Representatives
- Pharmaceutical Companies’ Representatives
- NGO Representatives (including representatives from the Treatment Action Campaign)
- Health Care Providers and Researchers
- Peer Counselors (working at AIDS clinics)
- Other relevant stakeholders

These groups were selected because they represent the primary organizations or affiliations with an interest in Nevirapine policy decisions in South Africa. The “Government Officials” group could include politicians or bureaucrats; though high-level officials were not targeted as their perspectives had received a lot of media coverage, and it was believed they would be hard to reach. The “Media” group was targeted in an attempt to understand what was understood about Nevirapine PMTCT policy but not necessarily reported. The “Pharmaceutical” group has an obvious interest in drug policy, and because of the negative media attention members of this group often receive, it was thought that there may be more depth to this perspective than had been commonly

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23 The Thesis Advisory Committee for this research included a sociologist, an anthropologist, a maternal and child health expert/psychologist and a policy expert. In addition to these mentors, an advisor in South Africa also contributed to the development of this research: a physician and bioethicist, who has written widely about health care in South Africa.
addressed. The “NGO” group consisted of any person with an NGO affiliation; organized activist groups, like the Treatment Action Campaign were included in this category. The “Health Care Providers and Researchers” group was included to obtain the perspective of physicians and others working in the health field in South Africa. The “Peer Counselors” group included persons working at AIDS clinics or maternal and child health facilities, who are infected or affected by AIDS and who counsel and support patients at these centres. The “Other Relevant Stakeholders” group was included to account for individuals who did not fit in another group but who were referred to me by either the two contacts mentioned above or by another research participant. The goal of recruitment (described below) was to interview approximately 20 individuals who identified with one of the above stakeholder groups.

Significantly, this list excludes patients; not because it was believed that patients did not have an interest in Nevirapine policy decisions or because this policy was deemed insignificant to their everyday lives, but rather due to ethical and logistical concerns. Patients, and family members dealing directly with patients, who are in fact immediately affected by Nevirapine policy were not actively recruited. The reasons for this exclusion were threefold. First, because of financial constraints, interpreters were not available. While because of their professional obligations most people in the above stakeholder groups can speak English; many patients and their families may not (there are 11 official languages in South Africa, though government operates in English). This posed a significant barrier to the recruitment of patients and their families. Second, by avoiding patient and family recruitment, any potential for community stigmatization by being associated with this research was circumvented. Third, because the research hinged on
the issue of drug access, it was suggested that if patients or family members were included in the research, expectations about my being able to assist them in accessing treatment might develop. These concerns were bypassed by deciding against recruitment on the basis of HIV-status, or familiar association with an HIV+ person. Instead, social and cultural perspectives on HIV/AIDS, the practicalities of treatment, and what it means to receive treatment were understood through contact with health care providers and peer counselors. Moreover, people who identify with one of the above stakeholder categories could be HIV+, and as mentioned above, peer counselors often get their positions because they have had personal experiences at their employing health care facility (either as patients themselves or by supporting family members who are patients). Individuals who were HIV+ were therefore not excluded (particularly as the HIV-status of participants was not asked for and thus not necessarily known by me).

As this study is of an exploratory nature there are no other, more specific, inclusion or exclusion criteria other than participants’ ability to communicate in and comprehend English as a requirement for participation.

**Recruitment**

Twenty-one participants were recruited using purposive sampling (Creswell 1998) to attain diversity in three areas: 1) General Policy Stakeholders (including Government Officials, Media Representatives, Pharmaceutical Companies’ Representatives, NGO Representatives, Health Care Providers and Researchers, Peer Counselors and other relevant stakeholders), 2) representatives from the Treatment Action Campaign or other similar health activist movements, and 3) Health Care Providers. In order to meet the
research objectives, individuals identified in points 2) and 3) were interviewed as *General Policy Stakeholders* (as per 1) and also asked for specific information relevant to their association with the Treatment Action Campaign or other similar health activist movements or their position as Health Care Providers. The purposive sampling strategies used were criterion sampling modified to attain maximum variation (Creswell 1998:119): participants were chosen because they represented one of the stakeholder groups (the criterion), where the stakeholder groups were defined broadly to include a diverse range (maximum variation) of people. These sampling strategies were considered appropriate for case study research (Creswell 1998:122). Snowball sampling (Berg 2001:146) was also used, in that each participant interviewed was asked to refer me to any colleagues who might have information to contribute to the research topic. This strategy is common to ethnographic research as it relies on the ethnographer having a large “network of reliable guides” who can assist in wider participant access by “vouch(ing) for the legitimacy and safety of the researcher” (Berg 2001:146).

Prospective contacts were approached, as described in Phase 1b. After ethical approval of the research protocol, potential participants were approached by referral from these contacts or by referral from previously interviewed participants. All potential participants were contacted first by email using the Letter of Introduction included as Appendix C. I, as the investigator, had no preexisting relationship with any of the potential participants. Over fifty people were contacted, and 21 individuals from this contact group became research participants. The others either declined an interview or were unresponsive after the initial email contact and at least one follow-up phone call or email. Of those who were unresponsive, declined, or who were too busy to arrange an
interview, about half were physicians or researchers, six were NGO representatives (including TAC representatives), four were government officials, and one was a media representative. The participants were primarily from Cape Town, Durban or Johannesburg and their surrounding areas. Because funding was limited I had to prioritize certain geographical areas within the country. These three locales were chosen based on Schneider’s assessment that most of the researchers and health care providers involved in AIDS policy were based here (Schneider 2002), and because these were the places where most potential participants were located as of October 2002, when final decisions needed to be made regarding in-country travel. A breakdown of the affiliation of each participant is provided below. Participants who identified with more than one group, were placed under the group with which they held their primary affiliation, and the other group(s) they identified with are indicated in bold. The totals at the bottom of the chart indicate the overall total of participants who represented that group. Because activists (all those interviewed were members of the TAC) and health care providers were specifically approached to meet objectives beyond the scope of General Policy Stakeholders, they are identified in the chart after their participant number (as either “TAC rep.” or “HCP”).
Figure E. Participant Summary Chart

<table>
<thead>
<tr>
<th>Government Officials</th>
<th>Media Representatives</th>
<th>Pharmaceutical Companies' Representatives</th>
<th>NGO Representatives (including representatives from the Treatment Action Campaign)</th>
<th>Health Care Providers and Researchers</th>
<th>Peer Counselors (working at AIDS clinics)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participant 008</td>
<td>Participant 005</td>
<td>Participant 012</td>
<td>Participant 001 (also a researcher)</td>
<td>Participant 002 (HCP and researcher)</td>
<td>Participant 013</td>
</tr>
<tr>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant 016</td>
<td></td>
<td></td>
<td></td>
<td>Participant 003 (HCP)</td>
<td>Participant 014</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant 021</td>
<td></td>
<td></td>
<td></td>
<td>Participant 010 (TAC rep.)</td>
<td>Participant 018</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>Participant 004 (HCP and researcher)</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td></td>
<td></td>
<td></td>
<td>Participant 011 (TAC rep.)</td>
<td>Participant 006</td>
</tr>
<tr>
<td>5</td>
<td></td>
<td></td>
<td></td>
<td>Participant 017 (HCP and researcher)</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td></td>
<td></td>
<td></td>
<td>Participant 015 (HCP, also associated with a NGO)</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td></td>
<td></td>
<td></td>
<td>Participant 019 (HCP, also associated with a NGO)</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td></td>
<td></td>
<td></td>
<td>Participant 020 (HCP and researcher)</td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>7+2 = 7 3 TAC rep.'s</td>
<td>8+5 = 13 10 HCPs</td>
</tr>
</tbody>
</table>

95
3.2.2 Phase 2: Continuing the Literature Review and Drawing on Other Sources of Data

- To draw on publicly available documents and media resources, to use participant observation at the XIV International AIDS Conference in Barcelona, and to follow an intellectual property and health listserv to
  
  I. learn about the policy process that brought about the decision to implement pilot programs to prevent MTCT, with specific reference to historical, political, social and cultural influences and beliefs, and to explore the events subsequent to this policy decision,

  II. evaluate the activities of the Treatment Action Campaign and other similar social movements, and explore the health activist strategies and outcomes relevant to this policy process, &

  III. understand the perspective of health care providers throughout this policy process, including the difficulties they face with respect to Nevirapine policy related to the practical limitations (i.e. stigma, geography, etc.) of implementing universal access, and to the practical need to do so (i.e. high rates of HIV).

Phase 2a: An Ongoing Review of Literature

This phase was a necessary continuation of the Literature Review. As Nevirapine PMTCT policy development was ongoing, the Literature Review could not simply be halted at an arbitrary point, therefore I continued to follow the literature, as described in Phase 1a, until the end of the research data collection process.
Phase 2b: Participant Observation at an AIDS Conference

This phase came about because of the opportunity to attend the XIV International AIDS Conference in Barcelona in July 2002. It was deemed a valuable part of the research as it allowed for contact to be made in person with potential interview participants based in South Africa in advance of the fieldwork, which began in September 2002. Most of the stakeholder groups identified above were represented at the conference (I had contact with at least one person from each group, other than the “Media” group). The conference also provided an opportunity to observe first hand the coalition building between international activist groups that Schneider has previously described (Schneider 2002). Finally, the conference was a forum within which the TAC’s activities could be observed, by participating in seminars and presentations with TAC members, and through conversation and observations made at their conference booth. This proved to be extremely beneficial given that only 3 members of the TAC were available to be interviewed in South Africa. Field notes were taken to record observations, thoughts, and reflections.

Participant observation is a strategy often used in ethnography, and other forms of qualitative research (Berg 2001). A major benefit of participant observation is that it allows the researcher to study things (proceedings, individuals, etc.) in their natural state.

When you are involved with participant observation, you are able to observe the naturally unfolding worlds of the population under study. This includes those times when several parties in the field come together to spontaneously hold a conversation, discussion or argument. (Berg 2001:117).

It was these spontaneous meetings of TAC members and others at the conference that have provided some insights into the activities of the TAC, beyond those which could have been drawn from the interviews alone. While participant observation is often
described as intrusive, “since the presence of an observer in any setting is often a ‘foreign object’” which can create “reactivity” among the group being observed (Berg 2001:137, cited in); this effect was thought to be minimal in this study. The scope of contemporary International AIDS conferences are so broad and inclusive that virtually anyone is welcome to attend, and nearly all of the sessions are open to everyone. This format is ideal for participant observation as conference attendees are expected to be anywhere and everywhere.

Phase 2c: Listserv Participation

This phase was undertaken upon the recommendation of a Pharmacy faculty member and political scientist at the University of Toronto. The listserv I subscribed to is called ip-health. It is run by Consumer Project on Technology (CPTech)24, and deals with intellectual property issues related to health. International experts and activists debate issues related to global access to pharmaceuticals in this forum, and the pressing concern of access to AIDS drugs in particular, is a prevalent discussion topic. The TAC frequently posts messages on this listserv, and as the TAC’s court case against the government gained momentum there were numerous postings from others outside of TAC commenting on the court case. This listserv helped provide insight into the activities of AIDS activists internationally, and also into the activities of the TAC. Further, it demonstrated how connections among activists groups are formed internationally. The messages on the listserv became one of the “multiple sources” of data for this case study. My subscription to this listserv began in August 2002.

24 The Consumer Project on Technology was started in 1995 by Ralph Nader, the 2000 presidential candidate for the Green Party in the US. CPTech’s work is focused on intellectual property rights and health care, electronic commerce and competition policy (Consumer Project on Technology 2003).
3.2.3 Phase 3: Interviewing Stakeholders in South Africa

- To interview established contacts in South Africa and to develop and interview additional contacts to

  I. learn about the policy process that brought about the decision to implement pilot programs to prevent MTCT, with specific reference to historical, political, social and cultural influences and beliefs, and to explore the events subsequent to this policy decision,

  II. evaluate the activities of the Treatment Action Campaign and other similar social movements, and explore the health activist strategies and outcomes relevant to this policy process, &

  III. understand the perspective of health care providers throughout this policy process, including the difficulties they face with respect to Nevirapine policy related to the practical limitations (i.e. stigma, geography, etc.) of implementing universal access, and to the practical need to do so (i.e. high rates of HIV).

Interviewing is a common technique in qualitative research. In fact, Creswell identifies it as one of the four basic types of information that can be collected in qualitative studies, along with observations, documents, and audio-visual material, like photos (Creswell 1998:120). Interviews were chosen as the primary data collection strategy for this research, as they allow the researcher to understand issues that may be unclear or vague based on documents, observations and audio-visual material alone. Interviews differ from these other data sources in that they provide researchers with some control over the information to be collected, as researchers ask the questions of their
choice (as approved by a research ethics board), from the willing individuals they select to participate (Berg 2001). Interviews were used in this research as a strategy for getting at the lived experience of Nevirapine PMTCT policy; that is, getting at how stakeholders saw the development of this policy and how it affected them in light of their previous experiences, and understanding of politics, history, and culture in South Africa.

This phase was conducted from September to December 2002. All interviews were semi-structured. This type of interview stems from the assumption that the researcher knows some of the substantive areas of interest in the study, in enough depth to pose a set of questions, but needs to allow room for participants to expand their responses beyond this (Berg 2001:70). With this in mind, there were some broad, established questions that participants were asked, as well as a series of probes, used to delve more deeply into specific aspects of each response. Furthermore, when participants brought up issues they deemed significant to Nevirapine PMTCT policy, they were encouraged to elaborate on these. Finally, questions were often asked out of sequence, or modified based on a participant’s responses to earlier questions. This is common practice in qualitative, semi-structured interviews (Berg 2001), which attempt to flow naturally like a conversation. A copy of the Interview Guide, which includes a broad set of questions is found in Appendix F.

Each of the 21 participants was interviewed once, with interviews lasting from 40 minutes to two hours. Before beginning the interviews, participants were taken through an informed consent protocol (see below), and consent to the interview was granted in writing. Interviews were tape-recorded. Participants were asked for some demographic information (see Interview Guide) before moving into the topical questions.
Following the interview participants’ addresses were obtained so a copy of the study could be sent to them. Participants were also asked if they were agreeable to being contacted again if questions arose about the interview data. All agreed. Finally, I asked participants to refer me on to colleagues who they thought might contribute to the study, and any questions the participants had were addressed.

**Informed Consent and Ethical Approval**

This research was approved by ethics review boards at the University of Toronto, the University of Cape Town, the South African Medical Research Council and the University of Witswatersrand. The research protocol submitted to these boards included the details of obtaining informed consent for the interviews (see Consent Form in the Appendix D). However, the University of Witswatersrand’s board specified that a separate consent form was needed to confirm that the interviews could be tape-recorded, although this was mentioned in the general consent form. A form was drafted for this purpose, and all participants interviewed in areas under the jurisdiction of this board were given both the interview consent form as well as a separate consent form for tape-recording (see Consent Form (for tape-recording interview) in Appendix E). Informed written consent was thus obtained for all participants. Before beginning all interviews, I reviewed all information contained in the consent form with each participant. I ensured that each participant understood the information outlined in the form, including the risks and benefits and the measures being taken to ensure privacy and confidentiality. Only once it had been established that the participant understood all information, and it was
clear that the participant had voluntary capacity to give consent, was written consent obtained and the interview initiated.

Furthermore, because of guarantees of participant confidentiality made to participants as well all the reviewing boards, the names of participants are not given. Accordingly, descriptions are limited to avoid revealing the identity of any participant.

3.2.4 Phase 4: Interpretation, Analysis and Interview Data Preparation

- To engage in ongoing analysis, compile the interview data, and extract lessons learned that could inform health policy makers and stakeholders.

Phase 4a: Interpretation and Analysis

One of the most distinctive features of qualitative research is its emphasis on interpretation (Stake 1995:8). Qualitative researchers “do not confine interpretation to the identification of variables and the development of instruments before data gathering and to analysis and interpretation for the report” (Stake 1995:8). Rather analysis is ongoing, the researcher collects data and “simultaneously examines its meaning and redirects observation (data collection) to refine or substantiate those meanings” (Stake 1995:8-9). For example, while conducting the interviews described in Phase 3, questions were adapted slightly, and new questions arose, based on the information presented by previous interviewees. In case study research, the goal is to understand the case; therefore, “if early questions are not working, if new issues become apparent, the design is changed” (Stake 1995:9). In this way, data is interpreted and analyzed to some degree, once data collection begins.
Thus, interpretation began upon arrival at the International AIDS Conference in Barcelona, based on previous knowledge gained from the literature review described in Phases 2a and 1b. As observations were made in Barcelona, new information was brought to bare which contributed to this growing body of knowledge – either adding to it or challenging an existing idea. This process continued as more data was collected through the ip-health listserv, and especially during the interviews. At this stage, interpretation and minor analysis phased into full analysis. This analysis included information from all stages of data collection, but was guided by the interview data, which was most comprehensive. A discussion of how all the data was analyzed follows the description of the interview data preparation below.

Phase 4b: Preparation of Interview Data and Detailed Analysis

After all the interviews had been completed, they were transcribed verbatim between January and April 2002. Subsequently, all data (field notes from Barcelona, listserv printouts up until April, and interview transcripts) were reviewed to get “a sense of the overall data” (Creswell 1998:140). Creswell then recommends that data be reduced by developing “codes or categories” and then sorting text into these categories (Creswell 1998:140). Stake also recommends this approach for case study research, calling it “categorical aggregation” (Stake 1995:74). The aim of this categorizing strategy is to seek a collection of instances from the data, hoping that issue-relevant meanings will emerge (Creswell 1998:154). An initial list of categories and sub-categories were developed to winnow the data. This was reviewed and reassessed multiple times as the data was reread, before the current set of categories was finalized,
which most clearly represents the data. Data was then sorted by category. Within each
category, data was summarized, with some representative quotes from the interview
transcripts left in tact to convey the issues and their meanings as relayed by participants.
It should be noted that the categories among which the data were sorted, were developed
based primarily on interview data, but were supported by the other data that had been
collected as well as the literature that had been reviewed.

At this stage information was still being collected from the ip-health listserv as
well as some media sources, tracking more recent activities of the TAC and government.
These were included in the analytic categories where appropriate. All data collection was
stopped in May 2003, permitting finalization of the analysis and report writing.

3.2.5 Phase 5: Dissemination

- To disseminate results to research participants (stakeholders) and interested
  parties.

The implications of this study include informing policy processes related to drug
access, and exposing complexities of policy processes and the negotiated character of
policy outcomes. Because of the high level of involvement many of the participants
(policy stakeholders) had with Nevirapine PMTCT policy in South Africa, it was felt that
the final report of the research may be informative to them. Thus, dissemination was
included as an objective and phase in the research. This phase is currently ongoing as a
condensed version of the research report (thesis) is being prepared to be sent to all
participants.
CHAPTER 4: RESULTS - EXPLORING THE GOVERNMENT'S ROLE IN
PMTCT POLICY DEVELOPMENT

4.1 AN INTRODUCTION TO THE RESULTS

Section 2.3 included a chronology of key events preceding the Nevirapine PMTCT policy process, as well as events within the process from January 2001 until July 2002, providing a detailed description of what was known about the case prior to data collection. The information contained here and in Chapter 5, represents what was learned about the case during this study. This summary and analysis of data is based primarily on transcripts from the 21 qualitative interviews conducted with policy stakeholders in South Africa, as well as on observations made in Barcelona at the International AIDS Conference and what was learned from the ip-health listserv and ongoing literature review.

A number of themes emerged from the data that help to explain the Nevirapine policy process. These include a number of issues that were not anticipated, such as the strong emphasis that participants placed on the individual personalities of certain government officials and their ability to influence policy, attributed to the social ordering of government and ANC. The most common themes, as well as those that contributed to an understanding of the Nevirapine policy process, are the basis of Chapters 4 and 5. These are divided into major themes (i.e. 4.2, 4.3, etc.) and then into sub-sections below each major theme. Chapter 4 deals primarily with the response of government and gets at a few factors that help explain the government’s position in this case. Chapter 5, which
follows, addresses the response to government, as it was understood, by participants in this study.

Each theme is summarized, and represented by comments made by participants in the interviews. Where excerpts from the interviews are included, the following formatting is applied: quotes that include my questions for context have “I” for “Interviewer” inserted before them and are in parentheses “{}”; round brackets “()” represent my comments, for clarification or to provide context.

4.1.1 Introducing Participants’ Perspectives

Before launching into the thematic development, a few quotations have been selected that present the general feelings participants had about Nevirapine PMTCT policy. For example, most participants saw this policy process as complex, finding it difficult to keep up with the “ins and outs” of the process, particularly if they were not directly involved in the TAC’s court case. One participant, a pediatrician who understood the effects of Nevirapine policy through his care of HIV+ children, very generally summed up PMTCT policy development. His concern that he had “lost track of these things” emphasizes the number of details related to this case and presented in the media:

The struggles have been around MTCT (and) seemed to have been waged mainly between the government and the NGO, Treatment Action Campaign. And the government has not, I mean they’ve taken every single possible opportunity or way to squirm out of it (providing widespread access to Nevirapine). But they have their pilot sites where they claim to be doing research on to efficacy and replicability and so on. As you know, the officially sanctioned MTCT is happening in those pilot sites, um, but you’ll have to remind me (laughs), there is a Constitutional Court case that the Treatment Action Campaign wrote against the government. As you know they were told to do up a plan to implement it much more widely throughout the country. But, once again, they’ve appealed about the,
the appeal ran around the competence of the Constitutional Court to tell the
government how to implement policy and to what level the Constitutional Court
can dictate to the government what to spend where. And I’ve lost track of what’s
happened after that. But I think the policy at the moment seems to be to still limit
the provision of drugs to those pilot sites with an obligation to roll it out to the
rest of the country. And then over the weekend the newspapers were reporting a
sort of commitment to changing the whole face of AIDS by treating everyone, by
providing antiretroviral drugs to everyone who needs it. I mean that’s my limited
understanding of what’s happening, I’ve lost track of these things.

This participant correctly sums up recent developments in PMTCT policy (with the
exception that the TAC’s court case was launched first with the Pretoria High Court). At
the time of the interviews, the court case was closed and the government had been
ordered to roll out Nevirapine in places where the necessary infrastructure and capacity
already existed. The government was further mandated to establish, in a timely manner,
a plan of action for improving infrastructure and capacity in other areas so that
Nevirapine could be provided nation-wide. This court case had also moved forward the
debate about providing long-term treatment to people living with HIV, which is what the
participant is referring to. However, the media reports from “over the weekend” are
typical of the kind of coverage and attention this policy issue received. Frequently media
would pick up on a particular comment made by government that somehow indicated a
major policy shift. Yet, often these policy shifts were never realized in practice. The
inclination of media to readily pick up on comments indicating a new government
approach to AIDS, one that might do more to battle this pervasive disease, may have
been due to the negativity surrounding AIDS policy. A critical and pessimistic attitude,
brought about by Mbeki’s questioning of the causal link between HIV and AIDS and
other publicly unpopular policy decisions (like Sarafina and Virodene), seemed to
pervade most portrayals of AIDS policy in South Africa. In light of this, it seemed that
media latched on to any hint of a more conventional approach. However, such hopes were often not realized as the government has maintained its confusing and less popular approach. So while this participant recounted the media’s weekend coverage as indicative of government changing their approach, in terms of formal policy or practice, nothing changed.

This leads to another general impression left from the interviews. Participants clearly set up a good-guy/bad-guy dichotomy when they discussed the activities of the TAC versus the government. This was most clear in participants’ heralding of the TAC and their critiquing of government (specifically President Mbeki and the Health Minister). When asked what participants thought of the TAC’s activities challenging the government’s limited-access pilot policy, this view was clear. One physician and researcher said:

But, you know, ten stars to TAC for having that courage to go for it and I’m, you know, we were just thrilled that it worked out the way it did.

Another physician and researcher saw the TAC’s actions in this way:

Very positive, I’m full of admiration.

A third physician said:

I think it is very positive. No I see it as overwhelmingly positive. It needs to happen, as I said, I mean the country would be a much better place if there were a thousand TAC, around military matters, around police matters.

Considering participants who were critical of government, their negative views were never unequivocal. For example, while willing to criticize the government, they also provided some justification, or defense for the government’s response, alternatively they pointed out good things the government was doing in areas outside of AIDS. One physician and NGO actor described things this way:
Speaking about the human rights aspect, for a mother to give it (HIV) to her baby, (making him/her) HIV positive, it’s probably one of the worst forms of torture I’ve seen. Because, you know, a baby who dies from, I don’t know, meningitis or whatever infectious disease, most of them (are) gone in one week. HIV/AIDS is terrible, it takes months and months and months, and it’s months of suffering and months of this baby degenerating step by step, it’s really horrible, it’s torture. And so, one could say government did not take into account individual human rights, (it) depends, but the American government doesn’t take much into account (in terms of) individual human rights for example.

This participant is critical and defensive of government. First he describes the torturous nature of death from AIDS, particular for babies, implying that the government’s inattention to human rights is a contributor to the suffering of babies. Then he defends the South African government by rightly noting that other governments, even in more developed countries, have inadequately protected the rights of their citizens.

Other participants tempered their criticism of government by indicating that they did not paint all government actions with the same brush. A physician who had been involved in the anti-apartheid struggle said:

Well he (President Mbeki) is trying to, well not everything he says is bad. He’s trying to please the kind of, forces of globalization. And I don’t think that’s good, but I think he’s trying to engage the forces of globalization on behalf of Africa to bring about more equal relationships in terms of trade and power relations and so on. And I think, I think that’s good, I think that has to happen. There has to be a struggle at that level, at the global level, and I think he’s doing that. And that might, I mean that might have some positive spin-offs. But I think at the internal level there’s a failing.

Another participant, a physician who had been very involved in Nevirapine policy echoed this sentiment:

{I: And is this particular case of Nevirapine access, or even access to health care in general, similar to anything else you’ve experienced in your career?}
No (he laughs). I think this is, this is unique. I mean I think that history will judge Mbeki and his government very harshly, I think that in 5 or 10 years time people are going to say “I don’t believe we wasted so much time”, “I don’t believe we had to go to court”, “I don’t believe we were standing by while people died, denying that it was happening”. The government tends to take the line that
anyone who’s against them on issues of HIV, is against the government as a whole, and I don’t believe that that’s the case, and I think that, that TAC exemplifies that. Um, Zackie (the TAC head) and others are very supportive of government on many other issues, I think that the Department of Health has done a very good job of many of the health challenges in this country and is still doing a very good job. The fact that I don’t agree with the way they handle AIDS doesn’t mean at all that I disagree with everything else that’s going on, because I think it is different. I don’t believe that anything else has being subjected to this kind of approach. We’ve moved forward on TB, we’ve moved forward even on voluntary counseling and testing promotion, on AIDS prevention efforts (other than those that rely on drugs, like PMTCT), those things are moving and I think (they) are having some effect. The government has bought hundreds of new clinics (and) has really increased primary health care access considerably compared to what it was. So I think that in terms of, I think the Nevirapine saga is not reflective of South Africa’s approach to increasing access to health care, thank god.

In distinguishing between government activities that he supported versus those he did not, this participant pessimistically saw Nevirapine policy as in line with AIDS policy in general, although he mentioned AIDS counseling and testing and prevention as areas where the government had done well. Situating Nevirapine policy within the broader development of AIDS policy seemed to reflect this participant’s strategy for better understanding the government’s decisions about Nevirapine and PMTCT; previously, this participant had conveyed his confusion about Nevirapine policy.

{I:  Can you describe to me what’s happened in the past two to three years specifically with respect to Nevirapine policy and programs in South Africa?} Not without taking Prozac. The history of the Nevirapine policy as you well know is a complex one and one that doesn’t really make a lot of sense to anybody.

Although this participant had been involved in AIDS policy development for over a decade, he still struggled to make sense of this policy. His comments highlight the challenging task that prompted this study, to explicate this complex Nevirapine PMTCT policy process, marked by mixed opinions and views of government, and a struggle to make sense of these conflicting perspectives. His comments also imply strategies that
can be used to understand how and why Nevirapine policy development proceeded as it did, like linking it to other events or trends (i.e. broader AIDS policy).

**A Guide to Figure F**

Indicative of the breadth and complexity of the problem of access to Nevirapine, suggested in the above transcripts, I have developed a model based on the data collected during this study. This model maps the relevant policy brokers identified in this research. It draws connections between certain players who collaborated during the Nevirapine policy process, and outlines some of the factors that structured or mediated the relationships and activities of actors. This model was developed based primarily on the interview and observational data, but also on what was learned from the ip-health listserv and the literature review. It is by no means an exhaustive model, inclusive of *all* factors or players that may have influenced Nevirapine policy in South Africa, but it does highlight what participants in this study mentioned. Moreover, the model is a simplification of what is, in practice, an extremely complex policy environment. To this end, the model includes only those things that participants and the other data indicated as important to this policy process. Note that this model makes use of the concept of a policy subsystem, as described in relation to the ACF on page 84.

The model appears as Figure F. All the actors within South Africa are located inside the large circle shown in the model. The exterior of the circle represents the international milieu. Some actors and institutions cut across this circle as they operate both within South Africa and internationally. The figure is delineated to distinguish between state and non-state actors. The smaller, inner circle contains the policy issue:
PMTCT in South Africa using Nevirapine. The solid-border boxes represent institutions, countries, or bodies of actors. Three of these are shown as central to the policy issue: *the government in South Africa* (made up of multiple, interacting governments, departments of health and AIDS programs); *certain civil society actors*, who have played a significant role in advocating for access to Nevirapine (as with government, there are connections among all the groups listed below this heading); and finally *the pharmaceutical industry*, which manufactures the drug Nevirapine and others, and which affects drug access through setting drug prices, or, as in the present case, eliminating them. Note that the numbers shown in round brackets within particular boxes represent the number of stakeholders interviewed, representative of the group described within the box.

Other policy actors who have had an indirect, or secondary role in affecting Nevirapine policy are *AIDS dissidents*, who have liaised with the President; the *lay populous* (including Peer Counselors and people living with HIV/AIDS, though the latter group is also represented by NAPWA); *other countries*, and *outside activist groups*. The *lay populous* interacts and informs civil society and government, both of which, to a varying extent, represent the lay populous. *Other countries* are relevant to PMTCT policy in South Africa, either because they have demonstrated effective PMTCT and/or drug production programs in a developing country context, and in this way have assisted the TAC’s argument for wider Nevirapine access; or because they have supported a certain global economic agenda, discussed below. Outside AIDS activist groups have formed a number of coalitions with the TAC and MSF both in advocating for broader access to medicines globally, and by supporting the TAC in an international context.
In the hatched boxes are *internal* (i.e. within South Africa) and *external mediating factors*. These include the pervading legacy of Apartheid and the force of neo-liberal globalization, centralizing bodies and events (i.e. AIDS Conferences, the UN vis-à-vis UNAIDS), and regulatory bodies and guiding agreements (i.e. WTO, TRIPS, the Global Fund, the South African Constitution). Of special mention among these factors is the positioning of *the courts* in South Africa, namely the Constitutional Court and the Pretoria High Court. Officially the courts are part of the judicial arm of government, but they could also be viewed as an internal mediating factor because of their role in arbitrating over Nevirapine PMTCT policy. I have placed them in the latter grouping, seeing it as a better fit, in light of this policy issue. Finally, there is one special mediating group, that didn’t “fit” in any other grouping: *the media*. The media has brought Nevirapine PMTCT policy to international attention, and to this end has emphasized Mbeki’s questioning of the link between HIV/AIDS in numerous publications. The media has also been fundamental in transmitting information about this policy’s

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25 Globalization refers to the contemporary trend of “stretching of social, political and economic activities across political frontiers, regions and continents” and “the intensification, or the growing magnitude, of interconnectedness, i.e. flows of trade, investment, finance, migration, culture, etc.” (McGrew 2000:347). Globalization is linked to a speeding up of global interactions through advanced communication and transport systems, and is associated with a deepening impact of global interactions, such that “the effects of distant events can be highly significant elsewhere” (McGrew 2000:347). However, this basic definition of globalization does not clearly express the dominant political and economic forces that shape the process of globalization today. The “neoliberal” school of thought on globalization views it as a “benign force for change which, through free trade and capital mobility, is creating a global market civilization in which prosperity, wealth, power and liberal democracy are being diffused around the globe” (McGrew 2000:348). This neoliberal school of thought, held by multinational corporations and largely supported by the US Government and others, is founded on the belief that the spread of free markets and capitalist economies will be beneficial in global development. However, the dominance of a neoliberal economic model, and the subsequent increase in power accrued by multinational corporations in the global world order, is thought by many to have done just the opposite: “there is general acknowledgement that globalization is strongly associated with an intensification of global inequality” (McGrew 2000:353). Globalization today thus contributes to the rich getting richer and more powerful, while the poor get poorer which is certainly not good for development. Because of the dominance of neoliberal economics in the current world order, some call this “neoliberal globalization” to emphasize that although globalization could be, and is to some degree a positive force, in its current iteration it’s dominant effect is to contribute to widening disparities globally.
development to the lay populous within South Africa. The function of the media, as well as many of these other mediating factors, are referred to in this chapter. Further, the above-mentioned roles of the actors and institutions, and the relationships that exist between them will be elaborated on throughout Chapters 4 and 5.

With respect to the role of the USA (and other countries and institutions that support the following viewpoint), it has been cited as perpetuating the force of neoliberal globalization. This is expressed through, among other things, the US prioritization of the profit-driven interests of the pharmaceutical industry over the public health interests of developing countries. This was most clearly demonstrated in the pressure the US Government applied to South Africa when they made changes to their Medicines Act to enable more feasible access to drugs (these changes also motivated the later PMA court case against the South African Government) (Barnard 2002; Bond 1999). In this model the US is highlighted because it has been an instigator in moves to protect corporate pharmaceutical interests – either by way of the WTO and TRIPS, or via pressure on individual countries, as in this example.
Figure F. Mapping Actors, Institutions and Relationships Relevant to Nevirapine PMTCT Policy in South Africa

External Mediating Factors
- Globalization
- International AIDS Conferences
- UNAIDS & the Global Fund
- WTO & TRIPS
- WHO, World Bank, etc.

Internal Mediating Factors
- Apartheid
- The Court System
- The South African Constitution
- Traditional African Beliefs and Culture
- Federated State Structure

Pharmaceutical Industry
- Boehringer Ingelheim
- Glaxo-SmithKline, etc.

Civil Society Active in Nevirapine PMTCT Issue
- TAC (3)
- Physicians & Researchers (12)
- Other NGOs, ALP, etc. (3)
- NAPWA (1)
- MSF (1)

Comparative Countries with AIDS Drug Programmes
- Brazil
- Thailand, etc.

Legend
- DOH: Department of Health
- Gov't: Government
- Nat'l: National
- Prov'l: Provincial
4.1.2 Nevirapine PMTCT Policy Development: July 2002 – December 2002

To put the data presented here and in Chapter 5 into context, this section updates the information presented in the literature review, by briefly summarizing developments from July – December 2002. Chapter 2 covered developments up until July 2002, when the Constitutional Court upheld the Pretoria High Court’s ruling, to mandate the government to provide nation-wide access to Nevirapine. Because this ruling instructed facilities with the capacity to provide Nevirapine to do so immediately, while the government was instructed to plan and implement a timely expansion of the program to other sites, differential access to Nevirapine was still the common at the time of the interviews (September - December 2002) (kaisernetwork.org 2002i).

To add yet another layer of complexity to this case, questions had been raised in the US about Nevirapine’s registration for use for PMTCT; nearly four months after this, when the Constitutional Court announced its ruling, attention in South Africa focused on what had happened in the US. In March 2002 Boehringer Ingelheim had withdrawn its US FDA application for Nevirapine for its PMTCT indication. This was due to procedural problems with the HIVNET 012 study, not related to the study’s validity (Medicine Control Council 2002). Further, the drug was still considered safe for long-term antiretroviral use and the US Public Health Service Task Force continued to endorse its use in PMTCT; the WHO and UNAIDS had also released a statement supporting this position (kaisernetwork.org 2002k). Although the US FDA issue had been played out in March, when the South African court decision was announced in July, some months later, the Health Minister used the withdrawn FDA application to legitimize her previous concerns about the safety of antiretrovirals. She stated that Nevirapine was “poison” and
that: “the High Court has decided the Constitution says I must give my people a drug
that isn’t approved by the (US) FDA. I must poison my people” (kaisernetwork.org
2002k). This led to concern that the government might continue to fight the court order
(kaisernetwork.org 2002k), however this concern never materialized. The Medicines
Control Council in South Africa did decide to review its approval of Nevirapine for
PMTCT, though during the review the drug would remain registered (kaisernetwork.org
2002l). A report that came out after this, in October 2002, said that the government had
now “accepted” the court ruling and Vice President Zuma26 announced that Nevirapine
was being distributed beyond the 18 pilot sites (kaisernetwork.org 2002i). The MCC
however, was still reviewing Nevirapine’s safety and efficacy (kaisernetwork.org 2002i).

Other developments in the summer and fall of 2002 included the former
President, Nelson Mandela taking a public position in support of the struggle for access
to treatment. In late July Mr. Mandela met with Zackie Achmat, head of the TAC.
Following this meeting he said would meet with President Mbeki to try to convince him
of the urgent need for these medicines, and alert him to Achmat’s own crusade: to refrain
from taking antiretrovirals, despite having AIDS, until all South African’s had access to
these drugs (kaisernetwork.org 2002e). The debate around access to long-term treatment
continued to heat up as major mining firms in South Africa, like De Beers and Anglo
American, announced that they would provide antiretroviral treatment to workers who
were not covered under their current medical aid plan (kaisernetwork.org 2002c;
 kaisernetwork.org 2002g).

26 This refers to current Vice President Jacob Zuma, who serves under Mbeki, not to be confused with Dr.
Nkosazana Dlamini Zuma, who was the Minister of Health under Mandela and is the current Minister of
Foreign Affairs under Mbeki.
The TAC maintained committed to both monitoring the government’s compliance with the court order and pressuring the government to now provide long-term antiretrovirals. In late August of 2002 they met with activists from 19 other African nations to create a “pan-African” advocacy group that would lobby governments and international institutions to widen antiretroviral access (kaisernetwork.org 2002a). In line with this initiative, in September 2002 TAC and COSATU launched a complaint with the Competition Commission in South Africa against GlaxoSmithKline and Boehringer Ingelheim for excessive pricing of antiretrovirals (available in the private sector) in South Africa (Achmat 2002a). Finally in November 2002 the TAC threatened to launch a non-violent civil disobedience campaign unless the South African government came up with an HIV/AIDS treatment plan by the end of February 2003. In an interview with Business Day, a South African periodical, TAC spokesperson Nathan Geffen emphasized the following: “We have a history of having tried to work with government using standard civil society mechanisms, and our actions have been the model of restraint. Yet all these years later, we don’t have an (AIDS) treatment plan and an unambiguous commitment to providing antiretrovirals” (kaisernetwork.org 2002o). He continued, stating that there was little faith in the government because it had previously “broken its promises” in regard to HIV/AIDS treatment (kaisernetwork.org 2002o). The South African Press Association reported TAC representatives as saying, “in the absence of trust, continued social mobilization is our only guarantee to save lives” (kaisernetwork.org 2002o).

Also in November of 2002, the International Association of Physicians in AIDS Care (IAPAC), based in Johannesburg and Paris and representing physicians and other health care professions from over 89 countries, released a statement saying they were
encouraged by recent steps the South African Government had taken (International Association of Physicians in AIDS Care. 2003; kaisernet.org 2002j). IAPAC President Jose Zuniga was reported as saying “although ‘a coherent plan that would safely supply antiretroviral medication to the millions who need them’ has not yet been established in South Africa, the government has indicated that it supports the goal and is finding ways to reach it” (kaisernet.org 2002j). Then in December 2002 the South African Medical Association (SAMA), an independent body representing medical doctors in South Africa, launched a program designed to provide free antiretroviral therapy to 9,000 patients (kaisernet.org 2002d; South African Medical Association. 2003).

Despite these comments and pledges by health care providers, the government had still not committed to a national treatment plan for AIDS, with the TAC’s February deadline fast approaching. In opposition to government inaction, the following two civil society-led initiatives began towards the year’s end. In late December, the TAC brought a suit against Mpumalanga province’s Health Minister Sibongile Manana and National Health Minister Manto Tshabalala-Msimang for non-compliance with court ordered Nevirapine roll-out (kaisernet.org 2002m). The TAC claimed that access to Nevirapine had failed to be extended beyond the two pilot sites in Mpumalanga province, and held this to be the responsibility of both ministers (kaisernet.org 2002m). Then, on Christmas Day, 2002, the NAPWA began a “Black Christmas” hunger strike outside the offices GlaxoSmithKline to demand that industry and the South African government provide free antiretrovirals (kaisernet.org 2003a).

Three significant items were also reported in late December that add to the confusion surrounding AIDS policy and the government’s commitment to provide
antiretrovirals, or at least to have a plan in place by February 2003. First, with negative implications for AIDS policy, President Mbeki was criticized for making only a “fleeting reference” to HIV/AIDS in his opening of a five day ANC conference (kaisernetwork.org 2002f). Second, in a move highly condemned by the TAC, Health Minister Tshabalala-Msimang was quoted in the UK-based daily, The Guardian, as saying that her department could not provide antiretrovirals to the estimated 4.5 million South Africans with HIV/AIDS declaring “We don’t have the money for that. Where would it come from?” (Achmat 2002b). When asked by The Guardian if the money could come from defense savings, by not purchasing submarines as part of an arms deal, the Minister indicated that South Africans needed to protect themselves against aggressors: “Look at what Bush is doing. He could invade” (Achmat 2002b). TAC members ridiculed this comment. They also pointed out that it was in opposition to her government’s October budget and policy statement, which indicated 3.3 billion in new funding for AIDS in South Africa; the new money had been prioritized to go towards continued PMTCT roll-out as well as treatment programs.

The third event, in contrast to the first two, appeared favorable, honoring the government’s commitment to provide treatment. On December 19, the ANC announced that it would make HIV/AIDS their top priority (kaisernetwork.org 2002m). At that time, ANC spokesperson Joel Netshitenzhe said that his party now understood that AIDS had “ballooned into a huge problem” since the party’s last conference in 1997, and that they were “ready to deal with it” (kaisernetwork.org 2002m). While this bodes well for continued efforts to bring HIV/AIDS in South Africa under control through the development of a plan for widespread treatment, comments made by Mbeki and
Tshabalala-Msimang create uncertainty about the government’s intentions; such contradictions and confusion has been characteristic of the AIDS policy response since pre-PMTCT policy (see Chapter 2). At the end of December 2002 it was still unclear whether the government had committed whole-heartedly to increasing access to AIDS medicines in South Africa.

4.1.3 Socio-political Relationships and Policy-making

While it is debatable whether the controversy surrounding the PMTCT policy process hinges on a decision of limited access to Nevirapine, or rather a non-decision with respect to national rollout of Nevirapine, participants have made it clear that the government’s (in)action is linked to a number of AIDS policy events, as well historically structured socio-political relationships, both within government and between government and civil society. In their book *The Policy Process in the Modern Capitalist State*, Christopher Ham and Michael Hill reject Aaron Wildavsky’s claim that policy analysis “must remain anchored in the current pattern of social relationships” (Wildavsky 1979:396) by stating that:

> We believe that policy analysts should not restrict themselves to examining how policies may be improved within existing social and political relationships. Rather these relationships themselves should be part of the field of enquiry. Policy analysis need not be conservative if it focuses on non-decisions as well as decisions. (Ham and Hill 1993:20)

Ham and Hill’s response is particularly relevant in examining the South African PMTCT policy process, due to the socio-political relationships that participants identified as structuring the behaviour of certain government officials and their relations with civil society, discussed below. As alluded to by Ham and Hill, there is a need to understand
these relationships in order to potentially transcend them. Furthermore Ham and Hill suggest that a liberal examination of policy highlights not only decisions but also non-decisions, illuminating how the perspectives of government and civil society can be at odds within these socio-political relationships.

The examination of relationships that have been central to this policy process, as discussed subsequently, revealed the significance of both macro-sociological factors, such as Apartheid, as well as micro-sociological influences, such as individual personalities within government. Interview participants discussed these, and other factors, and their relevance to the PMTCT policy process, at length. In order to understand the myriad of factors that participants identified as having influenced PMTCT policy, it is first important to elaborate on how government operates, namely who has power, and where, or at what level of government, this power operates. Furthermore, it is important to recognize that there are differing interests within government. Therefore, the next section, 4.2, deals with how government was perceived to operate, who (in which positions) was seen to hold power, where interests diverged, and where jurisdictional authority was seen to lie, when it came to making decisions and implementing policy.

The third section of this chapter, 4.3, sets the stage for an in-depth look at the PMTCT policy response by describing the broader AIDS policy environment. This section examines earlier policy decisions (or non-decisions, depending on one’s perspective) that were identified by participants as shedding light on the PMTCT policy process, or as initiating a trend by government, which culminated in the PMTCT debacle. The fourth section, 4.4, explores historical factors and the structuring of socio-political
relationships that were identified as supporting the government’s approach to PMTCT. Finally, Section 4.5 looks at PMTCT policy barriers: it both examines the legitimacy of barriers that were publicly identified by government representatives, and summarizes additional barriers cited by participants.

Chapter 5 will further elaborate on socio-political relationships by addressing the perspectives of those involved who were outside of government, namely the TAC and physicians/researchers.

4.1.4 A Note Regarding the Limitations of the Research

This section reviews some limitations to this work. Because these limitations become most apparent in the following two results chapters, they are presented here. The first point addresses the orientation of my analysis in response to interview data regarding the influences on government’s policy decisions. The second addresses those voices that were not adequately represented, due to resource limitations.

An Emphasis on Individual Actors versus Institutions

The following results chapters place a significant focus on the role of certain individuals in policy-making in South Africa. This focus reflects the emphasis put on particular policy actors by interview participants themselves. For example, nearly all participants mentioned President Mbeki’s influence in the Nevirapine policy process. Furthermore, Mbeki’s influence was noted by a number of participants as an explanation for the development of Nevirapine policy. In order to accurately reflect the ideas and
thoughts of participants, the results that follow accentuate the role of certain individuals in policy-making.

Although broader structural and historical factors are also noted throughout the results, this emphasis on “individuals” may appear narrow. For that reason, I clarify here that other approaches could be used to explore policy decisions and policy-making; however, due to resource constraints and in the interest of accurate participant representation, alternative approaches have not been applied to this case. One alternative approach, institutional analysis, is briefly described here as it appears to have potential relevance to this case.

Institutional analysis aims to examine how institutional arrangements influence policy choices. One example of this approach can be found in Paul Pierson’s work, which explores “the implications of one set of institutions – those associated with federalism – for the politics of social policy” (Pierson 1995). Pierson examines how federalism shapes the activities of policy brokers and thus ultimately shapes policy. The application of institutional analysis to this case could warrant some useful conclusions, thus it is mentioned here as an area for future study.

**Stakeholders: Un-represented Voices**

Another area of this research that may appear narrow is its focus on certain stakeholders, to the detriment of other stakeholders. Due to the recruitment goals and strategies for this study (see Section 3.2.1), a large number of physicians and activists (i.e. TAC representatives) were interviewed. While these groups were undoubtedly important to the development of Nevirapine policy, there are other groups with a known
and/or hypothesized interest in this case. These groups are noted here because they are either examined cursorily in the following chapters (namely in Section 5.3), or because they are not mentioned at all.

Some of the groups who warrant further study in terms of their involvement (or lack thereof) in Nevirapine policy include pharmacists, nurses, organized groups of health care providers (like the SAMA, South African Medical Association, or the South African HIV Clinicians Society), and universities’ health/medical faculties. Surely there are others who have been omitted here, however, the list above provides some indication of the broad range of groups who may have an interest in Nevirapine policy, and furthermore, who may have the ability to help shape health related policies.

4.2 DEFINING THE WHO AND WHERE OF GOVERNMENT

Many participants prefaced comments about the government’s handling of PMTCT policy by differentiating between types of actors; for example, those in bureaucratic positions vs. those with a political affiliation. Furthermore, participants pointed out the differences in policy implementation among the provinces and between the provincial and national governments. These emerged as two ways of differentiating government actors that were seen as significant in Nevirapine PMTCT policy, as participants relied on these differences to make certain claims about government or to theorize about government (in)action. Therefore, the development of the other themes
relies on initially defining “who” government actors are, and how participants group them, and “where” in government power exists or operates.

Representative of this notion, one NGO representative and researcher said:

When one talks about government, one has to be very clear that government is not homogenous… government is Parliament, it’s the Judiciary, it’s the Executive; it’s your officials in your Departments who are very different; it’s your nine different Provincial Governments. There’s not a single view, there’s a diversity of views (within government). So, I think… that’s also one important thing is that there (are) different Departments, so Health doesn’t necessarily speak on behalf of others, depending on the Minister and things like that, and the strength of the Minister.

This participant highlights the political vs. bureaucratic differentiation within government, as well as the differences between National and provincial governments.

However, also highlighted is an emphasis on the individual: “Depending on the Minister… the strength of the Minister”. This conveys the idea that it is individuals who make up governments, and that individual beliefs, values, and modes of expression can greatly influence policy, and the socio-political relationships Ham and Hill refer to.

### 4.2.1 Distinguishing Political vs. Bureaucratic Government Actors

Participants were clear in the divisions they saw within government. For example, when discussing and explaining Nevirapine policy, many participants categorized the role of President Mbeki and Health Minister Tshabalala-Msimang as unique from other actors within the government, such as bureaucrats within the National Department of Health, or personnel within the National AIDS Unit. One researcher said:

When you talk about the government you have to be specific of who you mean. I mean “the government” is not monolithic, and certainly if you’re talking about the President and his views on HIV/AIDS, his unorthodox views, or his dissident views on HIV/AIDS, I mean it’s clearly been a disaster for this country. Yeah, I mean he’s done damage to the country’s response to HIV/AIDS. If you’re talking
about the government in terms of the Department of Health, in terms of their framework, their, their policy framework and their strategic framework - it’s excellent, it’s good, it’s comprehensive, and it’s an appropriate balance between prevention and care.

This same participant continued:

No, no - I mean, when I talk about the Department of Health I exclude the Minister, because the Minister is part of the political, um, confusion, that’s really centered around the President. So, the Minister’s statements around toxicity, (and her) questioning (of the safety of antiretrovirals), I mean they, they are all, um, very irresponsible and inappropriate. I think she latched on to this whole confusion caused by the NIH and the FDA (in the US\textsuperscript{27}) to justify her previous comments questioning the toxicity of antiretrovirals, and it was completely unprofessional and uncalled for and irresponsible. So yeah, I mean I distinguish the Department of, when I talk about the Department of Health I’m talking about the officials, um, the bureaucrats, as opposed to the politicians. And they’ve taken a cautious approach to antiretrovirals. An approach centered around learning from experience and piloting, which I believe is the right approach. But that approach has been undermined by the politics surrounding the President’s views. It’s also been undermined by a lack of capacity within the Department to do proper studies and proper evaluations of the cautious pilot approach. So it’s the right approach that’s been undermined by the politics and by a lack of capacity to implement that approach.

In summary, this participant saw the Department of Health’s approach as adequate.

Representatives from the TAC would disagree, claiming that the cautious pilot approach is too slow when babies are being infected with HIV and lives are being lost every day.

Nevertheless this approach was deemed to be “undermined” through first, the politics surrounding both the views of the President and subsequently, the Minister of Health, and second, a lack of capacity within the Department of Health. Another participant, also a researcher, agreed with the first line of reasoning, making reference to his view that both the President and Health Minister often relied on or cited information that may not have been well-founded, for example, taking information from AIDS dissidents and relying on their analysis of AIDS.

\textsuperscript{27} The participant is referring to Boehringer Ingelheim withdrawal of their application to register Nevirapine for PMTCT with the FDA in the US.
I don’t doubt the overall purpose and motive of government, I mean, I think they would, the Minister of Health and, Cabinet, the President, I think they’d like to see, I mean, I truly think they’d like to see equitable health services. I don’t doubt that. I have suggested already part of the problem is that they don’t analyze this (problem of HIV/AIDS) correctly, and (act on) analysis that they could get from anywhere.

This kind of comment was typical of respondents, who while critical of government, and especially the President and Health Minister, also defended them to some degree. This often involved the balanced perspective, mentioned previously (see Section 4.1.1), where good aspects of government were highlighted when pointing out failings. This type of balanced viewpoint sometimes prefaced the presentation of a participant’s personal theory about why the President and Health Minister had taken such a controversial approach, and why, according to many interviewees, things had gone so terribly wrong with respect to AIDS policy in South Africa. These theories generally get at the “personalities” or personal characteristics of the President and Health Minister, and will be explored in more detail below.

**Capacity and The Department of Health**

The other factor that posed a barrier to the Department of Health’s cautious approach was a lack of capacity within the Department. Despite this, participants saw the bureaucrats within the Department of Health and the AIDS Unit as committed to Nevirapine PMTCT programs. One physician commented that:

I think that the National AIDS Program staff have fought very hard internally to get (the PMTCT program) up and running. I think that they believe in the program that they are very much in favour of seeing it expand and seeing it work, but there are levels of political uncertainty beyond that, within national government certainly, that have not wanted to move forward.
Another physician expanded on this, highlighting his perspective that decisions made within lower levels of government can be made quickly.

And when the barriers, you know, maybe at the top of the government are absolute, or relatively absolute, but, beneath that level there’s a great deal of motion and a great desire for progress, and, I mean, you can change policy in a week.

Other participants reinforced lack of capacity as a barrier in the Department of Health with one government official summing things up this way:

\{I: At the national level, how do you think national policy has been developed over time...\}

Too slow. Too slow, um, absolutely incoherent national (backing), very little national infrastructure and support. As much as, this is going to be anonymous?

\{I: Yes.\}

As much as they say they have this national task team, the ministerial task team, we only met twice. There’s nobody there to put us together, to help… So, I think national (government), when they do offer training sessions for GPs or for clinicians, so far it’s just been such a farce, you know, do they really know what they’re doing?

\{I: And by they, do you mean the Department of Health, or the entire...\}

The Department of Health, within the AIDS, the HIV/AIDS Directorate.

\{I: But it seems like the HIV/AIDS Directorate itself has been relatively positive about trying to rollout access to treatment?\}

Yes, yes, yes, but uh, highly dysfunctional when doing so. No, no, their heart is in it, they want to do it, but the know-how is not there.

Whether the lack of capacity had anything to do with the government restructuring that had been ongoing since Apartheid was unclear. Some of the capacity issues brought up were a deficiency in the ability to study and evaluate programs, as well as a lack of “know-how” or experience in setting up a comprehensive program. Moreover, organization was an issue. Again, it was unclear whether this lack of organization and
coordination was an intentional political strategy of subversion handed down by high level officials as a stalling tactic, or whether it was due to a lack of foresight and leadership within the Ministry and Department of Health; or if it was a natural response to a very complicated policy environment, possibly compounded by the existence of one or both of the first two factors. Capacity will be explored in more detail in Section 4.5, which addresses PMTCT Policy Barriers, while “the politics” surrounding the President and Minister of Health are explored here.

Individual Personalities within Government

An environment of political tension was created by comments made explicitly by President Mbeki and the Health Minister, regarding the cause of AIDS as well as the safety and efficacy of antiretroviral drugs. Participants, whether physicians, peer counselors, government officials or otherwise, generally held that these comments were unfounded based on a superficial analysis of the AIDS situation in South Africa. AIDS was rampant; many people were dying on a daily basis; businesses, the economy and in fact the entire social fabric of the country were being torn apart by this pervasive disease. Drugs were available to curb transmission rates and sustain life: in many ways this seemed a simple answer to a complex and devastating problem. Of course, civil society, and namely the participants in this study, realized that there were many barriers to overcome in order to get these drugs safely and equitably to the people of South Africa. Nevertheless, they were swayed by the simple logic that using (potentially beneficial) AIDS medicines had to offer in the face of an otherwise terminal illness, and confused by the views of the President and Health Minister. In an effort to come to terms with these
views, which were seen as having a significant impact in National policy-making, 
participants dug deeper, drawing on personal characteristics of these individuals to 
explain their strange behaviour. In some cases, participants found no easy answer, and 
remained puzzled. One physician commented:

It’s a question of balance… you can say well, they (the President and Health 
Minister) only take into account public health. In terms of public health, it has 
been demonstrated that if they don’t do prevention (for MTCT), then hospital 
beds (get filled and another hospital is required)… I think Mbeki thinks mainly in 
terms of money, because that’s his training. He’s a macroeconomist. Uh, even if 
you turn a blind eye on public health issue, and even if you turn a blind eye on 
human rights issue, then you start to calculate and even if you calculate, in fact 
you can demonstrate, and it has been demonstrated that you save money by 
implementing MTCT, so there’s no reason left.

Another participant, a researcher and NGO representative, also found no satisfactory 
rationale to justify the position of Mbeki and Tshabalala-Msimang, though defended 
some of their actions.

*I: Do you have any other thoughts on why the President and the Minister of 
Health have been forces that were blocking wider access to public health?*

No, no, I think you need a team of psychologists to answer that one (laughing). I 
mean, I think on some of what they’re saying it’s completely correct and 
appropriate: to stress the link with poverty and to stress the link with the kind of 
social, cultural dimensions of HIV/AIDS; to talk about the neo-colonialism and 
imperialism that’s built into the whole medical industry, and the medico-
pharmaceutical industry; it is appropriate and correct. But all this stuff about 
whether HIV causes AIDS and…the question marks around toxicity and whether 
it’s poison is completely bung. So it’s been very difficult to support some of 
the good bits of what the President’s been expressing without it being confused with 
the very bad bits. And what he’s done is to harm and undermine those people 
who are arguing for a more wholistic look at HIV/AIDS, of which, antiretroviral 
treatment is a part, but, but it really does require more than just a focused 
attention on antiretrovirals, I mean you can overdo the antiretroviral focus. But 
why? Who knows? I think you really need to talk to some anthropologists, and 
sociologists, and psychologists.
A physician who had been active in the anti-Apartheid struggle, came up with his own ideas about Mbeki. He thought Mbeki had “some very serious failings, weaknesses”, including a complex about his race, which was connected to his ideas about HIV/AIDS.

Mbeki’s race issue? Well this is a personal belief. I think he hates himself for being black. I think he hates us for being white. I don’t think he knows that, but I think it’s deep in his, kind of sub-conscious. And one day it just came to me when I was reading something he’d written that he hates himself and um, subsequently, being now biased, I can see it in most of the things he says. I think his upbringing, you know, in exile, going to kind of, high powered institutions, universities and so on, it gave him some kind of inferiority about um, Africa. I mean I know this goes against everything he’s saying about NEPAD (the New Partnership for Africa’s Development) and his African Renaissance idea, but I think underlying all that is some really deep issue, that he cannot acknowledge, maybe can’t even see.

The exact connection between Mbeki’s racially-motivated insecurity and his ideas about AIDS is unclear, but it is likely wrapped up in what others have alluded to as a distrust of Western medicine, and the “neo-colonialism and imperialism that’s built into the whole medical industry, and the medico-pharmaceutical industry”. The point here is not to explore Mbeki’s psyche, but to make explicit the extent of the theories members of civil society in South Africa had come up with to explain the President’s “bizarre” behaviour, and more generally, the contempt that participants held for the President and Minister of Health, whose positions were seen as counter-productive to progressive AIDS policies. An important caveat with this data is that it does not represent the views of the President or the Health Minister, with the exception of a few media clips and government documents. Rather, this data focuses on the understanding that policy stakeholders, including civil society actors, government bureaucrats and media, had of Nevirapine PMTCT policy.
4.2.2 Distinguishing Federal Government from Provincial Government

Another division within government was between provincial authorities and the national government. Because of the flexibility in the distribution of provincial and national responsibilities, and due to the political space for non-ANC provinces to interpret policy, there was high variability among the provincial response to PMTCT rollout. This differential response meant that some provinces (Western Cape, KwaZulu Natal and Gauteng) moved ahead, and decided to expand access to PMTCT services in advance of the final, July 2002 court decision. Conversely, it also meant that other provinces, like Mpumalanga, mentioned earlier in this chapter, were very slow in widening access to Nevirapine, even some months after the July 2002 ruling. The provinces that moved ahead were aided by better-developed health care infrastructure and capacity within their provinces. The Western Cape in particular, has been seen as a leader in this regard in having both the capability and commitment to providing PMTCT interventions. In this way the Western Cape was viewed as influencing national policy by showing that a PMTCT program could be implemented in South Africa; it further served as a demonstration site to other provinces. Cape Town (Western Cape province), Durban (KwaZulu Natal province) and Johannesburg (Gauteng province) were perceived as three Centres of Excellence, in that many of the researchers and academics working on PMTCT issues were located in one of these three cities. The expertise from these centres was freely offered to other areas and provinces to transfer knowledge about how to create a successful PMTCT program.
Participants explained how certain provinces were different and accounted for these differences in various ways. One researcher explained the Western Cape’s position this way:

I mean, the Western Cape merged ahead very quickly, ahead of National, and the reasons for that are because of personalities within the Western Cape Department of Health, and secondly, their (capacity) for moving ahead with a more comprehensive treatment response to HIV, and because the province was governed by a non-ANC party. So it’s really a consequence of a few factors, well the first factor is that the Western Cape has the infrastructure and the resources that many other provinces don’t have, and there’s a strong lobby within the medical fraternity of the province that was also pushing and supporting a faster rollout of treatment to HIV. The effect of this is to raise question marks about who sets policy, national or provinces, and what’s the relative role of the two levels of government – those are ongoing areas of debate and interrogation. I mean, certainly the Western Cape has shown that provinces can forge ahead and develop their own policy, irrespective of what happens at the national level. We’re still testing out the boundaries of intergovernmental relations and the way in which governance is structured in this country. If this was an ANC, or of this had been an ANC-led province, it’s hard to know what would have happened, but more than likely they wouldn’t have been able to have done what they did. But now that the province is ANC-led, I think the ANC are unable to revert any decisions that were made. So in that sense it will be interesting to see how the Western Cape influences national policy. And, I think it’s begun to do that already, I mean there’s many other factors that influence National Policy, but I think there will have to be an acceptance of treatment-based programs, antiretroviral-based programs, now that the Western Cape is ANC-run.

Based on these views, which were reiterated by a few other participants, there was an opportunity for the Western Cape to forge ahead with PMTCT programs. This opportunity arose, first from a non-explicit division of responsibilities for health care between national and provincial governments (some responsibilities overlap or are shared, as mentioned in the literature review in Chapter 2; see Section 2.2.2 in particular), and secondly from the political space that existed to oppose the national government, since at the time of the Western Cape’s decision to roll-out access to PMTCT medicines, it was not ANC-led. Other participants elaborated on the idea of “political space”,

pointing out that the PMTCT program in the Western Cape was actually created by two ANC members, but because the province itself was non-ANC, this space existed.

The Western Cape at the time, when all the controversy started, was run by the New National Party and the Democratic Party. So the ANC was not in power in the Western Cape, which kind of gave the Western Cape Government a bit of space. What’s quite bizarre is that the program was initially set up by the Provincial Minister of Health at the time, who is, was Ebrahim Rasool, who’s head of the ANC in the Western Cape. So it was very much initially, it was very much an ANC program; and if you have a look at the head of the HIV/AIDS program in the Western Cape, he is a strong ANC person. So it’s come across as (being) a National Party (initiative). I mean now, the ANC and the National Party are in a coalition government in the Western Cape, ruling the government and they just continued with it. But the people who pushed the program initially were ANC people. But the space was there because it then was an opposition ruled thing, and opposition does what opposition does best – and AIDS has been used very well to this effect – “if government is not doing it, we’ll do it because it shows them up”. So there was the political space where the implementers were able to actually go ahead and do it and, and that was really amazing.

Further, certain conditions allowed the Western Cape to move: it has a much more advanced health care infrastructure and staff capacity compared to other provinces and it had strong leadership within the Department of Health. The first participant’s reference to “personalities” within the Department of Health, and the second’s reference to ANC-affiliated HIV/AIDS program head, point to one person (whose name was brought up by a number of other participants) – Dr. Fareed Abdullah, the Department’s Deputy Director-General, and head of the province’s AIDS program. Participants saw Dr. Abdullah as a strong leader and advocate for their PMTCT program. This highlights, in addition to the above discussion about Mbeki and Tshabalala-Msimang, the role that individual personalities played in policy-making. One physician made reference to this:

I think the Western Cape, I mean, the leadership of the Western Cape and specifically, Fareed Abdullah, undertook a course of action which was politically unpopular but morally correct, which was women with HIV needed to be tested, cared for, treated and that I think his perspective was the correct one… part of what I’ve observed happening then, is that the Western Cape is actually almost
more like a model for other provinces, saying here’s what we’ve done, here’s how we’ve done it, we are willing to help people who want to know more about what we’re doing and translate it to other provinces. Was that something that was recognized in advance of making this unpopular political decision? No, no, I mean, I think it was a by-product of it.

This participant highlights the leadership of Dr. Abdullah, and also elaborates on the leadership role that the Western Cape then took, as a province, in knowledge sharing. Further, the Western Cape also served as a demonstration site, where people from other provinces could actually come and observe their program. There was a great degree of technical capacity in the Western Cape, but participants also identified similar capacity in Johannesburg and Durban. Many researchers, some known internationally for their work on PMTCT, are located in these centres, and according to interviewees, they have generally been happy to share their expertise with others across the country. In this way, participants from the Western Cape felt that as a province, they had influenced national policy. One physician participant said “I think we have more effect on the national policy than the national policy affects us here”.

With reference to KwaZulu Natal and Gauteng provinces, one participant explained their forging ahead in this way:

KwaZulu Natal’s (move to roll-out) was because of its (non-ANC) Inkatha Freedom Party Premier. They were initially opposed, but then after the first judgment (in the TAC’s court case), they then decided that they didn’t want to take on the appeal (that the National Government initiated) and they were going to implement. And then… Gauteng announced an expansion of its program. So it was the first ANC controlled province, wholly controlled province, which kind of announced. And there was a lot of trouble with the (National) Minister (of Health) saying that they’re acting out of line and outside of policy, and they managed, with semantics, to kind of smooth things over. But in effect what it meant was this province was pushing ahead regardless of what the courts were going to say.
The ability of the three provinces to move ahead of national government on this policy, forced one participant, a researcher, to re-think how the government had been established post-Apartheid:

One thing that it shows to me, and a lot of people, is the whole concept of a federal split of powers. It was something that the ANC never wanted, it was something that minority parties wanted, so most progressive people didn't like the idea of having provinces with legislative powers and things like that... It was part of my thinking (that) the kind of transformation the country needed, need(ed) a strong central government, a unitary state, and it was really a compromise where we came to the kind of division of powers that we have... but what this has shown is that when you have certain powers at the local level, it's almost like one province can become a laboratory, or can, you can actually push things through. So a lot of what had happened in the Western Cape, a lot of the protocols and the roll-out plans and all of that, really influenced the outcome of the matter (in court)... (then) what has happened is that the judgment has basically given them (other provinces) the space to do what they want to do. So I think you have quite a strong leader in the Premier of Gauteng Province, Mbazima Shilowa, but the fact that there is now this court order, really gives him the space to (continue to) move ahead. You'll see other provinces that have really been dragging their heels and until they're actually told to do so by the Central Government, they're not going to do anything... (the division of provincial and national power) certainly gives the space to move, but it also means that recalcitrant provinces can (obstruct policy implementation), so it kind of cuts both ways.

In this analysis, both the government structure and the court case provided the space provinces needed to act as they wished. As this participant said, this can be a double-edged sword, as it meant that some provinces will move forward, while others, with less capacity, infrastructure, and/or political will, will stagnate. It is important to remember here that provinces do not have the power to raise taxes; all funding comes through the national government. Because of this arrangement, the national government does have a degree of control.

National government can’t tell provincial governments what to do, they can’t tell them (provinces) how much to allocate, but they can, through National Health Policy, influence what needs to be done. So, it can’t be the specifics, because health is an area of concurrent legislative competence: both national government and provincial governments can legislate on health and the Constitution tells how
you deal with what legislation would override what. But (in dealing with) the things that require national uniformity (provinces) can’t (go against policy), national will override… So, even though national government can’t determine to the Rand exactly what is spent, it can set the broader policy.

Therefore, as mentioned in the Chapter 2 (see Section 2.2.2), it is unclear how the federal government can respond to provinces that act outside of policy, particularly if their official health care obligations have been met\(^\text{28}\). Because this was a case of acting “beyond” policy rather than non-compliance per se, there was a mixed understanding of the kind of the mechanism the national government had at their disposal to reprimand the three provinces that moved ahead of national policy, beyond publicly chastising them.

No participant could clearly address what the national government had done to put a stop to those provinces that had moved ahead, though one participant brought up the government’s prior use of labour law to this end. In a case where a hospital superintendent provided antiretrovirals, which were not part of the national health policy, he was fired for insubordination (this example is referred to in more detail later). Despite the uncertainties about the national government’s recourse, there was some worry, at least in the Western Cape, when they initiated a PMTCT program, as one participant said:

> In the beginning it was totally clandestine. The guys in the Provincial Department of Health (in the Western Cape), started this thing on a low scale, totally low profile, you know, not wanting National to know about it.

> In effect, the leadership in the Western Cape opened up the possibility of advancing PMTCT without national support. As one participant alluded to, the Western Cape’s decision may have been motivated by a desire to commit to a “morally correct” course of action. The provinces that followed, KwaZulu Natal and Gauteng, may have

\(^{28}\) An entire study could be done in South Africa regarding the formal versus informal latitude that provincial governments have in interpreting how to act in response to policy determined by the national government.
had more of a political motivation. One participant from the former said she believed this to be the case in KwaZulu Natal because elections were upcoming. Beyond these reasons, there were a number of conditions that permitted these provinces to act: relatively good capacity and infrastructure compared to the rest of the country, and the political space that existed for provinces that were non-ANC led or that was created due to the court case. For those provinces that followed the national government, it was seen as “a combination of obedience and (a) lack of resources”. Broadly speaking, the fact that some provinces did move ahead certainly helped move Nevirapine PMTCT policy forward in the national context, as it could be demonstrated, in practice that such a program could work in South Africa.

4.3 THE AIDS POLICY ENVIRONMENT: THE POST-APARTHEID RESPONSE

The previous section laid out the different positions taken by government actors, and points out in particular the influence of President Mbeki and Health Minister Tshabalala-Msimang, in creating an environment of political tension around AIDS policy in general. This begs two questions: 1) why had Mbeki and Tshabalala-Msimang taken such an unpopular approach, questioning the link between HIV and AIDS and the safety and efficacy of antiretrovirals; and 2) how had this approach influenced developments in Nevirapine policy? The first question was addressed to some degree in the previous section, where participants brought up personality characteristics of these actors to try to
explain their behaviour, or simply gave up trying to understand it, referring to the need for “a team of psychologists” to get an answer. However, beyond the micro-sociological, personal level factors that may have shaped the current national government’s AIDS response, it was also motivated by historical, macro-level factors. Clearly the ability of the current national government to act on the PMTCT issue was shaped by the existing health care infrastructure and National Health Policy that was already in place. By looking back historically, the PMTCT policy response has a much clearer logic. It is not an isolated event, but the culmination of what was popularly viewed as a flawed response to AIDS by national political leaders, and the ongoing dissent of civil society actors vying for a more conventional and comprehensive approach.

4.3.1 Early (In)action

The legacy of Apartheid on health care and the country’s transition to democracy in 1994, were explained in Chapter 2. In interviews, participants often referred back to this period of transition as the starting point for the national government’s flawed response to AIDS. As participants saw it, it had all begun with Mandela’s government, who has a less than perfect record when it came to their handling of AIDS. However, this response was distinguished to some degree from the now Mbeki-led ANC response. Mandela’s government was partially excused for being inundated with the massive restructuring needed in all sectors of post-Apartheid society.

The post-Apartheid restructuring undertaken is described by this participant, who points out that it was “almost impossible to implement any programs” at that time. This period was also marked by the acceptance of the NACOSA AIDS Plan by the Health
Department and not the President’s Office; one of the first participant identified flaws in the national government’s AIDS response. Recall from Chapter 2 that those involved in the NACOSA process had wanted AIDS to be cross-cutting issue, addressed by a number of departments and not just the Department of Health:

In the period 1990 to 1994, in the initial transition period, you had these incredibly participatory processes where everyone was coming together to sit down and draw policy and get involved… in the AIDS field, there was very, very wide spread mobilization and it culminated in the NACOSA National AIDS Plan, which was a very symbolic document of that participation. That document immediately got accepted by the new government, within the Health Department, quite importantly not from the President’s Office, where it was supposed to be. But, it was immediately adopted and quite a lot of money mobilized through the donors. It was at a time when government was in the very profound period of restructuring and transition and the whole political structure of the Government was being reorganized from this chaotic administration into nine provinces. At the same time it was decentralizing and creating a federal state, so it was almost impossible to implement any programs during those first two years.

In light of difficulty in implementing policy during this period, just what did the Mandela Government do? One physician described Mandela’s response in this way:

I think that the Mandela Government, as Mandela himself has realized and has admitted now, the Mandela government didn’t move quickly enough on HIV. I think they have some valid excuses, there was a lot of restructuring to do, there were many other priorities, but I think it was the wrong judgment. They made a wrong judgment call and they didn’t see HIV/AIDS as a priority. And that has, that has come over into the Mbeki government. I think what is worse about the Mbeki Government is the fact that we’ve had to live through the so-called Presidential Advisory Panel, and the kind of flirtation with AIDS dissidence and “HIV doesn’t cause AIDS” theories, that have paralyzed service delivery not only in health but in the social services, and have in fact undermined HIV/AIDS prevention and care across the whole government, within all the ministries… So, I think that the Mbeki Government has, has a lot more to answer for. I think the Mandela Government did something and it wasn’t enough, but I don’t think they were as destructive as this (Mbeki-led) government has been.

Another participant, Pat Sidley29, a journalist, agreed with this assessment of Mandela:

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29 This participant made a point of indicating that her name could be used (which is reflected on her consent form). Patricia or Pat Sidley, has written widely political issues in South Africa, and in particular, covered
Mandela simply didn’t deal with it. It just wasn’t on his radar screen, which I think he now regrets and I think that’s why he’s busy working hard on it now. It wasn’t on his radar screen, it’s probably the major flaw in his presidency. It just wasn’t there. They just didn’t see it looming. In fact the commission on inquiry (a formal inquiry administered by government)… (looked) into the financing of health care in the country and had a specific emphasis on financing of public health care and then private health care. They believed, as a basis for how they contrived the costs in that thing, (made) estimates of costs, that AIDS could be coped with as a normal disease within the context of public hospitals. That’s not long ago, that’s 1996. They absolutely believed it... but that’s during Mandela’s time, and they just didn’t see it coming. And then when they saw it coming they were afraid to acknowledge it. So that’s, that’s what happened.

She later explains how being “afraid to acknowledge it” or in denial, was a logical explanation for the whole botched response to AIDS:

In any event, there they (the ANC) were, out of the country (of exile), looking at the promised land longingly, and about to inherit it, and finally the great day of liberation draws, and what have they got? A catastrophe. And to me, (their response) explained itself very easily without even the paranoia and the anti-drug company stuff. It explained itself wonderfully just with that… that “we can’t face this… this here”, and they doctored the figures as well through Stats SA (a government agency that collects the official statistics for South Africa), and they just didn’t want to deal with it. They really didn’t want to.

These comments help explain why the Mbeki Government had difficulty with AIDS policy: it had been an under-addressed area, with AIDS spreading rampantly while interventions were contemplated. The historical status quo of inadequate action on AIDS, entrenched by Mandela’s Government, allowed Mbeki to respond to AIDS as a non-crisis. Mandela’s response is therefore also a factor contributing to the current government’s response to AIDS, adding to those already discussed, like the personal characteristics of President Mbeki and his Health Minister. With some understanding then of what pre-empted the current response to AIDS, and Nevirapine policy in particular, the next section explores the initial policy events that characterized this

its ongoing AIDS policy battles. Her work appears in a number of South African periodicals and she writes freelance for the British Medical Journal.
response. Participants saw certain policy events during Mandela’s leadership, when Mbeki was Deputy President, as part of the government’s flawed response to AIDS. That is, participants identified a series of policy events, beginning during Mandela’s time, that led up to the very public controversy over Nevirapine. This series of events is prefaced by a breakdown of trust between civil society actors in the AIDS field and the government. To understand the implications of this breakdown, it is important to recognize that the struggle against Apartheid had been waged by a united sector of civil society, led by the ANC. The ANC members who now led government, had been comrades and partners with many of the anti-Apartheid activists- and physicians-turned-AIDS-advocates, who have been active in challenging the government on AIDS. Because many of the actors, both within and outside of government, involved in contemporary AIDS policy contestation were once united against Apartheid, the breakdown of trust between the now government and its civil society counterparts was especially significant.

**Recommendations Not Followed, Promises Not Kept**

The credibility of the government began to come into question not long after Mandela took power. With respect to the government’s plans for AIDS, a number of initiatives were suggested, discussed, and sometimes even committed to, only later to be dropped, or not followed through on. One participant, who had been involved in the NACOSA process as well as other AIDS committees set up by government, said this:

I have been involved with (writing a section of the original NACOSA AIDS plan), which they’ve forgotten about.

*I: And what year was that?*
In 1994, it was before, actually just before the government came to power… I was also on the government’s (committee name omitted for confidentiality reasons) and am, more recently, (part of a group within) the South African National AIDS Council… which doesn’t meet.

*I: Between the provincial and national governments, its particularly confusing to me, at what levels policy gets decided, policy gets implemented, all those things. So when you’re speaking of different boards and committees that you’ve been involved with, can you give me some sense of which ones actually have a role and actually make things happen and which ones are sort of just…

I don’t think anybody knows, and that’s one of the peculiarities of AIDS policy in particular, in that there’s been a number, over the past decade there’s been a number of consultative processes, all of which have not really been led to implementation. The provincial and national steering committees for the mother-to-child rollout are obviously important in that they are overseeing the program implementation now. Um, but the kind of policy level is confusing, even to people who participate in it.

{Ok, and when you’re talking about the plan that you were involved in developing in 1994, the NACOSA plan, that was then forgotten about, can you give me a little bit more detail about what happened to that plan?}

The National AIDS Convention of South Africa, or NACOSA, was formed before the change in government and actually included both the Apartheid government and the ANC and other stakeholders in trying to develop an AIDS plan in preparation for the new government coming in. The process was a very consultative process with NGOs, academics, (and) various stakeholders which resulted in, (what) I think (is a) pretty good strategic plan, that was never adopted however by the government. They took, they cherry-picked some pieces of it, and I think the interesting thing is, that if we were to look back at that now, it was in 1994 before anybody was actually recommending moving on mother-to-child transmission, and that plan had a whole section on research needs and local adaptation of international guidelines that were coming into place. At the time when Zidovudene (AZT) was only starting to be used in developed countries, the original plan in this country actually did have a provision for moving forward on getting somewhere, so its unfortunate that that got dropped.

This participant suggests that the operation of government was less than clear, or beneficial: the NACOSA plan wasn’t fully adopted; committees were set up but then never met; the process of policy development and implementation was confusing, even to those who were involved. The foresight had been there – although earlier a participant
mentioned that AIDS wasn’t on Mandela’s radar screen, it certainly was on the screen of some doctors, researchers and activists in the country. In fact, they had even written it into the AIDS Plan, from which policy was to be based – but their directives weren’t followed. This participant indicates that “getting somewhere with the response to AIDS meant providing drugs like AZT; an approach that the government explicitly rejected. Had this well-thought-out AIDS plan been put into practice, the Nevirapine issue might have been averted, and many lives might have been saved as well. In reference to these more recent Nevirapine PMTCT policy battles, one physician and NGO representative mentioned that it was nothing new:

It has been going on for a long time, (the PMTCT problem) was started already with the former Minister of Health, promises were never kept.

What were these promises that hadn’t been kept? One TAC representative explained the TAC’s inaugural campaign for PMTCT and how just before TAC’s initiation, the government committed to a five-site pilot program, which was later cancelled:

It was one of the first calls, and it was at the launch of the Treatment Action Campaign, one of the first calls was for a program to prevent mother-to-child transmission. There had been, prior to that… certainly it was under Dr. Zuma’s time as Minister of Health, there were, I think five pilot projects that were to be set up in Gauteng province, and those were then pulled, at the last moment.

Moving from this disappointing government decision, he goes on to explain how the relationship between NGOs and government began to shift:

It fell off the agenda for a short while, the MTCT, but I think there was a whole lot of other stuff, a lot of other areas of struggle where we (the TAC) were working quite well with government, (and) a lot of areas that we were having conflicts with government, there was a lot happening at the time which hadn’t been dealt with before... So, I don’t think it was a conscious choice (by government) not to deal with this issue, but there was so much else that was going on. So it was the kind of, the beginning of the end of (good relations between government and NGOs), there had been a really good working relationship between NGOs and government and these various scandals and a whole range of
things (caused this breakdown), and it was also a shift to a new economic policy and a shift from the Mandela Government, in preparation for Mbeki, so… a lot of changes and things were happening.

Again, there is some confusion about exactly how and when the relationship between government and civil society shifted. Certainly, as this participant mentioned, it was the result of a number of factors, including the “various scandals” referred to. These “scandals” have been mentioned in the literature reviewed in Chapter 2, and will be explored from the participants’ perspective next.

4.3.2 Policy Events

There were a number of policy events, or “scandals”, that have been identified previously and were again identified in this study as part of a series in a flawed response to AIDS in South Africa. To reiterate, the Nevirapine policy controversy stood as a culmination of the growing animosity between government and civil society that had been prompted by these AIDS scandals and earlier discussions that initiated feelings of distrust. First was Sarafina II, followed by Virodene, followed by the government’s flirtation with AIDS dissidence. Each will be discussed in turn as part of this series of scandals, however this discussion also sheds some light on the workings of government, addressed in Section 4.3, as well as expanding the discussion of personalities within government and their effect on policy.

Sarafina II

Sarafina II was a musical on AIDS prevention that Mandela’s Minister of Health, Nkosazana Zuma initiated. “Sarafina I was the story of a schoolgirl, during the 1976
Soweto uprising. So it was a quite strong popular imagery and the idea with Sarafina II, was building on that, but it was a play about AIDS.” As this participant explained, it was to be a play about AIDS, by the playwright who had written Sarafina I. There were problems with the initiative from the beginning: the play had been decided on privately, and there were questions around the tendering process as well as questions about the relevance of spending large amounts of public money on a play about AIDS prevention versus initiatives focused on care and treatment of people living with AIDS. One participant, a researcher, explained how Minister Zuma’s personality came into play in the Sarafina II initiative:

The government had publicly committed itself to this (NACOSA) AIDS Plan, and had raised money and needed to do something about it. And so the Minister (Zuma), who at the time was this very strong willed… kind of personality, someone who believed very strongly in the needs of the people, and she’s credited with a huge number of innovations. But at the same time was very authoritarian in her style… (she) didn’t consider herself to be a consulter, and so she made a decision on how to spend this money and contracted quite a famous playwright, Mbongeni Ngema, to do a play called Sarafina II… a huge budget, done secret, secret deals in a sense, didn’t follow all the normal tender procedures and stuff, and there was a huge outcry and it was a big scandal for government in the end. And so there’s been, and so Sarafina’s, in a way started a kind of conflictual cycle with the non-government environment.

One physician, who had worked with the Natural Progressive Primary Health Care Network (NPPHCN), a health advocacy NGO, explained current Health Minister, Manto Tshabalala-Msimang’s involvement in the Sarafina scandal:

She (Manto) used to work in (the NPPHCN)… when she came back from exile she joined that organization as a paid employee, and then she became head of the Portfolio Committee on Health in Parliament after the first general, democratic election. The Minister of Health then, was our current Foreign Minister, Nkosazana Zuma, and (Manto) was the Director of Health, Director General of Health, the most senior health civil servant in the country. (Manto) was, not the political chief but the, kind of, service chief. What happened was, the AIDS program that we had in the NGO had a funding crisis, there was a gap between grants from overseas donors, and we had trained, a... number (of) community
AIDS workers in most of the provinces, all except the Northern Cape, as far as I can remember. And their salaries had to be paid, so we approached the Minister of Health (Nkosazana) with a request for bridging the loan, it was turned down. It was about 700 000 Rand… (Manto)… was then the Head of the Portfolio Committee… and she was (also) our ex-employee, a comrade of ours if you like. And they refused to give us this loan, so the whole program folded, all those workers were entrenched, and about a month or two later Sarafina II (happened)… Sarafina II was an attempt to educate the country about AIDS, but it was to be done through a play… the government put 14 million Rand into that play. And that play was only going to be held in one area at a time, and people were going to be charged (a) 20 Rand admission fee, etcetera, etcetera. So it was a completely crazy thing to have done. The Portfolio Committee in Health is the Committee in Parliament that is meant to hold Ministers accountable, there are a number of Portfolio Committees, one for Transport, for Defence, etcetera. They’re a parliamentary… committee, whose task it is to make sure the Department is run efficiently under the Minister. We drew up a list of questions for the Portfolio Committee to ask the Minister about Sarafina II, like how were the tenders decided, who else submitted proposals, that sort of thing, how was the decision actually made. Innocuous questions we needed (answered)… to be able to understand this thing… We didn’t, we couldn’t understand it because what we were doing was relevant and this was a completely irrelevant thing. We wanted less than a million and they got 14… The Minister, firstly the meeting was called off, the Portfolio Committee meeting with the Minister of Health and the Director. Then it was re-instituted at the command I believe, of the then Deputy President Mbeki. But the questions, it was a white wash, it was never really a serious attempt to hold them (Ministry of Health) accountable. And the next thing that happened was Manto became the Deputy Minister of Justice. So she was promoted. And I can only think that that was a final nail in the coffin of her… integrity (by not pushing the issue of getting an accountable response from the government in her Portfolio Committee position). And in the run up to that meeting that she was… actually, she was very courageous. I think there was a lot of pressure put on her, to kind of white wash that thing… But, anyway… that never happened, and she became, she went up, in the ranks.

Eventually, because of the large public outcry, the Sarafina II initiative was cancelled, and the NPPHCN never received its bridging loan. This participant describes, from a personal point of view, how NGO’s view of some government officials, post-Apartheid, shifted from “comrade” to a more oppositional role. This shift is significant as it helps to explain the critical, yet sympathetic, way in which most participants described the government’s response to AIDS. Participants’ critiques of government typically also
point out good things government had done, both for AIDS and the rebuilding of the nation, or defend in some way government’s less popular decisions. Another unpopular move by government was the Virodene controversy, this event forms the second in the series of scandals that depict the growing alienation between government and civil society, that culminated in the Nevirapine battle.

Virodene

The Virodene scandal, explained in Chapter 2, followed. To summarize briefly, this scandal involved South African researchers who had come up with a supposed cure for AIDS. The government, alerted to this potentially huge discovery – a truly African response to an African problem – decided to invite the researchers to present their findings to Cabinet. Mbeki’s desire for an African Renaissance may have fuelled the pressure that was then applied to the MCC to approve this medicine for human trials. It was later determined that this drug, which contains industrial solvents, was quite toxic to humans. To clarify, the MCC is “an independent body, making it’s decisions in the best interest of the country, not under the influence of the Minister of Health or the Department of Health”, as one participant explained. A physician participant describes how the independence of the MCC was jeopardized by this pressure, which also gave civil society another reason to question the motives of government, and thus served to increase the growing alienation between the two groups:

There’s been some basis for my arguing that these institutions are paralyzed, because people have a tremendous pressure put on them to tow the line. I mean a notable person would be Professor Peter Folb who headed the Medicines Control Council and who was actually, you know they (government) tried to get him to soften his stance on a substance for wood which was called Virodene, which is poisonous… he refused and he was pushed out… He was trying to make the
Medicines Control Council do what it should have to do… I think he had enormous pressure put on him and I think he did the right thing (in not approving it for human trials)… Whether he was pushed out or whether he jumped, I’m not quite sure, but I’m afraid that’s what happened (that he was pushed).

Looking specifically at the motives of government in the Virodene scandal, participant Pat Sidley, a journalist, made the following comments:

For some time people have asked whether money was a motive somewhere... they (government) definitely, lots of them, had shares (in Virodene), they did think they were going to make money; Thabo and Nkosazana Zuma (former Health Minister) were actually (pinpointed) in that whole picture. That was why Folb (former head of the MCC) was fired, because he wouldn’t allow human trials… but… the money, I really didn’t think that that was a prime motivator.

Another participant similarly felt that money wasn’t the only, or biggest factor in the Virodene scandal. Rather, this participant, who had had close contact with Minister Zuma at the time, emphasizes the pressure she was under, her weaknesses and other personal characteristics of individuals in government, and the poor analysis that led to the pressure to approve Virodene. The drug was not approved, however this participant also explains the implications that might have had, as well as how features from that policy decision have been relevant in the Nevirapine issue:

I think that in the urgency and the pressures of political change from 1994 onwards, the new Minister of Health, Dr. Zuma, who was appointed in 1994, in the urgency and the pressure of change, there was so much to do and they had so much to repair, this was one of any number of issues in her mind… I think Dr. Zuma, who was the architect of much of the present health policy, she took advice, she set up committees, on one of which I sat, so I saw her first hand. I think whatever criticisms I may have of her, I think she is serious, dedicated, determined, which were all very fine qualities. Rare qualities (laughs). So I had quite a lot of respect for her, and I certainly had a very acute feeling and understanding for the pressures on her. Part of the pressures were of her own making… she didn’t know how to and where from to take advice, so she was not advisable. And (this), for a person who struck me as rather inexperienced in the business that she was dealing with… I’m sure she was and is an experienced politician and freedom fighter, for which I did have a lot of respect. In terms of dealing with the enormity of her country’s health problems, many of which had been badly neglected, under her predecessor, I thought that Dr. Zuma wasn’t coping with some key issues. She probably coped with other issues, and she
certainly showed resolve, but she had this enormous weakness of not knowing where to turn for advice and trusting it, being able to take it. Now within that setting I don’t think anyone’s adequately captured that, because there’s great admiration for her, admiration that as I’ve indicated to you, in part I shared, in part. But, in that setting, and in that pressure, and in the pressure to impress as a politician… I think that she made the following kind of calculation about HIV. First of all I think somehow, for reasons that I do not understand, they, that is she and Mbeki, both of them… for reasons that I can’t understand they misread and underestimated the HIV problem, and that is very deep-seated and somewhere in their minds, and I can’t actually sort that out, I don’t know enough about them. It’s either just bad thinking and analysis or it’s much deeper than that. And I can’t do more for you on that one. I think it’s both, but that’s guessing. Bad analysis it was, and in that setting came this drug Virodene… They were determined to get this drug which was a stupid thing and dangerous, and potentially dangerous to health services. They were determined to get this registered, approved, and sold. And they had a financial interest… it (Virodene) was proposed to them, and a financial interest to the party was proposed to the them at the same time… It was a colossal misjudgment… it followed the Sarafina thing… and it hasn’t been properly analyzed… but in my view… whatever the explanation for much of what happened there, it was very, very deep seated within the psyche of the individuals and the party (ANC). And there was a financial interest for the party. I never suspected individuals of wanting… I never thought that Dr. Zuma was interested in making money, never, I always thought she was (completely committed) to her cause, and I never thought that Mbeki was interested in making money, but I think they were interested in making money for the party and I think they misread that thing completely.

This participant continues by connecting concerns he had about government’s analysis in the Virodene scandal to his current concerns about the government’s response to Nevirapine policy:

Now that led to quite a lot of upheaval… what was special about that, that has relevance to what you’re asking and to the continuity of policy, again a profound ignorance and lack of advisability about HIV (within the current government). A profound misreading of what HIV positive patients want, because they (patients)(had) turned against the government on that particular issue, so there was a profound misreading of public sentiment, which is what politicians are especially interested in. There was a profound misjudgment about what might be in the best interest of the country. And had this happened, that Virodene would have got through, and the pressures were enormous on the regulatory authority, (in fact) the regulatory authority itself (was) divided so there were people in authority on the Medicines Control Council who wanted to see it go forward because government wanted it.
This participant then makes a second reference to how the Virodene issue has relevance to current policy:

Now had that (Virodene approval) happened there would have been, I think, an absolutely impossible situation in terms of control of AIDS, because people would have regarded AIDS as curable, preventable and so on. So it had profound implications for AIDS policy. How does this carry through? Well, I think that Dr. Zuma, had worked out for herself or been advised, and I don’t have detail of this or substantiation of it, I thought that she had reckoned that treating AIDS in the conventional way was not achievable in this country. Just not going to happen, you wouldn’t have to be too great of a mathematician to work out this was going to cost billions. The total health budget four years ago when these things were happening acutely, the total health budget for the country was about 30 billion, 30-35 billion Rand, of which about 12 billion, one third, was on pharmaceuticals. And they (the government) were looking at potentially a budget that would match that for HIV, and they were reckoning, they, I’m sure, they were reckoning (that) it would have probably have doubled the pharmaceutical budget… so she was reckoning or being told (that) was not affordable. And again you’ve got to have some sympathy for that, haven’t you? But it was totally lacking in creativity and imagination, except Virodene, it was their only creative move. It was totally lacking in inspiration and creativity and thoughtfulness, because after all, it didn’t necessarily follow that all those prices would be fixed at that level, that the government would have to pay for it all, that there weren’t hundreds of people and institutions cuing up, asking what can we do to help. So there was enormous, you would have picked up some of this in your work so far, there’s enormous potential energy in this country, a real energy, and determination, after all the country had managed to avoid a revolution, managed to achieve a change in government, and one that was not acrimonious, so I mean some big things have been achieved. It was not beyond the possibilities, the potential of this country, to do something quite startling about AIDS. This is not your ordinary African country in pharmaceutical terms; we spend 80 dollars per person per year on pharmaceuticals in this country, the average in 42 sub-Saharan African countries, other than South Africa is 2 dollars. So we are log orders different… that is where there was this disaster in analysis… That was the failure of analysis and the failure of Dr. Zuma (who) was famous for saying to people, she said it rather carelessly and quite insultingly to those people who were doing their best to advise her, that “she didn’t know who to trust”, and I believe her when she said that. I think that was not so much a judgment of the quality of the people she was dealing with as a political thing, she wanted someone who was of good quality, who’s opinion she knew she could rely on, also someone who would see the interests of the party (ANC). That’s my interpretation of that famous remark of hers that she would speak to whenever she had the opportunity, “I don’t know who to trust”. And of course the people who were wanting with all sincerity to help her were alienated by that. She had a great skill at alienation.
This participant had a lot to say about the factors that prompted the Virodene scandal. In summary, there are a good deal of positive comments about the Minister in this excerpt, indicative of participant’s balanced view of government – critique tempered with praise. In terms of critique, this participant points out a number of factors that prompted the Virodene scandal. First, the context of post-Apartheid restructuring is brought up as a confounding factor, which made it difficult to focus on any one policy area. Money was a factor, however in line with the previous comments, this participant minimizes the role that government’s financial interest in Virodene played. Next, Minister Zuma’s inability to take advice and her subsequent alienation of those around her, were factors. Finally, there were a number of points made related to a failure of analysis: an underestimate of the severity of the AIDS problem, a misreading of what people living with AIDS wanted, a misreading of public sentiment, and an uninspired notion that antiretrovirals were too expensive and that this barrier was insurmountable. The explanation for this misjudgment about AIDS was seen to be “very, very deep seated within the psyche” of both individuals in government (Zuma, Mbeki and possibly others) and within the ANC party. Reference is also made to two points that “carry through” or have significance to the “continuity of policy” with respect to Nevirapine. First, the current Mbeki government (Mbeki was Deputy President when the Virodene scandal erupted) is also seen as having a “profound ignorance and lack of advisability about HIV”. While both these characteristics are to some degree personal traits, the ignorance of government can be seen as following from a number of poor judgments made about the severity of the AIDS problem, starting with Mandela’s government in 1994. The lack of advisability among government officials is more challenging to explain, however it may be related to
issues of loyalty, addressed in Section 4.4, or such a focused belief in an African Renaissance, that certain government leaders were determined not to let AIDS stand in the way. To the contrary, they attempted to use AIDS as a vehicle for African solutions vis a vis Virodene.

The second point that has implications for Nevirapine is the idea that government had appeared to come to terms with the idea that conventional antiretroviral treatment was unaffordable for South Africa. As this participant explained, this viewpoint is lacking in creativity by discounting the approaches of lobbying for lower prices or engaging non-governmental agencies for funding (both are approaches taken by South African doctors and activists who have refused to view the problem of access to AIDS medicines as insurmountable). This participant implies that this governmental view, of AIDS drugs being too costly, is still pervasive. This may help to explain the government’s hesitation with PMTCT programs, as many in South Africa saw PMTCT as a wedge: once PMTCT was widespread and drugs delivered to people for this purpose, it would open the door to wider access to long-term antiretrovirals. This view is elaborated on in Chapter 5 in discussions about the TAC and it’s court case. However, participants felt that this awareness was in the mind of government as well: if government provided PMTCT drug interventions then it would soon be forced to provide long-term antiretrovirals, which it felt were unaffordable. This connection between PMTCT drugs and long-term antiretrovirals may have been a key motivator in the government’s stubbornness with respect to Nevirapine rollout for PMTCT.
AIDS Dissidence

A third policy event that was highlighted in this series of scandals came later, after the June 1999 elections, when Mbeki became the new President. This third event, the government’s questioning of the causal link between HIV and AIDS, also sheds light on the Nevirapine case.

The story goes that Mbeki was trawling the internet, surf(ing) the net, and I imagine plugged in Zidovudene or AZT and came across the dissident site. Which was questioning not only the toxicity (of) the drugs (antiretrovirals) but also the link between HIV and AIDS, and therefore you get that kind of emerging afterwards and then you get the Presidential (AIDS Advisory Panel), and… what you get is this constant kind of response and counter response on both sides (government and civil society)... (while) Government just more and more dug in its heels.

Again, this participant sees the AIDS dissidence issue as a contributor to the growing alienation between government and civil society. This excerpt implies that the more civil society questioned and critiqued government, the more it “dug in its heels” to hold its ground. The government actually engaged officially with the dissidents, setting up a Presidential Advisory Panel made up of dissidents and mainstream scientists to wage a debate over the “true” cause of AIDS. Participants feelings were especially strong on this issue, with all who mentioned it agreeing that the government had really taken things to a ridiculous extreme in questioning the basic science behind AIDS, a debate that had quelled in the US some years ago. Some participants explicitly connected the government’s dabbling in AIDS dissidence to PMTCT policy. When asked what he thought had prevented government-initiated Nevirapine roll-out, one physician replied, “I have no doubt that it’s the highest levels of the national government that have slowed it down.” When asked to provide more insight into this, the same participant responded:
I don’t know why, I suspect that it is tied up with the kind of, denialist agenda that the President developed, around the time, just, almost exactly around the time in fact of wanting to move mother-to-child transmission along, and that has put the brakes on anything with regard to antiretrovirals.

A clear connection existed between the government’s anti-AZT stance, and AIDS dissidence – as one of the explanations that the dissidents offered was that AZT actually caused AIDS. The connection to Nevirapine was less explicit, but one participant explained how this link was very clear to her. Certainly there was a close temporal association between the Nevirapine struggles and the government interests in the dissidence line. The sole media representative in the study, Pat Sidley, connected the two in the following analysis:

Whether one wanted it or not, all the issues around mother-to-child over here were very quickly politicized and became issues of a policy war… where I started taking notice of it was at the AIDS conference two years ago in Durban. The Minister of Health (Tshabalala-Msimang) had just come back from Uganda some months before preaching the virtues of Nevirapine in a mother-to-child study, which turns out to be the HIVNET study. But at that particular conference (Durban), where things blew up on a policy level generally, Boehringer Ingelheim had just made known its offer (of free Nevirapine for PMTCT for 5 years)… when Boehringer made that offer, then obviously one wanted to know whether or not the Minister was going to take it up. Now, as long ago as Durban two-years ago, they (the government) were tempted to take it up but hadn’t given an answer yet to Boehringer… At that stage also, the President had announced his bunch of funnies, the AIDS Advisory Panel, and it was in full cry, in fact at the time they’d had a meeting just before and all the loons were actually in Durban as well.

*I: And it’s the AIDS Advisory Panel who started forwarding the idea of HIV doesn’t cause AIDS?*

Well, the President had come across this himself initially with the help of some lunatics here, he had then found his fellow lunatics around the rest of the world and called them together to ask the profound question about the (cause of AIDS). That was well underway by the time Durban rolled around and by the time Boehringer Ingelheim had made its offer and it became clear that they were in three minds as to whether to take this thing or not, and then as you know they didn’t take it.
At that time did you have a sense for the key factors in their decision making process about whether or not they should accept the offer?

No, not a total sense, I knew as others who were watching it closely knew that the President had a bee in his bonnet, he did not believe and probably still does not believe that that (HI) virus causes AIDS. His Ministers who had had the benefit of good education then knew better (but) were way too protective of their own interests whether they were hierarchical or pecuniary, whichever way it was. They were hesitant to challenge him, and they wouldn’t challenge him, and didn’t challenge him, and to this day haven’t challenged him. And some of them landed up agreeing with him totally, even the ones with the good education similar to mine. As in, white people with the same education in the cabinet. So one was conscious at that stage that that debate was raging and that they (other members of cabinet) were tempted to believe it. At least the President himself, at the very least the President, but you were conscious of the fact that several people around him must believe it’s true, certainly wanted to believe it because it was easier to deal with by labeling everything poverty, easier to deal with than having to grapple with the very big problem. You know, by then it was clear on their own figures we had big, big problem. Going into denial was the obvious easier way out, and you were conscious that that was going on at the (Durban) conference. And on mother-to-child there was no hint that they were even going to explore the issue, none whatsoever, so you knew already, not just from the conference but from the debates around you knew by then also that it (Nevirapine) was busy saving lives in the United States and in Europe… and here we were busy equivocating with a donation on the way. And, you’d have to have been retarded as a reporter if you didn’t link that immediately to the policy makers doubts about the virus.

Sidley had covered this issue since July 2000, the time of the Durban AIDS Conference. She describes it as a “policy war”, and begins by describing how this came to be. Prior to Durban, the Minister of Health had returned from the HIVNET 012 study sites in Uganda, with praise for Nevirapine. Around that time President Mbeki was initiating his Presidential Advisory Panel (Sidley refers to the dissidents as Mbeki’s “bunch of funnies”, “lunatics”, and “loons”). As Sidley describes, the whole thing erupted in Durban – Boehringer Ingelheim made their offer; for Mbeki’s benefit, scientists signed a declaration saying they believed that HIV caused AIDS; activists took to the streets, marching together for access to AIDS medicines. The pressure was on government more
than ever to take a mainstream approach – to accept that HIV was the cause of AIDS, and begin to deliver antiretrovirals to their people. But the government didn’t do it, they didn’t accept Boehringer Ingelheim’s offer. As Sidley explains, there was an obvious journalistic “link” between the government’s hesitation with Nevirapine and their “doubts about the virus”. She elaborates on the loyalty that existed within Mbeki’s cabinet, as by and large, his Ministers stood by faithfully, not publicly questioning his approach. She also explains that Mbeki’s viewpoint was attractive in that it labeled everything as a result of poverty rather than AIDS.

Sidley’s perspective as a journalist is particularly revealing as she later summarized how Mbeki and his views were portrayed by the media to the lay public. She also explains how AIDS was connected to poverty alone, rather than HIV.

*I: In terms of the doubt about the virus, conceptually can you explain to me how the politicians portrayed their view that HIV didn’t cause AIDS and how that then meant that poverty was a catch-all?*

They didn’t all say that. I mean the President’s office will tell you over and over again that he never said that the virus did not cause AIDS, he just created an environment in which everyone believed that, they believed that it didn’t cause it. But they (the President and some cabinet members) did believe it, I mean definitely the President and few around him did believe that HIV did not cause AIDS. Now, conceptually they put that out by saying that it was intellectually dishonest not to ask the question. In fact the President used the analogy of book burning by Germans in the 2nd World War. And he used an analogy with Nazis to say that he should have been allowed to ask questions without (people trying to stop his quest for information)… you know burning witches, book burning, stopping questions from being asked and information from being given. Those were the images that he used repeatedly… and then he also got into the slightly more familiar game in these parts, of bashing corporations, that the drug companies are inventing the disease to flaunt their pills. So, once you watch that pattern developing again you really have to have no brain at all not to work out what was going on.

*I: And then how did he link things all to poverty?*
Well there was this nonsense about the syndrome, AIDS as a syndrome not a disease. He’ done some rudimentary homework somewhere and he’s come up with the damn word syndrome, which I’m now allergic to hearing the word syndrome. So what he said was all these things that you can see, each symptom… (was) caused by poverty. And he’s not wrong on that, the trouble is he got his fundamentals wrong, the rest would be OK. You know you have to say that poverty has exacerbated this, it’s exacerbated every other disease pattern in the country, and AIDS is no exception, but what he did was he took out the causal link between the virus and the disease, and/or syndrome, and then cast it as a function of poverty alone.

Sidley explains how Mbeki justified his views: he said that not asking the question about the HIV-AIDS connection was “intellectually dishonest”. While some South Africans sided with Mbeki, seeing it more reasonable to believe their President than some “American, or French” scientists, others questioned his views and struggled to understand their basis. A few participants made reference to a speech Mbeki had made at the University of Fort Hare, an institution where many blacks were educated during the Apartheid years. This speech, made in October 2001, well into the Nevirapine policy struggle, helped explain the foundation for Mbeki’s views in what one participant called “revealing text”. During the speech Mbeki says that “there are still some in our midst who would rather that they remain ‘mis-educated Negroes or natives’”, making reference to an earlier quote he used in the speech by Carter G. Woodson (cited in Mbeki 2001). The quote, from 1933, explained how “Negroes” were taught to “have an attitude of contempt toward their own people… taught to admire (other races) and to despise the African… convinced of their inferiority in being reminded of their role as germ carriers” (Mbeki 2001). Mbeki applies the image of the “mis-educated Negro” to current affairs in South Africa, explaining that some leaders of today still have the trappings of a “mis-educated Negro” and thus view Africa as doomed because Africans are unable to control their lust:
And thus does it happen that others who consider themselves to be our leaders take to the streets carrying their placards, to demand that because we are germ carriers, and human beings of a lower order that cannot subject its passions to reason, we must perforce adopt strange opinions, to save a depraved and diseased people from perishing from self-inflicted disease. These have no possibility to derive inspiration from what Pixley Seme said almost a century ago, that Africa is like some great century plant that shall bloom in ages hence. Convinced that we are but natural-born, promiscuous carriers of germs, unique in the world, they proclaim that our continent is doomed to an inevitable mortal end because of our unconquerable devotion to the sin of lust. (Mbeki 2001)

One participant explained nicely how this text pertained to Mbeki’s questioning of AIDS and his belief in an African renaissance:

The speech he gave at the University of Fort Hare in Eastern Cape… it’s very much tied in to the discourse about sex and sexuality and being African, and if you (“outsiders and mis-educated Negroes”) say we have a serious AIDS problem in Africa, you are saying that we are like animals, we can’t control our sexual impulses. It’s all part of that assigning of blame, and to see everything (related to AIDS) as only being as the result of a sexually transmitted virus, it can’t be. So why are you saying we are an immoral people? It’s part of that whole discourse… and he’s preaching the African Renaissance and this great rebirth and renewal.

According to this participant, Mbeki questioned the causal link between HIV and AIDS because he believed that the disaster facing the country, brought on by AIDS, supposedly through the sexual transmission of a virus, equated to a claim that Africans were “promiscuous” with “an unconquerable devotion to the sin of lust”. Mbeki could not accept that AIDS, so prevalent in Africa, was primarily derived from a sexually transmitted virus, without connecting that to an implication that Africans were thus “human beings of a lower order” who couldn’t control sexual impulses. This relates to what an earlier participant said about Mbeki hating himself. Mbeki, like the “mis-educated Negroes” had also been taught that blacks were inferior. While rejecting this notion in his speech, and looking to an African Renaissance, Mbeki appears defensive.
So ready to fight for equality for blacks, Mbeki seems to create an opponent – those representing Western, Eurocentric ideals, who in understanding AIDS to be sexually transmitted also in Mbeki’s eyes, took aim at the morals of Africans. Mbeki categorized some AIDS “leaders” within South Africa as “mis-educated Negroes” for believing the Western (scientific) claims about AIDS. Thus, it seems that part of Mbeki’s questioning of the causal link between HIV and AIDS was as much a critique of the global imperialism of the Western scientific process as it was denial (a view supported by Schneider’s second work reviewed in Chapter 2 (Schneider 2002)).

With this understanding of what, personally, may have prompted Mbeki’s fascination with understanding the “true” cause of AIDS, the next section moves from the personal to the political and structural factors that influenced the Nevirapine policy process. Before moving on however, it should be noted that Mbeki’s AIDS Advisory Panel, which was set up for a short-term only, finalized their report in the spring of 2001. Further, in response to the overwhelmingly negative public attention Mbeki’s questioning of AIDS brought about, the President resolved to no longer publicly deal with AIDS. One participant commented that he was hopeful that this was this case in practice:

I hope it’s something that has happened in the past and that we are in a different era now, certainly there’s some hope to believe that things are different and that things are moving now. Whether or not the President has changed his views, no one really knows? Or if he’s just decided he’s really not going to deal with it? You know, before he had said he’s not going to deal with it, but he was still kind of calling the shots, even though publicly he wasn’t dealing with it. If he’s now just hands off and letting people get on, that’s another story, but, I think (his actions do) stem from a belief that there is no link between HIV and AIDS.
4.4 THE PMTCT POLICY RESPONSE (AND THE STRUCTURES/FACTORS THAT SUPPORTED IT)

As established previously, an environment of distrust had been created between government and civil society, namely due to a slow initial response to AIDS characterized by scandals like Sarafina II, Virodene and the engagement with AIDS dissidents. However, Section 4.2 examined the perception of participants that distinguished certain actors within government from high-level politicians like Mbeki and the Health Minister, and expressed that not all government actors or efforts were viewed in a negative light. These divisions are also apparent in the evolution of Section 4.2 and 4.3 as government actors like Fareed Abdullah from the Western Cape were praised, while President Mbeki, Health Minister Tshabalala-Msimang and former Health Minister Zuma were critiqued, giving the impression that many of the flaws in AIDS policy are attributed to persons in the highest levels of the national government. Certainly many participants would agree with this analysis, and they had a number of comments about how the role and perspective of the ANC, the ruling national party, evolved post-Apartheid. This discussion focuses mainly on how a less open, participatory and democratic form of leadership evolved within the ANC and became enshrined in certain government actions. Furthermore, this section explains how this style of leadership has influenced the breakdown of trust between civil society and government, and how it has influenced the Nevirapine policy battle. However, all of the four actors mentioned above represent the ANC, so clearly this form of leadership and resultant actions are not characteristic of all ANC members; although participants felt that the most influential and
dominant forces within the ANC and government supported this approach to leading the
country. This section then places the discussion of the personal characteristics among
government officials within the political context of the ANC’s interests. It further
explains how government actions were structured because of historically enshrined
leadership styles and the dominant political figures within the ANC. Finally this
discussion relates these features to the Nevirapine policy response.

4.4.1 Loyalty and the ANC

First, participants had the impression that there was a strict code of loyalty that
surrounded President Mbeki and the ANC in general. In explaining the lack of open
criticism of Mbeki’s approach to AIDS, participants attributed it to party loyalty; they
described an environment where loyalty was essential for promotions and advancement
within government. Furthermore, participants noted that the distinction between the
national government and the ANC was blurred due to the number of people who held
high-level positions in both. One physician-participant who had been active in the anti-
Apartheid movement explained one of the reasons there had been failings in the
government’s response to AIDS:

Then there’s… the sort of culture of fear, or the climate of non-questioning
acceptance that’s grown up around (Mbeki).

{I: In that others accept what he says without question?}

Yeah, I cannot believe that within government there isn’t, there aren’t serious
divisions on HIV/AIDS. There must be. I’m sure that not everyone agrees with
him or her (the Minister of Health), but no one says it. It’s never explicit. It’s got
to be there. Why, why, why is there so much silence about it?
In response to this comment I later asked this participant where he thought this environment of unconditional support had developed from; whether the government structure itself created that environment, or if was in response to something? He answered:

No, I think it’s in the ANC. It’s a way the African National Congress functions. I think that culture comes from the movement in exile. The internal opposition to Apartheid was different; there was a vibrant democratic culture in the internal opposition (represented by) the United Democratic Front (UDF). (The UDF) was linked to the ANC in exile, and one of the key mistakes, this all underlies this MTCT (issue), one of the key mistakes after liberation movements were unbanned (and the ANC returned from exile), was the disbanding of the United Democratic Front. And I think that is based on ANC feeling threatened by everything that happened internally, by the structures that had developed in that struggle… You know, there were a bunch of leaders who were living in exile and there were leaders that sprung up organically, internally, and there was obviously going to be some kind of conflict when the exiles returned, some kind of power struggle, and to cut a long story short, the returnees (from exile) kind of won that power struggle. Not through force of argument or anything. But even those of us that were insiders, didn’t really understand what it was that the UDF was. The UDF was a civil society network essentially. It was a front made up of cultural organizations, church groups, women’s groups, sports clubs, you name it, any kind of street committees, civic organizations. Any issue that would affect people’s lives would be taken to the UDF. And people would organize; people would develop structures and processes and so on to deal with those issues. It was very rooted at community level, and it was very accountable, in fact to a fault. It couldn’t easily make decisions at a high level without going through the process of consultation. And that is completely different to the culture of the (ANC) people that came back (from exile). So I think that one the legacies is the victory, in inverted commas, of the returnees, and the disbanding of the United Democratic Front.

{I: So it was when the ANC returned and gained power that the UDF disbanded?}

…the UDF had two onslaughts against, the one was the state of emergency of the Apartheid government, you might not know about that. It was an immensely violent internal struggle between the white, de Klerk government and this loose association of NGOs (and) civic organizations, called the UDF, with the ANC in exile, linking up with the UDF. And the government declared a state of emergency, and detained thousands of UDF leaders, and tortured them. All that
stuff came out in the TRC\textsuperscript{30} report. …so that was the first major onslaught on the UDF, the second was when the ANC came back, and disbanded it. And we were all agreed that that was the right way to go because now the ANC would come in and take over the job of the UDF. But the ANC can’t do it, can not do it, because it’s agenda is power. The UDF’s agenda was issues, grassroots issues – to oversimplify it… So now, the only thing that smells and tastes and sounds like the UDF is the Treatment Action Campaign. If you want to get some kind of flavour of what the UDF was like, think of the TAC but multiply it by thousands, and broaden it to affect other issues, not only antiretroviral treatment but traffic safety, all sorts of things, sports issues, church issues.

This participant explains that a lot of what characterized the internal struggle against Apartheid as participatory and democratic was a result of the UDF. Though the ANC was also highly involved internally and worked with the UDF, it also had a strand of members waging an anti-Apartheid campaign in exile. This participant describes two factors that led to the disbanding of the UDF: the detainment and torturing of UDF members by the Apartheid Government, and the return of exiled ANC members to South Africa. Although this participant says he was supportive of the ANC initially, he deemed that the ANC was not able to simulate the function of the UDF because the primary agenda of the ANC was power rather than grassroots concerns. However, this participant also points out the participatory, consultative type of leadership that characterized the UDF was cumbersome and didn’t allow for decisions to be made easily or quickly – a major disadvantage of this approach to governance.

Helen Schneider makes reference to these two contrasting approaches to leadership in her article mentioned in the literature review. She explains that the approach of the ANC members in exile developed like that of an underground military struggle, where lines of command had to be quite clear and thus an authoritarian form of

\textsuperscript{30} The TRC is the Truth and Reconciliation Committee that investigated a number of injustices said to have occurred during the anti-Apartheid struggle, typically involving the abuse of citizens by the Apartheid government.
leadership was necessitated. In contrast, the internal ANC actors developed a different style of leadership, also characterized by the UDF, which was very open, inclusive and participatory stemming from the mass mobilization that typified the internal struggle.

One participant made explicit reference to Schneider’s analysis in his comments:

One of the things is explained in Helen Schneider’s piece, that is the way in which people, many of our leaders who were in exile during Apartheid, how they worked together and by necessity a lot of people who were in exile operated in a very closed, kind of Stalinist kind of approach… whereas in South Africa the internal leadership was much more open, democratic, open to debate… and (it was) those kind of conflicting traditions which clashed. The Mandela Government was much more a government of the kind of people who had been here, either in prison or been in South Africa. The Mbeki Cabinet is much more people who had been in exile. It’s not as clear cut as that, but it is to some extent. So, it’s very much a question of people who operate with an inner circle, and that’s how, that’s how a lot of people understand Mbeki to operate – with a small inner circle, people get chosen because of their loyalty, loyalty is number one, ability (is) not necessarily at the top of the list of requirements. An independent clear thinker is not even on the list. So that’s my understanding… I don’t know if it’s correct… (is is also) my perception and I think there’s enough evidence to support this, that he (Mbeki) surrounds himself with people who he knows will be very loyal. And, to some extent that’s how the Health Minister fits into it. The Health Minister is married to, her husband is also very much part of Mbeki’s inner circle, (and has been) for many years. He’s currently the Treasurer of the ANC, Mendi Msimang. He was our previous High Commissioner to London, to the U.K. Our current Health Minister was very much part of the exile community, in that she wasn’t a great shining star when she was in exile, she was actually quite mediocre, she was not one of the great up and coming stars at any point… she was there, she was very much part of the circle, but she certainly wasn’t one of the leading lights at the time.

From Schneider’s analysis, this participant launches into his own assessment, which makes reference to nepotism within Mbeki’s government, with loyalty to Mbeki and the ANC being prime factors in gaining entry to his inner circle. This participant notes that these traits seem to be favoured over others – like the ability to think clearly. Also elaborated on here is which actors were of the “external” variety, like Mbeki, Zuma and Tshabalala-Msimang, and which were based in the internal struggle, like Mandela.
Another participant, a government bureaucrat, highlighted loyalty to the President as a key motivator in Ministers’ actions. “I think (the problem with HIV/AIDS policy in this country) starts with the President’s view on HIV and AIDS, and the need for all other Ministers to sort of go with the flow of what the President is saying.” A physician participant also elaborated on the concept of loyalty, referring to one provincial Member of the Executive Committee (MEC) for Health, and her compliant behaviour:

I think what happened in Mpumalanga (was that) the MEC there has decided she’s going to tow the line at all costs…

{I: And she is an ANC affiliate?}

She is ANC. And so she is saying “Mr. Mbeki says HIV does not cause AIDS, therefore this (court mandated PMTCT roll out) is all ludicrous and nonsense and it mustn’t happen and I won’t allow it to happen in my province”. And you know it’s without any rational thinking coming into it at all. So to my mind, she’s behaving like some kind of stooge.

This participant makes reference to Mpumulanga province’s compliance with Mbeki’s line of thinking, and non-compliance with respect to the PMTCT court orders (discussed in Section 4.1.2).

Another physician explained that one could determine whether government was truly democratic and representative by looking at who government was accountable to:

It boils down to accountability. Who are you accountable to? (If) you’re accountable to your members then that’s appropriate. If you’re accountable to someone higher up, that’s bad, and I think that’s where the problem lies, is that most people in the Ministry of Health, most people in the ANC, most people in government seem to account upwards and not downwards.

In explaining that government is accountable upwards, this participant implies that loyalty to the interests of higher-level officials is prioritized over a commitment to the interests of the electorate. Furthermore, this participant points out that this “upwards” accountability is characteristic of national government and the Ministry of Health, as well
as the ANC. He later clarifies that, in fact, the difference between the national government and the ANC is not clear cut. “What happens in cabinet meetings, I really don’t know, but the distinction between the ANC and government is pretty blurred.”

Therefore, participants felt there was an inner circle of “cronies” who surrounded Mbeki and placed loyalty to him above other interests, like those of citizens. Further, this type of loyalty was apparent within the national government and the ANC as an organization – the distinctions between which were unclear.

So how was it that government actors with an ANC affiliation, like Fareed Abdullah, the Deputy Director of Health in the Western Cape, could get away with diverting from Mbeki’s official position? One physician from the Western Cape province explained this:

Now, interestingly, in the Western Cape, where clearly things are being tried, and yes we’ve always been seen as the renegade province in a way, but, he (Fareed Abdullah) is being allowed to do it and you’ll have to ask somebody higher up there to know exactly why or how, but I mean to our good fortune. So, he plays the system very well, understands it. I think he’s an insider, you know, and he’s been part of the ANC for a very long time and so I think he has their ear, which helps obviously a lot. But he also seems to be playing the game very well, you know, going far enough but not too far. And it’s almost as if they’re saying well, we’ll let the Western Cape be our test case, then let’s see what happens, maybe we’re far enough away (geographically speaking from the national government offices in Pretoria), for it not to be too anxiety provoking.

Thus, for reasons that are not clearly explained here, there was some room for ANC members to independently interpret and respond to the National government’s policies, as exemplified in the ANC-controlled Gauteng province’s forging ahead on PMTCT roll-out in advance of the final court decision (see Section 4.2.2). While many high level officials seemed prepared to “tow the line” either as loyal ANC party members or because they were vying for a better political position through membership in Mbeki’s inner circle, a
few government actors, including Abdullah, seemed committed to public interests and were prepared to defy Mbeki, though they were thought to do so carefully.

In referring to loyalty and the ANC, one participant, a physician, went so far as to imply that whole institutions were wrapped up in politics of AIDS, as certain actors within these bodies also had loyalty to the ANC, Mbeki and even his questioning of the cause of AIDS:

I think there’s a creeping, kind of institutional paralysis to do with this (ANC) loyalty thing. I think that institutions are being loaded. Institutions are divided, it seems to me… It is a very unfortunate historic development, but I think it’s happening, that they (institutional actors) are split for example on HIV – those who have loyalty to Mbeki for example. And as the institutions transform, which is desirable in the post-Apartheid era, they seem to be getting bogged down in these divisions between AIDS orthodoxy and AIDS dissidence. And I think, I’ve got a feeling that the ANC is kind of infiltrating, getting itself into all sorts of committees and institutions and so on… I’m guessing; but (in) the Health Professionals Council, I think similar things are happening, the Medicines Control Council, university bodies, I think that’s what’s going on...

{I: So you’ve got some sort of division within…}

Within each little structure there are divisions broadly around race and any insurgency.

{I: So when you’re saying loyalty to ANC meaning that, you mean that there are people who just want to continue to support the ANC because of the good things they have done…}

Yeah, they’ll block, if a committee decides it needs to criticize the government position on Nevirapine, the loyalists will block that and nothing goes on. Coupled to that, there must be some kind of a moral weakness, because people who oppose the committee should walk out of it. These are all theories, you don’t have to take this, seriously, but this is what I think is happening.

No other participants commented about loyalty outside of the government structure, though certainly there was a good deal of respect and admiration for the ANC’s anti-Apartheid leadership among the general public. It is not clear whether the institutional
paralysis that this participant refers to was a result of ANC pressure tactics or sincere loyalty to the ANC, or possibly some other cause.

4.4.2 Public Vs. Private Discourse

Thus, the AIDS policy environment was marked by loyalty to the ANC and Mbeki and little public criticism of his unorthodox views. One participant, mentioned above, speculated that internal debate must have been going on, but it wasn’t manifested publicly. Another participant echoed this sentiment:

So you’ll find that within parliament, even though, we hear of many people who will privately tell you, “we don’t agree with what’s happening”… publicly, there are very few people within the ANC who will criticize. So, it isn’t, whether or not the criticism is taking place internally, I’m really sure it is, but it’s certainly not taking place in the public forum.

With respect to debates about MTCT and the controversial views of the President, reporter Pat Sidley confirmed that indeed vigorous internal debate was ongoing, and that as a journalist you could get a sense of this if you “did your homework”. Nevertheless, few if any of the non-media participants had much sense of this debate, seeing it as mainly hidden from public view.

Participants dated this closed style of leadership, where debates happened internally, within the private quarters of government, as far back as 1994:

Between 1994 and 1996, when the Sarafina thing exploded, there was very little contact between government and people outside. There were attempts at finding out more and it was unclear and government’s mechanisms to involve civil society weren’t fit in place.

The lack of a means to involve civil society shifted to official policies, which specifically excluded civil society. Specifically, in the year 2000 when the South African National AIDS Council (SANAC) was constituted it “exclude(d) all of the major civil society
players that have been embroiled in (AIDS) contestation”. This participant, a researcher, refers to the fact that many of the key AIDS experts and scientists were left out of SANAC to the favour of media personalities and popular athletes. Participants saw this as in-line with other private or exclusionary practices of government that likely stemmed from the Mbeki government’s more “authoritarian” style of leadership, and emphasis on loyalty to the party (ANC).

One participant, a TAC representative explained how this closed, authoritarian style was also a factor in the TAC’s PMTCT court case. He explains that the Human Rights Commission in South Africa had agreed to come in to the case to provide their perspective until government officials supposedly pressured the Commission not to:

The Human Rights Commission were coming in, then they got pressurized by government to not interfere. There was some very dirty stuff going on there… after having deposed the affidavit, to say that we bring this particular perspective… because of the Human Rights Commission’s role in monitoring government’s social and economic rights and obligations, (and) then suddenly they said we have nothing new to bring to the table… there was talk that the Counsel for the State and the President’s Legal Advisor had actually phoned the Chairperson of the Human Rights Commission to say, “do not intervene in this case”.

Another way the government had attempted to keep certain views secret was by not releasing an important document that was thought to inform decisions around PMTCT rollout. Apparently the government had conducted a study, the findings of which supported rollout. In an attempt to protect their decision to limit Nevirapine distribution to 18-pilot sites rather than full rollout, the government attempted to keep this document hidden. The same TAC participant describes this, alluding to the leaked copy of the document TAC had accessed:

Minmec is the Minister (of Health) and the, the MECs… Members of the Executive Council, which is basically your Provincial Ministers (of Health)… So
Minmec get together and policy usually gets adopted there… that’s really where health policy is determined… In fact one of the things which is talked about in the case is called the Minmec Minute and you can see that referred to, and that was really the decision at Minmec where they… limited (the PMTCT program) to the 18 pilot sites. The most interesting (part) is that the Minmec Minute has never officially been seen, (but) we (TAC) have a copy of it… Now, the reason they never released it is because one of the single costing studies that they (the Ministry of Health) did said that they must implement (widely)… but basically they decided not to implement it (a universal PMTCT program). So the Minmec Minute actually doesn’t provide a very strong basis for the decision that they actually took, and… they refuse to release that. So the very document that the policy was based on, is not a public document and nobody has official access to it and you’ll read it in the judgment, there’s a provision dealing with transparency and openness and accountability and it says, how can a national policy be reasonable if it’s kind of conducted in secrecy and no one actually knows what the policy is… So that kind of goes some way to explaining how policy gets (made)… This (decision about Nevirapine policy) was not about public hearings in Parliament, people coming in and having their say, everyone debating it. It was something that happened behind closed doors, the document that actually sets out the policy, never having been made available, to anyone.

This secrecy of government contributed to the growing alienation of civil society from government. It also undermined the credibility of government, as the public wanted clear justification for why Nevirapine access was limited and how policy had been decided.

However, participants felt that in addition to inadequate public justification of their policies, government was inflexible to change even when the public was consulted. A representative from NAPWA explained: “but what I’ve noticed about their policies (is that) they will design it, (and then) you will come in and you raise your (concerns), (but) if they’ve designed it, it’s designed. They’re not going to change it, it’s there whether you approve it or not”. This has implications regarding the aforementioned lack of advisability of some government officials, who seemed unresponsive to the advice of civil society and particularly groups representing people living with AIDS, like NAPWA.

Interestingly, this secrecy and inattention to civil society’s concerns in policy
development may have had to do with a particular perception of government, described
next.

One participant, a NGO representative and researcher, explained that because of
the ANC’s role in the liberation movement, which was inclusive and participatory, that
some individuals, now members of the government, believed the views of the ANC were
a proxy for public opinion, even though these open processes had dissolved. Related to
this, was a sense that the ANC did not trust civil society; because certain ANC members
felt that they represented the interests of the people, they questioned who civil society
groups, like the TAC represented, since the government and TAC’s viewpoints clearly
differed.

But there is quite a strong element within Government that honestly does not trust
civil society, thinks that there is an ulterior motive, thinks that they know what’s
best for the people, and (that) any other point is not a legitimate viewpoint… Part
of it also is a sense that, and this comes straight from the Minister of Health’s own
mouth, I have a reliable source, it is hearsay but it’s a reliable source, and
basically it’s a feeling which I think a lot of people within the ANC hold, not all,
but (it is that) “we are the people; who is civil society, who are these people
outside”. “We are the people who fought for liberation, we represent the people,
we’ve been elected to govern, let us govern”… So part of the bargain was that
sure we (government) get elected, but there are certain principals that we have to
account to and there are certain processes, and that’s the role of civil society, to
ensure that we comply with our obligations – but that’s not part of the discussion
(within government), the discussion is “we are the people, so who are these other
people, who are these organizations out there”, (and) a lot of it is also, “why
should we listen to you, because we know what’s best”… So, I think that goes a
long way (in) explaining much of the policy and hostility.

This section describes the historical foundations for the type of leadership that
dominated within government and the ANC: authoritative, characterized by debates that
were closed to or hidden from the public. Furthermore, there was a strong sense of
loyalty to the ANC that was apparent in government (in)actions, and that repressed what
might have otherwise been very public dissent against Mbeki and his questionable views
about AIDS. Finally, much of the government’s discourse was kept hidden or secretive, and this may have been attributed to a perception that the ANC members within government represented the people, even in the absence of a commitment to open and inclusive procedures. This style of leadership and the secrecy surrounding much of the government’s actions, like the AIDS scandals discussed previously, furthered the breakdown of trust between government and civil society. Moreover, this historically structured leadership style contributed to the actions of government during the development of Nevirapine PMTCT policy: as indicated, this issue was characterized by secretive documents and the suppressing of involvement by so-called independent government agencies. These closed and secretive processes contributed to the confusion participants had about why Nevirapine policy developed as it did.

4.4.3 A Rationale Response?

The final component of this section deals with the contention that despite these closed, non-inclusive processes, initiating the Nevirapine program at pilot sites only was an adequate and appropriate beginning. A few participants explained the rationale behind the pilot sites and made a good case for piloting in advance of wide-scale rollout.

This (PMTCT) Steering Committee was established to implement the mother-to-child transmission program using Nevirapine at two sites (per province) only, to understand the operational issues concerning Nevirapine, concerning counseling and testing for HIV, concerning provision of formula feed. Remember all three have never been introduced into the public sector, it’s very first time. And, with an already disadvantaged medical care system we knew we had obstacles. So, that was a reason for the pilot.

This participant, a physician, explains why the pilots were needed. Another participant, a researcher, also heralded the pilot approach as appropriate, citing similar concerns. As
with many medical interventions, particularly those involving drugs, there a number of complexities that have to be monitored to ensure safety and efficacy. With Nevirapine, potential problems include inadequate testing and counseling procedures, drug delivery at inappropriate times, drug resistance and many others; so a concern with operational issues was well warranted. However, another participant pointed out, that there were still many unanswered questions with respect to AIDS, but that that was the nature of the beast, and it was something that had to be accepted to some degree with any AIDS interventions:

The only thing (that) I think that’s important about the whole issue is that they’re (government) going to turn out to be right in some respects on mother-to-child, there are going to turn out to be things we don’t know about. But this whole disease is marked by the fact that everybody is… walking guinea pigs. And it’s just a function of it. So there are going to be a whole lot of “I told you so’s” as soon as something happens (and new information is discovered about AIDS).

This participant implied that any failures in the court-ordered response to MTCT would be highlighted by government as justification for their “cautious” pilot approach. Nevertheless, this participant supported the TAC’s actions. This implies that there is relative validity, with respect to differing policy arguments as a case can clearly be made for both the government’s cautious pilot approach and the TAC’s urgent approach, due to the sheer number of people infected and dying of AIDS each day in South Africa. What seemed to concern most participants though, was not that government had initiated PMTCT programs on a pilot basis, but rather that because of the lack of trust that had developed between civil society and government, they couldn’t be sure government would ever rollout as opposed to just finding more reasons to proceed with caution. Thus it appeared that many of the issues of contention surrounding Nevirapine policy had developed as a result of two factors: first, the desperate need to protect more babies from
being infected with HIV and second, the changing relationship between government and civil society, chronicled throughout this work.

### 4.5 PMTCT POLICY BARRIERS

With respect to the idea of relative validity of opposing policy arguments, participants elaborated on their views of the barriers to PMTCT implementation, as proposed by the government. While participants rejected cost and questions about the safety of Nevirapine as barriers, they presented a number of other barriers connected to capacity and infrastructure. In participants’ discussion of barriers, the differential in approach of civil society versus that of government is manifested: while government saw certain barriers as absolute, many participants representing civil society felt that barriers could be creatively overcome with appropriate leadership.

One participant, a physician, highlighted his concern about pilot projects being a tool for delays, an issue that arose due to the breakdown of trust between civil society and government. He also pointed out some of the positive effects of pilot programs; they were a good strategy as they allowed drugs to start to be delivered in some sites right away:

> You’ve got to start somewhere; you cannot wait until you can treat everybody that is just completely illogical. If you were to wait until you could treat everybody and say, okay, tomorrow let’s start, nothing would happen, because there is no infrastructure out there to do this. I could tell you that getting antiretroviral therapy is time consuming and without attention to minute detail, will not work… and then you might as well pour the stuff out on the ground. So, access to antiretrovirals is not the only thing. It has to be sort of viable access and viable access entails a lot of work from a lot of people. So I think you have to start
somewhere, I think the answer is, they call them pilot programs, I suppose that’s all right. What bothers me about the pilot program (approach is that) it sounds like you can have a pilot program running for twenty years and then, it kind of excuses the fact that there isn’t more access elsewhere.

In his discussion, this participant identifies some of the key concerns with any antiretroviral program: that attention to minute detail is critical and that access must be “viable” (i.e. the drugs need to be delivered at the right time in the right setting, along with voluntary counseling and testing, etc.). Many other participants elaborated on what “viable” access would entail, in their discussion of PMTCT program barriers. However, before turning to that discussion, it is informative to examine participants views on the commonly repeated barriers government cited as reasons for stalling on PMTCT: cost and drug safety.

4.5.1 Barriers; As Stated Publicly by the Government

Participants clarified, that although media often presented the government’s barriers to PMTCT as “cost” and “safety”, these were actually terms that needed explanation. Certainly cost and safety had been issues with AZT when it was considered for PMTCT interventions, but AZT hadn’t been offered free for five years, and with respect to safety, AZT was of particular concern because dissidents claimed AZT caused AIDS. Had these same arguments been haphazardly applied to Nevirapine as well? Participants explained what they understood the government’s cost and safety concerns to be with Nevirapine – though these were explained as distinct from the AZT concerns, this message was not clear from most media’s portrayal of “cost and safety” as generic barriers to Nevirapine as well as AZT provision, without detailing exactly what either one meant.
With respect to safety, participants commented that the main, substantiated, concerns about safety were made public shortly after the final July 2002 court decision. While the Health Minister had previously mentioned safety of Nevirapine as an issue, she hadn’t provided good evidence to support her view. The implication was that government believed all antiretrovirals to be a safety concern, likely stemming from the government’s engagement with dissidents, who linked the cause of AIDS to AZT. While all antiretrovirals are toxic to some degree by necessity (to allow them to work against the replication of HIV in the body), all drugs approved by the WHO and the MCC, like Nevirapine, have undergone extensive clinical trials to ensure that risks are minimal (Medicine Control Council 2002). In light of this, the government found reason to question the safety of Nevirapine once it was made public that Boehringer Ingleheim had withdrawn their FDA application to have Nevirapine approved in the US for PMTCT. As mentioned previously, this withdrawal was due to administrative procedures and was understood to have no implications for the safety of the drug, a view supported by the WHO and UNAIDS. One participant summarized the issue, drawing attention the fact that people within the Department of Health still believed the drug to be safe.

So clearly the questioning of the efficacy of Nevirapine, which has only cropped up because of the NIH’s and the FDA’s questioning of the (HIVNET) drug trials in Uganda, is appropriate and you know, they (the MCC) have got certain rules and regulations and procedures that they have to abide by. But, no one in the Department of Health believes that the questioning of the Uganda trial is anything more than a questioning of administrative procedures with the trial as opposed to a real questioning of the efficacy or safety of the drug.

While this belief may have been held among most within the Department of Health, Health Minister Tshabalala-Msimang used the FDA withdrawal to legitimate her view that Nevirapine was in fact toxic.
Then (the Health Minister) started raising questions again about Nevirapine, and it’s safety.

{I: And did anyone ever publicly question her about why she had at one stage said Nevirapine was a solution and a wonder drug after her visit to Uganda, and now kind of made a 180 degree spin on it?}

Yes, I think everybody asked her the question, and you know all she relied on was, the NIH who questioned it next… She’s relied on that as a reason for her change of heart… she relied on what had happened (in the US) to suddenly give some air to the debate.

With respect to the MCC’s role in evaluating the safety of the drug, one physician and researcher noted that they may not have been acting strictly according to scientific principles:

The Medicines Control Council I think has also been influenced by that (the President’s questioning of the HIV-AIDS link, and the dissidents idea that antiretroviral drugs were to blame for AIDS). They took a long time to (approve) Nevirapine for this (PMTCT) indication. They are still very skeptical, I think, about the Nevirapine program, about the drug itself; not always based on the science from what we can see. So, I think that they’re probably linked, quite honestly. I’m not saying that there’s direct pressure on the Medicines Control Council, but there may be a perception that that’s what they should do and so therefore that’s part of the way it’s moved.

Thus, with the exception of the Minister of Health, possibly some other high level officials, and to some extent the MCC itself, most people agreed that Nevirapine was safe. This point was reiterated by a number of participants, many of whom are known internationally for their contributions to AIDS research. Further, some participants agreed that the Minister of Health had re-questioned the safety of antiretrovirals, and in particular Nevirapine, after the court case, as a stalling tactic. Therefore, the safety of Nevirapine did not seem to be a legitimate concern for the delays in initiating a PMTCT program.
The other factor that was frequently cited as a barrier to the establishment of a national PMTCT program, was cost. One participant, a TAC representative explained what the government’s cost issues with a Nevirapine PMTCT program were:

*I: Didn’t government say that that cost was an issue all along?*

Not cost of the drug, cost of everything else. The cost of the testing, cost of the counseling, training of health care workers, all of that stuff. Cost of AZT originally, they said was a problem. (But the Boehringer Ingleheim Nevirapine offer) certainly gave additional ammunition to us, it strengthened the (court) case… I think it certainly made government out to be worse, what they were doing and less rational, but (the offer), I don’t think it swayed the decision either way.

Another participant elaborated on the influence of the Boehringer Ingelheim offer – he agreed that in terms of cost, the impact of the offer was minimal.

*I: What do you think the role, if any, has been of the, Boehringer Ingelheim’s offer to provide Nevirapine?*

Minimal, uh, the cost of Nevirapine is inconsequential.

*I: Relative to the budget of the Department of Health?*

No, relative to the budget of PMTCT program. I mean the drugs cost next to nothing. Free infant formula is almost five times, if not more, the cost of Nevirapine.

*I: And what are other kinds of costs, or barriers?*

The biggest cost is staff, definitely, so if you include personnel costs, the cost of Nevirapine is a drop in the ashes, I mean it’s completely inconsequential. Any talk around the cost of the drug is really a red herring. The major cost is around personnel, and infant formula, and to some extent, um, physical refurbishment of clinics to make them more amenable to counseling and testing.

And just what is the cost of Nevirapine? A participant and representative from Boehringer Ingelheim worked out the cost of the tablet that is given to mothers and the suspension given to babies. The combined cost of these two does, enough to reduce MTCT rates by up to 50%, was “60 U.S. cents or less than that”. Even in South African
terms, at roughly 5 Rand, this price was reasonable. This price would have been reduced to nothing if the South African government had agreed to accept Boehringer Ingelheim’s offer; however, at the time of the interviews the National Government had not accepted – though Western Cape and KwaZulu Natal provinces had accepted, and the Free State was in the process of accepting, according to this participant.

Another participant, a physician, elaborated on what the hesitation had been with the National government in accepting this offer:

Well the government has had the Boehringer offer of free drugs for a period of five years available since it was made, which was a year, 18 moths ago. I think the hesitation has been that one of their excuses (for not providing it) has always been cost and they would lose that if they do it. If there is a degree of concern that this would be another big pharmaceutical offer that was made and then in 5 years time (the company might) bump the price up and they (government) are landed with having to buy, and those kind of issues. So, I think those (reasons) initially were part of it… but I think also that because there wasn’t a commitment to a national roll out they wouldn’t accept it… they really have no reason now, they have a court order to go for a national rollout, they have every reason to accept it and I suspect that negotiations are continuing behind the scenes but I don’t know where they are.

This participant believed that the cost of the drug had been part of the government’s hesitancy, or “excuse” for not providing Nevirapine. It is not clear whether this was well founded or the result of the common misperception, supported by media portrayals, that the excuse of “cost” was linked up to the cost of Nevirapine explicitly. As a participant above explained, this was not the case. However, this physician-participant also points out a valid concern related to accepting the Boehringer Ingelheim offer: once the 5-year term expires the price of the drug could be raised significantly, posing a huge threat to the continuation of an established program. The Boehringer Ingelheim participant highly doubted that this would happen, but from government’s perspective it is a serious apprehension since there had been no guarantees with respect to price.
Critical of the government’s excuse that cost was a barrier, one participant, a researcher, gave the explanation that what was needed was “better investment by government”. He provided the following analysis with respect to this:

Government under-spends on the poor, it’s got much more money than it is spending. It’s not spending because its badly organized for the purposes of spending. It’s under-organized and performs poorly in mobilizing international funding support… (Also, if the government initiated it) pharmaceutical companies would engage constructively… I mean I have no special sympathy for any pharmaceutical company, but neither do I automatically feel antagonistic (towards them) and I am convinced that the Boehringer Ingelheim motives were pretty good… I think quite a lot of engagement could happen with industry and should, not necessarily for nothing but for really constructive engagement and concessions regarding patents.

This participant refers to broader structural issues that affected government, possibly as a result of restructuring post-Apartheid. Also highlighted, is the fact that the government had not made a concerted effort to engage pharmaceutical companies and have “really constructive” negotiations with them. This seemed typical of what participants perceived the government’s approach to be, in that certain barriers were viewed as insurmountable. This approach was in contrast to that of participants, who while detailing a number of potential barriers, felt they could be overcome with adequate and innovative leadership.

4.5.2 Barriers; As Identified by Participants

Some of the cost-related barriers mentioned by participants have been referred to above: these include the cost of staff and training of health care workers, the cost of the infant formula, and to some extent, the cost of physical refurbishment of clinics to make them more amenable to counseling and testing. One participant elaborated on these needs, describing money as the barrier:
In general, I think money is always a barrier, and it is a real barrier. I think staff are even more of a barrier. There’s a critical shortage of trained, competent health staff, nurses even more so than doctors, I think. Primary health care nurses who’ve been on the job for years and years don’t actually have the training to expand their scope of work, doctors are leaving the country madly. The infrastructure development is (also) not kept up and hospitals are collapsing, clinics are not being maintained, new clinics are not being built at a rate that they would need to be. So I think that there are certainly real and major challenges to health equity. My concern is that if you wait for the world to be perfect it (AIDS drug access) will never happen and that to some extent equity is being used as an excuse to not move forward with things that could happen. It’s especially so in HIV. There are many places today that could start looking at HIV treatment issues and I think that would be a reasonable way to go, to create the expertise, to work a system out with the eventual long-term aim of getting to equity. And I think there’s a philosophical difference between how you approach health equity, you either say, “unless everybody can have it, nobody can have it”, which has been the Health Minister’s approach, or you can say, “this is our aim, and here’s the road map to get there, and these are the stages that we’re going to go through”, and that to me is a more sensible way, because if we wait for everyone in the country to have a house and clean water and electricity and everything else, (then) we won’t have a population left in order to be equitable.

This participant explains some of the major barriers to setting up a PMTCT program, and further explains that because of existing inequities, the criteria of equity is not appropriate in determining whether to initiate health interventions, as achieving real equity is South Africa is still far off, in terms of access to housing, water, and other basic necessities of life. Another participant, a physician from the Western Cape, agreed with this analysis, highlighting inequities among provinces:

You know, it will always be difficult to live in the Eastern Cape, contrary to the Western Cape. It will be, I know, I’ve worked in the Eastern Cape and yes, infrastructure is not as good, and it does mean you have to travel. I mean there’s that sign that says Red Cross, pointing “that way”, in the middle of nowhere in the Eastern Cape. It’s a sort of hint of the Red Cross. And I think it speaks to the problem, that there are inequalities in the country, but they are everywhere. If you go to the inner cities in America, there are inequalities, it’s utopia to think that, you know, we will get that right before we can do anything. Because we won’t get it right, and therefore we end up doing nothing and that’s dreadful.
With respect to achieving equity, one participant, a researcher also from the Western Cape, highlighted the barriers that needed to be overcome:

The barriers are a shrinking health budget, or an inadequately expansive health budget. I mean, there is a pie that has to be divided up between the provinces and amongst different health care needs, and infections. So when you’ve got a restrictive budget, redistribution, (because) promoting equity requires redistribution, (is difficult). So you have to take from one and give to another, and there will always be resistance and opposition to that, and so, so that’s the first thing. The second thing is over 70% of total health care expenditure is in people, and it’s very hard to move people. You can move drugs, you can move equipment, but moving people from Cape Town to come work in the Eastern Cape is very difficult if not impossible. So, redistributing resources is difficult for those two reasons. And, the other thing is that equity is not just about resources but also the quality of those resources. So when you look at the biggest line item in the health care budget, which is people, you can have the same number of nurses in the Western Cape and the same number of nurses in the Eastern Cape and that doesn’t necessarily mean equity if the nurses in the Eastern Cape are poorly trained, poorly equipped, (and) poorly skilled compared to the nurses here; similarly with health managers. And for historical reasons the quality of personnel in the poorer provinces is lower than the quality of personnel in the richer provinces, and partly because more skilled people tend to gravitate to urban areas like Cape Town and Johannesburg. So that’s a major barrier to improving levels of equity, that we just don’t have the strength of leadership, the experience around management, the kind of public health understanding, or the public health professionals in the poorer provinces that we have in the richer provinces. Then the third thing is to look at the health budget… to look at the allocation of money to the health care sector (from) the overall government budget.

*I: Which is?*

Inadequate. Particularly if we want to really address equity. If we really want to address equity we need to be committing much more money to developing the health care infrastructure in the poorer provinces, which requires a bigger budget.

This participant clearly explains a number of barriers, both to equity, and to some degree even to the initiation of PMTCT sites in poorer provinces. Of particular interest are his comments about staff. While the skills of staff certainly varied from province to province, the attitudes of health care personnel also varied. Some participants noted that this was a barrier, as some staff were so overworked that they were less than responsive
when it came to adding a PMTCT program in to the existing spectrum of care pregnant mothers and new babies received.

The Public Health Services just can’t cope with the load that they’re dealing with. Staff doesn’t get paid well, so there’s very low moral amongst the staff. You’ll seldom find a staff member that has been there for fifty odd years.

Further, one participant explained that staff motivation to work with AIDS patients is often lacking, until individual health care workers learn that some of their own family members could actually be helped by PMTCT interventions:

(Many nurses) don’t see it (PMTCT) as important, because they don’t know what’s best out there. Again, the thing is a lack of information for them, they are most un-informed. They don’t know much. If they do know, (then) I think the lack of commitment is also a lack of interest, a lack of personal interest, a lack of empathy, a lack of humanitarianism, all of that. If somebody says to me that they just don’t have the time for this (PMTCT) program, then I believe that’s the reason. I always say to many health workers during our trainings, when are you going to wake up and say I’m going to do something about it (AIDS)? Is it when your sister comes in to the ward and tells you that you’re HIV positive, or your daughter who is pregnant, then tests positive. And in many instances, I’ve actually discovered (that to be so)... during our research at the hospital facility nurses used to be really stubborn and create huge obstacles if we had to implement research. “Aw, it’s a study, you do it, we wanted to be paid”. It’s amazing, during the course of the study when they realized what we were doing... you had nurses coming on board because they had relatives or daughters-in-law who were on the research study... They changed automatically. So do we have to wait for that? When we actually see a member of the family die. It’s health care worker attitudes, there has to be change.

Finally, other participants mentioned that the introduction of PMTCT program actually boosted staff morale, as now they could at least offer something to HIV+ patients.

To add Nevirapine onto it (the perinatal services already provided), is giving staff that’s basically already overworked, one more thing to have to deal with, which is difficult and maybe not so great for staff moral. But then on the other hand, you’ve got the perspective that, as a health care provider, I have obligations to provide my patients with the best care possible and if a lack of resources is inhibiting me from doing that, (then I have) a sort of moral and ethical conflict
with myself. So at least now, if I have treatment, yeah it’s one more thing I have to do, but at least I can offer people something

Another participant added:

The whole thing is about access to appropriate health care, it’s a lot of work, it’s quite an onerous project, but the staff in fact, flourish because they know they’re doing what they should be doing. They don’t have the sense of helplessness and hopelessness.

Ultimately there were mixed reviews about the receptivity of health care providers regarding the addition of PMTCT to the range of services that were already being provided in health care settings. It should be noted however that the variable views of “staff” mentioned here, were in contrast to the perspective of all the physicians interviewed in this study, who felt an obligation and deep desire to provide any kind of AIDS interventions, including treatment, to their HIV+ patients. The perspective of physicians will be dealt with explicitly in Chapter 5, however few other types of health care providers were included in the study, so their views are not directly represented.

Many other barriers, and/or ways of overcoming them, were highlighted, including further reference to infrastructure, and staff training and capacity. Other concerns raised were to do with the need for long-term treatment programs for parents, to avoid creating many orphans because of the introduction of PMTCT. Furthermore, social programs were mentioned as an area for improvement, as the current financial grants (Social, Disability and otherwise) available to HIV+ people were deemed inadequate. A broader response to AIDS was also recommended, one that dealt with the social issues related to AIDS more effectively, and one that involved all sectors of government as opposed to just health. This later comment was based on the example that a person who needs access to health care also needs access to roads, for example, to get to a clinic. So
if the Department of Transportation is not concerned with AIDS, then access to health will be a barrier despite efforts made by the Department of Health. Moreover, participants brought up culturally inappropriate protocols for protecting patient privacy and confidentiality as an issue. One physician in particular highlighted his understanding of the African tradition of involving family in major decisions, and the fact that current procedures of one-on-one counseling and testing for HIV didn’t allow for this. Perhaps inline with the view that some health care providers were uniformed, community immobilization and AIDS stigmatization were also seen as barriers, along with decisions on how to handle infant feeding, where the scientific evidence is still unclear. These are very complex issues that require a separate study to be adequately explored.

While participants certainly had no trouble indicating the many barriers that existed to the implementation of universal PMTCT programs in South Africa, as well as other AIDS programs, they were generally optimistic that some of these barriers could be overcome. A few participants from the Western Cape even highlighted creative ways of overcoming barriers, like through the inexpensive and highly beneficial introduction of peer counselors within PMTCT programs. As mentioned earlier, one caveat participants mentioned was that equity was not a realistic goal. With the more manageable aim of implementing PMTCT and similar AIDS programs where infrastructure and capacity existed, while planning for future roll out in other areas once basic infrastructure and capacity issues had been dealt with, participants were clear that a lack of innovative leadership was a major barrier. One participant referred to the concept of political will, or highly committed leadership:

The problem at this stage is political will… Public health services is a huge army (of civil servants), if you will. If there is instruction to implement, they will
implement; if they are told it is part of the job description. It’s what people call political will, (and it) does not exist – contrary instructions are given, not to implement in the country.

A second participant expanded on this idea, indicating that what was really needed were innovative approaches and the mobilization of more energy:

But… my colleagues have told me, it’s all very well calling for antiretrovirals but when you’ve still got a maternal mortality that’s way up there, you’ve still got infants dying of basic diarrheal disease and that sort of stuff, (then) shouldn’t you be fixing all that first. Well… on the one hand, but on the other hand, the biggest health risk that we have at the moment… is an HIV epidemic that’s wiping out our population, and I just think it calls for more. (It) calls for saying, right, we must keep working at the problem areas, where there isn’t vaccine coverage, where there isn’t clean water, we must continue to beat at that, but we now need extra energy to say what can we do about HIV. This epidemic is not going to wait for us to fix everything first, so we have to find extra energy to say, well what can we do about the HIV problem in addition to dealing with all these other issues… I think that’s what I’m trying to say, is that Nevirapine policy has saved (many lives), (and) what has shown me, (though) I’m anxious that I’m saying it from the Western Cape where things may be rosy, but (it has shown me) that you can actually add this (Nevirapine) thing on… without too much problem. And you could still be trying to address the other problems in tandem. But it does mean (that) yes, you will have to throw a little bit more resource at it, yes, you will have to galvanize more energy and look at innovative ways of doing it, but I think in the face of the epidemic as we see it, (that) we cannot wait to fix all the other things first.

These points suggest committed, enthusiastic and innovative leadership, as a condition for overcoming the barriers to successful PMTCT implementation, and the creation of other AIDS programs. This type of leadership did not appear to exist in the current government. The broad discussion of the government’s response to PMTCT policy, outlined in this chapter, has focused on identifying the powerful actors in government, charting the breakdown of trust between government and civil society, and finally, highlighting the structures that have impeded outstanding leadership and recommending strategies for overcoming policy implementation barriers. The next chapter supplements
this discussion by focusing of the activities, perspectives and ideologies of non-governmental actors, with particular attention given to the TAC and physicians.
Like Chapter 4, this chapter draws on data from interviews held with PMTCT policy stakeholders, the ongoing literature review, the ip-health listserv, and observations made in Barcelona at the 2002 International AIDS Conference. However, in this chapter in particular, observations made in Barcelona were especially important in describing the activities and perspectives of the TAC. Moreover, the ip-health listserv was an important source for learning about the TAC, as representatives made frequent postings. Chapter 4 presented a detailed discussion of the government’s role in Nevirapine policy, placed in the context of the broader response to AIDS, as expressed in the data collected for this study. The perspectives and theories presented in Chapter 4 are based on interviews with policy stakeholders. As the high level officials seen to be at the crux of the government’s AIDS failures were not interviewed, the views outlined in Chapter 4 are those of physicians and researchers, NGO and TAC representatives, and other stakeholders. Thus, while Chapter 4 represents the impressions that some civil society actors had about government, Chapter 5 explores the ideologies, views and activities of civil society actors from their own perspective. This chapter begins by addressing the leading role of the TAC in the PMTCT policy battle, and follows by examining other groups involved, including physicians and researchers, other NGOs, the lay populous within South Africa, and, very briefly, the international community and the pharmaceutical industry.

While the TAC had been active in the AIDS field since 1998, physicians had been involved since much earlier on in the epidemic. Many of the physicians that I spoke to had very strong feelings about advocacy and equity – a number of them had practiced
during Apartheid, and been involved in the resistance in some way. As Apartheid ended, many of these dedicated individuals had a new concern to devote their attention to: AIDS. Since as early as the NACOSA process, beginning in 1992, physicians and scientists have been advocates for progressive AIDS policies in South Africa. The TAC also has roots in the anti-Apartheid struggle, with a few of its leading representatives having been ANC members. Perhaps, because of this shared background, rooted in the anti-Apartheid resistance movement, the TAC and certain physicians were extremely supportive of each others’ efforts in attempting to increase access to AIDS medicines.

While the ANC government also shared this historical association with the anti-Apartheid struggle, because of changing styles of leadership within the ANC, this supportive relationship did not exist between government and either the TAC or physicians, with the exception of a few specific actors within government (i.e. Fareed Abdullah, the Deputy General for Health and head of the AIDS programme in the Western Cape, and some members of the National Department of Health).

In reference to the role of physicians and researchers in the eventual roll-out of PMTCT, one participant who identified with both of these groups, explained the early influence of this sector of civil society:

I think in terms of influencing roll-out (of PMTCT), the initial advocacy and the initial raising of awareness actually came from the research community, and it came (from researchers at Baragwanath Hospital in Johannesburg) and from their colleagues in Durban. And I think that those are without doubt the two places that… started to push government in the direction (of PMTCT). I think the next major factor was Treatment Action Campaign, which I think has been… successful in showing how civil society can influence (policy) and how you can use the courts to promote an agenda of justice, really, which is what it is. So I think those are the things that have pushed it along. In terms of what’s prevented it I have no doubt that it’s the highest levels of the national government that have slowed it down.
This participant explains that the current court-ordered rollout of PMTCT is the end-result of ongoing pressure from both the medical and research community and then later from the TAC. While TAC led the more recent campaign against the government to expand access to Nevirapine, a TAC participant explained how physicians were mobilized around their court case:

I think what the case did, and the mobilization around the case, was that it brought in a whole range of other parties. So as part of the applicants, you also had the group of pediatricians Save our Babies, they came on board. I mean that forms much of the broader work that TAC does and that’s mobilizing health care workers as well.

This TAC representative also added that besides TAC and it’s collaborators, there wasn’t much other pressure on government for PMTCT implementation. “In fact, outside of TAC and organizations closely linked to TAC, (the) AIDS Law Project, (the) AIDS Consortium, there wasn’t much of a call (for PMTCT)”. Many physicians and researchers were supportive of TAC and involved with the court case, either as applicants or experts who provided affidavits backing the TAC’s position. Thus, the role of physicians and researchers was much less public than that of the TAC, with the former groups providing much of the technical expertise and clinical context for the case. The TAC was, far and away, the most well-known and leading group in this struggle, though they had close partnerships with other organizations like the AIDS Law Project, the AIDS Consortium, NAPWA, and other NGO groups. This collection of actors shaped much of the civil society response to the government’s restrictive Nevirapine policy, as well as AIDS policy in general. This chapter explores the role of these groups of actors and their relationships, it also mentions the perspective and involvement of the lay populous.
5.1 THE TREATMENT ACTION CAMPAIGN

TAC’s background and involvement in the PMTCT issue is described in Section 2.3.1, therefore this section will only mention background details brought up by participants or necessary for understanding the ideas presented here. One TAC representative explained, that although the TAC officially began in 1998, that its historical roots were deeper:

It (the call for PMTCT) started before that and I wasn’t really involved much of what was going on at the time, but, at the time when the initial pilot sites in Gauteng, when those were pulled, there was a lot activism. I think the AIDS Law Project was quite involved in that, and the AIDS Consortium, TAC wasn’t. There wasn’t a TAC at the time, in fact, the current chairperson of TAC, Zackie Achmat, was head of the AIDS Law Project at the time. So a lot… was happening (before 1998).

This participant mentions the role of the AIDS Law Project (ALP) and AIDS Consortium, two NGOs who take a rights-based approach to AIDS, and that have been highly involved with the TAC’s activities. As mentioned, the TAC’s chairperson Zackie Achmat, once led the ALP, an organization founded by Justice Edwin Cameron. Achmat has since become internationally known for his high profile involvement with TAC and refusal to take AIDS medicines himself until they are publicly available in South Africa. Despite having connections to the ALP, TAC was actually initiated as a campaign of the National Association for People Living With AIDS (NAPWA), having since become its own autonomous organization.

One TAC participant explained how TAC’s call for access to AIDS treatment evolved out of broader work being done by the ALP in response to the emerging crisis in South Africa:
There was quite a lot happening in the late 1990s (involving the AIDS Law Project)... (this included) getting the legal framework in place (forming a basis from which the rights of people living with HIV/AIDS could be protected), (but) not even looking at issues of access to treatment at the time. It was only at the Vancouver Conference in 1996 when HAART (highly active antiretroviral therapy – long term treatment) was really, I mean that was when people first started speaking about it. I mean hell, these (antiretrovirals) had been available for a number of years before that, but really it was only in 1996 when people really saw the benefits of triple therapy and all of that, so that was quite late (in the global epidemic). That was all about the mid-1990s (and) there wasn’t really even a discussion of (providing treatment in South Africa) yet. Also, the epidemic was quite late to hit South Africa, so we weren’t seeing the same kind of impact. We were seeing, certainly seeing a lot of… discrimination of people living with HIV, but there wasn’t the kind of impact, kind of bodies piling up of people dying at that time.

At this time, the ALP was involved with AIDS, primarily addressing rights and discrimination issues; as treatment issues began emerging, the TAC was created to advocate for access to AIDS medicines for people living with the disease in South Africa. Continuing his explanation about how the movement for treatment in South Africa came about, this participant explains that the TAC’s response was shaped by a number of factors including “what (drugs were) available, the state of the epidemic, and the state of the scientific knowledge at the time”. Further, TAC’s approach was unique from the big “push” for more research into AIDS treatments and the involvement of people living with AIDS in decisions about clinical drug trials that characterized the earlier AIDS movement in the U.S., as one TAC representative commented:

There’s never really been the same kind of push in South Africa like there has been in the U.S., you know, about developing drugs and so a lot of the activism in the U.S. was, “we’re dying to spend money on developing a cure or (for) research in this field”, that was North America, that was not happening here.

TAC’s approach seemed to be more grounded, connected to people at the grassroots level – while much of the AIDS movement in the U.S. had gained strength from previous struggles for gay rights, in South Africa the AIDS movement has been informed by the
resistance movement to Apartheid, which as noted previously was very participatory and involved widespread mobilization.

Chapters 2 and 4 chronicle many of the TAC’s activities since their inception in 1998. A few significant points not mentioned in those chapters highlight the changing relationship between government, TAC and the public. Shortly after TAC was created and made their initial call for national PMTCT programs, the current government was elected. One TAC representative explained the shifting relationship with government around the time of the elections:

There was a meeting just before the 1999 elections with (Zuma), the Minister of Health (and the TAC) and there was some kind of a thawing of the tensions… and they (government) really looked like they were moving forward and then talking about… a joint march against pharmaceutical companies and she (Zuma) was going to lead the march… (it didn’t happen), and then the elections came and the elections passed and a new Minister of Health was appointed and things really shuffled then.

Another participant, a researcher, made the following observation about TAC, which indicates that the potential for cooperation between the TAC and government had broken down through this shuffle and become more oppositional:

I think they (TAC) have changed the public perception, number one, around mother-to-child transmission and around creating a public demand for health care, that I don’t think was there until they started on it. I think it was there previously but I think it had been lost. In the anti-Apartheid struggle there were very strong civic organizations involved in health care and involved in advocating access to health care, but they had become pretty dormant, and I think that TAC has to some extent revitalized that kind of civil society activism around health. I think they’ve also shown that the politicians working in the health field have to obey the courts. And I think that that’s part of the drama around the court case, is that the politicians feel that the courts are interfering in areas where they shouldn’t interfere, and they (politicians) are not in fact answerable to anybody. I think that again, it’s reinforced the public perception that politicians do still have to answer. I think one of the reasons that government finds them (TAC) so threatening is that they can foresee the day when this will happen for treatment as well, for ongoing treatment, and they’re terrified about it. They’re terrified by the financial implications, by the political implications, but I also think that TAC has become a
force that can’t be ignored, and that’s been fascinating to watch and fascinating to see the ripple effects of that.

From the perspective of this participant, TAC had made politicians accountable for their decisions and changed public perception, raising awareness about access to health care issues and government responsibility. Further, this participant explains that because TAC was so effective in their PMTCT crusade, government officials feared that policy regarding long-term treatment would be similarly influenced. This participant explains that the government saw the TAC as threatening; another researcher participant echoed this sentiment, bringing in TAC’s style of activism as an explanation:

Those (inclusive, participatory) forms of leadership (during the anti-Apartheid struggle) represent a tradition and a certain past… Participation by civil society was very strongly linked to these kind of formal alliances… (like the) Tripartite alliance, (and) political alliances… The AIDS field was linked to that through its history, but in reality was quite different and also expressed these different kinds of forms of activism – quite militant forms of activism, like sitting in the drug company offices and marching and being strong and defiant… And Government (had) discomfort with that kind of open dissent, when actually the whole world and the whole country was so much in support of this new (post-Apartheid) government.

This participant’s comments are useful in understanding how trust broke down between government and TAC, even though many individuals in these groups had been unified in the resistance to Apartheid. This participant suggests that because TAC’s approach was outside of formal alliances developed in the anti-Apartheid struggle, and because TAC used more militant approaches to express “open dissent”, that government was uncomfortable and threatened with TAC’s activities, because of the TAC’s open and persistent challenges. Interestingly, it was largely in response to what was seen as a flawed approach to AIDS by government, that TAC was initiated and persisted as it did.
This was one in a series of factors that provided TAC with opportunities for activism, legal action and to some degree, success.

5.1.1 Opportunity

There were a number of things that participants, including TAC representatives, identified as creating an opportunity for TAC’s development and prominence, as well as their ability to challenge the government in court. These included the government’s failings in their response to AIDS, the established science behind PMTCT interventions, and that the government had established a pilot PMTCT program, which formed the basis for the TAC’s court case. Moreover, vying for access to PMTCT interventions was viewed as supportive of the TAC’s broader objective of ensuring access to long-term antiretroviral treatment in South Africa.

Journalist and participant Pat Sidley explained how the government’s failings were a prime motivator for the TAC’s development and centrality in the AIDS movement in South Africa.

{I: Do you have any comments or ideas about what specific factors have helped the Treatment Action Campaign to have been so successful, and what has driven them to take things as far as they have?}

The major factor is the government’s own stupidity. That’s the major factor. They simply would have been a small group fighting for human rights... and legal rights of each AIDS patient, as the AIDS Law Project did, and that’s all they would have been if policy was OK. In fact, policy is OK on many of the human rights issues, except access to lifesaving treatment. You know, the law that Mark (Heywood, the TAC secretary and ALP head) works with to enforce, as a lawyer, is law (that) this bunch (government) put there – statues that say you cannot discriminate in this way, our statute for instance, and the equity bill and those sorts of things, and the Constitution of course. They put it there. So, that’s what they (TAC) would have been confined to, is a bunch of dedicated people fighting for the rights of individual people living with AIDS. So I think, to me, the major factor is government stupidity. Denial might be a more tactful word.
Sidley, highlights both the government’s AIDS policy failure and the existing laws and Constitution, which aspire to protect a wide range of rights, as key contributors in the persistence and success of the TAC. In addition to these broader factors, there were also more specific reasons that TAC’s court case against the government developed. A TAC representative commented on this:

We ultimately knew that regardless of what the court said, in the end, once you started the program, even if it’s only 18 sites, there’s no going back… I’m not sure if they (government) thought that through initially. They thought… (that) they’ll have the 18 sites, (and) it will diffuse tensions, because there had been a lot of pressure (for PMTCT) that had been building up. It wasn’t as if the idea of 18 sites was something that government had had for a while and wanted to implement. It was under pressure that they implemented, thinking it would smooth things over, but really what it did was it provided the access point… by the time (that the case) came to court it was a question of, not should or shouldn’t there be a program, but (rather) government has a program, and government has chosen Nevirapine as it’s drug of choice…. TAC has never said that Nevirapine… (is) the ideal drug. In fact, it’s not the ideal drug… (although) it’s certainly the cheapest and the simplest regime to use… it’s not the most effective. It works, but it’s not as good as other interventions, which are more difficult and more expensive. But it was government’s choice (and) they had a program… (and despite) all it’s limitations, that then provided the ideal basis to challenge it, because you challenge an existing program, not the non-existence of a program.

Thus, this participant contended that it was due to pressure from TAC and others, that government initiated the 18-site pilot program, which in effect just opened the door to more concentrated pressure by TAC, via the courts.

There were other reasons, besides the existence of government pilot program and the continued focus the TAC had maintained on PMTCT, that made it an appropriate focus for legal action. As one TAC participant explained:

There are a number of reasons why it (PMTCT) was chosen. Part of it is strategic, part of it was because it does fit into a broader struggle for access to (long term) treatment. Part of it was also because that was really the glaring gap, narrowly speaking, in Government’s prevention program… the glaring gaps (were PMTCT)... and post-exposure prophylaxis. So really, from our side it was looking at well, if we’re going to have a comprehensive approach to dealing with
this epidemic, what is it going include, what are we going to need to do, and it kind of makes sense that you’ve got to cover all your bases…. Also, I think… the science of PMTCT was much clearer (than for post-exposure prophylaxis).

The struggle for PMTCT contributed to the broader strategy of pushing for access to long-term treatment. Further, the science behind PMTCT was clearer than for post-exposure prophylaxis\textsuperscript{31}, another hotly debated issue at the time, making a legal case for access easier to pursue with PMTCT interventions. This participant later expanded the idea that, although PMTCT was strategically speaking a “stepping stone” to long-term treatment access, it shouldn’t be viewed as taking advantage of public sympathies for “dying babies”.

Because of a range of reasons, it (PMTCT) is a simpler case to fight. It is, in some respects a stepping stone. But it mustn’t be understood… (as) just something that was expedient to use because it was, you know, the dying babies and it’s easy to mobilize (around) and how can government be so callous and, you know, innocent victims and all of that stuff. That wasn’t (part of our motivation)… part of it was (that) this a crucial part of a prevention campaign… even if we’re not talking treatment, if we’re just talking prevention, how can we talk about prevention when we’re not doing anything to prevent children from being infected.

\subsection*{5.1.2 The Court Case}

Participants had varying opinions about the function of the TAC’s court case against the government\textsuperscript{32}, attempting to increase access to Nevirapine. Most were in support of the case and TAC in general, though some were concerned about the repercussions the case might have. Some thought the case would decrease equity in

\textsuperscript{31} Post-exposure prophylaxis refers to a short-course of antiretroviral therapy given, typically given after potential contact with HIV, for example, after a women is raped.

\textsuperscript{32} The fact that this policy was set by the courts as opposed to government may have implications regarding the concept of representative democracy. It is inferred that in this case it was the courts who actually represented the citizens of South Africa and not their democratically elected government. This difference between democracy and representation can be explored further by referring to the theoretical work of Hannah Pitkin and/or the more contemporary work of political economist, Adam Przeworski.
South Africa, as a result of the increased pressure it put on government to act, potentially beyond its means. Others thought the case would promote equity due to increased monitoring of government to ensure compliance with the court decision. Most felt the court case had increased public awareness, about both treatment issues, and social and economic rights. Some believed the court case represented a victory for truth. Others were more pragmatic, seeing the court case as a tool to ensure Nevirapine rollout within resistant provinces and among unwilling health care administrators. Finally, some saw the court case as one part of the immense pressure put on government to effect policy change.

In reference to the pressure that the TAC’s case put on government, one participant, a researcher, defended the government to some degree. This researcher pointed out that the TAC’s case undermined the pilot program, which government had already established and which had mechanisms for reporting, evaluating and making recommendations. This participant suggested that non-recognition of these mechanisms stemmed from “a misunderstanding of what two-years means”.

Two-years is a period for piloting a program, but there are periods in between, or within those two-years, at which point interim findings can be made... (and) the first interim reports (for the government’s PMTCT pilot have already been brought out) which made recommendations on the basis of what was found – and which included saying that, “there is no reason not to expand the provision of Nevirapine”. But there are other questions that can’t be answered within a time period less than two-years, so you need a two-year timeframe for some questions, but not for all questions. So, yeah, there’s a misunderstanding about what is meant by “two-year pilot study”.

This participant continued that the TAC’s court case was significant because it pushed the government to act, perhaps beyond its capacity:

I think the court action is very significant… (because it) will, in a sense force the hand of government to implement a program that it had in its own mind (already)
considered implementing across the country in a more phased manner, with a much slower approach. So I mean that, that carries significance. The impact of this has been to cause some confusion within the Department (of Health) about what exactly the court… required the Department to do… Really, it’s up to the Department now to interpret that judgment and come up with clear guidelines on how to apply the court judgment (though they had planned for a slower, more phased approach).

Furthermore, with respect to what resources government had available to devote to rollout as per the court decision, this participant voiced concern:

(The court case has) the potential to promote equity if the call for greater access to treatment recognizes the need to inject a considerable amount of funding to develop the health care infrastructure of the poorer provinces. But, it has the very real danger of making inequity worse. Because the effect of forcing government to implement a complex and expensive program, a relatively complex and relatively expensive program, in a country like South Africa is that you’ll make it possible in the better resourced area and you’ll make not just impossible in the poorer resourced areas, but you could actually undermine the provision of more basic primary health care services (which may be subject to funding cuts to accommodate PMTCT rollout). (This could occur)… by trying to force something more complicated and expensive on an already inadequately functioning health care service.

In contrast, another researcher felt that the court case would decrease inequities, because it brought attention to the operation of the health system within the country.

Such increased awareness would pick up on inequities in the rollout of Nevirapine.

The MTCT stuff, I think, was caught up in the politics and became a symbol of it, became a symbol of the government’s ability to control the policy process, on its own terms. I think that if it hadn’t been as politicized as it was, that actually it would have been implemented without any fanfare, probably quite badly, you know, in quite an inequitable way, in the way that the health system works here… you know, the areas that are traditionally poorly served in the country would have been poorly served by it, and (in) the way drug supplies are poor, it would have been poor. Whereas now, with all this attention and all this evaluating of what is going on, what you are getting through the MTCT process is a highlighting of all the health system deficiencies… It’s been a somewhat contradictory process in a way, (in) that things have been delayed and there’s been a lot of kids (who) could have got this stuff much earlier, but on another level… all this conflict… (was beneficial because implementation was monitored and deficiencies highlighted)… I think that, by the fact that it (the court case) brings with it a whole lot of scrutiny
and monitoring and evaluative processes, it begins to highlight the broader questions, (from) which (government) can then begin to tackle the equity issues.

These two participants had quite opposite views about the implications for equity in health care following the court case. Ultimately these comments represent two different ideas about what contributes to policy inequities in the first place: a lack of resources to develop programs and enhance capacity in certain areas, or a lack of widespread vigilance in monitoring policy implementation, from which necessary resources can be mobilized.

Other differences in participants’ perspectives stemmed from their ideas about what the court case did for government-civil society relations. One participant noted that “things got resolved through the court case”, implying that the court case gave closure to the earlier conflicts between the government and civil society actors. Another participant, a researcher, provided a different analysis:

This whole process of going through a court action with civil society has created a environment of conflict and confrontation, which is unhealthy, and it puts the Department (of Health) on the defensive. And it’s created a very adversarial atmosphere within the field of HIV/AIDS. So, there is a lot of suspicion, there’s a lot of paranoia, there’s a lot of antagonism, so that’s unfortunate. Not pointing the finger at anyone, but, it’s just an unfortunate way in which this country has allowed itself to slide down. There is obviously now a need to build bridges between the activist community, the scientific community and government; and to try and find common ground that is rational, sensible, and which will allow policies to be implemented in a more effective, equitable, efficient manner.

While this participant felt that the court case had caused conflict, which now needed to be overcome, this was not necessarily negative for the future of AIDS policy. In recognizing that strong, trusting relationships between government and civil society would lead to better, fairer policy implementation, this participant identifies the need to
build bridges. If the fallout from the court case permits or encourages the building of these bridges, it could have very positive implications for AIDS policy in South Africa.

Other differing perspectives pertained to the effect the court case would have on the future of health policy outside of AIDS. As one participant noted:

There’s much broader constitutional implications in that this (court case), it sets a precedent in the health sector as to how courts can become involved in determining policy, and how courts interpret the constitutional rights of people. So, Nevirapine today, what’s next? Kidney dialysis, cancer treatment, etcetera? Where do you draw the line between what is a constitutional right of people versus, what isn’t (with respect to the distribution of government resources)?

On the other hand, another participant felt that the case had brought attention to and promoted the concept of social and economic rights. Since the right of health is among this broader set of rights, this was considered good for citizens and the development of health policy:

The fact that the court case was won as one of social and economic rights, I think was extremely significant, and it brought (these rights) to the fore and has been linked very much to broader social and economic rights struggles in this country.

In general, the court case was viewed as a “public education tool”, which increased awareness about AIDS interventions and human rights among the public. To this end another participant agreed that the promotion of consciousness about human rights through the court case had been positive, empowering citizens to take advantage of AIDS services in the health sector:

I think… if there’s anything that’s good, that’s come out of the court case and everything else, is that it’s actually made the community very aware of… their rights and I think we have community buy in (to AIDS programs) as a result of it.

Building on comments made in Chapter 4 about the government’s failures of analysis – failure to recognize the significance of the AIDS problem in South Africa, failure to accept conventional thinking on the causes of AIDS and effectiveness of
antiretrovirals, and failure to address the AIDS crisis is an open and progressive way – some participants felt that the court case was a victory for truth. Through the court case certain facts were brought to bare and the court’s decision enforced the idea that policy should be based on science, and current, accepted knowledge. One participant referred to comments made by Justice Edwin Cameron related to this:

Edwin Cameron calls a crisis of truth telling, and that really policy has not been based on good science… whether it’s social science, whether it’s medical science… And what this judgment… really says (is) that when you’re dealing with something like this (the problem of AIDS), you’ve got to base your policy on science, and on what the facts are and what the best available scientific knowledge is, not (on) what you think may happen, it’s what we know now and what the consensus is on something right now.

Another participant, a physician and researcher, also highlighted the “outing” of truth through the court case:

I think (the court case) made the government realize that the activist community, who represent the electorate, were not going to sit down and play dead. They were actually going to demand rights. But they had an exemplary case… I saw some of the affidavits that came from various high powered members of our Health Ministry and their arguments were flawed, they were really problematic in the face of very good evidence – that MTCT has a role to play, does little harm and (is) not that expensive or difficult to implement and therefore (there are) really, very little grounds for not allowing it to happen. In my opinion, and I can say this because I was somewhat objective, I was sort of watching the process happening, the argument for MTCT roll out so very outweighed the argument against. I can just understand why Judge Botha said (that) “the evidence is overwhelming, of course we need to roll this out”. And I think it was a triumph for truth really, because I’m absolutely involved in HIV care and antiretrovirals, (and) I cannot understand what the hang up with government is with this issue. You know, it just may be… chang(ing) – I think in a way that view is endorsed when we saw the kinds of things that (government) were writing in order to make their case. It really held little water, and TAC came with a very strong case and I think it was proven, by the fact that a trustworthy judge stood up and said “I have to agree with it, this has to happen”. I think in terms of health policy, but in terms of bigger, broader aspects (too), that if we truly have the most wonderful constitution that we do have, and I believe in our constitution, that… when truth is truth it must out, regardless of what people’s personal beliefs are, what their prejudices are, what their difficulties are. The truth has to come out and I think that that was a triumph for that.
This participant notes the significance of truth and current scientific knowledge over personal beliefs as a basis for policy-making. From her perspective, the court case formally expressed this sentiment. Finally, one TAC affiliated participant noted that just the threat of having to justify policy publicly (i.e. through the courts) would result in better policy-making:

It (the court case) certainly opens it (policy) up to scrutiny and that’s what a lot of the proponents of socioeconomic rights were saying, it wasn’t whether or not you could actually get government to change its policy, the whole question was that government would know that it, it faced the possibility of having to come before court and justify what it was doing. And that in itself would then result in better policy-making.

Other participants were less philosophical about the function of the court case and viewed it as a practical tool to enforce Nevirapine rollout. When asked about the effects of the court case, one government official explained that it gave her a mechanism for applying pressure to hospital managers who were uncooperative in facilitating Nevirapine rollout:

For example, if for some reason one or two of the hospitals have been quite laid back about this (PMTCT rollout), then I use that as a real threat. I use it as a threat because it means… they have been given the support to run the program, but just haven’t been able to manage it on their own, because there’s no commitment.

Another participant, a physician, highlighted the flipside of this strategy, noting that managers who were optimistic about Nevirapine rollout could use the court decision to threaten Provincial or National officials to provide support:

(TAC’s) legal strategy is useful because for MTCT (there is) legal back up now, that every single hospital, or district that has the capacity to implement, should implement and it’s their right to receive supply from the provincial or national program.
Finally, other participants saw the court case as one component in the immense pressure that was placed on government to provide universal access to Nevirapine.

Journalist Pat Sidley described the pressures on government to take a more mainstream approach to AIDS, the court case being one of these:

Their (the government’s) case was that the courts shouldn’t be an instrument for policy-making. The court, of course, vigorously disagreed; it said that’s not what it was doing. However it (the court) had the effect of changing government policy because it (government) was compelled to provide it (Nevirapine), which is of course what all court orders do everywhere. But what it did was to help the build up on the dam wall. The Treatment Action Campaign had been the driver of this all the way through… (In the end) the discussions around how policy evolved essentially did not take place in the policy-making corridors of power, it was outside of them, which is an old South African habit. You know, the government resists and things change anyway. That’s what… happened in mother-to-child, if you work on the assumption that they’re now willingly providing it. The policy change is a function of immense pressure and not because of a change of heart. Among the immense pressures were ambassadors reporting back to the ministry of Foreign Affairs that they were having trouble abroad with this wacky AIDS policy, investors had made it very clear in their treatment of the Rand among other things that this was too damn wacky to touch and AIDS was a big issue. The scientific community had us very firmly in the book of the top ten banana republics… and then the G8 countries told Thabo that he could shove his NEPAD (New Partnership for Africa’s Development) if he didn’t fix the AIDS thing. Of course it was the community over here (that) was aggressively moving ahead with things in any event. (Also) all three private health care initiatives were providing mother-to-child quite a lot… and Mandela pitched in and tipped the balance. So the policy was not formed by policy makers it was only formed by the public pressure outside.

Based on this perspective, the court case was one major factor, among others, including the perception of outside investors and the G8, and the activities of those internally, that put pressure on the government to adopt a more conventional approach to AIDS in general, in addition to offering a nation-wide PMTCT program.
5.1.3 Combining Strategies

This section explores why and how TAC was so successful. Clearly many participants were avid supporters of TAC and their battle against the government. Further I realized through my observations at the AIDS Conference in Barcelona and through the ip-health listserv, that TAC had gained international support and acclaim. With respect to the latter, TAC appeared in almost idyllic form at the AIDS Conference. For example, I stood in lines just to get a chance to speak with some higher-level TAC representatives. I heard about many other researchers who had plans to investigate the TAC and their great achievements. I witnessed first hand the energy that could be mobilized by the TAC. And most significantly, I shared a celebratory moment with many attending TAC members in a hotel conference room in Barcelona, when the final Constitutional Court decision was reached, faxed through to Spain, and read aloud at our conference session.

While trying to make sense of the South African government’s response to AIDS, which had initially piqued my interest in this case, I found myself more and more intrigued by the TAC. I became equally interested in understanding the role that TAC had played in policy development, how they had been able to achieve such success\(^{33}\), and whether any lessons could be drawn from TAC’s development that would inform treatment access movements in other countries. As I contemplated these ideas, I came to realize that while TAC had been very influential in policy processes in South Africa, and had a lot to offer in terms of translating their strategies to other groups, that in many ways

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\(^{33}\) In discussing success, I refer specifically to the PMTCT policy process and the court case and decision, embedded in this process. While the court decision and ultimate conclusion of this process was certainly a victory for TAC, I think that many TAC representatives will not feel they have been truly successful until a national long-term treatment program is approved and put into place by government.
the TAC was unique. (In fact this recognition extended to the entire PMTCT case in South Africa.) Unique in terms of history – TAC was shaped through the anti-Apartheid struggle, as well as the legal and human rights framework that permeated through the work of the ALP into many of the TAC’s activities. Unique in their frame of reference – while many activist organizations are specific to one cause, like the liberation of blacks, or the interests of one group, for example gay men, TAC was extremely popular, and represented the interests of a large number of groups. Generally speaking, TAC represented people living with AIDS and their interests. Informally, and in the context of South Africa, this meant that TAC stood for poor black women, gay men, dying babies, and persons representing any number of other combinations of class, race, gender, age, and sexual-preference. Formally TAC had formed coalitions with many, if not most, of the various organizations dealing with AIDS in South Africa. This included close links with the ALP, NAPWA, and the international humanitarian group MSF; and more limited contact with medical associations, groups based at churches, and other service-based NGOs. Globally TAC had alliances with a many of the major players involved in AIDS activism and treatment advocacy, like ACT-UP, Health GAP, CPTech, and again MSF. I also found that the TAC even had formal links to Canada; through a partnership made via the ALP, TAC had worked with the Canadian HIV/AIDS Legal Network based in Montreal.

Based on this variety of observations, as well as the interview data, what was it then that had made TAC so prominent, successful and vibrant? I have separated my findings about TAC’s activities into two strands of activism, and purport that it is the ability to meaningfully engage in each strand that has contributed greatly to the overall
success of the TAC. For lack of better distinguishing terms I have called these strands “elite activism” and “grassroots mobilization”. These concepts are discussed in the following section.

Grassroots Mobilization

“To me, the Treatment Action Campaign is my voice. I know I can talk through them. So it’s (a way) to empower yourself.” These were the comments of one peer counselor when asked about the TAC. He had become involved with TAC during a time of anger, dismay and frustration after finding out that he, his girlfriend and their new baby were HIV+. For this participant, from one of the poorer township areas in South Africa, TAC was a means through which he could express and empower himself. It was a way to channel his anger by doing something to thwart those forces that prevented him and his family from accessing potentially lifesaving PMTCT interventions and from receiving the treatment they would soon need. There are many other similar stories about how individuals became involved in TAC, typically after realizing they were either infected, or otherwise affected personally by AIDS. Another participant, and a TAC representative explained her involvement this way:

Why did I become involved in TAC? I became affected because a member of my family was diagnosed as HIV positive last year, in September… I didn’t know how to support her, and I thought the best way for me to show her that I care and support her is to get involved, know more about HIV, know how to treat her, because basically I didn’t know anything about HIV before now. I mean, I didn’t think it would affect me, I thought it was for those people who (were) sleeping around and all that… But unfortunately I was still a student (then) and I didn’t have enough time to get engaged with (TAC), so I volunteered my services at (another organization), I became a peer educator…. Then (in) late January, I came to the TAC offices to find out more about TAC because I heard that they were giving hope to the people living with HIV, (and that) it can be combated through treatment. So I wanted my sister to have (these medicines), I know (that)
my family, we couldn’t afford (it) because they were talking about the expensive (cost) of the drugs, and you have to pay for those… then I said, at home, “(we) cannot afford that”, if TAC’s saying that people can get this treatment for free why not… get involved and find out about that so my sister can have access.

This participant conveys what motivated her involvement with TAC and leads to one of two generalizations about what helped TAC gain grassroots support.

There were then two driving factors that contributed to the TAC’s success, in terms of mobilizing the lay populous, or grassroots, around their cause. The first was just alluded to – the overwhelming feeling of devastation and helplessness experienced by many South Africans upon learning that they or someone close to them was HIV+. In South Africa, where there is very little that the medical community can do to help or treat someone living with AIDS because of restrictive policies and limited resources, however, many of the people I spoke to felt they had to do something – other than sitting back and watching those around them die. For many of these people, once AIDS hit home, literally, their desire to participate in moving the AIDS debate forward and feel supported by others who were going through similar experiences came about naturally. Certainly this attitude, which appeared to be fairly widespread, helped the TAC in mobilizing thousands of South Africans in their MTCT campaign as well as other initiatives. Of course, the down side of an observation like this is that it implies that someone must become infected or affected by the disease before they will act. This may be true to some degree, though it is not clear from this research whether this was true.

The second factor that helped TAC mobilize at the grassroots level was the previous experience many TAC representatives had gained during the resistance against Apartheid. TAC appeared to know how to appeal to people – through education, community involvement and the coordination of marches and protests, the TAC
mobilized thousands in their numerous campaigns and events. In this respect, the TAC’s strategies were broad, including the distribution of TAC newsletters and handouts that taught about antiretroviral treatment and politics as well as the fundamentals of AIDS and how to care for someone living with HIV/AIDS. The TAC was also active in schools and had offices located in a number of communities badly hit by AIDS, these were among their strategies to gain widespread appeal. With respect to education, one TAC representative explained the range of issues she learned by becoming involved with the TAC:

When I was involved in TAC, because I got to engage with many people, I became aware of many issues that I didn’t think (about previously). I always thought that our government was perfect, but then they said, OK, TAC is fighting for the right of people living with HIV and those who are not living with HIV because they are making sure that the health care infrastructure of South Africa is beneficial for everyone. They will do the workshops on other medication, actually not related to HIV, such as you have to know which medicine is generic to what...

Another participant, a physician, explained that TAC’s education and mobilization strategies were simple, and thus more effective than other similar initiatives in the country. He explained “what TAC is doing is actions in schools… they go in schools and talk to them (students) about the disease before they’re infected”. This physician emphasized TAC’s ability to convey a simple message that appealed to many South Africans by comparing the TAC’s work to the sometimes convoluted and confusing messages presented by LoveLife, a prevention education group in South Africa, sponsored by the National Government. Furthermore, the court case assisted to this end, as one TAC representative clearly expressed: “the court case was really used as a mobilizing tool and as a public education tool”.
One participant explained that the TAC has been successful because they truly represented the interests of people living with AIDS in South Africa, and that had impact in their campaigns:

They (the TAC) are national, they are living with HIV, (and) they are the first beneficiary… (like) when you have the mother, (a) member of TAC going to parliament saying “my baby has been infected because I could not benefit from MTCT”, I think it makes an enormous impact.

Finally, Pat Sidley explained from her perspective, why TAC had prevailed. She directly made the link between TAC member’s former anti-Apartheid experience and their current ability to mobilize people:

They’re aggressive and they’re bloody effective, and they have their eye on the ball. They’re also quite well clued up on science… A lot of them are political activists of old, like Zackie was (involved) with the ANC, and he did lots of time in jail himself. He knows how to rustle up a good crowd very effectively, and that’s what these guys (the TAC) are, they’re like the old anti-Apartheid activists… (Also,) with what landed up in the newspapers, I mean that was very important, they (the TAC) were well connected with all of us in the press. And it was very easy to talk with them, and they were always accessible and available; by then the government was gone to ground and wasn’t answering phones and people couldn’t get to them quite as easily…. but you could see when they (government) were ducking and diving, the Treatment Action Campaign simply marched the damn thing forward, the MTCT thing (and) all their campaigns. The fact that we will get antiretrovirals in the public sector will again be attributed purely to the Treatment Action Campaign.

This participant had the utmost confidence in the TAC, mentioning that they would be the force behind making long term antiretrovirals publicly available. She also outlines a number of things TAC had done that contributed to their success. She mentions mobilization techniques learned from the Apartheid struggle already discussed above. However, she also brings up the other strand of activism that TAC had been involved with beyond grassroots mobilization – that is, “elite activism”. The activities she mentions that I connect to this elite form of activism include a detailed understanding of
science and technical information, and the ability to liaise effectively with media. These and other aspects of the TAC’s elite activism are discussed next.

**Elite Activism**

As I learned about the TAC’s activities I found there was a disconnect – on one hand, TAC had engaged many poor South Africans with limited education, as described above; on the other hand, TAC liased with academic audiences at international conferences, debated issues related to patents and international trade law, and successfully organized and argued complex legal cases. I was confused by the way that TAC could appeal to groups on different levels, seeming to modify their approach to suit each audience. Perhaps some of TAC’s appeal came via the simple morality of their plea: to get existing AIDS medicines to the people who were most devastated by the disease. However, the more I learned about the TAC and the international AIDS community in which they were situated, the clearer my understanding of the TAC became. In fact, TAC was a model of what many NGO’s should strive for if they hope to help oppressed people in an era of globalization. TAC’s ability to mobilize people on the ground, partly because TAC members were also people on the ground, while also engaging in broader political debates, allowed the TAC to represent and fight for the interests of the people through mechanisms recognized by those less-connected to struggles on the ground. Unlike those in high levels of government, who, as participants have indicated, were not particularly aware of the needs of people living with HIV, TAC understood and knew from personal experience what it meant to be HIV+ and living without the hope treatment offered. What made TAC special is that they were able to
transcend the personal-political divide that is often created by modern day political institutions, by appealing to these bodies on their own terms to represent the interests of people living with HIV/AIDS (PLWHA). For example, if TAC wanted to engage academics they could, through their ability to verbalize well-developed, logical arguments. Similarly, when TAC wanted to engage government, and after they had attempted to do so through traditional civic means (letters, meetings with government, marches, protests, etc.) with limited success, they appealed to government through it’s own formal mechanism: the courts. It should be noted that TAC did not do these things alone, but through alliances with researchers, medical doctors, and many others.

Thus, in addition to the exemplary grassroots mobilization undertaken by TAC, they also participated in elite activism. Elite activism is what I call the type of activism that many thriving NGOs, faced with the pressures of globalization, have learned to engage in. It includes having a good understanding of science and technical details as well as an ability to convey a message to differing audiences, who have the power to effect and enforce change. More and more often, these audiences tend to include high-profile international bodies like the WTO, the PMA and governments representing countries other than one’s own. In some cases there are mechanism to deal with these powerful counterparts, in other cases there are not. Regardless, any engagement with this type of high-powered institution, particularly from the perspective of a grassroots group, requires coherent articulation of an argument that is scientifically grounded. Many NGO and grassroots groups have accomplished this with the assistance of academics and through coalition building with both intra- and extra-national organizations; the TAC exemplifies this strategy well.
In terms of the Nevirapine PMTCT issue, TAC’s use of “elite activism” included engaging the media, as mentioned by Pat Sidley above, but was predominantly represented in the forming of coalitions and alliances with other actors and groups in South Africa in support of their court case against the government. While TAC clearly had extensive liaisons with international groups, supported through meetings at AIDS conferences and the use of the internet and listserv postings (like those on ip-health), these elite activist connections were not as significant in resolving the PMTCT issue. While international groups made clear their support for TAC in its PMTCT case, and as mentioned earlier, investors were hesitant about South Africa because of their worrisome AIDS policies, the PMTCT struggle was mainly waged between and influenced by national actors.

Highlighting the national coalition building that TAC had made use of for their PMTCT court case, one TAC representative described other groups that came on board:

Yes, there are other key role players. Like the labour movements, the faith-based organizations, and the SAMA, the South African Medical Association, they are also playing a leading role, you know in trying to change the policy of the country… It is just that we (TAC) are on the forefront in demanding the HIV treatments and the improvement of the health care system, but there are people that are also supporting us and assisting us.

While many actors and groups supported and contributed significantly to the court battle, it was the TAC’s highly organized, well-coordinated approach that put these efforts together to challenge government and eventually succeed.

While it was a combination of the TAC’s grassroots and elite-level approaches that ultimately contributed to their success in the PMTCT court case, it should be noted that other contextual factors enabled this conclusion. For example, that South Africa has such a liberal constitution was certainly a contributor to this outcome. More broadly, the
protection of South African’s civil and political rights allowed them to publicly challenge the government without fearing for their safety; this is in stark contrast to many lower income countries. Finally, because South Africa is relatively well resourced and well developed compared to some of its African continent counterparts, the courts were able to reach a decision that forced PMTCT rollout; in poorer, less developed countries this outcome would have been unlikely due to greater constraints on resources than experienced in South Africa.

5.2 PHYSICIANS AND RESEARCHERS: COVERTLY BYPASSING POLICY

Physicians and researchers, who made up a good number of the participants interviewed for this study, had a notable role in challenging the government on PMTCT issues. In addition to supporting the TAC through the writing of affidavits for the court case, as well as increasing pressure on government through letter writing and op-ed pieces, physicians and researchers covertly bypassed the government’s limited access Nevirapine policy. The details of this subversion are best demonstrated through participants’ own stories, recounted below. As a preface to these, it should be noted that many of the views expressed here are those of physicians and researchers who had been particularly involved in the PMTCT issue, and are likely not representative of all physicians in South Africa. Furthermore, many of the participants interviewed from these groups were both physicians and researchers, and thus their activities were dually motivated. However, the discussion that follows pertains mainly to the clinical role of
these actors, rather than their research-based functions. Finally, many of these participants had insights into what the role of researchers and the medical community should be, as well as what the appropriate activist role was for a physician, whose primary duty is as a caregiver.

First, many of the physicians interviewed had quite interesting philosophical ideas about AIDS care in South Africa, and these ideas motivated their desire to do more than official policy permitted. One physician explained the questions posed by AIDS, and likened these to those raised during Apartheid:

Well I think that there are very important similarities between this (AIDS) situation and Apartheid situation. Why does someone with chronic liver disease get everything (in terms of needed care and treatment), but someone with chronic immune deficiency disease gets nothing? Unless this person is not quite human, you know, unless this person is somehow devalued in terms of humanity. Is it because the person is a child? Is it because you stick a label of HIV on that patient? Is it because most of them are black? What is it? You know there’s a multi-pronged labeling process around stigmatization that happens within the profession. I mean we profess to let nothing intervene between us and our patient, so how can we treat some patients better than others just because of the disease that happened. Is this patient being given less because there are many others that have the same problem? What is it that makes us regard this patient (differently)?

Now, under Apartheid it was quite clear it was colour. Now I think that it’s maybe more complicated but it’s there, some people are being treated as less than human despite our Constitution’s bill of rights. So I think there are similarities… like who would of thought that a new disease would emerged that’s as stigmatizing and as dehumanizing as Apartheid?

Based on the idea that patients should be treated equally, and out of the helplessness experienced by some clinicians because they weren’t able to offer treatment to patients with AIDS, physicians found ways around policy. For fear of being stopped or reprimanded because of this, many physicians bypassed policy in a covert way. One physician expressed this by bringing up the example of the Medical Superintendent at Rob Ferreira hospital in Mpumalanga province – this example was brought up earlier,
mentioning that labour law was used to fire this Superintendent for insubordination.

Through an NGO group with private funding, the hospital had been providing post-
exposure prophylaxis for rape victims, before this had been adopted as an official policy
by government. The MEC for Health in the province responded by dismissing the
Medical Superintendent at that hospital, citing noncompliance with policy. This situation
caused concern among many physicians, including this particular participant. She
explained that the Western Cape was fortunate in having the leadership to protect
physicians inclined to do more for their patients, but that without political support
physicians were at risk of being “stopped”.

I have to say and I’m very outspoken about this, that Fareed Abdullah is a
blessing in the Western Cape. Someone in his position with his gumption and
courage has made all the difference in the Western Cape. He has actually pushed
the envelope, as it were… So I think we (physicians) need a body like that, either
in the AIDS Directorate or the Health Ministry of the Province, to say “we will do
this (provide increased medical services to PLWHAs)”. I think Mpumalanga
proves that even if the health care providers on the ground have the spirit for it
and want to do it, you know, they can be stopped… If you don’t have the people
in power agreeing or at least being non-obstructive, then you’re stymied. So even
the most talented, the most enthusiastic people on the ground can get nowhere, if
people have been stopped in doing what they need to do.

Another physician agreed with this sentiment, going so far as to say that he felt
physicians were “persecuted” by the government and that they “are really courageous
people because they risk (being) fired for treating people in danger of death with drugs
that exist”.

Following are some examples of this initiative. Many physician participants in
this study had set up or initiated programs that contravened government policy, and did
so because they felt it was their only option.

*I: Tell me how, as a health care provider, you deal with the fact that you have
an ethical responsibility to be able to provide the people that you’re seeing with
the best care you can, but yet you’ve got certain limits on resources and policies that conflict with that.

Well, I think it’s hugely problematic, the way we’ve dealt with it is that we have, in a way, stepped out and said we will go and find the money ourselves. And that was how we (started). Initially, for MTCT, we went to crusade (abroad) and came back with (a few) million Rand. Now that money is not needed for MTCT (because of the court decision) and will go into (long-term) antiretrovirals. But the way we dealt with it was that (we decided), we will just go and do it… The one thing we have realized, beyond a shadow of a doubt is that both MTCT and antiretrovirals are absolutely essential. It has revolutionized our care, before, as I said, it was a demoralizing, totally nihilistic kind of thing. And I’ve seen good health care professionals go down the tubes, because HIV has just worn them out. But, suddenly, (with) treatment and being able to do something positive, it turns that all around and that has strengthened us to say, “well, blow you, if we don’t get support from you, we’ll just finance it ourselves and we’ll keep our heads down, and we’ll go for it”… (but) we’re very careful to not play the party politics game, to not be seen to be manipulating, we inform, we keep it fairly low profile, we don’t make a big rah rah of it and that’s been our strategy, to try and just get it done.

Another physician conveyed a similar story: he had found funding and set up a program that provided antiretrovirals, and even went so far as to include income generation projects within the program. However, because national policies at the time did not permit this physician to provide antiretrovirals, he networked with other physicians to find a way around this.

To give you an idea of how it works, I was up at a meeting with (other physician colleagues)... and we were discussing (this) project (we were involved in) and Sid34 was sitting behind me and I told him… “there’s this (foreign) charity that’s going to give me three quarters of a million Rand a year, and I can buy treatment but I can’t use it in the hospital service (because of national policy), how must I solve the problem?”, and Sid got on his cell phone basically and two minutes later, literally, he said “what you must do, so and so says, write (a) research proposal”.

By claiming his program was for research purposes and collecting data to support this end, this physician was able to bypass government policy. With the program up and

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34 Fictional name used.
running this participant commented “everyone feels good about the project because it’s something positive, it’s a general morale booster”.

A third participant presented a similar story to the first physician. He rationalized that since government wasn’t providing MTCT, “we’ve just found other ways to do it”. Through external funding this physician also set up a PMTCT program. He continued that:

There’s never been a question about whether or not we would do it, we’d had a commitment, we believed that as researchers we had a commitment to make it happen and that’s what we’ve gone out and found ways to do… I think it is very frustrating for clinicians to watch people dying when you know there’s something out there that could help.

Finally, a fourth physician had another approach to expanding PMTCT access in advance of the court decision. Taking advantage of the fact that government did not define “a pilot site” within their 18-site PMTCT program, this participant and colleagues had designated multiple clinics/hospitals as one “pilot site”. “We were being clever to expand as much as we (could)” this participant explained. Apparently there was more than one province that made use of this loophole.

Though these four participants had all acted in ways that were beyond normal expectations, the physicians interviewed had varied ideas about whether they considered themselves activists or subversives. Further, participants had a range of views about the appropriate role of a physician, both in this case and other similar situations. One physician referred to his subversion of government policy, described above:

You can hear I’m not a big policy maker, so you can hear that, but one hopes that (this type of activity – starting programs covertly) might give policy makers an idea. It’s a sort of activism, but it’s not a placard waving, standing on a corner type of activism.
Another physician responded to the idea that she was an activist, after explaining that in her role as a researcher, she had been involved in advocacy work. “So I was an activist perhaps, maybe I should have said that at that point.” Another participant noted that she “had always been involved in, particularly in health politics, since I qualified actually, mostly through the South African Medical Association”.

One physician highlighted that while PMTCT was important, babies who are born HIV+ despite this intervention were also in dire need of antiretrovirals. In bringing up what he saw as a paradox, this participant found good reason for trying to motivate treatment for some of his pediatric patients:

We have a patient who has had a kidney and liver transplant, and in some of the other beds we have children with AIDS. This child (with the transplant) has absolutely no limit to the amount of resources that are being allocated to her, there’s no limit. This child (one with AIDS) will have the PCP pneumonia treated (a common AIDS-related infection), but the cause will not be treated. And that’ll cost somewhere around 500 or 600 Rand a month (about $90-$110 CDN), to treat this child for AIDS… So there’s injustice here, there’s no doubt about that. Major injustice... The whole thing is unacceptable, the whole thing is obviously, clearly unacceptable; but I sort of see it as a wedge, you know, once you’ve got a few persons on treatment you could start saying well why this person and not that one, you know. And hopefully that’ll open up the field. But, of the children with PCP pneumonia (and AIDS) admitted to the Intensive Care Unit, about 70% of them survive the ICU, but we think that most of those are dead within 6 weeks to two months after that (leaving).

Another doctor supported action by the medical community in dealing with AIDS:

There are ways to do it (get around policy). I think physicians in this country, as everywhere in the world, have been, in the majority, much too conservative, not very concerned about the issue – except the few hundreds that have been very actively involved in advocacy.

He added that physician involvement in activism and signing declarations helped legitimate the nation-wide access to PMTCT demand:

It’s very important then to have physician signing at the bottom of the page, (it) makes it more, I would say, respectable for the government officials if you have
Professor X or Professor Y signing there, than if it’s just a bunch of lunatic leftists pushing the thing.

Two participants used Apartheid as a frame of reference for their comments on how physicians should be responding to the AIDS crisis:

On the issue of government making policy that we disagree with, that happened 20 years ago, and the profession failed to address the injustices under Apartheid. Now the profession during the AIDS era is failing again to limit the injustices of the present system, and I see really serious annuities there, on our duty to, I mean we have a duty to critique government policy, at least that’s a very minimal thing, and we’re not doing it. We are beginning to do it a little bit through the medical association (SAMA), but the (University) faculties are really failing… It’s absolutely in their, they (the medical profession) has to do it.

The second physician felt the appropriate role of physicians and scientists should be less critical and activist-oriented, and more that of a neutral technical expert:

\{I: What role do you think that physicians in particular have, if any, in being activists or helping to mobilize the populous against government when these kinds of things are happening, when physicians are in a situation where they’re unable to treat their patients because government isn’t mobilizing those resources.\}

That’s terribly interesting for me to answer. I’ve spent my professional life in the country and have been involved in many initiatives against Apartheid, so I have considerable belief in what activism can achieve. But I think that we physicians and scientists have a very special role that goes beyond activism, I think what we have best to offer is dispassionate and high level analysis – science and scientific argument – and that’s what we can offer especially… That doesn’t discount the importance of activism like that of people like the Treatment Action Campaign and others, they depend on good scientists, otherwise no one knows and everyone’s guessing. And it’s actually extremely difficult to combine those roles, so, what role for activism do (we have)? I think people like ourselves, myself and my colleagues, we all have different functions, but I think we need to get the message across all the time as to what the implications are of decisions. We need to share by analysis how much can be achieved, we need to share by example how much we can do, we need everyone to feel confident that they will get a fair answer from us.

The ideal of different roles, among dispassionate analysis, leading by example, activism and, as previously mentioned, critiquing government, held positive implications for progressive health policy. Another participant, however, took a less adamant view,
asserting that although physicians had different roles, they mainly worked within the status quo, with only some doctors challenging the politics around health and health care:

> There are people who are perfectly content to see patients everyday in the office and they just work within the status quo. And it’s great, you know, when I get sick I want to go to a doctor’s office and find that the person is interested primarily in my health. But there’s also people who are involved in public health who want to try and shift the status quo, that’s where I find myself. It doesn’t make me any better or worse than anybody else, I mean I just think they’re different roles.

Related to the idea of working within the status quo, a few participants expressed less activist-oriented perspectives, while others pointed out the uninspired views of those who sought justification for maintaining the status quo. A TAC representative alluded to the preservation of the status quo in AIDS policy by pointing out that few physicians and health care providers had really been involved in struggles around AIDS:

> But certainly… for many years we haven’t really had doctors and health care workers kind of at the forefront at any of these struggles. (They were) kind of doing the work and being frustrated, or whatever, but not actually coming to the forefront (until TAC mobilized around the court case).

While a few physicians and researchers had been very active in these struggles, this participant correctly points out that many others weren’t involved or at the forefront. A physician-participant suggested possible reasons why many doctors were not inclined to be involved in wider political struggles. In contrast to other participants, she seemed accepting of the fact that interventions had not been available for people living with HIV/AIDS:

> At the end of the day, you do what you can and then most times you just have to say I’m sorry, you know, it’s not available… You actually don’t even, I mean what I find is when you work in the public sector you actually just do the work, you’re so busy, you just go from one patient to the next until your day is done and you don’t think beyond that. You don’t think of the implications of what you’ve just done or you know? You actually don’t think of it at all, and I think that’s how people are coping because they’re just doing the work.
Another participant explained that the previous physician’s views were not unique.

Referring to a presentation he had recently attended, he noted that a number of physicians asked questions in order to justify their non-action on AIDS. He then drew on Apartheid as a potential explanation for apathy towards “the other”:

At the end of the talk, about five or six pediatricians stood up and asked questions. The kind of questions they asked were “Surely the side effects are terrible?”; “Surely resistance is almost immediate?”; “Surely the children vomit out the medicines ‘cause they taste so terrible?”; “Surely adherence is terrible?”; in other words, they were looking for reassurance that not doing anything was okay. So I think there’s huge guilt, it hasn’t quite become anger. And there’s a relative apathy and I’m not sure, I hope it’s not the case, but I’m not sure if apathy doesn’t stem from this kind of mental idea that the people who are sick are “the other”. As Bishop Tutu said, “it’s the new Apartheid” and whether people who’ve got HIV are actually just not some other people. They’re not us and therefore, we don’t have to worry about them as much as we worry about ourselves, because we’re not looking to do for them as we’d like to do for ourselves, ‘cause they aren’t like we are. So, I just wonder if there isn’t that (perception), and it might be from the old Apartheid hangover; not necessarily there along racial lines but just along the habit in South Africa of thinking of certain people differently.

Finally, with respect to what needed to be in the future to bolster the response to AIDS and increase attentiveness to health-related rights, one participant, who considered herself to be politically involved, had very clear ideas about what physicians should be doing:

I think HIV has taught us that there needs to be quite a lot of advocacy and that it is not sufficient to say, “The leaders won’t do it, well, we’ll just sit by”. One of our roles (as physicians is advocacy), and I think that advocacy has to happen in two ways. On the one hand, we have to be out there standing on our soap boxes saying this is the right thing to do, but on the other hand, I think we need to be encouraging our patients, our clients or the people we interact with, to do the same… I think that, other than people who join TAC, there is very little of that happening. So I see part of my role as informing my patients, my clients what their rights are and almost inciting them, to also be demanding their rights, to join TAC, to back up organizations that are pushing for these things. But then I also have a responsibility to write, I mean I write editorials. (And) in any meeting where I have the opportunity, I say the need for MTCT, the benefits that are
I think that the medical profession, particularly because we’re perhaps on the British model, we tend to be conservative, we tend not to rock the boat, but I think in this field, we have no choice. It’s a travesty what is happening and we have to move out and say our piece. So perhaps the third arm is that we have to encourage our peers and you know, colleagues to do the same, because it’s invariably one or two people who are prepared to stand on the soapbox, but we actually need more… So I think that those are our responsibilities as health care providers and I think just sitting back waiting for the government to do something is not acceptable.

5.3 OTHERS

Of course many people beyond the TAC and medical/scientific community were involved in the response to government against their restrictive PMCT policy, however, either by design of the research or because others had a less central role, I collected very little data regarding the perspectives and activities of those groups not already addressed in this chapter.

One of the other groups that I learned had some involvement in the PMTCT policy process were NGOs and civil society organizations other than those previously mentioned (i.e. those closely aligned with TAC or physicians, like NAPWA, the ALP, MSF, SAMA, etc.). For example, the Health Systems Trust was involved in research directly related to PMTCT policy: this NGO monitored and reported back on the status of the government’s 18-pilot sites and continues to research PMTCT implementation. Many of the other AIDS NGOs or civic groups I learned about had a service orientation in their involvement with AIDS, and limited political involvement; these included church
groups and community based organizations that fill gaps in the official AIDS services offered by government.

A second group who is clearly a stakeholder in PMTCT policy is the lay populous, a large number of whom are HIV-infected or affected. It was not clear from this research how the interests of the lay populous were represented outside of the TAC, who as mentioned, mobilized many citizens and had quite wide appeal. To some degree, lay interests were forwarded by those physicians who advocated for their patients and attempted to access medical resources on their behalf. Some of the perspectives of this group are represented below in comments made by peer counselors and some TAC representatives, who until recently, because of these affiliations, were relatively unaware of the politics of accessing AIDS treatment and care in South Africa. It appeared that these lay individuals benefited from the public education and mass mobilization strategies employed by the TAC.

A third group, the international community, had some involvement in the PMTCT debacle, however this appeared to be mainly indirect. For example, many international organizations supported TAC, but it is not clear that they had direct influence on either the South African government or in the court case. Further, many international donors gave funds for the covert physician programs highlighted previously; any resultant influence over policy was again considered to be indirect. Finally, mention has been made previously to the roles of other countries and investors in influencing PMTCT policy, however the data offered no new information, other than that already presented to further these discussions.
Lastly, the pharmaceutical industry, which is both a national and international actor, has influenced PMTCT policy via Boehringer Ingelheim’s offer of 5-years of free Nevirapine. However, no other mechanisms of direct influence on this case have been identified from the data.

There may be other actors or groups who were involved in shaping the Nevirapine PMTCT policy process, like, for example, nurses, pharmacists and other non-physician health care providers, though they were not identified in this study.

5.3.1 Local NGOs: A Special Role?

With respect to NGOs such as the Health Systems Trust and it’s other service oriented counterparts, they seemed to play a supportive role, which was especially important in a country like South Africa. These organizations offered expertise and service, that in more developed countries might come by way of a government agency or body. Because of limited resources and capacity within government, these types of groups seem to evolve naturally to fill gaps in service delivery and health systems monitoring. As noted above, the Health Systems Trust, a NGO which was established to support the transformation of the South Africa’s health system post-Apartheid (Health Systems Trust 2003), continues to lead research monitoring and evaluating PMTCT implementation.

As for the service oriented NGOs, many are involved in the provision of services related to PMTCT. For example, one participant mentioned a NGO working in collaboration with a PMTCT site, that sold nutritional supplements and subsidized milk formula (for after 6 months post-birth when free formula is not longer provided) as well
as running a support group. Another participant described a NGO that operated in communities outside of an urban centre, running support groups and employing lay counselors to work at clinics offering PMTCT.

Based on these observations, other NGOs, besides close affiliates of the TAC and physicians, played an extremely supportive role in PMTCT activities. Without these groups AIDS services in South Africa would be further limited, and the development of the health system less appropriate to suit the need of South Africans.

5.3.2 The Population at Large

The general population in South Africa was represented by the views of peer counselor and some TAC representatives, who prior to these affiliations had not worked in the AIDS field or in areas related to health care or policy. Thus information presented here is based exclusively on the perspectives of a few individuals in this study. There is no way to determine if this is representative of the general perceptions of the entire lay populous in South Africa. Nevertheless, the views presented here represent two changes in the general perceptions of participants since they had become involved in the AIDS world, either as peer counselors or through the TAC. First, either because of the TAC’s mass public education strategy, or through their training and work as peer counselors, these participants appeared to be truly empowered by the new awareness they had gained about AIDS treatments and the politics of access to medicines in South Africa through these endeavors. Second, many of these participants expressed anger towards the government, which was often a result of this new-found knowledge.
Many of the people affected and infected by AIDS in South Africa are disempowered, either because of economics, race, and/or a host of other factors related to these broad issues, not the least of which is their disease-state. One physician participant gave an example of how this disempowerment manifested itself in his pediatric clinic where long-term antiretrovirals had been made available to some patients:

For one of the mothers, the doctor forgot to give her a new diary card when she saw the mother at the clinic. This particular mother took her old diary card and filled it in until it was full and then when it was full, she stopped giving the child medication because there wasn’t any more space on the diary card. Now, my interpretation of that is, here we have a mother who feels completely powerless. Despite everything we’ve told her about the antiretrovirals, despite the consent form that we go through, despite all the information she’s had, that little piece of paper is more powerful than her will to give medication in the absence of such a piece of paper. So, I think that’s a good illustration of just how powerless the population is that we are trying to treat. I mean, they’re powerless for a myriad reasons, I’m sure you know lots of them and that’s what we have to deal with… in fact, when we start treating these children or when we start looking after these people in the clinic, they don’t yet know what it is that they should be asking for, they don’t realize, they don’t yet know what they should be demanding from health services.

Among other things, this physician identifies a lack of education about rights to health and knowing what to ask for in terms of health services, as a concern. This is precisely the kind of knowledge that the TAC’s education strategies aimed to provide. Others got this information from their work as peer counselors. In either case, these affiliations and gains in knowledge contributed to participants’ feelings of empowerment as well as anger directed at the government.

One peer counselor who had been loosely involved with TAC explained that he was now committed to fighting for treatment because he understood the issues and what a united front could achieve: “I should join TAC’s strength, ‘cause I know that the more
voices there are, the easier the fight will be”. Another peer counselor, who had received Nevirapine herself while pregnant, explained the hope it had given her:

Now, I don’t know if the Nevirapine… worked yet because I haven’t checked, I haven’t tested my baby yet (this test requires that the baby is 9 months old)…. But usually we’ve got, we don’t have a baby who is positive in our group. I think we are 20 mothers in our group and 15 of them are already tested and they’re all negative… (Having access to Nevirapine), that was a blessing…. I felt great to know that I can prevent (transmission), I can save (my baby) from the virus. The thing is I don’t want her to get the virus from me. If she wants the virus she’ll go and get the virus. Now, I will be guilty from now on if my baby will get positive because of me.

This mother’s hope, and potential guilt also brought with it anger. This was directed at the government, for what this well-informed peer counselor felt were uncaring, unsympathetic policies:

We didn’t vote for them (government) to leave us, we vote for them to work for us, but now they do what they want to, they don’t care about people… Before (I became HIV+ and then got more involved in the AIDS field), I didn’t know because I had no information, I didn’t know what was the government doing, and what was the people with HIV doing. I didn’t know. I thought maybe the government is doing the right thing. I thought maybe there was not even a drug (to treat AIDS or prevent MTCT)… (Now), I’m feeling, I’m sorry to say this but, I’m angry at our government, especially to the President. I think if our former President (was) still as the President today, different (things) would be happening…. I feel very, very, very mad. And you know, there is this woman called Manto Tshabalala-Msimang, she is one of Health what-what…

{I: The Health Minister?}

Yes. (Now), Mandela is a black person, she is a black person, Thabo Mbeki is a black person, our President, he is our person, and the people who are dying from HIV most is black people. Jacob Zuma, the Deputy President, is our person, he is also a black person. But they don’t feel a thing. I don’t know. You can ask another question (exasperated).

This participant was very angry, so much so that she couldn’t quite finish her last thought and asked me to move onto the next question. She struggled to understand how the government, the ANC, who had represented the interests of blacks during Apartheid,
could now turn their backs on their people. This peer counselor later made reference to the fact that the government had spent a large sum of money recently buying weapons, and viewed this with contempt as well:

I think it was two months ago where they (government) bought army, fighting things… They bought guns. What about the children? Who are they going to protect with their guns if you get die, if you get die with AIDS? Why they don’t first get us cured and then get guns to protect us. If we, ok, let’s say in 2007 it will be war, in 2007 how many people will be died from HIV? Maybe they say all of the people will be died from HIV, who are they going to protect with those guns and things? You get what I mean?

A TAC representative echoed this participant’s comment, expressing what she had learned through the TAC and how her political awareness had increased:

I thought that the government, our government that we voted for, was doing enough for our people because I wasn’t that politically minded. Not that I am even now, but I am health-wise politically-minded through TAC. When I joined TAC, when I read all these treatment issues and … about the Minister of Health, toxicity and all that, but (also that) there has been professors that have proved that Nevirapine is working, then I said to myself, if this government cares for us why can’t they be able to do this, as in providing Nevirapine to pregnant women so that we can give babies a chance? And then by knowing that the government was reluctant to provide proper health care for people, then I became more involved in political issues and health care, as again… our government is still buying weapons each and every year, upgrading his (Mbeki’s) pilot, or his jet, but he is unable to provide Nevirapine because sometime(s) the argument (is) that they’re saying toxicity and all that. They are sometimes mentioning that if a women undergoes MTCT program, she isn’t supposed to breastfeed so they will have to provide formula feeding, so they’re saying that if they do afford Nevirapine, they won’t be able to afford formula feeding and over and on. But after the calculation that has been done by the UCT Actuarial Department it has been found that it’s more affordable than taking the patient to hospital, than hospitalizing someone. Giving Nevirapine is much better than taking care of each other living with HIV. So then I’ve become more involved in different issues more than health care, on a political side. So I still believe that our government is not doing enough.

This TAC representative continued that others did not understand what the government was doing, and had blind faith in the ANC because of their leadership against Apartheid.

That’s one of the problems, people thinking that that government is doing what they (the people) want… (But) the one other thing that TAC has done, TAC
empowers people. One of the problems is people, they think the government is doing enough because they don’t know enough… if they had enough knowledge they would know that the government is not doing what its supposed to do. So politically, on that side they are not empowered enough to stand up against their government. And the one other thing, this political thing in South Africa who’s who, who is this party and that party, is also playing a very important role, because most of the people in South Africa, they believe in ANC. So if it’s ANC, if ANC says this, they sort of believe it, (and) our government is being ruled by the ANC, so if the government says this then the government is right because it’s the ANC, it’s the people’s party. But it’s no longer the people’s party now… instead its Thabo Mbeki’s party. He’s no longer leading the people now, he’s forcing the people, because if he was the leader that he is supposed to be, if he was saying Nevirapine is effective and there are people who have submitted their affidavits, there are people who have said, it’s working, “I have been on the MTCT program” and, there are people saying that, and if it was, if Thabo Mbeki was the leader enough, he would have sat down with those people and seen what are the barriers, how can we function from these people who are saying it’s effective. But still, even then, if there are people submitting their affidavits, he’s still standing on the other way saying, no, it’s toxic, I cannot kill my people and all that.

The high level of political knowledge these participants had, given that they noted a prior lack of awareness about these issues, is quite significant. It shows that education is very important for empowerment, and it has helped these participants to use their anger to critique government and articulate such analysis to members of their family and community.
CHAPTER 6: DISCUSSION

The previous two chapters (4 and 5) have addressed a number of themes pertaining primarily to the activities of three groups: government, the TAC and physicians/researchers. The themes discussed help explain who was involved in the Nevirapine PMTCT policy process, their perspectives and motivations (or in the case of high level government officials, study participants’ perceptions and interpretations of these), and the historical and structural factors that shaped their activities.

A brief summary of the findings is a useful prelude to this discussion. Section 4.1 introduces the results. To begin with, the model shown as Figure F introduces these three aforementioned groups of actors. It also highlights some of the relationships that exist between certain actors or institutions, relevant to the PMTCT policy issue. In Section 4.1 the significance of socio-political relationships in policy-making is also elaborated.

Section 4.2 introduces the two main lines along which government officials were distinguished in this study: political versus bureaucratic, and national versus provincial. This section also highlights the role of President Mbeki and Health Minister Tshabalala-Msimang as the main architects of South Africa’s highly criticized and unconventional AIDS and PMTCT policies. Moreover, certain provincial government actors (i.e. Fareed Abdullah from the Western Cape) and bureaucratic actors (such as those within the National Department of Health) are presented as working with the TAC and others to oppose official government policy (or at least to oppose the President and Health Minister) by way of supporting a more conventional approach to AIDS treatment.
Section 4.3 situates the Nevirapine policy process within the government’s response to AIDS as a whole. It identifies historical factors, like Mandela’s inadequate attention to AIDS, and the relationship of this inattention to grand-scale, post-Apartheid reorganization and restructuring. This section also highlights specific policy events, such as Virodene, Sarafina II and AIDS dissidence, that were seen as underpinning the government’s later Nevirapine PMTCT response.

Section 4.4 highlights some observations and theories that supported and help to explain the government’s PMTCT-related actions. Noting the changing relationship between the government and post-Apartheid civil society, the ANC (and current national government) is identified as subscribing to a loyalty-based approach for political advancement. This approach is further characterized as closed, or non-participatory. Study participants account for this by noting the predominance of authoritarian styles of leadership among exiled ANC members during Apartheid. They further speculate that this approach was linked to ANC members’ beliefs that the ANC represents the people, rather than the civil society groups that claim to represent citizens’ interests; an idea likely fostered through the ANC’s leading role in overcoming Apartheid. Section 4.4 closes by considering the idea that despite these potential flaws in the ANC’s approach to governance, a pilot approach to Nevirapine was in fact a rational response, given the significant barriers within the health system in South Africa.

Section 4.5 expands on the issue of barriers to PMTCT implementation – it addresses those perceived by government (and made known via public discourse and media portrayals) and those understood by policy stakeholders who participated in interviews for this study. Interview participants identified a number of barriers to policy
implementation, while rejecting the government’s two primary “excuses” of drug cost or drug safety as barriers. Furthermore, participants were optimistic that barriers could be overcome with creative and appropriate leadership.

Chapter 5 summarizes the response to government, addressing primarily the roles of the TAC and physicians/researchers. The perspectives and roles of the lay populous, the international community, and the pharmaceutical industry are also noted, although they are insufficiently developed in this research. On the basis of the current study, the TAC was accepted as leading the opposition against the government’s inaction around a comprehensive Nevirapine policy for PMTCT. However, both the TAC and physician-activists have roots in the anti-Apartheid struggle that underscored their PMTCT involvement and had implications for their relatively strong inter-relationships in pushing for wider access to Nevirapine. It is noted that physicians who agreed to be interviewed for this study are unlikely to hold views that are representative of all South African practitioners.

Section 5.1 identifies the TAC’s opposition strategies against the government; these are classified as either grassroots mobilization or elite forms of activism. Also, this section addresses how the TAC’s court case against government arose, and discusses participants’ thoughts on court-ordered policy. A range of reactions to the TAC’s court case are presented, including everything from “the court case as a victory for truth” to the case as a potential promoter of inequity, since the victory forces government to divert resources to PMTCT programs at the expense of other governmental programs.

Section 5.2 addresses the role of physicians and researchers, who were often one and the same. The unique context in which some physicians operated amounted to the
subversion of the government’s limited-access approach to Nevirapine. This subversion was characterized by physicians seeking out money to fund their own initiatives as an “in-the-field” strategy for overcoming their impotence in not being able to provide lifesaving drugs to patients with HIV/AIDS.

With the above key findings in mind, this chapter continues by drawing on these as they relate to each of the four in-study objectives. Each objective is addressed in turn. For each objective, the relevant findings are first related and then discussed in reference to the literature, such that some overarching, general conclusions can be made.

Next, the findings are related to the Advocacy Coalition Framework (introduced in Chapter 3). Three components of the Framework are applicable to the research findings at this stage: the concept of policy-oriented beliefs as integral in policy-making; the idea that in response to a policy problem, coalitions are formed based on these beliefs; and the notion that policy-oriented learning can occur given the technical information brought to bare during policy contestation.

Finally, a few lessons are extracted from this case study that may have applicability elsewhere, and one physician-participant’s thoughts for the future of AIDS policies within South Africa are included. This participant’s commentary highlights the reality that Nevirapine policy is merely a stepping-stone for activists and physicians alike. The next battle, already ongoing, for access to long-term antiretroviral treatment begins the cycle of policy contestation once again.
6.1 UNDERSTANDING THE NEVIRAPINE PMTCT POLICY PROCESS: CONCLUSIONS AND INSIGHTS RELATED TO THE RESEARCH OBJECTIVES

This section summarizes conclusions based on each of the four in-study objectives (as opposed to the fifth, ongoing objective). Recall that the primary objectives of this study were 1) to describe the Nevirapine PMTCT policy process, and more specifically to deconstruct and understand the rationale for the government’s initial limited-access policy (as per Objective A), and 2) to explore the factors influencing the continued pressure being put on government to adopt a nation-wide PMTCT program (as per Objective B). The secondary objectives were to understand the ideologies and strategies of the TAC (as per Objective C), as well as the perspectives of health care providers (as per Objective D; though based on the data collected in this study this could only be addressed with respect to physicians/researchers). All four objectives are addressed here by summarizing the relevant results and relating these results to germane theories or ideas from the literature. While all the data presented in the previous two chapters are important in contributing to an understanding of the PMTCT policy process, this section extracts a few overarching conclusions from these more extensive findings.

6.1.1 The Rationale for Limiting Nevirapine Access and Insights Based on the Imperialism of Western Biomedicine

With respect to Objective A, which aims to understand the government’s decision to limit Nevirapine access to 18 pilot sites, participants pointed out several differing
reasons for this. First, in light of the deficiencies within the health care system in South Africa, which require capacity and infrastructure limitations to be overcome, a cautious pilot approach, centered on learning, can be seen as prudent. A second explanation used by participants pointed out that the government may have instituted the pilot project with the hopes that it would quell the TAC and others, who were pushing for wider access to drug interventions for AIDS, and in particular for PMTCT. A third, less explicit explanation relies on the subtleties of participants’ comments as well as insights from the fields of political anthropology and political economy. While the first two simpler explanations for the government’s initial limited-access decision may provide sufficient justification, the third explanation, which will be developed here, includes reference to a few key comments which were emphasized repeatedly by a number of participants. Thus, this third explanation relies on data that were more pervasive among participant responses, and therefore is suggests a more complex conclusion to this objective. Participants’ reliance on the AIDS dissidence argument to explain the PMTCT policy process, as well as their comments about President Mbeki’s belief in an African Renaissance provide clues that there may have been more to the government’s decision to reject a comprehensive Nevirapine program than a desire to address health system deficiencies or silence activists.

In accounting for a limited access approach to PMTCT, the actions of both President Mbeki and Health Minister Tshabalala-Msimang were identified by participants as significant. Both these actors had contributed to confusion surrounding AIDS policy by taking contradictory or unconventional stances: Tshabalala-Msimang expressed optimism about the potential use of Nevirapine in South Africa after visiting a research
site in Uganda, and then later claimed that Nevirapine was toxic; Mbeki engaged with AIDS dissidents and questioned the causal link between HIV/AIDS. Moreover, the government implicated pharmaceutical companies in conspiring against AIDS patients, and Mbeki wrote about the need to address a uniquely African problem with uniquely African solutions rather than imposed Western solutions.

What had motivated this response, in the face of solid (Western) scientific evidence that AIDS drugs were both safe and effective? A recent paper by Helen Schneider and Didier Fassin helps to get at what may have been the underlying impetus for Mbeki’s and Tshabalala-Msimang’s positions. Schneider and Fassin use a political anthropology approach to “make some sense of what is often presented as merely irrational”, namely Mbeki’s flirtation with AIDS dissidence and questioning of established understandings of the etiology of AIDS (Fassin and Schneider 2003:486). Schneider and Fassin reiterate that the government suggested that AIDS was part of a “conspiracy against Africans, either from the country’s white conservatives or from the pharmaceutical industry” (Fassin and Schneider 2003). Schneider and Fassin explain that these concerns, related to a distrust of Western biomedicine, are not unjustified when viewed in light of historical experiences. For example, they note that even before Apartheid, “epidemics had often been used to enforce racial segregation”, citing the bubonic plague of 1900 which was used “to justify the removal of African’s from their homes to the first ‘native locations (homelands)’” (Fassin and Schneider 2003). Further, Schneider and Fassin explain:

When AIDS appeared in South Africa it was immediately interpreted in racist terms: some leaders evoked a supposed African “promiscuity”; they denounced the danger that infected black people posed to the nation; and they even publicly
rejoiced over the possible elimination of black people by the disease, as one member of parliament did in 1992\textsuperscript{35}. (Fassin and Schneider 2003:496)

Moreover, Schneider and Fassin note that as recently as the last years of Apartheid, government laboratories were developing biological and chemical weapons to eliminate black leaders (i.e. with anthrax), and “researching contraceptive methods to induce sterility in the African population” (Fassin and Schneider 2003:496).

In addition to these historical events that supported a cautious and critical approach to the imposition of Western biomedical solutions in an African context, Debabar Banerji’s political economy approach also provides some foundation for these concerns. A political economy approach seeks to understand “how power is realized through our economic, political and social institutions” (Navarro 2002:2). Banerji’s analysis describes the colonial origins of health services in developing countries, and the detrimental consequences this imposition has had (Banerji 1984). The imperialism of Western biomedicine has undermined the progress of locally developed health services that are in line with local cultural values and beliefs. By inhibiting the growth of health services as “organic components of their respective social structures” the negative impact of colonial influence on contemporary developing world health services is highlighted by Banerji, and further supports a justified distrust of Western imposed solutions (Banerji 1984:257).

Thus a distrust of Western biomedicine is a possible and reasonable explanation for both Mbeki’s questioning of the causal link between HIV and AIDS, and his preference for African solutions to an African problem, rather than the “Western imposed” solutions of pharmaceutical companies.

\textsuperscript{35} This is referred to in the review of the literature in Chapter 2 (see page 45).
While Mbeki’s perspectives and his hypothesized motivation for these views do not represent the views of all government officials, participants identified loyalty as fundamentally important within the ANC. Thus, it was suggested that although some members of Cabinet may have disagreed with Mbeki’s approach, their concerns for personal political advancement may have prevented them from speaking up.

Thus, the beliefs and views of the President were identified as highly influential in the development of a limited-access PMTCT policy, and these views are more easily understood in light of political anthropology and political economy.

6.1.2 Beliefs, Relationships, and Continued Pressure on Government

Objective B, which sought to explore the continued pressure on government to implement a more comprehensive approach to PMTCT, can also be related to beliefs. In this case, these are the differing beliefs of ANC government actors relative to certain members of civil society. Contrasting beliefs led to distrust in the relations between government and civil society post-Apartheid. I argue here that this relationship was central to the continued pressure on government, primarily applied by the TAC, to push for wider access to Nevirapine. While other factors set the stage for this ongoing pressure, such as the government’s limited access policy (discussed above) and the TAC’s mandate (addressed next), I contend that the adversarial character of the relationship between these two groups was a key contributor to the ongoing and persistent nature of this pressure. Furthermore, I argue that the PMTCT controversy represented more than just a fight for wider access to PMTCT interventions, it also represented a battle between differing ideologies related to the handling of AIDS (a
conventional approach advocated by the TAC vs. Mbeki’s approach, clouded by AIDS dissidence) and related to the appropriate style of leadership in handling the AIDS crisis (an open and democratic style exemplified by the TAC vs. an authoritarian approach ascribed to Mbeki and the ruling ANC government).

During Apartheid, the ANC and civil society actors were united in a common struggle against white minority rule. After Apartheid was defeated and exiled ANC members returned to South Africa, study participants made mention of a power struggle for leadership within the ANC – between those who had been in exile and those who had been involved in the ANC’s internal movement. The result of this power struggle was that formerly exiled members of the ANC gained a significant amount of control within government. Because of circumstances in exile, these ANC members, (including the current President and Health Minister), were thought to have adopted an authoritarian approach to leadership. Furthermore, perhaps because of their representation and leadership of “the people” in overcoming Apartheid, participants claimed that the ANC believed that it continued to represent the interests of the people. To this end, participants noted the ANC’s distrust for civil society actors, such as TAC activists, who also claimed to represent the people.

With respect to the perspective of TAC representatives, and other civil society actors who were previously involved in the internal anti-Apartheid movement, these actors perceived their victory over Apartheid as founded on participatory, and open-democratic processes. During Apartheid, this inclusive activism was led by the now defunct United Democratic Front (UDF), a group to which TAC has been compared. The conflicting ideals and practices, promulgated by the formerly exiled ANC activists versus
former UDF-associated and internal activists, set the stage for a breakdown of trust between civil society and government.

With respect to the current case study, participants identified the conflicts over PMTCT policy as being waged mainly between the TAC (and its collaborators), and President Mbeki and Health Minister Tshabalala-Msimang. The adversarial relationship between high-level government actors and the TAC helps to address the objective of exploring the sources and effects of the continued pressure on government to expand PMTCT programs. Based on the above description of the exiled ANC members’ beliefs and approach to governance, it is not unreasonable to connect the government’s commitment to their limited-access PMTCT pilot program with a desire for self-legitimacy and a desire to oppose the TAC, a group that could be viewed as competing to be the voice of the people. Beyond this potential threat to the government, the TAC also promulgated a conventional approach to AIDS and demonstrated an open and inclusive style of leadership; thus the success of the TAC represented increased danger to the legitimacy of the government’s approach. This logic might explain why the government resisted TAC’s attempts for a negotiated policy conclusion prior to the court case, and further, why the events subsequent to the government’s pilot site announcement played out as they did – in an ongoing, adversarial way.

6.1.3 Ideologies, Activities and Outcomes: The Role of the Treatment Action Campaign and Insights from US-Based AIDS Activists

Objective C aimed to evaluate the ideologies, agendas and activities of health activist groups, including the TAC. Based on this research, there did not appear to be any
other organized groups who were as vocal as the TAC, or as involved in PMTCT policy. Thus, the discussion of this objective is limited to an evaluation of the TAC and its activities. Objective C is addressed here by providing a brief summary of some major insights gleaned about the TAC, and then by comparing the agenda and activities of the TAC to other similar AIDS-related social movements in the US.

In line with the breakdown of trust between the TAC and government, some participants noted that although the government may have had good intentions in initiating an 18-site PMTCT pilot program, this did not necessarily imply that government would build on this base and eventually expand access. With a recognition that each day lives were being lost to due a limited access Nevirapine program, the TAC took matters into its own hands. Based on the premise that access to essential, life-saving medicines is a human right, the TAC employed both grassroots mobilization strategies and elite forms of activism to bring about wider access to such medicines.

This two-stranded, grassroots and elite approach by TAC has been used by activists previously. Robert Wachter, a physician and former organizer of an International AIDS Conference, notes that US based activists used a similar approach. Wachter argues that “activists’ unprecedented modus operandi is a study in contrasts: street theatre and intimidation on one hand, detailed position papers and painstaking negotiation on the other” (Wachter 1992:128). That the South African AIDS activist movement followed the AIDS movement in the US means that TAC may have consciously or unconsciously benefited from lessons learned and approaches used in the US struggle.
Other insights into US-based AIDS activism proved distinct from the experiences of the TAC. Wachter noted in 1992 that AIDS activist groups in the US were becoming increasingly diverse. While this had the potential to be beneficial, it divided activists based on their agendas (Wachter 1992:130).

Attracted by the success and high visibility of the activists, recent entrants into the AIDS movement, some of them sero-negative, have more complex motivations. The primary goal of these people is often to eradicate the social ills of homophobia, racism and sexism. The conflict between “treatment” activists and the “social agenda” activists has led to infighting within the movement and even to the breakup of ACT UP into two distinct chapters in San Francisco. (Wachter 1992:131)

Brett Stockdill brings up the same issue in his book “Activism Against AIDS”, where he builds on the social movement scholarship on AIDS by highlighting insights based on the fact that a number of oppressed groups are combined in AIDS activism (Stockdill 2003). Stockdill concludes that the mixing of “LGBTs (lesbian, gay, bisexual and transgendered persons), injection drug users, people of colour, poor people (and) prisoners” in AIDS movements in the US have resulted in internal movement conflict due to “conflicting ideological frames” or interests (Stockdill 2003:148). The conflict within the movement served to stratify the movement and promote an unequal distribution of resources within the movement; it also undermined the potential for a united front against AIDS (Stockdill 2003:153-55).

In contrast to these observations, TAC has been a model of an inclusive civil society approach, highlighted by one participant’s comparison between the TAC and the United Democratic Front. Mark Heywood, the ALP Head and the Secretary for TAC gave a presentation at the International AIDS Conference in Barcelona, highlighting the TAC’s now successful strategies in the PMTCT court case. First, Heywood points out
that litigation should be a last resort and should be viewed not as oppositional but as inspiring of public debate (Heywood 2002). To this end, the TAC utilized widespread advocacy and mobilization, current scientific evidence, and supplemented legal argument with real life stories (Heywood 2002). This would not have been possible without certain fundamental partnerships made by the TAC: the TAC relied on experts and further built alliances with activists, scientists and health professionals. Based on the TAC’s inclusive strategies and their deep rooting in the anti-Apartheid struggle (with more shallow roots in the gay-rights movement), the TAC successfully avoided the type of conflict that Wachter and Stockdill describe. Thus, both widespread appeal and the ability to focus on a concern common to all those living with HIV/AIDS, regardless of “ideological frames” associated with groups affected by differing forms of oppression (i.e. being black versus being gay) helped to determine TAC’s success.

It is possible that the TAC and its supporters had too much at stake for people to become involved in infighting. While the pressure on the government to provide long-term treatment to PLWHAs has never been stronger, a united front is needed to continue to challenge inequitable government policies effectively. Once the struggle to reduce HIV infection rates and implement treatment access is overcome, TAC may be subject to the same kinds of conflict that plagued ACT UP and others in the US. For now, all interests seem unified towards treatment access, such that competing interests have been held at bay.
6.1.4 The Perspectives of Physicians: A Call for Activism?

In reference to the final objective to be addressed, Objective D, the perspectives of physicians have been varied. Some physicians maintained the status quo when it came to AIDS – that is, they performed their duties with respect to patient care, but went no further when it came to ensuring access to medicines for their patients. Others provided dispassionate technical expertise (i.e. by writing scientific affidavits for the court case), and third group was more aggressive in their response to the epidemic. This final group either publicly critiqued government policy, or covertly bypassed it, raising funds independently to provide antiretrovirals to their patients. While approaches varied, physicians’ views of their role also varied. Some felt they were activists, while others avoided the term. Some saw their more outgoing approaches as an expected professional response to a moral problem, and rejected the idea that they could simply standby and watch their patients die, particularly when drug interventions existed. This summary of responses and associated perspectives is based on interviews with physicians who, by and large, were politically oriented, refusing to take the status quo approach; thus, this summary may not be representative of all the varied approaches physicians in South Africa have undertaken in response to AIDS.

Two physician-scientists address the issue of what an expected response to AIDS might be. In his book “A Fragile Coalition”, Robert Wachter explains how his experiences in International AIDS Conference planning exemplify “the political evolution of the physician-scientist in the AIDS era” (Wachter 1991:xiii). Wachter refers to this evolution as a normal process experienced by physicians who happen to become involved in the care of PLWHAs, implying that it is difficult to avoid becoming
politically involved in the field of HIV/AIDS. A call for physicians to be more political with respect to AIDS is also offered by Benatar, who uses a bioethics approach. In his estimation, physicians dealing with AIDS need to address ethical concerns not just on a micro-level at the bedside but also at a meso-level, by addressing considerations for order and justice:

The responsibility of physicians here is viewed more broadly and includes concern for equitable access to health care, public health, and the common good. Considerations of justice, the “social contract” and utilitarian considerations necessarily impact on the physician/patient relationship. Morality here requires an institutional component embracing attention to public health and the management of resources. Interpersonal relationships are broadened to encompass the concept of civil citizenship with primary responsibilities complementing the primary rights of individuals and the correlative duties of others in order to achieve rights in practice. (Benatar 2002:171)

Thus Benatar recommends an expanded role for physicians, one that institutionalizes attention directed to public health care resource allocation (Benatar 2002). By classifying this expanded role for physicians in a bioethical context, Benatar implies that such a response is a professional expectation.

Physicians in this study were generally more than bedside actors, they had experienced the political evolution, described by Wachter, and were active in one way or another in advocacy, rights education, the preparation of technical information, and monitoring of government. Although not all physicians have become involved in AIDS activism, per se, in South Africa, a good number of well-respected scientists and physicians have made public their outrage at the government’s heel-dragging response to AIDS (Abdool Karim, Abdool Karim, Adhikari, Cassol, Chersich, Cooper, Coovadia, Coovadia, Cotton, Coutoudis, Hide, Hussey, Maartens, Madhi, Martin, Pettifor, Rollins, Sherman, Thula, Urban, Velaphi, and Williamson 2002; Cohen 2000).
6.2 UNDERSTANDING POLICY CHANGE: INSIGHTS FROM THE ADVOCACY COALITION FRAMEWORK

As mentioned in Chapter 3, the Advocacy Coalition Framework (ACF) theorizes about long-term policy change (with a focus on change that takes place over a decade or more). It deals specifically with the phenomenon of coalition building, based on shared beliefs and in this way suggests that policy actors are affiliated by their policy related beliefs and not by primarily bureaucratic divisions. Thus actors within the state and those in civil society could fall within the same coalition, so long as their policy related beliefs are shared. It is suggested that because actors negotiating within a “policy sub-system” (a functional unit of analysis used in this approach) are policy elites and not members of the general public, then “most actors will have relatively complex and internally consistent belief systems in the policy area(s) of interest to them” (Jenkins-Smith and Sabatier 1993:30). Furthermore, the ACF suggests that policy issues should be seen as including actors at all levels of government, “to examine policy change only at a national level will, in most case be seriously misleading” (Jenkins-Smith and Sabatier 1993:17).

With respect to the Nevirapine PMTCT policy process, it is much too early to tell if the assumptions of the ACF will be supported as this case (PMTCT) continues to develop. However, some ideas forwarded by the ACF have at least preliminary applicability and will be addressed here in turn. These areas include 1) the relevance of policy-oriented beliefs in policy-making, 2) the premise that coalitions are formed based on these beliefs, and 3) the concept of policy-oriented learning in the post-policy contestation period.
6.2.1 Policy-Oriented Belief Systems

The notion of beliefs as central to policy-making, forwarded by the ACF, is confirmed by the data uncovered in this research. Beliefs have been identified as critical in explaining Nevirapine policy, including in the discussion above, regarding the rationale of government in initially limiting access to Nevirapine to pilot sites, and the ongoing nature of policy contestation. Moreover, participants alluded to the importance of beliefs in their attempts to better understand policy by examining the personal characteristics of political actors like Mbeki and others. Within belief systems, as described by the ACF, there are three levels within which beliefs can be categorized relative to their susceptibility to change (Jenkins-Smith and Sabatier 1993:30). Deep core beliefs are the least susceptible to change, followed by near core (policy-focused) beliefs, and lastly, secondary beliefs. The belief of the ANC in loyalty for advancement would be considered a near core or policy-related belief, while Mbeki’s (hypothesized) distrust of Western biomedicine would be a deep core belief as it relates to knowledge production and the values associated with this. The equity- and human rights-related beliefs of the TAC would also be considered core beliefs. Deep core beliefs are related to values and their application in policy-making. For example, whether “freedom” is more, less or equally as important as “health” requires a value judgment, and by applying values to these concepts (freedom and health), decisions regarding policy can be made. Deep core beliefs are very difficult to change: they are “akin to religious conversion” (Jenkins-Smith and Sabatier 1993:31). The focus on beliefs in the ACF stems from the concept that policy decisions are not always rational but nevertheless are attributable to some interest of decision-makers, for example their policy-focused beliefs and the shared
beliefs of their coalition members. This appears to be upheld in the case of PMTCT policy. In the ACF, belief systems are an organizing concept, and form the basis for coalition formation, discussed next.

6.2.2 Coalitions

In the PMTCT case, actors could be roughly divided into two coalitions. Those who believed access to AIDS treatment and health care were fundamental rights and who gave relatively high priority to individual rights and freedoms (in line with Western thought) could be classified as one coalition. This coalition would include the TAC, government official’s like the Western Cape’s Fareed Abdullah, doctors who supported the TAC, and others involved in the PMTCT policy process who supported these beliefs. Other beliefs held by this initial coalition might include an open and democratic approach to leadership, and the use of scientific evidence in policy-making. This coalition is representative of the idea, promulgated by the ACF, that coalitions are restricted by beliefs and not political affiliations or bureaucratic divisions. The opposing coalition, in this analysis, included Mbeki and those who supported him (it is unclear whether all those who supported him actually shared his beliefs, or if they were rather ascribing to party loyalty). It is difficult to describe exactly what the beliefs of Mbeki’s coalition were as no member of this coalition was interviewed, and the true beliefs of government actors were often not made clear publicly. Nevertheless, a distrust of Western medical practices was hypothesized to be part of this coalition’s beliefs, as supported by the analyses of Schneider and Banerji. Other beliefs persistent in this coalition might be that an authoritarian, centralized style of leadership is best suited to post-Apartheid South
Africa, making loyalty to the ruling party an important factor in policy decision-making. Further, the belief that the ANC represents the people legitimized this authoritarian approach to leadership deleting the need for open, participatory styles of leadership and policy-making. It should be noted here that the beliefs associated with Mbeki’s coalition were not substantiated by those who may have held these beliefs, but are based rather on the study participants’ perspectives. Thus, the tenet of the ACF that coalitions are formed based on shared beliefs appears to be upheld by the data from this research.

6.2.3 Policy-Oriented Learning

It is pertinent to note here that the ACF conceptualizes policy contestation between two competing coalitions, mediated by sovereigns—usually a government (Jenkins-Smith and Sabatier 1993). For example, in considering a policy problem regarding air pollution, there might be a coalition of car manufacturers competing against a coalition of environmental activists. During the policy struggle, both parties could bring technical information to the table, and often do; this information is typically interpreted by government, who uses their values, beliefs and other criteria, to evaluate the worth of the technical knowledge presented and to determine how to respond with policy. The application of this new knowledge in future policy decisions is called policy-oriented learning (Jenkins-Smith and Sabatier 1993). However, because permitting Nevirapine rollout was not a policy choice, but rather a court decision forced on government, the impact of technical information is not clear. As noted earlier, the relationship between government and civil society was characterized by a breakdown of trust, and animosity. In light of the negative public attention surrounding the government
due to the PMTCT court case, it is unclear whether the ANC Government, likely to be
defensive of their position, will gain as much from the technical knowledge used in
support of the court’s decision about Nevirapine policy, as government actors would
when mediating between two outside groups.

Early estimates suggest more delay and a lack of frankness and openness about
AIDS policy-making. In April 2003, after continued pressure on government to agree to
a national AIDS treatment plan, the TAC followed through on their civil disobedience
campaign, which they had threatened to begin by February 2003 had the government not
instituted a plan\textsuperscript{36} (kaisernetwork.org 2002o). This campaign intended to show the
TAC’s frustration with the government’s delays. Just before this report was completed
there were still significant tensions between government and the TAC with respect to
access to long-term treatment, with no sign of immediate resolution. As recently as July
2003, TAC leaked a government document about its treatment plan – still not in place –
indicating, "Our actions only publicly express the frustration and pain of people who die
quietly at home and in our hospitals, in the face of a torrent of excuses and delays." In
response, Government spokesperson, Joel Netshitenzhe, said that the treatment plan
report is only a "very first draft," adding, "There is no need for theatrics in dealing with
the matter of HIV and AIDS," referring to TAC's release of the document
(kaisernetwork.org 2003b). The full effects of a court-ordered policy decision in a tense
and antagonist government-civil society environment remain to be seen.

\textsuperscript{36} This campaign is referred to in Chapter 4 (see page 123).
6.3 CLOSING REMARKS

This final section addresses some of the lessons that can be taken from this policy case study in South Africa and applied to other contexts. A thought on the future of AIDS policies in South Africa, and perhaps continued contestation, is included from a physician-participant.

6.3.1 Lessons Learned

There are a number of lessons that can be drawn from this case study, which may have applicability in other settings. However, before launching into this discussion it is important to recognize that South Africa is unique. Much of what explains and/or underlies the Nevirapine policy process, as presented here, are South Africa’s historical experiences under Apartheid. In one way or another, the legacy of Apartheid influences social relations, politics, and virtually every aspect of life in South Africa today. For this reason, many of the findings from this research will not be directly applicable to policy problems in other settings. With this broad caveat in mind, there are some similarities among South Africa, and its other African, as well as developing world counterparts. Namely, these countries are by in large new or “newer” democracies (relative to Western world), and thus issues related to governance are commonly of concern. Three lessons that have relevance to the concept of good governance are presented here.

First, the Nevirapine case highlights the need for civil society to be involved in policy-making. By involving relevant civil society actors in policy development from the outset, tension between government and civil society, as well as costly drawn out
processes (like court battles) may be avoided. Observe that in the South African context civil society had been involved in policy-making, for example, through the NACOSA process. However, civil society involvement must be accompanied by the government’s good intentions with respect to this involvement, and with a commitment by government to sincerely address the concerns/suggestions/technical expertise brought to bare by civil society actors. The involvement of civil society is in vain if its input ends up shelved in a report, or cast aside by politicians. Therefore, it is not enough to have the token involvement of civil society; rather their engagement in the policy process must be seen through and accounted for by government.

This leads to a second lesson, pertaining to the responsibility of citizens in a democracy. It is up to citizens to challenge what the government does, to be active and participatory in ensuring that the voices of “the people” are heard. The TAC is an exemplary model for citizen involvement in governance and policy-making. Other organized civil society groups could learn from the TAC’s approach, which combines mass mobilization strategies as well as savvy technical and scientific arguments. It should be noted that TAC has already partnered with other groups in Africa in order to promote both their plea for wider access to HIV treatment, and to help them learn from their successes as activists. Other similar groups in Africa that share some of the TAC’s objectives include the Kenya Coalition on Access to Essential Medicines and Nigeria’s Treatment Action Movements. Moreover, Zackie Acmat, the TAC head, recently helped initiate the Pan-African HIV/AIDS Treatment Access Movement, which, in seeing health as an integral part of development, aims to lobby for wider access to HIV/AIDS
treatments across Africa (kaisernetwork.org 2002a). These encouraging developments imply that lessons are already being learned from the TAC’s experience.

The third and final lesson pertains to physicians, and namely the education of physicians. As has been demonstrated in this research, many physicians involved in AIDS care become activists, or at the very least politically minded. Because of the power accorded physicians in most societies, they are ideally positioned to act not only as advocates, but also as activists for access to health care. However, as some participants noted in this study, medical school does not adequately train students to become activists, or even actors involved in non-medical social development work (for example, one physician interview had set up income-generating bead work projects that patients could take part in while they waited to see their doctor). This is a serious omission from medical curricula. Physicians need to be politically aware and understand how they might effect political change if they hope to be advocates for health; this point is particularly poignant in resource-poor settings, but is becoming increasingly relevant in all health care settings, as governments opt to spend larger quantities of money on defense, or on economic development, as opposed to health care (Achmat 2002b).

These three lessons are broad in nature, and have relevance in both developing counties, and increasingly in the Western world. While these lessons seem simple on paper, putting them into practice is not. It will be a challenge for South Africa, as well as other countries to learn from and build on these lessons.
6.3.2 Looking to the Future: A South African Perspective

It seemed apt to end this written analysis with the voice of a participant, a voice from South Africa. Here a physician-participant conveys her thoughts for the future, indicating that the struggle for access to AIDS medicines in South Africa is far from over.

The question probably in all of our heads is where to from here? The country needs to catch up as a whole, but the one thing we have become more and more aware of is that Nevirapine is not going to cut it. It’s almost like, “Oh, my God, we just all convinced them that Nevirapine is the way to go, (now) we’re going to hit them with the fact that it’s actually, it’s going to be disappointing”. So, we’re going to have to have another strategy quite quickly, you know, where you can, so people’s spirits don’t drop again… We’ve got this in the pipeline, (but) I think there’s still a long and difficult road to walk and it needs quite careful strategy to keep the sort of, pot brewing, as it were. And that we don’t go too down in the dumps kind of thing, you know, too quickly. Alongside that, the question that must come now is that antiretroviral access (must come)… I think will overshadow to a certain extent what’s happening to the MTCT, but it will also assist, because it will allow us to use other drugs and to bring in other concepts to MTCT, so the two must happen together… I don’t think Nevirapine is actually going to be the panacea that’s going to solve all our problems, (not) by a long shot; but it was a start. It got us out of the starting blocks, it got us moving, it was an enormous morale boost, it’s had wonderful other offshoots, like HIV is out there now - people, women are voting with their feet, they have something they can do to protect their children, instead of that hopeless impotence that we had about HIV, where we were just doing nothing. We suddenly have something we can do. And it just, for health care professionals as well as for the electorate, it’s just so important… but hold on, we have not arrived.
GLOSSARY

AIDS: acquired immune deficiency syndrome
ACF: Advocacy Coalition Framework
ACT UP: AIDS Coalition to Unleash Power
ALP: AIDS Law Project
ANC: African National Congress
AZT: the nickname for the antiretroviral drug with the chemical name, Azidothymidine, and generic name, Zidovudine, and brand name Retrovir® (Manufacturer: Glaxo-SmithKline)
COSATU: Congress of South African Trade Unions
CPTech: Consumer Project on Technology
FDA: Food and Drug Administration in the US
GPA: WHO Global Program on AIDS
HAART: highly active antiretroviral therapy
Health GAP: Health Global Access Project
HIV: human immunodeficiency virus
IAPAC: International Association of Physicians in AIDS Care
MTCT: mother-to-child transmission of HIV
MCC: Medicines Control Council of South Africa
MEC: Member of the Executive Committee (i.e. MEC for Health is the provincial equivalent of the Minister of Health in South Africa)
MOU: Midwife Obstetric Unit
MSF: Médecins Sans Frontières
NACOSA: National AIDS Convention of South Africa
NAPWA: National Association of People Living With AIDS/HIV
NEPAD: New Partnership for Africa’s Development
NGO: non-governmental organization
NPPHCN: National Progressive Primary Health Care Network
NVP: the nickname for the antiretroviral drug with the generic name, Nevirapine, and the brand name, Viramune® (Manufacturer: Boehringer Ingelheim/Roxane Laboratories Inc.)
PMA: Pharmaceutical Manufacturers Association
PMTCT: prevention of mother-to-child transmission of HIV
PLWHA: person living with HIV/AIDS
R: Rand (South African currency)
SANAC: South African National AIDS Council
SAMA: South African Medical Association
STD: sexually transmitted disease
TAC: Treatment Action Campaign
TRIPS: Trade Related Aspects of Intellectual Property Rights
UDF: United Democratic Front
UN: United Nations
UNAIDS: Joint United Nations Programme on HIV/AIDS
WHO: World Health Organization
WTO: World Trade Organization
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Appendix A: Sample from the 2002 International AIDS Conference Program

Appendix B: Sample ip-health listserv Posting

Appendix C: Letter of Introduction

Appendix D: Consent Form

Appendix E: Consent Form (for tape-recording interview)

Appendix F: Interview Guide
Appendix A: Sample from the 2002 International AIDS Conference Program

Program: Oral Session

Title: SyE03 Toward a Political Economy of Access

Symposium Session

Venue: Hall 2:4

Date: Thursday, July 11, 2002

Time: 10:30 - 12:00

Chairs: Jean-Paul Moatti, France
       Richard Laing, United States

10:30 ThOrE1421 Breaking the excuses: New knowledge about patents and international aid financing, and why AIDS treatment isn't happening
       A Attaran
       Harvard University, Kennedy School of Government, Cambridge, United States

10:45 ThOrE1422 Technology transfer for local production of HIV/AIDS-related drugs in African countries: collaboration between Thailand and Africa
       K Kraisintu
       Government Pharmaceutical Organization, Bangkok, Thailand

11:00 ThOrE1423 Chile’s Informal Market for Antiretrovirals (ARV). Features, Challenges and Lessons for Optimal Regulation
       C Morales¹, A Brousselle², and the Chilean Drug Access Initiative ANRS Study Group³
       ¹Université de Montréal, GRIS / CMIS, Hôpital Sainte-Justine / Chilean Drug Access Initiative ANRS Study Group

11:15 ThOrE1424 The impact of national production of ARV drugs on the cost of the ARV therapy in Brazil, 1997-2000
       C L Szwarcwald
       Fundação Oswaldo Cruz, Rio de Janeiro, Brazil

11:30 ThOrE1425 Litigating AIDS: background, strategies and outcomes of the Treatment Action Campaign’s (TAC) case to prevent mother to child HIV transmission in South Africa
       M J Heywood
       AIDS Law Project, Johannesburg, South Africa

From:
Dear All

On Friday 14 February 2003, between 15000 and 20000 people in South Africa marched on our Parliament in Cape Town. Our President, Thabo Mbeki said less on HIV/AIDS than George Bush said about peace. Although, he spent less than three minutes on HIV/AIDS, all the marchers spent three hours listening to music, poetry, speeches and then marched. People from every layer of society marched to demand access to treatment -- people living with HIV/AIDS from every part of South Africa, trade unionists, religious leaders, lesbian, gay, bisexual and transgender people, employers, nurses, sex workers, doctors, teachers, principals, school, technikon and university students called on government to sign and implement a national treatment and prevention plan.

The memoranda below was handed over at Parliament to Ms. Xoliswa Sibeko from President Mbeki's office, Mr. Ebrahim Ebrahim from Deputy President Jacob Zuma's office, Mr James LV Ngculu - Chairperson of the Parliamentary Portfolio Committee on Health and Ms Barbara Ann Hogan - Chairperson of the Parliamentary Portfolio Committee on Finance.

A memorandum was also handed over to the US Embassy and TAC called on all people to support the anti-war demonstrations on Saturday.

We want to thank everyone who assisted with the march, people who organised, devoted time, travelled long distances, people across the world who wrote letters to the South African government.

A fuller report coupled with our plans for the next 6 weeks will be circulated soonest.

Regards
Zackie Achmat on behalf of the Treatment Action Campaign Executive.

From:
Appendix C: Letter of Introduction

UNIVERSITY OF TORONTO
SCHOOL OF GRADUATE STUDIES
Faculty of Pharmacy, Department of Pharmaceutical Sciences

Letter of Introduction

Dear participant:

My name is Melanie Campbell. I am a Master of Science student at the University of Toronto, Canada and I am the Principal Investigator for a study entitled “Women’s Access to Nevirapine to Prevent Mother-to-Child Transmission of HIV: Examining Policy Development in South Africa.” The purpose of the study is to examine the politics of drug access with specific focus on the prevention of mother-to-child transmission of HIV (MTCT). The goals of the study include understanding how MTCT prevention policy, and maternal and child health policy in general, have been influenced with reference to historical, political, social and cultural legacies and beliefs in South Africa over the last decade. My research will attempt to understand the policy process that has led to piecemeal access to the drug Nevirapine in South Africa, and the health advocacy activities of the Treatment Action Campaign and other members of civil society. Further, I will explore the perspective of health care providers throughout this process. I am working under the direct supervision of an advisory committee composed of established scholars in this field. This study is being funded by the Canadian International Development Agency.

To achieve the goals and objectives of this study I am requesting that you participate in an interview. This will involve a discussion with me about your opinions, knowledge, experiences, and feelings related to maternal and child health policy in South Africa, and specifically policy related to women’s access to Nevirapine to prevent mother-to-child-transmission of HIV. The interview will take approximately one hour. I will conduct all interviews. No one else will be present at the interview except you and I -- this is called an in-depth interview or key informant interview. All interviews will take place between September and December 2002 in South Africa.

I will keep your identity as a participant in this study anonymous and all information confidential. This study will give you the opportunity to share your knowledge and experience, and contribute to the research aim of exposing the policy process related to access to Nevirapine. You should be aware that there would be no financial compensation for participating in this study.
If you are willing to participate in the study please contact me at your earliest convenience. As I will be travelling across the country between September and December 2002 we can arrange for the interview to take place at a mutually convenient time and place.

If you have any questions about the study please contact me at melanie.campbell@utoronto.ca or contact my project supervisor, Dr. Peri Ballantyne, Professor, University of Toronto at 19 Russell St., Toronto, Ontario, M5S 2S2, Canada; tel: (416) 946-5995; e-mail: p.ballantyne@utoronto.ca or fax: (416) 978-1833. You may also contact Dr. Solomon Benatar, Professor of Medicine & Bioethics Centre Director, University of Cape Town at Observatory, 7925, Western Cape, South Africa; tel: 27-21-406-6115; e-mail: sbenatar@uctgsh1.uct.ac.za or fax: 27-21-448-6815.

Thank you for your consideration of this request,

Melanie Campbell
M.Sc. Candidate
Dept. of Pharmaceutical Sciences
Faculty of Pharmacy
University of Toronto
19 Russell Street
Toronto, ON, M5S 2S2
tel: (416) 946-3911
tel: (416) 925-3389
fax: (416) 978-1833
e-mail: melanie.campbell@utoronto.ca

082 585 9668 in South Africa (Sept. – Dec. 2002)
Appendix D: Consent Form

UNIVERSITY OF TORONTO
SCHOOL OF GRADUATE STUDIES
Faculty of Pharmacy, Department of Pharmaceutical Sciences

Consent Form


Introduction/Purpose of the Study. My name is Melanie Campbell. I am a M.Sc. candidate at the University of Toronto, Canada and I am the Principal Investigator for a study entitled “Women’s Access to Nevirapine to Prevent Mother-to-Child Transmission of HIV: Examining Policy Development in South Africa.” The purpose of the study is to examine the politics of drug access with specific focus on the prevention of mother-to-child transmission of HIV (MTCT). The goals of the study include understanding how MTCT prevention policy, and maternal and child health policy in general, have been influenced with reference to historical, political, social and cultural legacies and beliefs in South Africa over the last decade. My research will attempt to understand the policy process that has led to piecemeal access to the drug Nevirapine in South Africa, and the health advocacy activities of the Treatment Action Campaign and other members of civil society. Further, I will explore the perspective of health care providers throughout this process. I am working under the direct supervision of an advisory committee composed of established scholars in this field. This study is being funded by the Canadian International Development Agency.

Procedures. To achieve the goals and objectives of this study you are requested to participate in an interview. This will involve a discussion with me about your opinions, knowledge, experiences, and feelings related to maternal and child health policy in South Africa, and specifically policy related to women’s access to Nevirapine to prevent mother-to-child-transmission of HIV. The interview takes approximately one hour. I will conduct the interview. No one else will be present at the interview except you and I -- this is called an in-depth interview or key informant interview. With your permission the interview will be tape-recorded. Today I am asking you to give written consent to provide information to be used for the study. You will be provided with a copy of this form.

Risk/Benefits. You should not experience any discomfort as a result of your participation in the study. I will be taking all possible steps to ensure you complete anonymity and keep the information you provide confidential. Your participation in this study will provide me the opportunity to share your knowledge and experience, and contribute to the research aim of exposing the policy process related to access to
Nevirapine. You should be aware that there will be no financial compensation for participating in this study.

**Privacy and Confidentiality.** As a participant in this study your anonymity will be protected. Today you will be assigned an identification number. A single master list will hold the identification numbers and the names/positions of you and other participants in the study. This list will be safeguarded in a secure locked cabinet that only I will have access to. Everything we discuss in the interview will be kept completely private and confidential. The written notes I will be taking today as well as the tape-recording will be all be kept in a locked secure area. The data will be transcribed into a computer file under your identification number, with any other identifying information removed. The information that you provide will be shared with my supervisory committee at the University of Toronto and may be published in scientific literature. However, any access to the final results of the study (the information provided by you and your colleagues when it is compiled) and the information that you provide for the study will not be directly linked to your identity. Your participation in the study is completely voluntary. You have the right to withdraw from or stop the interview at any time and/or request that the tape recording be stopped without adverse consequences.

If you would like to talk to anyone, either before you agree to an interview or after, or if you have further questions about this study, please contact, my supervisor Dr. Peri Ballantyne, Professor, University of Toronto at 19 Russell St., Toronto, Ontario, M5S 2S2, Canada; tel: (416) 946-5995; e-mail: p.ballantyne@utoronto.ca or fax: (416) 978-1833. You may also contact Dr. Solomon Benatar, Professor of Medicine & Bioethics Centre Director, University of Cape Town at Observatory, 7925, Western Cape, South Africa; tel: 27-21-406-6115; e-mail: sbenatar@uctgsh1.uct.ac.za or fax: 27-21-448-6815. You can also contact me at 082 585 9668 in South Africa (Sept. – Dec. 2002); e-mail: Melanie.campbell@utoronto.ca.

If you agree to participate in this study please sign the following statement with your name below.

I, Mr./Mrs./Ms./Dr. ____________________________

authorize the use of a tape-recorder during my interview with Melanie Campbell for research purposes and understand there will be no financial compensation for participating in this study.

Informant’s Signature

______________________________________________

Principal Investigator’s Signature ____________________________

Date ____________________________________________________

Day/Month/Year
Appendix E: Consent Form (for tape-recording interview)

Consent Form (for tape-recording interview)


My name is Melanie Campbell. I am a M.Sc. candidate at the University of Toronto, Canada and I am the Principal Investigator for a study entitled “Women’s Access to Nevirapine to Prevent Mother-to-Child Transmission of HIV: Examining Policy Development in South Africa.” This consent form is specifically for permission to tape record the interview you have agreed to participate in, based on your signature on the previous consent form, for a study entitled “Women’s Access to Nevirapine to Prevent Mother-to-Child Transmission of HIV: Examining Policy Development in South Africa.” The purpose and goals of this study are detailed on the previous form. As well information about the procedures, risks and benefits, and privacy and confidentiality is outlined in the previous form. Please note that you can participate in the interview without consenting to it being tape-recorded.

If you agree to having the interview tape-recorded, the following measures will be taken to ensure your privacy and confidentiality. As a participant in this study your anonymity will be protected. Today you will be assigned an identification number. A single master list will hold the identification numbers and the names/positions of you and other participants in the study. This list will be safeguarded in a secure locked cabinet that only I will have access to. Everything we discuss in the interview will be kept completely private and confidential. The written notes I will be taking today as well as the tape-recording will be all be kept in a locked secure area. The data will be transcribed into a computer file under your identification number, with any other identifying information removed. Once the information from the tapes has been transcribed the tapes will be held indefinitely in a locked cabinet in case clarification is needed regarding the data at a later date. Upon deeming that no more information is needed from the tapes, they will be destroyed. The information that you provide will be shared with my supervisory committee at the University of Toronto and may be published in scientific literature. However, any access to the final results of the study (the information provided by you and your colleagues when it is compiled) and the information that you provide for the study will not be directly linked to your identity. Your participation in the study is completely voluntary. You have the right to withdraw from or stop the interview at any time and/or request that the tape recording be stopped without adverse consequences.

If you would like to talk to anyone, either before you agree to an interview or after, or if you have further questions about this study, please contact, my supervisor Dr. Peri Ballantyne, Professor, University of Toronto at 19 Russell St., Toronto, Ontario, M5S 2S2, Canada; tel: (416) 946-5995; e-mail: p.ballantyne@utoronto.ca or fax: (416) 978-1833. You may also contact Dr. Solomon Benatar, Professor of Medicine & Bioethics
Centre Director, University of Cape Town at Observatory, 7925, Western Cape, South Africa; tel: 27-21-406-6115; e-mail: sbenatar@uctgsh1.uct.ac.za or fax: 27-21-448-6815. You can also contact me at 082 585 9668 in South Africa (Sept. – Dec. 2002); e-mail: melanie.campbell@utoronto.ca.

If you agree to participate in this study please sign the following statement with your name below.

I, Mr./Mrs./Ms./Dr. _____________________________ authorize the use of a tape-recorder during my interview with Melanie Campbell for research purposes and understand there will be no financial compensation for participating in this study.

Informant’s Signature

__________________________________________________________

Principal Investigator’s Signature ____________________________

Date ______________________________________________________

Day/Month/Year
Appendix F: Interview Guide

UNIVERSITY OF TORONTO
SCHOOL OF GRADUATE STUDIES
Faculty of Pharmacy, Department of Pharmaceutical Sciences

Interview Guide

For South African Health Policy Stakeholders Participating in the Study
“Women’s Access to Nevirapine to Prevent Mother-to-Child Transmission of HIV: Examining Policy Development in South Africa”

DEMOGRAPHIC DATA

To be completed by interview participant

1. What is your current position?

2. How long have you held this position?

3. How long have you been working in the health care/policy/administration system?

4. Describe how you came to be involved with this study.

5. If you referred by someone please provide that person’s name.
6. Which of the following groups do you identify with? Please be specific.

- Government Official
- Media Representatives
- Pharmaceutical Company Representative
- NGO Representative
  - Representative from the Treatment Action Campaign
  - Other. Specify
- Health Care Provider
  - Specify
- Peer Counselor (working at AIDS clinic)
- Other relevant stakeholder
  - Specify

INTERVIEW GUIDE

In what capacities have you been involved with health policy related to prevention of mother-to-child transmission of HIV?

[PROBE: Please explain your involvement. How long have you been involved in each capacity? Have you been specifically involved with women’s health? HIV/AIDS? Pharmaceuticals? Drug access? Women’s access to Nevirapine? ...]

Describe to me what has happened is the past 2-3 years with respect to Nevirapine policy and programs in South Africa.

(PROBE: How has this policy affected your life? Explain. Describe any specific factors that may have affected how Nevirapine policy came to be developed. Key players in the development of Nevirapine policy? What was their contribution? What would you like to see happen with respect to Nevirapine access in the future? ...)

The way I understand it, in January 2001 the Dept. of Health announced that they would begin an 18-site Nevirapine pilot project. Then, in August 2001 the Treatment Action Campaign filed a lawsuit against the government to mandate that Nevirapine be provided to all medically indicated pregnant women in South Africa, not just those women at the pilot sites. How have these events been significant to health care policy in South Africa?

(PROBE: Do these developments have any implication for the promotion of a more equitable health care system in South Africa? How would you justify the position of the government in this case? Treatment advocates? ...)

What do you think are barriers to equitable health care in South Africa?

(PROBE: Why? ...)
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FOR HEALTH CARE PROVIDERS ONLY

If participant is not a health care provider go to *

Describe your patient population and the kind of access your patient population has to Nevirapine to prevent mother-to-child transmission of HIV.  
(PROBE: How has this affected your role as a doctor/nurse/etc.? Is this like any other problem you’ve encountered (re. Differential access to in health care)? …)

*Summarize the key points mentioned and ask about anything that is not clear. Is the summary correct – additions, changes?  
Please tell me what issues, if any, we did not touch upon?  
(PROBE: Significance to MTCT/Nevirapine/health policy? …)

Is there any information that you think I should be referred to regarding the topics we have discussed? Who else do you think I should meet to discuss these topics?  
(PROBE)

Finally, do you have any questions for me?

________________________________________________________________________

FOR PARTICIPANT TO COMPLETE AT THE END OF THE INTERVIEW

Are you agreeable to being contacted again for clarification about something we discussed today?

☐ YES  ☐ NO

If you would like to receive a copy of this study by mail, once it is complete, then please provide the mailing address that it should be forwarded to.

Name

Address line 1

Address line 2  Code  Country

Other contact information – email, phone or fax.
LIST OF PUBLICATIONS AND ABSTRACTS

“A Case Study of Health Activism in an Era of Globalization ~ Women’s Access to Essential AIDS Medicines in South Africa”
May 2003 – presented at Issues in Women’s Health: Biology and Beyond, sponsored by The Centre for Research in Women’s Health, University of Toronto; Toronto, Canada

“A peri-conceptional nutritional origin for non-infectious preterm birth”

“Women’s Access to Nevirapine to Prevent Mother-to-Child Transmission of HIV: Examining Policy Development in South Africa”
March 2003 – presented at The Koffler Institute for Pharmacy Management Seminar Series, sponsored by The Department of Pharmaceutical Sciences, University of Toronto; Toronto, Canada

“Women’s Access to Nevirapine to Prevent Mother-to-Child Transmission of HIV: Examining Policy Development in South Africa”
February 2003 – presented at The International Conference on the Impact of Global Issues on Women and Children, sponsored by McMaster University, Canada and Burapha University, Thailand; Bangkok, Thailand

“A Health Outreach Program For Refugees In Toronto: A Collaboration Between Students From The University of Toronto International Health Program and COSTI” (Coauthors: Gold, E.; Zilber, R.; Harvey-Blankenship, M.)
October 2002 – presented at The 2nd Annual Conference on Children and Youth New to Ontario, sponsored by The Hospital for Sick Children and University of Toronto; Toronto, Canada

“Women’s Access to Nevirapine and Appropriate Care to Prevent Mother-to-Child Transmission of HIV: An Analysis of the Policy Development Process in South Africa”
May 2002 – presented at Issues in Women’s Health: An Afternoon of Graduate Student Research, sponsored by The Centre for Research in Women’s Health, University of Toronto; Toronto, Canada

“Women’s Access to Nevirapine and Appropriate Care to Prevent Mother-to-Child Transmission of HIV: An Analysis of the Policy Development Process in South Africa”
May 2002 – presented at Graduate Research in Progress (GRIP), sponsored by The Department of Pharmaceutical Sciences, University of Toronto; Toronto, Canada