

**“Our struggle to overcome AIDS”:
Science, Politics and the Boundaries of Citizenship in Post-Apartheid South Africa**

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Thesis submitted in partial fulfillment for the degree of BACHELOR OF ARTS in
DEVELOPMENT STUDIES,

Development Studies

Brown University

16 April 2010

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In memory of Andrew Warlick

Acknowledgements

First, I have to profusely thank Professor Lundy Braun. Without Professor Braun, this thesis would never have happened. She has been my biggest cheerleader from the very first day, always pushing me forward (gently) despite several setbacks along the way. I always leave her office feeling inspired, as she makes me believe that what I am doing is actually important and of significant value. I am eternally grateful for her support.

I also must profusely thank Professor Geri Augusto, whose guidance and expertise have been crucial to this project's completion. I admire Professor Augusto both for her abundant wisdom and for her ability to always reach beyond the surface. Her confidence in me is appreciated.

At Brown University, I have been fortunate to study with a number of professors who encouraged the development of my research project. Cornel Ban has been an invaluable resource of information and guidance. Professor Tony Bagues and his courses provided me with several important questions and ideas that guided me throughout all of my readings. Professors Ethan Pollock, Gianpaolo Baiocchi and Patrick Heller all taught courses that gave some direction to my intellectual energy. Rick Benjamin was, as always, a crucial source of support along the way.

In South Africa, Professor Steven Robins directly inspired my project and pushed me to take a science studies perspective. Professors Di Cooper and Jonny Myers of the University of Cape Town both granted me important interviews at the last minute. The support staff at the Centre for African Studies welcomed me with open arms and provided me with a second home.

At the National Office of the Treatment Action Campaign, I worked alongside several inspiring activists who wholeheartedly supported my project. Thank you to both Catherine Tomlinson and Rebecca Hodes, who not only granted me highly informative interviews but also made my research sharper, up to date, and informed. Tabeth, Nono, Viktor, and Vuyiseka all independently inspired my work. Victoria and Liz were the best fellow interns I never expected. Also, I can't forget to thank the late Andy Warlick for all of his help with my project.

Thank you to the staff of the Watson Institute's International Scholars Program, who provided me with enough financial and institutional support to conduct my research.

Several friends at Brown have made significant contributions to this process. I must thank: Donata, an incredible source of strength; Einat, a constant source of resilience; Johanna, an understanding friend and co-coordinator; Caitlin, a friend who never failed to push my research further; Henry, a partner-in-crime; and Ivy, a never-ending source of energy, confidence, and Nelson Mandela quotes.

Thank you to Lauren Wiending, who tirelessly proofread drafts of this thesis.

Lastly, I would like to thank my family for granting me the freedom to attend Brown, travel to a foreign country independently for three months, and undertake this strange and complex research project. Your support has been crucial.

Abstract

The global HIV/AIDS epidemic has impacted millions upon millions of human lives while simultaneously pushing the boundaries of human capacity. In the past three decades, waves of successful HIV/AIDS activism have spread across the globe, claiming roots not only in the United States but also in Brazil, Thailand, and South Africa.

Taking public participation in scientific governance, or the involvement of civil society actors in science-based policymaking, as a theoretical lens, my thesis explores three historical models of this phenomenon to explore how civil society actors shape (and are shaped by) government policies. In addition, my thesis considers how South African citizenship has evolved and continues to play a role in the formation of HIV/AIDS policies.

Building upon this foundation, my thesis examines the most recent developments and undertakings of HIV/AIDS activism and policymaking in South Africa. After contextualizing this activism and policymaking within South African history, my research focuses upon how the national struggle against the HIV/AIDS epidemic has explicitly produced new and local (though also profoundly global) understandings of science, politics, and citizenship. In very recent years, the reframing and reproduction of this knowledge has occurred, in large part, through the South African National AIDS Council (SANAC). Since 2000, SANAC has acted as a scientific advisory council designed to draft and endorse HIV/AIDS policies for the South African Department of Health.

With SANAC as a central site of inquiry, my thesis thus investigates how the most prominent and vocal South African HIV/AIDS civil society organization, the Treatment Action Campaign (TAC), has successfully pushed for the restructuring of SANAC to allow for increased public participation. This research shows how, even through the increased democratization of SANAC, TAC has emerged as the most prominent voice within SANAC. In addition, the science-positive voices of lay participants within TAC has had significant implications for the science-based policies produced by SANAC.

Through a case study of a very recent SANAC policy, in which guidelines were established for the roll-out of medical male circumcision (MMC) after scientific research claimed that MMC is linked to decreased HIV transmission, this thesis illustrates how TAC has produced a form of *hegemony* within SANAC that ultimately restricts the production of scientific knowledge within this context. In addition, I suggest that TAC's promotion of active and responsible citizenship is also directly linked to this restriction of knowledge production and subjugation of alternative knowledges.

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Abbreviations

ANC	African National Congress
ARV	Antiretroviral
NEDLAC	National Economic Development and Labour Council
NGO	Non-Governmental Organization
RDP	Reconstruction and Development Programme
SANAC	South African National AIDS Council
STS	Science and Technology Studies
TAC	Treatment Action Campaign
UNAIDS	Joint United Nations Programme on AIDS
WHO	World Health Organization
ZAR	South African Rand

Chapter One

Unsettling Boundaries

Introduction

During the Opening Session of the 5th Annual International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention, held in Cape Town, South Africa, in July of 2009, an impressive collection of speakers welcomed the thousands of visiting scientists, policymakers, and activists. The last to speak to the delegates that night was Stephen Lewis, the former United Nations Special Envoy for HIV/AIDS in Africa, with his impassioned speech, “Scientists as Activists.” Crossing an extraordinary range of emotions, Lewis placed his own personal experience against the backdrop of the global HIV/AIDS epidemic, compelling the audience to work collaboratively to end the spread of HIV/AIDS. At several points throughout the speech, Lewis challenged the scientists in the audience to use their unique expertise to solve the most pressing global social problems, such as female oppression:

This business of discrimination against and oppression of women is the world’s most poisonous curse. Nowhere is it felt with greater catastrophic force than in the AIDS pandemic... What has to happen, with one unified voice, is that the scientific community tells the political community that it must understand one incontrovertible fact of health: bringing an end to sexual violence is a vital component in bringing an end to AIDS. The brave groups of women who dare to speak up on the ground... should not have to wage this fight in despairing and lonely isolation. They should hear the voices of scientific thunder... No one can challenge your understanding. Use it, I beg you, use it. (2009: 2)

As this selection reveals, Stephen Lewis seeks to unsettle the conventional boundaries between and the pre-existing perceptions of science and politics. He appears absolutely convinced that scientists engaged in HIV/AIDS research have the potential to inhabit two occupations at once: one as scientists and one as HIV/AIDS activists. With this dual role, he believes, scientists not only have significant moral authority within controversial public science debates, but also they can legitimize political and community activism. Together, these propositions elicited a strong, positive reaction from the delegates. In hindsight, however, a more

critical analysis of his remarks is possible. What further presumptions were implicit within Lewis's speech? In other words, where exactly does Lewis envision the boundary between science and politics?

Given the national venue of the conference, it is important to place Lewis's claims regarding the science-politics relationship in the context of South African history and society. After all, it is not a coincidence that Lewis prepared such a political speech for his audience in South Africa. As this thesis will recount, public figures within the South African government once temporarily blocked public access to HIV/AIDS treatment after raising questions about the authority of western biomedical science.¹ Today, the enormous success of South African AIDS activist organizations, especially the Treatment Action Campaign (TAC), in convincing the government to provide HIV/AIDS treatment is known throughout the scientific community as a triumph of science within politics. Furthermore, as a result of this science-positive activism, the dominance of western biomedical science within contemporary South African political discourse appears to be indisputable.

Lewis's speech can therefore be read as an attempt to both recall the importance of AIDS activism and to encourage the further promotion of biomedical science by politics in South Africa. Lewis suggests the need for continued AIDS activism in South Africa and abroad, but implied within his comments is the assumption that this activism is only legitimate as long as it accepts the tenets of western biomedical science. Along these lines, AIDS activists are only useful for the power of their collective bodies and voices, not for their understandings of science, illness and treatment. Science has the potential to simultaneously support and silence individuals within the public sphere.

¹ The labels of western and traditional are too simplistic in describing the full range of information, philosophy, and practices within each body of medical knowledge, but there are not many helpful terms to replace them.

Still, there is no immediate shortage of unique narratives of HIV/AIDS within South Africa. Every day, almost six million South African citizens living with HIV or AIDS wake up to another day. They proceed with their daily routine—taking care of their families, heading to work, and engaging with their communities. Some are aware of their HIV status; many are not. Some take the prescribed medication; many ascribe their weakened health to another cause or illness. Some do not survive another day; most do. In the end, the public discourse surrounding HIV—a virus not just capable of killing citizens, but currently “rewriting the global geopolitical coordinates within which we think and act”—remains frighteningly uneven in South Africa (Comaroff 2007: 198). Without increased knowledge sharing, discussion, and cooperation among scientists, policymakers, and citizens, the HIV/AIDS epidemic will continue to spread across borders and destabilize the country at an alarming pace.

Fortunately, several steps have been taken in the direction of increased public engagement around the HIV/AIDS epidemic. As this thesis will explore, the most important development has been the recent emphasis of the South African National AIDS Council (SANAC) on greater public participation in its national policymaking process. However, given the ubiquitous nature of HIV/AIDS in South Africa, further public engagement will be necessary. South African President Jacob Zuma made this argument in a speech on World AIDS Day 2009 in Pretoria. Echoing the shifting boundaries within Stephen Lewis’s speech, he directly compared the struggle against HIV/AIDS to the anti-apartheid struggle:

At another moment in our history, in another context, the liberation movement observed that the time comes in the life of any nation when there remain only two choices: submit or fight. That time has now come in our struggle to overcome AIDS. Let us declare now, as we declared then, that we shall not submit. We have no choice but to deploy every effort, mobilise every resource, and utilise every skill that our nation possesses, to ensure that we prevail in this struggle for the health and prosperity of our nation. (2009: 5)

Through his recollection of the anti-apartheid struggle in order to gather support for “our struggle

to overcome AIDS,” President Zuma intentionally invoked fresh memories of a unified South African public striking against a common scourge: the apartheid government (2009: 5). In doing so, Zuma also presented an image of a cooperative state and civil society, prepared to take on the largest threat to the prosperity of post-apartheid South Africa.

Of course, HIV/AIDS in South Africa will not be contained solely by public engagement in the realms of both science and politics. In order to comprehend both the full capacity and the limits of this phenomenon, this thesis will briefly explore the history of civic engagement with science in South Africa and will attach this narrative to the recent national struggle against HIV/AIDS. By tracing the precise institutional arrangements through which members of the South African public are able to shape HIV/AIDS policy, especially in the case of one particular policy initiative, this thesis will pose important questions regarding the complex relationship between various South African ‘publics’ and HIV/AIDS. Through an interrogation of the nature and the boundaries of South African citizenship, this thesis will also investigate the implications of the flexible relationship between science and politics in South Africa for future HIV/AIDS policies.

Given the capacity of HIV to unsettle boundaries, this thesis follows three topics in which this theme manifests itself: the citizen-science relationship, the science-politics relationship, and the past-present relationship. Together, these topics constitute an important glance at the constantly shifting social dynamics of post-apartheid South Africa. However, the true heart of this thesis rests within outlining and unsettling the complex boundaries between citizens and science in this fragmented setting. To do this properly, observations about these boundaries are placed in historical context, a frame that shows why scientific knowledge has been both absorbed and contested by various South African ‘publics’ in recent years. In addition, this thesis traces

how scientific authority and expertise govern other public knowledge paradigms. Though broad, these questions are filtered through a specific case study of HIV/AIDS policymaking in order to show how this citizen-science relationship ultimately influences national HIV/AIDS policy in South Africa.

The primary research question of this thesis is twofold: **How has public participation in scientific governance shaped HIV/AIDS policy in South Africa? And how has HIV/AIDS policy shaped South African citizenship?** Stated generally, this thesis asks how civil society and public policy reciprocally influence each other in a newly emerging context. Rather than focus on the overall relationship between state and civil society in South Africa, this study looks more closely at sites where those boundaries are unsettled, such as citizenship. The following chapters will thus examine how the movement and the understanding of scientific knowledge by elite and non-elite citizens have specifically influenced the HIV/AIDS policymaking process. Along the way, several pertinent questions will complement this research: Can the inclusion of lay knowledge in HIV/AIDS policymaking bring forth more culturally-sensitive policies than professional experts? Or does public participation in scientific governance merely privilege the priorities of a few civil society representatives, resulting in skewed and potentially ineffective policies? And how do these policies affect the contours of South African citizenship?

My thesis comes at a pivotal moment for the global struggle against the HIV/AIDS epidemic. As I witnessed with my own participation in the International AIDS Society Conference in South Africa, there is a growing desperation for measurable progress. Without any sign of a cure, a vaccine, or even more effective prevention methods, scientists within the HIV/AIDS field are keen to advance biomedical treatments and to stimulate research in new directions. Furthermore, activists and citizens living with HIV are also desperate for new

treatment solutions. In this context rests the central topic of the fifth chapter of this thesis: a purported positive link between medical male circumcision (MMC) and reduced HIV prevalence. With its potential of reducing HIV contraction by almost sixty percent in adult males in high-risk communities and networks, MMC thus represents an exciting promise: for the scientific community, a chance to show signs of progress in research efforts; for policymakers, an opportunity to reach a brighter future; and for the greater public, a possibility to help stop the HIV/AIDS epidemic.

And yet, the emergence of MMC as an HIV prevention method requires further scrutiny from both scientific and social scientific perspectives; recent research studies have examined the biological plausibility of MMC as a prevention method, the potential harmful impact of MMC on women, and the numerous human rights dilemmas facing policymakers. Similarly, the growing popularity of public participation in scientific governance, or science-based policymaking, demands some clarification and exploration. By merging these two topics in one case study, my hope is to add a critical, yet well-intentioned, voice to the ongoing debate over HIV/AIDS policymaking in South Africa. Additionally, by building on the burgeoning scholarship on scientific governance, this thesis expands the current Science & Technology Studies (STS) literature to more concretely involve South Africa. After all, this is a context that, as Steven Robins notes, historically holds “a deep distrust of ‘western’/‘white’ science” (2002: 5).

Research Design, Sources, and Methodologies

I will approach the focus of this thesis, scientific governance in post-apartheid South Africa, through a *disciplined interpretive case study*. This method is the most appropriate for the content of my thesis, as it will attach STS theoretical insights to a history that has not yet been

framed in this manner; as John Odell notes, this type of case study “interprets or explains an event by applying a known theory to... new terrain” (2001: 163). Through an application of recent STS literature on scientific governance to the current structure of the South African National AIDS Council (SANAC), the national advisory council for South Africa’s HIV/AIDS policies, I will illustrate how lay citizens and scientific knowledge interact within this context. To stay within the scope of an undergraduate thesis, I restrict my detailed analysis to the latest events in South Africa promoting the link between a decreased risk of contracting HIV and MMC. Using the case study approach, I will be able to trace how lay participants within SANAC discover, interpret, and communicate scientific knowledge, and then finally how they act upon it to bring forth science-based policies.

Resources accumulated over the past two years of study, research and travel have allowed me to take an increasingly informed, contextualized and aware perspective on this case study. Thanks to my three-month stay in South Africa from June to August 2009, working as an intern for the Treatment Action Campaign (TAC) National Office, I had access to a number of official documents, policy memorandums, presentations, transcripts and reports from SANAC, TAC, and South African government-sponsored events. Together, these (mostly digitalized) papers provide the most official record of meetings, research studies, and ongoing debates within South Africa related to the HIV/AIDS policymaking process. Many of my resources are available through the official websites of the respective organizations; I also retrieved several papers through my internship or personal contact with individuals involved with these organizations. In addition, I found many useful academic papers from South Africa by means of private archival research at the African Studies Library of the University of Cape Town (UCT).

One of the benefits of working with TAC was the opportunity to immerse myself in the daily environment of an organization so central to this thesis topic. Even as a full-time intern at the National Office, I was allowed to conduct independent research and interviews for this thesis. Full inclusion in meetings, conferences and the everyday routines of the TAC National Office offered me the chance to perform basic ethnographic participant observation. With this dual opportunity, I developed a more complete and informed understanding of TAC, especially its current priorities and strategies. While growing academic literature on the history and accomplishments of TAC is now available to foreign researchers, ethnographic participant observation truly allowed me to grasp more fully why this one organization has been so successful at advancing widespread social change in South Africa. In my case, I saw specifically how TAC encourages public participation in scientific governance.

During my time in South Africa, I conducted seven semi-structured interviews with key actors, including one TAC member, three TAC officers, one SANAC official and two UCT academics linked to the larger public debate. Interview subjects were primarily chosen based on my degree of access to each subject; accordingly, six of the interviews were conducted in the Cape Town area, while the remaining interview was conducted during a weekend trip to Johannesburg. My high-level entry point as a TAC National Office intern allowed me to interview several well-informed and relevant individuals within the MMC policymaking debate. Additionally, I purposefully interviewed individuals with opposing or dissimilar perspectives within this debate. I allowed the interviews to take on a conversational flow, and I asked new questions whenever it was appropriate to the interview. In terms of content, I primarily asked for details and perspectives on major events and processes within TAC, SANAC, and South African society at large. All of these interviews were recorded with a personal digital recorder. For the

purposes of interview transcription, only one participant asked to remain anonymous; the rest of the interview subjects gave me full permission to use their names and positions in my thesis. A full list of interviews and the Institutional Review Board (IRB) clearance to conduct these interviews are available in Appendices A and B of this thesis.

After my return to the United States, I remained in touch with a few TAC officials at the National Office in order to stay up-to-date with my research. Through these connections, I was able to receive updated drafts of the official MMC policy. I also conducted another interview through Skype, a follow-up interview with a TAC official who had since been promoted to a higher position within the Policy, Communications and Research Division.

In order to supplement my own experiences and to place recent events in historical context, I have widely consulted secondary literature from several disciplines. The field of STS provides the most illuminating examinations of public participation in scientific governance, in addition to providing key insights into the public understanding of science and the historical relationship between science and politics. The disciplines of history, sociology and political science, including subfields like political sociology, bring forth crucial insights and details to the history of science, AIDS, social movements, and government organizations in South Africa—all of which I attempt to weave together throughout my thesis. Also, I place a great emphasis on sources from South African academics and researchers whenever appropriate to promote a more complete dialogue.

Research Limitations

By choosing this case study for a thesis, I recognize that South Africa here acts as a unique case due to its relative absence within STS. Also, by adapting STS literature to SANAC's

recent shift toward public participation in scientific governance, I run the risk of falling into one of the major case study pitfalls as described by John Odell. As “most events give rise to more than one interpretation,” I must be aware of my own possible “selective reconstruction of the event to support a favored theory... [and] underplaying evidence inconsistent with the theory or alternative interpretations or both” (2000: 3). Still, I believe that a disciplined interpretive case study of public participation within SANAC is necessary, especially when the academic work on this process in a South African context is so limited.

Without a doubt, there are several immediate limitations to the reach of this thesis. Despite my own site-based research, as detailed above, my research was almost entirely limited both geographically and temporally to three months in central Cape Town and a weekend trip to Johannesburg. Furthermore, my research was restricted to English-language resources, media, and academic articles; although I believe that my research would have strongly benefited from access to Xhosa-, Zulu-, and even Afrikaans-language resources, I did not have the resources to employ proper translators. Also, while I participated in TAC meetings and events, I was an intern during a period of massive internal restructuring. I was not able to observe any SANAC plenaries or sector meetings during my time, although I had been formally invited to a meeting of the SANAC Women’s Sector. Further research on both TAC and SANAC can illuminate my own observations and trace their respective developments.

Thesis Structure and Organization

The second chapter of this thesis (*Historical and Theoretical Considerations*) expands upon my primary research question concerning the reciprocal relationship between citizens and HIV/AIDS policy in South Africa. In this chapter I present the theoretical foundation for the

thesis topic: the relationship between lay citizens and western science in South Africa. After defining key terms, I elaborate on the science-politics relationship and provide descriptions of the three basic models for public participation in scientific governance. From here, I introduce some preliminary thoughts on the interlocking narratives and histories within this thesis. I also provide a background narrative of the political history of South Africa through the lens of citizenship.

Three empirical chapters follow this comprehensive overview. The first empirical chapter (*“Whose science?”: AIDS, History, and Public Knowledge in South Africa*) provides an historical examination of the relationship between lay citizens and ‘western’ science in South Africa, from the colonial through the post-apartheid era. More explicitly, this chapter seeks to understand the historical spread of scientific knowledge production in South Africa and how this impacts the present. Considering how science and politics have interacted in the past fifteen years, especially during the AIDS ‘denialism’ controversy under President Mbeki, this chapter represents a preliminary effort to contextualize the AIDS struggle within the complex, historically-rooted relationship between South African citizens and ‘western’ science.

The second empirical chapter (*“Science, or truth”: Boundaries, Hybrids, and Epistemic Communities within SANAC*) analyzes the South African National AIDS Council and its role in shaping the relationship between lay citizens and western science in post-apartheid South Africa. Through an in-depth investigation of key elements and processes within SANAC, from prominent communities of practice to the role of scientific knowledge production and analysis, this chapter seeks to both elucidate and complicate understandings of how organizations such as SANAC function—and ultimately shape—science-based policy. The chapter also discusses how

SANAC's current organizational structure and culture exclude certain considerations and voices that could shape the current relationship between lay citizens and 'western' science.

The third empirical chapter ("*I am responsible*": *Navigating Circumcision, Culture and Citizenship*) discusses the passage of the MMC policy and the implementation guidelines over a three-year period in South Africa. Tracing the movement of scientific knowledge and authority through the global public health regime, this chapter reveals how internal debates within SANAC brought forward a strong push for a MMC policy. Furthermore, this chapter considers how SANAC's consultations with traditional leaders have led to a further subjugation of alternative knowledge systems within SANAC, shedding further light on the relationship between lay citizens and scientific knowledge.

The final chapter (*Concluding Thoughts: HIV/AIDS and the Boundaries of Citizenship*) examines the significance of my research findings and asks further questions regarding the development of South African citizenship, especially those questions which could not be fully answered by an undergraduate thesis. In addition, a brief analysis of the emerging biopolitical public health regime in South Africa raises notable questions regarding the implications of the MMC policymaking process. The thesis concludes with a discussion of the shifting relationships between lay citizens and science, science and politics, and the past and the present in South Africa—and, in light of all of these findings, pushes for a re-negotiation of these relationships.

Chapter Two

Theoretical & Historical Considerations

Introduction

In this chapter, I introduce a number of theoretical and historical insights that will provide a coherent backbone for this thesis. First, there are a few key terms which require elucidation. Next, I will present a small review of existing literature on the relationship between science and politics, emphasizing the three existing models of public participation in scientific governance. I will bring the chapter to a close with an overview of my approach to historical narratives, finally ending with a consideration of the history of South African citizenship.

Important Terms

Before delving into the main theoretical and historical foundations of this thesis, there are a few terms to clarify. The first, *civil society*, refers to the space in which the collective, voluntary, and organized movements of non-state, non-market actors exist (Habib 2005; Lehman 2008; Glaser 1997; Ballard et al. 2005).² In light of contemporary globalization, Mary Kaldor imagines civil society in two distinct forms, the *neoliberal* and the *activist*; in the former, actors replace the social welfare organizations of the state, while the latter emphasizes social movements and individual empowerment within the public sphere (Kaldor 2003). Both of these definitions are pertinent to an analysis of South Africa. Although the African National Congress (ANC), the dominant political party in post-apartheid South Africa, initially imagined post-apartheid civil society in its neoliberal form, the last fifteen years has proven that the activist type coexists with the neoliberal type (Ballard et al. 2005; Habib 2005; Orkin 1995). This is in line with the longstanding history of grassroots activism in South Africa. However, it is important to note that contemporary civil society—only a nascent concept due to the recent birth

² A significant contribution to my understanding of this term also rests with Antonio Gramsci, who imagined an emerging space for activities separate from formal politics and the intimacy of the family (Gramsci 1979).

of the liberal democratic state in South Africa—does not take one single form. As noted by Adam Habib, “the set of institutions within this entity [contain] diverse and even contradictory political and social agendas,” from non-governmental organizations (NGOs) as well as radical social movements serving the needs of marginalized communities (2005: 672).³ This understanding emerges later in the thesis as it examines the role of a prominent civil society organization in shaping public policy.

The second term to define, *public participation*, is often understood simply as civil society representation within the state. In this thesis, public participation refers more directly to engagement with non-state, non-market actors through the “co-production” of scientific knowledge (Bucchi and Neresini 2007; Jasanoff 2004: 3).⁴ While traditional models of public engagement suggest that scientific knowledge should be communicated to the public in a top-down process, new understandings of scientific and lay knowledges insist that the public—in all of its manifestations, from lay citizens to medical patients—can co-produce scientific knowledge in conjunction with experts and scientists, be they doctors or laboratory workers (Bucchi and Neresini 2007; Irwin 2007). In addition, there is the assumption that public participation is not a unique event or opportunity, but rather it is a fluid process that takes into consideration various forms and sources of knowledge (Bucchi and Neresini 2007; Irwin and Michael 2003). Left open to interpretation is how exactly the public participates. In other words, what are the obligations of public participants? Some argue that current public participation mechanisms strive to keep publics marginal to the actual processes of knowledge production, only allowing citizens “to express... concerns, interests or values” that complement scientific research (Peschard 2007: 3).

³ And yet, even using the term *civil society* is much contested within post-apartheid South Africa; as suggested by the Comaroffs, “the manner in which the concept is deployed is often as vacuous as it is appealing” (2003: 447).

⁴ As Jasanoff writes, “work in the co-productionist idiom stresses the constant intertwining of the cognitive, the material, the social and the normative... [it] occurs neither at random nor contingently, but along certain well documented pathways” (2004: 6).

Others point out how lay knowledge is essential not only for the legitimization but also the co-production of scientific knowledge (Bucchi and Neresini 2007; Epstein 1996). This thesis thus investigates whether or not lay and expert citizens co-produce scientific knowledge in the MMC policymaking debate in South Africa.

The third term relevant to this thesis is *scientific governance*, or the way in which the state and its publics interact with, develop, frame, and control scientific knowledge (Irwin 2007). Conventional participatory governance involves the formation of “spaces that readjust the boundaries between the state and citizens” (Fischer 2006: 21); here, governance also includes the full range of “organizational mechanisms, operational assumptions, modes of thought, and consequential activities involved in governing a particular area of social action”—in this case, science and technology (Irwin 2007: 584). Unlike previous conceptions of science-based policy and development falling under the protection of the nation-state, Alan Irwin suggests that the world is currently facing a new form of scientific governance in which de-centered networks and assemblages of power, drawn from both the state and its publics, influence the co-production of scientific knowledge (Jasanoff 2004; Leach and Scoones 2003; Irwin 2007; Irwin and Michael 2003). Accordingly, in each model of scientific governance, “experts and lay people are configured and mutually articulated in a distinctive way, which reflects on the practical form of the adopted democratic governance... [and] thus each model contributes to the shaping of its own conception of techno-scientific citizenship” (Bourdourides 2002: 4). Based on this definition, I believe that SANAC deserves to be categorized as a nascent form of scientific governance.

Another important term for this thesis is *expertise*. Within Science and Technology Studies (STS), expertise is a “social and performative” quality belonging to individuals or communities

that requires “familiarity with the formal aspects of knowledge along with the capacity to act and respond to circumstances” (Evans and Collins 2007: 610). While previous conceptions of expertise (or expert knowledge) imagined strict boundaries between certified professionals and the public, with these experts called upon to guide policymaking efforts, more recent studies have traced the social construction of expertise through a multiplicity of specific epistemic, bureaucratic, and technocratic domains that grant credibility and proficiency (Leach and Scoones 2003; Boudourides 2002). Additionally, science studies scholars such as Steven Epstein have advocated for equal recognition of *lay expertise* within the policymaking process. This term indicates the capacity of public citizens to not only provide their own personal, transformative insights but also, through strategies such as the procurement of cultural competence or political representation, engage in the co-production of scientific knowledge, (Epstein 1995). For my case study, I also consider the recent push for new categorizations of expertise by Collins and Evans, who call for a strict differentiation between *interactional expertise* (enough expertise to comprehend scientific knowledge) and *contributory expertise* (enough expertise to participate in the production of scientific knowledge) (Collins and Evans 2003).

The final term, *citizenship*, is also the least straightforward; this is in part due to its extensive history within political thought. For this thesis, I recognize a number of diverse interpretations of citizenship that identify it as delineating the boundaries between civil society and the state. These foundational definitions include: the liberal definition, whereby citizens gather to further their own interests when the state fails to do so (Marshall 1950); the civic republican definition, whereby citizens gather together around common identities and cultures (Habermas 1984); and more recent post-structuralist definitions which recognizes the capacity of citizens to hold multiple, even convergent identities, and gather with other citizens with similar

identities only in particular contexts and toward specific targets (Ellison 1997). For this thesis, I will emphasize a definition of citizenship that builds upon prior definitions but is defined in more integrative and performative terms as “practiced engagement through emergent social solidarities” (Leach and Scoones 2007: 16). Although this definition is less stable than some previous conceptions, it acknowledges how today’s active citizens build new coalitions only as necessary and to fight against emerging threats to citizenship. My thesis incorporates this definition and places it within a South African context; additionally, I provide a brief overview of South African citizenship below.

Science, Politics & Scientific Governance

The relationship between science and politics, especially in regards to science-based policymaking, is fraught with complexity and shifting boundaries. As science studies scholar David Guston notes, there is a historical record of a “delegatory, contractual, or representative relationship” between science and politics, in which science takes the dominant, authoritative role (2000: 18). Steven Epstein adds that, when it comes to this form of policymaking:

Increasingly, science is the resource called on to promote consensus, and experts are brought in to ‘settle’ political and social controversies. Yet this ‘scientization of politics’ simultaneously brings about a ‘politicization of science’ ... political disputes tend to become technical disputes. (1996: 6)

However, whether or not this blurring of boundaries between science and politics is useful or effective is still unclear. In her case study of Ukrainian citizenship in the wake of Chernobyl, Adriana Petryna observes that the “spheres of scientific production and politics are in a constant process of exchange and mutual stabilization” within the modern state, suggesting that the blurring may be necessary to maintain order (2004: 271). David Guston also argues that intentionally separating science and politics from each other makes the policymaking process

less productive and effective (2001). I will specifically investigate this claim through my illustration of the MMC policymaking process in SANAC.

In order to carry out this study, I must address the most recent research from STS on public participation in scientific governance. While participatory governance is currently a popular topic within social science disciplines, it is rare for publications outside of STS to meaningfully explore public participation within scientific governance. In addition, many of those publications analyze this topic through the frame of environmental politics as opposed to health policy and politics.⁵ Only one major publication so far, Baccaro and Papadakis's *The Promise and Perils of Participatory Policy Making*, analyzes the participatory governance structure of the South African National AIDS Council, or SANAC. However, it does so solely through a conventional sociological frame that is not up-to-date (Baccaro and Papadakis 2008). Thus, in this chapter I introduce SANAC as a new point of research for public participation in scientific governance. Here, I present three existing models of this participation from the STS literature.

'Deficit' Model of Public Participation

The first theoretical model of public participation in scientific governance is often referred to as the 'Enlightenment' or 'deficit' model. Presupposing the universality of science, in which scientific knowledge is viewed as homogeneous, objective, and discoverable, this model argues that only elite experts can and should participate in scientific governance—as they are the only population equipped with the proper skills and understanding of science (Irwin 2007; Boudourides 2002). The non-elite public, in contrast, is seen as guided by irrational beliefs and myths about scientific knowledge (hence a 'deficit'), which automatically prevent them from

⁵ A prominent example is Brunner et al.'s study of the public management of natural resources in America (2005).

having any direct say in scientific knowledge production. Thus, there should only be a flow of knowledge from experts to silent and passive citizens (Irwin 1995). An important characteristic within this model is the authority of professional expertise, gained from access to objective scientific knowledge. According to this model, the most effective science-based policy results from the contribution of professional expertise (Holmes and Scoones 2000).

The only existing form of public participation under the ‘deficit’ model rests in official citizen representatives within the state, such as senators or other public officials. It is these few private citizens, chosen by the wider public through elections, who are capable of speaking for other citizens. Often, they are expected to push forward the assumed public desire for scientific-led progress (Irwin 1995; Boudourides 2002). Otherwise, the public is meant to be educated through a top-down, disseminated communication process about scientific and technological developments. This takes place through both official and unofficial means, such as formal education, policy popularization and media reports (Irwin 2007; Jasanoff 2004; Boudourides 2002). Without any public interference, there is a broad assumption that policymakers across the globe will all settle on the same facts of scientific knowledge, leading to a convergence of science-based policies for the environment or for the development of technology (Jasanoff 2004).

While the ‘deficit’ model captures the modern belief of the strict division between experts and lay citizens, it excludes most of the public and fails to take any knowledge outside of professional scientific circles into consideration. Even as scientific knowledge remains a considerable and widely-noted source of authority in both the global North and South, Alan Irwin argues that controversies over politicized scientific knowledge, such as Europe’s collective outcry over genetically-modified crops, have led citizens to lose trust in forms of expert

knowledge that do not accurately represent their lay understandings (Irwin 1995). Similarly, Jasanoff offers up the notion of *civic epistemology*, which she defines as the “culturally-specific, historically and politically grounded, public-knowledge ways” that play an important role in legitimizing knowledge claims in society (2005: 249). With these understandings of lay knowledge, it is no longer a matter of simply educating the public, but allowing them to shape scientific knowledge production. Another important note is that a lack of public participation on matters that significantly impact human populations no longer acceptable at a time when public participation is increasing rapidly within other public sectors (Bucchi and Neresini 2007).

Public Debate Model of Public Participation

The second model of public participation in scientific governance, known as the Public Debate model, places a great emphasis on the exchange of knowledge between professional experts and lay citizens. This model seeks to involve diverse lay populations in order to build a more deliberative, democratic state (Elam and Bertilsson 2002; Boudourides 2002). Accordingly, this model privileges lay knowledge and urges research scientists to reflect on their responsibilities to the world, challenging them when their research threatens human populations in any way (Kerr et al. 2007). While scientific and professional expertise still remains an essential component to this model, there is the assumption that it—in addition to lay expertise—is itself a form of local knowledge, enriched by interaction with other knowledge and expertise (Boudourides 2002).

Public participation within the Public Debate model works through a variety of methods, most often through deliberative and inclusionary processes (DIPs) in which traditional expert-driven policymaking is bypassed in favor of dialogues with lay communities. Typically, DIPs are

utilized to establish some form of consensus between citizens and scientists for the sake of more effective policy (Holmes and Scoones 2000). DIPs do not take on any one specific structure, but most take into account Jurgen Habermas's idea of "communicative rationality"—that is, consensus among parties that is reached not through an appeal to logic or science, but through an exchange of historically-based, subjective understandings of knowledge (Habermas 1984; Holmes and Scoones 2003). Other forms taken by the Public Debate model include community-based and participatory research, consensus conferences, public consultation hearings, and citizen juries (Chopyak and Levesque 2002; Boudourides 2002).

Despite the Public Debate model's intention to improve human communication, there are still several strong critiques of this model. First of all, this model frequently supposes that public participation is a unique, one-time event that does not allow for active or sustained dialogue between experts and lay publics (Bucchi and Neresini 2007). In addition, the model does not account for potential gaps due to power relations; without any dedicated support to non-elite or marginalized populations, it is unlikely that public participation in scientific governance and knowledge production would be anything more than public consultation (Irwin 2007). Moreover, the full acceptance of professional scientific expertise within the DIPs creates an inherent power differential that lay populations may never challenge (Holmes and Scoones 2000).

Another argument against the Public Debate model asks whether true consensus is ever possible in these contexts. Even if an agreement is reached, there is a strong possibility that the values, interests, and even voices of some participating populations will be silenced rather than taken into account (Irwin 1995; Bucchi and Neresini 2007). Kerr et al. also points out that existing DIP forums, often due to their firm structure and high expectations of lay participants, treat lay positions and opinions "as an adjunct, rather than an alternative, to expert dominance of

discussion and decision-making” (2007: 407). Rather than incorporate lay knowledge, these forums continue to privilege technical knowledge and treat lay knowledge as an inherently inferior form of knowledge (Kerr et al. 2007).

Model of Hybrid Collectives

The final model of public participation in the framework of scientific governance is commonly referred to as the Model of Hybrid Collectives. Here, Sheila Jasanoff’s idiom of the co-production of scientific knowledge comes to life. Jasanoff suggests that with the eventual integration and interdependence of professional experts and lay publics in society, new instruments and techniques for knowledge production will be “co-produced” (Jasanoff 2004: 3). This process thus allows for the shifting—and in some cases, dissolution—of strict boundaries surrounding professional expertise and lay knowledge (Jasanoff 2004; Irwin 2007). Through the co-production of scientific knowledge, then, social identities are capable of shifting between lay citizens and experts. Moreover, power is increasingly recognized as produced within certain practices and interactions rather than in pre-determined locations, such as the laboratory (Irwin 2007). Over time, these Hybrid Collectives, or heterogeneous networks of lay and expert citizens, begin to form and influence scientific governance from within. This is illustrated best by Steven Epstein’s account of American AIDS activists altering the direction, focus and efficiency of scientific research on HIV and AIDS (Epstein 1996; Jasanoff 2004). Often, these forms of patient groups involve themselves directly within scientific governance, representing patients on official policymaking committees (Boudourides 2002).

Even though this model of public participation has only emerged in the past two decades, many critics within STS have argued over the model’s assumptions and beliefs, especially

whether or not lay experience translates into expertise (Prior 2003). One major argument is that the existence of supposed Hybrid Collectives is few and far between; these participatory structures are only able to form in very rare circumstances, such as the example provided by Steven Epstein, and they are not replicable on a global scale (Irwin 2006). Another critique suggests that the public will never inhabit designated expert-only spaces, such as the laboratory or the hospital operating room; as a result, the co-production of scientific knowledge may not be an actual possibility, despite any other influence that lay citizens can hold over scientific governance and decision-making (Prior 2003). A final critique rests in the belief that the privileging of *lay expertise* is a dangerous contradiction that could impose public misinformation on scientific knowledge production (Collins and Evans 2002).

These three theoretical models of public participation in scientific governance suggest a variety of outcomes for public policy—from the disruption of science-based policy by a misinformed public to the enhancement of scientific knowledge through its co-production.⁶ As this thesis explores a scientific advisory council that promotes the contributions of both lay citizens and professional experts, the Public Debate model and the Model of Hybrid Collectives hold especially relevant. Rather than dismissing the Public Deficit model of scientific governance, however, I will continue to hold it as relevant and informative. As stated before, South African society maintains a variety of perspectives on the relationship of western science to society, and a complex picture of scientific governance is sure to emerge. The task at hand, then, is to examine SANAC through many complex frames and to address whether or not its form of participatory governance disrupts pre-existing models of scientific governance.

⁶ Of course, I must emphasize that the implementation of one model of public participation in scientific governance does not automatically imply a specific, determined policy or knowledge outcome.

The Past, Present & Historical Memory

Before the next chapter, an introduction to the historical approach and context of the entire thesis is necessary. After all, this thesis stands primarily as an historical account of the status of scientific authority and expertise throughout the HIV/AIDS epidemic in South Africa. I do not intend to provide an authoritative narrative of the controversy over President Thabo Mbeki's "denialism," nor do I write a complete description of how TAC and its allies successfully challenged and altered the post-apartheid state; these two parallel narratives are provided elsewhere.⁷ Rather, I will draw on a multitude of sources in order to show how western biomedical science was privileged, challenged and subsequently re-privileged by the South African state and its publics. Starting with the replacement of indigenous knowledge systems by colonial science under the British colonial empire, this thesis traces the standing of western science through the apartheid and post-apartheid states, in addition to the impact its enhanced status has had upon public knowledge and public policy.

First, a reorientation in the approach to this history is vital. Traditionally, historians of colonial science or biomedicine have offered accounts that place Europeans and Africans, in addition to their respective cultures, in opposition. Destructive power relations under colonialism and apartheid among indigenous populations and European explorers certainly contributed to this perceived polarization; thus, it is no surprise that the scientific practices of the European population were privileged far and above similar practices from indigenous populations (Dubow 2006). The result has been an undermining or even silencing of indigenous knowledge; this legacy is not easily rectified by the post-apartheid state, which struggles to stop the artificial removal of tradition from modernity (Xaba 2007). Instead of continuing this false dichotomy,

⁷ See Nattrass (2007), Cullinan and Thom, ed. (2009), and Robins (2004).

this thesis seeks to blur the lines, placing the past within the present in order to arrive at a more complete reading of the history of science and biomedicine in South Africa.

This interpretation of history is rooted in Michel-Rolph Trouillot's *Silencing the Past*, an account of Haitian historiography that seeks to trouble traditional accounts of the Haitian Revolution and shows how, within human memory, "the past does not exist independently from the present" (1995: 15). This relationship between memory and history finds a parallel within what anthropologist Didier Fassin refers to as the "embodiment of the past" in South Africa (2008: 317). As Fassin describes, this relationship involves "the way in which individual trajectories and collective histories are transcribed into individual or collective bodies," whether through emotions, diseases, or mourning (2008: 316). In this frame, the memories and histories of colonialism and apartheid in South Africa remain alive today in HIV and AIDS, which continue to ravage individual and social bodies throughout the country. Furthermore, as this thesis reflects, attempts to move beyond the past—what Jean Comaroff identifies as "the postcolonial moment," when freedom finally appears within reach—have only led to new manifestations of the past within the present (2004: 2). Looking to the present, then, also involves a serious excavation of the buried past.

On that note, I call upon Achille Mbembe, who argues that:

...because Africa is moving in several directions at once, this is a period that, at the same time, has been, is not yet, is no longer, is becoming—in a state of preliminary outline and possibility. The mirror reflects a figure that is in the present yet escapes it, that is, at once, in front and behind, inside and outside, above and below, in the depths, and that is hard to nail down because, at some point, it participates in a phantastical sequence. (2001: 241)

Mbembe's text challenges our own constructions of (South) African history. Even with the relatively chronological account presented in this thesis, there is still a constant need to push against a narrative of progress, dichotomies, and stable identities. As stated before, science

remains a contested discipline throughout recent history, and its uptake or rejection by South African politics has always relied upon contextual factors. In addition, just as western scientific knowledge has never been fixed, solidified or completely dominant in South Africa, the same principle of fluidity applies to politics; as stated before, both domains are constantly shaping and stabilizing each other. Any close analysis of science and politics, as undertaken in the following chapters, thus requires an awareness of the past—even a distant or mostly forgotten past—that remains buried in the present and will continue to shape the future.

Historical Overview of South African Citizenship

As raised by my research question, I intend for this thesis to not only illustrate how citizens shape HIV/AIDS policies in South Africa but also to trace how, in turn, these policies shape notions of South African citizenship. Although I have already sketched out a rough definition of citizenship, emphasizing active engagement with the state in moments of need or struggle, I have not yet indicated why citizenship deserves such significance as an object of study in this thesis. I argue that, within new forms of public participation in scientific governance, notions of citizenship are subject to change—and thus, new citizens are likely to emerge and deserve full investigation. As Sheila Jasanoff asserts, “it is no longer possible to deal with such staple concepts of democratic theory as citizenship... without delving into their interaction with the dynamics of knowledge creation and use” in the democratic state (2005: 6). This argument, I believe, also applies in the opposite direction.

With its history of both European-led colonialism and the apartheid state, South Africa certainly has a complicated history of citizenship. Under those two forms of government, specifically, the state established most of its non-white population as an entire class of non-

citizens (Mamdani 1996; Worden 2007). Even as the boundaries of the state were prone to adjustment, the formation of separate townships and a migrant labor system for non-white populations drew them in as non-rights bearing humans at the mercy of the South African state (Magubane 2001). As a consequence of these dismal living conditions, both urban and rural communities crafted new forms of citizenship for themselves. At the forefront of these efforts were civic organizations within the townships that relied on resident participation (Mayekiso 1996; Adler and Steinberg 2000). These organizations “presented the liberation project for the first time with a viable and potent internal weapon” for the anti-apartheid struggle (Adler and Steinberg 2000: 5). Furthermore, the participatory governance structures of civic organizations, in addition to people’s courts and economic development institutions, engendered “new organs of people’s power” that planted important roots for emerging notions of citizenship (Mayekiso 1996: 68).

With the rise of the liberal, democratic state in 1994, in addition to the ratification of a brand new Constitution, the government has allowed for the production of new understandings of citizenship. Key to this shift was the expansion and protection of human rights to all South African citizens (South Africa 1996). With its extensive history of public participation, from the participatory process of writing the Freedom Charter in 1955 through its first election manifesto in 1994, the Reconstruction and Development Programme (RDP), the ANC had an obligation to prioritize public participation in the new government (Mayekiso 1996). And, with the formation of participatory governance structures such as the National Economic Development and Labour Council (NEDLAC) in 1995, the ANC provided the clearest signs of its continued commitment to public dialogue on crucial state matters (Makino 2009). Although there are still difficulties in implementing participatory structures on a local or even national level, and major challenges to

South African citizenship have become apparent during recent waves of xenophobia, it is important to recognize that citizenship has undergone enormous changes within a very short timeline (Deegan 2002; Friedman and Kihato 2004). This thesis will then examine some of the transformations of citizenship, but also some of its limitations, in the context of the struggle against HIV/AIDS.

Chapter Three

“Whose science?”:

AIDS, History, and Public Knowledge in South Africa

Introduction

In April 2001, twenty-two year old Vuyiseka Dubula was diagnosed with HIV. Just two years into the first term of South African President Thabo Mbeki, an HIV diagnosis for a resident of Khayelitsha, one of the largest informal settlements in the country, was considered a death sentence. Vuyiseka was told that she had only a few years to live. A few months later, however, Vuyiseka discovered the Treatment Action Campaign (TAC), which had recently set up a branch in Khayelitsha to provide a support network for the HIV/AIDS treatment research study established there. Before long, Vuyiseka was promoted from a daily volunteer in Khayelitsha to TAC's National Literacy Coordinator, where she organized and distributed material on the biology of HIV and anti-retroviral medicines (ARVs). In 2008, only ten years after the founding of TAC, she ascended to its highest leadership role as General Secretary, instantly becoming a global symbol for one of the most prominent AIDS advocacy organizations in the world (Dubula 2009).

Standing in front of the 5th Annual International AIDS Society conference in mid-July of 2009, in the midst of a global economic crisis, Vuyiseka conveyed a message concerning both science and politics, telling delegates that "HIV is not in recession." (Dubula 2009: 3) Of course, her spirited presence, in addition to the speed of such impressive accomplishments, brought up a range of important questions concerning the history of HIV/AIDS in South Africa: How did a young woman living with HIV come to lead one of the most powerful social movements in South Africa? How was an activist who had only recently received her college degree sharing the stage with a Nobel laureate and a former South African President? Who was this woman to tell scientists what was urgent and what was not? In other words, how had the HIV/AIDS epidemic in South Africa transformed notions of history, science, and expertise?

In the previous chapter, I introduced key terms, discussed the relationship between science and politics, and offered a preliminary historical overview of South African citizenship. In order to illustrate how these concepts and relationships actually manifest themselves within post-apartheid South Africa, especially within the context of the South African National AIDS Council (SANAC), this chapter seeks to complete three objectives. First, I will place the national struggle against HIV/AIDS within the broader framework of the history of science and medicine in South Africa. Next, I will describe how the South African state and civil society each responded to the HIV/AIDS epidemic. Finally, I will describe how the rise of TAC has specifically contributed to new notions of national citizenship.

Science & Medicine in South African History

Historical accounts of colonial medicine and empire generally involve a series of claims linking the political aims of European colonizers with the intrusion of western science and evidence-based medicine, with science as an essential instrument of the colonial project. Indeed, prominent historian of colonial medicine David Arnold asserts that “all modern medicine is engaged in a colonizing process,” whereby professional European-based medicine claims superiority over indigenous medical traditions through its direct legitimization by the colonial state (1993: 9).⁸ While research on South African indigenous medical systems shows how these bodies of knowledge “had a holistic approach to health and illness, an egalitarian nature in which knowledge was not the preserve of only specialists,” and non-invasive methods of treatment, these systems were disrupted by the imposition of western biomedicine (Xaba 2007:323).

⁸ This thesis does not seek to disprove this theory. After all, medical discourses recovered from the archives reveal frequent attempts to declare the universality of western scientific knowledge and apply this knowledge to the populations and environment found in Africa, often with the result of “creating and reproducing racial and gendered discourses of difference” (Marks 1997: 210).

Twisted conceptions of mainstream biomedical science not only gave some self-worth and pride to the actors within the colonial state, but it also provided justification for the segregation of indigenous populations (Dubow 2006).⁹ The direct result of the introduction of western biomedical science was both the production of a set of medical practices but also a growing separation between medical experts and the lay public in South Africa.

Throughout colonialism and apartheid in South Africa, this divide between the white elite experts and the non-white public grew substantially. European settlers presented South Africa as a new site for the production of scientific knowledge through experimentation, and scientists seized this opportunity. As David Arnold notes, “science delineated the relationship of power and authority between rulers and ruled” under both colonialism and apartheid (1993: 2). In so doing, scientific practice granted further legitimacy to European expert scientists, who noted differences between themselves and their African subjects (Dubow 1995). Scholars Zine Magubane and Saul Dubow build upon this notion and demonstrate individually how the western scientific discourse of tropical medicine, inextricably linked to western scientific authority due to its foundation in the European metropole, gave South African settlers the power to construct—often, by themselves—an image of Africa as a new and foreign world to be used for their own purposes (Magubane 2003; Dubow 2006).

White-dominated colonial science had remarkable continuity under the Afrikaner-led apartheid government of the twentieth century, where western science served as a unifying force for white rule. Anthony Butler and Didier Fassin also note how concurrent public health measures before and under apartheid, such as the 1897 Public Health Act which served as the

⁹ Gilbert and Gilbert note that “there is evidence to suggest that in the second half of the 19th century western-white healers did not treat traditional indigenous healing and healers with the disdain and arrogance apparent in later years...[but] this co-operation disappeared during the apartheid years due to a marked government bias towards western medicine” (2004: 253).

first legal segregation policy in South Africa, were used to justify racial separation and control the growth of the black population (Butler 2005; Fassin 2007). Despite international condemnation of brutal apartheid policies, the Afrikaner government still viewed its state-of-the-art science and medicine as evidence that South Africa should rank among the most developed countries of the time (Dubow 2006).¹⁰

The implications of this heavy faith and investment in western scientific practices in South Africa are widespread. As settlers entered South Africa and moved into the interior of the continent, their authority was mirrored by their accompanying scientific practices. Western science and notions of expertise, as a result, became further entrenched in South African society (Dubow 2006). Indigenous black populations were purposefully excluded from the institutions that produced this expertise, leading to an extreme imbalance in scientific education between the white and black populations in South Africa—a legacy that still exists today.¹¹ Today, the majority of scientific experts and medical practitioners in South Africa remain upper-class, white professionals, a stark contrast to the small amount of black or non-white scientists and doctors.

As Saul Dubow writes, though, “western science can no longer be seen as an all-conquering set of truths, a definer of ‘advanced against more ‘primitive’ civilisations” (2006: vi). Accordingly, basic notions of *expertise* and the *public* in South Africa must be problematized. Even as western science is prioritized by higher education and scientific research institutions, due to the demands of the global economy, there is considerable state-led effort to encourage indigenous knowledge production, especially traditional healing practices. The intended outcome should be a country of pluralistic medicine, where western science is not considered superior to

¹⁰ One important example is the first live human heart transplant, conducted at the Groote Schuur Hospital in Cape Town in 1967 (Dubow 2006).

¹¹ As a recent New York Times report notes, South Africa’s education system “is often failing the very children depending on it most to escape poverty” (Dugger 2009).

any other set of beliefs. Even as the post-apartheid era brings forth a shift in public knowledge, however, western scientific knowledge production remains largely a white-controlled enterprise. This observation becomes extremely clear through the lens of the AIDS epidemic in South Africa.

The ‘Early Years’ of AIDS in South Africa: 1981-1999

AIDS did not happen overnight in South Africa. Predominantly social and biomedical-driven accounts suggest that the HIV/AIDS epidemic occurred through a mixture of multiple sexual partnerships and through a lack of access to proper contraception. This chapter argues, instead, that the epidemic was the result of historical and structural forces converging with the emergence of the HI virus in the beginning of the 1980s. Although few proper accounts of the history of HIV/AIDS in South Africa exist, the conditions under apartheid that enabled the spread of HIV can easily be drawn from Randall Packard’s accounts of the political economy of disease in South Africa. In his texts White Plague, Black Labour and The Making of a Tropical Disease, Packard argues that the South African tuberculosis and malaria epidemics of the twentieth century were both “a product of a particularly pathological intersection of political, economic, and biological processes,” with large culpability falling upon the apartheid state and its negligence of black populations, especially migrant workers, for several decades (1989: 19; 2007). The “hidden violence” of the apartheid state, as Shula Marks and Neil Andersson describe in detail, was in:

...the decimation of the black population by preventable diseases of infancy; the systematic destruction of family life and human health under the migrant labour system; the inadequate protection of workers' lives and safety; the deep insecurity and violence of township life; and the humiliation and degradation forced upon the majority of the population as second class citizens. (1987: 177)

These same conditions provided the foundation for HIV/AIDS; as Marks concluded later, HIV/AIDS “was a pandemic *waiting to happen*” (2002: 17, emphasis mine).

Of course, this conclusion arrives only in hindsight. Even after the first case of HIV was diagnosed in South Africa in 1982, the virus was barely noticed by health officials and the apartheid state did not take much action. The general global perception in the 1980s was that HIV/AIDS only affected homosexual men—a population mostly ignored or suppressed by the apartheid state (Mackintosh 2009). Moreover, as the incidence of HIV/AIDS grew throughout the non-white South African populations, some Afrikaner politicians began publicly celebrating the virus as a method to control the growth of the black population (Butler 2005). Later, the political struggles and rising violence over control of the South Africa state effectively obscured the threat posed by HIV. The cruel irony of the new South African democracy, of course, was the emergence of a brand new threat to the stability of the country: AIDS.

By this point, there was little political support for HIV prevention and treatment measures. The first National AIDS Plan of the government, agreed upon during the transitional period in 1992, was underfunded and caught up in bureaucracy despite the support of the first Minister of Health, Nkosazana Dlamini-Zuma (Gevisser 2009: 277). The only major initiative carried out at this time was *Sarafina II*, an AIDS awareness play designed to tour the country. Yet, even that project was immediately criticized and abandoned by civil society actors after over 14 million ZAR of government funds—an astronomical figure at the time—was spent for what was considered an ineffective and confusing production (Mackintosh 2009). No other effective measures to counter the underlying causes of the HIV epidemic were taken on at the national level at this time.

Even if this lack of action signaled “the demise of a shared vision for AIDS in this country,” there still had not yet been any challenges to the orthodox science underlying conventional understandings of AIDS causality (Fassin 2007: 40). Unlike in America, where scientists such as Peter Duesberg notoriously criticized the scientific establishment over the claim that HIV was the direct cause for AIDS, South African scientists and leaders did not initially question the underlying scientific assumptions and expertise surrounding HIV and AIDS (Epstein 1996; Mackintosh 2009). One of the first instances of questioning HIV as a cause of AIDS in South Africa, then, was the national controversy over Virodene, a locally-produced pill which its Afrikaner producers, Olga and ‘Zigi’ Visser, claimed was able to completely eliminate HIV and AIDS from the human body (Myburgh 2009; Russell 2009; Gevisser 2009).

According to James Myburgh, Virodene was an attractive promise in the early post-apartheid era of 1995. As a medicine produced in South Africa, it was presented by the Vissers as an alternative medicine with the potential to “racially affirm the new government, and disprove once and for all Western stereotypes of black African capacity” (Myburgh 2008: 4).¹² Expectations were raised within the Mandela government—especially with his Deputy President, Thabo Mbeki—and direct action was taken by the ANC to work around typical drug regulatory authorities in order to approve Virodene (Myburgh 2008). Eventually, Virodene was revealed to be nothing but a mixture of industrial solvent produced by two lab technicians with no toxicological experience (Myburgh 2008). This revelation left the ANC government embarrassed by its support of pseudo-science, but undeterred in its drive for its own cure to the HIV epidemic.

¹² It is also possible that Virodene’s appeal was in direct response to the 1995 Rugby World Cup, where South Africa’s win on the global stage provided a form of ‘racial affirmation’ for the new government.

Thabo Mbeki and “Denialism”: 1999-2006

The history of (what is referred to as) AIDS “denialism” in South Africa requires some context. Thabo Mbeki may leave a mixed legacy as President of South Africa, but only an analysis of Mbeki as both President and as his own ‘public’ allows for a more complete understanding of his rhetoric and actions in this narrative. As a figure literally born into the struggle due to his parents’ heavy involvement in the ANC and South African Communist Party (SACP), Mbeki was primed for political involvement at an early age. Educated abroad in England and Russia, he worked for the ANC in exile as both a high-level operative, speechwriter, and a lead diplomatic representative (Gevisser 2009).

Mbeki thus served as a ‘public intellectual’ within the ANC, earning higher positions of power as the struggle against apartheid intensified and respect for him grew (Gevisser 2009). This was widely apparent during his reign as the Deputy President under Mandela. During this period, he delivered several speeches that revealed his vision of a triumphant African Renaissance, a bold attempt to achieve “the total emancipation of our continent from the social, political, and economic legacy of colonialism and apartheid as well as to reclaim our history, identity, and traditions” (Mbeki 2006: 3). In his speeches, Mbeki sought a common link with other African nations which shared the brutal violence of colonialism; this bond would enable a powerful unity among nations to transcend the limits placed upon the continent from the West. For Mbeki, AIDS was a global threat to the future of Africa, but one that had to be confronted with a uniquely African solution (Posel 2008: 20).

The following events of President Mbeki’s history have now been told and retold, as if to cement some inconceivable fact of history into a collective memory.¹³ Mbeki’s first year as

¹³ Again, I do not mean to provide an authoritative account of Mbeki’s rhetoric. Rather, my description of his “denialism” allows for an informed discussion of how scientific authority was challenged.

President involved e-mail contact with prominent AIDS dissidents David Rasnick and Anthony Brink, out of which emerged a joint understanding that HIV does not exactly lead to AIDS. Though repeatedly discredited by prominent AIDS scientists over the past two decades, Brink's arguments spoke to Mbeki's need to problematize the largely biomedical understanding of HIV/AIDS dominant at the time (Epstein 1996; Posel 2008).

Following this contact, Mbeki articulated a multi-faceted argument through both private letters to current heads of state and public speeches against conventional AIDS science in line with his vision of the African Renaissance. First, he joined AIDS dissidents in rallying against the idea that HIV was the sole cause of AIDS and that ARVs were more harmful than beneficial to individuals living with HIV/AIDS (Posel 2008). Second, he argued that Western theories and histories of HIV—in where he perceived a largely homosexually-transmitted trend—were not applicable to the heterosexual epidemic recorded throughout the African continent (Mackintosh 2009; Posel 2008). Third, he viewed the racialized HIV prevalence and discourse as the result of structural causes, not a strictly biomedical narrative (Mackintosh 2009). These three arguments were completely in line with the overall discourse of the ANC and its partners in the anti-apartheid struggle; as Anthony Butler notes, the “history of apartheid division, exile, and racist science predisposed numerous powerful and rational decision-makers to doubt the benevolence and coherence” of a purely biomedical explanation for the spread of HIV/AIDS (2005: 612).

Thus, through his background as an intellectual within the anti-apartheid struggle and his later self-education in dissident AIDS science, Mbeki had developed an extreme distrust of the western scientific establishment. With the assistance of his loyal Minister of Health, Manto Tshabalala-Msimang, Mbeki set up the Presidential AIDS Advisory Panel in 2000 to discuss the supposed complications of AIDS science (Nattrass 2007). With 37 members, the panel

comprised equal amounts of scientific experts and AIDS dissidents. Through the creation of this panel, Mbeki effectively re-politicized AIDS science, using his position of political and social authority to present an image of disorder within a portion of western science (Nattrass 2007; Cherry 2008; Posel 2008). The most contentious result of this engagement with discussion (rather than policy) was the refusal to distribute life-saving treatment for South Africans living with HIV and AIDS (Nattrass 2007).

Another clear result of Mbeki's questioning of scientific authority was the opening up of a public space that attracted a variety of individuals and organizations with the same critical questions. As mentioned before, Mbeki found a close ally with South African lawyer Anthony Brink, who openly characterized the pharmaceutical enemy and its products, ARVs, as a distributor of poison; Brink later received the support of both Mbeki and Mbeki's own personal doctor, Dr. Sam Mhlongo of the Medical University of South Africa, to launch his own advocacy coalition, the Treatment Information Group (Cullinan 2008). Another notable individual within this movement was Dr. Matthias Rath, a German doctor and businessman, who established his own alternative medicine operations in the Khayelitsha township (Cullinan 2008). In 2005, these two figures joined forces when Dr. Rath employed Anthony Brink to bring together large, biomedical science-critical organizations into his fold, including the Traditional Healers' Organisation (THO), the South African National Civic Organisation (SANCO), and the National Association of People Living with AIDS (Napwa) (Cullinan 2008).

The question remains, then: why was this public debate over AIDS science so convincing to both South African politicians and the greater society? Certainly, Mbeki's own critique of scientific authority, as contextualized within his own understanding of South African history, may have been significantly boosted by the social authority afforded to him by his status as one

of the ANC elites. Furthermore, this firm distrust of western science could have some roots in the evident backlash against scientific authority and expertise, as described by Ulrich Beck's account of the emerging "risk society" (Beck 1992: 1). However, the popularity of Dr. Rath's alternative medicine scheme in the Khayelitsha township probably had more to do with local concerns about national political authority rather than its strong connection to the Mbeki government (Colvin and Robins 2009). As mentioned before, Dr. Rath's close collaboration with local-level civic organizations in the townships allowed him simultaneous access to the highest and lowest levels of political control. In the post-apartheid era, according to Colvin and Robins, civic organizations such as SANCO have grown increasingly discontent with the centralization of and alienation from political power by the ANC government; Dr. Rath apparently tapped into this disaffection with political authority by framing his critique of western science within the powerful community sentiments (2009). Thus, the public questioning of scientific authority was also inextricably tied to larger societal concerns about South African society and politics.

TAC and "Responsibilised Citizenship": 1999-2006

The backlash against Mbeki's public efforts to debunk scientific authority was quick and widespread in South Africa. Most notably, anti-apartheid and gay rights activist Zackie Achmat enlisted a group of friends to protest for increased HIV/AIDS treatment on Human Rights Day, December 1st, 1998; this protest evolved into one of the most prominent AIDS advocacy social movements in the world, the Treatment Action Campaign (Mackintosh 2009; Robins 2008).¹⁴

¹⁴ In pushing for TAC's status as one of the most successful AIDS advocacy movements, I must also recognize the global context in which it emerged. Not only did TAC build upon the foundation of the American AIDS movement (Epstein 1996), but also the work of AIDS activists in Brazil who "forced the government to draft two additional legal articles that would allow compulsory licensing of patented drugs in a public health crisis" (Biehl 2004: 115).

TAC's message was clear from the start: there was a need to follow the global biomedical understanding of HIV/AIDS science and to provide ARVs at no cost to South African citizens, per the liberal requirements of the South African Constitution. As Steven Robins concisely summarizes, TAC "drew on arguments about rights and responsibilities and moral and scientific truth in their responses to what they claimed was President Mbeki's AIDS denial" (2008: 101). Through organizing mass grassroots mobilization, claiming the moral high ground, and teaching basic scientific literacy to those affected by the HIV/AIDS epidemic, TAC enlisted the support of thousands of citizens from all classes and colors for protests and it effectively empowered those living with HIV or AIDS to become effective advocates for the treatment that they needed (Robins 2008).

In thinking through the success of TAC in galvanizing significant civil society action, it is important to recognize the origins of its defining characteristics. Notably, two of its perceived major strengths, its mass mobilization capacity and pursuit of the moral high ground, link TAC directly to the anti-apartheid struggle of South Africa (Hodes 2009; Fassin 2007). The utilization of *toyi-toyi* dancing during protests, the adaptation of 'struggle songs,' and the practice of politicizing funerals to garner public attention to the cause—among many other protest tactics—reveal the extent to which the political culture of the past is brought forward for the purposes of the present (Hodes 2009; Robins 2008). While many of these mobilization strategies are linked to the United Democratic Front (UDF), the prominent anti-apartheid organization which brought together members from across the racial, ethnic and class spectrums, TAC also has an incredibly explicit link to the strategies of the ANC (Fassin 2007). The most important link is the common pursuit of the moral high ground (Colvin and Robins 2009).¹⁵ As TAC founder Zackie Achmat

¹⁵ Another unexplored connection between the two organizations is the notion propagated by the ANC's Science Desk, in the 1980s and 1990s, that there should be 'Science for All.' (Augusto 1995).

claims, morality is both a basic organizational principle and an important resource used to appeal to diverse constituencies in South Africa. Similar to how the ANC has viewed its moral underpinnings as crucial to its struggle for a just society, TAC strongly believes in the capacity of a common morality to persuade citizens to join its fight for HIV/AIDS treatment access (Hodes 2009).

Another major strength of TAC has been its science-positive approach and its concurrent production of expertise. From its inception, TAC has strongly advocated for modern scientific approaches to HIV/AIDS treatment, especially the wide distribution of antiretrovirals (ARVs), earning global praise for TAC for its upholding of scientific truth. As Helen Schneider notes, a notable feature of this AIDS activism is “its ability to obtain and transmit expert knowledge about scientific and policy developments,” especially through its middle class base in various South African professional communities (2002: 158). TAC always collaborates with partners with diverse forms of expertise; for example, TAC has utilized the legal knowledge of the AIDS Law Project (ALP) for its court cases against the government.

At the same time, TAC engenders its own unique form of lay expertise among its membership. Through TAC’s longstanding Treatment Literacy programs, held across the country in order to provide citizens the most accurate information about HIV/AIDS prevention and treatment, citizens living with HIV/AIDS are empowered to discuss AIDS science with authority and also understand the specific benefits and disadvantages of each form of HIV/AIDS treatment (Robins 2005). In addition, citizens provide TAC with the lay interpretations of AIDS and illness that prevent broader access to health care (Robins 2005). This feature has consequently brought a reframing of scientific authority to South Africa, whereby the public no longer views scientific knowledge as exclusively for elite professionals but also for public understanding.

Attached to this scientific literacy program is the notion of “responsibilised citizenship,” specifically engendered by TAC through its liberal, rights-based discourse (Robins 2008). As Robins notes, TAC produces and promotes this ‘responsibilised citizenship’ in South Africa “whereby ‘targets’ of HIV prevention/treatment programs are required to develop new ways of being responsible in their sexual lives, diets, lifestyles, and adherence to treatment regimes and medical check-ups” (von Lieres and Robins 2008: 55). This phenomenon is not restricted to South Africa. Largely as a result of the globalization of HIV/AIDS, community-based AIDS treatment organizations across the world have increasingly drawn on similar practices of personal responsibility and self-help; in turn, these practices shape new forms of health citizenship, characterized by political claims and demands from the state (Robins 2008). Later chapters examine the implications of this new form of citizenship.

Battles over Boundaries

Through national legal victories that first provided affordable ARV treatment for pregnant mothers and later for all citizens living with HIV, TAC gained crucial national and international support for its cause (Posel 2008). The court case over access to PMTCT (Prevention of Mother-to-Child Treatment) programs, which forced the government to provide proper anti-HIV medication to pregnant women living with HIV, is cited by TAC members as one of its defining victories (Hodes 2009). Additionally, the victory “showed the significance of constitutional court cases as a formal channel for strengthening civil society [and of] combining formal litigation with protest” (Kumiko 2009: 122). Later, TAC challenged Dr. Rath in the same court after uncovering his sham operations in Khayelitsha. Although Dr. Rath claimed that his

self-produced vitamins provided a cure for HIV/AIDS, TAC's legal challenge on account of false advertising was successful, further advancing the legitimacy of TAC (Cullinan 2008).

Even with these legal victories, TAC still faced an enormous challenge from the stubborn national government. However, I would like to be clear that this challenge did not take the form of a battle between state and civil society. Rather, Zackie Achmat and his TAC associates were careful to avoid labeling themselves as enemies of the state (Kumiko 2009). TAC's heated discourse was instead aimed directly at who they viewed as the "denialists" and sponsors of pseudo-science: President Mbeki and Health Minister Tshabalala-Msimang (Robins 2005). Furthermore, TAC explicitly advanced an agenda of "strategic and critical engagement" with the state in which it alternately supported the government (in a lawsuit against international pharmaceutical companies) and critiqued its inability to implement important HIV/AIDS treatment policies (such as the PMTCT and ARV programs) (Robins 2002). TAC's actions against the state began to indicate a battle not just over science but also over the boundaries of citizenship.

The lack of much direct communication between the state and the civil society during this era signaled another clear fact: as Anthony Butler explicates, the two sets of actors were pursuing two separate, if co-existing, intellectual paradigms. While TAC followed a 'biomedical-mobilisation' paradigm that stressed its pro-science, pro-activism position, President Mbeki enlisted a 'historical-sociological' paradigm that recalled the South African past (Butler 2005). As evidenced by his public and private rhetoric, in addition to an ANC-sponsored document linked directly to Mbeki, *Castro Hlongwane*¹⁶, Mbeki existed within a frame in which the past lived within the present. His rhetoric was undoubtedly inspired by his understanding of the

¹⁶ As Steven Robins describes: "*Castro Hlongwane* reads as an African nationalist defence of the AIDS dissident position in the face of what its authors claimed was a racist representation of AIDS as a 'black disease' associated with... the inability of Africans to control their sexual appetites" (2004: 660).

violent history of colonial and apartheid biomedicine, as recounted above (Fassin 2007; Mbali 2004a). Since the biomedical science dominating AIDS research and championed by TAC did not move beyond racist depictions of Africans, Mbeki sought and found an alternate ‘public’ space for his ideas within the dissident science.

Furthermore, the evidence from this struggle also indicates that TAC was not interested in producing a battle against the state; indeed, TAC was more interested in engaging the state throughout the struggle. In the early years of the post-apartheid era, after all, it was both rare and bad-mannered to criticize the same government that had successfully led the anti-apartheid struggle. As the ANC government made a marked shift toward neoliberal economic strategies which left civil society out in the cold, however, organizations and social movements found themselves more willing to speak out against its policies (Makino 2009). Throughout this time, TAC mostly avoided direct criticism of the ANC government. Rather, TAC voiced concerns through formal channels such as the National Economic Development and Labour Council (NEDLAC), a participatory structure designed by the ANC government to promote public participation, and later the South African National AIDS Council (SANAC) (Makino 2009).

In looking back on this timeline, it is easy to think of TAC as a ‘winner’ in a supposed battle with the state over scientific authority. This is not exactly true. Rather, I argue that what TAC has achieved is not a victory within any ‘science wars’ but a reshaping of South African notions of citizenship and scientific authority. As mentioned before, TAC popularized a discourse surrounding ‘responsibilised citizenship’ in which South Africans became more responsible for their everyday lifestyle choices, especially regarding health (Robins 2008). Furthermore, scientific authority in South Africa has been reasserted by TAC through its display of and performance of expertise formal and institutional channels (Richey 2008).

A Restructuring of the Struggle?: 2006-Present

What is evident from this entire sequence of events is the constant government approval or support of science-critical efforts. Even in 2006, Health Minister Manto Tshabalala-Msimang appeared at the International AIDS Conference in Toronto with a government-approved display of vegetables and vegetable products, including garlic, beetroot, and olive oil—the result of a close relationship with Dutch citizen Tine van der Maas, who existed within the same network as Brink and Dr. Rath (Posel 2008; Cullinan 2008). Prompted by publicly-stated critical comments of the ANC government’s lack of scientific support from Stephen Lewis, the United Nation’s Special Envoy for AIDS in Africa at the time, Tshabalala-Msimang famously responded with the question: “Whose science?” (Posel 2008). Although Mbeki and Tshabalala-Msimang no longer made incendiary comments in public regarding HIV/AIDS treatment, Tshabalala-Msimang continued to frame her rhetoric in ways that explicitly avoided disparaged scientific authority (Mbali 2004a; Posel 2008).

However, in 2007 significant changes in the struggle against HIV/AIDS in South Africa began to emerge. Both Mbeki and Tshabalala-Msimang, widely recognized as having caused untold damage to the discourse surrounding the HIV/AIDS epidemic, were no longer visible in public discussions—even if their questions about science had remained unanswered. By the end of 2008, they were almost completely removed from public life altogether, having been forced out of office by an ANC in crisis—and, by the end of 2009, Tshablala-Msimang had passed away from extended illness. Although their presence remains felt, TAC and its supporters have made large steps toward reversing the government’s prior actions. Through significant pressure from civil society, the South African National AIDS Council was completely restructured in early 2007, allowing high-level civil society representation to affect HIV/AIDS policy. Around

the same time, TAC underwent its own restructuring, with former General Secretary Zackie Achmat leaving his position in order to make way for Vuyiseka Dubula and a new generation of TAC activists. Even with new, significant cooperation with the ANC administration of Jacob Zuma, TAC continues to lead civil society initiatives for AIDS advocacy.

One of the most remarkable aspects of the current situation, of course, is the presence of a different attitude towards scientific discourse. Instead of state ownership and the protection of scientific knowledge, the strongest advocates of scientific knowledge are now civil society organizations and actors. This enormous shift is fundamentally tied to the rise of ‘responsibilised citizenship,’ closely related to the notions of “biological citizenship” (Petryna 2004; Rose and Novas 2005) and “therapeutic citizenship” (Nguyen 2005) describing the illness-based movements through which citizens attain lifesaving medical treatment in developing countries. In these movements, citizens are expected to refashion themselves “on the basis of one’s biomedical conditions and responsibilities, worked out in the context of local moral economies” (Nguyen 2005: 142). I argue that TAC’s activists have reproduced this set of relations in South Africa, adopting the strategies of successful political movements (from South Africa and abroad) in order to redraw the boundaries of citizenship and guarantee access to HIV/AIDS treatment.

With this drive towards western scientific knowledge comes a (partial) reorientation away from traditional knowledge systems. As this chapter reflects, traditional knowledge in South African communities has been marginalized by the state in recent centuries in favor of western science. This legacy has played out clearly in the national struggle against HIV/AIDS. While President Mbeki and his administration pushed for a relativist position on traditional knowledge systems, attempting to give it equal status in the fight against HIV/AIDS, TAC and its allies have argued that this relativist position undermines attempts to implement the most

effective, scientifically-based HIV/AIDS interventions (Robins 2008). This is not to say that TAC ignores indigenous beliefs and knowledges. Indeed, TAC has approached traditional healers for assistance, but “has done so explicitly within a paradigm that privileges science” (Nattrass 2007: 181). The result is an approach to health that portrays indigenous beliefs and knowledges as peripheral to science.

This chapter has very concisely provided a glimpse at the history of science and medicine in South Africa and has incorporated it with the history of the HIV/AIDS struggle. Certainly, it took a long time before state and civil society cooperated, and in the meantime, many millions of lives were lost. What has been gained, however, includes a significant victory for civil society members: high-level participation in SANAC. The next two chapters will explore the implications of this victory through an investigation of the internal structure of SANAC.

Chapter Four

“Science, or truth”:

Boundaries, Hybrids, and Epistemic Communities within SANAC

Introduction

At the Opening Session of the International AIDS Society's 5th Annual Conference in Cape Town, South African Deputy President Kgalema Motlanthe's speech was both extraordinary and entirely ordinary. It may not seem fair to compare him with his predecessors, but if Mandela was the charismatic leader, Mbeki the intellectual, and Zuma the contemporary firebrand of the African National Congress (ANC), then how does Motlanthe fit in?¹⁷ After all, Motlanthe is just as important politically as the others, serving in Umkhonto we Sizwe during the anti-apartheid struggle and even spending a decade on Robben Island.¹⁸ However, what distinguished Motlanthe on this July night and what made his speech both extraordinary and entirely ordinary was its content. Lacking both the earnest questions that intrigued Mbeki and the trademark struggle songs that accompany Zuma, Motlanthe's speech was a simple, straightforward plea for top-of-the-line, science-based HIV/AIDS treatment and continued global financial resources for South Africa's renewed fight against HIV/AIDS.

Clearly, Motlanthe's remarks were quite encouraging for both the professional scientific and the lay activist audience present at the IAS Conference. As the Deputy President of South Africa, Motlanthe is also the *de facto* Chairperson of the South African National AIDS Council (SANAC), the government-sponsored advisory organization for national HIV/AIDS policy. Motlanthe's presence and sincere speech, then, was a clear rebuke of the past decades of South African HIV/AIDS policy. As the last chapter detailed, the past decade was characterized by a protracted struggle against the HIV/AIDS epidemic. This led to new public understandings of biomedical knowledge, expertise, and history in a South African context. Through this narrative,

¹⁷ Motlanthe briefly acted as President in the interim between Mbeki's abrupt departure from the Presidency in 2008 and the election of Zuma in early 2009.

¹⁸ Umkhonto we Sizwe was the armed wing of the ANC. Robben Island, the location of a prison just outside Cape Town during apartheid, served as an important rite of passage for anti-apartheid struggle leaders.

the Treatment Action Campaign (TAC) emerged as a powerful community of activists and experts, gaining societal influence through the adoption of ANC strategies and the promotion of ‘responsibilised citizenship.’

This chapter will reveal the contemporary implications of the South African struggle against HIV/AIDS. Keeping in mind the theoretical crux of this thesis, the potential for public participation in scientific governance, this chapter will analyze how civil society actors, both professional experts and lay members, enter into the restructured, participatory structure of SANAC. Through a narrative that parallels and intersects with the historical narrative of the previous chapter, I argue that the restructuring of SANAC has directly led to the further ascent of TAC’s leaders within the policymaking process. I will also discuss how the merging of science and politics within the context of SANAC has major implications for the HIV/AIDS policies of South Africa.

Emerging Boundaries in Post-Apartheid South Africa

Before my discussion and analysis of SANAC, it is essential to place its democratic and participatory structure within the context of governance initiatives in post-apartheid, democratic South Africa. Of great importance is the difficulty of not only creating but also maintaining participatory structures. Echoing the historical framework of the previous chapter, scholar Preben Kaarsholm notes how the legacies of colonialism and apartheid have negatively impacted the potential for a cohesive public sphere in post-apartheid South Africa (Kaarsholm 2009). Even with the dominant-party system led by the ANC, the isolation of non-white populations from white, urban areas enforced by colonialism and apartheid still exists today (Kaarsholm 2009). Still, multiple initiatives throughout the country in the past few decades have demonstrated the

potential success of participatory governance on both a national and local level. During the last decade of the anti-apartheid struggle, for example, new civic organizations promoting public participation and deliberation were crafted in order to improve basic service delivery provisions; after the surprise un-banning of the ANC in 1990, these participatory civic organizations flourished even more with the push for full democratization (Seekings 2000).¹⁹ Since the formal end of apartheid, new forms of governance have been established, with a focus on ensuring a voice for the previously and currently voiceless within matters of public housing, local budget priorities and even public health (Friedman 2006).²⁰

The South African National AIDS Council initially formed during a time of enthusiasm for participatory governance, but also, as I have argued, during an intense national debate over the HIV/AIDS epidemic. A separate organization from President Mbeki's Presidential AIDS Advisory Panel²¹, SANAC was established in January 2000 for the purpose of serving as an advisory council to the government for HIV/AIDS and also mobilizing resources for the new five-year Strategic Plan against HIV/AIDS (Baccaro and Papadakis 2008).

Despite its visible demarcation from the Office of the President, SANAC was effectively ineffective at its inception, lacking basic measures of public accountability and transparency. Additionally, as civil society organizations argued, its initial form lacked many representatives calling for science-based HIV prevention and treatment policies (Thornton 2008). Even with several civil society representatives in this incarnation of SANAC, there were two notable exclusions: TAC and the AIDS Consortium. Neither of these two organizations, the two most prominent HIV/AIDS-focused civil society organizations at the time, was given space on the council (Thornton 2008). Instead, the ANC had chosen the controversial National Association of

¹⁹ Most of these organizations were replaced by the formal institutions of the new democracy (Seekings 2000).

²⁰ Unsurprisingly, criticism of these forums focuses on their concentration in urban areas (Friedman 2006).

²¹ The Panel was designed to explore Mbeki's own set of questions regarding HIV/AIDS, not construct policy.

People Living with AIDS (NAPWA) to act as a representative of the nonprofit sector. This is now interpreted by civil society as an entirely calculated move, as the participation of NAPWA in SANAC gave the impression of as a representative council even though NAPWA was closely aligned with President Mbeki's science-critical agenda (Baccaro and Papadakis 2008). To understand the ramifications of this clear politicization of a science-based advisory council, then, I turn back to the STS literature.

Earlier in this thesis, I established SANAC as a form of scientific governance in which the state and the public interact to form and shape scientific knowledge into policy. In order to comprehend how this specific form of scientific governance operates, I argue that SANAC can be classified as a *boundary organization*. This term was developed by David Guston to delineate the growing set of organizations capable of bridging two separate disciplines or fields, such as science and politics (Guston 2001). According to Guston, boundary organizations "exist on the frontier of two relatively distinct social worlds with definite lines of responsibility and accountability to each" other (Guston 2001: 93). These organizations thus provide a space for *boundary work*, a term used to describe how citizens create and stabilize the boundaries between and preserve the authority of knowledge in two separate fields (Gieryn 1983).

As a boundary organization, SANAC should thus provide adequate space to perform the necessary boundary work to negotiate the boundaries between the fields of science and politics. And its membership certainly suggests this possibility; SANAC brings together policymakers, scientists, and even the public in order to produce policies based on the heavily politicized AIDS science. However, with the deliberate exclusion of non-state actors such as TAC and the AIDS Consortium, the initial form of SANAC was not conducive to the depoliticization of AIDS science. As the ANC government chose all of the council's preliminary representatives, it also

directly influenced the council's policy recommendations. This early politicized agenda, as evident now, brought about a distinct lack of science-based HIV/AIDS policies.

An existing illustration of the German scientific advisory agency the Gezondheidsraad, as undertaken by Bijker et al., proves especially useful for my description of boundary work and how citizens draw boundaries between science and politics (2009). As Bijker et al. write, boundaries are drawn quite strictly and in very specific ways within the Gezondheidsraad. According to this study, participants within the Gezondheidsraad intentionally draw boundaries between science and politics through acts such as the selection of committee members and the development of science-based policies. By deciding who is considered an expert and who is not, participants within this agency “play an active role in making distinctions between scientific knowledge and other knowledge” (Bijker et al. 2009: 40); it is this very distinction which grants authority to the agency. The authors also note that there is a constant redrawing of boundaries from within the agency, with a “controlled access to information, people, [and] interests” shaping what is and what is not considered legitimate knowledge (Bijker et al. 2009: 104). This reflects my previous argument that science and politics are engaged in a reciprocal process of shaping and stabilizing each other. I will now trace how participants in SANAC draw similar boundaries.

Building and Redrawing Boundaries

The first restructuring of SANAC in 2003, in order to create a more participatory and representative structure free from outside political influence, materialized through a combination of pure determination (on behalf of TAC) and pure chance. With President Mbeki withdrawn from the public debate over HIV/AIDS and with several important legal victories to its name, TAC found itself directly responsible for two notable changes to SANAC by 2003. Not only did

TAC gain official representation on the council, but now individual SANAC sector representatives were to be selected by their own constituencies, not by the government (Baccaro and Papadakis 2008). This first restructuring implied the state's willingness to engage with civil society in a more effective manner and hand over significant responsibilities to citizens.

The push for increased civil society representation on SANAC proceeded over the course of the next several years, coming to fruition in early 2007 only after Health Minister Tshabalala-Msimang's widely protested appearance at the International AIDS Society conference in Toronto (Nattrass 2008). After the conference, Tshabalala-Msimang temporarily went on sick leave and was replaced by Deputy Health Minister Nozizwe Madlala-Routledge. Almost immediately, Madlala-Routledge publicly decried the government's lack of effective HIV/AIDS policies as "denialism at the highest levels," and initiated better relations with civil society, especially TAC and the AIDS Law Project (Nattrass 2008: 3). Even though Tshabalala-Msimang returned to office a few months later and Madlala-Routledge was fired soon after, this brief period of reshuffling had two significant results: a brand-new HIV/AIDS National Strategic Plan for 2007-2011, focused on both treatment and prevention, and also a complete restructuring of SANAC (Nattrass 2008). Along with President Mbeki's pending departure from public office, AIDS activists rejoiced at the opportunity to bring South Africa back into the global struggle against HIV/AIDS (Nattrass 2008).

Yet, to what extent did the structure and membership of SANAC really change between 2000 and 2007? Clearly, the growth of an organization from thirty-one government-selected members to an entire plenary representing seventeen unique public sectors, with representatives chosen by each constituency, represents an extraordinary organizational shift towards public participation. Given the lack of an official visual breakdown of the current SANAC structure, I

have crafted my own version to capture my vision of the various committees, connections, and nodes through which SANAC members interact, draw boundaries, and form policy: **Figure 1**. Although there appears to be a strict hierarchy within SANAC reinforced by this picture, I also carefully place arrows denoting the strongest connections and flows. For example, the Secretariat oversees the Civil Society, but there is also civil society representation on the PIC committees.

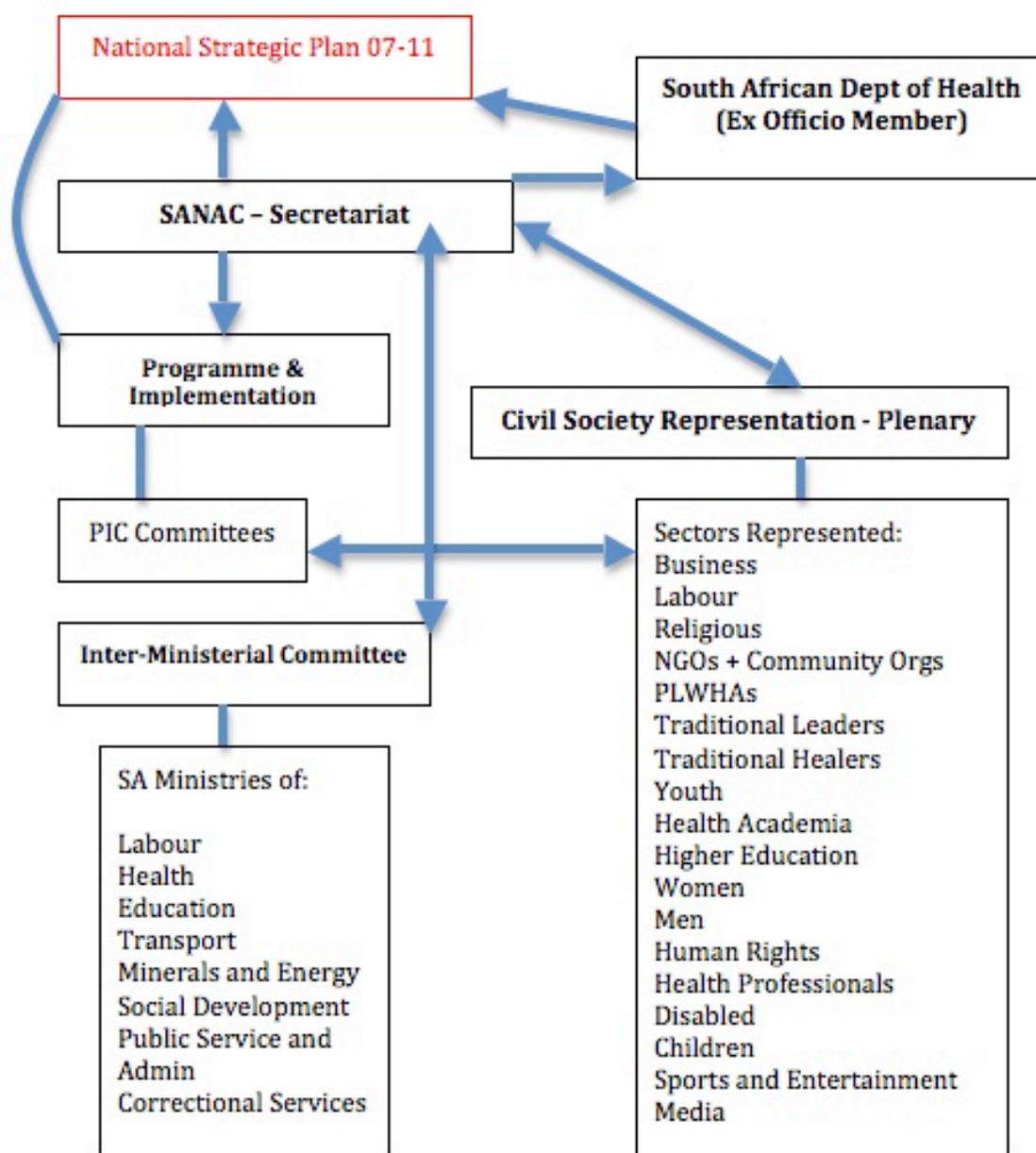


Figure 1

As **Figure 1** shows, SANAC is a prime example of David Guston's boundary organization. It provides the space for politicians to meet with both scientists and representatives of the public to perform the boundary work through which representatives seek to "preserve the integrity and autonomy of science in the face of external challenges" (Irwin 2007: 588). Participants work together outside the direct realm of the South African government in order to produce HIV/AIDS policies. Furthermore, in this context, a policy such the *HIV/AIDS National Strategic Plan for 2007-2011* (illustrated within **Figure 1**) can be considered a *boundary object*: an item familiar enough "to allow members of different communities to work together around them and yet to maintain disparate identities" (Guston 2001: 89).²² The production of specific HIV/AIDS policies through SANAC's committees thus allows representatives to negotiate the terms of science-based policies while maintaining their heterogeneous societal roles.

Even with this intention of maintaining a separation between scientific experts and lay citizens, the restructuring of SANAC has unquestionably led to the redrawing of traditional boundaries between lay citizens and expert knowledge. Through participatory governance initiatives such as SANAC, the South African government acknowledges that public participation in governance is both legitimate and worthwhile; citizen representatives are recognized as capable of participating in the knowledge production of policymaking (Irwin 2007). This unique form of contribution is given names such as "situated knowledge" or "citizen science" (Haraway 1988; Irwin 1995); both Haraway and Irwin describe it as not merely a knowledge base to tap into, but rather as "forms of knowledge and understanding [that] are contextually generated and simultaneously embody understandings of both the natural and social

²² Star and Griesemer first described boundary objects in 1989, identifying them as objects "both plastic enough to adapt to local needs and constraints of the several parties employing them, yet robust enough to maintain a common identity across sites" (Star and Griesemer 1989). Guston elaborates that any object or thing which conveys different meanings to two separate individuals, such as a treaty can be considered a boundary object (Guston 2001).

worlds” (Irwin 2008: 595). This frame is useful for understanding the significance of SANAC’s civil society plenary, the main forum through which scientific experts and lay citizens deliberate. I argue that the structure of this plenary bears many similarities to the Model of Hybrid Collectives described earlier in this thesis; within this model, the combination of lay and expert identities allows for the co-production of scientific knowledge and, ultimately, the loosening of boundaries between scientific and lay knowledge (Jasanoff 2004). The rest of this thesis will examine whether or not this co-production of scientific knowledge really occurs within SANAC.

From Boundaries to Hybrids

By the end of 2007, it appeared as if all of the necessary pieces were in place for a renewed and ambitious push for more effective HIV/AIDS policies in South Africa. With the election of TAC co-founder (and also AIDS Law Project director) Mark Heywood as the Deputy Chairperson of SANAC, civil society representatives were effectively handed leadership of SANAC’s operations from the government. This practically ensured that more public voices would be heard and protected. As Mark Heywood’s assistant, Paul Booth, described to me:

Essentially [SANAC] does include everyone, everyone now has a voice on SANAC... [Our] biggest strength is the way it’s able to pull everyone to the table... [although it] hasn’t used that strength in that way yet... [It’s] getting people in the same room—only now is everyone coming. (Booth 2009)

As Booth mentions, even with a reconfigured structure to prevent the government’s direct re-politicization of science through HIV/AIDS policies, SANAC still faced massive barriers to policy implementation. This reality became evident within the next two years. The HIV/AIDS epidemic in South Africa, as detailed in the South African Human Sciences Research Council’s *HIV Prevalence, Incidence, Behaviour and Communication Survey* in 2008, continued to escalate. Most importantly, HIV prevalence for multiple population groups, including young

women and older men, are still expanding alongside a national decline in knowledge of HIV prevention (TAC 2009). In addition, national funding shortfalls for HIV/AIDS and other public health initiatives were increasingly common, with condom shortages reported throughout the country; the 2008 global economic crisis only provided a further threat to necessary financial resources (TAC 2009). If there was any moment for the state and civil society to work together, now was the time. Yet, how precisely would this cooperation work?

A more thorough and precise analysis of SANAC is thus necessary in order to comprehend how it productively carries out its mission as a boundary organization in this environment. Even as a relatively nascent concept within STS, the concept of boundary organizations has already faced significant critique for its lack of international breadth. Science studies scholar Clark Miller, for instance, argues that the established model of a boundary organization is based entirely on U.S.-based organizations, limiting its geographic range and applicability (Miller 2001).²³ Additionally, attempts to clearly differentiate scientific authority from formal politics through boundary work, which presupposes the distinctiveness of two domains even as it recognizes the fluidity of boundaries, are certain to have only a limited grasp of the situation (Miller 2001). Even if the greater American or South African public recognize science and politics as two distinct fields or sets of practices, research on boundary work reveals that “the distinction of what is and what is not science (or politics)... turns out, in practice, to be quite fuzzy” (Miller 2001: 484). In other words, science is always embedded in politics. Thus, rather than viewing scientific governance initiatives such as SANAC as pure boundary organizations—with rigid delineations between what is considered the political and what is considered the scientific—Miller argues that these initiatives should instead be understood as

²³ Similar to Sheila Jasanoff’s study of national civic epistemologies, Miller argues that the entrenched relationship between science and politics evident within the United States is not truly replicated anywhere else (2001).

elements of *hybrid management* (2001). Here, the process of both combining or detaching the domains of science and politics occurs within an extensive “web of mutually constraining activities and practices” reaching outside the borders of any organization (Miller 2001: 487). In essence, any analysis of a boundary organization must also always focus on the networks and connections surrounding and shaping the boundary organization.

Analyzed through this lens of hybrid management, the policymaking process begins to revolve around the handling and production of *hybrid objects*, or products of two or more domains. A hybrid management perspective, instead of signifying a fixed set of actors meeting in an exclusive site to discuss one agenda, recognizes that several flexible communities with unique knowledge bases compete across several sites to construct both the guidelines they work within and also to produce final, hybrid objects—such as science-based policies (Miller 2001). Policymaking decisions are not solely based on politics or science, but on a hybrid combination of the two. Another major feature of this view is that the relationship between science and politics is never held to be static—and thus, the boundaries established by boundary organizations are “constantly being delineated, criticized, defended, and adjusted over time as participants respond to events” (Miller 2001: 493). For my analysis of SANAC, this perspective indicates a need to understand the influence of co-existing knowledge bases within the comprehensive framework of public participation. Thus, my study shifts to the prominent, hybrid-character communities embedded within and attached to this organization.

Epistemic Communities, Hybrid Knowledge

A significant portion of contemporary STS literature concerns itself with the concept of *epistemic communities*, described initially by science studies scholar Peter Haas as “a network of

professionals with recognized expertise in a particular domain and an authoritative claim to policy-relevant knowledge within that domain or issue-area” (Haas 1992: 3). This definition centers on research scientists or medical doctors, the modern scientific communities viewed as legitimate authorities due to their accumulation of advanced degrees and licenses. The twentieth-century reliance on these communities for policy-relevant knowledge in the United States and Europe would certainly suggest the same (Haas 1992). On the other hand, Knorr-Cetina provides a definition in which epistemic cultures are those professional communities that “make up how we know what we know” (Knorr-Cetina 1999: 1).

Given Haas’s and Knorr-Cetina’s varying standards for what constitutes an epistemic community, in addition to more recent research directions on this topic, I suggest that epistemic communities today must not be uniformly composed of all professionals and instead can maintain a hybrid character (Haas 1992; Knorr-Cetina 1999; Vandormael 2007).²⁴ As it turns out, the most important feature of an epistemic community is an expert knowledge base that does not belong to one or two individual actors, but rests in “the shared thinking... through which the identity of the community is defined” (Boudourides 2002: 10). Additionally, as long as an epistemic community within scientific governance can differentiate itself and can provide some form of knowledge and expertise, gained either through academic degrees or lived experience, it can position itself as a pertinent actor in the policymaking process (Vandormael 2007). As Haas observes, this expert positioning often occurs during periods of great national or global uncertainty (1992).

Yet, even a quick glance at the participatory governance structure of SANAC reveals multiple, coexisting epistemic communities—not just one dominant community. Apart from the

²⁴ Stated succinctly, Haas’ four standards for an epistemic community include “(1) a shared set of normative and principled beliefs... (2) shared causal beliefs... (3) shared notions of validity... and (4) a common policy enterprise” (Haas 1992: 5).

national government-based Inter-Ministerial Committee, which provides a substantial amount of technical and bureaucratic expertise to SANAC, the Civil Society plenary includes a remarkable array of knowledge bases around comparable fields; for example, not only is there a Health Professional sector, but there is also apparently equal space for People Living With HIV/AIDS (PLWHA), Traditional Healers, and Health Academia representatives (SANAC 2010).

Evident within this structure, then, is official state recognition of hybrid expertise. While there are numerous licensed professionals recognized as scientific or health authorities within SANAC, representatives for indigenous knowledge systems, including both Traditional Healers and Traditional Leaders, are also granted equivalent space within the rules and regulations of the organization. The question that arises from this hybrid composition, then, is how co-existing *epistemes*, or knowledge bases, can constructively interact and produce fair and equitable policies for a national, multicultural population. In order to answer this question, I propose that my analysis must look beyond what is listed within the rules and regulations of SANAC in order to examine the dynamics of the predominant epistemic community: the Treatment Action Campaign (TAC).

In the previous chapter, I described TAC as the premier social movement in the post-apartheid struggle against HIV/AIDS in South Africa. However, with the restructuring of SANAC in the past few years, the upper echelon of TAC leadership has very quickly transformed itself into the dominant epistemic community within SANAC (Vandormael 2007).²⁵ To borrow from Mark Wolfson's analysis of the American antitobacco movement, there appears to be tremendous *interpenetration* of TAC into SANAC, as it has become rather unclear "where the movement ends and the state begins" (Wolfson 2001: 145). This interpenetration occurs

²⁵ This understanding of TAC as a epistemic community is paralleled by João Biehl, who describes how Brazilian "AIDS activists left behind antagonism to the state and together with health technicians, epidemiologists, medical and social scientists, economists, and psychologists constituted a new epistemic community within the state" (108).

through the placement of TAC leaders in prominent roles within both organizations. For example, Mark Heywood, the current Deputy Chairperson of SANAC, was a co-founder of TAC and still serves on TAC's National Secretariat, while Nomfundo Eland, the current Chairwoman of the SANAC Women's Sector, simultaneously led TAC's Women's Rights Campaign in 2009. Interviews with TAC officials reveal that TAC leadership has full access to SANAC's plenary meetings, settings in which TAC representatives are often responsible for internal presentations (Hodes 2009; Tomlinson 2009). Additionally, TAC leadership has drafted most of the prominent policies approved by or currently circulating in SANAC; TAC credits itself for writing much of the most recent HIV/AIDS National Strategic Plan, an update of the national HIV testing guidelines, and several other new HIV/AIDS treatment recommendations (Tomlinson 2010).

By framing TAC as the dominant epistemic community within SANAC, I must emphasize that TAC has directly transplanted its science-positive attitude onto SANAC. This is most evident through the passage of policies specifically promoting biomedical prevention methods, such as medical male circumcision (MMC), or even privileging western models of care and treatment. However, I also stress that TAC's epistemic community has consisted mainly of lay citizens who have accumulated a shared base of expert knowledge through self-education and a reliance on external, global networks of scientists and professionals (Vandormael 2007). Thus, I argue that the claimed scientific expertise of TAC's own epistemic community within SANAC is really an *interactional expertise*, designating enough accumulated knowledge in order to communicate and work with experts, instead of a *contributory expertise*, designating enough knowledge to shape the production of expert knowledge (Collins and Evans 2002). Closely resembling the story of American AIDS activists, in which lay communities "found ways of presenting themselves as credible within the arena of credentialed expertise" and ultimately

shaped AIDS-related research and policies, I argue that TAC has used its interactional expertise to place itself in a prime position to coordinate the hybrid management of SANAC (Epstein 1996: 3).

SANAC, TAC & Hegemony

By arguing that TAC exists as the predominant epistemic community within SANAC, I recognize that many other competing epistemes and epistemic communities still reside within SANAC. Yet, what I wish to emphasize is that there may be little to no resistance to the leadership and intellectual approach of TAC within SANAC; there is most likely no other organization willing to endure the same global criticism as the Mbeki government. Drawing on the previous chapter, where I explored the idea of a protracted struggle over HIV/AIDS policies and priorities, I argue that the emergence of SANAC's participatory governance structure should be viewed as a form of TAC victory—after all, the push for democratization was successfully led by Mark Heywood and TAC (Booth 2009). As such, the strong attachment of TAC's science-positive epistemic community to SANAC and the disappearance from public of any strong, opposing voice represents a shift toward TAC leadership and intellectual dominance within HIV/AIDS policymaking.

In interviews, TAC leaders were adamant that TAC representatives in SANAC are not the sole voice of civil society during the production of HIV/AIDS policies (Hodes 2009; Tomlinson 2009). According to TAC officials, the reality is much more complicated. As Catherine Tomlinson, a Senior Researcher at TAC's National Office, said:

People still look to TAC for leadership. If you go to SANAC meetings, they're all experts in their fields... I don't know necessarily if TAC is as much a leader now than as a participator. Historically, TAC has been the leader in promoting evidence-based policies... and the evidence-based policies coming through

SANAC are all directly due to TAC's work over the past decade. (Tomlinson 2010)

This comment suggests that TAC does not constitute the principal voice within SANAC, a claim substantiated by SANAC plenary minutes filled with the names and statements of other civil society representatives (SANAC 2009). However, as my interviews have revealed, the TAC epistemic community is directly accountable for the drafting and passage of scientific, evidence-based HIV/AIDS policies during the past few years. This leads me to ask an important question: if TAC claims to no longer be the dominant voice of civil society on issues of HIV/AIDS, how can it trust SANAC's participatory structure to pass its science-based policies?

I turn to scholar Janet Cherry's account of civic participation and organizations in a township under the apartheid government in order to illustrate the importance of this question. As Cherry reveals, supporters of the African National Congress in the 1980s used participatory governance as a means through which to build *hegemony*, or dominance, over competing parties:

“Activists were concerned with building grassroots democracy in a very real sense, and with building the hegemony of the ANC among the majority of the black population. There was a clear realization that it was only through democratic mass organization and mobilization that such hegemony could be built... Committees sought to ‘conscientize’ or build revolutionary political consciousness among ordinary residents. This conscientization took two forms. The first one was the building of loyalty to the ANC, and the propagation of ANC ideology, through informal means and through the culture of struggle... secondly, there was a formal process of political education within the street and area committees.” (Cherry 2000: 100)

This account reveals that ANC activists used two non-coercive methods, the popularization of the struggle culture and political education, in order to gain the necessary support for the African National Congress. As Cherry claims, “this was hegemony in the Gramscian sense of the opposition bloc obtaining ‘moral authority’” (2000: 100). Cherry's analysis has clear parallels with my own analysis of TAC culture in the previous chapter, in which the recalling of the

struggle culture and a massive push for scientific literacy education allowed TAC to obtain its moral authority within the South African public sphere. Here, then, I wish to suggest that the public authority assumed by TAC has subsequently granted its epistemic community a hegemonic, unchallenged status within SANAC.

Hardening Boundaries

In the beginning of this thesis, I proposed a primary research question revolving around the dynamics of public participation in scientific governance, with an aim to explore the complex relationship between lay citizens and science in post-apartheid South Africa. Until now, my thesis has been largely contextual and historical, laying an extensive foundation exploring the history of scientific knowledge production in South Africa, the successful ascent of TAC into national politics, and the concurrent restructuring of SANAC. Along the way, I have introduced numerous terms and concepts from STS, piecing together an analytical framework that places scientific knowledge production and expertise in a central role. In this chapter, then, I have sought to establish TAC as both a prominent and predominant epistemic community within SANAC which bears a claim to interactional expertise.

This argument sheds further light on the complex dynamics of public participation in scientific governance. While I argue that spaces of public participation such as SANAC are crucial towards creating and shaping notions of citizenship, the clear distinction between interactional and contributory expertise (as I illustrated in this chapter) points towards a hardening of the boundaries between lay citizens and science in South Africa. As mentioned before, TAC blurs the distinction between expert and lay knowledge communities in South Africa through its hybrid strategy of legal challenges, popular protest, and the promotion of

‘responsibilised citizenship.’ In addition, TAC brings a welcome push for further democratization within South Africa, especially a democratization of scientific expertise. Yet, due its to limited interactional expertise, TAC still must defer to the contributory expertise of global scientific networks and institutions. In this position, TAC’s deference to scientific authority enables a situation in which western science becomes the primary, unchallenged episteme underwriting HIV/AIDS policy. South African lay citizens, even those with some understanding of science or a fulfillment of the requirements of ‘responsibilised citizenship,’ are seemingly left unable to participate within the the co-production of scientific knowledge—a stark contrast to the history of American AIDS activists.

The implications of TAC’s hegemonic status within SANAC are enormous. Without any legitimate challenges to its policy positions, whether from any other epistemic community within SANAC or even in the South African public sphere, the science-positive culture of TAC will continue to reign supreme over the policy-making process. As Cherry points out in her study of township governance, “a form of territorial hegemony was built [by the ANC], and those outside of it were defined as ‘the enemy’” (2000: 106). Thus, as exemplified by TAC co-founder Zackie Achmat’s own statement that “science, or truth, does not modify itself for our ideological wishes,” there is no room for alternative ideologies, approaches or knowledges within SANAC (Robins 2008: 112). Competing epistemic communities, while part of SANAC, are essentially left voiceless within a governance structure dominated by TAC’s own science-based ideology. I argue that this silencing has contributed to the hardening and entrenchment of a new set of boundaries between lay citizens and science in South Africa. In the following chapter, I will closely trace and examine the passage of one specific policy within SANAC in order to show the precise implications of these hardened boundaries.

Chapter Five

“I am responsible”:

Navigating Circumcision, Culture, and Citizenship

Introduction

As the President of the International AIDS Society and the Chair of the 2009 IAS Conference, Dr. Julio Montaner was the first to take the stage in Cape Town. Even with the knowledge that the conference would not reveal any groundbreaking research in HIV/AIDS treatment, he approached his speech with remarkable energy and candor. He tracked the history of the HIV/AIDS epidemic in South Africa over the previous decade, noting the “dramatic progress in access to treatment, care and prevention” (Montaner 2009: 1) Of course, as he pointed out, there was still a long road ahead. Here, Dr. Montaner spoke directly to both the research scientists and the activists in the audience, convinced that—in the wake of the economic recession—even more collaboration between the two groups was necessary. Carrying a final message of responsibility, he pushed the audience to “keep our shared goal [of ending the epidemic] in sight... with your help, we can and we will achieve this goal” (Montaner 2009: 3)

Then perhaps it is no surprise that just under five months later, the South African government announced a national HIV/AIDS campaign, centered around this push for increased responsibility. With the theme of “I am responsible, we are responsible, South Africa is taking responsibility,” the new campaign brought forth news of encouraging prevention and treatment initiatives (SANAC 2010). Spearheaded by Health Minister Aaron Motsoaledi at the cost of 1.4 billion ZAR (\$188 million), this campaign involves the distribution of millions of male condoms, renewed funding for lifesaving HIV/AIDS treatments, and an increased drive for HIV/AIDS testing. The launch of the campaign has also prompted promising rhetoric from the new government administration. Speaking on World AIDS Day 2009, President Jacob Zuma told the nation that “much more needs to be done” for prevention, treatment and care (2009: 1). Furthermore, he reinforced the message of the campaign, saying that “we have to overcome HIV

the same way that it spreads – one individual at a time. We have to really show that all of us are responsible.”²⁶ (Zuma 2009: 5)

In the previous two chapters, I traced how the struggle against the HIV/AIDS epidemic in South Africa shifted notions of scientific expertise and citizenship. While AIDS activists are accountable in large part for the restructuring of HIV/AIDS policymaking in South Africa in order to increase public participation in science-based policymaking, I also discussed how the Treatment Action Campaign (TAC) had specifically engendered a new kind of ‘responsibilised citizenship’ that placed the organization at the forefront of the struggle against HIV/AIDS. This final empirical chapter thus illustrates the implications of these shifts. I seek to further my primary analysis of the relationship between public participation in scientific governance and HIV/AIDS policy through a case study of the development of the “Implementation Guidelines for Medical Male Circumcision” within the South African National AIDS Council (SANAC).

The Travels of Medical Male Circumcision

In order to understand the policymaking process for medical male circumcision (MMC) within SANAC, it is important to note how scientific knowledge travels across the globe. In this case, knowledge produced by scientists in sub-Saharan Africa spread across North America and Europe before its full acceptance by the global HIV/AIDS community in scientific journals. By the end of 2005, three separate (though linked) scientific research teams in South Africa, Kenya, and Uganda had made the claim that MMC “provides a degree of protection against acquiring HIV infection, equivalent to what a vaccine of high efficacy would have achieved” (Auvert et al.

²⁶ It is worth noting that in the weeks following World AIDS Day 2009, President Zuma became embroiled in a national scandal as the media revealed that he had fathered a fifth child with a woman he was not married to. According to many civil society organizations, including TAC, Zuma’s private actions severely undermined his public rhetoric within the new HIV/AIDS campaign; regardless, the campaign moved forward.

2005: 1112; Bailey et al. 2007; Gray et al. 2007). Though this assertion had been made casually over the previous two decades by demographers, these three research studies ostensibly provided the most incontrovertible proof yet of the MMC/HIV link (Gray et al. 2007). As the trials were all randomized control trials (RCTs), in which research participants are randomly placed into either a control or an intervention group, they were jointly accepted as the absolute ‘gold standard’ of medical research (Bonell et al. 2006). With the publication of the three studies in the *Lancet* and *PLoS Medicine*, HIV/AIDS experts agreed on a meeting to discuss how to integrate MMC into the existing HIV prevention plan.²⁷ Thus, in March 2007, scientists and activists came together in Montreux, Switzerland, for a special meeting in which UNAIDS and the World Health Organization (WHO) both endorsed the evidence and consequently pushed for MMC policy implementation in countries with high HIV prevalence (WHO 2007).

With the dual seal of approval by the WHO and UNAIDS, this set of scientific knowledge moved back to sub-Saharan Africa. Over the past sixty years, the WHO has had an extraordinary influence over public health discourse and policies throughout the developing world, often in collaboration with the World Bank’s neoliberal agenda of “privatization, liberalization of trade, and [the] rolling back of government” (Gilbert and Gilbert 2004: 247). This influential position has entailed the consolidation of scientific expertise and authority; as Wiebe Bijker et al note, the WHO is “an explicitly political organization” that collects and draws from scientific expertise for its own global development agenda (2009: 20). Similar to Michael Goldman’s analysis of World Bank projects in which he claims that expert “findings and practices make their way into the global circuit in which... artifacts and idioms travel and become transformed into global knowledge and expertise,” the WHO also produces a set of knowledges, which is considered not only accurate but also authoritative (Goldman 2001: 194). Though national and transnational

²⁷ These two journals are considered two of the most prestigious scientific journals in Great Britain and the USA.

social movements have pushed against these global agencies, seeking to regain control of local governance structures or development projects, and have sometimes succeeded in bringing about changes in program operations, the WHO has continued to assemble a strategy “whose aim is to integrate non-western nations into a global public health regime” (Brown and Bell 2008: 1572).

In the case of MMC, this strategy to unify the developing world with a single health agenda appears to be somewhat effective. For example, in the past three years, the extraordinary authority of the WHO has compelled several countries within sub-Saharan Africa to enable new HIV prevention policies containing MMC measures. While there are small differences in policy among these countries, at least nine countries apart from South Africa have plans to draft or to approve a new policy that incorporates MMC into existing HIV prevention strategies.²⁸ In this context, SANAC faced considerable pressure to match the policy efforts of its neighboring countries. Furthermore, as the previous chapter explored, the restructuring of SANAC has directly brought about the emergence of a South African public health apparatus, adhering to the same scientific expertise as the WHO. In this chapter I will explore the process by which a MMC policy emerged within South Africa as well as the ramifications of this policy. I will show how the authoritative scientific knowledge produced by the WHO was adapted by SANAC and how SANAC continues to prioritize the expertise of the global scientific community and to subjugate alternative knowledge systems (Goldman 2001).

MMC Arrives in South Africa

After the WHO released its recommendation for MMC in March 2007, health activists in South Africa acted quickly to incorporate this finding into its policy. By this time, SANAC had

²⁸ As a July 2009 WHO report indicates, these nine countries are: Botswana, Kenya, Namibia, Rwanda, Swaziland, Tanzania, Uganda, Zambia, and Zimbabwe (WHO 2009).

been restructured and the strong influence of civil society on HIV/AIDS was beyond question, even if they deferred to global institutions for expertise. On April 15, 2007, TAC released its own briefing paper on MMC on its website written by TAC Secretary Nathan Geffen with assistance from SANAC Deputy Chairperson Mark Heywood. The briefing paper quickly places itself within the domain of scientific authority. Not only do the WHO/UNAIDS recommendations heavily influence the paper, but South African experts on MMC also appear to have reviewed it. Thus, after endorsing the preliminary findings of the three RCTs, the paper discusses the potential risks of implementation in a South African context. Reflecting on the ethics of such an invasive and irreversible procedure, Geffen insists that MMC should only be performed under the specific legal standards of informed or parental consent. In addition, the paper includes a brief paragraph on traditional circumcision (TC), reflecting TAC's limited engagement with indigenous knowledge and practices. This paragraph states that:

“Boys and young men in South Africa are usually circumcised as part of religious or traditional ceremonies. These circumcisions are seldom done by medical experts. Often they are performed under non-hygienic conditions. It will also not be easy to convince people who wish to have their children circumcised religiously or traditionally to rather do so using the health system. Traditional and religious male circumcision rites should be allowed, but the state must ensure they are carried out safely and in accordance with national and provincial laws governing circumcision.” (Geffen 2007: 4)

As this paper indicates, the tension between two coexisting (though unequal in power) knowledge systems—western science and traditional indigenous practices—appears as an immediate point of concern. However, as articulated in this statement, the only solution is the medicalization of the traditional practice.

Why, one might ask, did TAC so quickly embrace MMC as an HIV prevention measure? I suggest that there are two primary reasons. First, in light of new advances in biomedical interventions such as ‘treatment as prevention’ (that is, using ARVs to ward off HIV infection)

or microbicides, MMC presents itself as a ‘magic bullet’ that will eventually end the spread of HIV—a framework directly reinforces the dominance of western science (Lewis 2009). Similarly, as expressed by Tabeth Maseku, Researcher for the General Secretary of TAC, MMC was immediately significant to TAC just as “anything that will reduce infection is important to TAC” (Maseku 2009). Thus, the status of MMC as a proven, biomedical prevention method was enough for TAC’s science-positive approach. Secondly, I suggest that TAC adopted MMC as a HIV/AIDS policy priority because MMC fit in well with its promotion of ‘responsibilised citizenship.’ As I explained in the third chapter, TAC activists encourage fellow citizens to become more responsible and accountable for their everyday health decisions. For TAC, MMC represents an opportunity for (male) citizens to become more proactive about their own health. As Geffen writes in the initial briefing paper on MMC:

Circumcision in the public health system offers an opportunity to counsel and test men for HIV. HIV counselling across the public health system is currently often poor and unstandardised. But... by offering testing coupled with counselling, more men can find out their HIV status and, if they test positive, can immediately enroll in the public sector's monitoring and treatment programme. (Geffen 2007: 3)

In this perspective, MMC no longer represents a challenge to the South African public health system to extend itself, but rather an opportunity for more (male) citizens to involve themselves and seek out their own ‘responsibilised citizenship.’

Interestingly, this association between citizenship and circumcision did not simply emerge with the introduction of MMC to South Africa. Traditional male circumcision, as practiced by multiple cultures within South Africa, often involves the bestowing of additional rights and responsibilities upon the male citizen (Mavundla et al. 2010). Chief among these is the new status of the circumcised male as a man. However, outside of indigenous communities, the social meanings attached to traditional circumcision are not immediately recognized. As Mavundla et

al. recounts, the South African public's perception of traditional circumcision is often as a problematic tradition:

The foremost issue is the performance of the ritual in unhygienic environments, with traditional instruments that are often reused without being sterilized. Procedures performed in a hospital setting are considered forgeries because the ritual is, in essence, a test of manhood, and elements of pain and bravery are essential components of this test. Consequently, most initiates are adamant about completing the rite of passage in the traditional manner, even if this happens at the cost of their well-being. Seeking western medical help is considered a taboo and results in a failed initiation. (2010)

Yet, as reflected in the TAC Briefing Paper on MMC, the medicalization of the traditional procedure appears to the scientific community as the only proper method of promoting HIV prevention among the greater South African public.

Initially, the push for a MMC policy in South Africa did not lead anywhere. But, by the end of 2007, the full SANAC plenary had agreed upon a further investigation of MMC, but no concrete action had yet been taken due to the inability of SANAC sectors to meet frequently.²⁹ Within just a few months, the situation would end. As Paul Booth recounted, the AIDS Law Project office hosted a five-hour meeting on the potential adoption of an MMC policy in April 2008 with eight SANAC delegates, including individual representatives from TAC, the Religious, the Men's and the Women's Sectors (Booth 2009). The direct result of this meeting was the creation of a position paper in May 2008 in favor of a MMC policy, drafted by the SANAC Civil Society Sector and endorsed by seven other SANAC sectors. The position paper closely echoes the pro-science, pro-responsibility themes of the initial briefing paper by TAC:

“...not only does male circumcision offer significant protection for heterosexual men against HIV infection, but its implementation could provide opportunities to engage and strengthen dialogue with men on sexual health and responsibilities.”
(SANAC Civil Society 2008)

²⁹ One of the largest concerns about SANAC in my interviews was not that its policies were ineffective but that SANAC plenaries and sectors did not meet enough to be effective.

With this strong recommendation to move forward, the SANAC plenary meeting on May 27, 2008, included a full discussion in which “there was a large degree of consensus [on MMC] and delegates urged Government to move this into the realm of policy” (SANAC 2008a). Additionally, delegates within the SANAC plenary agreed to involve traditional leaders and authorities on traditional medicine in the forthcoming discussions (SANAC 2008a).

At this point, the MMC policymaking process had finally commenced in South Africa, representing some form of victory for civil society—especially for TAC and its allies within SANAC. Indeed, the plenary agreement to pursue a MMC policy also indicated that this model of scientific governance allows for a high level of public participation and engagement. As this example shows, civil society representatives (led by TAC’s epistemic community) successfully introduced a policy initiative involving biomedical knowledge through this new model.

However, there is not yet any indication of the co-production of scientific knowledge; to the contrary, the entire process has relied on the scientific expertise and authority of the global public health community, including the WHO. While the prominent position of TAC’s epistemic community within SANAC suggests national trust in the interactional expertise of TAC representatives, as I explained in the previous chapter, TAC’s leadership within SANAC policymaking has merely led to a reliance on the contributory expertise of outside scientific authorities. Additionally, TAC’s promotion of ‘responsibilised citizenship’ is also linked to the adoption of biomedical prevention policies by SANAC. Still, this policymaking process has remained rather unscrutinized until now.

MMC Policymaking

Within the next few months, the pace of the MMC policymaking process increased. By

July 31st, nine sectors within the SANAC plenary (including Men, Women, Research, Traditional Leaders, Traditional Healers, and Law & Human Rights) had agreed to collaborate as a Civil Society delegation in a working group on MMC with the South African Department of Health (DoH). Based on this collaborative effort, delegates at the SANAC plenary in October 2008 recommended further sector consultations on a full policy for MMC, with the intention of eventually finalizing a policy that would allow MMC as a voluntary HIV prevention procedure (SANAC 2008b). At a special meeting of the SANAC Programme Implementation Committee (PIC) in the January of 2009, a small selection of civil society delegates offered two strategies: a phased approach for MMC, focusing primarily on high-risk populations, or a more aggressive approach involving a total of 7.5 million circumcisions to be performed by 2015 (SANAC 2009a). During the SANAC plenaries in February and March of 2009, delegates proceeded to develop a draft policy and communications strategy in conjunction with the DoH and in consultation with traditional healers and leaders (SANAC 2009b). Individual sectors continued to meet and deliberate over the developing MMC policy over the next few months; by July 2009, the first draft policy had been completed, distributed, and endorsed by the SANAC plenary (SANAC 2009c).

Understandably, a great deal of concern by delegates was placed on the economic feasibility of launching a MMC policy targeting a large population in the wake of the 2008 economic recession. Several external research groups had conducted studies on the cost-effectiveness of an MMC policy in South Africa, concluding that it would save the government hundreds of millions of dollars in the future (Auvert et al. 2008). Moreover, the SANAC PIC utilized the data sets and accounting tools designed by UNAIDS for measuring the cost-effectiveness of MMC in each national context (Booth 2009). Other major discussions within

these meetings involved the potential impact of MMC on women's health and the feasibility of rolling out an advanced biomedical intervention in South Africa; the Women's Sector and NAPWA within the NGO Sector raised these issues (Tomlinson 2009). Also, as will be discussed in the next section, an enormous amount of discussion was devoted to cultural sensitivity and the progress of SANAC's consultations with traditional healers and leaders.

Absent from these deliberations was any critical discussion of the science behind the proposed link between MMC and a decreased contraction of HIV. Despite continued debate and research in prestigious academic journals over this science during this period, interviewees all suggested that the recent SANAC discussions never broached these critical discussions. As Paul Booth said:

What's been happening is just general discussions saying the science says yes... everyone sees [MMC] as what we need to have... [now] it is a matter of this is what the science says, we've had long discussions, we've shared our concerns... I think we're nearly there.

The lack of any record in any SANAC and PIC meeting minutes of critical discussions around the science³⁰ suggests that there is little co-production of scientific knowledge within SANAC. Rather, the only public debate on MMC regards non-scientific knowledge, such as culture. Furthermore, the full embrace of scientific knowledge (and the complementary accounting tools) directly from the WHO and UNAIDS reinforces the complete deference of SANAC delegates to another source of expertise. More than anything, this move signals that there are significant boundaries between the broad, but interactional, expertise of the SANAC delegates and the global collection of technical, contributory expertise by the WHO and UNAIDS.

With the rapid completion of this draft policy for MMC, SANAC certainly took a step forward in pushing the policy towards implementation. At the same time, its passage represents

³⁰ Meeting minutes suggest that there were presentations on the science, but only basic education about the underlying scientific mechanisms of MMC and HIV.

further evidence that the boundary work within SANAC is incomplete. As I argued in the previous chapters, science is embedded in politics, and the process of hybrid management involves the mutual stabilization of the two domains. This is most evident in the minutes of the SANAC plenaries, in which delegates articulate a strong urgency to pass the MMC policy with speed, silencing any potential debate on the science (SANAC 2009a). Often, these notes contain stark references to the past failures of South African HIV/AIDS politics, including a firm request not to repeat the 2003 delay of the national ARV rollout (SANAC 2009d). However, the thorough nature of this process of consulting with traditional authorities not only kept the policy from quick passage but also revealed the growing tension between western scientific and traditional practices.

Consultations & Considerations

As described previously, SANAC delegates consistently pushed throughout the MMC policymaking process for official consultations with traditional leaders and healers. They also demanded that traditional leaders and healers be given the proper time to provide input; after all, male circumcision is both a ritual and medical practice within several South African cultural groups, often with significant cultural meaning and deep historical roots (Vincent 2008). What this push for consultations reveals most clearly is the existing tension between western science and traditional practices. As Paul Booth notes:

Our main concern is around traditional cultural practices. It's something we find difficult to tackle in SANAC... saying there's got to be an understanding of the importance of culture. Culture plays a very strong and important role, so we need to find a way to not stamp on traditional culture. But safe and efficacious practices of medical male circumcision... clash with traditional circumcision in the bush ... [and thus] we're not sure how that's working. How can we deal with it in a way that's sensitive and that doesn't isolate a large chunk of the population? (2009)

As Booth suggests, public debate around traditional circumcision centers around its status as an unhygienic and unregulated practice, conducted outside the reach of the state in rural areas (Vincent 2008). Indeed, scientific research on these topics echoes this specific point of tension, noting that traditional circumcision—even as an unmedicalized procedure—results in many more medical complications (such as delayed wound healing, infections, and the spread of diseases like HIV) and more direct fatalities than MMC procedures (Taljaard 2009). At the same time, these reports note that the strong cultural meanings attached to traditional circumcision signify that MMC will not be an option for every male citizen. This situation creates an enormous dilemma for the SANAC plenary over how to properly incorporate traditional circumcision into the MMC policy. Furthermore, this dilemma also puts forward the question as to whether the government has the authority to both articulate and incorporate traditional practices into a biomedical policy.

For SANAC, the accepted procedure for answering these two questions rests in the practice of consultations. In the post-apartheid era, consultations are especially common for seeking consensus with a multicultural population; the ANC government has conventionally “turned to traditional leaders as uncomfortable allies... on every government initiative” as a method of seeking legitimacy for policy passage and implementation (Koelbe and Lipuma 2000). However, as Michael Goldman points out, consultations in developing countries typically represent an (institutionalized) attempt by a government or multinational agency to “normalize asymmetric relations” with indigenous populations (Goldman 2001: 203). As he explains, these consultations are efforts to improve policies or to make them palatable, not cancel them; in other words, authorities will tend to dismiss calls to end a project during consultations (Goldman 2001).

With this in mind, it is crucial to recall that the post-apartheid government has a historical record of tension with traditional leaders over state regulation of traditional circumcision (Vincent 2008). After the government instituted new legislation demanding the use of safer surgical instruments by registered traditional leaders, Thembela Kepe writes, “traditional leaders claimed that as custodians of African culture they should be given the resources and authority to oversee the regulation of practices such as male circumcision” (2009: 414). Furthermore, many prominent traditional leaders claimed that they were not consulted during the drafting of the earlier legislation on surgical tool safety and state regulation (Kepe 2009). The result of the tension has been a temporary stall in government regulations but a notable increase in public consultations.

Therefore, thorough consultations for the MMC policymaking process with traditional leaders were imperative. For this process to succeed, SANAC had to find a way to productively discuss and negotiate a cultural practice. Although some South African scholars such as Louise Vincent claim that tensions over the government regulation of traditional circumcision reflect an overriding division between “indigenous African communal” and “western liberal individualist” cultures, SANAC refuses to see these false divisions, let alone any cultures, in opposition. For example, internal SANAC presentations often include quotations such as “embrace traditional and western ways to stop people dying,” arguing that there is a “reciprocal link between biomedical practitioners and traditional practitioners” (SANAC 2009). In discussion with Paul Booth over this matter, he noted that he saw no true tension:

It’s a lingering thing from the Mbeki era... a refusal to engage with western science and medicine in a way that tries to not in opposition, but accepting that ARVs may be more beneficial for your health than certain herbs. (2009)

Nonetheless, even with this evidence, there is still a tendency within SANAC to see some indigenous cultures and practices as barriers to progress. In SANAC literature and plenary minutes, there are repeated concerns over how to incorporate traditional circumcision. For instance, one set of meeting minutes reports a discussion over the “complex and nuanced process of renegotiation around the adaptation of culture” (SANAC 2009c). Above all, this form of rhetoric suggests that SANAC delegates have discussed traditional cultures more in depth than the western science that they are expected to regulate.

With the completion of the draft MMC policy by July of 2009, after several rounds of consultations with traditional leaders, SANAC delegates finally decided upon an approach to traditional circumcision. As the MMC policy is a set of guidelines rather than a state policy that would mandate MMC for citizens, this allows SANAC delegates further flexibility to integrate traditional circumcision into their practice guidelines. Along these lines, delegates have called for further regulation, monitoring, and training for practitioners of traditional circumcision, albeit with sensitivity to the authority of traditional leaders. Additionally, MMC will be heavily promoted among populations that practice traditional circumcision. More than anything, this development reflects an entrenchment of tense relations by the civil society representatives within SANAC, further re-privileging western science and subjugating traditional practices.

Final Guidelines & Implementation

With the release of the final draft of the 50-page “Implementation Guidelines for Medical Male Circumcision” in early December 2009, the stage was set for its implementation. According to TAC and SANAC, the final MMC policy will be passed in time for the April 15, 2010 launch of the new national HIV/AIDS campaign (“I am responsible”), in which the MMC

policy plays a large role. In this context, MMC serves not as a replacement for other HIV prevention measures, but as part of a comprehensive sexual health package for male citizens. As mentioned before, the MMC policy does not require South African citizens to submit to MMC, but it rather gives guidelines “intended to provide programmatic and operational guidance to decision-makers, programme managers, technical support agencies and potential funders” (SANAC Guidelines 2009). Along those lines, MMC procedures are to be conducted only in strictly hygienic conditions by medical professionals. References to traditional practices are minimal, but they are still important, with the guidelines recommending “that MMC services in traditionally circumcising communities evolve to embrace safe and effective (complete removal of the foreskin) surgical practices as well as comprehensive HIV prevention” (SANAC Guidelines 2009). Moreover, the guidelines recommend that traditional circumcisions are only performed by “well-trained practitioners in aseptic settings” (SANAC Guidelines 2009).

From a broad perspective, the passage of the MMC policy and implementation guidelines suggests yet another TAC victory. With this policy, South Africa appears as a science-positive nation with forward-thinking policies in line with global public health recommendations. Once again, TAC will play a leadership role in the implementation of the MMC policy. As TAC Senior Researcher Catherine Tomlinson told me, TAC will be a prominent participant in the national HIV/AIDS prevention campaign, in addition to launching some new organizational measures to educate the public about the new MMC policy that it has promoted from the start. And, as I mentioned before, this policy falls closely in line with TAC’s conception of ‘responsibilised citizenship,’ whereby citizens are expected to become more accountable for their daily health choices. With MMC, TAC expects its male members and fellow citizens to seek out MMC services as soon as possible; in the next two years, clinics designed especially for MMC

services will be expanded from an initial launch in KwaZulu-Natal to other provinces with high HIV prevalence.

On this note, I argue that the push and ultimate passage of this MMC policy represents an even clearer picture of how SANAC operates. Although lay citizens are included and play an important role in choosing which policy initiatives come to fruition, the inclusion of lay citizens here has not resulted in discussions about scientific knowledge but rather about mainly socio-cultural concerns. In addition, SANAC's push for consultations with traditional leaders indicates an important glimpse into how many figures within the government view traditional practices as subservient to western science. The next chapter contains my concluding analysis of these questions and the social boundaries through which these questions emerge.

Chapter Six

Concluding Thoughts:

HIV/AIDS and the Boundaries of Citizenship

Introduction

As a delegate to the 2009 International AIDS Society (IAS) Conference in Cape Town, I watched with awe as the diverse collection of speakers—scientists, activists, and politicians—took to the stage, each one representing a specific audience. While each speaker gave separate accounts of the seemingly endless struggle against HIV/AIDS, these voices all conveyed a message of shared responsibility to end the epidemic. Scientists, activists, and politicians are all humans, they collectively argued, and thus have a moral obligation to end the global HIV/AIDS epidemic that affects everyone. (And as some argued, if this requires advanced biomedical interventions such as medical male circumcision (MMC), then so be it.)

As a narrative frame for this thesis as a whole, the Opening Plenary of the 2009 IAS Conference has allowed me to show just how multiple, converging identities and communities interact within a common space. While the IAS Conference does not operate with the same purpose as the South African National AIDS Council (SANAC), the primary focus of my thesis, I find remarkable similarities between the two settings. Both acknowledge the co-existence of several expert systems; both set out to stabilize the boundaries between politics and science; and both spaces primarily exist in order to find solutions for the HIV/AIDS epidemic. Thus, even in the absence of my own experience with SANAC, I hope that my personal insights into the IAS Conference have provided the reader with a small glimpse into the contemporary workings of SANAC.

In this thesis, I have illustrated how South African citizens have collectively carried out the long-term mission to end the HIV/AIDS epidemic. Each chapter has documented separate, though related, narratives: the rise of the Treatment Action Campaign (TAC) and its privileging of biomedical science, the TAC-led restructuring of SANAC, and the passage of MMC guidelines through SANAC. By placing these histories together, I have traced a greater narrative

concerning the phenomenon of public participation in scientific governance in South Africa, in which civil society members engage in the HIV/AIDS policymaking process. This final chapter will provide some concluding thoughts on this topic as well as additional impressions regarding the most important themes of this thesis.

Citizens & Science, or Public Participation in Scientific Governance

The heart of this thesis remains the complex relationship between citizens and science in South Africa. As discussed, the unique political history of South Africa—prior to the colonial period to the post-apartheid era—has dramatically shaped public engagement with western biomedical science; the constructed boundaries between the white and non-white populations during each political era have kept scientific knowledge production, to this day, almost entirely within the domain of white populations. Still, with the emergence of the liberal democratic state in 1994, new possibilities for citizen engagement with science have become available. Most notably, President Thabo Mbeki publicly challenged the authority of HIV/AIDS science after his own, private self-education, prompting a global outcry that gave rise to the South African-based TAC. In turn, TAC promoted (AIDS-specific) scientific literacy throughout the South African public and, through a series of legal victories and mobilization campaigns, publicly re-privileged the claims of western biomedicine. This narrative reveals how the full democratization of South Africa has brought about a new series of questions regarding the democratization of science and the manner in which citizens can productively engage with scientific authority; furthermore, it reveals that as lay citizens privilege the claims of western science, indigenous knowledge systems continue to be relegated to a secondary, marginal status.

For a final analysis of how this citizen-science relationship plays out through SANAC, I must refer back to previously cited academic literature in the second chapter. I discussed three distinct models of public participation in scientific governance, or how citizens interact with science-based policymaking, in order to shed light on my analysis of SANAC: the Enlightenment Model, the Public Debate Model, and the Model of Hybrid Collectives. Each model provides distinct levels of citizen contribution and deliberation; while the Enlightenment Model maintains strict boundaries between professional experts and lay citizens, the Public Debate Model and the Model of Hybrid Collectives both seek out the voices of lay citizens. Furthermore, the Model of Hybrid Collectives expects lay citizens to participate not only within governance but also in the co-production of scientific knowledge. My thesis has asked whether this co-production occurs within SANAC, as its contemporary structure allows lay citizens to not only act as representatives of civil society but also to shape the direction of HIV/AIDS policy. This full inclusion of lay citizens within the SANAC plenary thus suggests a replication of one of the latter two models of scientific governance.

As suggested by my characterization of TAC, South African citizens are certainly capable of claiming some expertise on the intricacies of HIV/AIDS science, whether through the lived experience of HIV/AIDS or through TAC's Treatment Literacy programs. However, as detailed through my description of the MMC policymaking process, the inclusion of lay citizens within SANAC has not produced any evidence of the co-production of scientific knowledge, as expected within the Model of Hybrid Collectives. Rather than debating the strengths or weaknesses of the scientific knowledge underlying the link between MMC and HIV contraction, SANAC plenary debates for MMC centered on economic and socio-cultural concerns. With this insight, I concluded that the expertise claimed by the TAC epistemic community within SANAC

is often, according to the framework provided by Evans and Collins, an *interactional expertise* that relies on the *contributory expertise* of multinational agencies and scientific institutions. In this light, I conclude that this incarnation of SANAC most closely represents the Public Debate Model of scientific governance; civil society representatives (including TAC) understand scientific knowledge, but they do not themselves visibly participate in its production.

Permeable Boundaries

Rather than providing any evidence that the co-production of scientific knowledge is taking place on the ground, this study provides a glimpse into the permeability of the various social boundaries embedded within TAC, SANAC, and the greater South African society. Here, I refer not only to the relationship between citizens and science but also to the science-politics and past-present relationships. As shown throughout this thesis, boundaries within these relationships are often unclear, unsettled and subject to modification, despite the efforts of scientists, activists or policymakers to clearly delineate the boundaries.

With regards to the relationship between science and politics, I argue that while science remains permanently embedded within politics, the two domains also continue to shape and secure each other's respective boundaries. My thesis illustrates this inseparable nature through the history of HIV/AIDS science in South Africa. Since the beginning of the epidemic under the apartheid regime, the rhetoric and understanding of HIV/AIDS has been rooted in its respective political context. In the post-apartheid era, the newly democratic state provided for the democratization of AIDS science, witnessed through both President Mbeki's own re-politicization of HIV/AIDS and the further politicization of HIV/AIDS by civil society, especially TAC. I argue that this science-politics relationship is reproduced in the context of

SANAC. From its initial conception, SANAC has operated as an inherently politicized public space through which explicitly political agendas, often hidden under the guise of scientific authority and the recommendation of a global agency, are acted upon. My study of the MMC policymaking process in SANAC thus reveals that TAC's own political agenda brought forward the introduction, passage and implementation of the policy. The result of this relationship is recognition that political and scientific agendas are indivisible, with neither domain able to separate itself from the context of the other domain.

Another important theme in this thesis revolves around the blurred relationship between the past and the present. With my emphasis of South Africa, I have argued that the post-apartheid era is characterized by Michel-Rolph Trouillot's observation that "the past does not exist independently of the present" (1995: 15). One way in which this plays out is through the unequal, racialized distribution of scientific knowledge under colonialism and apartheid that continues to outline the channels of public engagement with science during the post-apartheid era; another way the past lives within the present involves the continuation of pre-existing social tensions between western and traditional healing systems. Furthermore, I have drawn parallels between the anti-apartheid struggle and the struggle against the HIV/AIDS epidemic in South Africa, articulated most clearly through President Zuma's World AIDS Day 2009 speech (introduced in the first chapter). Though there are clear differences between the two struggles in mission and membership, TAC has often drawn directly upon the strategies of the African National Congress (ANC), utilizing mass mobilization and aiming for the moral high ground. And, as the fourth chapter revealed, TAC's recalling of the ANC's particular strategies within participatory governance structures has brought about a form of hegemony whereby separate actors within civil society and SANAC reproduce TAC's science-positive approach.

HIV/AIDS & the Boundaries of Citizenship

In addition to my argument that all of these social boundaries are permeable and are thus subject to further shaping, I also suggest that the current state of South African HIV/AIDS policymaking represents, more or less, a hardening of these boundaries. I do not wish to propose that any boundaries are on the verge of losing their permeability. Rather, the unique history of the South African HIV/AIDS epidemic—especially the ongoing boundary work performed by the SANAC plenary—has directly resulted in the emergence of more rigid boundaries that are constantly entrenched by the daily activities and routines of citizens. More specifically, I argue that the establishment of hegemony by TAC’s epistemic community (in urban areas) and its reproduction by TAC members (in rural areas) has brought forward a new set of relations that will continue to shape the boundaries of citizenship.

Accordingly, I argue that the recent passage of the MMC policy is closely tied to this notion of ‘responsibilised citizenship’ produced and promoted by TAC. As I described before, this form of citizenship requires citizens “to develop new ways of being ‘responsible’ in their sexual lives, diets, lifestyles, and adherence to treatment regimes” (von Lieres and Robins 2008: 55). This concept closely echoes the notions of “biological citizenship” and “therapeutic citizenship” described by Rose, Novas and Nguyen (2005; 2005). Rose and Novas provide a particularly revealing passage that illuminates how powerful this form of citizenship is:

Biological citizenship is both individualizing and collectivizing. It is individualized, to the extent that individuals shape their relations with themselves in terms of a knowledge of their somatic individuality. Biological images, explanations, values and judgments thus get entangled with a more general contemporary ‘regime of the self’ as a prudent yet enterprising individual, actively shaping his or her life course through acts of choice. (2005: 5)

Within this notion of citizenship, human biology “is no longer blind destiny... it is knowable, mutable, improvable, eminently manipulable” (Rose and Novas 2005: 5). I argue that this is most

clearly reflected in the South African MMC policy, where the opportunity to alter one's biology is immediately available through the state-sponsored removal of foreskin. In the same measure, the MMC policy appears to lead to an alteration of one's own biological citizenship.

The clearest implication of this biological citizenship, in which citizens are tied even more closely to the state, is that citizens are implicated in the social welfare and service delivery functions of the state. Even more, citizens involved in SANAC are tied directly to the state's production of scientific knowledge. These two consequences suggest that TAC and its allies have shifted into the *neoliberal* form of civil society; as defined earlier, this civil society partially replaces the state to perform essential responsibilities. Whether this shift away from the *activist* form of civil society, and thus away from any clear delineation between state and civil society in South Africa, is productive, it remains to be seen. (After all, just as all of these other boundaries have been fluid, so have the boundaries between state and civil society).

If in fact TAC and SANAC have popularized this form of biological citizenship, I also argue that there are several other boundaries limiting the full potential of citizens:

- 1) Access to Population – Given the enormous size of the country and multiple constraints in reaching many rural communities, how can TAC and SANAC effectively reach both urban and rural populations? Is there a way to engage both urban and rural populations through participatory governance structures, or will rural populations (and their knowledges) only participate in consultations that treat alternative knowledges as secondary? As Steven Robins writes:

“It remains to be seen what degree MSF and TAC will be able to extend their social mobilisation and treatment access campaigns to other contexts, for instance the countryside of the former homelands, where patriarchal cultures and the politics of shame and denial continue to frustrate efforts to make the public health system more accessible to HIV-positive people.” (2008: 126)

- 2) Recalling the Past – As I have shown, TAC members actively recall the political strategies of its predecessors in order to advance its own agenda. While this has often brought it success, I argue that there must be a limit to which TAC can recall the past before it simply reproduces the mistakes of the past. In the case of MMC policymaking, this may particularly manifest itself within the reproduction of any earlier tensions between the state and traditional authorities over the regulation of traditional circumcision, which does not assist TAC or SANAC in its efforts to involve more citizens in their efforts.
- 3) Discourse of Rights and Responsibilities – Again, the popularized discourse of human rights and citizen responsibilities in a liberal democratic state, most clearly evident through civil society’s engagement with the state, may not be received as well by citizens who face unemployment, poverty, violence, and massive inequalities on a daily basis and who do not receive even the most basic state services (ie, housing, electricity, and the protection of citizen rights).
- 4) Avoiding Standardization and Decontextualization – Rather than considering each citizen as a standardized subject of the state, lay citizens participating in HIV/AIDS policymaking must avoid adopting the same health strategy (ie, the same HIV prevention method) for each individual citizen. Rather, appropriate social context must always be taken into account, whether in an urban or rural setting.
- 5) Expertise – Even as lay citizens are increasingly cast in a light in which their personal experiences and narratives are privileged, there are, as Collins and Evans point out, limits to the experience-based expertise of lay citizens (2002). Especially within the context of scientific governance, the interactional expertise of lay citizens should not

be confused with the contributory expertise of professional experts—while, at the same time, that contributory expertise should not be the only form of policy guidance.

Renegotiating Boundaries

Before I finish, I must recall the words of Paula Treichler:

AIDS is a real disease syndrome, damaging and killing real human beings. Because of this, it is tempting—perhaps in some instances imperative—to view science and medicine as providing a discourse about AIDS closer to its ‘reality’ that we can provide ourselves. Yet the AIDS epidemic—with its genuine potential for global devastation—is simultaneously an epidemic of a transmissible lethal disease and an epidemic of meanings or signification. Both epidemics are equally crucial for us to understand, for try as we may to treat AIDS as an ‘infectious disease’ and nothing more, meanings continue to multiply wildly and at an extraordinary rate. (1999: 11)

Even as I discuss the intricacies of citizenship in South Africa, it is necessary to recall both the extraordinary destruction HIV/AIDS has caused in South Africa and the potential for this virus to perpetuate a global epidemic for years to come. Furthermore, the multiplication of meanings is an immediate concern in South Africa. Circumcision, whether performed in a hospital or as part of a traditional ceremony, holds specific meanings for both recipients and cultures. In thinking through the upcoming implementation of the MMC policy, it is crucial to think of the potential difficulties of navigating through these cultural meanings. For this, I turn back to Wiebe Bijker et al., who claim that:

As it is hard to strictly delineate science and politics from each other, so it is difficult to consider politics in isolation from the practice to which they apply. In the course of a policy-implementation process, policy and practice both change in their mutual interaction. Not surprisingly, then, the effectiveness of guidelines proves to be especially dependent on the measure in which experts succeed in accounting for the practices they have to regulate in the advice to provide. (2009)

Moving the MMC policy forward effectively through implementation thus might require more than public education; it will require the renegotiation of some existing boundaries.

While I do not wish to articulate here the precise mechanisms through which the boundaries of citizenship may be renegotiated, I will argue that this renegotiation demands, at the very least, a repositioning of civil society apart from the state. TAC, in addition to the rest of civil society, must recognize that merely serving the needs of the state through SANAC does not mean that the boundaries between the state and civil society must always be blurred. Instead, I argue, there must be enough tension between the two sites so that each domain has enough space to mutually shape and stabilize the other.

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Appendix APersonal Interviews

Anonymous. Interview conducted on July 30, 2009, in Cape Town, South Africa.

Booth, Paul. Interview conducted on August 7, 2009, in Johannesburg, South Africa.

Cooper, Professor Diane. Interview conducted on August 18, 2009, in Cape Town, South Africa.

Hodes, Rebecca. Interview conducted on August 12, 2009, in Cape Town, South Africa.

Maseku, Tabeth. Interview conducted on August 18, 2009, in Cape Town, South Africa.

Myer, Professor Jonny. Interview conducted on August 18, 2009, in Cape Town, South Africa.

Tomlinson, Catherine. Interview conducted on August 4, 2009, in Cape Town, South Africa.

Tomlinson, Catherine. Interview conducted on March 19, 2010, via Skype.

Appendix B

25 May 2009

Human Subjects Protocol

**TITLE: NEW AND FUTURE DEVELOPMENTS IN HIV/AIDS
POLICY IN CONTEMPORARY SOUTH AFRICA**

Principal Investigator:

Lundy Braun, Ph.D., Professor of Pathology and Laboratory Medicine and Africana Studies,
Brown University

Co-Investigator:

Patrick Martin-Tuite, Undergraduate Student, Brown University

A. PROJECT DESCRIPTION

1. Specific Aims

Scientific research prior to 2006 has suggested the possibility of using male circumcision (MC) as a tool to decrease contraction of HIV by up to 60% in male citizens. However, it was not until three identical research studies in Kenya, Uganda, and South Africa that the World Health Organization endorsed these findings. Recognizing the growing burden of HIV and AIDS in Sub-Saharan Africa, several countries accepted the WHO's recommendations and adopted plans for mass MC programs. This abrupt shift in public health policy is only now encountering close scrutiny at a pivotal moment in South Africa, with national elections occurring in late April 2009.

In order to address this gap, this research project will engage with various South African experts and activists to investigate how the socio-cultural and political dimensions of the accelerating global debate over MC as a public health intervention will impact future public health policy in South Africa. Also, by examining how MC has been recently transformed from a traditional practice into a medical solution, we hope to bring to light how the current debate, examined from a strictly scientific point of view, ignores the imperial context of earlier and current public health interventions.

We anticipate that the primary component of this project will be historical, requiring an in-depth study of primary scientific literature and primary sources available in Cape Town. However, Mr. Martin-Tuite will also be conducting interviews with South African university professors and public health officials to gain insight into recent developments in national health policy. In addition, Mr. Martin-Tuite plans to conduct oral histories with several local activists involved with the Treatment Action Campaign, South Africa's largest and most successful AIDS advocacy organization, to understand future directions for HIV/AIDS advocacy in South Africa.

2. Methodology

Lundy Braun, Ph.D., Professor of Pathology and Laboratory Medicine and Africana Studies, is the principal investigator for this project. Co-investigator, Mr. Patrick Martin-Tuite, undergraduate student, will be in charge of the implementation of the research. Mr. Martin-Tuite will conduct all necessary interviews and organize the paperwork while in Cape Town under the guidance of Professor Braun. Interviews and oral histories will be conducted in English, requiring no additional staff.

The anticipated duration for this project will be about three months. All interviews and oral histories will be conducted between June 1st and August 22nd, 2009, in Cape Town, South Africa.

Mr. Martin-Tuite will plan to interview approximately 8 local professors and 5 local public health officials. All interview participants will be selected on their publicly-declared interest in HIV/AIDS policy in South Africa (ie, research and publications). We anticipate that interviews will only take about one to two hours and will be conducted at a location to be chosen by the interviewee. Contact will be made by phone or email.

In addition, we plan to conduct oral histories with approximately 12 community-based activists. The activists will be selected based on their affiliation with the TAC and involvement with HIV/AIDS advocacy work. Participants will also be selected in discussion with the TAC, as detailed below. We anticipate that these semi-structured interviews will take 1-2 hours each, conducted at a location to be chosen by the interviewee. Contact will be made through the TAC by phone or email.

The procedure for identifying participants for the oral histories is as follows: I will create a short list of candidates who are currently employed at either the Cape Town or Johannesburg branches of the Treatment Action Campaign. I will consult with TAC officials about who will be interviewed and the details surrounding the interview (time, place, length, questions, etc) in order to determine appropriateness. Specific criteria I will use to determine eligibility: residency in the greater Cape Town or Johannesburg area; extended length of employment with TAC (1 year or longer); role within the TAC (researcher or related role). The consent process will be conducted in privacy with no involvement of the TAC beyond initial suggestions.

Because this research investigates the intellectual contributions of local professionals and academics and the participation of activists to local HIV/AIDS policy as it pertains to this debate, the names of the interviewees will be included if the interviewee consents. If they do not wish their name to be used, the interview or oral history will be reported anonymously and their affiliations or community location will be masked, as well as any other identifying characteristics of the interviewees. If the interviewee requests anonymity, the records of the interview or oral history will be kept in a locked container in a secret location and there will be no identifying characteristics in the records or in future publications. Mr. Martin-Tuite will keep a log of people interviewed so as to prevent repeated contact, but this log will be kept in a separate location from the transcripts of the interviews and NO ONE other than Mr. Martin-Tuite will have access to the

log except him. (*I will keep this log of interviewees with names so I do not repeat contacts. However, the log will be kept in a separate location from the study data which will be entered by number, age, and sex of interviewee. I have no need for additional identifying data.*) IF the interviewee requests anonymity, transcripts of the interviews will not include names or identifying characteristics, and recordings will be destroyed once they have been transcribed.

B. RISKS AND BENEFITS TO THE INTERVIEWEES

The risk to the participants in the interviews and oral histories is minimal, unless the participant is directly involved in current litigation. In this case, the participant may wish to remain anonymous. However, this scenario is unlikely, as all TAC members are open about their affiliation and most are interested in gaining increased public recognition for their work. Mr. Martin-Tuite has been in contact with the TAC and can confirm that they are expecting to openly discuss their efforts.

While South African HIV/AIDS policy has been a controversial issue in the past decade, recent structural changes to the South African Ministry of Health in late 2008 have allowed more open criticism of government policy in the public forum. In addition, with the national democratic elections in April 2009 and the arrival of the biannual International AIDS Society conference to Cape Town in July 2009, open and detailed discussion of national HIV/AIDS policy will be anticipated.

There will be no immediate benefit to the interviewees from the results of this research. However, research into the primary scientific literature and other primary sources in Cape Town may allow participants in this global debate to seek increased context for their arguments. A summary of the research will be provided to the TAC.

C. METHODS OF OBTAINING INFORMED CONSENT

Verbal consent will be obtained from each of the TAC participants. *It is likely that many of the TAC activists are from informal settlements and have limited literacy. They will feel uncomfortable signing a document, especially given the history of apartheid in South Africa. We will leave them with documentation of who to contact with questions as indicated below.* The information from the attached consent form will be read in detail to all interviewees and discussed with them. Contact information with Professor Braun and Mr. Martin-Tuite's phone numbers and email addresses as well as that of staff from the Research Protections Office will be given in writing to each interviewee. Interviewees will be informed: 1) that this is a research study whose purpose is to explore recent developments in South African HIV/AIDS policy and 2) that the oral history may involve several sessions with Mr. Martin-Tuite.

They will be assured that participation is completely voluntary, that all information collected will be anonymous if they wish, that there will be no identifiers used publicly or privately if they indicate this at the time of the interview or after the interview, and that the log that Mr. Martin-Tuite will keep will only be accessible to him. TAC members will be informed that there are potential benefits for their activist work. Mr. Martin-Tuite will give all interviewees his contact

information (school address, e-mail address, and phone number) and the contact information of Professor Lundy Braun (department address, e-mail address, and department phone number).

D. INTERVIEW INSTRUMENT

One-on-one interviews comprise an important part of this research. At the beginning of the interview, participants will be asked how long they have been engaged with South African HIV/AIDS policy in their profession and how they became interested in the topic. After this, I will ask a series of questions (included below) to prompt detailed responses related to South African HIV/AIDS policy, especially as related to male circumcision. At no point will participants be expected to discuss their own personal lives beyond their own research experience, nor will they ever be asked to reveal personal identifying characteristics (such as ethnicity or HIV status). *The information obtained from academics and public officials will not in any way relate to them as individuals.* After this, I will begin the formal portion of the interview with the questions included below.

There is also an oral history component to this research. At the beginning of the interview, participants will be asked what the nature of their involvement in the TAC is, how they became interested in working with the TAC, how long they have been working on this area, what developments they have witnessed during their activist work, what inspires their activist work, and what their personal goals for the TAC are. *I intend to obtain in-depth information about the activists only concerning their roles and participation within the Treatment Action Campaign. It is the intent of the research to obtain information about why they work for the TAC and their own perspectives on the research topic, based on their own personal experience.* I will prompt these participants to discuss their views on recent developments in HIV/AIDS policy as related to male circumcision and the TAC's recent efforts to promote effective HIV/AIDS policy in South Africa. At no point will participants be expected to discuss their own personal lives beyond their involvement with the TAC, nor will they ever be asked to reveal personal identifying characteristics (such as ethnicity or HIV status). *[However, TAC members are known for their public advocacy work against HIV-related stigma and may reveal their own HIV status during the course of the oral history. If this is the case, I will confirm with the member that they wish to disclose their HIV status. Should the interviewee choose to keep this information secret at any point after disclosing it, I will not include this information in any transcript and will destroy the original recording.]* I will then let the participant direct the oral history.

Participants will be reminded of where and how that information may be disclosed (in an academic paper) and will be offered the opportunity for anonymity and/or for striking this particular information from the research record. I will also take great care to explain that we are not interested in such information as HIV status.

INTERVIEW QUESTIONS

Would you consider HIV/AIDS policy a national priority? If yes, should it be considered the number one national priority? Is this a change from the past?

What do you consider the Treatment Action Campaign's largest success?

If you had to name one local political force that continues to have the largest impact on HIV/AIDS policy in South Africa, what would it be? How about one national political force? How about one international political force?

Do you believe that there will be a need for the Treatment Action Campaign in a year from now? Five years from now? Ten years from now?

What developments in South African HIV/AIDS policy do you expect to see in the next year? The next two years? The next five years?

How do you expect the new government to address prior controversies in HIV/AIDS policy in South Africa?

How do you expect the new government to address the latest scientific developments in HIV research? How will they react to any recommendations made by the World Health Organization or a related institution based on scientific research?

Do you expect male circumcision to be promoted by the state as an effective tool against HIV contraction?

If yes, how would you expect this effort to be communicated to the public?

If yes, how would you expect this effort to be funded? Would you expect budgetary cuts to be made to other HIV prevention efforts?

Do you believe that increased scientific research on the relationship between male circumcision and HIV needs to be done before further policy action can be taken?

How would you expect the state to address specific South African populations, such as the Xhosa, which already practice male circumcision as a tradition?

How would you expect the state to address specific South African populations, such as the Zulu, which do not already practice male circumcision as a tradition?

Do you believe that any South African group or community will be focused upon in future South African HIV/AIDS policy, including male circumcision?

F. INVESTIGATORS

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CONSENT FORM

1. THE PROJECT

The purpose of this study is to explore recent developments in South African HIV/AIDS policy in addition to its connection to scientific research on male circumcision's relationship to HIV contraction. This is a Brown University research study, which is limited to individuals over 18.

2. WHAT WILL BE DONE

I would like to speak with you about your work with the TAC and your understanding of the TAC's mission, goals and accomplishments related to HIV. I will ask you general questions about your own involvement and the nature of your work. This discussion might be completed in about an hour or longer. If the session extends longer than an hour we can meet again at another time. You have the option of stopping the interview at any time and can withdraw from this study at any time.

3. RISKS

There should be very little risk to you from your participation in this study. You can choose to remain anonymous in the records of this research and in any publication that results from this research. Participation in this research study will not have any effect on your relationship to the TAC.

4. BENEFITS

There will not be any direct, immediate benefit to you or any individual, but more knowledge from people like you engaged in HIV advocacy and prevention work may benefit other workers in the future.

5. CONFIDENTIALITY

Participation in this study and information gathered from the study will be kept confidential to the extent of the law. The names of individual participants will not be identified in any publications resulting from this study, unless you wish that your name be used. You may also ask me at any time during this conversation to take out of the permanent record some or all of the information you.

6. DECISION TO PARTICIPATE AND RIGHT TO QUIT AT ANY TIME

Participation is completely voluntary and you may decline to participate at any point during this interview. You may also change your mind about having your name attached to this work at any point prior to publication.

7. WHO TO CALL

Questions about the study should be directed to Patrick Martin-Tuite, who can be reached at his office at the Centre for African Studies at the University of Cape Town (021-650-4034) and also at his cell phone number (078-242-5814). You may also call Lundy Braun at Brown University in the United States, phone number (401) 863-3308. Questions about the rights of a research subject should be directed to Susan Toppin in the Brown University Research Protections Office at 401-863-3050.

Checking this box, in your presence, indicates that you would like your name attached to any statement or information that you give me.

Participant's Signature

Date

Researcher's Signature

Date

Researcher's signature confirms verbal consent was granted.