

The Politics of Knowledge Production in HIV/AIDS Research about Ontario's African, Caribbean, and Black Communities

by

Kimberly Anne Gray

A thesis submitted in conformity with the requirements
for the degree of Doctor of Philosophy

Dalla Lana School of Public Health
University of Toronto

University of Toronto © Copyright by Kimberly Anne Gray 2015

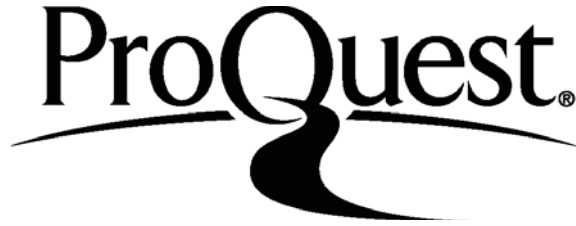
ProQuest Number: 3743274

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest 3743274

Published by ProQuest LLC (2015). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code
Microform Edition © ProQuest LLC.

ProQuest LLC.
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106 - 1346

The Politics of Knowledge Production in HIV/AIDS Research about Ontario's African, Caribbean, and Black Communities

Kimberly Gray

Doctor of Philosophy

Dalla Lana School of Public Health
University of Toronto

2015

Abstract

HIV/AIDS science has long been a site of contestation by civil society actors. Early activists originating in the gay community affected the course of HIV/AIDS science by challenging the definition and treatment of the disease. However, little is known about the politicized efforts of other groups disproportionately affected by HIV/AIDS, particularly Black communities, to mobilize and shape research about their communities. This thesis interrogates social relations and power in research about HIV/AIDS in Ontario's African, Caribbean, and Black (ACB) population. Using Pierre Bourdieu's field theory, together with concepts from the sociology of science and race theory, I investigate tensions and struggles over the definition and production of ACB HIV/AIDS research. Through a review of research grants and 21 semi-structured interviews with actors engaged in research, I characterize the field of ACB HIV/AIDS research and explore the struggles therein. I also examine what is at stake in these struggles and their implications for the reproduction of, and resistance to, systems of domination.

My findings indicate that the field of ACB HIV/AIDS research is composed of interlocking scientific disciplines and non-scientific domains. Struggles over the field's organizing principles are represented in the different stances that participants adopt concerning the legitimate definition of research. Some academic-based actors define HIV/AIDS research

according to empiricist principles oriented toward technical control and prevention of disease. These serve to depoliticize science and defend scientific authority and the social order. Other actors, both academic- and community-based, depict HIV/AIDS research through a social justice lens focussed on the empowerment of the ACB population and improvement of its social position. Community-based ACB actors in particular resist the epistemic dominance of science and argue for the legitimacy of non-scientific actors as “knowers” of the ACB population, and research as a socio-political tool. These subversive strategies challenge scientific authority and threaten to disrupt the status quo. The findings suggest that ACB actors navigate between utilizing existing mechanisms of science and resisting the dominance of science in shaping knowledge about their lives. My research contributes to the sociology of science scholarship concerning the politics of knowledge, scientific boundary work, and health movements.

Acknowledgments

My thanks and gratitude...

To Peggy McDonough, my supervisor, for making me a Bourdieu convert and guiding me through this journey, from theorizing the “problem” to crafting the words. Your insightful feedback not only helped to shape this thesis, but also enriched my academic habitus.

To Mathieu Albert and Erica Lawson, for your overall guidance as committee members and individual insights. You are exceptional mentors and inspiring scholars.

To Joan Eakin, Liviana Calzavara, and Ann Robertson, for your encouragement and profound influence on my intellectual development.

To Winston Husbands, my community advisor, for helping me conceptualize this research, always making time, and keeping me grounded in things that matter.

To my SSH/SBHS family – I know without a doubt that I would not have achieved this without your unequivocal support and collective wisdom.

To my kith and kin, wherever you are in the world, for being the roots that allow me to grow, and especially to my parents, for believing in my academic potential before I did.

To Albert, my partner in everything, for your unwavering encouragement (bird by bird!) and willingness (and skill) to have whatever conversation I needed to, from formatting to social theory quandaries. To whoever put us in the same “Intro to Public Health” group, I owe you.

Most importantly, to all of the participants and community members who shared their thoughts and vision for how we might be able to think about, and do, research differently – thank you for trusting in this project.

Funding Acknowledgements

My doctoral studies were supported by the Social Sciences and Humanities Research Council, the Ontario Graduate Scholarship (OGS) Program, and the Inge and Ralph Hoffman Scholarship (OGS in Science and Technology Program).

Table of Contents

Abstract.....	ii
Acknowledgments.....	iv
Table of Contents.....	v
List of Tables.....	viii
List of Figures.....	ix
List of Appendices.....	x
Chapter 1 Introduction.....	1
1.1 Introduction.....	1
1.2 A Bourdieusian-inspired Framework.....	3
1.3 Thesis Organization.....	4
Chapter 2 Background and Literature Review.....	6
2.1 Introduction.....	6
2.2 A Socio-Political Lens on Relations between Civil Society and Science.....	7
2.2.1 Approaches to Understanding Civil Society's Engagement with Health Sciences.....	7
2.2.2 Health Activism and the Production of Scientific Knowledge.....	9
2.2.3 Summary.....	12
2.3 Civil Society and AIDS: The Birth of the Engaged Patient.....	12
2.3.1 The Mobilizing of AIDS Activists.....	13
2.3.2 The AIDS Movement and the Production of Science.....	15
2.3.3 Ontario's HIV/AIDS Civil Society: From Direct Action to Bridging Fields.....	18
2.3.4 Summary.....	20
2.4 Race and HIV, Race and Health.....	21
2.4.1 Race and Health Activism.....	22
2.4.2 ACB Communities Respond to HIV/AIDS in Ontario.....	27
2.4.3 Summary.....	30
2.5 Conclusion.....	31
Chapter 3 Theory.....	32
3.1 Introduction.....	32
3.2 A Bourdieusian Framework.....	33

3.2.1	Bourdieu's Field: A Place of Struggles over Legitimacy	33
3.2.2	Struggles in Scientific Fields	37
3.2.3	Summary	42
3.3	Critiques and Limitations of a Bourdieusian Approach	42
3.3.1	Bourdieu's Determinism and Ambiguity Towards Race	42
3.3.2	Limitations of Bourdieusian Approaches to Address Race	45
3.4	Seeing Race and Contextualizing Resistance	47
3.5	Conclusion	49
Chapter 4	Methodology and Conceptualizing the Field	50
4.1	Introduction	50
4.2	Methodological Orientation	50
4.2.1	A Bourdieusian-inspired Field Analysis	51
4.2.2	Seeing Race, Defining Community	51
4.3	Study Design	53
4.3.1	Defining the Field to Build the Sample	54
4.3.2	Recruitment and Interviews	63
4.4	Data Analysis	66
4.4.1	Transcription	67
4.4.2	Data Analysis and Interpretation: Breaking it Down, Building it up	69
4.5	Ethics and Trustworthiness	73
4.5.1	Confidentiality and Anonymity	73
4.5.2	Quality and Rigor	75
4.5.3	Positionality	78
4.5.4	Power Dynamics	82
4.6	Conclusion	83
Chapter 5	Results Part One: The Structure and Doxa of the Field	84
5.1	Introduction	84
5.2	The Nature of the Field	84
5.3	Evidence-based Approach as Doxic	90
5.4	Structuring the Field: Scientific and Community Capital	95
5.5	Conclusion	101

Chapter 6	Results Part Two: Struggles Over the Definition of ACB HIV/AIDS Research.	102
6.1	Introduction.....	102
6.2	An Empiricist Approach: The Objectivity and Universalism of Science.....	102
6.3	Challenging the Dominance of the Scientific Perspective and Empiricist Claims.....	107
6.3.1	Politics and Interests Shape Research.....	108
6.3.2	The Preoccupation with the Scientific Perspective.....	111
6.4	Redefining HIV/AIDS Research with Social Justice Principles.....	114
6.5	Conclusion	119
Chapter 7	Results Part Three: Who can be Legitimate Producers of Knowledge?.....	121
7.1	Introduction.....	121
7.2	Defending Scientific Authority.....	121
7.3	Challenging the Field Structure	126
7.4	Redefining the Field with Community Capital.....	133
7.5	Tensions Within the ACB Community.....	137
7.5.1	Resisting Research: Research as a Strain on Community Organizations.....	138
7.5.2	Challenging Representation and Leadership	141
7.6	Conclusion	142
Chapter 8	Discussion and Conclusion.....	145
8.1	Introduction.....	145
8.2	What is the Nature of the ACB HIV/AIDS Research Field?.....	145
8.3	What are the Struggles Over?	147
8.3.1	Challenging the Definition of the Field, Challenging the Social Order	149
8.3.2	Defending Empiricism, Defending the Structure.....	151
8.4	Implications for Knowledge about ACB Resistance Efforts	152
8.4.1	Becoming Agents of Knowledge.....	153
8.4.2	Implications of Participating in the Struggles for ACB Actors	155
8.5	Contributions to the Political Sociology of Science	158
8.6	Limitations, Challenges, and Future Research	160
8.7	Concluding Remarks.....	166
References	168
Appendices	183

List of Tables

Table 4.1	Types of ACB-oriented Grants Funded from 2003-2010.....	58
Table 4.2	Types of ACB-oriented Research Funded from 2003-2010.....	59
Table 4.3	Community and Academic Presence on Research Teams.....	60
Table 4.4	ACB Composition of Academic-led Research Teams	60
Table 4.5	Overview of Recruitment Outcomes	65
Table 4.6	Individuals Who Did Not Reply/Refused to Participate.....	65
Table 5.1	Fields Represented in the Research Sample	86
Table 5.2	Study Sample Demographics.....	87

List of Figures

Figure 4.1 Hypothesized Structure of the ACB HIV/AIDS Research Field.....	62
---	----

List of Appendices

Appendix A – Funding Databases	183
Appendix B – Information Letter	184
Appendix C – Consent Form	186
Appendix D – Interview Guide.....	189
Appendix E – Guidelines for Transcription of Interviews.....	191
Appendix F – Glossary for Transcription of Interviews.....	194
Appendix G – Key for Participant Acronyms in Results Chapters	195

Chapter 1 Introduction

The very foundation of the scientific world is a universe of competition for the monopoly of the legitimate handling of scientific goods...of the correct method, the correct findings, the correct definition of the ends, objects, and methods of science. (Bourdieu 2004:43)

Research is not an innocent or distant academic exercise but an activity that has something at stake and that occurs in a set of political and social conditions. (Smith 2012:5)

1.1 Introduction

A third of a century into the pandemic, the HIV/AIDS “problem” is still with us.¹ Worldwide in 2012, there were 2.3 million new infections and 35.3 million people living with HIV (UNAIDS 2013). AIDS continued to be a leading cause of death globally with 1.6 million deaths in that same year (UNAIDS 2013; WHO 2014). In response, an estimated \$10 billion annually is allocated to fighting HIV/AIDS per year, while five classes of HIV medications and at least 20 individual drugs are available for treatment or prevention (UNAIDS 2007). Indeed, HIV/AIDS has become an industry—a global network of institutions, organizations, and actors spanning fields and sectors that have come together in complex dynamics to respond to the pandemic. This nexus of invested groups and actors is also a space of competing “sites of knowledge” (Treichler 1999) over how to best define and respond to HIV/AIDS.

From the early days of HIV/AIDS, knowledge production has been a political process involving the crossing of scientific boundaries, and collaborative and acrimonious relations between institutional actors (e.g., scientists, medical professionals) and members of civil society who make up the “AIDS movement” representing communities affected by HIV/AIDS. These civil society actors have been intimately involved in defining HIV/AIDS by challenging the institutional responses stemming from scientific and health-related disciplines.

¹I use the abbreviation “HIV/AIDS” throughout this document when discussing either HIV infection or AIDS, the latter being a category that is applied when the disease has progressed to an acute and life-threatening phase. Although they have different biomedical meanings, this research does not explore the semantics of the words but, rather, is concerned with the general disease they represent. However, at times I specifically use one or the other term where doing so improves the clarity of the text (e.g., in reference to preventing HIV infection or an earlier time in the epidemic when AIDS was the only term to describe the disease, such as “AIDS activism” or “AIDS movement”, both of which remain commonly used today).

By questioning expert control over knowledge, activists have helped to change the practice of HIV/AIDS science and set the stage for lay actors to legitimately interact with scientific experts (Altman 1994; Epstein 1996).

Yet the AIDS movement is not a homogeneous group of activists with agreed-upon strategies (Stockdill 2003; Gould 2009). As the general nature of HIV infection shifted from an acute and life-threatening disease to a manageable long-term illness (in Western countries at least), the civil society response changed from a primarily White, gay-led social movement oriented towards direct action (e.g., public protests) to a more institutionalized set of practices. Today, HIV/AIDS civil society in North America consists primarily of community-based organizations that provide services, advocacy, and support tailored to the different groups affected by HIV/AIDS (e.g., ethnocultural communities, drug users). These affected communities have different histories of mobilization and engagement with the institutions charged with formally responding to HIV/AIDS. The literature suggests that the early HIV/AIDS scientific and research agenda most closely reflected the interests of White, male activists because of the high degree of social and cultural capital, such as education and professional skills, that they were able to utilize in their activism efforts (Epstein 1996; Stockdill 2003). The contributions and direct action tactics of these AIDS activists were widely acknowledged to have affected the course of HIV/AIDS science, notably, by stimulating changes to clinical trial protocols and improving access to treatments for patients (Epstein 1996).

By focussing on biomedical solutions for the HIV/AIDS problem, however, other ways of responding were sidelined (Stockdill 2003). For example, activists from communities of colour argued for greater attention to the social drivers of HIV/AIDS, including the socio-political dynamics and inequities that fuel the disease in Black populations (Stockdill 2003; Royles 2014). Moreover, Black community-based organizations and actors have had to contend with dominant discourses, epistemologies, and practices of a predominantly White HIV/AIDS industry and AIDS movement that, in their view, has not responded adequately to the needs of Black communities (Lemelle 2002; Stockdill 2003; Royles 2014). This marginalization can have significant consequences in health and social terms, especially because Black communities in North America are disproportionately affected by HIV, both in prevalence and incidence (Public Health Agency of Canada 2009; Centre for Disease Control 2014).

In Canada, Ontario has the highest concentration of HIV infection in the African, Caribbean, and Black (ACB) population (Public Health Agency of Canada 2009).² With the creation of the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) in 2003 came a resolute call for self-determination and power over agenda-setting, including identifying and facilitating community-relevant research priorities (HIV Endemic Task Force 2003). Yet these mobilization efforts have also been fraught with tensions and struggles. For example, ACCHO (2010) identified difficulties around building a cohesive response to HIV/AIDS in the ACB population and resistance from the “mainstream” HIV/AIDS sector concerning the implementation of ACCHO’s social-justice oriented initiatives.

Given the challenges that the ACB community has faced within the HIV/AIDS sphere, what do their struggles say about the current politics of HIV/AIDS knowledge? That is, who gets to decide how research is used in the production of HIV/AIDS knowledge and, indeed, what kind of knowledge is defined as legitimate? Scholars have documented the struggles of early AIDS activists as they mounted epistemic challenges and questioned the dominance of experts over the conceptualization and treatment of HIV/AIDS. However, little is known about the politicized efforts of other groups disproportionately affected by HIV/AIDS, particularly Black communities, to mobilize and shape research. With the pivotal role that science plays in defining the knowledge needed to respond to HIV/AIDS, it is important to draw attention to the ongoing struggles of these actors to affect and, indeed, define the production of research about their communities.

1.2 A Bourdieusian-inspired Framework

This thesis investigates social relations and patterns of power in research about HIV/AIDS in the ACB population in Ontario. In order to understand the struggles of ACB actors to become legitimate producers of knowledge, it is also necessary to examine the mechanisms that are employed by academic actors to defend dominant scientific practices and reinforce scientific

²I use the phrase, “African, Caribbean, and Black” (ACB), as a label designated by the organized community in Ontario to reflect how different actors of African-descent have come together to address HIV/AIDS in their communities. This grouping refers to people of African descent currently living in Canada, either Canadian born or those who have immigrated to Canada. Furthermore, I use “ACB community” to refer to the group of actors who have mobilized around HIV/AIDS, and “ACB population” to refer to the larger demographic of ACB people.

boundaries. Pierre Bourdieu's approach to the field of science as a "universe of competition for the monopoly of the legitimate handling of scientific goods" (Bourdieu 2004:43) provides an ideal conceptual framework with which to examine the social relations of a domain populated by a variety of actors attempting to affect the definition of ACB HIV/AIDS research. This lens leads to the following over-arching questions that guide the study:

- What is the nature and structure of the field of ACB HIV/AIDS research?
- What is the nature of the struggles in the field? Specifically, what is being challenged, what is being defended, and what is at stake?
- What are the implications of these dynamics for the reproduction of, or resistance to, systems of domination?

To implement a Bourdieusian approach to these questions, I consider the various field actors' respective social locations in relation to their definition of "legitimate" HIV/AIDS research. This type of analysis locates epistemological perspectives in material struggles and provides insights into the hierarchical nature of field relations and mechanisms of domination and resistance. In addition to employing a Bourdieusian lens, I also refer to race scholarship to give context and meaning to the struggles of the ACB community and to understand what is at stake for these actors as they resist modes of domination in the scientific field.

1.3 Thesis Organization

The thesis is organized as follows. In Chapter 2, I provide a critical review of the empirical literature concerning social relations between civil society and science, focusing on credibility struggles in health social movements and politicized challenges to the production of HIV/AIDS science. I also address mobilization efforts in the ACB population around race, health, and HIV/AIDS, and place these within larger socio-political dynamics. In Chapter 3, I present the study's theoretical framework based on Bourdieu's conceptual tools, emphasizing the dynamics of struggle in the scientific field. Additionally, I address key critiques of Bourdieu's approach, and discuss how race is considered in my theoretical framework. The study design is presented in Chapter 4. Here, I reflect on issues of methodological congruency between the theoretical framework and analytic approach, and explain my iterative approach to data analysis. I also discuss matters of reflexivity, ethics, and quality in the research. Turning to the results of the study, Chapter 5 is an exploration of the forms of capital valued in the field and assumptions that underlie field-specific practice. In Chapter 6, I begin to explicate field struggles by focusing on

challenges to, and the defense of, legitimate definitions of ACB HIV/AIDS research. Chapter 7 examines struggles over the field's power structure through the defense of, and challenges to, scientific authority and the assertion of community legitimacy in knowledge production. The thesis ends with a discussion of the study results in Chapter 8. I first revisit the research questions, considering the nature of the field and dynamics of struggle and how these feed into mechanisms that reproduce or disrupt the social order. Thereafter, I speak to the implications of these findings for what we know about Black resistance and AIDS activism and the contribution of my research to scholarship in the sociology of science. Finally, I reflect on study limitations and challenges I faced in employing a Bourdieusian lens, and suggest future directions for research.

Chapter 2 Background and Literature Review

...It is unlikely that knowledge-making practices can be substantially democratized, except when efforts to do so are carried out in conjunction with other social struggles that challenge other, entrenched systems of domination. (Epstein 1996:352)

2.1 Introduction

Civil society and politicized groups have been formally interacting with science for over 50 years, challenging its practices and attempting to democratize its production. Health movements, in particular, have developed and used alternative forms of “expertise” to shift the boundaries of scientific credibility, affect the practice of medicine and the implementation of health policy, and redefine relations between institutions involved in the production of biomedical and health research. In the HIV/AIDS field, relations between civil society and health, science, and policy institutions have set the stage for the conduct of research and who can be involved in its production. This chapter is concerned with politicized challenges to the production of HIV/AIDS science and the socio-political context of the current field of HIV/AIDS research about the ACB population. To understand these issues from a sociological perspective, it is useful to consult scholarship at intersecting fields associated with the sociology of science and social movements.

The chapter is divided into three sections. First, I review sociological approaches to the study of civic engagement with science and then highlight scholarship that explores challenges that health social movements have mounted against scientific authority and boundaries. In the next section, I provide an overview of the AIDS movement, concentrating on dynamics associated with the insertion of lay actors into the institutional responses to HIV/AIDS. I also explore relations between activists and institutions of science and medicine that have resulted in the simultaneous shifting, blurring, and protecting of scientific boundaries. The third section is centred on socio-political dynamics that have shaped how ACB communities have organized around HIV/AIDS. Finally, I provide a history of ACB mobilization in Canada.

2.2 A Socio-Political Lens on Relations between Civil Society and Science

In this section, I review how sociologists have approached the study of civil society's interaction with scientific fields related to health.³ I then critically examine the scholarship concerning social relations between health social movements and science, including challenges raised by key health movements concerning power, participation, and democracy in the production of scientific knowledge. As I discuss, these challenges can trigger both a shift in definitions of "good science" and a defense of scientific boundaries.

2.2.1 Approaches to Understanding Civil Society's Engagement with Health Sciences

Scholarship concerning civil society's engagement with health-related sciences has generally fallen under the categories of the sociology of social movements and/or the sociology of science. Social movement researchers examine the strategies that actors employ when challenging institutional responses to health issues and demonstrate how activism has been important in dynamics of social change (Brown et al. 2004). Phil Brown and Stephen Zavestoski (Brown and Zavestoski 2004; Brown et al. 2004; Zavestoski et al. 2004) have carved out a sociological niche by naming and conceptualizing these dynamics within a larger category of health social movements. This literature combines medical sociology with social movement theory to systematize the study of these movements and understand the collective impact they have had on public health, medical research, and health-care delivery (Brown et al. 2004:680).

Broadening out from the social movement literature is sociology of science scholarship that examines the politics of health, illness, and biomedical research. These works lie at the intersection of various domains of theory and research, such as the aforementioned social movement theory and medical sociology combined with the related fields of sociology of knowledge, social studies of science, and science and technology studies (Archibald and Crabtree 2010). For example, Hess (2004) identifies an emergent synthesis between medical

³ Although I use the general term of "civil society" to represent the larger domain of groups that have mobilized around a given issue, it is not homogenous in membership or political goals. This issue is more fully addressed below in relation to the AIDS movement.

sociology and the sociology of science that is concerned with the affect of health social movements on medical research communities through challenges to scientific authority and epistemic regimes in medicine. This convergence is also found in empirical pieces that examine power relations among actors involved in the production of scientific knowledge, such as “non-scientist” participation in scientific knowledge production and science policy decisions (Moore 2006:11). This scholarship falls under the general umbrella of the political sociology of science as it brings an understanding of how the “politics of expertise and technology play out in various political arenas” and the knowledge-making process (Hess et al. 2008:473).

These areas of socio-political scholarship also explore the circumstances for resistance and agency and consider the “broader dimensions of public engagement with science and technology” (Epstein 2008:501). For example, scholars have examined how illness “sufferers” or affected communities use their experiences as “epistemic grounding” for contesting dominant and normative scientific assertions, laying claim to formal knowledge usually produced by “experts”, and developing alternative knowledge claims (Epstein 1995; Clapp 2002; Klawiter 2004; Epstein 2008). Others have focussed on the social, political, and institutional organization of scientific knowledge by examining “undone science”—areas of research that have been identified by civil society as having potential social benefit but have been left “unfunded, incomplete, or generally ignored” by scientists and policy makers (Frickel et al. 2010:444-445). For example, Frickel et al. (2010) explored how approaches focused on environmental risk factors in breast cancer research were marginalized in comparison to the “dominant epidemiological paradigm” (Zavestoski et al. 2004) that emphasizes lifestyle and genetic factors of the individual. Environmental risk factors, therefore, remained “undone” as key research agenda items within science. These scholars are moving beyond the study of “patient groups” as discreet entities to examine “the institutional and cultural webs” in which they are entangled and the scientific boundaries they navigate (Epstein 2008:507).

Finally, sociologists have explored how rhetorical boundary lines are drawn and blurred between science and “non-science” (Gieryn 1999). The process of boundary construction can involve deploying methodological tools, such as assessment criteria for research procedures, or privileging particular approaches to research to demarcate scientific quality (i.e., “good science”) (Albert et al. 2009). The process of maintaining boundaries around science is part of larger credibility struggles where scientific claims “win credibility” as legitimate knowledge (Shapin

1995). Consequently, “claims-makers” can use that legitimacy to present themselves as the “sort of people who can voice the truth” (Epstein 1996:3). As will be seen in the empirical literature that follows, political pressures from social movements can trigger responses of defence and maintenance around scientific “boundaries”. These challenges can also act as conduits for blurring the boundaries between “expert” and “lay”, and “science” and “politics” (Epstein 2008:506).

2.2.2 Health Activism and the Production of Scientific Knowledge

Over the previous three decades, health movements have reflected a larger trend of participatory science. This has involved the expansion of the democratic practice in science, as non-scientists become more involved in the design, production, and use of science (Moore 2006). Participatory science in the US has been linked to social movements in the 1960s and 1970s that critiqued and challenged the “rule of expertise” and scientific authority (Hoffman 1989). For example, scientists were accused of hiding behind claims of objectivity to mask political decisions in areas such as the weapons industry (Moore 2006). Moreover, medical professions that served minorities and poor populations were criticized for their perceived self-interest and class and racial biases (Hoffman 1989). There was a concurrent acknowledgement by scientists themselves that they needed to be more responsive to the public’s needs (Moore and Hala 2002), and a growing belief that the collaboration with research “subjects” could lead to better scientific knowledge (Hall 1993). These developments preceded, and then co-existed alongside, community-based health activism initially led by women and African Americans. Activists explicitly linked health disparities to social inequities and challenged the medical establishment’s conceptualization of their communities’ illnesses in individualistic terms (Hoffman 1989; Nelson 2011). Since then, scholars have documented the contribution of health social movements to social change by serving as a “critical counter-authority” aimed at democratizing and reshaping social policy and the science of health and disease (Brown and Zavestoski 2004).

Social movement scholars have developed a typology of “embodied health movements” (EHMs) to analyse movements that address disease or illness by challenging science on aetiology, diagnosis, treatment, and prevention (Brown et al. 2004). EHMs introduce the “biological body” to social movements through the embodied experience of people who have the disease (Brown et al. 2004). Their experiences lend “moral credibility” to the mobilized group in the public sphere

and scientific world (Brown et al. 2004). However, movement actors are usually dependent on science to gain funding for research and to raise the resources necessary to support programs and services that address their constituents' needs. The more that scientists can attest to the legitimacy of those needs, the stronger the claims of the advocates (Brown et al. 2004). Collaboration is, therefore, necessary as it allows movement actors to ally with scientific authority structures even as they simultaneously attempt to subvert and co-opt them (Archibald and Crabtree 2010).

The breast cancer movement and the AIDS movement are regarded as two of the most successful health social movements. Scholars have argued that these movements profoundly affected how research and medical knowledge are produced (Epstein 1996; McCormick et al. 2003). Movement actors transformed their identity from patients to knowledge-challenging activists and mounted epistemic challenges based on experience to build credible "counter-expertise" (Hess 2004). This resulted in a more public shaping of science as activists took on roles as "lay experts" who could contribute to funding and policy decisions, produce alternative conduits of knowledge, and directly challenge research programs. To accomplish their goals, these actors often went through an "expertification" process themselves by obtaining additional education. As patient groups became educated and mobilized over the disjuncture between their personal experiences of illness and institutional understandings (Kleinman 1981; Brown et al. 2004), they began to challenge not only official knowledge about disease but also the underlying "epistemic authority" of modern scientific medicine (Hess 2004). These movements also helped to reconfigure the roles of actors in disease fields, mainly the role of patients and their interaction with healthcare providers. The "educated patient" (Epstein 2008) is now involved with the "pragmatics" of information-gathering (Barbot and Dodier 2002) and strategies of "illness management" (Barbot 2006). Through these efforts, educated and mobilized patients cross boundaries between the lay and expert (scientific) domains.

Brown et al. (2004) have referred to EHMs such as the breast cancer and AIDS movements as "boundary movements". Actors in boundary movements push the limits of what is defined as "normal" scientific practice and blur boundaries between lay and expert forms of knowledge and between activists and the state. For example, AIDS treatment activists, armed with medical and scientific knowledge, demanded an audience with health policy makers, scientists, health care providers, and the pharmaceutical industry. Activists became full participants in the production

of science when their form of lay expertise was legitimized through formal inclusion in institutional decision-making mechanisms (e.g., scientific peer review boards) (Brown et al. 2004). Boundaries are also blurred when scientists, policy actors, and others not usually considered as movement actors take on the role of “advocacy scientists” (Krimsky 2000). This is part of a larger 20th century trend of scientists entering the political arena in collaboration with social movement actors to oppose dominant policies that fuel inequalities and to support social responsibility in science (Hess et al. 2008). The AIDS movement, for instance, blurred boundaries between social movement activism and expert authority when physicians also took on activist roles (Epstein 1996). These blurred boundaries create complex dynamics and tensions as social movement actors and scientists navigate uneasy alliances that can often move into conflict and hostility, even as they generate new research programs and scientific knowledge (Hess et al. 2008).

Boundaries between different social and health movements can also be blurred. AIDS activism has inspired other organized challenges to biomedicine from groups that have constructed their identities from disease categories (Epstein 1996). For example, breast cancer and mental health movements developed a new “militancy” and demanded a voice in how their conditions were conceptualized, investigated, and treated (Epstein 1996:348). Furthermore, politicized identity movements, like those oriented around LGBT or women’s issues, have merged with specific disease movements (e.g., cancer and HIV/AIDS) to form constituency-based “spillover” health movements that address health inequalities based on race, gender, or sexuality differences (Meyer and Whittier 1994; Brown et al. 2004). In linking disease and institutionalized medicine and health care to social inequalities, these mobilized groups argue for the reform of wider social and scientific institutions and medical practices (Zavestoski et al. 2004). Spillover movements also reflect the collective identities, strategies, and organizational structures of their previous movements (Brown et al. 2004). Indeed, the AIDS movement’s early oppositional tactics were derived from gay men living with AIDS and female activists who had previous experiences with LGBT direct action and women’s health activism.

Using previously honed tactics and their collective capital as educated, professional, and experienced activists, health activists challenge how scientific knowledge is produced and medicine is practiced. However, these challenges do not go unanswered by the scientific community. As Epstein (1996:8) argues, scientists often police the boundaries of their

professional domain to keep out “unqualified interlopers”. Building on Gieryn’s (1999:xi) conceptualization of boundary work, that is, how scientific boundaries are “established, sustained, enlarged, policed, breached, and sometimes erased in the defense, pursuit, or denial of epistemic authority”, Hess (2004) explored the reaction of the medical research community to challenges from health social movements. As an initial response, Hess (2004) claimed, “paternalistic progressivism” rebuffed epistemic challenges while emphasizing the “purity” of scientific knowledge. Boundary work was used to maintain and legitimize the link between science and biomedical knowledge and portray the knowledge of patients and others involved in producing alternative knowledge claims as “non-science”. However, according to Hess (2004), “medical modernisation” has recently emerged whereby evidence-based medicine and science becomes the model from which decisions are made about the integration of alternative knowledge claims (e.g., complimentary and alternative medicine) *into* the traditional medical model. In this case, more alternatives are included in what is considered legitimate medicine but the overall evidence-based model remains largely uncontested. As will be discussed in the next section, scholars have argued that these dynamics were present in the AIDS movement with the inculcation of treatment activists into the scientific orthodoxy (Epstein 1996; Berridge 2002).

2.2.3 Summary

The late twentieth century saw a convergence between various politicized and disease-based identities. This convergence resulted in health social movements that have mounted epistemic challenges and questioned the dominance of health and medical institutions over the conceptualization and treatment of diseases and illnesses. Scientific boundaries became increasingly porous as activists became experts and scientists took on activist roles. However, despite the loosening of scientific boundaries to accommodate external pressures, struggles over epistemic authority remain. I now examine AIDS activism as an example of an embodied health movement that has contributed to social change within the field of science by blurring and shifting scientific boundaries and challenging the boundary work of the scientific enterprise.

2.3 Civil Society and AIDS: The Birth of the Engaged Patient

This section provides insight into AIDS movement dynamics and key historical junctures for AIDS activism and civic involvement in scientific research. Although I am not undertaking an analysis of contemporary AIDS activism or advocacy per se, it is important for the work that

follows to understand the origins of the current social relations in HIV/AIDS research and the evolution of the politics of research production. I first provide a brief history of AIDS activism in North America. I then focus on empirical scholarship that examines credibility struggles and social relations between HIV/AIDS scientists and “non-scientists”, and consider the unintended consequences of activists crossing scientific boundaries. Thereafter, I introduce AIDS activism in Canada as background to the mobilization of Ontario’s ACB community around HIV/AIDS.

2.3.1 The Mobilizing of AIDS Activists

AIDS activism grew out of the gay movement and women’s health activism, both of which were gaining strength in the 1980s. The mobilization of AIDS activists developed in response to the failure of health, policy, and corporate institutions to mount an effective and timely response to the unfolding epidemic and the large numbers of AIDS-related deaths in marginalized communities (Shilts 1988; Deresiewicz 1991; Corea 1992; Cohen 1999). Collective action included underground clinical research, buyers’ clubs for medications, peer education, sit-ins and rallies, alternative media projects, activist conferences, and clean needle exchanges (Stockdill 2003). Activists also established grassroots agencies that offered peer prevention programs, community clinics, information-oriented services, and a range of advocacy services (Stockdill 2003). Through formal political channels, activists campaigned to prevent the spread of HIV, decrease stigma and inequities around AIDS, and increase funding for treatment and prevention. They also challenged the development and availability of medications. These efforts were conceptualized as part of an AIDS social movement because they were centred on a group of people who used “politics by other means” (McAdam et al. 1988) to challenge dominant institutions to address their collective interests and change society’s response to HIV/AIDS.

As the epidemic evolved, direct action tactics favoured by the AIDS Coalition to Unleash Power (ACT-UP) and other groups gave way to the institutionalization of grassroots organizations, the professionalization of activism, and the reorientation of affected populations (e.g., gay men, women, drug users, ethnocultural communities) towards their respective community’s interests (Patton 1990; Altman 1994; Gillet 2003; Gould 2009). As access to HIV medications improved, oppositional activism declined (Gould 2009). With people infected with HIV living longer and AIDS agencies becoming key actors in policy and programming decisions, and academic, clinical, and industry research, attention turned to improving service provision. These efforts

were grounded in principles of self-determination and self-empowerment, as reflected in the “Denver Principles” drawn up by AIDS activists in 1983. The text called for the inclusion of people living with HIV/AIDS in their health care as “equal partners” (UNAIDS 2007). This was part of a broader trend of public participation in health care, as seen in the 1978 Alma-Ata Declaration that stated, “people have a right and duty to participate individually and collectively in the planning and implementation of their health care” (International Conference of Primary Health Care 1978). This trend coincided with calls for community-engaged scholarship (CES) in academic institutions based on principles of service and finding answers to the “most pressing social, civic, economic, and moral problems” in society (Boyer 1996:19-20).⁴

In practice, these principles translated into people living with HIV/AIDS (PHAs) fighting for the right to participate in decision-making processes in political, social, and legal spaces (UNAIDS 2007). The principles were formalized at the 1994 Paris AIDS Summit as “greater involvement of people living with HIV/AIDS”, usually known as the GIPA Principle, which was endorsed by United Nations member states in 2001 and 2006 (UNAIDS 1999; UNAIDS 2007). According to UNAIDS (2007), GIPA rests on two main assumptions concerning potential benefits. First, it is the right of the person living with HIV/AIDS to be involved in decisions that affect their care. This provides benefits to the individual through increased self-esteem and improved mental health, and access to health information and care. Second, benefits also accrue at the community and systems levels. By involving PHAs in the conduct of HIV/AIDS programming (e.g., as volunteers or employees), they are seen as productive members of society rather than stigmatized as AIDS “sufferers”. Furthermore, their involvement in programming would improve effectiveness by ensuring that services were acceptable and relevant. There are many practical and social barriers that affect whether GIPA principles can be enacted (Travers et al. 2008) and concern that GIPA can act as a mechanism of “governance” and co-optation (Guta et al. 2013). Nonetheless, it has been one of the most enduring discourses associated with the pandemic. In fact, in an effort to address these challenges, GIPA is now often replaced by MIPA, the

⁴ Formalized policies and partnerships in the US and Canada now exist to promote CES and social responsibility in higher education institutions (e.g., Kellogg Commission 1999 <http://www.aplu.org/page.aspx?pid=305>; Community Campus Partnership for Health <https://ccph.memberclicks.net/assets/Documents/10annivreportfinal.pdf>; Community-Engaged Scholarship Partnership <http://engagedscholarship.ca>).

meaningful involvement of people living with HIV/AIDS. For example, the Ontario AIDS Network (OAN) has drawn up “The Ontario Accord”, a statement that outlines GIPA/MIPA principles and extends those to include aims of personal and social transformation and “going beyond service alone” (Ontario AIDS Network 2011). The widespread and institutional acceptance of these principles has solidified the notion of the “engaged patient” and formalized the involvement of community actors in every aspect of the response to HIV/AIDS. As will be discussed next, these struggles to participate in the institutional response to HIV/AIDS can be seen as an effort to legitimize the credibility of “lay expertise” and shift scientific boundaries.

2.3.2 The AIDS Movement and the Production of Science

The ways in which AIDS activism influenced the development of treatment and the delivery of healthcare programs are well documented (Keefe et al. 2006; Vandormael 2007; Parker 2009; Vincent and Stackpool-Moore 2009). Activists also helped to expand research and policy funding for HIV/AIDS, and secured the inclusion of affected populations in government and corporate decisions-making bodies (Arno and Feiden 1992; Gould 2009). In the biomedical domain, activists brought greater attention to alternative treatment approaches, and contributed to the reconfiguring of scientific procedures, such as changes in the conduct of clinical trials to speed up the drug-approval process for people with life threatening illnesses (Arno and Feiden 1992; Epstein 1996). In challenging the idea of certainty in drug development, activists pressured pharmaceutical companies and policy makers to make medications available earlier. This amounted to a change in the definition of “evidence” in drug development. The AIDS movement become known as a patient movement that successfully engaged with, and helped to shape, expert knowledge and policy while also playing an essential role in the creation of scientific knowledge (Jamison 2006).

However, these dynamics were also fraught with politics and struggles over credibility. As activists challenged scientific boundaries in the early days of AIDS research, they also sought to have their own knowledge claims and status as “lay experts” legitimized (Epstein 1996). AIDS organizations pushed to increase the credibility of grassroots knowledge by sponsoring and co-implementing community-based clinical trials of early AIDS drugs (Indyk and Rier 1993). This “bottom-up” pattern of knowledge production went against traditional “top-down” science generated and disseminated by experts, and carried over into policy and planning. For example,

the Center for Disease Control (CDC) created a database of grassroots organizations' programs and materials for public use and consultation for planning of HIV/AIDS programming (Indyk and Rier 1993). This grassroots incursion into traditional scientific processes also upended conventional protocols for knowledge dissemination, with activists interpreting and publishing data themselves because, they claimed, researchers took too long to publish data from clinical trials. Moreover, when publishing articles in community-based outlets, activists would gather anecdotal information from various sources, including informal conversations with physicians, patients, and scientists, to add to the results of scientific research (Indyk and Rier 1993). These community-based publications were both information sources for PHAs and resources for researchers and administrators looking for information on experimental treatments that was difficult to access through traditional scientific avenues. The acceptance of these publications by researchers lent further credibility to grassroots knowledge production and contributed to the redefinition of HIV/AIDS science (Indyk and Rier 1993).

Mainstream science, however, was not universally accepting of grassroots knowledge production. In response to pressure and competition from community-based actors, scientists attempted to construct "defensive boundaries" around their domain (Indyk and Rier 1993:20), for example, by deriding community-based research (Arno and Feiden 1992). In the US, principal investigators on early National Institutes of Health (NIH) clinical trials fought against the inclusion of grassroots organizations and PHAs in the design and conduct of the trials (Nussbaum 1990). The editor of the *New England Journal of Medicine* attacked an underground and unauthorized clinical trial conducted by community-based organizations and compared it to "black magic". The editor's criticisms were mainly directed at the study design for its lack of a control group (i.e., it was not a randomized controlled trial) and grassroots groups for disseminating information on experimental medications (Indyk and Rier 1993). This example of boundary work cast the grassroots sector as marginal to the world of "real science" because of its use of "unscientific" methods and practitioners (Indyk and Rier 1993).

Despite such opposition, activists helped to change traditional notions of "good science" by appealing to notions of scientific credibility and validity. To gain credibility and resist scientific boundary work, activists taught themselves the necessary technical language and appropriated scientific culture, forcing "credentialed" experts to deal with their arguments (Epstein 1996).

These activists were able to portray themselves as credible representatives of the HIV/AIDS

community and assert their claims to “expertise” in ways that corresponded with scientific norms (Epstein 1996). Activists translated their political goals into technical scientific language by combining moral and political stances with methodological and epistemological arguments. For example, they maintained that the inclusion of women and minority groups in clinical trials was both morally ethical and scientifically generalizable (Epstein 1996). Moreover, activists pressured researchers to consider the relevancy of trials for patients themselves, rather than only focussing on clinical importance. These changes to clinical trials also benefited the research enterprise by helping to ensure participation and compliance from patients (Epstein 1996).

The scientific credibility of some activists was also bolstered by their HIV-positive status, which allowed them to be the voice of the potential population of research subjects (Epstein 1996). As Epstein (1996:337) argued, HIV-positive AIDS activists had something to say simply because of “where they stood”. These activists were invited to participate on review boards at hospitals and research centres, community advisory boards for pharmaceutical companies, and policy advisory committees of the NIH, Food and Drug Administration, and other government agencies.

Organizations, such as ACT-UP, were also popular with the media and regularly consulted as “experts” by journalists (Epstein 1996). As activists blurred the line between lay and professional expertise, they helped to create different pathways to credibility in HIV science. This led to the field of HIV/AIDS science encompassing not only “mainstream” researchers but also grassroots actors (Epstein 1996).

Early AIDS activism profoundly affected the response to HIV/AIDS and expanded the scope of those who could be considered credible and legitimate actors in the conduct and development of research, policy, and programming. Today, activists, advocates, and lay community members sit alongside scientists on research teams, occupy research positions, and produce HIV/AIDS knowledge in community settings. Nonetheless, there may be unintended consequences from activists becoming legitimate actors in the production of science. For example, Epstein (1996) contended that through the engagement with expert knowledge, activists became entrenched in the institutional and expert systems of knowledge construction. Becoming “activist-experts” in HIV medicine and treatment not only affected how clinical trials were carried out and the availability of treatment, but also the direction and focus of the AIDS activist movement itself (Epstein 2000). Direct action was focussed on gaining access to treatment and creating a bond with the medical field through securing roles for activists as community advisors and treatment

experts in their own right. As Epstein argued in an interview, the AIDS movement altered the practice of medical science, but the relationship between activists and the medical field also changed and complicated the identity and strategies of the movement; the acquisition of expert knowledge remade the “activist self”, which then became embedded in formalized scientific ways of thinking (Mykhalovskiy and Rosengarten 2009). In her examination of HIV/AIDS organizations in the UK, Berridge (2002) claimed that after an initial phase of direct action, activism returned to supporting more orthodox models of treatment and trials. Moreover, gains in research ethics and patient involvement could even be considered an extension of medical self-regulation as patients were integrated into the existing biomedical structure. Berridge (2002) ultimately complicated the concept of “patient power” by characterising activists as subordinate players in “pharmaceutical” public health. Like Epstein, she suggested that AIDS collective action was geared toward changing the way biomedicine functioned without challenging the traditional hegemony of biomedical sciences. Alternative ways of responding to the disease were sidelined as the focus remained on treatment of the individual patient.

In gaining credibility within science and forging legitimate avenues for affected communities to engage with expert knowledge, activists also became invested in the science of HIV/AIDS. As will be shown in the next section, AIDS activists in Canada have also been intimately involved and invested in the production of HIV science, as they challenged biomedical boundaries and bridged the various domains involved in the production of HIV/AIDS research.

2.3.3 Ontario’s HIV/AIDS Civil Society: From Direct Action to Bridging Fields

AIDS hit Canadian gay urban communities in the early 1980s, with the first case reported by public health officials in 1982 (Public Health Agency of Canada 1982). The first wave of AIDS activism during the early part of the decade focussed on providing peer support and counselling services, hospices, and grassroots prevention education, leading the way to the creation of community-based organizations such as the AIDS Committee of Toronto (ACT) (McCaskell 2012a). The second wave began in the late 1980s with the emergence of direct action tactics of AIDS Action Now (AAN) in Toronto, an organization that consisted mainly of activists who were HIV-positive. In Ontario, AAN disrupted question period in the provincial legislature, held

“die-ins”, and chained activists to furniture in the Minister of Health’s offices in their fight for access to costly treatments and experimental medications.⁵ AAN refused funding from government or the pharmaceutical sector, and its lobbying efforts were confrontational and pressure-oriented rather than collaborative. Activists worked at “figuring out the science” to effectively pressure for standards of care and access to early medications (McCaskell 2012b). They joined forces with ACT-UP New York to storm the 1989 International AIDS Conference in Montreal, an event that up to that point had been the domain of government officials, doctors, and scientists. Thereafter, “community” was formally included in all future International AIDS Conferences. In fact, the International AIDS Society (2014) now describes the conference as “a unique forum for the interaction of science, community and leadership”.

As HIV treatments became more effective and accessible, the landscape of AIDS activism and advocacy in Canada changed. In particular, the establishment of the Canadian Treatment Advocates Council (CTAC) in 1996 as the “national voice of people living with HIV/AIDS within governments and industry on HIV treatment issues” (Canadian Treatment Advocates Council 1999) signalled a shift of treatment activism towards greater institutionalization. The majority of early members instrumental in setting up the organization were gay activists living with HIV/AIDS who had a history of advocating on biomedical issues. CTAC was seen by the pharmaceutical research industry as a legitimate stakeholder because of the accumulated technical expertise of these treatment activists and their ability to act as representatives of the “patient community” (Maguire et al. 2004). At the same time, despite receiving funds from pharmaceutical companies, the activists who worked for CTAC retained credibility within the HIV/AIDS advocacy sector because of their HIV-positive status and activist history (Macquire et al. 2004).⁶ Today, the organization continues to act as a bridge between the community and government bodies and pharmaceutical companies, carrying out advocacy efforts and developing policy and programs concerning HIV treatment (CTAC 2014).

⁵ The resulting Trillium Drug Program ensures that Ontario residents can obtain necessary medications even when cost exceeds affordability for an individual (McCaskell 2012a).

⁶ Although CTAC still exists, it has undergone numerous changes in structure and purpose. It is unclear whether the organization still holds credibility with HIV/AIDS organizations.

The Ontario HIV Treatment Network (OHTN) is another organization that has attempted to formally bridge fields in the HIV/AIDS domain.⁷ The OHTN is a network of researchers, health service providers, policy makers, community members, and people with HIV/AIDS. In addition to conducting in-house research and providing research-related support to the larger HIV/AIDS sector, OHTN holds think tanks and an annual provincial research conference. OHTN requires researchers seeking funds to address GIPA, clearly identifying how community stakeholders will be engaged throughout the research process and outcome and evaluation stages (OHTN 2009a). Community stakeholders are also involved in the OHTN provincial research conference, which promotes “knowledge exchange between people living with HIV, researchers, policy makers, community groups, and health service providers” (OHTN 2009b). Through its funding and research-related activities, and its advocacy role in the development of community, health services, and research policies, OHTN occupies a strategic position in setting research agendas and brokering relations among stakeholders. Indeed, OHTN arguably holds the most scientific credibility of all not-for-profit organizations in Ontario’s HIV/AIDS sector because of its strong focus on research and the academic affiliations of its network members and staff. OHTN has provided formal mechanisms for civil society and other non-scientists to formally engage in the production of HIV/AIDS knowledge and, consequently, has contributed to the institutionalization of social relations between actors involved in HIV/AIDS research.

2.3.4 Summary

HIV/AIDS has become a site of contestation over definitions of scientific legitimacy and expertise. AIDS activism and the overall legitimization of public participation in health care has led to the formalized involvement of lay community members in programming and policy decision-making mechanisms, setting the stage for multiple actors to contribute to the production of HIV/AIDS research. Activists have mounted epistemic challenges to the production of science through the forging of new pathways to credibility and blurring the lines between lay and expert knowledge. In response, scientific boundaries have shifted, and also been defended. In Canada, the involvement of lay actors in HIV/AIDS research has been institutionalized through funding policies and organizations that act as bridges between the various institutions and domains

⁷ Currently, the organization is funded by the AIDS Bureau at the Ontario Ministry of Long Term Health; however, it also acts as an independent funding body for HIV/AIDS research in Ontario.

involved in the production of research. However, despite existing literature on the history and accomplishments of AIDS activism, there is a dearth of empirical work that utilizes social theory to examine social and political relations between various scientific and non-scientific actors in the current HIV/AIDS field. Moreover, although lay involvement in research is now institutionally sanctioned, it is unclear whether the range of groups affected by HIV/AIDS, and that together make up AIDS civil society, have achieved legitimacy as knowledge producers.

I now shift attention to the mobilization of the ACB community around race, health, and HIV, placing these efforts within larger race movements and dynamics within the HIV/AIDS sector. I argue that what is missing is attention to the political dimensions of the efforts of the ACB community to affect knowledge production about the ACB population. Because of the legitimacy that science holds in decision-making processes for health and social issues, understanding the struggles of less dominant groups sheds light on the mechanisms within science that feed into dynamics of domination.

2.4 Race and HIV, Race and Health

Although scholarly literature on Black health activism in North America has only recently begun to surface, it has been argued that health advocacy has been a focus of Black political culture since the 19th century, spanning the range of Black institutions, community organizations, and social movements (Nelson 2011).⁸ In Canada, there has been no systematic study of ACB health activism or how these communities have resisted dominant approaches to health-related issues and associated forms of inequities. Therefore, I explore race and health politics in the US to provide context and backdrop to the Canadian situation. Undeniably, the socio-economic and political contexts of race differ in the two countries (Frazier et al. 2009). Canada has higher heterogeneity within Black communities (e.g., more recent immigrants from Caribbean countries) and an overall smaller Black population (Frazier et al. 2009), affecting notions of race, ethnicity, and nationhood. For example, the rhetoric of multiculturalism in Canada has been shown to hamper upfront discussions about race and racism, including those relating to major health issues (Rodney and Copeland 2009). This is accomplished by obscuring racism and

⁸ I will use the term “Black” when referring to African Americans in the US as this is the commonly-used descriptor for the population.

exploitation through the celebration of ethnicity (Lee and Lutz 2005). People from non-White communities are led to believe that they possess “cultural rights”; however, there have not been meaningful gains in political, economic or social rights of citizenship (Lee and Lutz 2005:17).

Despite these differences, the two countries share a colonialist legacy that has “historically infiltrated” almost every aspect of colonized societies and defined the colonized as the “other” from the standpoint of White European culture and society (Said 1978:19). Black communities in both countries exist in a backdrop of systemic stigma, racism, and other dynamics resulting from being seen as a racialized population within a White nation (Bannerji 2000). Consequently, Black communities are socially and symbolically excluded. This marginalization is institutionalized through the country’s social, political, economic, and legal institutions (James et al. 2010:89). Racism has also been significant in the formation of these nations, with racialized ideologies playing a part in the construction of national identities (Lee and Lutz 2005).

In this section, I first explore the context of Black struggles to mobilize, focussing on the politics of race and health activism and how these have affected the course of mobilization and shaped the epistemological and political positioning of activists and advocates. I discuss how Black communities were part of, but also separate from, mainstream AIDS organizing as they dealt with their own set of inequities and power dynamics within the movement, the HIV/AIDS sector, and society. I then return to the situation in Canada, concentrating on Ontario’s ACB population and their efforts to organize and improve the response to HIV/AIDS in their communities.

2.4.1 Race and Health Activism

Nelson (2011) traces the origins of formal Black health advocacy in the US to the Black Panther Party’s channelling of civil rights activism to fight against biomedical neglect and racially segregated medical institutions. Almost 50 years later, mobilized Black gay men in the US continued to look for inspiration in the Black Power movement, Black feminism, and Afrocentric traditions to address HIV/AIDS in their communities (Royles 2014). In Canada, ACB community-based organizations, health advocates, and service providers have also been concerned with racially-oriented social and health inequities. For example, the community health centre Women’s Health in Women’s Hands was created through community consultations and mobilization in the late 1980s to reflect feminist principles, such as anti-oppression, anti-racism, and community participation (Women’s Health in Women’s Hands 2014).

Black health activists and community-based workers have brought a socio-political lens to health issues by making connections between poor health and structural inequities, linking local health problems to global problems, and providing community-based health services that cross over into social advocacy for the whole community. A socio-political lens conceptualizes the Black body as representative of the broader treatment of Blacks in society where they are systematically excluded socially and economically (Nelson 2011). When health is seen as a social issue, it is used to expose larger injustices and becomes a “prism” through which struggles for equality can be refracted (Nelson 2011:5). Black AIDS activists have connected the spread of HIV in their communities to the unequal distribution of power across society and ongoing racial, economic, and sexual marginalization (Stockdill 2003; Royles 2014). For example, inequities in health care access and provision, housing, and education contribute to the vulnerability of communities of colour and create the context for HIV to flourish (Cohen 1999). Linking social inequality to the course of the epidemic in this way creates a more “radical” vision of HIV/AIDS compared to a quest for a biomedical “magic bullet” (Royles 2014:xx/226). Similarly, Canadian Black HIV/AIDS organizations have argued that structural inequities are the root causes of HIV/AIDS because they impact risk behaviours and the experience of living with HIV/AIDS (ACCHO 2013). ACCHO has stressed the importance of ensuring that HIV programming efforts reflect the broader determinants of health, such as racism, homophobia, and gender inequity (ACCHO 2010:20). In fact, its most recent strategic document, the Ontario HIV/AIDS Strategy for African, Caribbean, and Black Communities 2013-2018, focuses largely on how these issues affect the context of HIV at individual, community, and provincial levels (ACCHO 2013).

The social justice efforts of Black AIDS activists have not been limited to local or national boundaries. Rather, activists have extended the notion of “community” to encompass the global Black population. In the mid-1990s, Black protest organizations, such ACT-UP Philadelphia, redirected their efforts away from developing medical solutions to poor access to health care and other structural inequalities that drive HIV in poor communities both locally and globally (Royles 2014:xxxi). Internationally, ACT-UP Philadelphia played a role in the creation of PEPFAR, the Presidents’ Emergency Program for AIDS Relief, a fund for AIDS initiatives in Africa and other countries deeply affected by HIV/AIDS (Royles 2014). At a practical level, activists have fought to change international free trade and debt cancellation policies to allow African countries to redirect their economic resources towards the development of health care

infrastructure and manufacturing of generic medications. Black activists have also facilitated collaborations between local and global activists to build on the experiences and gains of the earlier AIDS movement (Royles 2014). In Canada, ACCHO has facilitated national efforts for ACB organizations and communities to formally organize, and played a key role in developing the African Black Diaspora Global Network, an international body whose mission is to end HIV/AIDS across the African/Black Diaspora.

In addition to raising attention to social inequities locally and globally, Black health activists have also addressed pragmatic issues associated with service provision. In the US, they created community-based medical services in the 1970s to provide medical care for poor Black communities and extra-medical patient advocacy around issues such as housing and employment (Nelson 2011). These activists were also vocal critiques of medicine's involvement in the construction of race through genetic claims of racial inferiority and the linking of race (via biology) to violence. In an effort to check the authority and racialized claims of biomedicine, they offered suggestions for racism-free genetic science and campaigned to eliminate medical discrimination and experimentation on Black subjects (Nelson 2011). AIDS activists built on this tradition and drew on instances of medical discrimination and exploitation to argue that services provided by Black community members were necessary to counteract a historical mistrust of health services (Stockdill 2003; Royles 2014). This practice of community-based service provision can also be seen in Ontario's ACB organizations and community health centres, which provide peer-led programming, outreach services, HIV clinical care, and a range of support for auxiliary social issues.

Black activists have also raised concerns about social justice and equity within the AIDS activist movement itself and throughout the larger HIV/AIDS sector. Early AIDS activists in North America were primarily middle-class, White gay men, whereas other affected groups (e.g., women and Black communities) were less represented (Stockdill 2003; Gould 2009). It has been argued that a general "AIDS consciousness" existed across the movement that recognized the role of prejudice and inequality in exacerbating the impact of AIDS (Stockdill 2003:27). However, this consciousness was expressed in different ways depending on the core identity politics of the different affected communities—for example, as LGBT consciousness (Gamson 1989; Gould 2009), feminist consciousness (Corea 1992), and anti-racist consciousness (Cohen 1999; Stockdill 2003). Black activists challenged the distribution of resources allocated for

HIV/AIDS services, demanding more targeted resources and funding for African American communities and critiquing primarily White organizations for not sharing their resources or recognizing diverse needs across the communities affected by the epidemic (Stockdill 2003; Royles 2014). Black activists have also worked to address racism within the larger gay community and homophobia within Black communities, thus extending the scope of activism to encompass LGBT and Black politics (Stockdill 2003; Royles 2014). In Ontario, ACCHO has collaborated with Gays and Lesbians of African Descent (GLAD) and Women's Health in Women's Hands to host two anti-homophobia forums with the goal of reducing homophobia in ACB communities (ACCHO 2010).

These intra-movement differences and power dynamics created problems for the building of alliances between affected groups (Stockdill 2003). Ideological battles were waged over the framing of the crisis, with women and Black activists criticizing the AIDS movement for failing to develop political strategies to deal with racism, poverty, or sexism (Stoller 1998). A key focus of the early AIDS movement was the conceptualization of AIDS as a discrete social problem unrelated to sexism, classism, and racism. This translated into an emphasis on biomedical approaches relating to treatment and research and finding a cure for HIV/AIDS (Stockdill 2003). In contrast, women and Black activists tended to situate their analyses and strategies within a larger political vision and a more complex framing of the disease (Stockdill 2003). Additionally, tensions arose along racial lines concerning the preferred style of activism and protest activities. As Cohen (1999) argued, in contrast to aggressive political tactics of civil disobedience, the political strategies in African American communities were less confrontational and more oriented to compromise and education. Civil disobedience raised complicated issues for Black activists who, unlike middle-class White men, had to contend with a historical legacy of institutionalized racism in policing and faced harsher consequences if arrested (Stockdill 2003; Royles 2014).

These tensions mirrored larger socio-political challenges faced by ACB communities during their attempts to mobilize around HIV/AIDS. Structural dynamics of racism, stigma, and material inequities created not only the context for HIV to continually increase in Black communities, but also led to challenges in developing a cohesive and effective community response (Quimby and Friedman 1989; Cohen 1999; Lemelle and Scott 2006). In the global context, countries with strong ethnic and racial divisions typically have had delayed or less

cohesive responses to HIV/AIDS, as discourses about AIDS are conflated with ideas about ethnic difference (Leiberman 2009). In the US, institutional practices of exclusion, such as federal government neglect and ideological narratives of deviance, resulted in the cumulative marginalization of African-American communities and had a profound effect on the community response to HIV/AIDS (Cohen 1999; Lemelle and Scott 2006).

Moreover, despite a long history of race activism in the US, ideological paralysis among Black political and religious authorities concerning HIV/AIDS and mobilization efforts led by non-representative elites created challenges to building community solidarity (Quimby and Friedman 1989). Black AIDS activists and workers have had to constantly weigh concern over the well-being of individuals affected by HIV/AIDS with maintaining the respectability of Black communities in the eyes of dominant groups (Cohen 1999). Early in the epidemic, African American communities were cast as blameworthy for not attending to their own care (Patton 1990) and Black gay men were disregarded by both White institutions and established Black organizations (Cohen 1999). The stigma and invisibility of communities dealing with multidimensional marginalization resulted in the distancing of more traditional Black organizations and Black political leaders from HIV/AIDS. These myriad challenges led to a delay in Black community members coalescing around the need to address HIV/AIDS in their communities. Because of this “late-stage” mobilization, African Americans continued to face challenges over producing micro-level, grassroots initiatives that could respond to the needs of different sub-populations affected by HIV/AIDS (Hinote and Wilson 2006).

Furthermore, scholars have highlighted the tension for ACB communities over fighting against being labeled as a homogenous and binary epidemiological risk category (i.e., being of Black descent as a “risk” factor), while also stressing how the disease has disproportionately affected the population. Designating entire populations as “risk” groups has significant implications. As differences among members are obscured and lines of safety are demarcated, it is implied that those outside the “boundaries of stigma” (Schoepf 2001:338) or the “social fault line” (Bolton 1992) are not at risk. This ultimately reinforces a racialized social order that “others” non-White communities and marks them through discourses of disease (Philip 1997). Given these systemic issues, responding to HIV/AIDS for Black communities is more than simply addressing a disease—it forces to the surface interlocking issues of identity, community membership, and power (Cohen 1999).

2.4.2 ACB Communities Respond to HIV/AIDS in Ontario

ACB communities make up 2.5 percent of the Canadian population. However, 12.2 percent of those infected with HIV (58,000) in Canada are from countries where HIV is endemic, the majority of which are African or Caribbean.⁹ Moreover, infection rates are 12.6 times higher in Canada's ACB population than among other Canadians (Public Health Agency of Canada 2009; Statistics Canada 2008). In Ontario, 11.7 percent of all HIV diagnoses (27,621) have been attributed to individuals of African or Caribbean descent, even though they represent only 3.9 percent of Ontario's population (Remis et al. 2008; Statistics Canada 2008). Furthermore, the number of new infections in the ACB population has been increasing steadily since the epidemic began by an average of 11 percent per year from 2000 to 2005 (Remis et al. 2007). As of 2009, there were 43 organizations running 57 projects to address HIV/AIDS in the Canadian ACB population; 70 percent of those projects were in Ontario (Public Health Agency of Canada 2009) and four organizations were focussed solely on addressing HIV/AIDS in Ontario's ACB population.¹⁰ However, prior to the mid-1990s, the ACB population was not identified as a priority. Only through the efforts of ACB community-based organizations and actors working with key researchers did this population gain recognition as a community deserving of HIV/AIDS-targeted funding and resources.

In Ontario, the community-based effort to address HIV/AIDS in the ACB population began in the early 1990s, with several ethno-cultural organizations funded to provide direct client services, such as prevention and peer education and support for people living with HIV/AIDS (ACCHO 2010). Anecdotal reports from these service providers and physicians working with ACB communities noted an increase in HIV/AIDS in their clients and patients (Tharao and Remis 2002). By the mid-1990s these service providers and physicians were working together

⁹ HIV is considered endemic in a country if the prevalence is above 2 percent in women accessing prenatal care, the ratio of male-to-female infections is 2:1 or less, and 50 percent of infections are attributed to heterosexual transmission (Public Health Agency of Canada 2009). For the HIV surveillance systems in Canada, the term "communities from countries where HIV is endemic" is an epidemiological term and is used interchangeably with "Black communities from African and Caribbean countries" because 92 percent of those in the former category are from African or Caribbean countries.

¹⁰ These organizations are: the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO), Africans in Partnership Against AIDS (APPA), Black Coalition for AIDS Prevention (Black CAP), and People to People AID Organization.

with policy makers from the AIDS Bureau at the Ontario Ministry of Health to plan a response to HIV/AIDS and develop an ACB-specific strategy (Husbands 2009). In 1997, Africans in Partnership Against AIDS (APAA) held the first forum to discuss HIV/AIDS in local African communities. Together with the Black Coalition for AIDS Prevention (Black CAP), other community-based organizations, and federal and provisional governmental health bodies, the HIV Endemic Task Force (HETF) was created in 1999. The HETF was charged with developing an HIV strategy for ACB communities and eventually creating an umbrella organization for groups and individuals working with, and on behalf of, the ACB population (ACCHO 2010).

In developing the strategy, the HETF was left to rely on anecdotal reports from community workers and health services professionals to make the claim that the ACB population was disproportionately affected by HIV/AIDS. This was because the first epidemiologic report to focus on HIV/AIDS prevalence in the ACB population was not produced until 1999, the year the HETF was created. This was despite repeated calls from community-based workers and academic researchers for the development of this epidemiological data to support their efforts to alert policy makers and research funders to the high rates of HIV/AIDS in Ontario's ACB population (HIV Endemic Task Force 2003). Even then, the data were based on statistical modelling rather than documented risk (Remis and Whittingham 1999).

The report itself was not well received in ACB communities. ACB activists and advocates claimed that the media presented the report in an alarmist manner, portraying individuals of ACB identity as responsible for the spread of HIV in Canada. Advocates and community members alike were worried that the attention garnered from the report was fuelling racism, stigma, and discrimination towards ACB communities (Tharao and Remis 2002; ACCHO 2010).

Furthermore, the mobilized ACB community took issue with some of the epidemiological language in the report. Common practices at the time called for the use of the phrase "from HIV-endemic countries" to sub-categorize heterosexual individuals who were from those areas (Remis and Whittingham 1999). Rather than using an epidemiologic category to label countries according to their HIV status *first*, ACB activists argued for the less stigmatizing term "from countries where HIV is endemic" (ACCHO 2010). Moreover, since the majority of individuals in this category were of African or Caribbean origin (92.7 percent) (Public Health Agency of Canada 2009), community activists also insisted that future references make clear that these were the communities disproportionately affected by HIV.

The two highest profile outcomes for the HETF were the development of the Strategy to Address Issues Related to HIV Faced by People in Ontario from Countries Where HIV is Endemic (HIV Endemic Task Force 2003) and the creation of the African and Caribbean Council on HIV/AIDS (ACCHO).¹¹ The overall goal of the Strategy was to “reduce the incidence of HIV among African and Caribbean people in Ontario and to improve the quality of life for those infected and affected by HIV/AIDS” (HIV Endemic Task Force 2003:9). The Strategy was developed as a mechanism for greater accountability from community-based organizations, government, and health institutions. HETF developed recommendations for federal policy makers, including increasing funding for research and ensuring consultative processes were in place to involve community-based organizations working with ACB communities. Throughout the development of the Strategy, HETF involved a range of ACB organizations and lay individuals through one-on-one consultations, education events, and a community forum entitled, “For Us, By Us, About Us”. These community engagement activities reflected one of the main objectives of the Strategy—to incorporate community development in the response to HIV/AIDS (HIV Endemic Task Force 2003).

ACCHO was tasked with carrying out the Strategy’s objectives and acting as a coalition organization for agencies, researchers, and individuals working on HIV/AIDS in the ACB population. It was conceived of as a “bridging” organization funded and supported by provincial and federal government bodies to connect service delivery, research, and policy, rather than as a community-based, direct service provider (ACCHO 2010:12). Two-thirds of ACCHO’s voting members must be of ACB identity, and diversity within the ACB population is represented in its membership (e.g., ethnic and national origin, sexuality, gender, language, age). Since its official launch in 2005, ACCHO has developed a social marketing campaign (Keep it Alive, www.preventaids.ca), created an informational website (www.achho.ca), and developed an HIV prevention manual, all in the support of the Strategy. Additionally, new ACB HIV/AIDS prevention workers were placed in various locations across the province with the mandate to serve as a direct link to, and support for, the Strategy.

¹¹ I henceforth refer to this document as the “Strategy” for reasons of simplicity.

In turn, the Strategy was included in the general Ontario HIV/AIDS Strategy and adopted by funders as the benchmark for proposed research and programs. Consequently, all applications for funding from the Public Health Agency of Canada's AIDS Community Action Program were required to demonstrate "alignment" with the Strategy (ACCHO 2010). The Strategy also highlighted research as a priority target for ACB advocacy efforts. In response, ACCHO pushed research funding bodies to more strongly reflect ACB community-specific issues and approached researchers to work with them to conduct research they identified (HIV Endemic Task Force 2003). This led to research partnerships between ACB service providers, policy makers, researchers, and lay community members, and a series of research forums to develop ACB research priorities, connect stakeholders involved in ACB research, and facilitate the involvement of community-based organizations in academic research (ACCHO 2010). Furthermore, ACCHO has collaborated on key research projects with Ontario's ACB communities, including the HIV/AIDS Stigma Study and Mabwana: Black Men's Study of Vulnerability to HIV/AIDS, while providing community forums and summits to disseminate and address the results. In ACCHO's renewed Strategy for 2013-2018, research continues to be a target of community advocacy, particularly in the areas of the social determinants of HIV/AIDS and interventions to prevent HIV or respond to the needs of those living with HIV/AIDS (ACCHO 2013).

2.4.3 Summary

Black health activism has been built on previous race movements and is rooted in principles of social justice and broader notions of community. It has taken different forms, ranging from advocacy to service provision both inside and outside centres of power. Because early AIDS activism focused on the disease as a discrete problem, Black advocates struggled to raise awareness concerning the social nature of the disease, such as the skewing of HIV/AIDS along racial lines. In Canada, the first organized response to HIV/AIDS in ACB communities was a grassroots effort. ACB-oriented community-based organizations provided services and advocated to institutional bodies for a more coordinated funding, policy, and research response. Regardless of the form it has taken, Black AIDS activism in general has attempted to blur boundaries between health and social inequities, and civil and health rights. Literature on African American activism has shown how forms of marginalization affected the community response to HIV/AIDS and shaped relations within the AIDS movement among affected groups. However,

there is no scholarship in Canada that documents the struggles of ACB activists to define the response to HIV/AIDS, or asks whether the community agenda for the production of HIV/AIDS research is being realized.

2.5 Conclusion

The efforts of health activists have helped to shape political and epistemological struggles over the defining of diseases, and blurred scientific boundaries of expertise. Empirical literature has provided insight into the effects of early protests and activism on the scientific and political response to HIV/AIDS. AIDS activism originating in the LGBT community has been the focus of the majority of the empirical work as it was the first coordinated effort from civil society. The literature has documented the impact of activism on research- and policy-oriented institutional responses to HIV/AIDS. However, there have been few recent empirical studies that have employed a social theory lens to more deeply examine social relations between scientists and non-scientists in the current HIV/AIDS field. Furthermore, there is a dearth of scholarly literature that examines how minority populations affected by HIV/AIDS have approached community activism or engagement with institutionalized science. Consequently, although ACB activists have used a social justice lens to fuel their arguments, it remains unclear how this perspective affects their efforts to shape the production of knowledge about their community. Moreover, no work has attempted to investigate power relations between actors involved in the production of ACB knowledge in either the North American or Canadian contexts. This is an important area of study because science acts as a fulcrum of legitimization in the HIV/AIDS arena, allowing those with scientific authority to define institutional responses to HIV/AIDS.

In the following chapter, I outline how bringing social theory into the empirical study of relations between actors involved in the production of research can provide a richer analysis of the dynamics of the convergence of political movements and institutionalized science. By closely examining relations between field actors and epistemological weapons used to defend dominant positions, it is also possible to move beyond an analysis that focuses only on social movement actors to one that provides insight into the maintenance of scientific boundaries.

Chapter 3 Theory

3.1 Introduction

Theory is inescapable because it is an indispensable weapon in struggle, and it is an indispensable weapon in struggle because it provides certain kinds of understanding, certain kinds of illumination, certain kinds of insights that are requisite if we are to act effectively. (hooks and West 1991:34-35)

An invitation to think with Bourdieu is of necessity an invitation to think beyond Bourdieu. (Wacquant 1992: xiv)

My interest lies in interrogating social relations and patterns of power in the production of HIV/AIDS research about the ACB population. I have chosen a theoretical lens informed by Pierre Bourdieu to frame these relations as struggles between different groups of actors to either challenge or defend dominant modes of knowledge production. Bourdieu was politically driven to examine and expose systems of domination across diverse social spheres in society, including power relations within the field of science. His quest to use social science as a “countervailing symbolic power” was motivated by his social justice orientation and civic morality (Wacquant 1998). Bourdieu accomplished this by developing a set of theoretical principles, conceptual devices, and “scientific-cum-political intentions” (Wacquant 1998:217) to look at the science of human practice and build a critique of domination. Utilizing Bourdieu’s conceptual tools thus enables an analysis that looks beyond scientific discourses and rhetoric to understand how particular epistemological devices constrain and dominate within the scientific field and how systems of domination are maintained.

In this chapter, I first provide an overview of Bourdieu’s framework, focussing on his conceptualization of “field” and associated dynamics of struggle. Next, I review Bourdieu’s ideas concerning competition and conflict in the scientific field over the production of knowledge, with particular attention to the mechanisms involved in the reproduction and challenging of dominant scientific principles and practices. I also discuss specific issues associated with scientific fields that heavily intersect with non-scientific arenas, such as the bureaucratic sector and political movements. Next, I engage with critiques of Bourdieu’s framework including his tendency to focus on social reproduction rather than transformation and his lack of attention to issues of race. Finally, I argue that while Bourdieu’s concepts can provide key mechanisms to frame and understand the struggles at a field level, insights from race

scholarship are needed to adequately contextualize the struggles of Ontario's ACB community within larger challenges to dominant practices of Western science and racial inequities.

3.2 A Bourdieusian Framework

Bourdieu's conceptual tools can be used to think about the reproduction of structural hierarchies in HIV/AIDS research. By clarifying the structure of the field, a Bourdieusian lens can help determine whose perspectives are imbued with legitimacy in a field and how this legitimacy is linked to domination. This approach also sheds light on struggles to resist and subvert mechanisms that support this domination.

3.2.1 Bourdieu's Field: A Place of Struggles over Legitimacy

Bourdieu developed a conceptual framework to explain the reproduction of the social order through relations of domination in social structures. His analysis of social relations focuses on how individuals are influenced by their external world (i.e., structure) and, in turn, how the practices of individuals shape structures (Bourdieu 1977). These are represented in Bourdieu's framework by the respective concepts of *field* and *habitus*.

Bourdieu defined a field as a distinct social space with its own rules associated with practice. Accordingly, the limits of what is "thinkable or unthinkable are always partly dependent on the structures of their field" (Bourdieu 2000:99). A field, therefore, mediates what social actors do in particular circumstances and contexts. However, each individual also shapes social structures (i.e., different fields) based on logic gained through previous exposure to fields, hereby giving a historical and relational shape to social practice. Bourdieu utilized the concept of habitus to link the individual to structures. Habitus refers to a "system of schemes of perception, appreciation, and action" which is embedded in actors as dispositions (Bourdieu 2000:139). Bourdieu considered these dispositions to be both adaptive and structuring. They are adaptive in that they provide an actor with a "practical sense" of how to act and be, even in novel situations (Bourdieu 2000:139). At the same time, dispositions are also structuring when the actions and strategies they produce further support the structure of a field. For example, Bourdieu (2004:41) describes the scientist as the "scientific field made flesh" in that the structure of a field is inscribed in the cognitive structures of the scientist. The scientist's practice is oriented to the expectations of the field (i.e., scientificity) and the scientist's habitus takes particular forms (i.e., dispositions)

depending on the disciplinary specialty and secondary principles such as education, social origins, and other variables that are linked to an individual's social position and trajectory (Bourdieu 2004). Habitus is useful for understanding how actors embody structures and practices of domination. In this research, however, I do not explicitly employ the concept of habitus.¹² Instead, I focus on the mechanisms employed by actors during the defense or challenging of the social structure of the field. I, therefore, devote the remainder of this section to describing the concept of field and its associated dynamics.

Fields are social networks in a particular area or discipline (e.g., law, policy, art, media, or science) that operate as distinct social spaces that correspond to governing principles (i.e., “rules of the game”), underlying assumptions, and forms of *capital* (i.e., assets) that are valued (Bourdieu and Wacquant 1992). The structure of a field is made up of the distribution of “positions” (occupied by actors in the field) that can be analyzed according to the amount and types of capital associated with a given position (Bourdieu 1986). Any resource that achieves recognition of legitimacy, and can be converted into profit (e.g., wealth, prestige), can become a form of capital. All capital is symbolic in that it can only be “perpetuated so long as it succeeds in obtaining belief in its existence” (Bourdieu 2000:166). That is, capital only exists through the recognition and beliefs of others. According to Bourdieu, capital can present itself in three fundamental guises: economic, cultural, and social (Bourdieu 1986). Economic capital refers to resources in the form of monetary assets. Cultural capital takes on different forms depending on the field in question, and can include assets such as education, scholastic achievements, or a mastery of “artistic sensibilities” that are often passed down domestically (Bourdieu 1986:244). Cultural capital can be embodied (i.e., instilled into the actor's physical “way of being” in the world), objectified in material objects (e.g., writings, paintings), or institutionalized through institutional recognition (e.g., educational qualifications). Social capital refers to relationships and networks that an actor can mobilize to gain material or symbolic profits (e.g., relationships in neighbourhoods, communities, workplaces, and families). Because capital is specific to each social field, what constitutes capital in a given field can only be determined through empirical analysis.

¹² I explain in the methodology chapter why it was not possible to include habitus in the analytic approach to the study.

Bourdieu developed a map to visually represent the structure of the field, which involves plotting positions based on the type and volume of capital held by actors in these positions (Bourdieu 1984). Therefore, a field is “objective” in that it is defined according to the distribution of assets.

The field has an objective structure that is nothing other than the structure of the distribution (in both statistical and economic senses of the word) of the pertinent and therefore efficacious...assets that are effective within this field... and the power relations constitutive of this structure. (Bourdieu 2004:61)

The relations between positions represent power dynamics in a field (e.g., domination, subordination) (Bourdieu and Wacquant 1992). Field positions are not static as they represent a temporary state of power relations and ongoing struggles for domination over a field. Actors struggle to distinguish themselves from one another in the field’s hierarchy by accumulating capital. For Bourdieu, capital is both a weapon, which allows its possessor to wield power or influence, and an asset or stake in the struggle (i.e., something to be won) depending on the logic of a field (Bourdieu and Wacquant 1992:98). Each actor pursues an advantageous representation of him/herself and the imposition of a social reality most favourable to his/her social being, both individual and group-based (Bourdieu 2000). The success of actors depends on their access to capital and, in turn, capital is socially constructed in ways that benefit those who already have power. Bourdieu saw all practices, even those deemed unconscious, as “interested” practices in that they are invariably oriented toward the maximizing of symbolic or material profit (Bourdieu 1975). Struggle is natural in fields as dominant and dominated actors attempt to “usurp, exclude, and establish monopoly over the mechanism of a field’s reproduction and the type of power effective in it” (Bourdieu and Wacquant 1992:106). Those who “win” these struggles possess the symbolic power to further define their forms of capital as the dominant forms. The social world, therefore, is both the product of, and what is at stake in, symbolic struggles over recognition in a given field.

Yet, despite the central role that disputes over capital play in Bourdieu’s understanding of social relations, he was clear that these struggles and strategies are not necessarily undertaken consciously. Rather, struggles arise from interactions that are historically embedded in a field and subconsciously re-enacted. Bourdieu (2000) referred to this as a field’s “epistemic unconsciousness”, which plays out in relations and interactions between actors. Field dynamics reproduce relations of domination without the need for direct intervention by members of dominant groups. The success of “winners” is seen to be a result of their superior performance,

rather than a function of systemic dynamics geared toward their success. This creates the illusion that capital has intrinsic value and that group superiority and capital accumulation are natural outcomes (Bourdieu 2000). Symbolic violence is exercised as inequities are masked through this process of naturalization as well as through the imposition of systems of meaning that legitimize and solidify structures of inequity (Wacquant 1998). The structure, then, takes on an assumed natural order even though it serves the interest of groups with the most capital and reproduces practices that support relations of domination.

To help understand how assumptions about the natural order are reproduced, Bourdieu used the concept of *doxa* to represent the various self-evident “truths” within fields. Identifying doxic assumptions brings to the surface “truths” that are used as weapons in relations of domination. Doxic beliefs “go without saying” and therefore remain unquestioned by social actors in a given field (Bourdieu 1977). Doxa is “common-sense” in that it establishes consensus in a field and defines the limits of perception.

Common sense is a stock of self-evidences shared by all, which, within the limits of a social universe, ensures a primordial consensus on the meaning of the world, a set of tacitly accepted commonplaces which make confrontation, a dialogue, competition and even conflict possible. (Bourdieu 2000:98)

Because doxa shapes the reality of a field and informs the system that underlies all other practices, the structure and political order of a field are seen as natural rather than one possible and arbitrary order among others (Bourdieu 1977). Fields are distinguished from one another through their doxic assumptions which shape the “fundamental rules and laws, discursive forms, normative beliefs, expected actions and behaviours, and barriers to entry” of any given field (Deer 2008:125). For example, in the field of science a doxic belief in scientism (i.e., science as the way to know the world) shapes the principles, practices, and structure of the field and defines these elements and dynamics as natural.

Fields in which all actors accept the doxa are said to be orthodox in nature. However, doxa can be challenged by those with competing beliefs. In such cases, a discursive exchange between actors in different positions about these beliefs leads to a “field of opinion” and the nature of a field becomes heterodox (Deer 2008). Actors take different stances concerning classificatory

schemes and principles that organize the field's social order (Bourdieu 2000).¹³ Accordingly, positions in a field correspond to stances or strategies that are possible in a given field. Dominant actors take orthodox stances (i.e., they reflect doxic assumptions) whereas less dominant actors take heterodox stances that challenge the practices and beliefs that support the status quo of a field. Beliefs originating in other fields can disrupt a field's autonomous set of principles by influencing and questioning the doxic assumptions and the tacit "rules of the game", and lead to heteronomy in a field (Deer 2008).

3.2.2 Struggles in Scientific Fields

Bourdieu believed that the scientific world was like any other social field—a site of struggles that comes with a particular distribution of power and monopolies, interests, and profits (Bourdieu 1975:19). As a social universe, the scientific field serves the interests of those who are in dominant positions.¹⁴ Because of the link between symbolic power and the ability to define legitimacy in a field, Bourdieu cast a critical and reflexive eye on how "reason" became a defining principle of science (Bourdieu 2000). Accordingly, Bourdieu was interested in the conditions of knowledge—the dynamics that make the construction of the scientific "object" and the scientific "fact" possible (Bourdieu 2004:79). Moreover, examining the taken-for-granted naturalness and superiority of scientific "rationality" also provides insight into the mechanisms of symbolic violence in the scientific field, that is, epistemologies and practices that support the field's hierarchy and status quo.

The structure of the field offers only a limited range of legitimate ways to handle scientific "goods" such as the "correct method, the correct findings, the correct definition of the ends, objects, and methods of science" (Bourdieu 2004:45/59). These methodological and epistemological approaches are accepted as pairs of opposites, such as theory and empiricism or formalism and positivism (Grenfell 2008a), that unite scientists as they fight over them or

¹³ Stances and strategies that actors assume are also shaped by their habitus, which has been defined by previous interactions with fields they have been exposed to over the course of their lives and the current fields in which they occupy positions.

¹⁴ Although Bourdieu (1975) saw science as a social universe, he also believed that the "private" interests of scientists could still potentially serve the scientific. This reflects Bourdieu's belief that science was both logical *and* social (Bourdieu 2000:113).

through them (Bourdieu 2000). These pairs of opposites represent social oppositions in the field and define the space of legitimate discussion; consequently, any attempt to produce an unforeseen stance is excluded from the discussion (Bourdieu 2000). Furthermore, epistemological choices are used to support principles claiming universality. Once these principles are accepted as having universal applicability, they can then be used as symbolic weapons in struggles over scientific legitimacy (Bourdieu 1975, 1993). It is therefore important to interrogate how these claims to universality are constructed, critique the foundations of these universalisms, and expose the logic of the universalism when it is interest-driven (Bourdieu 2000).

The field's structure is made up of the differential distribution of scientific capital. This form of symbolic capital incorporates products of "recognition", for example, the achievement of grants, publications, and tenure (Bourdieu 2004). The scientific "credit" gained is not necessarily economic, but a reward allocated through peer review (Bourdieu 2004:52). Groups and actors are unequally endowed with scientific capital and those who already have scientific capital will naturally gain more (Bourdieu 2004). That is, the scientific field gives credit to those who already have it.

The scientific field is always the locus of a more or less unequal struggle between actors unequally endowed with the specific capital, hence unequally equipped to appropriate the produce of scientific labour...and the specific profits (and also in some cases, the external profits such as economic or strictly political benefits). (Bourdieu 1975:29)

Therefore, the structure of a scientific field is defined by the current state of power relations between the field's actors and the distribution of capital that has accumulated in previous struggles. The stances or strategies adopted by actors on issues related to science are investments oriented towards the maximization of the specific scientific profit offered by the field (Bourdieu 2004). Actors justify their own position and stances in the field while attempting to discredit actors who occupy opposing positions and stances. These strategies have two sides to them: a scientific function, which is a quest for "reason" and "truth", and a social function, pertaining to the struggles for dominance that actors are engaged in (Bourdieu 2004).

It then follows that struggles in the scientific field are over the legitimate representation of “real” science (Bourdieu 2004).¹⁵ As Bourdieu (1975) explains, what is at stake in these struggles is scientific authority and the recognition of legitimacy.

The scientific field is the locus of a competitive struggle, in which the specific issue at stake is the monopoly of scientific authority, defined inseparably as technical capacity and social power, or... the monopoly of scientific competence, in the sense of a particular actor’s socially recognized capacity to speak and act legitimately (i.e., in an authorized and authoritative way) in scientific matters. (P.19)

As there is no independent authority that exists to validate the “truth” of a given stance or epistemological choice, scientific authority is determined solely through the outcomes of the struggles within the field. Accordingly, any claims to legitimacy come from the relative strength (i.e., capital) of the group(s) whose interests they express. Each actor’s choices and stances signify his or her position in the field and the amount of symbolic capital he or she possesses. Actors in dominant field positions (i.e., those who hold a greater amount of scientific capital) take on strategies of conversion to defend the current structure of the field and ensure the perpetuation of the established scientific order to which their interests are linked (Bourdieu 1975). Newcomers or dominated actors opt for strategies of succession or subversion to improve their position and potentially overturn the established scientific order. Those employing succession strategies seek to improve their position within the field without changing the definition of the field. In other words, they learn the existing rules of the game and adhere to them so they can acquire capital and move up the field’s hierarchy. Succession strategies are risk-free in that they work within predictable and authorized limits of the field. In contrast, subversion strategies are riskier because profits will only be achieved if actors can successfully challenge the field’s fundamental principles and definition of legitimate science and reconfigure the very structure (i.e., social order) of the field (Bourdieu 1975).

The winners of these struggles are imbued with scientific authority, which can be accumulated and converted into symbolic power (Bourdieu 1975). This power is not purely symbolic, however—the dominant players are able to impose, as a universal norm for the field, the

¹⁵ Legitimate, according to Bourdieu (2004:70), means “being capable of being recognized or validated...in the present state of the instruments of communication, knowledge, and criticism”. In other words, to be legitimate is to be validated through the current structure of the field.

principles and strategies of their own scientific practice. In this way, the stances of the dominant players become the measure of all things and the “right way” to do science, one that discredits all other ways (Bourdieu 2004). The stakes are material, as scientists compete to gain access to the field’s resources (e.g., funding) and control definitions of “good” and “bad” science (Albert and Kleinman 2011). In other words, scientific authority has significant material value in that its possessors define how science is practiced, whether knowledge produced is legitimate, and who can gain access to the field.

Bourdieu was particularly interested in how scientific authority can be threatened by “external” forces (i.e., fields outside of science) and, consequently, how these threats affect the autonomy of the field. Moreover, scientific disciplines, as local fields within the overall field of science, obtain autonomy through struggles for independence that impose new entities and boundaries to defend and protect the discipline (Bourdieu 2004). The autonomy of a given scientific field is dependent on the result of previous and current struggles to maintain the given “scientificity” of the field (Bourdieu 2004:47). Autonomy is also accomplished through the imposition of entry conditions in that actors are allowed to enter the field only if they possess the requisite symbolic capital (e.g., academic conditions). The implicit or explicit price of entry, such as scientific capital and competence, rises with the process of autonomization. Fields with high autonomy and few external forces and pressures to contend with also have higher field entry requirements and a stronger belief that the “game” is worth playing (Bourdieu 2004).

The relative autonomy of a given scientific field also determines who can be granted recognition as having scientific authority. The more independent the scientific field is from other fields, the recognition of what constitutes scientific authority tends to be progressively narrowed to the group of scientists in that given field (Bourdieu 1975). Scientists are then able to protect the logic and practices of the field from outside influences that may drive apart or separate the “constituent parts” (Bourdieu 2004:47). Fields that are less autonomous are more open to challenges from non-scientists or “politicization”. Bourdieu (2004) explains that what is at stake for the scientific field is its autonomy.

The autonomy that science had gradually won against the religious, political or even economic powers, and, partially at least, against the state bureaucracies which ensured the minimum conditions for its independence, has been greatly weakened. The social mechanisms that were set in place as it asserted itself, such

as the logic of peer competition, are in danger of being subordinated to ends imposed from outside. (P.vii)

Bourdieu was clearly concerned that the importing and imposing of external forces into the general scientific field would generate heteronomy (Bourdieu 2000). That is, Bourdieu's concern was oriented towards protecting the scientific field from the "tyranny" of political (i.e., nation-state) or economic powers that attempt to intervene in science (Bourdieu 2000:104). However, he also acknowledged that certain local fields of science were less autonomous by nature and "interlocked" with various other fields both within and outside of the scientific field (Bourdieu 1988). Scientific fields that focus on objects that are socially and politically contentious bring scientists into competition with a variety of actors who feel they can speak with equal, if not greater, authority on subjects related to the field. These interlocking fields have "multi-spacial, multi-level, and inter-relational modes of knowledge production" (Camic 2011:283) owing to their links with other fields. Accordingly, these fields have weaker autonomy and entry conditions because of the various forms of external pressures (e.g., economic and political) that come along with producing knowledge about social issues (Bourdieu 2004). Because these types of fields are nested within a matrix of fields, they draw differently upon them for scientific models and intellectual tools (Camic 2011). How this intellectual borrowing manifests depends on the positions occupied by actors and institutions in their respective fields and the relative positions of these fields in the overall social hierarchy. This structural configuration then determines what symbolic domination looks like in an interlocking field.

The idea of an interlocking field can be used to understand the domain of ACB HIV/AIDS research. Although this "local" domain is situated within the larger scientific field, it occupies an interlocking position between a range of fields that have a stake in HIV/AIDS as a substantive issue, including scientific disciplines, political movements, the service sector, and the bureaucratic sector.¹⁶ The interlocking nature creates dynamics of struggle as actors from non-scientific fields challenge the current scientific authority to define HIV/AIDS research.

¹⁶ Of course, there may be other interlocking fields that make up this field. However, I concentrate on those represented in this research study.

3.2.3 Summary

Bourdieu's conceptualization of field can be used to situate particular domains of research, including the actors who generate the research and their respective positions. His ideas concerning conflict and competition in the scientific field offer insight into struggles over the production of knowledge. To understand these struggles, it is necessary to examine challenges mounted against dominant scientific principles (e.g., epistemologies) and practices (e.g., methods), and the mechanisms involved in their defense that serve to protect the current legitimate definition of the field. Moreover, linking actors' stances with their positions in the field elucidates its structure and hierarchy. For example, dominant actors adopt orthodox stances that reproduce the status quo and less dominant actors challenge it with heterodox stances. However, there have been critiques of Bourdieu's approach to understanding dynamics of struggle in a field, particularly relating to his propensity to focus on the reproduction of the social order rather than its transformation. In the next section I review these critiques and then argue that Bourdieu's conceptual tools nevertheless remain useful for understanding mechanisms of resistance.

3.3 Critiques and Limitations of a Bourdieusian Approach

Bourdieu's conceptual model has been criticized on several accounts, but two are most relevant to this study. First are the claims that his framework is overly deterministic and does not provide adequate space for agency or practices that may lead to transformation of systems of domination. Second, Bourdieu did not attend to issues of race in his overall body of work. Although this has not prevented scholars from employing his concepts to understand dimensions of race, these approaches focus on aspects of social reproduction and racial domination rather than on how resistance might be enacted in racialized communities. In this section, I outline these two critiques, review how Bourdieusian scholars have taken up race, and argue that, despite these limitations, his conceptual tools can be employed to understand mechanisms of resistance in the course of racialized social struggles.

3.3.1 Bourdieu's Determinism and Ambiguity Towards Race

Bourdieu stated that actors cannot fail to adhere to "structures and agents of domination" (Bourdieu 2001:35). This has resulted in charges of structural determinism and an overemphasis on relations of domination. For example, Jenkins (1992) has argued that Bourdieu's field theory

is one of equilibrium and the maintenance of the status quo. Relatedly, the relationship between field and habitus is circular, as they are “bound together in a closed feedback loop, each confirming the other” (Jenkins 1992:51). Because the dispositions of the habitus are compatible with the objective conditions of the structure (i.e., fields), they are “pre-adapted” to the demands of the structure (Jenkins 1992:50). In other words, Bourdieu prioritizes the social structure when he argues that it is mediated through the habitus. Butler (1999) contends that the habitus must give way to the field because submission is part of the nature of habitus. Indeed, since the “structuring force” of a field frames the habitus, an actor incorporates the social structure in the “formative condition of its very being” (Butler 1999:119). This circularity, Jenkins (1992:50) suggests, reflects a model of social reality that is similar to structural functionalism, with an explanatory focus on social stability through the internalization of shared beliefs and norms. This circularity makes it difficult to envision how actors might transform social institutions or “intervene in their own history” (Jenkins 1992:51), rather than merely reproduce the existing social order. Moreover, Bourdieu’s emphasis on the consensual nature of habitus leaves little room for the role of critical reflection or consciousness. King (2000), for example, argues that the possibility of social change is practically non-existent if individuals act according to fields in which they are embedded, which themselves are set up to reproduce existing social and power relations.

Bourdieu (2000) attempted to account for larger scale social disruption through the concept of *hysteresis*, which he characterizes as discordance between the habitus and field. This may arise during periods of crisis when drastic change occurs in a field and the habitus is no longer aligned with that field. For example, Bourdieu (2000) claimed that the difficulty that colonized actors experienced in adjusting to a new established order was due to enduring dispositions adapted to the rules and regulations of colonialist state. The disconnect between structural and individual expectations can trigger a challenging of, and resistance to, underlying field assumptions. However, it is unclear what other conditions might produce similar kinds of social disruption or why some changes in the structure lead to transformative practices, while others do not (Adkins 2003). Furthermore, while hysteresis might be appropriate for understanding historical moments of crisis, it does not account for actors engaged in resistance activities on an ongoing basis (e.g., in social movement organizations) or the overall “durable impetus to critique in contemporary

society” (Crossley 2003:45). In fact, Bourdieu viewed ongoing radical political activity as an exception to his theory of social reproduction (Crossley 2003).

Other critics have claimed that Bourdieu prioritized class-related interests over other markers of social identity (e.g., race or ethnicity) in structures of domination (Alexander 1995; McCleod 2005). Jenkins (1992:58), for instance, argues that Bourdieu displayed an ambiguity towards these other elements of social life and did not interrogate mechanisms that contribute to ethnic boundaries. Indeed, while Bourdieu did not spotlight race or ethnicity in his theoretical or empirical works, he did co-author a polemic (Bourdieu and Wacquant 1999) concerning discourses of race in the Americas. In this paper, Bourdieu and Wacquant (1999) accused race theorists in the US of the “McDonaldization” of intellectual thought by exporting their scholarly traditions and discourses of racial stereotypes to the study of race relations elsewhere. They claimed that this “cultural imperialism” has the effect of universalizing the American concept of race and serves to conceal other forms of domination in society. This commentary was heavily criticized, first and foremost for its lack of engagement with existing scholarly works and debates on race in North and South America (French 2000; Hanchard 2003; Healey 2003). American race scholars attacked their argument over its “ethnocentrism”, profound lack of knowledge about the realities of race in the Americas, and portrayal of the context of race relations in South America as static and ahistorical (French 2000; Hanchard 2003). Bourdieu and Wacquant were also faulted for disregarding the role of non-state actors (i.e., civil society) in race relations and for consigning Black actors to a dominated social role rather than acknowledging them as cultural producers or political actors (Hanchard 2003). By ignoring the work and advances of these dominated groups and using a “French” ethnocentric lens to view the issues, Bourdieu and Wacquant were accused of enacting the very symbolic domination they set out to oppose (Healey 2003).

It is unfortunate that this heated debate represents the only work where Bourdieu addressed issues of race or racism in the North American context. Nevertheless, others have utilized his analytic framework to examine racialization and racial domination. These scholars generally fall into two areas: (1) those who use habitus and capital to examine how race and ethnicity construct social difference in everyday experiences; and (2) those who focus on the perpetuation of racial domination at systemic levels through state mechanisms. In the discussion that follows, I provide

example of these approaches and argue that they are conceptually inadequate for addressing my research questions.

3.3.2 Limitations of Bourdieusian Approaches to Address Race

Educational scholars have utilized Bourdieu's concepts of habitus and capital to understand how racialized practices are reproduced in classroom settings. For example, Reay (1995) employed habitus to reveal how gender, class, and race operate in the classroom as the embodiment of social differences. In this setting, prejudice and racialized stereotypes were ingrained in the habitus of individual students, as observed in White students engaging in marginalizing and excluding behaviours, and Black working class students taking on "helping" roles. In their study of race and family-school relationships, Lareau and Horvat (1999) also set out to understand the reproduction of social inequality in school settings. They found that Black parents were less able to "activate" their cultural capital—in this case, their class status—when they interacted with schoolteachers and administrators and challenged school policies. The authors argued that the historical legacy of racial discrimination made it difficult for Black parents to comply with institutional demands that parents "display positive, supportive approaches to education" (Lareau and Horvat 1999:38). In contrast, being White was a resource (i.e., capital) because White parents were better able to comply with school policies. Thus, the rules of the game in this institutional setting implicitly privileged White families. This body of empirical work is useful for understanding the mechanics of racialization and racism via the habitus; however, the analyses did not extend beyond a resource-focussed approach (i.e., the presence or absence of capital). This is reflective of the origins of Bourdieu's analytic framework, which was initially developed to account for patterns of class differentiation and reproduction based on the acquisition and enactment of social and cultural capital (McLeod 2005).

The second empirical approach to analysing race with a Bourdieusian lens expands beyond a framework based on habitus and capital. Wacquant (2001, 2009, 2010), in particular, has explored the intersection of class and racial domination in the US through his study of the criminal justice system. Wacquant (2005, 2009) argued that prison now acts as the main vehicle for "race making" in the US by shaping the meaning of Blackness through the hyperincarceration of Black bodies. Rather than attempting to locate victims and "culprits" in specific cases of racism, Wacquant (1997, 2009) sought to expose systems and mechanisms of domination by

uncovering the linkages between symbolic and material mechanisms in specific socio-historical cases of “racial ruling”. In moving on from an analysis that only considers the embodiment of racialized habits (i.e., habitus), Wacquant (2009) cultivated a theoretical and empirical lens that linked the body, the social, and urban marginality (Wacquant 2009). This lens, while insightful, nevertheless places Black actors in dominated social roles, and leaves little space for an analysis of social action or field dynamics other than those associated with oppressive mechanisms. It is also subject to the previous critiques of Bourdieu’s framework concerning the lack of attention to resistance efforts of dominated groups and forms of practice that may have transformative implications for fields.

In summary, critics have asserted that actors within Bourdieu’s conceptual model have little room to act outside of prescribed norms that are objectively structured and function to reproduce the status quo. Scholars who have applied Bourdieu’s framework to the study of race have stayed close to its concepts to examine the embodiment of race or racialization, or focussed on the reproduction of racial domination to the exclusion of resistance efforts.

Following Crossley (2001), I argue that determinism is too strong a characterization of Bourdieu’s approach. Rather, his interpretation of social reproduction captures the pragmatic nature of adaptation and realism that actors express after being repeatedly subjected to a given social reality (Crossley 2001:91). What is useful about a Bourdieusian approach, then, is that it can be used to problematize that social reproduction by exposing how taken-for-granted classifications and other dominant representations of social reality justify and hide underlying power relations (Swartz 2012:25-26). Moreover, because Bourdieu’s overall concern was to understand the nature of struggles as relational dynamics (i.e., there are defenders *and* challengers of the status quo), his tools can be employed to examine efforts of dominated groups to change a field. By attending to the enactment of resistance, it becomes possible to transcend the labelling of the Black community as a monolithic, dominated group at the mercy of social forces. To move beyond a habitus orientation of race (i.e., the embodiment of “Whiteness” and “Blackness”) while still recognizing the “saliency of race” (Dei et al. 2004) in field struggles, it is also necessary to consider how the defence and reproduction of a field is linked to structural dynamics that shape race-oriented systems of domination. To aid in this endeavour, I consult principles of race scholarship as a lens to “see” race in the struggles of this social field.

3.4 Seeing Race and Contextualizing Resistance

Critical race theory provides principles and strategies that foreground race equity in research, such as valuing the perspectives of racialized groups, developing a race consciousness when researching social contexts, and acknowledging the social construction of race (Ford and Airhihenbuwa 2010). This transdisciplinary domain recognizes that contradicting dynamics exist in social struggles by asserting that institutions possess the potential to emancipate and empower, as well as oppress and marginalize (Yosso and Solórzano 2005). These principles can be incorporated into various methodologies to address and study the relationship between race, racism, and power (Yosso and Solórzano 2005; Delgado and Stefancic 2012). Critical race approaches also require the interrogation of the social power and hierarchy of race and the “colour-blind” discourse as a contemporary form of rationalizing racial power (Crenshaw 2002). Looking to critical race theory, I begin with the assumption that racial domination is situated in institutional power which, in the Western context, communities of colour have never possessed (Yosso and Solórzano 2005). Moreover, because social relations are organized hierarchically around race, any struggles of racialized communities can be situated within larger systems of racial domination.

Critical race principles also extend analyses of systems of domination to recognize that these social spaces can act as sites of resistance. Although a central component of this study is the examination of how structures of domination are reproduced through the valuing of particular forms of scientific capital, it is also possible to appreciate the cultural resources that are available to the ACB community and enacted during struggles over community self-determination. The critical race concept of “community cultural wealth” broadens a Bourdieusian interpretation of cultural capital to include accumulated assets and resources found in communities of colour that are typically overlooked with a deficit model of capital (i.e., a focus on what capital communities are lacking) (Yosso and Solórzano 2005). Cultural wealth typologies include community-specific social capital and resistant capital (Yosso and Solórzano 2005).¹⁷ Social capital, seen through a community wealth lens, refers to networks of people and community resources that help actors

¹⁷ Although I reference Yosso and Solorzano throughout my discussion of cultural wealth, they clearly state that these concepts were developed cumulatively, through engagement and re-thinking of existing concepts of social capital and resistant capital (Yosso and Solorzano 2005).

navigate through society's institutions (Yosso and Solórzano 2005). Although this is similar to Bourdieu's conceptualization of social capital, the focus is extended from individual social networks to the collective sharing of resources and information within the larger ACB community. Resistant capital refers to the willingness of community members to work toward social and racial justice by cultivating and demonstrating oppositional behaviours to structures of racism. The multiple dimensions of community cultural wealth are often maintained and passed on as part of resistant capital (Yosso 2005).

In regards to methodological considerations, race scholars have argued that the knowledge of people of colour is critical to understanding and analyzing racial oppression (Yosso and Solórzano 2005). This acknowledges that social actors have experiential knowledge and understanding of the power relations in given fields. At the same time, however, this does not amount to "epistemic privilege" (Hartsock 1983) that essentializes or prioritizes the viewpoints of ACB actors. Rather, it is possible to start from the perspective that groups and individuals who occupy dominated positions in particular fields and larger society have valuable subjective insights into power relations and inequities. In practice, this means looking to those insights to inform the analysis and interpretive processes.

Finally, critical race scholars have also analyzed mechanisms of domination in science. For example, they have argued that the invoking of principles of objectivity and universalism in science serves to justify race neutrality in research and validate the knowledge that dominant White intellectuals produce (Collins 1998; Hunter 2002; Yosso and Solórzano 2005). These arguments align with Bourdieu's (2004) ideas concerning the use of epistemic principles as weapons in the defense of dominant forms of scientific practice. In this case, epistemologies that rely on notions of objectivity in the scientific method can serve the interests of the dominant group by reifying particular racial realities (i.e., White realities) and minimizing the importance of contemporary inequality (Hunter 2002). Furthermore, echoing Bourdieu, Collins (1998) argues that elites possess the power not only to legitimize the knowledge that they consider to be universal, normative, and ideal, but also to obscure the presence of their own power in determining what counts as science and knowledge and to denigrate the knowledges of less powerful groups that may express contrary standpoints (Collins 1998:xiii). The perspectives of these race scholars inform the study's theoretical framework by providing the epistemological context of ACB actors' struggles against mechanisms of domination in science.

3.5 Conclusion

A Bourdieusian-inspired theoretical framework permits me to investigate the various struggles taking place in the social field of ACB HIV/AIDS research. To do so, it is necessary to understand the structure of the field and examine the stances of differentially situated actors on HIV/AIDS research. This requires interrogating the ways of “knowing” in the field and locating the struggles for dominance in the defense of or challenges to particular scientific epistemologies. To understand how principles of science are defended, it is necessary to identify which epistemological principles are used as weapons to exclude other ways of knowing and acting. A Bourdieusian conceptual toolbox can also be used to examine resistance efforts to redefine the field in various ways that might benefit the interests of the ACB community. By making visible the challenges to scientific authority, it is then possible to see the struggles of ACB actors as part of larger resistance efforts to address systems of racial domination across social institutions.

Chapter 4 Methodology and Conceptualizing the Field

4.1 Introduction

In this chapter I present the methodological approach of the study. First, I discuss my epistemological orientation and relate the study's theoretical framework to the overall design of the research. Next, I develop a conceptualization of the "field" of ACB HIV/AIDS research and develop the data collection process and sampling frame accordingly. I then outline my iterative approach to data analysis and demonstrate the ways in which the results are grounded in the data while also being shaped by the theory. Finally, I adopt a reflexive perspective to addressing issues of ethics and quality and consider my position in this research as part of the knowledge construction process.

4.2 Methodological Orientation

To review, this study is concerned with understanding the struggles to define HIV/AIDS research about Ontario's ACB population. It is a critical examination of social relations between actors involved in the production of HIV/AIDS research, that is, the defence and challenging of dominant scientific practices. I hypothesize about the nature of the field and consider what types of actors are included within its boundaries. I am also attentive to the invoking of race in these struggles and the context of the ACB community's resistance to scientific modes of knowledge production.

My epistemological position falls within the interpretive tradition of qualitative research. This tradition recognizes the self-reflective nature of qualitative research and the role of the researcher as an interpreter of data (Creswell 2007). I have chosen an approach to the research that reflects a constructivist structuralism framework within a general critical theory orientation. A constructivist lens brings a focus to the constructed realities and meaning-making activities of actors (Guba and Lincoln 2005), in this case, how different groups of participants view and construct definitions of legitimate HIV/AIDS research. However, fitting with Bourdieu's (1989) constructivist structuralism, I consider how these constructions also feed into (i.e., are constitutive of) the social structure and larger social dynamics and inequities. Taking a critical orientation means I approach the research endeavour as a form of "social criticism" that

addresses issues of power and justice through the examination of “competing power interests” between specific groups of actors (Kincheloe and McLaren 2005:304-307).

4.2.1 A Bourdieusian-inspired Field Analysis

Although I engage with a Bourdieusian framework throughout the dissertation process, I do not look to Bourdieu for a methodological prescription. Instead, I use his concepts as “thinking tools” (Grenfell 2008b) to ask certain questions and identify points of tensions between actors involved in HIV/AIDS research. In following a Bourdieusian “inspired” approach, I employed three concepts in particular: field, capital, and doxa. Field is useful for situating social relations in dynamics that, Bourdieu argued, are inherent to social fields, such as struggles over the definition of legitimate practice in the field. Capital provides insight into the resources and assets needed for actors to participate in the field and define legitimate practice. An analysis of capital, and who possesses it, gives shape to the current field structure and defines power relations between actors. Finally, an examination of shared beliefs about HIV/AIDS illuminates doxic assumptions about the field that enable the reproduction of the social structure.

In order to employ these concepts, the study design and data analysis were focused on understanding the range of perspectives about the production of research. As will be discussed, this involved identifying actors who represent different positions in the field, and designing a research instrument to elicit beliefs and opinions about what is valued, or not valued, in the production of ACB HIV/AIDS research.

4.2.2 Seeing Race, Defining Community

A Bourdieusian analysis can speak to struggles over defining the field of research and locate these in power relations and the unequal distribution of capital in the field. However, there is a risk that this type of analysis could yield “colour blind” results. That is, the racialized context in which actors come to the struggles might not be given sufficient attention. Therefore, in designing the study and considering the methodological approach, I consulted scholarship in race theory to be sensitized to racial dynamics.

This scholarship was also important for informing the conceptualization of “community”. I recognize that this term is often fluid, vague, and disputed. I have therefore tried to be specific throughout the dissertation concerning what it represents. “ACB population” refers to the wider

population of ACB communities—people of African and Caribbean descent—whereas “ACB identity” describes the origin of individuals. “ACB community” is the politicized group of actors who have mobilized to address HIV as a threat to the ACB population.¹⁸ These actors from across different ACB sub-populations have organized over collective racialized experiences and the potential to be affected by HIV both individually and as a group (i.e., their “risk” of acquiring HIV). “Community”, therefore, represents a group that has “shared histories based on their shared location in relations of power” (Collins 1997:376). This conceptualization of the ACB community also goes beyond a descriptive category of identity to focus on the group occupying a “common location within hierarchical power relations” (Collins 1997:376).

However, I also acknowledge the binary and “Eurocentrically politicized” (Harding 2008) nature of these labels and the potential for homogenization. This means recognizing there is diversity across the community based on social characteristics (e.g., nationality, class, and related standpoints based on gender and sexuality), which brings a fluidity and multiplicity to “community” (Collins 1997). Although I am not able to attend to these various identities in the study, I do highlight key areas of difference between participants from the ACB community, for example, noting differences between academic-based researchers, community-based researchers, and advocates who occupy varying social locations within the ACB community and field of HIV/AIDS research.

It is also important to clarify that I am not attempting to make universalist claims about the ACB population, the field of HIV/AIDS research, or relations between actors. Rather, my aim is to explore these social relations at this historical and socio-political time through this particular theoretical lens. My construction of the ACB community and the social actors who have participated in the study is shaped by the current context—the external and internal field characteristics—and choices I made throughout the analysis based on the theoretical framework.

¹⁸ As mentioned at several points in the dissertation, “community-based” refers to community-based organizations and advocates who are involved in service provision and advocacy for ACB populations.

4.3 Study Design

This research project was qualitative in design and consisted of a two-stage data collection process. The objective of stage one was to develop a working definition of the field. This meant hypothesizing about the structure of the field (i.e., possible positions) based on a review of existing grants relating to research about the ACB population.¹⁹ This analysis informed the parameters of the sample and which actors would represent the field positions. Stage two involved interviews with these actors. The interviews were focussed on eliciting the range of perspectives currently held in the field and the relation of these to its structure and dynamics.

According to Bourdieu, mapping a field and determining its boundaries—or even determining whether a social space *is* a field—must be done through empirical investigation (Bourdieu and Wacquant 1992). Through empirical analysis of these social worlds it is possible to “assess how concretely they are constituted, where they stop, who gets in and who does not, and whether at all they form a field” (Bourdieu and Wacquant 1992:101). As part of a field analysis, Bourdieu suggests analyzing the position of the field in relation to the larger field of power (i.e., power structure in larger society), mapping the positions of field actors (i.e., objective relations between actors), and analyzing the habitus of these actors (Bourdieu and Wacquant 1992). Conducting these forms of analyses would require gathering objective data concerning the distribution of resources and assets (i.e., capital) in the field by calculating how much of these assets—social, cultural, and economic capital—are possessed by different field actors. However, it was beyond the scope of this project to gather all of these types of data, primarily due to the need to protect the anonymity of participants in a small field.²⁰ Rather, I used the information I had available to hypothesize about the field structure. I developed maps of the field as heuristic tools to help me

¹⁹ Initially I planned on conducting a formal thematic analysis of key documents produced by or about the ACB population concerning HIV/AIDS research. However, upon initial review of the texts, I realized they would not directly serve my goal of exploring the struggles and tensions between particular groups of actors. Instead, I referred to the documents in the literature review chapter and to inform the development of the interview guide. Additionally, these documents pointed to actors and organizations that might be important in the production of research, which corroborated and added to the more formal review of funded projects below.

²⁰ In fact, I initially attempted to obtain participants’ CVs to assist with mapping the structure of the field. However, after receiving negative feedback from several participants about anonymity concerns, I realized this would not be a feasible component of the study.

ascertain which actors are involved in the production of research, build a sampling frame, and theorize about links between particular stances and social positions in the field.

The following sections outline the iterative process of determining the nature of the field. As I reviewed funded research, I refined my ideas concerning its structure and developed an approach to sampling that would ensure study participants would represent a range of field positions.

4.3.1 Defining the Field to Build the Sample

From the beginning of this research I had several challenges associated with taking a field perspective. First, what “field” am I actually referring to? Second, how would I define the structure of the field? I began by using my intuition and experience to map out who might be involved in ACB HIV/AIDS research (Emirbayer and Williams 2005). I hypothesized that there *is* a field of ACB HIV/AIDS research made up of various actors involved in the production of research. This hypothesis was based on a surge in funded studies specifically about ACB communities after the release of the Strategy in 2003 (HIV Endemic Task Force 2003). The Strategy, financially supported by the Public Health Agency of Canada and the Government of Ontario, highlighted research as a priority in the response to HIV/AIDS in the ACB population. This created field-like dynamics where researchers, policy makers, community advocates, service providers, and others with an interest in HIV/AIDS in the ACB population compete for resources (e.g., ACB-specific funding streams). An example of these dynamics could be seen in ACB research think tanks (James 2009), where community-based researchers, volunteers, academic-based researchers, and policy makers gathered to discuss research priorities and the utilization of research in the response to HIV/AIDS. Struggles over the definition of the field were reflected in the roundtable sessions where research priorities were discussed, debated, and prioritized within and across different scientific tracks (i.e., basic science, clinical science, epidemiology, socio-behavioural sciences).

Defining the structure of the field was an iterative process. As I reviewed the funded research projects, I developed various versions of the field’s structure. I conceptualized actors involved in producing research as representatives of field positions. To identify these actors, I looked to research projects funded through peer review channels, which are a cornerstone feature of the

scientific field because of the importance placed both on the acquisition of funding (i.e., economic capital) and validation from peers (i.e., legitimacy).²¹ These research teams contain a range of actors representing different social positions in the field who come together to produce research about ACB communities.

4.3.1.1 Review of Funded Research to Inform Sampling

The main goal of the funding review was to elicit information that could inform the conceptualization of the field structure and development of the sampling criteria.²² The review helped me to understand the range and nature of funded research and clarify field positions. Part of this process was identifying which characteristics are associated with being a “successful” researcher in the field of HIV/AIDS research to conceptualize the field’s capital. This involved creating a map to place actors in relation to one another based on the capital they possessed. Reviewing funded research projects also allowed me to identify which disciplines and fields were represented in the field.

I compiled a database of funded research projects from 2003 to 2010, including research operating grants and training grants (e.g., capacity building, fellowships, and investigator awards) that addressed HIV/AIDS in the ACB population.²³ To be included in the review, a research project had to specifically mention an ACB community as a priority population in the research rather than simply a variable to be measured. I searched public funding databases of the major funders for HIV-related research projects in Ontario (Appendix A) using the following search terms: HIV or AIDS; ethnocultural; African; Caribbean; Black; race; racism; immigrant or immigration; newcomer; and refugee. In addition to standard research grants, I also searched the databases for fellowships and investigator awards that were associated with researchers

²¹ Although I recognize that funding is not necessary for carrying out all forms of research, the majority of studies are supported through some form of funding and have been subjected to a peer review process.

²² Although this funding review was an integral part of developing the sampling strategy, it was not a formal analytic piece of this research project.

²³ I chose to begin with 2003 because of the release of the ACB HIV Strategy and concurrent general increase in research about the ACB population.

conducting HIV/AIDS research relevant to the ACB population.²⁴ For those databases without search functions, I manually reviewed all the research within the designated time period, looking for the relevant terms to indicate ACB-related research. Because there was no official list of research projects funded by government organizations, specifically the Public Health Agency of Canada and the AIDS Bureau, or hospital-sponsored research projects, I also consulted various reports about HIV/AIDS in the ACB population (e.g., the Strategy). Based on my discussions with researchers active in the field and a thorough review of major funding databases, I am confident that the overall patterns reflect general trends in this area of research during these years.

For each research project, I compiled information on the funder, type of grant, type of research, amount of funding allocated, and research team membership. To determine appropriate grant categories, I developed general descriptions based on similarities across funders. The five types of grants identified were: research operating grants, fellowship and investigator awards, community-based grants, capacity building grants, and requests for proposals. Research operating grants cover the standard costs of a particular research project, whereas fellowship or investigator awards are provided to individual researchers to support their research careers. Community-based research grants are most often initiated by community-based organizations or, at the very least, require community partners as investigators. Capacity-building grants cover costs associated with research training for individuals located in community-based organizations and can be initiated by either community- or academic-based actors. Requests for proposals (RFPs) are research topics commissioned by a particular funder.

I classified the type of research based on OHTN categories of funded research projects: basic, clinical, epidemiological, and socio-behavioural sciences, and health services and community-based research (OHTN 2014). It is important to note that in practice these are not clear cut or discreet categories. For example, several larger projects included more than one type of research component, such as community-based research and health services, or basic/clinical and epidemiological science. Furthermore, it was difficult to distinguish between community-based

²⁴ I did not include the following types of awards as I did not feel they were directly related to the production of research: methodology development, research/knowledge synthesis, Masters' awards, meetings and dissemination grants, letters of intent, and program-related funding (i.e., direct service provision).

research and socio-behavioural research given the loose definitions associated with these terms and a shared general focus on social issues and community involvement in research. This raises larger questions about whether research claiming to be community-based research is truly reflective of community principles or whether it has become a generic term to describe research that merely involves community-based actors. Although a meaningful analysis of this issue is beyond the scope of this research, I do address the implications of the institutionalization of community-based participation in Chapter 8.

Of the 43 grants reviewed, the Ontario HIV Treatment Network (OHTN) (21) and the Canadian Institutes of Health Research (CIHR) (15) funded the majority. The remaining grants were distributed between the AIDS Bureau (3), Canadian Foundation for AIDS Research (CANFAR) (2), Social Sciences and Humanities Research Council (SSHRC) (1) and CIHR Social Research Centre in HIV Prevention (SRC) (1).²⁵ The types of professional positions represented on research teams included basic scientists, clinical scientists, social scientists, public health/allied health scientists, government officials, community-based researchers, and community advocates. However, these actors occupied different professional identities based on their social location and hierarchical arrangement within academic and community fields, such as tenured professor, pre-tenured professor, graduate student, head of organization, research manager/director, community-based worker, research coordinator, and volunteer/advocate.

The total amount of funds allocated was over 6.6 million dollars. The majority of these funds were allocated through research operating grants (Table 4.1).²⁶ The average research operating research grant (\$451,102.90) was 3.6 times higher than the average community-based research grant (\$124,909.40).

²⁵ It is unclear whether all of these organizations followed a similar peer review process.

²⁶ I could not locate funding information for four studies: a health sciences study and three socio-behavioural science studies.

Table 4.1 Types of ACB-oriented Grants Funded from 2003-2010

Type of grant	Number of grants	Total amount allocated (CDN\$)	Proportion of total grants (%)	Average amount of each grant (CDN\$)
Research Operating Grant (standard research grant)	7	3,157,720.40	48	451,102.90
Fellowship/Investigator Award	10	1,521,735.00	23	152,173.50
Community-Based Research Grant	9	1,124,185.00	17	124,909.40
RFP/Commissioned Research	6	576,952.00	9	96,158.70
Research Capacity-Building Grant	7	243,799.20	4	34,828.50
Total	39	6,624,391.60		
Missing data	4			

The largest grant was allocated to a basic/clinical science research project (\$2,364,625) (Table 4.2). This category also made up the largest proportion of all funds allocated to ACB HIV/AIDS research. However, the largest number of grants was found in social/behavioural sciences and community-based research categories. After removing fellowships/investigator and capacity building grants (leaving a total of 23 awards), basic/clinical sciences took up an even larger proportion of total research grants (up to 48 percent from 36 percent) while socio-behavioural research and community-based research dropped from 27 percent to 17 percent, and 25 percent to 19 percent respectively.

Table 4.2 Types of ACB-oriented Research Funded from 2003-2010

Type of research	Number of grants	Amount of funds allocated (CDN\$)	Average amount of each grant (CDN\$)	Range of individual grants allocated (CDN\$)	Percent of total funding
Basic/Clinical Sciences	1	2,364,625.00			36
Social/Behavioural Sciences	14	1,761,964.00	125,854.57	15,000-398,735	27
Community-Based Research	17	1,673,147.20	98,420.42	20,000-300,00	25
Health Services Research	5	543,250.00	108,650.00	8,250- 300,000	8
Epidemiological Science	2	281,405.40	140,702.70	21,860-259,545.40	4
Total	39	6,624,391.60			100
Missing data	4				

There was strong representation from the ACB community on research teams, with 81 percent (35) of teams comprising of at least one research team member of ACB identity.^{27,28} Over half (56 percent) of the teams were comprised of both academic- and community-based actors (Table 4.3). However, research team leadership was skewed heavily toward academic-based researchers compared to community-based researchers, with 84 percent (36 teams) led by an academic-based principal investigator. Of the academic-led research teams, the majority (75 percent) of lead principal investigators were not of ACB identity (Table 4.4). Actors based in government bodies were present on at least three grants.

²⁷ I categorized actors as either ACB identity or non-ACB identity based on information in their publically obtained biographies, or through my personal knowledge of their background.

²⁸ Five of the eight research teams without ACB representation were fellowships or investigator awards that do not allow for multiple investigators.

Table 4.3 Community and Academic Presence on Research Teams

Composition of actors on research teams	Number of research teams	Proportion of total research teams (%)
Academic- <i>and</i> community-based actors	24	56
Academic-based individuals <i>only</i> (i.e., no community-based individuals)	15*	35
No academic-based presence (i.e., community-based only or with government-based individual)	4	9
Total	43	100

*Nine of these grants were for fellowships or investigator awards.

Table 4.4 ACB Composition of Academic-led Research Teams

ACB identity of principal investigator (PI)	Number of research teams	Proportion of total research teams led by academics (%)
Non-ACB PI	16	44
Non-ACB PI with ACB co-PI ²⁹	8	22
Non-ACB PI with ACB co-Investigator	3	8
ACB PI	9	25
Total	36	100

From this review, I determined there is a range of research being funded about HIV/AIDS in the ACB population in Ontario and different types of actors involved in the production of this research. The main funders of HIV/AIDS research are bodies that use a peer review process to allocate funding. Although higher amounts of funding have been allocated to basic/clinical sciences, overall there were more socio-behavioural and community-based research projects. The majority of research teams included an individual of African or Caribbean identity, occupying

²⁹ There may be more co-PIs from the ACB community, but not all funders allow space for two PIs in the funding database (e.g., OHTN funding database). This may or may not indicate institutional policy concerning whether actors from community-based organizations are eligible to be PIs on research projects.

either an academic- or community-based location. However, the majority of teams were lead by a principal investigator not of an ACB identity.

4.3.1.2 Structure of the Field: Scientific and Community Capital

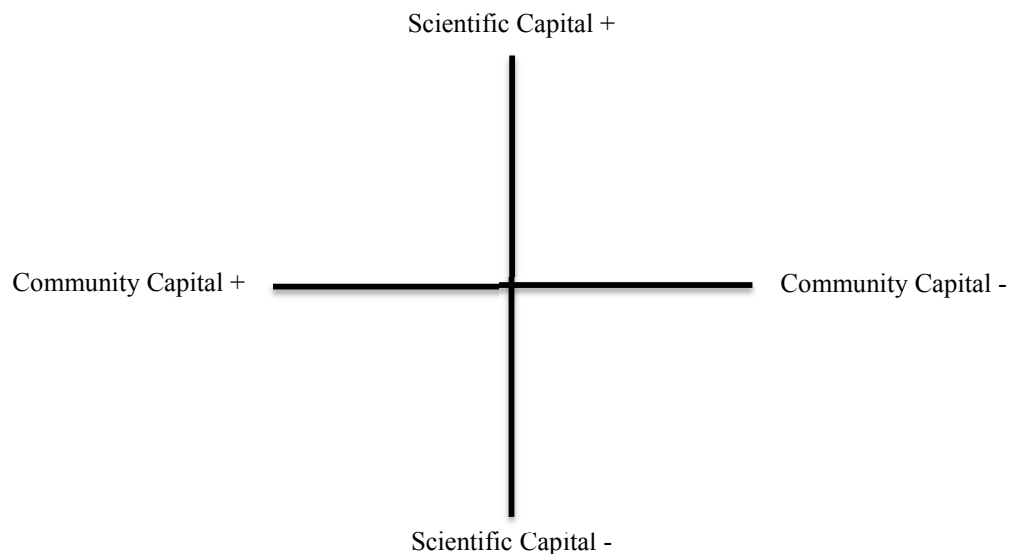
Based on the funding analysis, I posited that the field of ACB HIV/AIDS research could be considered a local field of science (i.e., sub-field of science) because the production of research is subject to a peer review process that is rooted in academic science. Furthermore, the actors involved in the production of this research are either located in academic scientific fields (e.g., researchers, professors, students) or partner with academic researchers on research grants. However, although I conceptualize this as a scientific field, I refer to it as a field of *research*, as “science” is too restrictive for capturing the type of practice in this field. For instance, at HIV/AIDS research conferences, research is broken down into tracks based on disciplines (e.g., basic sciences, clinical sciences, social sciences) (OHTN 2009b). However, there are also spaces for types of research that are situated beyond scientific disciplinary boundaries, such as health services research or research produced by community organizations, often in partnership with academia, that address issues around service provision. These works co-exist in the larger scientific domain and often have scientific principles embedded in them, yet they are not considered “science” in the traditional academic sense.

In conceptualizing positions for the field structure, I categorized research team members based on their primary location (i.e., community-based, academic-based, or government-based). “Community-based” refers to organizations that provide services or programs directly to members of ACB communities. Therefore, community-based positions are occupied by actors located within, or affiliated with, organizations that provide prevention and support services for people with or at risk of HIV, and their partners and families (AIDS Bureau et al. 2012). “Academic-based” refers to established researchers or researchers-in-training whose primary affiliations are at academic institutions. “Government-based” includes individuals located in the government who both commission research and sit on research teams as knowledge users. I choose to use these terms as representative of the professional location of these participants because it is likely to shape their engagement with research and inform their stances and epistemological positions. By using these terms I also reflect how the field’s actors talk about

these social locations themselves, contrasting academic institutional settings with the community-based sector.³⁰

I hypothesized that ACB identity, community sector affiliation or academic legitimacy are key entry requirements for participation in the field and success in acquiring research grants. This is based on the review of funded research that showed individuals with an ACB identity were present on the majority of research teams. Moreover, community-academic partnerships were the norm, with ACB actors from the community sector occupying investigator roles on 65 percent of the teams. This suggests that community-based actors are active participants in the production of research. Rather than attempting to distinguish between the importance of ACB identity or community association, I combined them into a larger category of “community capital”. Academic legitimacy, on the other hand, is reflected in the high number of principal investigators that were based in academic settings. I conceptualized academic legitimacy as scientific capital because of the importance placed on academic positions in the scientific field. Thus, I devised the initial mapping coordinates for the field structure to reflect community capital (i.e., ACB identity and/or community sector affiliation) and scientific capital (i.e., academic location) (Figure 4.1).

Figure 4.1 Hypothesized Structure of the ACB HIV/AIDS Research Field



³⁰ Although this is how I conceptualized these groups for the purpose of data collection and analysis, it is probable that these binaries are less oppositional in practice as actors cross fields and broader social locations and identities when they partake in the production of research. I expand on these issues in the discussion chapter.

With this map, I was able to plot actors throughout the course of data collection based on the information to which I had access: their professional position, relationship to the ACB community, and frequency of appearance in the funding review. The purpose of plotting the positions of potential participants was to ensure I was sampling a representative range of actors in the field based on their position relative to those of other actors (i.e., their possession of capital). In general, I hypothesized that those actors with academic credentials (i.e., PhD, academic position) and success with funding had relatively high amounts of scientific capital. High community capital, on the other hand, was related to ACB identity (i.e., African or Caribbean descent) and location in, or affiliation with, a community-based organization. The mapping of actors was an iterative process during all phases of data collection and analysis. This allowed me to explore relationships and make connections among actors and in relation to their stances and field positions.

4.3.2 Recruitment and Interviews

I choose a sampling strategy according to principles associated with maximum variation and stratified purposeful sampling. In line with a maximum variation approach (Miles and Huberman 1994; Creswell 2007), I aimed to reflect variations among the range of actors in the field and gather multiple perspectives about the production of ACB research. This would help me to identify patterns across the sample. I followed a stratified purposeful approach to facilitate comparisons between sub-groups in the sample (Patton 2002), recruiting participants to reflect the professional locations identified through the funding review according (i.e., community-based, academic-based, government-based). Combined, these two approaches led me to develop a sampling frame that reflected a balance between academic- and community-based actors and a range of academic disciplines, types of community organizations, and positions within these spheres.

During the document and funding review I developed a list of 39 individuals for potential recruitment. This was an ongoing process as I added and deleted names according to changing sampling parameters and whether I deemed someone involved in the production of research. In some cases, their involvement in the production of research was obvious, as certain individuals were present in numerous studies. For those individuals who appeared only once, I attempted to locate their CVs or professional profiles through Internet searches and determine whether they

were engaged in HIV/AIDS research. I did not include individuals who were on the periphery, such as community- or academic-based actors who are not regularly involved with HIV- or ACB-specific research.

Although I mainly consulted the database of funded projects I had compiled to devise the sample, I realized there might be active researchers missing, particularly those who occupy less dominant positions in the field because of career stage, geographical location—Toronto studies were more high profile than other areas—or use of non-traditional grants or funding. To address this, I reviewed the OHTN HIV research conference programs (OHTN 2011) and also noted any names that were raised during interviews or conversations with community members. I was careful not to discuss my intentions for recruiting these individuals. Through these avenues, I identified several established ACB researchers and junior community- and academic-based researchers involved in smaller grants who did not appear in my initial search. The junior researchers had all secured graduate fellowships and most had been added to established (i.e., funded) research teams. Although occupying less dominant positions in the field, these individuals were still research team members and had implemented their own research projects.

My goal was to recruit participants until I had maximum variation in the types of researchers and to purposefully stratify so there was a balance of community- and academic-based researchers. This translated to a recruitment target of an equal number of community- and academic-based researchers, the majority being of ACB identity and working either in social sciences or community-based research, with basic/clinical sciences also represented. Although I also aimed to interview several government officials, only one would agree to an official interview.³¹ Of the 39 potential participants (Table 4.5), 24 were interviewed from August 2011 to February 2012; however, three were later deemed ineligible. Of the remaining 15 individuals, five did not reply to my invitation, three refused, and four were deemed ineligible. The reasons for ineligibility included not being involved in the production of ACB HIV/AIDS research or currently working with me (i.e., conflict of interest). Reasons provided for refusing were: institutional restrictions (e.g., government policy); not available in the study timeframe; and simply “unable to

³¹ In fact, I had scheduled an interview with another government official, but upon arrival the person said they could only speak to me “off the record”. Rather than an interview, we had a general discussion about ACB HIV/AIDS research in Ontario.

participate”. I did not interview a further three eligible community-based individuals as I had met my goal to interview an equal number of academic- and community-based participants. Those who either refused or did not reply had similar social locations as those I interviewed (Table 4.6).

Table 4.5 Overview of Recruitment Outcomes

Recruitment outcome	Number of individuals
Interviews	21
No reply	5
Refusals	3
Not appropriate/ineligible	7
Not needed (already filled quota)	3
Total potential participants	39

Table 4.6 Individuals Who Did Not Reply/Refused to Participate

Type of individual	Number of individuals
Community-based researchers	2
Basic/clinical sciences academic-based researchers (non-ACB)	2
Socio-behavioural and health sciences academic-based researchers (ACB)	2
Government/policy officials	2
Total individuals who did not reply or refused	8

I contacted each potential participant via email and invited him or her to take part in the study; this email contained a university research ethics board (REB) approved information sheet about participating in the study (Appendix B). If the individual showed interest in being included in the study, I forwarded the consent form and arranged a suitable date and location. Participants were provided with a hard copy of the consent form at the interview that we reviewed together (Appendix C). Interviews were conducted at a location that was convenient to the person, the majority of which were at their home or office (16), two at the University of Toronto, two at a

public location, and one over the telephone. The average interview was 64 minutes long. Each interview was recorded on a digital audio recorder and a back-up digital device.

The interview guide (Appendix D) covered key areas associated with the production of research. The first section captured the participant's background (e.g., education and professional activities) and their position in the field of HIV/AIDS research (e.g., type of job and organizational affiliation). The second section of the guide focused on their role in, and perspectives on, the production of ACB HIV/AIDS research: the kind of research in which the participant had been involved; how they had secured research funding; their opinions on the types of research that should be prioritized for the ACB community; challenges the community has faced, including those relating to "race"; and how ACB research in general could be improved. The interview guide was used as a flexible tool, as is standard for interpretive qualitative research, and the interviews took a conversational tone that was suited to my professional relationship with participants and a co-constructivist approach to interviewing.³²

The purpose of conducting the interviews was to document the range of perspectives about the production of ACB HIV/AIDS research with a view to understanding doxic assumptions, and the dynamics of tension and struggle over defining the field. Therefore, the interview guide reflected a Bourdieusian framework in that it prompted me to elicit participants' opinions about how research should be produced and who should be involved in its production. This would later allow me to analyze the similarities and differences across actors who occupy different field positions. By prompting participants to consider issues of race in relation to challenges encountered in the production of research, I ensured that my analytic lens would be attuned to examining how race was, or was not, invoked in these struggles.

4.4 Data Analysis

The process of coding, conceptualization, and theorizing was done iteratively. This involved slowly building up from description to interpretation, and increasingly engaging with the study's conceptual and theoretical framework. I describe the steps involved in this analytic process, as well as the importance of transcription in the interpretive process.

³² I comment more on interview dynamics and my role in the co-construction of the interview later in the chapter.

4.4.1 Transcription

As part of assessing rigour in a study, Poland (1995) suggests outlining the steps taken to ensure trustworthiness of the transcripts while also acknowledging the interpretive nature of the transcription process. These steps include describing how audiotape quality was ensured, guidelines for transcribers, and how the transcripts were reviewed and assessed for trustworthiness (Poland 1995). Furthermore, an acknowledgement of the interpretive and incomplete nature of the transcription process shifts the focus from determining “what is the *correct* transcription” to considering “what is *useful* transcription for my research purposes?” (Kvale 1996:166). With this in mind, I chose a more “denaturalized” approach to transcription (MacLean et al. 2004) that focused on the content of the interviews—in this case, perceptions and beliefs that participants held about the production of HIV/AIDS research.

The prioritization of *what* participants are saying, rather than *how* they are saying it brings a focus to the substance of the interview and “the meanings and perceptions created and shared during a conversation” (Mason et al. 2005:1277). However, I do not submit to the ontological assumption that the transcript is a “faithful reproduction of the aural record” and an “embodiment of truth as an indisputable record of the interview” (Poland 1995:291). Rather, I recognize that the transcript is only a partial representation of the interview process and the various forms of nonverbal communication that transpire through the interaction between interviewer and interviewee. Like Poland (1995:295), I acknowledge the interpretive nature of the transcription process in that it is “individually and socially constructed and contestable”, yet still attempt to attend to issues of rigor in the transcription process by ensuring that transcripts capture utterances as closely as possible.

With these principles in mind, I developed guidelines to help maintain consistency in format.³³ I realized early on that the amount of transcription required would quickly overwhelm my novice transcribing skills, so I employed two professional transcriptionists.³⁴ To ensure the

³³ These guidelines were developed during transcription of the first five interviews and through discussions with the transcribers.

³⁴ The first transcriptionist transcribed three interviews, the second transcriptionist, fifteen, and I transcribed three interviews.

trustworthiness of the transcriptions, I reviewed each transcript along with its audio recording at least once for accuracy, and made all necessary edits. The transcription guidelines were based on suggestions and advice from McLellan et al. (2003) and Poland (1995) concerning verbatim transcription (see Appendices E and F for guidelines and glossary of terms). I aimed to produce an exact reproduction of the conversation, but steered away from strict technical notations associated with conversational analysis or other traditions that capture the nuances of linguistic interactions (Psathas and Anderson 1990). An expert transcriber offered insightful suggestions concerning the formatting and readability of the transcripts. Overall, the guidelines were developed to produce readable transcripts that could be easily formatted for coding and analysis. Key points in the guidelines included documenting long pauses, overlapping speech, and involuntary vocalizations. I also included response tokens, intentional mono- or bi-syllabic sounds (e.g., ‘Hm’, ‘Okay’, ‘Ah’, ‘Yeah’, ‘Mhm’) and involuntary communication (e.g., laughter) in the transcripts. Although I did not intend to analyze the interactional or conversational aspects of the interviews, I decided that the extra time and effort of including more subtle forms of speech and conversation would help me understand the flow of the interviews and meanings attached to an interviewee’s speech. This became another methodological tool in the course of interpretive analysis.

I also considered the ethical nature of transcript construction (Kvale 1996) when I made decisions over choosing quotes for the dissertation. As Bischooping (2005:142) states, ethical issues arise as researchers “transform interview transcripts into manuscript quotes”. An important ethical issue for this research was maintaining the anonymity of participants in a small research field. This involved ensuring any quotes used could not be linked to individual participants. Because I felt that the speech patterns and phrases of some participants could be used as identifying markers, I removed distinguishing words or phrases while retaining the integrity of the meaning.

In closing, I attempted to develop an approach to transcription that reflected the context and aims of the research (Poland 1995). This involved ensuring that the written account of the interview reflected what was discussed, and maintaining the general interactional nature of conversation to gain as much meaning from the text as possible. These transcripts were used as methodological tools to understand the perspectives and beliefs of participants, and to interrogate and interpret the meanings associated with these beliefs. However, because the text is a construction and

interpretation of speech, I acknowledge there can be multiple readings and interpretations of the interviews and suggest that there are other ways to transcribe interviews that would fit with other analytic objectives. These include a more socio-linguistic analysis of the co-construction process or power relations between the interviewer and the participants, or capturing the emotional tone of the conversation (Kvale 1996).

4.4.2 Data Analysis and Interpretation: Breaking it Down, Building it up

Wolcott's (1994) analytic framework provided a basis for breaking the analysis down into three stages: description, analysis, and interpretation. This approach stresses staying close to the data initially (i.e., letting the data "speak") and building to higher levels of abstraction through systematic analysis, dialectically engaging with the study's analytic framework, and integrating theory to provide context and meaning. As Wolcott (1994) suggests, developing a strong descriptive account provides the fulcrum from which to balance analysis and interpretation. Although in practice these stages bled into one another and were not linear in execution, they helped to provide structure to the data analysis, and allowed me to engage with theoretical concepts gradually, according to how the results unfolded. I also referred to Bryman (2004) and (Gibbs 2010) for guidance with coding, which I approached in four steps. First, I read the text to identify major themes. I then read the text to develop codes and analytic ideas. Next, I coded the text systematically, revised the codes as necessary, and organized them into themes. Finally, I related theory to the data interpretively through charts, diagrams, and thinking about relationships.

Throughout the entire analytic process I developed a three-part memo system to capture ideas concerning the practical components of analysis (e.g., analytic tools, organizational points), development of interpretive concepts and themes, and building of the theoretical and conceptual framework. These memos were invaluable initially for determining codes and categories and, subsequently, for moving beyond description to higher levels of abstraction and theorizing. Finally, I borrowed several techniques from the Framework Analysis approach (Ritchie and Lewis 2003; Barnard 2010) for data management, including developing a matrix for the data using one-line summaries of quotes from participants and organizing themes and sub-themes during the early stages of analysis.

I now outline the three stages, as per Wolcott (1994), I used to guide the data analyses.

LEVEL ONE: THE DESCRIPTIVE STAGE

This stage was concerned with asking “what is going on here” by describing what participants reported in the interviews (Wolcott 1994). To a certain extent, this type of analysis can be considered implicit because the design of the study is already theory laden. Implicit analysis is a precursor to explicit analysis, the next level where data are transformed through systematic procedures and engagement with an analytic framework.

The process I used to develop the descriptive categories and coding structure involved reviewing each transcript at least three times. The first review focused on confirming the accuracy of transcription. For the second review, I concentrated on understanding the data from a macro perspective by summarizing each interview and highlighting the main issues according to individual participants. This helped me become familiar with the range of issues discussed, develop broad descriptive categories (i.e., themes), and organize the data in manageable segments. During the third review, I engaged with the data at a micro level. This required a close reading of each transcript and making two sets of notes in the margins, one for the descriptive coding scheme and the other to capture interpretive observations for future reference. At this stage I was careful not to “code up” too quickly; I stayed close to the data and developed a descriptive coding structure. After the initial coding structure was established, I used a spreadsheet to organize and refine the categories (i.e., broad descriptive themes and sub-themes) and entered one-line summaries of quotes from participants as supportive evidence for each theme.

To develop the descriptive themes, I initially began to organize the data based on the interview questions, creating a coding structure accordingly (e.g., perceived gaps and challenges in HIV/AIDS research). However, this was too limiting at such an early stage of analysis and would not easily feed into later stages of interpretive analysis. Rather, I chose four broad overarching thematic categories, and then slowly built sub-categories based on the readings of the transcripts and the iterative process of thinking about larger themes and engagement with the data at a micro level.

The first two broad categories were concerned with what participants valued or did not value in order to compare across participants and determine whether or not struggles even existed. I attempted to be as inclusive and open as possible to capture the full range of issues discussed.

Because the interview questions were structured in a way to elicit opinions about research, determining what they did or did not value was a relatively straightforward exercise. The third category captured how race was invoked in discussions about research. In addition to issues relating to race being captured in the sections concerning what is valued or not valued, I kept the analysis open and made note of any instance where race was mentioned. I also noted what resources and assets participants felt were necessary to be successful in research as a part of hypothesizing about the field's capital.

At the end of this stage of analysis, I was able to describe a range of issues that were important to participants concerning HIV/AIDS research about the ACB population, including how research is and should be produced, the topics or issues that should be addressed, and what it takes to be successful in this area of research. As this level of analysis was focused on describing the data at face value, it provided a solid foundation for subsequent and more systematic analysis and interpretation based on the theoretical framework.

LEVEL TWO: ANALYSIS AND COMPARISON ACROSS SOCIAL LOCATIONS

The second level of analysis was focused on transforming the data through systematic procedures to identify essential features and relationships (Wolcott 1994). This involved breaking down, organizing, and re-grouping the initial four categories to build up and transform the data into larger, more abstract themes. After using Microsoft Excel to develop the initial coding structure and descriptive thematic categories, I employed manual procedures to re-envision these elements and identify patterns in the data that went beyond description. The descriptive categories (i.e., codes) and supporting quotes (i.e., one-line summaries) were printed out and cut into individual pieces that could be moved around, adjusted, and revised as I developed new themes and a revised coding framework. I then coded each transcript in Atlas.ti based on the main themes in this framework. This allowed me to explore the relationships and patterns between themes and cases, and between individual participants and groups of participants, and also continually check my tentative hypotheses against the data.

As an effort to begin to identify the struggles in the field, I looked across the coding categories to match participants with the different themes, and mapped out and charted relationships between participants based on similarities and differences in their stances. This was accomplished both manually, with visual mapping exercises, and with Atlas.ti's reporting and organizing features.

These data manipulation exercises allowed me to define areas of agreement and disagreement among the participants.

During the course of this systematic analysis and accompanying memo writing, I became more selective concerning which themes to develop. I determined this by being attentive to reoccurring themes across participants and issues that were contentious between different types of participants. This allowed me to identify patterns in the data that reflected field level dynamics, such as doxic beliefs and points of struggles between actors occupying various positions in the field. These dynamics could then be teased out through engagement with the study's theoretical framework.

LEVEL THREE: INTERPRETATION AND THEORIZING

After employing analytic techniques to the data and highlighting key patterns and relationships, I turned my attention to the third level of analysis, that is, the study's theoretical framework. Bourdieu provided a framework for me to analyze the field's structure and power relations, and place the struggles within dynamics that are common in scientific fields. Race scholarship provided points of entry to ask *why* the ACB community is involved in these struggles and inspiration to think more broadly, beyond scientific parameters, about the different forms of capital that might be enacted in these struggles.

Drawing on Bourdieu allowed me to conceptualize key features of the field, such as core, underlying beliefs (i.e., doxa) and struggles over how to define the field. As part of this interpretive process, I considered what participants' beliefs might mean in relation to larger epistemologies and which beliefs might be dominant in the field (i.e., the perspective of dominant groups). This involved constant conceptual mapping of the stances (i.e., positions that participants took on particular issues) according to the social location of participants, and revising and adjusting these diagrams as I built a framework for the results. During this process, I teased out areas of "agreement" across participants. These shared, "self-evident" beliefs were later developed into the field's doxa. This stage was also crucial for theorizing whether this social space is a field according to a Bourdieusian perspective. To support my hypothesis that it can, in fact, be considered a scientific field, I consulted literature concerned with empirical field studies in the sociology of science and incorporated these perspectives and concepts into my

analysis and clarification of the research object. Again, I made use of mapping techniques and conceptual diagrams to develop the final framework and refine the argument.

Race scholarship provided direction for contextualizing the ACB community's struggles within struggles for community self-definition and resistance to "mainstream" (i.e., White) ways of producing knowledge. I also drew on race theory to think about capital beyond a deficit model and be attentive to forms of capital that might be present because of the interlocking nature of the field. For example, ACB communities might possess forms of capital that fall outside of traditional academic or science-oriented capital, such as resistant capital or community social capital, that allow these communities to build solidarity and effectively participate in these struggles. To understand forms of community cultural wealth (Yosso 2005), I looked to the data to understand how participants of ACB identity talked about being "successful" in research and the advice they gave to their peers concerning the promotion of a research agenda consistent with ACB community values.

Through approaching data analysis in three interrelated stages, I was able to utilize conceptual tools from the study's theoretical framework while remaining grounded in the data, thus demonstrating trustworthiness in the interpretive process. The following section addresses notions of quality, rigor, and ethics to further expand on trustworthiness in the research.

4.5 Ethics and Trustworthiness

As Lincoln (1995) argues, in qualitative research there has been a collapse of the distinction between the formally separate consideration of ethics and the criteria for quality in research, as many of the standards for ethics also reflect standards of quality. Common issues include concerns relating to face-to-face research encounters and political and ethical pressures for openness around data collection, analysis, and presentation. In this section, I address issues relating to ethics, quality, positionality, and power as part of demonstrating the trustworthiness and reflexivity of my research.

4.5.1 Confidentiality and Anonymity

Key aspects of conducting ethical research include the interrelated issues of informed consent, privacy, and harm (Hammersley and Atkinson 2007). In this research, these were further complicated by the small field size and existence of established relationships between

participants. Moreover, although struggles often play out in public spaces, how individuals talk about their experiences can be deeply personal. Accordingly, confidentiality and anonymity were paramount, both in the interview process and during analysis and dissemination of results.

To ensure confidentiality of the data, I did not include participants' names or personal identifiers in the interview transcripts and only referred to their characteristics in broad terms in the results. During recruitment, I assigned unique study IDs to individuals, which were not connected to the consent forms or recruitment information. However, because this is a relatively small sub-set of participants, I clarified in the consent form that I could not guarantee their anonymity. This was an important point for participants employed at community-based organizations because they may hold different opinions from those of their organization, and public disclosure could pose a risk to their positions as employees. Several junior participants, both community- and academic-based, raised this concern because they were fearful of damaging relationships with more senior colleagues. I also planned to maintain anonymity across participants because of other potentially sensitive issues that might be discussed, including disclosure of HIV status and discussions about colleagues, mentors, peers, and others with whom participants may have personal and/or professional relationships. Because of the sensitivity of this issue and potential harm for participants, I was particularly careful to respect anonymity in the results and ensure identities were masked.

However, the university REB requested that I provide participants with the option of having their name used in the results if they wished. In practice, negotiating consent and anonymity was not straightforward and required a more nuanced approach than merely providing a “yes” or “no” tick box. During the first few interviews, I noticed that several participants were hesitant when we arrived at the anonymity section of the consent form. It seemed to me that they thought that I *wanted* them to consent to having their name used. This was most likely because of the section wording (i.e., “I consent to having my name used in the study results: yes or no”). After clarifying that I did not have a preference, and discussing what issues and topics might arise in the course of the interview, they chose to remain anonymous. These early interactions helped me refine my approach to the consent process and reminded me that informed consent is not only a procedural moment, but also a negotiated process that requires attention to subtle signals in the course of the interactions between the researcher and “researched” (Guillemin and Gillam 2004).

By the end of the study, 14 participants did not want their name used, one suggested I “use my judgment”, another would discuss the situation further if I wanted to include their name, and five agreed to have their names used in the research. However, I conducted the analysis anonymously because of the inconsistency in participants’ wishes. I believe this was ethically acceptable because I was concerned there was the potential of “outing” other participants through naming only some. These situations can be thought of as “ethically important moments” (Guillemin and Gillam 2004), as I was confronted with decisions concerning issues of anonymity that did not reflect the formal considerations. By rethinking the consent process in practice and choosing to conduct the analysis anonymously, I was respecting the “autonomy, dignity, and privacy of research participants” and mitigating the risks of failing to do so (Guillemin and Gillam 2004:275).

4.5.2 Quality and Rigor

Part of maintaining an ethical approach to the conduct of research is considering the role of quality and rigor in relation to the trustworthiness of the research (Lincoln 1995). However, assessing quality in qualitative research has elicited much discussion and debate (Patton 2002; Guba and Lincoln 2005; Silverman 2005; Creswell 2007). Standards for ensuring that research is rigorous and credible range from more scientifically conventional criteria that focus on validity and reliability, to a postmodern rejection of any imposed criteria (Murphy et al. 1998). Therefore, when deciding how to address rigor in a given study, qualitative researchers must consider what is appropriate, given their allegiance to a particular paradigm and the intended purpose of their research. As Patton (1999:1189) argues, the various philosophical and theoretical orientations lead to “issues of quality and credibility [that] intersect with audience and intended research purposes”. This perspective led me to tailor the criteria for ensuring quality specifically to “the research, paradigm, and community” (Lincoln 1995:286) under consideration. Accordingly, I chose a general three-pronged approach, as outlined by Patton (1999), to enhance the quality and credibility of the research. This included addressing technical rigor, credibility, and paradigmatic-specific preferences.

To enhance technical rigor in qualitative analysis, Patton (1999) suggests that researchers be thoroughly prepared for analysis, engage their creative insight, and apply systematic and rigorous analytic techniques. These details should be sufficiently reported in order for others to be able to

judge the quality of the findings. In addition to outlining my methodological process in the previous sections, I also employed the following specific techniques to ensure integrity in the analysis (Patton 1999). First, after inductively developing themes and patterns, I considered various ways of organizing the data and tested out alternate frameworks to contextualize and explain the participants' struggles, eventually dismissing contrary explanations. For example, I initially grouped themes according to academic- versus community-based participants, as well as ACB identity versus non-ACB identity. However, these groupings did not capture the epistemological-oriented struggles that cut across participants located in different spheres or were located within larger groupings of similar fields, such as natural sciences and public health, or among participants from the ACB community, both in academic and community settings.

Second, I looked for “negative cases” where participants did not fit the emerging patterns, in order to account for them and explore the issues more broadly. There is one key example of how this unfolded. I found several community-based participants who were critical of research to the point of being dismissive. However, I could not fit them into the initial framework which focussed on differences between community- and academic-based groups of participants—they appeared to be outliers compared to other community-based actors who, although critical of existing mechanisms in the production of research, were deeply invested in research. I continued to revise the framework based on further examination of the data and considered alternative ways of contrasting the participants' beliefs. Eventually, I realised that these participants were not entirely dismissive of research itself. Instead, they were part of the larger push by community-based participants to define research in the *community* setting rather than be bound to academic-based research. This realization made way for me to conceptualize these dynamics as a part of a quest for a sub-field of research that is less dominated by scientific authority.

The third component of technical rigor I employed was theoretical triangulation. Patton (1999) describes this as using different theoretical perspectives to look at the same data to offer deeper insights into the phenomenon under study. As Kincheloe and McLaren (2005) suggest, I used social theory not to determine how I would see this situation, but as a guide to help me devise questions and strategies for exploring it. Although the struggles seemed consistent with Bourdieu's theory (i.e., struggles between dominant and less dominant actors in a field over the definition of the field) I found this interpretation needed to be expanded beyond the boundaries of the HIV/AIDS field. Therefore, I consulted race scholarship to flesh out the struggles and

situate them in pre-existing sites of resistance that are relevant to the ACB community. As discussed in the theory chapter, I addressed issues concerning race in the analysis and used ideas I had come across in the race literature, such as self-determination over the production of knowledge (Collins 1989), to help conceptualize the data, frame the results, and critically engage with Bourdieu's framework. Although I began with Bourdieu, I brought in other approaches that were congruent with Bourdieu and could offer deeper insights into why these struggles are happening.

The credibility of the researcher can also be considered a key component when assessing the quality of research. As Patton (1999:1205) asserts, the "trustworthiness of the data is tied directly to the trustworthiness of the researcher who collects and analyzes the data". Reflexivity plays a key role in this assessment. Murphy et al. (1998:188) define reflexivity as "sensitivity to the ways in which the researcher's presence in the research setting has contributed to the data collection and their own a priori assumptions have shaped the data analysis". For example, a reflexive approach attends to the relationship of the researcher to the participants, the researcher's personal characteristics and social location, and theoretical assumptions that the investigator brings to the research. Furthermore, employing reflexivity is an acknowledgment that "every researcher brings preconceptions and interpretations to the problem being studied" (Denzin 1989:23).

Reflexivity, however, is not an exercise in identifying "bias" in order to reduce the impact of the researcher. Instead, reflexivity refers to the process of providing an honest account of how and by whom the research was constructed. This involves the author displaying honesty and authenticity by "coming clean" about his or her own stance and position (Lincoln (1995:280). Transparency allows the intended audiences to be able to assess the findings and judge credibility in "light of the assumptions which have shaped them" (Murphy et al. 1998:189). This requires an examination of the positionality of the researcher, such as their social and cultural position, and attending to issues of voice (i.e., "who speaks, for whom, to whom, for what purposes") (Lincoln 1995:280-282). I consider these issues in the following section on reflexivity and positionality, clearly laying out who I am as a researcher, providing context to my background and field position and how I came to decide on this research problem. This approach aligns with Bourdieu's perspective on the need for reflexivity at both individual and field levels, through examining the social origins of the researcher and their position within the organization

of the intellectual field (Bourdieu 2000). This reflexivity is not meant to be part of a larger claim to objectivity, but is part of declaring my subjectivity and building it into the context of the research.

Finally, there are paradigm-specific preferences and philosophical beliefs that underlie definitions of credible research for critical theories (Patton 1999). Although there are many forms of critical theory and differences between approaches, I refer to Tierney's (1993:4) conceptualization that defines critical theory as "an attempt to understand the oppressive aspects of society in order to generate societal and individual transformation". This involves exposing "the forces that prevent individuals and groups from shaping the decisions that crucially affect their lives" (Kincheloe and McLaren 2005:208). I consider this theoretically informed empirical research a piece of praxis because it is an effort in "committed understanding", a key component in the quest to "understand the world and then change it" (Stanley 1990:12). In this research, I critique and expose structural forms of domination in the field under consideration and facilitate spaces for dialogue and critical reflection about these social dynamics.

An additional principle of critical theory is serving the "purposes of the community in which it was carried out, rather than simply serving the community of knowledge producers and policymakers" (Lincoln 1995:280). This requires a commitment to ensuring the research has some relevance and legitimacy for those outside of academia. As explained in the next section, I developed this research after prolonged engagement with the ACB community and deep discussions with a community advisor about knowledge production and HIV/AIDS research. As I move from the dissertation process to knowledge translation and exchange, the issues of voice, relevance to the community, and potential action will be further explored.³⁵

4.5.3 Positionality

During the course of this research project I attempted to build in reflexivity by considering my role as a co-producer of knowledge and reflecting on my position within the field of ACB HIV/AIDS research itself. As an interpretive qualitative researcher, I acknowledge that I am part of an "inter-subjective enterprise" which consists of two people talking about common themes of

³⁵ I will be working with ACCHO and my community advisor to determine appropriate knowledge-to-action activities and to facilitate critical dialogue about the findings.

interest, where I lead up to topics and co-determine the course of the conversation (Kvale 1996). From this perspective, the interviewee's statements are not collected per se, but co-authored and co-produced. Because the resulting interpretation is a particular representation that is produced in a particular context, it requires a reflexive analysis of the conditions of production. To incorporate a reflexive lens, I begin with a reflection on my positionality, including my professional standpoint as a critical social scientist and feminist. As Bourdieu argues, part of analysis is locating one's "position in the social space, position in the field, and position in the scholastic universe" (Bourdieu 2004:94). Although a full analysis of these positions is beyond the scope of this chapter, I can acknowledge how I came to this research as a researcher with my own history in the field and a particular world view that comes from my position in the academic field and a White settler society. I focus first on my academic training and community involvement, which have created my "space of possibles" within a "system of intellectual coordinates and points of reference" (Bourdieu 1993:177), and affected interview dynamics. I then address my position as a White researcher.

My academic training originated in sociology and social anthropology, specifically political economy and feminist theory. Recent exposure to a range of critical theories and approaches to the study of health has positioned me to consider issues of power, structural forms of domination, and intersecting forms of oppression, such as racism, homophobia, and sexism. However, throughout the course of my career, I have also been deeply involved in the HIV/AIDS volunteer/community-based sector both personally and professionally. During my community-based work, I was struck by how AIDS treatment activists were deeply engaged in the construction of biomedical knowledge through their roles as advisors and challengers of clinical trials and drug development. However, I was also aware that other activists, primarily those who were female or Black, seemed to be more focussed on the social aspects of the disease. As I continued on with my career path that spanned both community and academic spaces, I became involved in dynamics between and within these sectors and was constantly aware of how these reflected larger social dynamics and power relations. My positionality as a researcher straddling academic and community fields has provided me with both an insider and outsider perspective on this research; I may have a pre-existing allegiance to community-oriented world views (e.g., social justice), but I have also spent a decade in academic environments that were directed toward more positivist-oriented social science research.

My “dual identity” afforded me access to both community and academic settings. However, the ease in which I built trust with participants varied according to their social position (in relation to mine). Although I explained to each person my background and goals for the research, I paid particular attention to ensuring that those from the ACB community understood my commitment to using critical theory. Whereas most of the White participants did not ask questions about the research or my particular theoretical inclinations, many of the Black participants were keenly interested in how I was framing the research and my plans for bringing the results to the wider community for input. One individual in particular was clear that they would not have partaken in the study if I was only using a Bourdieusian framework and that the inclusion of perspectives from race scholarship was paramount for their trusting my intentions and the research. These interactions most likely affected the interview dynamics as I created and cultivated different pre-interview discussions with the various groups of participants.

Furthermore, my pre-existing relationships with some of the participants complicated interview dynamics. Although I had easier access to these individuals and an existing base of trust, I had difficulty probing their responses that reflected taken-for-granted assumptions about research. There also were tensions around discussions of race. Because participants spanned disciplines, sectors, and racial and ethnic communities, I found it challenging to raise the topic of race in a consistent manner. Often I took the person’s lead but, in retrospect, I should have interrogated these issues more because of a general reticence for some White participants to engage in this topic. Upon reflection, I attributed my lack of probing about race to gendered power dynamics and challenges around managing my own responses to perspectives different from my own. As was pointed out by the transcriptionist, I tended to be quieter with participants who expressed beliefs that differed from my own. I suspect this was my way of dealing with internal struggles over my role as a “neutral” interviewer and my identity as a professional in the field of ACB HIV/AIDS research with my own opinions and beliefs about defining research.

As a White researcher currently based in an academic setting, I must also interrogate my position in the scientific field and larger social sphere, and how this shapes my perspective as a researcher examining issues affecting the ACB population. In speaking to issues of voice, Collins (1990) asserts that anyone can know about his or her own experiences, but must use caution when speaking for someone else. I, therefore, locate my social location as a “partial perspective” (Haraway 1988) and present the work in a manner can be held accountable—it is not a view

from “nowhere” or a view from above that attempts to make universal claims about the Black experience. With this in mind, I consulted various members of the ACB community to help me identify what kind of research would be appropriate for me to lead, taking into consideration my positionality and partial perspective. The most fruitful discussions were with an advisor who holds leadership positions in both the HIV/AIDS sector and the ACB community. Many discussions revolved around concerns over community mobilization efforts and relations with “mainstream” (i.e., White) academic researchers. Indeed, throughout the dissertation I found the advisor’s insights to be deeply valuable in helping me to understand and contextualize the community’s organizing efforts and current field dynamics.

Rather than writing about Black experience or subjectivities, my goals have been to examine structural dynamics that contribute to systems of domination in science, and to continue an already ongoing dialogue using critical theory to think through and open up these issues. As part of this effort, I see the study participants not as “objects”, but as actors with agency who are already part of a dialogue with academic and White communities and have entered into a particular conversation with me about these issues. This fits with my own ontology which is not based on the traditional scientific logic of “discovery” where the “codes of the world are ... waiting only to be heard” (Haraway 1988:593). Rather, this account is the result of a “power-charged social relation of ‘conversation’” (Haraway 1988:593). Additionally, this is not meant to be a fixed document that pins down and reifies power relations in the field. Instead, it is a reflection on dynamics in which field actors are currently engaged through a lens that can *only* be considered a partial perspective.

However, I must acknowledge that I have chosen to anchor this work in ideas originating from a male, White social theorist. I made this decision because I was interested in using Bourdieu’s conceptual tools to expose mechanisms of power in HIV/AIDS science. I felt that a Bourdieusian framework, combined with insights from race scholarship, could provide insights into mechanisms of domination and sites of resistance relevant to the ACB community’s struggles in this domain. I have examined the perspectives of ACB community members, not to appropriate them into White scholarship, but to use them as starting points to interrogate structural dynamics, social order, and power relations in a manner that fits with ACB community values, as I interpret them.

4.5.4 Power Dynamics

As part of a reflexive orientation, I was also aware, in my interactions with participants, of power dynamics “inextricably linked to wider race, class and gender divisions in society” (Reynolds 2002:303). Within a system that foregrounds the interests of researchers and reinforces their structurally dominant positions, research relationships most often reflect racial privilege and power (Reynolds 2002). Reflexivity is an important part of naming and considering these relations and taking steps against producing a “colour blind” piece of research (Bhopal 1995; Reynolds 2002). At a structural level, the work I produce will most likely be imbued with academic legitimacy. This placed me in “basic” position of power and authority during the interview and in making decisions about the design, implementation, and final reporting of the study (Reynolds 2002). Although I consulted with the community beforehand and have attempted to ensure the relevance of the findings to community concerns, I am ultimately responsible for the research.

However, power relations in interview contexts are not necessarily one-directional or unitary. Rather, power is understood and exercised in multiple and complex ways by both the researcher and those who are researched (Reynolds 2002). Many of the individuals I interviewed held positions of power in academic- and community-based organizations, bringing complexity to my interactions with them in several ways. As a student and someone who may eventually be looking for employment in this sector or seeking out community-based partners, I was aware of my own junior position and need for approval and support. Gender dynamics further complicated these interactions as I often felt intimidated in interviews with men and struggled to develop good rapport. Furthermore, although I was coming *to* these individuals for my own needs, some participants indicated the interview gave them an opportunity to have their voices heard. Moreover, research participants also exert power in terms of actively selecting what they will share (Reynolds 2002). Although these dynamics do not erase or mitigate racially located power relations, acknowledging them complicates a top-down view of racial power and moves away from a deficit perspective where the ACB community is always seen as “dominated” in academic-community relations.

4.6 Conclusion

In this chapter I have presented, and reflexively engaged with, the methodological approach to the research, study design, analytic procedures, and considerations of ethics and quality. A Bourdieusian lens and alignment with insights from race theory were present in all phases of the research project. Given my orientation to interpretive qualitative research and these critical theories, I strove to find balance between an inductive approach that kept me close to the data and the utilization of conceptual tools from my chosen theories. This allowed me to challenge my pre-conceived notions about how participants should be grouped and to think beyond my initial beliefs about field dynamics to eventually explore epistemological struggles.

In describing my trajectory, positionality, and experience in this field, I have provided context for this research and my role in the process of knowledge production. Furthermore, with a commitment to understanding the structural mechanisms that inform systems of domination, I also align myself with a social justice orientation and a belief in praxis. Although I am in no way prescribing a course of action for the ACB community or claiming this research is providing a pathway to “emancipation”, I do believe that by providing an analysis of the social conditions of hierarchies, they can be “challenged, transformed, nay, overturned” (Wacquant 1998:217).

Chapter 5 Results Part One: The Structure and Doxa of the Field

5.1 Introduction

The purpose of this chapter is to explore doxic assumptions that underlie field-specific practice and forms of capital valued in the field. To do this, I examine participants' beliefs concerning the practice of research and the resources needed to be involved in the production of HIV/AIDS research about the ACB population in Ontario. This chapter provides insight into commonalities across participants that indicate their shared investment in the field. As will be discussed, participants' belief in the evidence-based model conveyed assumptions concerning scientism—a belief that science is the way to “grow” knowledge (Halfpenny 2001). However, this is not to claim that all participants agreed on the importance placed on scientific authority per se, or how research, as a tool of science, should be defined. In fact, this chapter lays the groundwork for subsequent chapters that examine points of conflict over competing epistemological stances concerning the definition of legitimate HIV/AIDS research and who is authorized to produce it. These conflicts offer further understanding of the nature of doxa in this domain; when the naturalness of the field and its hierarchy is challenged, doxic beliefs are exposed.

In this chapter, I first describe the nature of the field based on the study sample as representative of the fields that are interlocking in this domain. Next, I examine doxic beliefs that support a scientism perspective. Finally, I explore the structure of the field according to what participants believe to be the necessary resources (i.e., capital) to gain entry into the field and be involved in the production of research. I conclude that scientific capital is dominant and community capital is less valued and, therefore, secondary to scientific capital in the field's structure.

5.2 The Nature of the Field

To begin to understand the nature of this domain, I turn to the study participants as representative of the different fields present in this interlocking field of science. Study participants came from a range of scientific disciplines, service-oriented and voluntary/advocacy organizations (i.e., community-based organizations), and a government body (Table 5.1, third column). I grouped participants' academic professional locations within sub-field descriptive categories (Table 5.1, second column). These groupings are not empirically defined but, instead, represent

epistemological commonalities among disciplines. For example, basic and clinical sciences tend to be oriented around a natural sciences model based on empiricist principles. Health sciences, although predominantly empiricist-oriented, are more applied in nature and may include various epistemological perspectives according to the discipline. Social sciences are the most epistemologically flexible of the groupings, as they span the humanities and applied social sciences.

Finally, I developed a classification structure (Table 5.1, first column) for participants' home fields inspired by the concept of *nomos*.³⁶ The purpose of this classification was to understand potential divisions within this field based on differences across the various interlocking fields. According to Bourdieu (2000), the *nomos* of a field represents the fundamental principle that organizes experiences and governs practices. The *nomos* of one field is not reducible to the *nomos* of another field. With this in mind, the “academic science” field is made up of academic disciplines with a shared orientation toward pursuing *knowledge*. I conceptualized the “political field” as advocacy groups and community-based organizations that have a common goal of achieving *social justice*. The “bureaucratic field” is comprised of bodies concerned with *public service and control*. This definition reflects Bourdieu's characterization of the bureaucratic field as the set of “public institutions officially devoted to serving the citizenry and laying claim to authoritative...classification” of society's institutions and people (Wacquant 2004:8).

Based on these categories, the study sample was almost evenly distributed between the academic science field and the political field, with minimal representation from the bureaucratic field.³⁷ The 11 participants in the academic science field were evenly split between basic/clinical sciences, health sciences, and social sciences.

³⁶ Rather than using “academic sciences field”, “political field”, or “bureaucratic field” when reporting the social spaces in which participants are located, I generally use the terms academic-based, community-based, or government-based.

³⁷ It is important to note that I am not claiming the actual field structure is split between academic sciences and politically-oriented community organizations. Although I am confident the sample is representative of the *types* of actors in this field, it is beyond the scope of this research to determine the actual breakdown.

Table 5.1 Fields Represented in the Research Sample (N=21)

Field	Sub-Fields	Professional Institution/Field
Academic Science Field (n=11)	Basic/Clinical sciences (n=3)	E.g., Basic Science Disciplines, Clinical Practices
	Health Sciences (non-clinical) (n=4)	E.g., Public Health Sciences, Allied Health Sciences
	Social Sciences (n=4)	E.g., Social Science Disciplines, Social Work
Political Field (n=9)	Community-based Sector (n=9)	E.g., Organizations representing and advocating on behalf of ACB communities; Organizations offering community services; Volunteer organizations
Bureaucratic Field (n=1)	Government (n=1)	E.g., Government divisions concerned with HIV/AIDS

To further contextualize the field and the social spaces participants occupy, I provide an overview of the study demographics. The majority of participants (76 percent) were of African or Caribbean descent and 67 percent were female (Table 5.2). Although I did not have enough participants to do a comparative analysis according to race, and I use caution when reporting identifying features of participants, I do make observations when there are obvious patterns relating to the racial make-up of a group of participants and their shared beliefs. Furthermore, the gender of individual participants will not be disclosed in the results to protect anonymity.^{38,39} Participants resided in cities across Ontario, with the majority located in the Greater Toronto

³⁸ As the study was not set up to look at gender, this was not specifically addressed in the results. However, I do discuss the influence of feminist theory on the beliefs of some ACB participants.

³⁹ It is worth noting, nonetheless, that the majority of female participants were located in community-based organizations as either community-based researchers or advocates.

Area. Although most individuals were English speaking, Ontario's Francophone population was also represented in the sample. One participant identified as HIV positive.⁴⁰

Table 5.2 Study Sample Demographics (N=21)

Characteristic		Number of Participants	Percent of Sample (%)
Race	African, Caribbean, or Black	16	76
	Non-African, Caribbean, Black	5	24
Gender	Female	14	67
	Male	7	33
Language	Francophone	3	14
Geographical area	Greater Toronto Area	17	81
	Eastern Ontario	2	10
	South-western Ontario	2	10
HIV status	HIV status unknown	20	95
	HIV-positive	1	5

During the reporting of results, I refer to the professional location of individual participants according to their overall field location: academic-based, community-based or government-based. As previously noted, I do not make references to specific characteristics of participants, in order to protect their anonymity. Below is an overview of group-level traits based on information gathered during the recruitment stage and the review of funded studies. I have also provided a key (Appendix F) to distinguish between participants throughout the results chapters based on

⁴⁰ This information was provided without prompting (i.e., I did not explicitly ask about HIV status).

their professional orientation (i.e., academic researcher by their discipline, community-based researcher, or community advocate) and race (i.e., ACB or non-ACB).⁴¹

ACADEMIC-BASED PARTICIPANTS

Academic researchers not of ACB identity (4 participants)

Academic researchers not of ACB identity are situated in various academic science fields: basic/clinical sciences (2), health sciences (1), and social sciences (1). They are employed by universities in fully tenured academic positions and occupy a range of additional positions that reflect different levels of academic prestige. However, on a whole, this group of researchers seems to hold a high amount of academic prestige based on their academic positions and history of being lead investigators on research grants (based on the funding review). Each of these researchers has been an investigator on a grant with a community-based researcher, although some are more involved in community partnerships than others.

Academic researchers of ACB identity (7 participants)

Academic researchers of ACB identity are located in various academic science fields: basic/clinical sciences (1), health sciences (3), and social sciences (2). They are employed by universities either in fully tenured or pre-tenured positions, or are PhD students based in universities.⁴² They are of African decent and represent a range of nationalities, ethnicities, and length of time living in Canada. All but one of these researchers have partnered with a community-based researcher or have worked closely with community advocates on research projects.

⁴¹ I did not include a notation for the race of community-based participants, as they were all of ACB identity. Similarly, I did not note the race of the governmental official; this was specified in the description of the sample as non-ACB.

⁴² I have conceptualized PhD students as academic-based researchers as they are fully immersed in the field of academic research and are invested in obtaining scientific capital. For example, all of the PhD students have applied for and received grants and are writing articles for academic publication.

COMMUNITY-BASED PARTICIPANTS

Community-based researchers (4 participants)

Community-based researchers are those occupying research-specific positions in community-based organizations or non-governmental organizations.⁴³ All of the community-based researchers in this study have some post-graduate education. They are of African decent and represent a range of nationalities, ethnicities, and length of time living in Canada. These community-based researchers facilitate and/or implement research that is relevant to their organizations' clients or target populations. In addition to initiating research themselves, they also may sit on research teams as knowledge users (i.e., to provide input as service providers).

Community-based advocates (5 participants)

Community-based advocates are based in community organizations, either as employees, contractors, or volunteers. They are of African decent and represent a range of nationalities, ethnicities, and length of time living in Canada. Community advocates are often co-investigators on research teams as knowledge users, if the research has implications for their programs and services, or representatives of particular sub-groups within the ACB population (e.g., ethnic origin, people living with HIV/AIDS). Some can apply for research grants on behalf of their community organizations through community-based research funding streams. They are involved in the implementation of research projects in the community (e.g., recruitment activities, gaining community support for particular studies). These participants either have some post-graduate training or are in the process of gaining more qualifications.

GOVERNMENT OFFICIAL

The government official, who is not of ACB identity, is involved in research as a knowledge user when particular research projects have implications for HIV-related policy and program development.⁴⁴

⁴³ Community-based researchers are also advocates in that they are involved in research as a way of advocating on behalf of their constituent populations. However, I have separated them from other community-based professionals (whom I have labeled as community-based advocates) whose work is not primarily devoted to research activities.

⁴⁴ I have kept the description of the government official to a minimum to protect the participant's anonymity.

In summary, the range of professional locations occupied by participants reflects the field's interlocking nature (i.e., interlocking scientific disciplines and non-scientific fields). There is a distinct racial divide in the sample: the majority of actors are of ACB identity, with all community-based actors being of ACB identity, and participants who are not of ACB identity are concentrated in the academic science field. The field has substantial representation by the community-based sector, suggesting a deep engagement with the political field.

I now explore beliefs that underlie field practices and inform the structure of the field. Understanding these beliefs also provides the basis from which to examine the field's struggles.

5.3 Evidence-based Approach as Doxic

Doxic assumptions underlie dominant practices in a field. Doxa has a common-sense nature and an imposed naturalness that supports the hierarchy of the field. In this section, I examine participants' beliefs about ACB HIV/AIDS research to begin to understand doxic assumptions about the naturalness of science as the way to know and respond to HIV/AIDS. The range of actors discussed the need for evidence, mainly through epidemiological research or various forms of applied research, to respond to HIV/AIDS and the necessity of research for supporting their claims about HIV/AIDS. Taking this evidence-based approach relies on a scientific lens to provide principles of experimental verification, which then has implications for what is considered legitimate practice in the field.

Participants discussed research in a manner that assumed a link between evidence and the "knowledge" needed to respond to HIV/AIDS in the ACB population. Based on this belief, several academic researchers explained that without research there is a "vacuum" in the knowledge base and no way to move forward with a course of action. Indeed, without research, there is "no problem".

So we need to continue to explore knowledge through research. And then research also enables you to draw out the weaknesses and the strengths of issues, to know where to direct your focus on, [and what] interventions or policies or programs you focus on. You know, it gives you the background information to a lot of other things. Because without research, you'd just be working on the, you know, you'd be doing things [in] a vacuum, more or less trial or error. Yeah, research sort of reduces your trial and error and makes it more focused. (AAS21)

Well, I think, you know, it's [research is] fundamental, it's key. I don't know how to say it other than to say that - without the research, there is no problem. And

without the problem, there is no funds to fix it. And then there is no services. And then it (HIV) just keeps happening. (AAH9)

Community-based participants believed that research can inform the response to HIV/AIDS in the community-service domain. Research can determine whom to target with programs and point to “better” ways of doing the work of service provision (CBR1; CBR38). According to a community-based researcher, before “moving forward” with developing more programs, there is still a need for research to provide basic information about HIV such as: “What do people know? What do *we* know about this epidemic? What *don't* we know?” (CBR38). Research also provides knowledge about the ACB population that can be used to distinguish it from other populations. As a community-based researcher explained, research can provide an understanding of issues specific to populations that are very different from the “mainstream” (i.e., White) population (CBR1). Furthermore, research can be used to obtain much-needed recognition and attention from policy makers and funders.

I actually started now looking at research from a really different perspective. Realizing that...this is what makes funders listen to you. Without it, forget it. So [I] thought, okay, we need to start building capacity around research. We need to start positioning ourselves around research. And we need to start thinking about how is that going to unfold. (CBR1)

Research then becomes a core activity for community service organizations to develop their programs and attract resources.

Epidemiology has been a key mechanism for defining HIV as a “problem” in and for the ACB community through the identification of the ACB population as a “risk group”. For numerous participants, epidemiological and surveillance data were portrayed as “foundational”, as the first step of the response to HIV/AIDS, and necessary for community workers to understand their “target” populations (GO11). A community-based researcher spoke about needing “basic” epidemiological and surveillance data to understand the epidemic in the community and whom to target for prevention interventions.

I think just around the surveillance information, just breaking it down further trying to get a better understanding of who's at risk. I think that's really needed. And like, who are we looking at? And the point at when people are becoming infected. I find that it's really difficult to target interventions, if we don't know who we're targeting really. We still don't have a very good understanding of who's affected. (CBR38)

These sentiments were reiterated by a community advocate who spoke about the importance of understanding transmission to improve “on-the-ground” prevention efforts (CA20).

Epidemiology, consequently, provides a way to “know” HIV as a disease that can be prevented, explained a basic/clinical sciences researcher (AAB30).

Once it is determined what is “knowable” about HIV/AIDS in the ACB population, funders and service providers pay attention and services are developed. For a researcher in health sciences, epidemiology provided a “transformative contribution” in the early days of the ACB epidemic as it provided quantitative “proof” of what health and service workers were seeing “in practice” (ANH3). This assessment led to HIV being defined as a problem in the ACB population, as indicated by the labelling of the population as a “priority area” in public health.

And that [putting numbers on it], you know, kind of changed the face of the situation in a way, because people could no longer sort of think that it was just a kind of a marginal phenomenon... [There was] at least some basis for quantitative assessment. (ANH3)

Because the data indicated that the ACB population is one of the “major” groups affected in Canada, it then could not be “ignored” (ANH3). As a community-based researcher explained, without these “objective” data, HIV is not seen to be a problem for the ACB population.

Epidemiology shapes it, and it tends to shape research. We don't think something's a problem until we see it in the epidemiological categories.... Unless we have a category that says 'Black' and then we say 'Look at all the Black people with HIV. We gotta do research with Black people.' I don't mean to be glib, but I do feel that we need to legitimize ourselves. We need to be objective first, before we can be subjective. (CBR23)

A community advocate also viewed epidemiology as “critical” because it constructs the “conversation” and every question thereafter. Consequently, policy and resource allocation are based on epidemiological data (CA26). In fact, as a health sciences researcher explained, in the early days of Canada’s AIDS epidemic, obtaining the first estimates of prevalence in the ACB population led to an increase in ACB-oriented HIV/AIDS programming and to the formation of ACCHO (ANH3). Following this line of reasoning, HIV/AIDS in the ACB population officially “exists” because it is now a legitimate scientific problem.

Also reflective of an evidence-based approach was a focus on applied research that is “solution-oriented” and “impact-driven”. According to several participants, starting from a solution-based perspective and asking from the outset how research can be “useful” helps to translate

knowledge into “action” (AAH9; ANS34; CBR23). A health sciences researcher spoke about being interested in “actually” creating solutions and using research information to improve “outcomes” (AAH28). Successful research, then, is outcome-oriented research that leads to policy change and more funding of HIV-related programs or services (ANB14).

Participants invoked the concept of “impact” such that research should have a definable and measurable outcome, either through prevention of HIV or leading to care and support services for people living with HIV/AIDS. As a social sciences researcher explained, researchers have to ask the types of questions they anticipate will have an “impact” (AAS6). This translates into research that is focussed on the short-term. Ensuring that research is relevant and meaningful in the “real world” also means dealing with the “highest priority” issues that can have an “immediate” impact, stated another health sciences researcher.

I am very sensitive to the fact that there has to be a very significant, applied consequence to doing this. And if it's not, at the end of the day, you'll learn something but it's not going to help change anything [in 10 to 20 years] ... I would be one of those people who would say ‘This is not going to help us. People are dying now. Like, this has to have some relevance within the next five to ten years, otherwise, let's not throw money at this when there's other studies that have more immediate relevance’. (AAH36)

With this argument, whether an issue or population is “high priority” or worthy of attention is, once again, determined by epidemiological data.

The need for research to have an impact was also reflected in critiques of researcher-driven studies. Several participants perceived them as examples of “research for the sake of research” (CBR1). Furthermore, a community-based researcher claimed that the ACB community would not support researcher-driven studies unless the “impact” is clearly defined.

I'm okay for ... researcher driven research. There are areas communities would never think about, for example, methodological research, but you have to highlight, ultimately, how is it going to impact the community you're talking about. So [if] it's research for the sake of research...I wouldn't be part of it. And I will not even support it. (CBR1)

Academic researchers also echoed this critique. From a health sciences researcher’s perspective, there is a need to diminish “curiosity driven” research; it is not enough for “some academic” to come up with a good idea (ANH3). Another academic researcher spoke about working with other researchers who “study stuff, just to study it”, which amounts to “making studies to make studies” (AAH36).

Critiques of curiosity-driven research were part of a wider discussion concerning the need for intervention research. Several participants argued that intervention research should now take precedence over “observational” research.

There's a recognition that we do need interventions, that...the time for just observational research is kind of passing. That's another, I think, message, I'd like to leave is: how much can you study the thing to death? Like, at a certain point... you have to stop taking pictures of people dying and [go] out and help them... But at a certain point, you gotta, it's like, in public health generally, at what point do you intervene in an outbreak, even though your information may be incomplete? Well, you can't wait until all the information is complete. (ANH3)

A community-based researcher also felt that the issues affecting the ACB population have already been identified and, therefore, there is a need to start developing interventions (CBR1). Intervention research is subject to an evidence-based model, with research providing the evidence to inform ongoing practice, which would then be assessed for its effectiveness. This is based on the premise that any intervention should be grounded in, and based on, scientific principles and evaluation (e.g., RCT model). For example, participants discussed the need for more “scientific” program evaluation (GO11), meaning that interventions and programs should be subject to the same scientific evaluation as other types of research. For a researcher in social sciences, interventions are really where you can begin to see “results” because outcomes can be “measured” (AAS21). Moreover, interventions and research are very closely “tied together” and, therefore, “rigorous” RCT models should be funded to evaluate intervention research projects, argued a health sciences researcher.

Relatively hefty budgets [are needed] to really put into place research at the different levels...if you want RCTs or other kinds of rigorous evaluative studies that can develop and examine and evaluate potentially effective interventions. And also evaluate in terms of more operational evaluation. (ANH3)

This researcher provided DEBI, a database that tracks HIV prevention interventions in the US, as an example of how systematically compiled data from intervention studies can help provide the “intelligence” needed to inform practice (ANH3).

Community-based participants spoke about using intervention research to address service delivery issues. This could include using an RCT design to assess healthcare services and improving access (CBR25). Several community-based advocates asserted that there are gaps in program-based research because research “flags” issues but does not move forward toward interventions (CA26; CA32). Furthermore, another advocate suggested tracking successful

interventions as part of collating “evidence” and also looking to “best practices” of programs in Africa that can be used in Canada (CA37). Again, the emphasis was on utilizing the tools of science to produce evidence and determine practice.

To summarize, research was seen by participants as a necessary part of developing practice (e.g., interventions, policy decisions) by providing the “evidence” in which to base decisions. Accordingly, every form of practice (e.g., service provision, prevention programs, interventions) can be subjected to scientific evaluation to determine its effectiveness. The emphasis on research having an “impact” reflects the prominence of the evidence-based model and the need for measured outcomes in public health fields. Furthermore, in order for the ACB population to gain the recognition of policy-makers and funders and obtain resources for the community, the “problem” of HIV/AIDS needs to be defined by research. This focus on evidence provides insight into doxic assumptions in the field; if evidence is needed for practice, then scientific tools are required to establish that evidence.

In the following section, I examine the forms of capital that facilitate entry into the field. Although an allegiance to the evidence-based model suggests the field’s doxa is based on scientism, the field’s capital is not limited to scientific capital. Rather, because this is scientific field that is interlocking with non-scientific fields, other forms of capital inform the field’s structure and definition of who can be a legitimate producer of research.

5.4 Structuring the Field: Scientific and Community Capital

According to the study’s theoretical framework, legitimacy in any given field is associated with having particular kinds of capital that are valued in that field. After the review of funded ACB research I hypothesized that both scientific capital, in the form of academic legitimacy, and community capital, as ACB identity and/or community location, were valued. I now turn to the study participants to explore how they understood the resources necessary for entry into, and success in, the field of ACB HIV/AIDS research. This further informs the conceptualization of the field’s social and cultural capital and how they structure the field. First, I examine scientific literacy, research skills, research networks, and educational qualifications as scientific capital. These skills and training allow actors with non-academic status to acquire scientific capital. Second, I discuss community capital as a form of social capital based on social connections to ACB communities. However, I argue that scientific capital is still dominant as it is required for

success in the field. This places community capital as secondary and less likely to be converted into symbolic power. This is further explored in subsequent chapters when I discuss efforts to maintain the structure (i.e., the dominance of scientific capital).

During the early stages of this research I theorized that academic legitimacy, through academic credentials (i.e., PhD, academic position) and success with funding, was representative of a form of capital in the field. However, this is only part of the larger scientific capital that is valued by actors in the field.⁴⁵ What is important here is not to confirm or disprove these as forms of capital, but to show that field actors, including those not based in the scientific field, understand the value of scientific capital and the importance of possessing this capital if they want to participate in the field. As one community-based participant explained, part of learning how to be successful in research is figuring out what is “valued” and learning how to play with the “big guys” (CBR23). In this section I conceptualize scientific capital as encapsulating both academic legitimacy and including other assets that are needed to be successful in the field. These include scientific literacy and training as cultural capital, and academic relationships and partnerships across scientific disciplines as social capital. These reflect an understanding across study participants that scientific literacy (i.e., understanding science as a methodological process) is valued in the production of research, but to be truly successful (i.e., occupy a dominant position), securing academic status and strong research partnerships are also required.

For those based in community organizations, scientific literacy can be gained through education and research training. Actors can use the legitimacy gained from this training to occupy roles as researchers and co-investigators on grants, rather than being restricted to knowledge user positions.⁴⁶ Community-based participants discussed how scientific training and education can potentially allow non-researchers to participate in research discussions and help them to be on “level ground” with other researchers (CBR25). A community-based advocate expressed frustration over difficulties in speaking up in research team meetings and feeling that not having an understanding of research means the discussions go “over your head” (CW20). Community-

⁴⁵ This is not a definitive examination of all possible forms of scientific capital in the field. I only focus on forms of capital that were discussed, and at times disputed, by participants.

⁴⁶ Knowledge users are members on research teams to utilize the outcomes of the research but do not necessarily design the research.

based actors, therefore, should have a post-graduate education such as a Masters degree, if they want to occupy positions on research teams (GO11). Furthermore, acquiring a PhD signifies to academic researchers that you “know what you are doing” (AAS21). This means an individual will be “recognized” or “prioritized” as a researcher instead of merely a knowledge user (CA37). Obtaining a PhD was also seen as necessary for going “up” in a career path compared to going “across” (CBR23). For those ACB actors who aspire to greater success in the field, studentships, career scholarships, and career orientation support will contribute to their academic legitimacy (ANH3).

Relatedly, academic training was seen as an important component of community leadership in HIV/AIDS. This is reflected in how community members with academic backgrounds become the face or voice of “community” in the research domain, according to a government official (GO11). Likewise, a health sciences researcher argued that current ACB community research leadership should be filled by those with an academic education and experience in public health (ANH3). Securing an academic position was deemed as important personally for ACB researchers and the mobilized ACB community. These positions provide legitimacy for ACB researchers to pursue research of interest to them. If the position is secure (i.e., tenured), it provides enough symbolic power to allow them to do the “work they want” (AAS6). This was also important for community-based participants. Having ACB researchers affiliated with universities provides resources and partners for community organizations (CW13). Furthermore, having Black researchers *within* academia is a way of “fighting the system” from within (CBR23).

While academic credentials and scientific literacy provide cultural capital in this field, relationships with academic researchers provide social capital. This was seen as particularly important for community-based actors who need “strong” academic partnerships to ensure success in their research endeavours.

And then find people. Academics, community members ... strong partnerships I think are really integral. Really integral...I just think that without, like a strong, academic-community partnership, you're not gonna get far in HIV research...And all of those projects that are doing well, are the ones that have strong partnerships. (ANS34).

Furthermore, partnering with influential academics provides scientific legitimacy to community-driven research projects—the success of academic-community relationships depends on the

success (i.e., relative dominance) of partnered researchers. A health sciences researcher claimed that it is difficult for community-based researchers to get funding without a “big name” academic researcher on the grant to bring methodological credibility (AAH28). For a community-based researcher, it has been important to align with people who “deliver” and who already have a “track record” because that is what funders look for (CBR23). This places importance on having research partnerships with those who occupy dominant positions in their respective academic fields. These networks also operate at an informal level, giving newcomers to the field the opportunity to learn from those who have already gained some success. A community-based researcher discussed the need for these relationships to go beyond formal mechanisms, much like networking principles of the “business world” where important relationships are forged through informal avenues.

I learned that a lot of things get done informally, even though we have formal venues. Which means, I don't know how to write a really good proposal? Well, I have a friend who knows how to write a really good proposal. ‘Tell me how to structure it.’ ‘Okay’. ‘Or better yet, you should talk to [organization X], they could help you write a proposal.’ ‘Really? How do you know this?’ ‘Oh, cause I have a friend who did that’. (CBR23)

Several researchers based in the social sciences noted the overall trend towards multi- and interdisciplinary research, which is suggestive of another feature of social capital (AAS21; AAS6). This is an example of a particular kind of scientific legitimacy that is common in health sciences that encourages cross-disciplinary collaborations. As a basic/clinical sciences researcher explained, bringing different people together is more effective than the traditional academic “silo” approach.

And part of the approach to this [research group] is to bring people together, ‘cause the solutions for HIV and AIDS are, really, that we need to do things differently. That working in silos and different expertise doesn't actually solve it. (ANB14)

At the community level, collaboration with different academic partners and larger research teams would spread the research “wider” and reduce duplication of research (CA37). This valuing of multi-disciplinary collaboration also reflects the interlocking nature of the field.

In comparison to scientific capital, community capital is the form of social capital that is oriented around membership in, and connection to, the ACB community. As will be seen throughout this thesis, participants across social groupings generally supported “community” involvement in research projects about the ACB population even if the meaning of that involvement varied.

“Community” was a broad term used to describe actors of African descent who are either academic researchers, workers in community organizations, or representatives of sub-populations and the wider lay ACB population. Formal community representation involves actors occupying positions on research teams or advisory boards. At the very least, if a research project affects the ACB community, then some form of community consultation is needed.

Participants discussed the necessity of having ACB representation to be successful with large funding institutions. Gaining the support of ACB community-based researchers on research projects helps with “validation” and “legitimation” of the project, according to a social scientist (AAS29). Representatives from community-based organizations are valued because funders look for population-specific representation through formal institutions. For example, ACCHO is recognized as an umbrella and representative body of the ACB population by funders.

Consequently, most researchers who work with the ACB population involve ACCHO.

... I know that now, [as] somebody who speaks, who sits on...the granting agency thing, sometimes they're considered a significant player in the sense that if you were doing a project around African and Caribbean populations and hadn't involved ACCHO, they'd be, like, ‘How is this even possible?’. (AAS6)

Community advocates confirmed that they are approached by researchers to represent the ACB population on research grant applications or to act as a conduit to link researchers to the lay population (i.e., potential research participants). As one participant stated, when academics want to do research on “Black people, they have to come *ask* the Black people” to help them (CA26). Without the involvement and input of the community, researchers will not be able to execute their studies. Moreover, because researchers and community representatives “go together”, neither can move forward with research without the other (CA13).

Being of ACB identity can also facilitate access to the wider ACB population. A health sciences researcher not of ACB identity believed that ACB community members can be suspicious of researchers “outside” of their community (ANH3). Moreover, several ACB academic researchers talked about the benefits of having an “insider” status. According to these participants, being a researcher who is also from the ACB population facilitates a mutual understanding with participants that becomes very useful when conceptualizing and implementing research.

I don't have challenges getting research done because I often do research with the community I belong to. Before research and after research, I belong to the community, I socialize in the community, I interact with the community, so I'm known in the community. When I work with the Black community I'm seen more,

in as much as I'm coming with my knowledge as an insider. And there's trust, a kind of trust, you know. (AAS21)

But most of my target population are my own people. So there's this cultural connection and besides that, I understand where they're coming from. You know? They understand where I'm coming from. The stories meet at a point. (AAH29)

For another ACB researcher, being “Black and living in it” helps the research be more intimately connected with what is happening in their community (AAH 36). Understanding the community from an experiential perspective translates into “better” research. For ACB community members, an “insider” status means direct access to the community, thereby reducing challenges that come along with implementing research. Because this is related to the production of “valid” research, having an ACB identity becomes a form of social capital. However, unlike scientific capital, it is “value-added”, rather than essential for actually conducting research.

In summary, the two types of capital identified for this field—scientific and community—contain elements of cultural and social capital. This reflects the interlocking nature of the domain of ACB HIV/AIDS research as a scientific field that interacts with various non-scientific fields and domains, specifically the politicized community-based sector. Scientific cultural capital includes scientific literacy, research skills, post-graduate education, and academic positions, whereas scientific social capital is found in research networks. Possessing scientific capital indicates an actor has the skills and knowledge necessary to navigate the research process, set research priorities, and negotiate academic partnerships. The more scientifically literate an actor is, the more able s/he is to be involved in discussions with researchers who hold dominant positions in the field. This extends to community-based actors—if community members are scientifically literate they can participate in discussions about the research needs of the community and have influence over agenda setting.

Community cultural capital refers to having an ACB identity and being able to represent the community either as an academic or a community researcher, or a representative from a community-based organization. Researchers who wish to conduct research in the ACB population need community partnerships (i.e., community social capital) to gain access to the lay population. Therefore, ACB “status” provides legitimacy in the scientific field because it helps to facilitate research. This legitimacy is also needed for research grants about the ACB population.

5.5 Conclusion

In this chapter I argued that the nature of this domain of HIV/AIDS research is a scientific field made up of interlocking fields represented by scientific disciplines, a politicized community-based sector, and the bureaucratic field. The defining principles of the field are grounded in principles of scientism for two reasons. First, there is importance placed on experimental verification as the basis for producing the knowledge that is needed for practice. Second, scientific legitimacy is prioritized because scientific capital is necessary for success in the field. Moreover, actors must understand the scientific “rules of the game” and the related “currency” in order to challenge the game. This extends to those who participate in the field not necessarily as independent producers of knowledge (i.e., researchers), but as actors who are invested and involved in the production of research by representing ACB community interests. If members of the ACB community want to affect the field, they must secure a minimum of scientific capital. Furthermore, if field actors want to define research, they must achieve enough scientific legitimacy to gain a dominant status (i.e., position) within the field.

However, because this field is an interlocking scientific field rather than an autonomous one, capital is not restricted to resources or assets that are scientific. Pressures from interacting with a politicized community-based sector have led to the legitimacy of community involvement in research (i.e., as community capital in the field). As will be discussed, this is not a straightforward issue. What it means to “be” community and represent community differs according to the epistemology and social location of actors. Moreover, community-based participants approach the field with an eye to playing the game and potentially subverting it.

These defining principles and doxic assumptions not only shape the field, they are also the basis of field struggles. If science is the way to “know” HIV/AIDS, then scientists are the dominant knowers and defenders of the orthodoxy. Challenges to these defining principles, however, create oppositional dynamics and struggles over defining the legitimate practices. In the following results chapters, I explore these struggles through the examination of epistemological positions and stances that represent challenges to, or defense of, the field’s definition and structure. Chapter 6 is concerned with struggles over defining HIV/AIDS research, whereas those documented in Chapter 7 concern who can be legitimate producers of knowledge about the ACB population.

Chapter 6 Results Part Two: Struggles Over the Definition of ACB HIV/AIDS Research

6.1 Introduction

In the previous chapter I argued that scientism is doxic in the field of ACB HIV/AIDS research. However, principles of scientism are not uncontested. In this chapter, I examine the field of opinion consisting of challenges to, and the defense of, principles that define the field and support the doxa. To do this, I compare participants' beliefs and epistemological stances concerning the legitimate definition of HIV/AIDS research. As I argue, a dominant scientific definition of HIV/AIDS research is defended through the invoking of certain principles of empiricism, while critiques of these principles lead to a redefinition of HIV/AIDS research that embodies social justice principles.

This chapter is organized in three sections. First, I explore stances that reflect epistemological principles relating to empirical theory, the “gold standard” of producing knowledge in a natural-scientific mode of social inquiry (Bishop 2007:46). These stances also represent a defense of the scientific definition of HIV/AIDS research through de-legitimizing the “political” definition put forward by ACB actors. Second, I outline critiques of these principles that function as challenges to an empiricist definition of HIV/AIDS research. Third, I present the alternative epistemological principles put forward mainly by ACB actors that serve to redefine HIV/AIDS research. As these actors bring the political (i.e., social justice principles) into the field of opinion, they challenge the naturalness of the scientific orthodoxy.

6.2 An Empiricist Approach: The Objectivity and Universalism of Science

In this section I explore how actors (all of whom were not of ACB identity) from various scientific disciplines and the bureaucratic field took empiricist-informed stances to define HIV/AIDS research. Although empiricism is associated with a mode of inquiry dominant in the natural sciences, it has also been applied to the study of human sciences. According to this approach, all “real” questions associated with social reality can be answered on the basis of empirical or formal methods (Bishop 2007:139). With its focus on maintaining objectivity in science, empiricism is concerned with finding “facts” via scientific methodologies and

experimental verification. Furthermore, scientific principles and methodologies produce universal “laws” that predict future occurrences of a phenomenon and, consequently, can inform practice (Bishop 2007). Empiricism also dictates a clear separation of testable and “factual” statements from “subjective” value judgements (Bishop 2007). This perspective requires the adoption of a “value-neutral” position when producing research. I examine how certain academic researchers in the basic/clinical sciences and health sciences promote and defend empirically oriented principles and methodologies as the legitimate way to know HIV.

Empiricism was present in the assumption that certain scientific methodologies can lead to the “truth”. For one academic researcher, in particular, to tell the “truth” about HIV means looking to scientific data, rather than relying on socio-political beliefs about the disease (ANH3).⁴⁷ The researcher argued the need to be “sceptical” of things that pass as “truth” outside the scientific arena (ANH3). This scepticism devalued non-scientific perspectives by creating a distinction between facts (i.e., real knowledge) and other ways of seeing the world. Following on from this perspective, epidemiology is “scientifically rigorous” and, therefore, can be used to define “what we are talking about” when it comes to HIV/AIDS (ANH3). Moreover, in speaking about risk behaviour data, this participant stated, “there it is”, implying that these data provide clear and obvious facts (ANH3). Through this empirical lens, HIV is cast as a public health issue that requires experimental verification to define the way forward.

I think [these data are] giving us some really good insights into what's going on in these communities and ... will help us potentially fashion some interventions that can be developed and tested. In the end, it has to do with public health - like, what can we change? What can we improve? And how do we do it? And how can we show, or not show that something is working? (ANH3)

Indeed, when ranking research priorities (i.e., what types of research should be funded), the participant prioritized epidemiological-oriented research and interventions as getting 40 percent of funding, with another 40 percent to basic sciences and 20 percent to clinical sciences (ANH3), leaving out social sciences and community-based research entirely. This suggests that socio-political research is not considered “real” science.

⁴⁷ Throughout this section, I refer extensively to this academic researcher because of the importance the researcher placed on principles relating to empiricism.

The empirical approach, as represented through an epidemiological paradigm, was contrasted with research that attempts to operationalize socio-political principles. Concerns over justice and equality of care were presented as secondary to the prevention of HIV as a disease.

In terms of care...there are gaps and lapses and there are things we can do better, but for the most part, I think they're getting pretty good care actually. You know? And the people I know who are taking care of HIV infected patients, I think are not racist... They're very sympathetic to the whole issue and very, you know, kind of involved. (ANH3)

Let's put the priorities... you save somebody's pain and suffering a lot more by preventing them from getting infected than you do from...kind of hugging them if they're infected. You know? Or whatever it is. (ANH3)

By focussing on how to “stop” the epidemic through targeting individual transmission, this perspective positions HIV as a technical problem to be solved rather than a complex social problem. Accordingly, HIV is seen as a disease to be prevented and treated through science, and as a behavioural issue that can be quantified and isolated from socio-political issues. For this researcher, larger social problems, such as racism and stigma, are too difficult to change. Because of these challenges, the focus should be on “controlling” behaviour and individual responsibility.

Sure there's racism. Sure that's, you know, a function. And sure there's stigma. And it ain't easy. But why don't we deal with things we can control? Why don't we sort of, you know, get our act together, on our own and develop some models...some leadership models for... kinds of safe behaviour... These are issues that you need to own. And yeah, there are extraneous factors, but it's not going to help that much. Because even if there is racism, it's not going to go away overnight. Um, so why don't we look at the things that we can control? And take responsibility and look at positive things in terms of behavioural change and self-awareness. (ANH3)

The focus on behaviour and transmission omits the impact of social or structural factors on the course of the disease, and defines HIV as a disease with individual origins. Dismissing the social effects surrounding HIV/AIDS also dismisses approaches that bring in social and political considerations to research.

Objectivity as principle of empiricism was present in discussions about the production of research, for example, in the assumption that determining the worthiness of a research project is an objective and rational process. A researcher argued that research is “right” or “wrong”, “good” or “bad”, regardless of who is the producer of that research.

Because, you know, I think anybody can do good research, and anybody can do bad research. And I think the important thing is, it's just like, it's not important whether I'm gay or straight. You know? If what I'm doing or saying is *right or wrong*, let's discuss that. Let's not discuss, you know, where I come from, or you know, what my religion is, or whatever. (ANH3)

From this perspective, because science is “objective” and “value-neutral” it can be separated from who is producing the science. These principles were also found in beliefs that the peer review process ensures the most “important” research is produced. Participants spoke about the peer review process as a neutral reflection of the scientific process and one based on merit. For example, one participant argued that there is a “universality” to good research in that “really good” and “really important” research should get funded in the existing peer review system (ANB15). Another researcher commented that there is no “magic” to getting research funded; if it is an “important” question, the proposal is methodologically strong, and the researcher is “persistent”, it will get funded (ANH3). To be successful, one must follow scientific rationality by making a strong argument, based on existing “evidence” for the importance of the research and its potential results.

The grants that you put in are assessed by your peers [and] based on how good an argument you make for this being an important question. And how good the preliminary information is that says you have a good idea and that you're going to actually come up with something. And what the importance of any potential results that you generate is going to be. (ANB15)

It is taken for granted that it is possible for the “importance” of the work to be measured objectively via peer review.

So I think that...probably a lot of the ones that didn't get funded, it's not out of any, you know, political agenda or anything else, to be honest. It's probably just because those issues weren't as important or weren't as well justified or the impact of what was going to be generated was not going to be as substantial. (ANB15)

That is, the peer review process does not reflect particular interests or “politics” of reviewers and can be trusted to discard research that does not meet scientific standards of “importance”.

Therefore, peer review is the arbiter of science by employing value-neutral and universal scientific standards of evaluation to research. This is part of science’s “approval conception” (Bishop 2007), which is supposed to prevent scientists from privileging the research they *want* to produce.

Belief in the importance of a value-free science was also found in claims that “politics” detract from finding research-driven, practical “solutions”. According to a researcher, ACB community members should not be too “hung up” on a social justice approach to research because it does not allow room to “move” (ANB14). In fact, it is “mumbo jumbo” when community members refuse to be involved with research projects that go against their political ideals (ANB14). The focus should be on trying to solve problems and figure out “solutions”, instead of “taking things apart” and not putting them back together again (ANB14). Furthermore, another researcher did not think race equity was an issue that needed to be addressed in HIV/AIDS research or in relation to community representation in the larger HIV/AIDS sector (ANB15). Accordingly, even though there are strong racial and political “agendas” in the ACB community, the participant asserted that “we have moved beyond that” and, therefore, should just “cool the rhetoric” and “get on with it” (ANB15). There were also critiques of anti-oppression frameworks and how they can act as “barriers” to getting research “done” (ANB14). The government official described these frameworks as potentially paralyzing in that they focus on things that are not controllable. Accordingly, approaches to research need to be more “practical” and “doable”.

I've been thinking a lot that... the anti oppression/antiracism perspective may not be working. Because I think it leaves people so paranoid. Like people wanting to do the right thing that they get overwhelmed with things. But there are things that we can't have control over. And I think it makes everyone freeze. It doesn't give people an agency to work. So there's the oppressed and the oppressor, and people don't seem to have any franchise within that... Every dynamic and interaction is fuelled by all this stuff. Everything is going to be oppressive and you're going to be oppressed and there's nothing we can do about it. What should we do about it? (GO11).

These stances suggest that social justice orientations are forms of politics that act as barriers to doing “good” science.

Finally, the empiricist principle of universality in the scientific approach was also present. The merits of basic and clinical research were portrayed as “globally” relevant, in comparison to local ACB community-oriented issues, because these forms of science can be relevant for “anybody” at risk for HIV (ANB15). Moreover, the government official argued that “we spend too much time on differences” (e.g., ethnic or racial differences) among those affected by HIV/AIDS; focussing on difference, therefore, does not allow research and programs to capitalize on similarities among groups affected by HIV/AIDS (GO11). This participant also found it problematic to attempt to capture diversity in the ACB population.

I think an ongoing problem is the problem of representation, i.e., countries of origin. [It is] not working because we get into dividing something into these little tiny slices, and I'm not sure if that's really good in the long run. (GO11)

As a way to mitigate these issues, there should be a “coming together” of community members rather than attempting to represent every nationality and indirectly feeding into the idea that “everyone is different” (GO11). These comments suggest a valuing of more universal approaches that bypass the “messiness” of socio-political issues. These stances emphasize universal solutions to HIV/AIDS and minimize how differences across social groups contribute to inequities relating to the disease.

In summary, academic-based researchers defined legitimate research through empiricist principles and methodologies that seek out objective solutions that can lead to the “truth” of HIV/AIDS. Empiricist principles were also found in the presentation of research as a scientific process that is objective, has a universal reach, and is a path to solving the “practical” problem of HIV. From this perspective, the scientific review process is value-free and merit-based; peers determine the legitimacy of science based on scientific “rationality”, rather than personal values or “politics”, which are an obstacle to getting research done. Moreover, socio-political issues are not considered legitimate areas for HIV/AIDS research, at least not via the scientific method, as they are either irrelevant or too difficult to change or control. Instead, research should be focussed on “tangible” data that could lead to developing scientifically informed interventions, preferably at an individual level.

These actors are invoking empiricist principles that reflect the dominant epistemology in natural sciences. In the following section, I examine ACB actors’ stances that represent critiques of these principles and challenges to an empiricist definition of HIV/AIDS.

6.3 Challenging the Dominance of the Scientific Perspective and Empiricist Claims

A range of actors, the majority of whom were of ACB identity, critiqued empiricist principles and the dominance of the scientific perspective. First, these researchers and advocates argued that the production of research is not neutral or objective; rather, it is a politically charged process that is biased towards “mainstream” (i.e., dominant White) perspectives and interests. Second, they took issue with the prioritization of the scientific “method” over outcome-driven

research. These participants also claim that the dominance of certain empirical approaches precludes attention to social issues. These critiques are epistemic attacks on scientific claims of value-neutrality and call into question the assumed universalism and superiority of science.

6.3.1 Politics and Interests Shape Research

Community-based participants, social science researchers, and several researchers in health sciences challenged notions of objectivity in science by claiming that mechanisms to determine the legitimacy of research (e.g., peer review) are shaped by subjective interests, political biases, and systemic inequities. As one participant asserted, research is not “a neutral thing” (CA26). Furthermore, because of these biases, those who are charged with determining legitimacy do not understand the ACB population. This translates into a research landscape that does not represent ACB community interests or perspectives.

ACB participants portrayed research as being shaped by political dynamics. For example, the allocation of HIV/AIDS funding, claimed several participants, is heavily influenced by government priorities. This results in different communities being prioritized at different times. Populations that are not a political priority are less likely to get a share of the resources and, therefore, less research will be conducted about that population.

There's a lot of power in funding bodies. If they don't see something as an issue, and they're shaped by government, whether it's provincial [or] federal, and it depends on what their priority areas are. Right now, I heard African, Caribbean, Black and women are a priority area. For how long? You know? It could be, it's not just based on epidemiology. And unless you get there, in terms of a priority need, that research doesn't necessarily get done. (CBR23)

But at the end of the day, we live in a city or a province where the funding only goes so far. It's supporting particular people. And race and gender, and you know Aboriginal status, those are all issues that are going to have implications for you. And if it's sexy, in the moment, your chances are going to be better, and if it's not then your chances are going to be worse. (AAS34)

Similarly, the peer review process was also characterized as a “political game” rather than an objective measure of what constitutes “good” research (AAB30; AAH29). According to an academic researcher, even if researchers produce a good research proposal, the peer review process is inconsistent across organizations and reviews are often “personal” (AAS29). Indeed, according to several participants, sometimes reviewers just “don’t like” or “just don’t want to fund” certain pieces of research (AAS29; CBR23).

Personal subjectivity can also be found in biases that come from closed social networks in Canada, claimed several academic researchers. Being educated outside of Canada creates challenges for ACB researchers attempting to break into “mainstream” research networks. Furthermore, because the HIV/AIDS research field is relatively small, success for researchers in training is based on whether or not their supervisor is influential.

So even when we talk about...peer reviewers, they are known among their peers ... whereas... asking a mainstream person to review my work is like, you know? But if you are schooled here ... that would give an extra edge above other people, you know? Because in that process you would have met your supervisor and other scholars at conferences, so they would get to know your work. (AAS21)

You address [the reviewer’s feedback] and you wonder what is going on... Is it something that has to do with my supervisor? I don't know what it is, but I think the HIV community is a very small community, right. And I think funding...it's a little bit of a political game. So if you don't have anybody in there, or if your supervisor is not somebody that carries a lot of weight...your proposal would easily be kicked out. (AAS29)

As one researcher argued, part of the politics of the “review circle” is whether reviewers already know you or your work, which will always be problematic for ACB researchers new to Canada (AAH36).

Participants also linked subjectivity in the academic review process to the social locations of reviewers. For example, an academic researcher suggested that the success of a research grant depends on whose “interests” are being represented on the review committee (ANS34). Another researcher contended that it often seems to come down to whether or not the reviewer feels personally connected with the work, “as if *they* had to be the ones to identify with the research, versus the people that it's targeted for” (AAH36). Relatedly, ACB participants strongly critiqued a perceived lack of awareness among reviewers concerning issues faced by the ACB population (CA20). Because reviewers do not understand these issues, peer review is not a level playing field for ACB researchers.

And I think the other reason could be because funders are not really aware of the issues. Right? And so you send a proposal, they have all these people who review your proposal, who might have no knowledge of what is going on in African Caribbean community. And they care less. (AAS29)

I think the people that reviewed it didn't understand. First of all, they didn't understand who are [the proposed participants] or how you work with them effectively. They totally missed that point...Sometimes they will give you

somebody who doesn't even have a clue about the community. The issues they raise for review just leave you wondering where they're living. (CBR1)

By not recognizing the issues, these reviewers are, in effect, denying the problems of the ACB population (CBR1). Therefore, reviewers are not always able or qualified to determine what may be of benefit to the communities (CA20).

Participants theorized about reasons for this lack of awareness, noting the over-representation of certain populations in the larger HIV/AIDS domain. An academic researcher believed that the “structures” in place have promoted research in the men-who-have-sex-with-men (MSM) population, while the ACB community has been historically under-researched (AAH28). A systemic reason for this exclusion, claimed another researcher, is a reliance on the public health approach to disease that involves waiting until rates are high before redirecting resources.

A lot of funding goes into gay HIV research. So... you wonder why funding is not going into African, Caribbean HIV research. Maybe they still think that the people who are affected are not significant, the number is not alarming. Do we have to wait till it's alarming? I don't know. (AAS29)

Because the MSM community has had a higher profile in the epidemic, these participants felt that reviewers generally have a better understanding of their issues (AAH36).

ACB participants also theorized that systemic inequities contribute to the politics of research funding. For example, a community advocate claimed that epidemiology is the “domain and bastion” of White men and, therefore, it is nearly impossible to get funding for studies done by ACB researchers (CA26). Several academic researchers argued that, regardless of the strength of the research proposals, structural racism affects chances of success.

So, there's racism. I mean, I'm not going to lie about that. There's racism, which is [an] undertone...And it's something that I learned from my Black mentors, that you know that you are writing a good proposal, you are submitting maybe one of the best proposals, but your chances of getting rejected is quite high. (AAH29)

[NIH] did this internal study and they found that if you look at all the objective measures and why studies don't get funded, none of these things make sense: the score; the educational background; history of publications; academic record; the university they're affiliated with. The thing that determined whether it got funded was race—if you were Black [you were less likely to get funded]. (AAH36)

This researcher provided the NIH example to argue that there are systemic problems with the review process and that objective measures do not explain who does or does not get funded.

Because of this systemic racism, ACB researchers have to carefully manage how they portray issues of race in their research, claimed several participants. Indeed, if their proposed research challenges the status quo, it is unlikely to be funded.

What I find is that you can talk about systemic racism, if you don't go too deep with it, or too heavy with it, people can take it. But you have to be very careful with it. When I first came into this job, somebody said to me, 'Well, you can't be talking about racism. Talk about racial differences. People, you know, can get on that.' (AAS6)

[If you are] challenging the status quo...it means you are taking on a bigger battle... How do you convince that person whose going to give you \$50,000 that, oh, by the way you're gonna challenge everything, including why they're only giving you \$50,000? (CBR25)

This community-based researcher argued that it is almost impossible to have these structural inequities recognized at an institutional level because the institutions themselves are implicated in the dynamics (CBR25).

These actors are enacting principles of critical epistemologies that challenge the presumed objectivity and “cultural neutrality” of science and critique structural biases in the legitimation process of science (Harding 2004). They claim that inherent biases restrict entry to the field and affect the ability of ACB actors to improve both their individual and group positions in the field. For example, because structural dynamics such as racism prevent representation of ACB interests, there is a lack of understanding about the ACB population in decision-making arenas, which has a carry-on effect for the success of ACB researchers. As critiques to core principles of the empiricist perspective, these are challenges to the presumed superiority of the scientific process.

6.3.2 The Preoccupation with the Scientific Perspective

ACB participants took issue with the dominance of particular scientific methodologies. These participants believed the definition of what is considered “scientific” to be too narrow. With importance placed on “traditional” scientific perspectives and quantitative approaches to research, models that are more social in orientation are devalued. Furthermore, participants argued, inattention to social issues, particularly those relating to racial inequities, are reflective of a larger reticence in science to acknowledge and attend to racial dynamics.

ACB participants condemned research they perceived to be narrowly focussed on the scientific perspective. According to several advocates, it is problematic to place the needs of the researcher above those of the community (CA37; CA32). An academic researcher believed there is an overemphasis placed on methodology, which obscures the actual reason for doing the research.

They are always talking about something—validity, credibility, representation...they tend to overemphasize something from a methodological issue and don't look at the, the *goal* of the research. (AAS21)

These issues were linked to what participants believed was a concomitant devaluing of research that goes beyond a technical focus. For example, engaging in “critical” research or “community-focussed” research is challenging, for a community-based researcher, because funders are not likely to support these approaches (CBR23). This sentiment was echoed by an academic researcher who believed that community-based research methodologies, while no longer on the “fringe”, still do not generate the same “excitement” as randomized control trials (AAS6). Furthermore, the “system” still values outputs that are related to academic science production, such as grants and journal rankings (AAS6).

Participants included approaches oriented around quantitative methods in their critique of the scientific perspective. These actors argued that there is so much emphasis on “getting the numbers” because quantitative data are valued by research and funding institutions (AAS21; CA32; CBR23). A community-based researcher felt there is a tendency for researchers to rely on formulaic scientific approaches, as represented by empirical and survey-driven research. However, these approaches do not allow room for other ways doing research.

But I don't find that...time and space is given to research. It's just sort of like (snaps fingers three times). And then we can just submit this and (snaps fingers) and then we can just submit that. And let's just go (snaps fingers) and then survey. So I do feel like there is an over privileging of empirical research and just... collecting information from people. (CBR38)

Moreover, participants were suspicious of quantitative research that relegates the ACB population to risk categories. As one community-based researcher argued, being defined as a risk category by epidemiology is “dangerous” for, and unwanted by, the ACB community, but it is the only way to get noticed by funders and policy makers (CBR23).

Relatedly, ACB participants claimed there is an over-attention to public health models that privilege risk and behaviour to the exclusion of socially or culturally relevant approaches.

Several participants maintained that assigning people to sexual behaviour groups, as is the norm in epidemiology, does not reflect how community members define themselves on a day-to-day basis (AAH36; CBR25). Yet, people fit themselves into these categories because researchers define them this way (AAH36). Moreover, because of disciplinary norms, researchers are forced to use these “Western” measures even though they may not be “culturally understood” by ACB research participants (AAS29). When researchers employ these “Euro-centric” and White theories to explain HIV/AIDS in the ACB population, claimed an academic researcher, they blame ACB actors when these theories do not work, rather than considering whether the approach itself is appropriate for the population.

One of my big, big, big, peeves are studies that use these mechanistic and Eurocentric theories to try to explain Black people: Black people's behaviour; Black people's patterns, social patterns, health patterns... But people still regurgitate, like, recycle these things and they keep getting funded. I think there are other possible explanations or perspectives for trying to understand what we see in African communities that cannot be accommodated, I think, by most of the theories that we apply. And, I don't think that the analysis or the critique ever implicates the theory. It always implicates the subjects. It always says ‘Oh my god, here's another study. The Black people won't come. They're not responsive to intervention. You do all this stuff and they never change.’ But nobody says ‘This whole model that you're trying to do is foolish.’ ... I think there's a reason why some of these interventions work well for White people and they won't work well for Black people. Because they're based on cultural models that are [White]. (AAH36)

What is missing in models of HIV/AIDS research, therefore, is an acknowledgement that there are different ways of “being and living” in Black culture compared to “mainstream” society, the researcher argued (AAH36).

For these participants, an extension of the epidemiological approach is a focus on the individual as a disease vector rather than addressing larger social issues that shape the disease. As a community advocate argued, HIV is not “just about two people”, it is about “power and equity and inequity” (CA26). According to an academic researcher, the “behavioural” paradigm has a “grip” on HIV because it is easier to blame individuals than society (AAH36). Another researcher claimed that the socio-political aspects of health are not considered “scientific”.

Social determinants of health - people get it but they don't. It feels too big or something so they don't think there's something that can be done with it. People kind of shy away a bit from laying on the table the social justice issues. It doesn't feel quite as scientific, to be saying racism is part of this. Sexism is part of this. Ah, stigma, colonization. All these things. (AAS6).

Included in this dismissal of the “social” is an inattention to race as a legitimate topic or concern in research, according to many participants (CBR23; AAS6). They argued that race is “obliterated” through a conflation of race and ethnicity in research methodologies, which ultimately defines the kind of data collected and the resulting knowledge (AAH28; CA26; CBR23). As an academic researcher argued, if issues surrounding race are not considered important, then race-oriented questions will not be included in research (AAH28). In other words, if there is no methodological tool to “see” race, it will not be considered a legitimate arena for research.

These critiques challenge the dominance of current research models and approaches, including disciplines and perspectives based on quantitative methodologies and the behavioural paradigm. There was particular concern over the lack of attention to socio-political issues identified as important to the ACB community, whereas critiques of Eurocentric approaches suggest challenges to universality as a principle in science. For these participants, the devaluing and dismissal of social and structural issues effectively strips cultural aspects relevant to the ACB population from research and maintains the dominance of a White scientific lens. Together with their critiques of the peer-review system, these actors are challenging the taken-for-granted nature of claims of neutrality, objectivity, and universalism in the scientific process. This amounts to challenging a scientific orthodoxy that prioritizes empiricist principles.

In the following section, I present how these participants move beyond critiquing the scientific orthodoxy by attempting to impose their own principles on the definition of HIV/AIDS research.

6.4 Redefining HIV/AIDS Research with Social Justice Principles

A range of participants, mainly of ACB identity, invoked epistemological principles grounded in critical and social justice traditions as the basis for a socio-political definition of HIV/AIDS research. With these principles, the aim is to achieve social and economic justice by attending to group-based inequities and oppression (Collins 1998:xiv). Stances that support these politically informed principles include the valuing of methodological approaches that address the social drivers of HIV and larger issues relating to social inequities, and using the research process itself to facilitate social change in the ACB population. Therefore, HIV/AIDS is seen as a social issue rather than a biomedical problem that can be controlled through individually focussed, technical solutions.

As a way to redefine approaches to ACB HIV/AIDS research away from traditional scientific tools, participants discussed the need for diversity in research methodology. They spoke about “alternative” ways of doing research that are valuable to community-based actors and considered types of research outputs that would be suitable for community-based practice.

Research can look...there's so many opportunities—mapping, community mapping, you know, rapid assessment. You don't have to have SPSS, or NVIVO to do research. I also think that there are alternatives [that] need to be looked into and valued. I think more research needs to be done in terms of understanding alternatives. (CA20)

And the benefit doesn't necessarily...the result of community-based research doesn't always come as a big document that you can put on your shelf. It could be a flyer. It could be a brochure. It could be training for people to learn how this works. That, for me, is community-based. (CA32)

For several participants, this need for methodological diversity extended to the value of interpretive or theoretically informed explorations, such as understanding issues at a deeper level and focussing on how people “think about their world” (CA20; ANS34). Furthermore, researchers should be able to construct research questions in a “critical” way, according to a community-based researcher (CBR38).

Participants discussed the need to address the social drivers of health as part of an overall social justice approach. This perspective links HIV/AIDS to social issues that lie beyond the biomedical model and connects the racialized structure of society to the epidemic.

HIV mirrors the experience of Black people within a mainstream society. It's historic. So it's not something that just happens because HIV came along. HIV came along and fitted within the context in which people understood race and gender, and ethnicity and sexual orientation. (CBR1)

Having a justice-oriented outlook, for one academic researcher, requires asking questions that go beyond the identification of disease and risk factors to understand how people live “full lives, quality lives, and just lives” (AAS6).

Through this socio-political lens, participants conceptualized HIV/AIDS as disproportionately affecting members of the ACB population, not because they are “unlucky” or because of a “coincidence”, but because HIV/AIDS is interconnected with, and fed by, social problems such as racism, sexism, poverty, and xenophobia (AAS6). HIV/AIDS should be considered in parallel with larger social problems and dynamics because they shape the ability of individuals to make

decisions. Moreover, those living with HIV/AIDS have needs based on their social identity and location, not just their disease.

Things that would fall under social justice...like things that I guess would fall under the social determinants. I think those things keep coming up. And they are so intertwined with what's going on. You may be asking about why didn't she use a condom [but] you go back to what people are dealing with on a daily basis because those kind of things shape what people do, the decision that they make, [or] when they don't make [a] decision, whether it is conscious or unconscious. (CBR25)

People are more than just HIV positive. They're mothers, they're...brothers or sisters...fathers...they're workers...they're students. Let's look at those other aspects of them. They want houses, they want a job, you know? They want to not be isolated; they don't want to be excluded in all their venues. (CBR23)

Taking a social determinants approach involves understanding the “systems that we live in” and how these feed into HIV/AIDS via group-based inequities (AAH28). For an academic researcher, this meant examining a person's “social position” within the social structure. This could be part of a “socio-political” approach to epidemiology specifically, and public health in general (AAH28). HIV/AIDS is also seen as a window into other issues affecting the ACB population and, consequently, can be a vehicle to change things “on the ground”, according to a community-based researcher (CBR38). In this sense, HIV is not just a disease, but a social issue that is connected to larger social processes.

ACB participants also connected these socio-political issues to healthcare provision and access. Several academic researchers linked the social vulnerability of the ACB populations and system inequities (e.g., racism, classism) to disparities in the healthcare system, and called for more research on these issues.

There's some very basic issues around access to primary healthcare that definitely are part of what makes the community vulnerable, in terms of HIV infection, and also makes it harder to live with an HIV-positive status. So, I think those basic issues of access, there's still lots of work to be done there. (AAS6)

You also need to look at how racism is interacting with classism for instance... And it has to do with social status, versus being a Black person and not being very well educated, or having language problems, and all of these other things going on. [So] they're unable to cope with [accessing health services]. (AAH28)

A community advocate also highlighted discrimination in healthcare settings as an important issue that rarely gets acknowledged in the field or addressed in research studies. This participant

spoke about the need to examine discrimination in healthcare delivery, specifically healthcare professionals' perceptions that Africans are "bringing the disease" to Canada and other discriminatory perceptions that shape health provider interactions (CA13).

Moreover, intersecting issues of stigma, discrimination, and racism were flagged by participants as important areas for research. A community-based researcher argued that there is barely a "basic" understanding of stigma at the community level (CBR38), while another discussed the need to "intersect the different types of stigma", such as racism, gender discrimination, and HIV/AIDS discrimination (CBR1). Indeed, the experience of being racialized shapes HIV/AIDS in the ACB community.

Looking at what is this experience of racialization for this segment, for these people who happen to be from Africa, historically, and how does it impact their ability to live with HIV, their ability to prevent themselves from being HIV positive and ability to support those who are affected by HIV in their communities. (CBR23)

Race "always" plays a role when it comes to research and health in ACB communities, according to an advocate (CA37). For example, because of the history of racism in public health research and systemic barriers to health care access, community members are suspicious and fearful that when "White people" do research, they will use the research to negatively affect ACB communities (CA37).

In addition to looking to research to produce knowledge that could lead to social change, ACB participants spoke about the research process itself as a potential vehicle for change in the ACB community. This moves away from scientific or technical outcomes to a valuing of the transformative potential of the research, such as creating opportunities for "self determination, liberation and emancipation" (CA26). For example, research has the potential to have an impact on participants by allowing them to tell their "stories" and think about what they usually take for granted, argued a community-based researcher (CBR25). Measuring the impact of research outcomes, therefore, should not only be determined by how many infections have been prevented, but also by whether the needs of the research participants are being met (CBR1). This includes addressing the immediate needs of participants and making an impact on their "daily" struggles (CBR26). It also involves bringing lay community members into the process of conducting the research, argued an academic researcher. This can help them to develop

themselves and, by extension, “their communities, their children, and their families” (AAH36). Thus, community building and advocacy can be valued outcomes of the research process.

Finally, community-based participants working in service organizations argued that knowledge translation is needed for social change to happen at a “grass-roots” level. For example, a community-based researcher claimed that research should always translate into social action.

Translation of research into action is the missing gap. We have research showing that poverty is an issue for people; stigma is an issue. [People] are having problems accessing [services]... But what are we doing? And when people start to ask the question, ‘You keep on coming back, over and over and over again. So what are you doing with the information? How has it benefited me as a person living with HIV?’ How do you support people to actually translate it into actionable deliverables that actually support people dealing with issues in their lives? (CBR1)

As part of building the link between research and action, this participant also argued that researchers should see themselves as part of the process of translating knowledge into action. This would involve building long-term relationships with research participants and stakeholders to develop services or other outputs relevant to the community, rather than focussing solely on the production of academic literature (CBR1). Relatedly, as service providers, they want researchers to “come back” to the ACB population with the results of research and communicate them in ways that community members can relate to, explained a community advocate (CA20). For another community-based researcher, knowledge translation should be built into the research project from the beginning.

Or maybe even starting from knowledge translation, in that research process. So, instead of leaving it to the end, starting from that place of ‘What is this research study hoping to achieve? Like, when we're done, what are we hoping to do?’ And *then* starting the research. (CBR38)

For community-based actors, research is not about gathering data and reporting to other researchers, but about being relevant to the communities they are studying.

To summarize, for this range of participants, a legitimate definition of HIV/AIDS research is based on principles and values of social justice. They envisioned research as a flexible tool that can be adapted to respond to the socio-political values and needs of the ACB community. These actors are enacting epistemological principles that define HIV/AIDS research in a manner that benefits, and legitimizes the interests of, the ACB community. This approach is overtly political in that it focuses on bringing the “social” into research. For example, topics such as racism,

stigma, and discrimination, are considered important areas to address because of the impact they have on the wider ACB population. Moreover, because HIV/AIDS is seen as related to these markers of inequity, the outcomes of research are valued if they affect social change in the community. In fact, the research process itself was seen as a way to effect social change at the individual level through involvement of community members, or at the community level through knowledge translation.

6.5 Conclusion

In this chapter, I explored rival epistemological principles and aspirational goals concerning the definition of legitimate ACB HIV/AIDS research. Participants who defended an empiricist perspective valued a scientific process that is grounded in natural sciences and produces unbiased research through an allegiance to peer validation and empirical verification. Challenges to this perspective came mainly from ACB actors who argued that science is not always neutral; rather, it represents particular interests through a biased peer review system that reflects existing inequities. These actors are arguing that scientific work is located *inside* society, not outside or beyond socio-political influences (Calhoun and Karaganis 2001). Relatedly, participants disagreed over whether socio-political influences *should* be part of research. Those who were enacting empiricist principles were not supportive of socio-political influences in the practice of research or defining research priorities. Instead, they valued research that focuses on empirically defined targets and outcomes that are related to reducing disease burden. ACB participants, on the other hand, were insistent that HIV/AIDS is *social* in nature and, therefore, science needs to accommodate and respond to larger social processes.

These different epistemological and aspirational stances represent struggles to define the field in ways that benefit particular “interests”. Actors are either attempting to maintain an empiricist scientific orthodoxy or challenge and subvert its dominance. First, there were epistemological disagreements over the approach to HIV/AIDS research, either as an empiricist scientific process that is rooted in universal and objective principles, or a flexible tool that can respond to socio-political concerns. Second, participants had either scientific or social aspirational goals for research. Empirical scientific goals are orientated around disease reduction, whereas socio-political goals are focussed on social transformation. Because empiricist principles are dominant in natural and biomedical sciences, the defense of these principles is homologous with the

orthodoxy of these scientific fields. Moreover, defending empiricist principles and aspirations against socio-political influences also serves to devalue perspectives that implicate current inequities in the field and larger society, particularly those that are racially oriented. In contrast, actors who took stances rooted in politicalized fields challenged these principles and offered competing symbolic orders to define the field (e.g., critical epistemologies informed by socio-political values). These actors are, therefore, attempting to change the parameters of what is “legitimate science” in the field (Collins 1998).

In the following chapter, I return to the structure of the field. I consider how participants’ stances concerning who can be legitimate producers of knowledge either serve to maintain the structure of the field and the authority of science, or redefine the field and its associated power structure.

Chapter 7 Results Part Three: Who can be Legitimate Producers of Knowledge?

7.1 Introduction

In the previous chapter, I explored competing epistemologies and aspirations concerning the defining of HIV/AIDS research and the manifestation of these dynamics in the defense and challenging of the scientific orthodoxy. At the heart of these dynamics, however, are struggles over *who* can be legitimate producers of research about the ACB population. In this chapter, I examine the defense of and challenges to scientific authority, and the assertion of community legitimacy in knowledge production. Whereas in the previous chapter, challenges to the scientific orthodoxy emanated from a cross-section of ACB actors, challenges to scientific authority originate mainly from those based in the community. Accordingly, they represent subversive challenges to the dominant structure and suggest a move toward a sub-field of research less constrained by scientific legitimacy.

This chapter is divided into three sections. First, I examine the defence of scientific authority through the relegation of “community” to supportive roles in the production of research and a narrowing of the definition of community capital that creates boundaries around community involvement in research. Second, I outline challenges to scientific authority and the presumed legitimacy of scientists (i.e., those holding academic capital) as “knowers” of the ACB community. Third, community-based researchers and advocates argue for recognition of community legitimacy in the production of research beyond a supportive role. Enacting of self-determination for the ACB community reflects a more expansive definition of community capital. Additionally, I have included a section on critiques raised by community-based participants about ACB leadership and representation, and the intrusion of research into service provision.

7.2 Defending Scientific Authority

This section is concerned with the role of “community” in the production of research. Academic-based participants (not of an ACB identity) in basic/clinical sciences and health sciences took stances that favoured academic researchers as the legitimate producers of knowledge by defining community as secondary to them in the production of research. Although these participants

indicated that community ought to be involved in research, their views suggested that community involvement should largely be shaped by the needs of the scientific enterprise. They, and the government official, were also wary of community input that is informed by politicized perspectives. These perspectives place community in an instrumental role that fits within a scientific paradigm, which also serves to maintain a narrow definition of community capital and protect the legitimacy of academic capital.

Several academic researchers in health sciences and basic/clinical science discussed the production of research in a manner suggesting that research ideas and projects are instigated and conceptualized by academic researchers and brought to the community for their input and involvement. By “community”, they mean the organizations or official gatekeepers that represent the ACB population. Researchers seek out the community for help with study recruitment and ensuring that research tools are “acceptable” to the wider ACB population.

So they gotta be involved, in that sense. And they do provide ...productive, useful, relevant advice and guidance. And then we also have a community advisory board, which is entirely of the community. I suppose, if you're really concerned about acceptability, you should do a pilot and see whether the questions, or even the approach, is acceptable to people chosen at random. I mean, there are various levels. And we're just not that smart, to be able to think, how, you know, somebody's going to understand a given question, just 'cause you've thought it up and you think it's pretty clear. We really do need to involve, you know, the local people. (ANH3)

Accordingly, these participants saw community involvement as advisory in nature and supportive to the researcher. This mode of community involvement is part of an empiricist approach to ensuring quality in research through measures of acceptability and validity. Another researcher also talked about the necessity of community acceptability for the development of biomedical prevention tools (e.g., microbicides, vaccines).

And the only way to apply those things [prevention tools], of course, is at the ground level in terms of community members who are going to be using them. So, you know, the community has to be involved in that dialogue. (ANB15)

The emphasis, for these researchers, is on the community being invited into the research process.

However, whether community is involved at all depends on the scientific literacy required by the different disciplines. Basic sciences, for example, require very specific forms of scientific literacy and, therefore, community involvement is limited, according to one researcher (ANB15).

If a basic scientist has an ACB identity, he or she may have a “natural connection” with the

community, otherwise, community input is generally not sought. Moreover, because the community has limited scientific literacy, they can only be involved in discussions about community-based research priorities and conduct community-based research.

You know, there's no interaction between the academic, necessarily, and anything outside of their lab, in terms of an ethics board, even, let alone the community, because this is all, sort of, pure theoretical work, really. That's one end of the spectrum. And then at the other end of the spectrum is obviously pure community-based research [or] qualitative research on the ground... Clearly there's lot of community-based research being done out there that doesn't need to have somebody who has a clinical or basic science hat [and] they can find out what those priorities are and then do it. *That* work can be done by the community organizations. (ANB15)

This places the legitimacy of community involvement on a continuum—the input of the community is valued only in the least “scientific” domains—and reinforces boundaries between academic researchers and community-based actors. In fact, a researcher expressed misgivings about research being based in the community setting and the community owning research.

...I think the community has to be deeply involved at every level. I've never been against community involvement, but I do have problems with so-called CBR... It's not a necessary or sufficient condition for something to be properly respectful of the community, that the community receive the cheque from, you know, CIHR. I'm not against that, but I personally don't think it's a good idea... I know it's gone long past that, but I think it shouldn't be community-based research, I think I should be community-oriented research. (ANH3)

Conferring “automatic legitimacy” to individuals with an ACB identity, for this researcher, is a “mistake” because they do not necessarily have the expertise to address HIV/AIDS (ANH3). These stances suggest that ownership of research should be in the hands of academic researchers as the “experts” and legitimate producers of knowledge. Moreover, conceptualizing research as *community-oriented* maintains academic control over research compared to *community-based*, which would allow actors in the community to own and produce research.

In addition to demarcating boundaries around community involvement, several researchers and the government official had clear ideas over who could be appropriate (i.e., legitimate) representatives of the ACB community. These participants critiqued the current leadership structure and community representatives who come to research with political “agendas”. For example, one researcher suggested a hierarchical leadership structure with academic-trained actors on the top (ANB14). In this scenario, the onus should be on the development of research experts rather than putting efforts into community consultations.

Well, yeah, don't have too many meetings and think tanks and stuff, to gather... You need to change the dynamics; get some people out in front and saying, 'Let's do this', you know. Identify one or two or three new trainees and say, 'These are the people who we want to take the lead'. Right? Like succession planning. Like who is it that can really, you know, take the baton? Who's the research leader? Or research leaders? Who are the next two or three leaders for the next ten years for HIV research in this area? (ANB14)

Moreover, the participant believed that by bringing a political (e.g., social justice) lens to the setting of research priorities, the existing community leadership is creating "barriers" for research.

But I think there's some strong personalities that have strong-held views that aren't opening up their eyes enough to allow room to move. You could have philosophies and approaches and ways things should be done, but you always have to have your eye on the ball. Things [are] not moving forward because...it doesn't fit the social justice or the anti-oppression framework and those are all important, but there's just so many people that care and talented people, its a barrier that's getting in the way [from] bringing people in. Getting the work done. (ANB14)

Again, this is indicative of a larger empiricist epistemology that aims for a separation of an actor's political values from science and focuses on the accumulation of knowledge over the social justice impact of the scientific process. Therefore, according to this perspective, actors who bring politicized values into research should not hold legitimacy in the field.

A mistrust of actors with political intentions was also present in the distinction between the organized ACB community and the lay population. Several participants expressed suspicion of organizations that come with predefined "issues" and questioned whether they are actually representing "real" community members.

When you're dealing with HIV there's almost two kinds of communities. There's people who work in ASOs and are advocates with an issue, and there are, what I call, real people who are out there just living their lives that [we're] trying to impact on... What I am uncertain of though, with ACB communities, is...we go through this kind of list of things that I'm not a hundred percent sure are the realities of ACB real people. Is this really what all the issues are or is this just what people sitting around the table think the issues are? (GO11)

I'm not sure sometimes, that we got that true community feedback. Because the people that I am seeing at the ground level...those are people...real community members. I would argue that all those community members we have, certainly at that research priority setting kind of level, are above that; [they're] not the community in which these organizations are rooted but they're above that. So we're all meta-community, really. Even if some people are originally from

community and some people not. What you need is to have [an] open way of getting some feedback from true grassroots community. (ANB15)

Echoing this scepticism, two researchers were unconvinced that the community consultation process is useful. According to them, “true” community feedback does not necessarily come from the organized segments of the population (e.g., community advisory boards). For these participants, the onus is on bypassing the “political” voices to get to the broader population.

I'm very sceptical about consulting community without thinking carefully about it for a variety of reasons. Because the community is like, five hundred thousand people. And usually the people who have something strong to say about it are not necessarily representative in either sense, either politically or statistically representative of anybody. (ANH3)

I think the assumption is we know what the community priorities are, because ‘Well, we've got a community advisory board here’, right? But...the people who are involved in that are people in organizations that are community-based. But they are not, you know, the *base*. They are, you know, above that base. (ANB15)

Moreover, the government official believed that organizations representing the ACB population come with their own “agendas” and politics.

[Also] community organizations or social services or health services that are organized around ACB communities [are] very fluid, sort of small groups that come and go, that have other agendas that I don't think any of us are fully aware of. I think there's a lot of stuff that happens because of politics and history from countries of origin that it's just impossible to keep on top of. (GO11)

The demarcation between the mobilized and lay community carries with it two assumptions. One is that “real” community members would not have political values, and a second is that advocates are not “real” community members. It also delegitimizes actors who have mobilized around socio-political issues, thus devaluing how the ACB community has organized around HIV/AIDS.

In summary, certain academic-based participants linked the value of “community” to methodological usefulness. Their perspectives placed community involvement in an advisory capacity to academic researchers, and created boundaries between community and academic spheres. Even with an advisory role, according to these participants, ACB representatives can speak mainly on “community” interests rather than “scientific” ones. Moreover, criticism of the community owning and housing research suggests a reluctance of some researchers to relinquish academic claim over the production of research. There was also a vagueness concerning how the

lay population should actually be represented and scepticism of organized representation and political intentions. Suggestions of a hierarchical leadership structure rooted in research expertise implied that legitimate leadership is based on academic capital rather than community capital. By conceptually separating the lay population from organized community representation, these actors are presenting “real” people as non-political and community organizations as “biased”. This carries an assumption that these two domains are inherently separate and that scientists themselves are not political.

In the following section, ACB actors challenge the belief that the community’s role should only be supportive to academic researchers and the legitimacy that academic researchers bring to the production of knowledge about the ACB population.

7.3 Challenging the Field Structure

I now discuss critiques over how science conceptualizes community representation and involvement in research. These views originate from several different groups of participants. In the first part of this section, ACB academic researchers and community-based actors argue that they, and the larger ACB population, are brought into research in a tokenistic manner. Their critiques speak to challenges of the definition of community capital according to the scientific orthodoxy. Next, community-based participants highlight the “bias of the expert” (Bishop 2007), which is a critique of the assumed legitimacy scientists are afforded for “knowing” the world. In the remainder of the section, community-based advocates expand on these critiques by linking tokenism to the dominance of academic legitimacy and arguing that these dynamics lead to exploitation and unequal power relations in the research process. These advocates are enacting “resistant capital” (Yosso 2005) as they challenge systems of domination in the field.

Most ACB participants challenged conventional scientific approaches to community involvement in research as they raised concerns about symbolic representation on research teams, cursory community engagement in the research process, and a lack of recognition of community-based actors’ skills and capabilities. Among several ACB researchers, there was a feeling that White researchers come to them because they need to show they have representation from their “target population” on their grant applications. As an academic researcher argued, this type of “non-exclusion”, rather than actual inclusion, equates to community involvement in name only (AAH28). Another researcher recounted experiences of being approached after a study was

already conceived. The participant explained that it impossible to contribute when you are brought into a project after it has already been conceptualized and designed.

I feel like a lot of times people want me to be on their stuff, because I'm Black and they need representation. And they really could care less about what I have to say [or] offer. They just need me to show up to a meeting, and be able to put my name on the paper—‘Can you send me your photo and a short bio?’ So that someone can say, ‘Oh, okay, [AAH36] is on the study.’ So I get a lot of that. And I don't like people coming in with studies that are already like, written and funded and about to launch and say ‘Hey, can you sign on?’ (AAH36).

However, because researchers need publications and research grants in order to “survive” in academia, they agree to “sign on” to the project and then have to deal with the challenges that come with tokenistic involvement (AAH36).

The majority of claims about tokenism, however, came from actors based in the community setting (i.e., community-based researchers and advocates). These participants spoke about experiences with academic researchers who ask for letters of support from community organizations without discussing the research or allowing for actual input. Often, as this advocate explains, they are just looking for access to the wider ACB population.

Rather than having an ongoing conversation between researchers and community, there is just a desire for researchers to access community members for their research. Because you get a lot of requests from people you've never heard of... ‘Can I have a letter of support for this research?’ I have no idea who you are. I've never been involved in this and all I have is a synopsis of your research. And I'm expected to support this without any further involvement. And oftentimes what happens is—if you, ‘Yes, I'll sign the letter’, you never hear from them again. (CA20)

According to other community-based participants, researchers come to the community with fully formed research ideas rather than after having consulted with the community (CA13). Like ACB academic researchers, a community-based researcher claimed that it is common for academic researchers to look for ACB individuals to “rubber stamp” their research questions so they can fulfill grant requirements (CBR1). This participant also recounted an experience of working with academic researchers who would not change their original ideas, regardless of what the community partners had to say.

They have their way [which] is what they think should work and they were so resistant to proposals around how communities could actually fit within the model they were actually proposing. And they didn't budge. No, they didn't budge. They approached *us*; they were interested in working with *us*. But when we proposed a

model for working with them, they were not happy. They wanted to do it their own way. (CBR1)

Furthermore, the community researcher argued that advisory committees can also be tokenistic because they are not allowed to be involved in the actual decision-making.

Researchers think that if you have an advisory committee, you have involved the community. That's not; an advisory committee is an advisory committee. You can advise me and I can chose to disregard your advice. So, an advisory committee does not involve people in decision-making [which is] made in the [research] teams. (CBR1)

For one advocate, this nominal involvement of community translates to mere community-*involved*, rather than community-*based*, research (CA20).

Critiques about tokenism were part of a larger concern over the lack of legitimacy afforded to community actors as knowledge producers. As one community-based researcher maintained, only academic researchers are considered “*true* knowledge generators” (CBR23). Community-based participants contended that they are seen as unskilled and, therefore, can only support academic researchers. Moreover, academic researchers “look down” on community-based actors, even though they cannot do their research without the community’s cooperation and input (CA13). This advocate also spoke of the frustration over attempts to get research funded at a community level; even with appropriate post-graduate education, it is almost impossible to be recognized as a principal investigator or to lead research projects because funding guidelines require academic partnerships (CA13). This implies that only researchers from academia can generate knowledge.

They said ‘No, community members cannot be co-PI’s on a CIHR operational grant. It’s only the community based research [stream they can apply to]’. So that tells you who is valued as a knowledge generator. So, ‘Researchers from the community—you cannot generate knowledge that is credible’. I guess that’s what they’re saying—it’s only researchers from academia who can do that. (CBR1)

One community advocate mused that it was “ironic” that funding bodies insist on academic affiliation, even on *community-based* research grants (CA20). This translates into a “non-recognition” of community and true community-based research, and sends the message that it takes academia to “validate” research and make it “credible” (CA20). This requirement of “sponsorship” by an academic “expert” creates an unequal partnership, according to another advocate.

It's not a partnership. They must have the quote unquote 'expert' and they must have the history of having gotten funding. It's a lack of trust of the community in terms of 'Well they're not capable of doing research unless it's attached to an academic institution'. (CA32)

These community-based actors are critical of the automatic legitimacy conferred to academic researchers and challenge the resulting authority over the knowledge production process.

This challenging continued with a questioning of the presumed superiority that comes with academic legitimacy. Several community advocates disputed that academic researchers are "experts" about the ACB population. From this standpoint, academic status does not ensure an understanding of the community. These participants claimed that academic-based researchers often do not have an interest in, or understanding of, the ACB population. A community advocate recounted a conversation with an academic researcher who used their academic status to argue that scientific analysis is superior to "experience".

They decided that academic knowledge, as a PhD, belongs in this particular place, and I don't have that thing. It wasn't said in a way that made any sense because one can have a PhD in anything. It doesn't necessarily mean that one's opinion on the particular thing that we're talking about would be relevant. (CA26)

According to this advocate, there is an assumption that community members do not understand what is happening in their communities and need academic scientists to tell them. However, the participant claimed that being a member of the community actually gives you an experiential understanding of what is "really" happening and, therefore, legitimacy for making knowledge claims.

I was saying 'Well, I don't think what you're saying makes sense. That's not how it's understood. That's not how relationships occur. They occur like this.' And this [person] tried to tell me that 'cause [this person] studies that data, that that's not how they occur... I know lots of Black folks ...hundreds, thousands, actually. My sample size is so big. And that's part of what strikes me, is that there's an assumption that I don't know things. I actually said, like, 'My sample size, in relation to the data, outweighs anything you've ever gathered'. (CA26)

Another community advocate also questioned the legitimacy of academic-based researchers by arguing that any individual with a university degree can do research.

So everybody is a researcher, in one way or another way. I don't get it, the differentiation between human beings, saying 'Okay, you can not do that because you don't have the background'. To me, it's discriminatory... Whatever you're [the researcher] going to come up [with], is not yours. It's coming from the community. It's coming from the people you interviewed. It's coming, the idea

and the response, is coming from them. You just gathered the response and then make it a document. Doesn't mean you are better than them. If they are not there, you will not be able to do that [research]. Let me put it this way...after you pass the bachelor's degree nobody cannot say to you that you don't know how to do research. (CA13)

From this perspective, to confer legitimacy only to institutionally sanctioned researchers is to deny the contribution of community members in the knowledge creation process.

Community-based participants also questioned the quality of knowledge produced by academic researchers. Interestingly, these critiques extended to the work of both ACB and White academic researchers. According to these advocates and community-based researchers, the lack of understanding of the ACB population's daily struggles, combined with the need to shape research through certain scientific lenses, leads academic researchers to create "stories" from the data that only make sense to them. Moreover, although the research itself might not resonate with community participants, they still provide answers according to what they think researchers want to hear. Nonetheless, the researcher claims to have superior knowledge of the community.

Well the questions are set at the academic level. They've determined that this is how we're gonna ask it. It might make sense, it might not make sense, but from a theoretical level, you can only ask this question in this particular way. And so go ahead and ask it, and you ask it and people tell you whatever right? I've told you that it doesn't make sense to ask this question, but you still go ahead and ask and you get an answer, but what does that mean? So then the same person who pushed for that question goes back and looks at the answer and then makes up a story and 'This is what we've found in those people' and 'By the way, I understand them more than [you]'. (CBR25)

You [the academic researcher] design it [the study]. Because this is the way you want the things to be done. But it's not their [community's] point of view. They will answer your question, because that's what you want them to answer. They will give you an answer, but you cannot know if this is truth - coming from the heart. Or they just give you an answer for you to go away. (CA13)

These participants took issue specifically with the legitimacy afforded to White academic researchers. Because are generally not present in ACB communities, they do not understand social and cultural issues unique to the population or have an interest in their "well-being", claimed one community-based researcher (CBR25). Furthermore, their connection to ACB communities generally does not go beyond one partnership with an AIDS service organization or with an ACB researcher (CBR25). However, the critiques over presumed academic legitimacy also extended to ACB researchers who are included on research grants as representatives of the

ACB population. One advocate maintained that ACB academics do not always know what is happening “on-the-ground” and, thus, are not “community” (CA20). In essence, these community-based participants are arguing that academic credentials, no matter who has them, does not necessarily translate into appropriate knowledge about the ACB population or the production of “good science”.

Community-based actors also argued that the dominance of academic legitimacy leads to exploitation and power imbalances on research teams and in the research process. Accordingly, there is a mistrust of the “research complex” at the community level (CBR38). For example, explained one community-based researcher, community-based actors can initiate a study but academic researchers are almost always the lead investigator and hold the research funds (CBR38). Yet, although academics have the “most to gain” or benefit from the research, they contribute the least to the teams (CBR38). This participant questioned how principal investigators could “put their name” on a study and not be “at the table”, especially as these unequal dynamics fuel tensions on research teams and negatively affect the implementation of the studies. Another community-based researcher discussed how unequal relations create feelings of being “used”, both for ACB researchers and lay community members.

And to a greater extent I think some people might find it as, ‘You’re using me’, you know? ‘It was convenient to have me as part of the partnership but I virtually have no role’. But from a community perspective it’s sort of like, ‘They’re using us...they’re taking advantage of us’ and ‘What is this good for anyway?’ (CBR25)

However, as argued by an advocate, if you speak up as a community “expert” and refuse to be exploited, researchers no longer come to you.

Well, I used to be able to give them all the information they need, until I got smart. I said ‘Okay, I am the expert’, ‘I am the person who has the experience. If you want my information, I will be willing to share it with you. However, I need to know how is that going to benefit my community’. And so, when I started responding to people that way, they're no longer coming to me, because I'm not giving them information without knowing. Cause I'm no longer the novice, right? I'm not willing to give it away for free anymore. Otherwise, why would I give you all this information so you can go and write a report and keep all that money in your pocket? (CA32)

These critiques suggest a deep mistrust of academic researchers and the power dynamics that are shaped and perpetuated by the dominance of scientific legitimacy.

Participants from the community looked to larger forms of racial domination to explain field-specific power dynamics and why ACB actors fail to attain legitimacy. Racism and oppression limit the value placed on community involvement in research and can lead to uncomfortable dynamics on research teams, claimed one advocate.

Racism is something that we face on a daily [basis]. If you think of the different forms of discrimination and oppression we face, it limits our involvement in research, especially when you have research teams where you don't have people you can identify with. And you find yourself questioning... And depending on how welcoming people are, or if they recognize where you're coming from and they try to accommodate you, or not, you may feel really uncomfortable. (CA20)

Another community advocate took issue with White researchers who try to “deracialize” themselves by “pretending that they're not White” and that there is not a “White power dynamic”(CA26). Furthermore, systemic racism leads to “erroneous assumptions” about the capacities or skills of ACB actors (CA20). These inequities are compounded when White researchers provide opportunities for others in their academic networks rather than partnering with ACB community members (CA26). A community researcher spoke with frustration about the lack of acknowledgment and discussion concerning racial inequities in the HIV sector.

You bring those issues forward and, yeah, you can be here and that's about it...but so then what? In that process the whole race analysis [is] missing, like completely. So for me it feels like sometimes you make so much noise that people say, well, okay, this person has made so much noise, put them at the table. Let them be there and we're just gonna [put them at the table] and then the conversation is just gonna happen as if you're not sitting there. (CBR25)

Community-based participants are linking the cursory involvement of ACB community members in research to issues of equity and racism in the wider HIV/AIDS sector and how these shape the research process and partnerships. In effect, they are displaying resistant capital as they take oppositional stances to, and verbalize critiques of, racial domination and the existing power structure in the field (Yosso 2005).

In sum, ACB actors argued against a devaluing of “community” in the production of research. They claim that although the ACB community is involved in research “on paper”, in practice, this often extends to symbolic representation only. Community-based participants challenged the assumption that academics are the “true” knowledge generators and questioned the presumed superiority of academic “experts” over community-based actors for understanding the ACB population. Moreover, they claimed that the control that academic researchers maintain over the

production of knowledge translates into *community-involved* research, which is not the same as community-based actors being knowledge producers in their own right.

These critiques from community-based researchers and advocates represent a challenge to the existing structure of the field and the dominance of academic legitimacy as a form of scientific capital. As discussed in the next section, community-based researchers and advocates are also attempting to increase their ownership over the production of ACB research and place more value on community capital as they struggle to redefine the field.

7.4 Redefining the Field with Community Capital

I now explore how ACB actors conceptualize community capital and its legitimacy. At the core of these conceptualizations are claims of self-determination and aspirations to be producers of knowledge about the ACB population. ACB participants also support and encourage the involvement of, and accountability to, the wider ACB population. This is an enactment of community social capital as these actors attempt to engage with the ACB population to distribute the benefits that may come from research (Yosso 2005). However, actors in community organizations, specifically, are fighting for more control and ownership over defining research priorities for the ACB communities they serve. Although this may involve partnering with ACB academic researchers, it also represents a direct challenge to the dominance of academic researchers in the field and a redefinition of the field's structure. In essence, these community-based researchers and advocates are attempting to move the definition of community capital away from symbolic representation based ACB identity to a wider conceptualization of "community" and an acknowledgment of community-based actors as legitimate producers of knowledge.

Both academic- and community-based ACB participants argued that "co-production" of research by ACB actors should be a minimal requirement in the field. As part of this co-production, the ACB community, either as represented by ACB researchers, advocates, or lay members, should be "meaningfully" involved in every step of the research process and occupy decision-making roles. For example, according to several participants, ACB researchers in both academic and community settings should be co-investigators on grants, and lay community members should be included as productive contributors to the actual study implementation (e.g., data analysis) and the translation of research into action (AAB30; AAH36; CBR1). Accordingly, researchers could

tap into the “front-line” community sector as “repositories of expert, on-the-ground knowledge” (AAS6). However, argued an advocate, researchers must actually value community input.

If a community member is there on the planning committee or something, if they give suggestions, they have to be valued, because that's exactly what's happening. Especially if the person is working day in, day out, with the community, they understand what are the issues. (CA37)

In addition to breaking down the “academic-community divide” (AAB30), meaningful community involvement, then, means legitimizing community-based knowledge.

Accountability to the wider population was a common theme among ACB participants. These actors are moving beyond a distinction between “real” community (i.e., the lay community) and formal community organizations to conceptualize a relational community engagement process involving ongoing dialogues and community consultation. Several community researchers and advocates indicated the need to have ongoing consultations with both lay individuals and service providers when defining research agendas. This involves using a range of consultative methodologies that are suitable to the communities to ascertain their needs and interests, suggested a community researcher (CBR23). Furthermore, rather than experts making decisions about the research needs of the ACB population, a community advocate argued that capacity building around research is needed for *lay* ACB actors. This would allow the wider population to fully participate in these dialogues.

People need a place to participate; it can't just be a conversation of experts, because it's something that affects the populace. We have to build the capacity of the community to have the conversation on their own terms. So they need to be in [the] room. (CA26)

Accountability to ACB communities also means taking research out of the academic “tower” by cultivating a dialectic relationship between academia and community, suggested an academic researcher (AAS6). As the participant argued, the larger community should have a role in determining whether or not research is valuable.

[The community should have] real opportunities to contribute to the research agenda and to respond to it... And really making them part of the audience that determines whether it's valuable all through the process. Like, they should be, they're stakeholders, obviously, right? So, there should be a way, to have a stake and a say in what are the questions that we think are valuable questions to pursue. (AAS6)

Not properly consulting the larger community then results in research that does not meet the needs of the ACB population. For example, a community-based researcher claimed that there is a general belief that lay community members are only interested in social research. However at a service level, community members have vocalized that they *are* interested in basic and clinical aspects of HIV, but are not given the opportunity to be involved in shaping these research priorities (CBR1).

To aid in preparing communities to participate in research discussions, several participants felt it is necessary to create opportunities and gain institutional support for mobilization among diverse community sub-populations (CBR25; AAH28). Because community-based research requires an “activist” component, one academic research suggested that community partners need to be empowered enough to “go out there” and speak about difficult issues (AAH28). If the community is not yet mobilized, argued a community researcher, it is necessary to tap into the “history of organizing” in the ACB population and utilize existing political resources (CBR25). Community mobilization and accountability are, therefore, seen as valued and legitimate components of research production, thus expanding the definition of community capital. Together, the valuing of community input and engagement, and emphasis on the mobilization of the larger ACB population, prioritizes the “collective” over the self (Dei et al. 2004). They also represent a building of community social capital (Yosso 2005) as community members make use of networks to navigate the research field, utilize existing scientific literacy in the community, and bring the potential benefits back to the ACB population.

At the core of these assertions of community legitimacy were principles of self-determination as a way to secure the power to decide the course of action for the community (Collins 1998). Community-based participants discussed formalized mechanisms for influencing and taking ownership over research about the ACB community. One community advocate proposed a new community organization that could act as a central repository for research about the ACB population to “pass through” (CA37). This organization could also develop mechanisms for protecting the larger ACB population in relation to participation in HIV-related research and reducing the amount of research done on ACB communities (CA37). The Canadian Aboriginal AIDS Network, according to a community-based researcher, is an ideal model because of their clear mandate to protect the Aboriginal community and their formal guidelines concerning the production of research and community ownership over the resulting knowledge (CBR23).

Similar terms of reference would help ACB organizations and researchers determine the circumstances in which the “community” should be involved in research and what mechanisms should be in place. Guidelines and partnership agreements, as an advocate explains, would help provide support to those navigating the various community roles (e.g., partner, advisor, investigator), bring legitimacy to their decisions about participating in research, and support their expectations of academic researchers.

[Guidelines] could provide some direction as to how we should proceed and how to make those decisions. And that provides you with clarity as well. Yeah. And that also gives you some leverage. ‘This is what’s [our] policy is if we’re going to be involved in this initiative - this is what we need or this is what it’s going to look like’. *And*, being able to walk away. (CA20)

For a community-based researcher, terms of reference could include measures of credibility based on *community* definitions of standards (CBR23). Furthermore, as an advocate suggested, as part of a larger commitment to anti-racism and anti-oppression, ACB organizations could help to develop guiding principles that could also be used in the ethics approval process in universities (CA20). This would bring social justice values formally into the production of research. In practice, these self-determination efforts could translate into actors having more power to determine the research agenda and potentially defining a “sub-field” of research not dominated by academic science’s principles or actors.

Self-determination also means that actors from the ACB community would have a say in what roles *they* want to play in research (CBR1). This is in contrast to being brought into research based on the researcher’s needs, explained an advocate.

Some people would rather be involved maybe a little bit later, through the process ... or data collection tool development or analysis, or developing proposals. Different people want to do different things: ‘I want to do interviews’ or ‘I want to do recruitment’ or ‘KTE is where I want to be involved.’ Allowing people to identify, self identify or self determine how they are involved. (CA20)

According to several community researchers, having the kind of independence over the research process needed to (self) determine the community’s role requires alliances with academic researchers who prioritize the “needs” of ACB communities (CBR1; CBR23). An advocate suggested building a pool of “credible” and “recognized” researchers as determined by community standards (CA20). Moreover, these participants placed importance on building support and professional social networks with these ACB researchers. For example, a community-based researcher suggested regular informal social networking events for Black

professionals to share and mentor one another (CBR23). For an academic researcher, having the encouragement and support of peers is invaluable because it can provide validation of their experiences as ACB researchers (AAH28). An advocate also suggested that senior researchers could support “upcoming” researchers to help them navigate the “politics” around research (CA37). Through encouraging social connections among ACB professionals, these participants are building and utilizing community social capital.

To summarize, ACB participants valued the involvement of “community” in research, specifically calling for a range of ACB actors to be included as co-producers. For example, ACB academic- and community-based researchers and advocates should be included as investigators on research teams and a scientifically literate lay population could be involved in discussions about the setting of research agendas for ACB communities. However, participants based in community organizations were particularly invested in mechanisms of self-determination. These mechanisms could lead to the community-based sector having more control over the conceptualization, implementation, and distribution of research, and ensuring that research reflects larger community and political values. This takes the setting of the research agenda beyond conversations between “experts” and ensures accountability to, and actual engagement with, the broader ACB population.

Despite these calls for self-determination, there was also some hesitance among ACB participants about the increasingly influential role of research in community-based organizations and concerns over how the ACB community is represented in research. The following section is a brief overview of these issues.

7.5 Tensions Within the ACB Community

There were several issues raised by ACB participants that were suggestive of other tensions and struggles in the field. Although there was not enough data to expand fully on the issues, they offer insights into challenges to a scientific doxa, and hierarchical struggles within the ACB community. In the first section, I examine reservations community actors have over the growing importance of research in service provision. Next, I present concerns raised about the current representation of the ACB community, including a lack of diversity in community research leadership and leadership hierarchies.

7.5.1 Resisting Research: Research as a Strain on Community Organizations

Several community-based researchers and advocates were concerned with the overshadowing of service provision work by research in community-based organizations. Moreover, although there appears to be an overall drive for self-determination and ownership of research by the community, not all ACB actors agreed that research should be housed and conducted in community-based settings. This resistance suggests tensions in the ACB community sector over the role of research in community-based organizations and service provision.

Overall, these community-based researchers and advocates spoke about research as a means to an end. In other words, the only reason to be involved in research is to address the needs of clients or the communities they serve. A community advocate explicitly stated that it is only necessary to be involved in research if there is an identified “gap” or a “barrier” in service provision (CA13). Similarly, for a community-based researcher, being involved in research is only to help the organization’s target population.

I think people have to recognize that some of us get involved in research for a specific reason. It's because I am looking for better ways to do my work! And to meet the needs of the population that I am working with. (CBR1)

However, if these needs are overshadowed by the demands of research, then the cost to the community organization is too high. Because of an increasing “expectation” from funding agencies to involve community in research without the concomitant infrastructure support, there is an added strain on service organizations that face challenges balancing day-to-day service provision with involvement in research activities.

But they [funders] don't provide the infrastructure support required for community-based organizations to participate. What juggling do they have to do, to be able to participate in research? And you know, those huge numbers of requests we get from researchers to participate in their research? Everybody is looking for a piece of the community organizations in their work. But I'm sure there are situations when people say, ‘You know what? Enough is enough. I can't take anymore.’ (CBR1)

A community advocate discussed the difficulties that frontline organizations face trying to find the time to even think about research when service provision is priority.

My question is, why are the researchers not coming from the communities?
... I can tell you why - it's difficult to do that. Because the way the work is constructed is you're so busy at the front end, running around trying to get it done,

that many people don't know how to step away and figure out how to do it different. (CA26)

These “competing priorities” are compounded because research timelines are often inflexible, according to one advocate (CA20). Another spoke about the lack of clarity around boundaries between being a service provider and researcher (CA37). For example, clients do not always understand the difference between interviews and other support work, and may come to you (as a worker in the organization) even after the study is closed. Furthermore, because research has to be done during work hours, other service provision responsibilities are compromised (CA37).

These critiques extended to a perceived absence of institutional resources to support volunteers and workers. Several community-based researchers spoke at length about difficult working conditions for community workers, peer researchers, and volunteers involved in research. According to one participant, many of these ACB community members are “overworked and underpaid” and just “sick and tired” of research (CBR38). Another community-based researcher likened the involvement of people living with HIV/AIDS in research to “Uncle Tom” figures because researchers use them to show the success of a research project.

I've talked to a peer research assistant and he says sometimes he feels subordinated, where you know, they put him up there and they put him on a pedestal—‘Oh look, we have a peer research assistant. You - talk. Talk, talk.’ Where you're an example of how good we're [the researcher] doing. And yet when the research is over, you're just left. And then your people look at you differently. (CBR23)

Moreover, a community advocate claimed that community volunteers do not gain from their contribution, even though the researchers get what they need from them (CA37).

With these difficulties, service providers find it hard to see the benefit of participating in research projects beyond pointing to a publication, according to a community-based researcher (CBR38). Therefore, this participant argued that because of the strain on personnel and the lack of direct benefit, community organizations should support studies and partner with researchers, rather than conduct research.

As more and more of these organizations take on research as an agenda, I think that there are a lot more capacity issues that aren't being addressed. And I don't think that agencies have the capacity to support a research person, to support research projects... So I think that, unless you're committed to really developing a research portfolio in your agency, I don't think piecemeal is going to do it. (CBR38)

Another community-based researcher maintained that organizations that represent and support the ACB population in research efforts should not also be expected to conduct research. Instead, their mandate should be to facilitate alliances, identify organizations that actually conduct the research, and partner with these organizations.

I think research bodies that support research should be separate from research bodies that conduct research. I think ACCHO should support research for African, Caribbean, Black communities, or for the Africa diaspora, but I don't think they should conduct it. I think it's better not to mix your agenda. And I think if your agenda is to support research for a particular group, that's what you should do. (CBR23)

Furthermore, there was doubt concerning whether new research is necessary to proceed with the provision of services. Several participants argued that there should be more emphasis on taking stock of what is already known instead of generating more research. Rather than continuing to do the same kinds of research, researchers should reflect on what has been studied already, argued a community advocate.

I think it's better to take a look at it [each proposed research project]. You guys [that] are researchers say, 'Okay, now we are doing research on ABCD - [lots of] research has been done on that. What next? What can we do better to overcome [HIV]?' (CA13)

A community-based researcher also flagged the need to help service providers navigate “information overload” from research, rather than generating more research that does not translate easily for community-based workers (CBR38).

In summary, as community-based organizations become more involved in research because of expectations from funders and to meet the needs of their clients, community-based researchers and advocates struggle to balance research and service provision. This has led to uncertainty over how involved the community should be in the actual practice of research and resentment over the requirement for participation in research studies without the corresponding infrastructure support. These critiques suggest challenges to the doxa of scientism that fuels the growing demand to produce research as a basis for practice. As such, it is reflective of a larger struggle on the part of community organizations to maintain their focus on providing services to their communities without getting subsumed into the larger field of science.

7.5.2 Challenging Representation and Leadership

Finally, several ACB participants raised concerns about the lack of representation of ACB sub-populations (e.g., ethnicities, nationalities) on research projects, and a dominance of particular groups or actors in community leadership positions. These concerns suggest struggles within the ACB community over the legitimacy to speak on behalf of the ACB population. For example, several community-based participants claimed there is a hierarchy within the ACB community concerning representation on research teams. They argued that the same ACB researchers get funded repeatedly, which has a carry on effect—community-based projects must have those representatives on board to get funded.

Well [the time that I've been in research] it's the same people that get funded. It's the same people that get grants. If you're not in that circle of people, you don't get a grant. So, if you don't have those people on board, does it mean that we're not going to get funding as a community? (CA37)

I think they are trying to put together these review teams that they are representative of the community [but] they are sort of like 'the big bosses', so it's still almost like recreating this hierarchy because it's the same peers, the same community researchers. And so I don't really know how different it's going to be [in the future]. (CBR38)

Funders attempt to have community representation, claim these participants, but end up reproducing existing hierarchies and funding the same kind of research. There was also a critique about the dominance of ACCHO as a voice of the ACB community. An academic researcher felt that ACCHO does not, and can not, represent all of the ACB population (AAH9). Instead, community representation should be more “fluid” and “reborn”, based on the needs of different research projects (AAH9). However, because ACCHO is widely recognized as the umbrella organization for ACB communities, the perspectives and issues they raise are perceived to be representative of the wider ACB population.

When the federal government, or the municipal or the provincial, wants some direction, they actually just move to certain connections that are already established [ACCHO]. And because they use those connections, you have the same thing(s) moving forward as being the priority issues. So what becomes a priority issue may not actually be for everybody, but just from what those folks want. (AAH9)

This researcher also felt that although ACCHO is an important link to ACB communities, it acts as a gatekeeper and creates an exclusionary culture. In this sense, if “you are in you are in”, but if you are not favoured by the organization, you are “on your own” (AAH9). The participant

claimed that ACCHO may not be representative of the “real” ACB community, but activist politics are still put forth as community-held values, rather than just the opinions of key leaders in the community (AAH9).

There was also a critique concerning a perceived lack of attention to, and representation of, ACB sub-populations. A community-based researcher described advocacy efforts and community leadership as generally reflective of first generation African and Caribbean populations who have relocated to Canada. However, Black Canadians (i.e., second generation or older) and other ethnic minority groups from the African Diaspora are not being represented.

And right now, we do have the voices of Africans and Caribbean, but I don't think we have the voices of Black Canadians yet... Also, we have to look at, are we looking at race or ethnicity? If we're looking at ethnicity, let's be honest and open it up and look at people who are African South Asian, African Asian, African White. If we're looking at race, then we should say 'African Caribbean Blacks who are from the African Diaspora' or 'African Diaspora', let's just call it that. (CBR23)

For this participant, once these distinctions are made and the community has defined itself, the next step is to have them represented in the community's “spheres of power” (CBR23).

To summarize, some ACB participants raised concerns over current community representation in HIV/AIDS research. These concerns extended to related claims that different sub-groups and perspectives were not being represented at a leadership level or through advocacy efforts. There were also critiques of existing hierarchies within the community and how these might be excluding other community members from leading or becoming involved in research. These tensions point to struggles within the wider ACB community over who can define HIV/AIDS research for the community and which perspectives are being represented.

7.6 Conclusion

In this chapter, participants defended and challenged the structure of the field of ACB HIV/AIDS research through assertions of scientific and community legitimacy. Although scientific and community capital are the structuring components of the field, how these play out in practice is not equal. Participants acknowledged that a certain amount of scientific capital is needed for meaningful participation, and indeed success, in the field. However the extent to which scientific legitimacy should be required, is disputed. A large part of this dispute concerns academic legitimacy. Community-based participants argued that academic legitimacy is prioritized in a

manner that excludes non-academic researchers or community advocates from being considered legitimate producers of knowledge.

Furthermore, although all participants agreed that ACB actors should be involved in HIV/AIDS research about the ACB population, how this involvement was conceptualized varied based on the social location of participants. For some academic-based participants, community involvement was generally discussed as just that—community involvement, a necessary and useful component of the research process where the community is brought *into* the process. This represents the academic model of researchers needing to own and produce research in order to demonstrate scientific legitimacy (i.e., gain scientific capital). Moreover, there was an overall reluctance on the part of several non-ACB academic participants to engage in political discourses around HIV/AIDS research. These participants took stances that supported the circumnavigation around politicized community organizations or mobilized groups. ACB participants, on the other hand, generally expressed a desire for *more* mobilization and an expansion of “community” to include wider participation and consultation, thus increasing the value and definition of community capital beyond ACB identity. Yet, concerns among some ACB participants over hierarchies in leadership indicated tensions and struggles around defining this representation.

Overall, ACB participants shared a focus on redefining the field in a way that is more equitable for the wider ACB population. However, there were differences in how they challenged the symbolic order of the field. Academic-based ACB participants tended to critique the structure of the field in relation to issues of equity and fairness, yet they are still invested in the larger scientific field through their position within it. Some community-based participants, on the other hand, expressed a desire to own research at a community level. If these actors gain the legitimacy and power to define the research agenda according to community values and principles, they would contribute to changes in the field’s structure. Although this is most likely too neat of a distinction—ACB academics are also trying to impose a definition of the field that represents political principles, and community-based researchers also represent principles from the scientific field when carrying out research—it does help to clarify how these struggles manifest in field dynamics. For example, in addition to fighting for more recognition of community values and political aims, community-based actors can be seen as attempting to gain recognition of *research* legitimacy. Research, in this case, is a methodological tool stripped of particular scientific epistemologies and infused with socio-political epistemologies and aims. Overall, this

would result in decreasing the scientific autonomy of the ACB HIV/AIDS field of research. Alternatively, it could lead to the beginning stages of a new sub-field of research that is based on a wider definition of community-oriented capital and less constrained by dominant empiricist principles that oppose political values in research.

In the following chapter, I revisit the initial research questions by considering the nature of the ACB HIV/AIDS research field, the struggles within it, and the implications of these dynamics for the reproduction of, or disruption to, the social order.

Chapter 8 Discussion and Conclusion

Science... is politics by other means. (Latour 1993:229)

Health is politics by other means. (Nelson 2011:ix)

8.1 Introduction

In this research, I have used Bourdieusian theory to understand field-level struggles over the production of research about HIV/AIDS in Ontario's African, Caribbean, and Black communities. To understand the dynamics of this conflict, I compared the stances and epistemological perspectives of actors located in various social positions in the field. In this chapter, I discuss my findings in relation to the study's key questions concerning the nature of the field and the dynamics of its struggles. I argue that the latter represent a conflict over the legitimate definition and organizing principles of the field. I then outline the consequences of these struggles for the reproduction or disruption of the social order. Next, I consider my findings in light of their contribution to knowledge about ACB resistance and activist efforts. I then situate my research within politically-oriented scholarship in the sociology of science. Finally, I reflect on the study's limitations and the challenges of employing a Bourdieusian lens, and suggest future directions for research.

8.2 What is the Nature of the ACB HIV/AIDS Research Field?

I have argued that the domain of ACB HIV/AIDS research is a scientific field that is made up of interlocking fields, including academic disciplines, the community-based sector, and the bureaucratic field, and is nested within a larger domain of HIV/AIDS research. In my review of ACB HIV/AIDS research (Chapter 4), I found that academic-based researchers in various scientific disciplines led the majority of research studies. Although the breadth of research was mainly concerned with socio-behavioural and community-based topics, a strong natural sciences presence was evident through the participation of researchers from these disciplines and the large allocation of funding to biomedical-oriented research. Regardless of which discipline holds a dominant position in the field, an actor's success is largely dependent on the possession of scientific capital. Moreover, the field's doxa assumes a scientific view of the world—the “problem” of HIV/AIDS can be solved with research, as a tool of science, because

science is the way to “know” the world. In other words, science produces the knowledge we need in order to act. The scientific orthodoxy, therefore, supports scientists as the legitimate knowledge producers.

Although the field is dominated by a scientific orthodoxy undergirded by scientific capital, it is interlinked with other non-scientific fields. Capital, therefore, is also drawn from a part of the political field—the community-based sector. Of particular importance is community capital, represented by ACB identity and/or holding a representative position in the community. Community capital allows those with less scientific capital to participate in the field of HIV/AIDS research. For example, research teams may consist of knowledge users (e.g., community advocates), as well as academic researchers. Because community capital is valued in the field, those who possess it are accorded a measure of legitimacy to speak about the ACB population. This can be seen as a shift in typical inclusion criteria for fields of science (Albert and Kleinman 2011) and is reflective of the influence of early AIDS activism on the production of science. Furthermore, because the field has relatively low scientific autonomy, its definition is open to challenges from non-scientific field actors.

As an interlocking field, structural positions are representative of actors’ different “home” fields (social science disciplines, the community-based sector, etc.) and are situated at varying degrees of distance from the larger scientific field. Academic researchers are “full” participants in the latter because their home fields fall under its umbrella. Community-based researchers, on the other hand, are primarily located in the community-based sector. They are brought into the field of science through partnering with academic researchers and producing community-based research, which is often subject to scientific governing practices through funding agencies. Although they are engaging in the practice of research, they generally do not hold academic positions in the scientific field. Community advocates are more peripherally located as knowledge users and, because they generally do not produce research, are not full participants in the scientific field. Government officials participate in the production of research when they provide funding and/or are included as knowledge users on research teams, but they are not full participants in either the community-based sector or the field of science.

Understanding actors’ positions in relation to the larger scientific field helps with understanding dynamics of orthodoxy or heterodoxy in the field of ACB HIV/AIDS research. That is, an actor’s

position speaks to the extent to which s/he may embrace or resist the field's doxa. For example, academic-based researchers, regardless of their discipline, are more likely to share views that are aligned with scientism and the importance of scientific capital. Actors who straddle fields, such as community-based researchers, may be aligned with both the political field *and* field of science. They, therefore, are attempting to maintain “dual citizenship” in these fields (Panofsky 2011). Accordingly, they may take conflicting stances that support scientism, but resist scientific authority. Community advocates, as actors from a field located on the periphery of science, will resist the doxa of scientism and dominance of scientific authority when they conflict with the governing practices and “political” doxa of their home field (i.e., the politicized community-based sector).

Given its interlocking nature, with some actors occupying peripheral positions and others maintaining “dual citizenship” across different fields, it is not surprising that the field of ACB HIV/AIDS research has heterodox dynamics—a discursive exchange consisting of competing beliefs about the doxa and social order. These dynamics manifest in struggles over the definition of the field.

8.3 What are the Struggles Over?

According to Bourdieu (2004:64), struggles in a field are hierarchically organized, with those in dominant positions defending a structure “that is favourable to their interests because they occupy the dominant positions within it”. Holders of the dominant forms of capital will, therefore, promote those forms of capital as legitimate. However, all actors make epistemological choices concerning the definition of legitimate research; these stances signal their position within the field. Oppositional dynamics arise when actors in different positions assert their respective epistemological stances on the field.

In the ACB HIV/AIDS research field, certain academic researchers worked to preserve a dominant definition of HIV/AIDS research based on empiricist principles. Conversely, community-based actors attempted to subvert this definition by challenging these principles and

offering alternatives based on community and political values.⁴⁸ These divergent orientations lead to different aspirational goals—“scientific” goals concerned with the control and management of populations (Collins 1998:114) versus socio-political goals focussed on the empowerment of the ACB population and improvement of its social position.⁴⁹ These orientations also position HIV/AIDS foremost as either a scientific or a social issue. As was seen in studies of early AIDS activism, the framing of AIDS as a discrete, scientific problem has been an ongoing feature of the HIV/AIDS domain and has been associated with actors in positions of privilege (Stockdill 2003).

Oppositional dynamics were also found in struggles over who has access to the “truth”. Academic actors defending the orthodoxy favoured empiricist principles and methodological approaches that can “objectively” produce science. Accordingly, the “truth” would be found by treating the human sciences like the natural sciences, where social and political issues are expunged and the “objective” principles of science are followed. This epistemological perspective was more likely to be put forward by actors from disciplines that generally have higher scientific autonomy (i.e., basic/ clinical sciences and health sciences), compared to those with less autonomy (i.e., social sciences). Consequently, those from the former disciplines were less likely to recognize epistemologies outside of empiricism as being able to produce “truth” about HIV/AIDS.

ACB actors, on the other hand, claimed epistemic authority through the valuing of community legitimacy. These participants placed a high value on “knowing” the ACB population through identity and community membership, implying that they had a more authentic understanding of their community. Moreover, some ACB participants claimed that research would not produce “truthful” results if the community was not involved in, or approved of, the research. For

⁴⁸ The study results hinted at the existence of other struggles in this field, such as those across disciplines and challenges from academic newcomers (i.e., junior academics) attempting to improve their positions. However, there were insufficient data to support an in-depth analysis of these dynamics.

⁴⁹ Interestingly, the government official tended to adopt perspectives in line with those of dominant scientific actors, at least in relation to minimizing political “influences” on the field. This suggests a shared investment with these actors in some of the current defining principles of the field. However, because this individual was the sole actor from the bureaucratic field, it was not possible to expand on this analysis or generalize about the position this actor occupied.

example, a participant argued that large, personal social networks were comparable to epidemiological data sets and, in fact, were more representative of the realities of the ACB population. These actors used “truth claims” of authenticity and epistemic authority to support their argument that the ACB community should be meaningfully involved in the production of the research (e.g., as co-producers). This echoes earlier AIDS activists’ appeals to scientific principles when they argued that community involvement in clinical trials would produce “good science” (Epstein 1996).

Struggles over who can provide the most truthful account of reality are struggles over epistemic superiority. What is at stake in these arguments is the legitimacy to speak about the ACB population and, consequently, define the course of action concerning HIV/AIDS.

8.3.1 Challenging the Definition of the Field, Challenging the Social Order

In attempting to change the definition of legitimate ACB HIV/AIDS research, ACB actors are, in fact, challenging the field’s fundamental power structure. This is true for both community-based actors and academic researchers of ACB identity. However, these challenges are not intended to dismantle science per se; rather, they are oriented around using science to “buttress” the knowledge claims of ACB actors (Collins 1998), while also reconfiguring the parameters of legitimate science to benefit the larger ACB population. These actors are attempting to expose biases in the structure and challenge the idea that “others know and understand them better than they know and understand themselves” (Dei 2003:217).

However, while ACB participants had a number of commonalities, it is possible to tease out differences based on their positions in the field of ACB HIV/AIDS research. ACB academic-based researchers are attempting to shift the balance of power in the field and make it more fair and equitable. The challenges mounted by these actors are not aimed at a complete redefinition of the field. Instead, they can be seen as succession strategies aimed at improving both their individual positions in this field (i.e., their professional position) and the ACB population’s position in larger society. The stances of some ACB researchers suggest they are acting as “outsiders within” the scientific field by reclaiming and recasting scientific tools to challenge the structure that grants them legitimacy (Collins 1998). For example, ACB researchers favoured scientific methodologies and analytic lenses that address socio-political issues and expose systemic biases and racism across society.

Community-based actors, however, defined legitimate ACB HIV/AIDS research in a manner that would imply a redefining of the field. These actors' stances suggest a strategic attempt to gain more control over research activities similar to the ways in which other contemporary indigenous populations and organizations have organized around principles of community self-determination (Smith 2012). Occupying more peripheral positions compared to their academic counterparts, community-based ACB actors may participate in the field to the extent that it yields some benefit for their constituents, but they are not vying for superior positions in the same way as full participants of the field. Instead, their challenges to scientific authority can be seen as attempts to create a sub-field with the potential to shift away from a reliance on "science" as *the* way to know the world, to science as *one of multiple* ways to know the world. This sub-field would legitimize politically informed approaches to research and a methodological focus on research as a *tool* of these approaches. These are subversive strategies that challenge scientific authority and could potentially disrupt the social order of the existing field of ACB HIV/AIDS research. However, their goals can only be realized if community-based actors can achieve legitimacy for their definition of the field, that is, one in which community-based actors are legitimate producers of knowledge and research is defined as much by community and political values as scientific principles.

The legitimacy afforded by this sub-field would support a community-led research agenda-setting process that shifts the focus from the self to the collective (Dei et al. 2004), thereby moving from an emphasis on interests of individual researchers to the collective ACB community. This requires a recognizing and valuing of non-empiricist oriented approaches to research, such as alternative forms of community-based research and community consultative practices, and conceptualizing the lay ACB population as having multiple strengths and community-specific sites of knowledge (Yosso and Solórzano 2005). However, it is important to note that the community-based participants in this study are still interested in the *applied* nature of research; they are merely aiming to broaden the principles of knowledge production to include political and social justice aspirations. This would allow ACB actors who are based in the community sector or political field to support research without having to abide by the narrow parameters of the scientific orthodoxy.

8.3.2 Defending Empiricism, Defending the Structure

Several academic researchers used empiricist principles to define “good science”, revealing an underlying belief in the rationality and objectivity of the scientific method. According to these principles, scientific practices can, and should be, value-neutral and based on standards of “reason, observation, and experimental testing” (Benton and Craib 2001:5). A belief in value-neutrality assumes that it is possible to disregard the personal characteristics and biases of the researcher in the course of evaluating knowledge claims, as was reflected in a researcher’s assertion that it should not matter *who* conducts the research, as long as the research is done *correctly*. This perspective is indicative of a universalism in science that conceals the “interests” of knowledge producers (Collins 1998:xiii).⁵⁰ In protecting universalistic standards of scientific “excellence”, these academic researchers disregard the workings of their own power. Moreover, in attempting to separate fact from value in pursuit of the “proper” method, there is a risk of losing track of the “value choices always involved in the production of so-called facts” (Kincheloe and McLaren 2001:308). Indeed, as Halfpenny (2001:377) argues, freedom from “values” is a value itself, “sinisterly hiding behind a façade of neutrality”. Hence, the defense of a value-neutrality masks the interests of the scientific “knowers” in maintaining a dominant vision of the field of ACB HIV/AIDS research based on scientism, which positions scientists as the “knowers”.

Bourdieu argued that these “epistemic things”, when imposed as rules, govern as unifying principles in the scientific field and become an “antidote against centrifugal forces” (Bourdieu 2004:66) and external influences, such as those from neighbouring or “intruding” fields (Wacquant 1998:222). Epistemic principles based on scientific rationality, therefore, can be used as weapons in the defense of scientific autonomy (Albert and Kleinman 2011). In the field of ACB HIV/AIDS research, the defense is targeted toward the interlocking political field, as represented by ACB community-based actors and politicized epistemologies that were seen as obstacles to scientific rationality. Scientific objectivity is used as a weapon that separates the production of knowledge from “biases” that are not authorized by scientific disciplines (Smith

⁵⁰ This “interest” is not conscious; it is instinctual and reasonable rather than rational (Swedberg 2005). However, as Emirbayer and Johnson (2008:37) argue, even if social action is not consciously oriented toward power relations, it has an effect on those relations.

1990:16). For example, several academic-based researchers claimed that the political orientation and goals of ACB actors “get in the way”, and are outside the boundaries of, “good science”. This elevates the scientific expert as one who “sits above the fray, seeing things with a clear eye” (Bishop 2007:334).

Socio-political issues were also excluded as legitimate topics for scientific study, as indicated by several participants who denied or deflected discussions away from the potential role of racism in HIV/AIDS. In addition to reflecting a depoliticization of science (Harding 1992), this defensive mechanism conforms to societal-level colour- and power-evasive discourses that assert that racism is “dead” and modern societies need not take notice of race in legal or political arenas (Feagin and O’Brien 2010). Black scholars have argued that in settler societies built around an identity of Whiteness, race is masked through notions of a multicultural experience that claims to “move beyond” race and culture divisions (Massaquoi 2007). Consequently, Canada lacks the language to talk about race (Walcott 2003) and exhibits myopia towards modern manifestations of racism in science and elsewhere.

In summary, empiricist principles are doxic when they support the “naturalness” of the field’s structure and political order (Bourdieu 1977). The nature of empiricist epistemology, by definition, excludes other ways of seeing the world and validating knowledge, and acts as a weapon in defense against alternative epistemologies that question the status quo (Collins 1998). These epistemic weapons and exclusionary practices are unlikely to be detected by the very scientists who yield them, as they are trained not to question the social location and priorities of the “institutions and conceptual schemes within which their research occurs” (Harding 1992:579). Accordingly, these doxic principles act as a form of “non-reflexivity” that prevents the dominant actors from seeing how power dynamics are embedded into scientific processes and field relations. Ultimately, these practices serve to defend the social order against challenges from ACB actors both within and outside of the field of science, while racial and empiricist myopia prevent those in power from recognizing the dynamics of racial domination at play.

8.4 Implications for Knowledge about ACB Resistance Efforts

This research contributes to the literature on AIDS activism that documents the struggles of minority groups affected by HIV/AIDS (Cohen 1999; Stockdill 2003; Royles 2014). Moreover, it provides an empirical example of critical traditions and resistance movements that have claimed

that racial domination is enacted through “objective and impartial” science (Collins 1998) and have championed the right of less dominant communities to become “knowers” in the processes of knowledge production (Collins 1998; Harding 2004). However, ACB actors face deep tensions as they attempt to balance their roles as knowledge producers embedded in the scientific field and racialized actors resisting the reproduction of the social order. In this section, I discuss how my research builds on existing knowledge about ACB resistance and activist efforts, and the implications for ACB actors of navigating between strategies of compliance to build capital and achieve legitimacy, and those of resistance aimed at changing the parameters of the field.

8.4.1 Becoming Agents of Knowledge

The majority of existing HIV/AIDS scholarship that examines mobilization efforts within North America’s ACB population has focussed on the difficulties faced by activists as they attempted to mount a coordinated response to the disease (Quimby and Friedman 1989; Cohen 1999; Stockdill 2003; Hinote and Wilson 2006). For example, in her study of the social, political, and cultural impact of AIDS on African American communities, Cohen (1999) documented multiple sites of stratification within the population and the systemic inequities that undermined community solidarity. Similarly, Stockdill’s (2003) examination of social relations within the AIDS movement found that racial, class, gender, and sexual differences among communities, organizations, and actors created divisions between and within marginalized communities. My findings also point to the existence of fractures within the ACB community, such as the concerns expressed by several participants over the lack of representation of ACB sub-populations in research circles. Apprehension about the increasing importance of research in service-provision domains suggests there may be tensions between community advocates and ACB researchers over the role of research in the response to HIV/AIDS. Moreover, as in the US (Cohen 1999), ACB activists in Canada have struggled to convince decision-makers that HIV is a serious problem in their communities, one that requires adequate funds and resources to address the epidemic (Tharao and Remis 2002; Husbands 2009; ACCHO 2010).

Yet, in spite of these tensions and struggles, my study indicates that the ACB community in Ontario has had some success in mobilizing. ACB actors are actively involved in the production of HIV/AIDS knowledge, as demonstrated by the funding review that showed the majority of studies included ACB actors as investigators on research teams. In addition, community-based

actors discussed strategies to build on their existing social capital and gain the legitimacy needed to exert more control over the production of research. This suggests that ACB actors both within and outside of the academic domain have not only learned the “rules of the game”, but have also become active and effective players in the game.

These efforts are characteristic of those minority scholars who have struggled to secure their autonomy, redefine themselves and their relations to the world, and become agents of knowledge instead of just being “known” (Collins 1998; Harding 2008). Whereas Collins’ (1998) work explored the efforts of Black female academics, my research documents how non-academic minority actors also fight against being treated as “objects of knowledge”. Like feminist scholars, ACB actors in this field have argued that politics and knowledge production are inherently linked, regardless of how dominant social institutions, and the disciplines that “service them”, present abstract and value-neutral conceptual frameworks (Harding 2008:121). The critiques mounted by ACB participants concerning racism and Eurocentricity in HIV/AIDS research also reflect feminist critiques of the inadequacy of objectivism to identify the androcentric and racist assumptions in elite academic discourses and many accepted scientific claims (Harding 1992; Collins 1998). In fact, rather than attempting to erase politics from research, these minority scholars have pushed for recognition of the inherent political nature of research and the involvement of groups that have been traditionally excluded from the production of “real science” (Collins 1998). For ACB actors in Ontario’s HIV/AIDS sector, this has involved bringing the “Black body”, both materially and conceptually, into research and politicizing research through prioritizing the “social”. Mirroring the efforts of feminist and female Black scholars, these actors are challenging scientific processes of arriving at the “truth” and attempting to subversively critique the “epistemological core” of science (Harding 2008:123).

My findings also build on Yosso’s (2005) conceptualization of community cultural wealth as forms of capital (e.g., resistant and social) that are present in communities of colour and can be used to support community mobilization and agency. Situated in critical race theory and starting from the premise that communities of colour are sites of multiple strengths, this approach can be used to understand how ACB communities make use of particular community resources to mobilize (Yosso 2005). For example, ACB participants who invoked principles of social justice associated with resistance movements to challenge systems of racial domination in the

HIV/AIDS field were building on the resistant capital of their communities. As Yosso (2005:81) explains, this form of capital is based on skills that have been gained through previous oppositional behaviour and a “cultural knowledge of the structures of racism and motivation to transform such oppressive structures”.

Additionally, through a community cultural wealth lens, the mobilization efforts of the ACB community can be seen as part of building social capital. ACB researchers described their interactions with other ACB professionals as important sources of support and community solidarity. These relationships become a resource when they provide communities of colour with “instrumental and emotional support to navigate through society’s institutions” (Yosso 2005:80). Principles of solidarity were threaded throughout the interviews as participants placed value on improving the daily lives of community members and consistently called for more community consultation, engagement, and mobilization. This focus on the collective survival of the community reflects an underlying assumption of mutual interdependence among community members (Dei 2003). Accordingly, community building is a political choice that becomes an enabling and mobilizing force in the struggle for social justice (Dei 2003:221).

8.4.2 Implications of Participating in the Struggles for ACB Actors

The ACB community has clearly had some success in utilizing capital to mobilize around HIV/AIDS and gained the legitimacy needed to be involved in the production of knowledge. However, there are natural limits to what struggles within a field can accomplish. According to Bourdieu (1993), any struggle can only lead to a “partial revolution” that can destroy the hierarchy in a given field, but not the “game” itself. This is because of a complicity that underlies all antagonisms based on the shared belief that, ultimately, the game is worth playing. Reproduction of the field continues because of the shared interests in the existence and stakes of the field; this occurs in spite of the desire of some actors to reshape the field to their own advantage (Emirbayer and Johnson 2008). Therefore, participation in the struggles may have consequences that are counterproductive to the ACB community’s goals of redefining HIV/AIDS research.

ACB actors in this study sought to challenge field-level power relations that sustain the dominance of particular scientific principles and authorities. At the same time, there is a risk of reproducing the principles and rules that dominate practice and support the doxa. This was

evident in at least three ways. First, experimental verification generally remained unchallenged by ACB actors. There appeared to be an overall agreement that research and the “evidence” it produces will improve the social position of the ACB population. That is, there is a belief that research leads to knowledge, which then leads to more effective practice. Even community advocates, although critical of the increasing dominance of research in service provision, were still invested and involved in the production of research. However, adherence to experimental verification as a foundational principle of practice means that “alternative” knowledge claims still have to be vetted through sanctioned research methodologies (Hess 2004), thereby extending the reach of the scientific gaze. Moreover, while empiricist-driven scientific study can reveal possibilities and identify limits, it cannot provide an evaluation of alternative ways of *seeing* the problem or reveal the tacit knowledge (e.g., shared understandings and implicit rules) that informs much of human behaviour and social relations (Benton and Craib 2001; Halfpenny 2001).

A second way in which the dominance of science might be sustained is through the widespread support of the need for research to have a defined “impact”. This reflects a larger “impact agenda” in the HIV/AIDS field that prioritizes applied research and short-term outcomes. For example, the OHTN has recently decided to concentrate on research that has the “potential to have a measurable impact in the short to medium term (i.e., in the next 2 to 5 years)” (OHTN 2014). Narrowly defining research in this way has implications for the legitimacy of research topics endorsed by ACB actors. Importantly, an emphasis on “impact” leaves little room for research that does not offer an immediately practical objective, such as approaches that aim to unpack social issues (e.g., social drivers/determinants of HIV/AIDS, various forms of systemic discrimination). As Auerbach et al. (2011) argue, to facilitate social change in respect to HIV/AIDS, research approaches must reflect the complexity of social-level phenomena and address them with a long-term vision.

Finally, although ACB actors challenged the dominant epidemiological paradigm, they also stressed the importance of epidemiological data for legitimizing the community’s claims over their priority status and entitlement to funding. However, if the data do not indicate that HIV/AIDS is a pressing problem in the ACB population, compared to other affected groups, then funding and resources could be redirected away. Furthermore, using data to raise alarm bells for future cases (i.e., HIV/AIDS as a *growing* problem in the ACB population) may reinforce stigma

by further entrenching the ACB “identity” as a risk factor. The epidemiological paradigm also supports the dominance of a scientific approach that reifies and transforms fluid and complex social characteristics into binary research variables that are concretized as “natural” (Shim 2000; Mukherjea and Vidal-Oritz 2006). For example, race is stripped out of its social context, social practices, and social structures to be located in individual bodies, rather than being seen as a relational construct (Epstein 2007). This individualizing perspective contrasts with the ACB community’s focus on the social and political drivers of HIV/AIDS.

As part of their attempts to resist scientific authority, community-based actors stressed the need for greater community ownership of research. Indeed, several argued that community-based actors should be able to initiate and conduct research themselves. However, there are potential costs if community-based actors become increasingly entrenched in the institutionalized process of knowledge production. What is sacrificed if limited resources are directed toward research? Several community advocates noted that human resources are already strained from organizational commitments to participate in studies. If community-based organizations conduct their own research, meeting the requirements of funders and sponsors would demand the further development of infrastructure (i.e., organizational operational costs) that may not be supported by research grants. Importantly, such involvement could subject them to scientific authority to an even greater extent.

The entrenchment of research into community-based settings also has implications for ACB resistance and activist efforts. As advocacy groups develop “insider” roles in formal knowledge hierarchies, their involvement in research becomes more institutionalized over time (Hess 2004). Moreover, because these actors come from peripheral and dominated positions in the field of ACB HIV/AIDS research, mechanisms of resistance can be coopted into formalized scientific spaces. As Collins argues, alternative knowledge claims are rarely threatening to conventional knowledge because they can be ignored, discredited, or absorbed and marginalized in existing paradigms (Collins 1989). Therefore, when community involvement is structurally validated without the concurrent acceptance of community principles (i.e., political and value-oriented epistemologies), “playing the research game” risks diminishing resistance mechanisms and becoming part of a “capture and control” scenario (Hess 2004). In this sense, community involvement can be seen as a way of maintaining scientific authority—the community is relegated to certain spaces where it is “allowed” to participate in research (e.g., social sciences,

community-based research) and the system accommodates it without altering power structures. Conversely, if community-based actors become further disengaged from the larger field of science—for example, by defining their own sub-field of research—their chosen epistemologies, methodologies, and approaches to research may be regarded as even less legitimate than they are now, putting at risk their access to research funding and institutional support.

These are constant tensions for ACB actors as they knowingly “play the research game,” while resisting scientific authority and attempting to redefine legitimate knowledge. The vacillation between critique and support of science, and resistance to, and compliance with, its governing principles is a consequence of the erosion of boundaries between science and politics (Epstein 1996). This mirrors the experiences of earlier AIDS activists and advocates who opposed some aspects of science and medicine, while also advocating for their benefits (Epstein 1996). Allowing certain beliefs to remain unquestioned, however, may also support the reproduction of systems of domination. In this case, power structures may be challenged, but the underlying scientific doxa may not be.

8.5 Contributions to the Political Sociology of Science

A final contribution of my research falls within the sociology of science scholarship concerned with the politics of knowledge. The approach I have taken acknowledges the social construction of scientific knowledge and its embeddedness in structural power dynamics (Frickel and Moore 2006:9). One of the ways in which struggles for scientific legitimacy have been examined is through the concept of boundary work (Jasonoff 1987; Gieryn 1999; Kleinman and Kinchy 2003). Introduced by Gieryn (1983), boundary work denotes the processes that scientists’ engage in to distinguish their practices from “non-scientific” intellectual activities. To accomplish this demarcation they deploy the attributes of science (e.g., methods, values, principles) to argue the legitimacy of their authority. As Albert et al. (2009) assert, however, Gieryn was generally concerned with historical examples of boundary work that resulted in the successful demarcation between the *institution* of science and another (non-scientific) intellectual activity (e.g., science versus religion). My research represents a contemporary instance of “boundary-work in the making” (Albert et al. 2009:173) between scientists and actors situated both outside and *within* the institution of science. Specifically, dominant scientists discursively construct epistemological boundaries around their definitions of legitimate HIV/AIDS research, thus defending empirical

characterizations of “good science”. This demarcation represents an attempt to prevent politicized epistemologies, espoused by both social scientists within the scientific field and peripherally located community-based actors, from crossing the boundaries of legitimate science. These results are akin to the research of Albert et al. (2009) on the enactment of cultural boundaries between basic/clinical sciences and social sciences in the health research domain. They found that basic and clinical scientists channelled principles of experimental science to reinforce boundaries around legitimate ways of conducting research and in defining the scientific value of health sciences research.

In using a Bourdieusian framework, I have also reflected on the implications of these struggles for power relations outside the parameters of “scientific” disputes. In other words, I have considered how scientists’ epistemological positions are related to their “interests” in structural relationships of power (Frickel and Moore 2006). Dominant scientists in this field share what Emirbayer and Schneiderhan (2012:141) refer to as a “common investment in the perpetuation of a social order of which they are the beneficiaries”. Importantly, although my research did not specifically seek to compare actors’ stances based on their gender or race, it is notable that those who held positions at the top of the scientific hierarchy were White males, whereas the vast majority of less dominant actors were Black females. This raises questions about whether the maintenance of the current scientific authority also contributes to the preservation of a social order in science based on racial and gender hierarchies and systems of domination (Collins 1998).

My research also provides an empirical example of resistance efforts in contemporary embodied health movements. The findings suggest that ACB actors have built on the achievements of previous AIDS activists and the credibility that their predecessors gained as “lay” knowledge producers (Epstein 1995, 1996) to mount their own resistance efforts. However, unlike Epstein’s work on early AIDS activists who used their newfound credibility primarily to affect biomedical approaches to the “problem” of HIV/AIDS, the current study has documented the efforts of advocates and community-based actors to assert the legitimacy of socio-political approaches to defining HIV/AIDS. They do so by appealing both to scientific “truth” claims, as well as critical epistemologies that challenge science with principles grounded in ethics and political values. The findings also illustrate that Bourdieu’s theory can be employed to demonstrate that epistemological mechanisms are used not only in defense of science, but also in ways that

challenge the scientific status quo. As Bourdieu (1993:183) argues, “the impetus for change” resides in the field’s struggles, as the opposition to, and a defense of, the field’s orthodoxy. In other words, social change is possible in a field characterized by heterodox dynamics. I have used a Bourdieusian lens to look beyond social reproduction to understand how these ongoing struggles and resistance efforts may shift the definition of the field of ACB HIV/AIDS research, or possibly even create a new sub-field of research.

Finally, the resistance efforts present in this study are akin to social movement scholarship on embodied health movements that have pushed the boundaries between lay and expert science and redrawn the lines between “good” and “bad” science (Brown et al. 2004). For example, Brown et al (2004) argue that the breast cancer movement has produced successful citizen-science alliances that have allowed women with breast cancer to be co-creators of scientific knowledge. In fostering a focus on research that investigates environmental risk factors, some activist scientists and lay actors are broadening the scope of “legitimate” breast cancer research away from the dominant epidemiological paradigm (McCormick et al. 2003; Brown et al. 2004). My study documents how current HIV/AIDS activists are also allying with scientific actors in attempting to redefine notions of legitimate science. Indeed, the former now occupy roles as principal investigators on research projects, suggesting that they are positioned to conceive and implement research that reflects community values and goals. Like earlier Black AIDS activists in the US (Stockdill 2003), “legitimate science” for these actors means concentrating on socio-political interpretations of HIV, such as understanding how racism, poverty, and other social issues drive the epidemic, and moving away from the dominant epidemiological paradigm that focuses on individual causal factors.

8.6 Limitations, Challenges, and Future Research

This thesis has made several contributions to the study of relations between civil society and science. As is typical for any research project, however, there are at least three limitations to the research. First, the study sample was limited to actors identified through a funding review and informal techniques, such as snowball sampling. Although major funding databases were assessed, it is possible that this sampling strategy overlooked actors involved in research who received funding from smaller bodies, their own organizations (e.g., hospitals), or pharmaceutical companies. Additionally, these recruiting approaches may not have captured

individuals who are involved in research relevant to the ACB population, but are located on the periphery of the field, such as basic and clinical scientists who may access funding through these other sources. Because their research may not require community involvement (i.e., they do not directly work with community advisors), these individuals may not have been identified through snowballing techniques with members of the community. Furthermore, there were several academic researchers in health sciences *not* of ACB identity whom I was unable to interview. It is my understanding that their epistemological perspectives might be similar to those of ACB actors (e.g., critical theory, social justice perspectives), even though they occupy more dominant positions in the field. Including them might have been valuable analytically if they are attempting to straddle fields (i.e., dual citizenship with the political field and scientific field) and epistemological perspectives. Given how the sample was compiled, therefore, I do not claim to have identified all of the positions represented by actors involved in ACB HIV/AIDS research in Ontario, nor do I suggest that the results are generalizable to all HIV/AIDS research. Instead, this study can be seen as a first step in conceptualizing what a field of ACB HIV/AIDS research might look like.

This leads to a second limitation concerned with building a robust Bourdieusian field model. According to Bourdieu, to determine the structure of a field it is necessary to map actors' objective positions in a field on the basis of the relevant capital they possess and their habitus (Bourdieu and Wacquant 1992). Initially, I had planned to compile those data by obtaining the participants' CVs, which would have provided information on their individual attributes, such as their educational background, current academic appointments, and funding history. This CV data would also have allowed for a wider conceptualization and analysis of scientific capital in the form of publications and awards, and community capital in the form of volunteer and political activities. Notably, this data would have allowed me to more specifically link an actor to a position in the field and analyse his/her investment in, or resistance to, existing power structures. Early in the study, however, several participants refused to supply their CVs. I understood this to reflect their concern with the small size of the field and the potential for identification. In the absence of these more "objective" measures, I was obliged to use the funding review data to informally identify the positions of actors in the field based on their appearances on research teams and whether or not they were principal investigators on research studies with the largest funded budgets. Although this was an admittedly crude approximation of the field's hierarchy, it

became a heuristic tool to help me think about the data in relation to the field's structure, specifically which stances might be associated with dominant positions and which forms of capital might be valuable. Ultimately, I did not feel constrained by the lack of objective data. By identifying the range of perspectives concerning the production of HIV/AIDS research, I was able to postulate about dominant forms of capital, link stances to different groups of actors, and tease out field-level struggles. I acknowledge that this study is only the beginning of constructing this field. Developing additional insights is a lengthy and laborious process of going back and forth between examining the logic of the field and identifying the forms of capital that operate within it (Bourdieu and Wacquant 1992:108).

A third limitation concerns the role of gender in the study. I did not investigate gender domination as a social phenomenon, mainly because the general relations between academic and community actors seemed to dominate public discussions about research efforts in the ACB community and, thus, appeared to be the most appropriate starting point to contemplate the struggles in the field. Nevertheless, the majority of female participants were located in social science disciplines and the community-based sector. Conversely, most of the male researchers came from basic/clinical sciences or health sciences. The prominence of male researchers in dominant scientific disciplines suggests that gendered power relations contribute to the framing of knowledge production in this field. Such gendered power structures can produce dominant discourses that “present a view of social reality that elevates the ideas and actions of highly educated men as normative and superior” (Collins 1998:45). Although methodological limitations prevented me from conducting a formal gender analysis, I did consider how the perspectives of community-based actors were grounded in feminist resistance epistemologies.

In addition to these limitations, I also encountered a number of challenges in the course of implementing a Bourdieusian framework. Employing the concept of field is challenging if the goal is to determine a purely “objective” structure through mapping its boundaries based on the distribution of relevant capital. As (Emirbayer and Johnson 2008:8) argue, the dividing lines between the “haves and have nots” (i.e., actors who possess capital versus those that do not) are constantly shifting, which makes it difficult to define an objective hierarchical model of the field. I also found that field was a crude concept with which to conceptualize the social spaces in which individuals were professionally and socially located. Placing them within distinct fields requires the imposition of discrete boundaries even when actors might be straddling them, such as

scientists who act as political activists, or community-based researchers who also hold academic positions. Therefore, boundaries between social positions are not always clear when actors cross fields and hold different positions of power in the various social spaces they occupy. Although I attempted to account for this duality analytically through the idea of “dual citizenship” (Panofsky 2011), a question arises as to whether field remains a useful concept when individuals may be embodying simultaneously the logics of different fields. Additionally, it was difficult to conceptualize the structure of the domain of research that community-based actors appear to be moving towards. I initially thought of this as a “breakaway field” of research, one that was not reliant on scientific capital for legitimacy. However, as it became apparent that these participants were not necessarily attempting to define a new field completely outside of science, I conceptualized this domain as a sub-field. This solution may not be completely satisfactory because it still assumes that the latter would fall under the overall umbrella of the scientific field, even though community-based researchers and advocates are not fighting for academic positions or scientific accolades. This issue requires further empirical study to determine where their subversive strategies might lead. However, I acknowledge that the difficulty in defining the boundaries of fields and where they may potentially overlap is not necessarily a methodological problem but, instead, “conveys a realistic account of the practical and contested character” of the social world itself (Swartz 2012:30). Accordingly, rather than seeing Bourdieu’s concepts as “straightjackets”, I have used them as tools designed to foster analytic insights (Swartz 2012).

As well as these limitations and challenges, questions and issues arose throughout the course of this research that deserve further consideration. As Stockdill (2003:24) found in the US, the AIDS movement can itself be seen as a “microcosm of interlocking inequalities”. However, there has been little work devoted to documenting and critically examining dynamics in the Canadian AIDS movement.⁵¹ Future research questions could include the following: What has been the course of HIV/AIDS activism and advocacy in Canada? What are the dynamics between the various “interest groups” (i.e., groups affected by HIV/AIDS) that have mobilized? What strategies have been used to push agendas forward, and how do they differ substantively and epistemologically among these groups of actors? It is important to consider social relations

⁵¹ An academic-led initiative was recently launched with the aim of documenting AIDS activism in Canada (<http://aidsactivisthistory.ca>).

between different mobilized groups who are competing for limited resources and legitimacy, and how these dynamics may contribute to existing forms of domination. Crossley (2006:552) has developed a compelling model based on Bourdieu's field theory for understanding "relations, alliances, and conflicts" in social movements. This "fields of contention" framework would provide an approach to understanding the current AIDS movement by addressing interactions among the range of groups and actors involved in protest and community-based initiatives, and drawing attention to the struggles in which these actors are involved, both within the movement and externally with other fields.

Concerning ACB activism specifically, the existing literature provides insight into the politics of mobilization within African-American communities (Cohen 1999; Royles 2014), but there has not been a systematic study of mobilization within Canada. A fundamental question has plagued this research from the beginning: What does AIDS "activism" in Canada's ACB community look like? Stockdill (2003:181) argues that, at least in the US, there is no longer a grassroots AIDS movement because the majority of direct action groups are either defunct or have been incorporated into service provision organizations that do not generally employ protest activities. Therefore, the first order of inquiry may simply be to determine whether a cohesive ACB AIDS social movement exists. Because these actors are enmeshed in the mechanisms of science production, critical thinking about how these relations began, and what they have become, would provide insight into current modes of community knowledge production and potentially challenge how we currently conceptualize activism or community-based research.

Questions can also be raised about what these actors have, or have not, accomplished in relation to the types of research that are currently being produced. Indeed, it behoves us to ask whether ACB research has actually changed as a result of the community's mobilization efforts. Are the demands of the ACB community for research that addresses the socio-political dimensions of HIV/AIDS being addressed by scientists, or are they still part of "undone science" (Frickel et al. 2010) in this field? This issue could be investigated by reviewing previous and current HIV/AIDS research about the ACB population, and categorizing studies based on their underlying epistemologies and methodological approaches. Combined with a historical analysis of ACB mobilization, this inquiry could offer insights into the effects of ACB activism on the production of knowledge and how it may, or may not, have affected definitions of legitimacy in the field of ACB HIV/AIDS research.

Another future avenue of research centres on whether a broader collective and oppositional consciousness has taken shape in the larger ACB population. As Taylor et al. (1992) argue, collective consciousness (i.e., conceiving of a situation as shared) must be achieved before actors can commit to challenging domination together. Several participants discussed the need to mobilize within ACB communities, suggesting this consciousness is in a developmental stage. Even the term “community” was invoked differently across groups of actors, either to distinguish between community-based actors and those in institutional settings (e.g., academia, government, pharmaceutical industry), or to refer to the collective ACB population (i.e., the ACB “community”). Future research on the intersections among “community”, identity, and mobilization around HIV/AIDS could unpack the notion of community and examine its use both in field struggles and mobilization efforts. Ultimately, community is a messy and contested concept that must be interrogated further in order to understand its role, both in resistance efforts and in forms of co-optation that serve to maintain the dominance of scientific authority.

Furthermore, as outlined previously, it was not possible to include an analysis of habitus, specifically the characteristics, backgrounds, and attributes of field actors. However, a habitus-focussed investigation could offer an avenue to understand how mechanisms of resistance are, or are not, embodied by individuals. For example, an examination of a person’s exposure to politicized epistemologies or social organizing around gender, sexuality, or race issues, would allow for an analysis of his/her propensity to adopt stances that challenge modes of domination in the field of ACB HIV/AIDS research. As Crossley (2003:50) suggests, participation in protest or resistance activities can create dispositions in actors that predispose them to further political activism, resulting in a “radical habitus”. Understanding the different forms of radical habitus would provide insight into the “inclination and know-how to fight” (Crossley 2003) and the effect of these dispositions on social change within the field.

Finally, throughout the history of the AIDS epidemic, both scientists and non-scientists have been involved in resisting and challenging dominant modes of scientific knowledge production. This study suggests that academics with an ACB identity experience tensions between their roles as researchers—as insiders in the scientific field—and activists or advocates for their community. As Smith (2012) argues, ACB scientists and academics can feel like “outsiders” due to their racial marginalization and the perception that they represent a “rival interest group” within science (Smith 2012). How do these ACB academic researchers, and indeed their

community-based counterparts, negotiate their joint insider–outsider status in relation to formal scientific and medical institutions (Hess 2004; Epstein 2008)? Exploring this question could offer insights into the construction of boundaries around actors’ different identities and their scientific and activist work, and provide direction for other researchers attempting to negotiate “dual citizenship” across science and political fields.

8.7 Concluding Remarks

...Thus ‘the scientific’ and ‘the political’—science and politics—are inexorably intertwined. (Harding 2008:25)

I set out to understand struggles over the legitimate definition of the field of ACB HIV/AIDS research. The interlocking nature of this field suggests that there is constant conflict over its autonomy. Although certain practices protect scientific autonomy and discourage the use of science as a “political” tool, others reflect the field’s deep engagement with sectors informed by political values of social justice. In fact, politicization is at the very core of this field; this is due, in part, to the legacy of the early AIDS movement, which set the stage for interactions and struggles between various scientific, political, and bureaucratic fields. Yet, as I have argued, the findings from this study indicate an ongoing defense of empiricist science that contributes to systems of exclusion and masks modes of domination.

That said, this dissertation should not be taken as an argument in favour of science serving as the “handmaiden” of political movements. Bourdieu himself was committed to protecting the autonomy of science from dominant political and economic interests. He believed that the encroachment of these forces would lead research “little by little in the direction of heteronomy” such that it would become a tool of ruling political and economic interests (Bourdieu 2004:viii). However, I argue that, rather than broadly conceptualizing political interests as a *threat* to scientific rationality and reason, each case of political “interest” should be examined specifically to understand the origins and contexts of struggles at play. I suggest that meaningful civic engagement can encourage reflexivity in the field of science, especially when research involves dominated populations. As Harding (1992:578) argues, scientific communities are designed to consist of like-minded individuals, a cultural homogeneity that can prevent actors from detecting the dominant culture’s values, interests, and biases. Challenges by those from dominated

communities both within and outside of the scientific field can provide a valuable check against the reproduction of modes of domination within the field that benefit particular social groups.

These challenges emanated from ACB actors asserting themselves as legitimate knowers of their community. At the heart of their struggles were tensions over playing and resisting the game—over being legitimate knowledge producers, while also refusing to be objectified by the very field in which they struggle to participate. As they strive for recognition and legitimacy, they grapple with the more durable components of the structure and, where possible, attempt to exploit them. Their strategies reflect a complex process of navigating between utilizing existing, legitimate mechanisms of science and resisting its dominance in shaping knowledge about their lives. Nonetheless, the consistency of their perspectives, regardless of social position, suggests that ACB researchers and community-based actors have coalesced and tapped into forms of community cultural wealth that can “serve their larger purpose of struggle toward social and racial justice” (Yosso 2005:69).

This research is part of a broader dialogue that exists already among actors in the ACB community and within the field of ACB HIV/AIDS research. My hope is that these findings contribute to further discussion and debate concerning the state of research about the ACB population and how, and when, scientific boundaries can be crossed, resisted, and blurred.

References

- African and Caribbean Council on HIV/AIDS in Ontario (ACCHO). 2010. *ACCHO - Engaging Communities and Supporting Action on HIV/AIDS Among African, Caribbean, and Black Communities in Ontario: A History*. Toronto, ON: African and Caribbean Council on HIV/AIDS in Ontario. Retrieved July 17, 2014 (http://www.accho.ca/Portals/3/documents/ACCHO_History_Final_En.pdf).
- African and Caribbean Council on HIV/AIDS in Ontario (ACCHO). 2013. *Ontario HIV/AIDS Strategy for African, Caribbean and Black Communities 2013-2018*. Toronto, ON: African and Caribbean Council on HIV/AIDS in Ontario. Retrieved May 1, 2014 (http://www.accho.ca/Portals/3/documents/resources/ACB_Strategy_Web_Oct2013_En.pdf).
- Adkins, Lisa. 2003. "Reflexivity: Freedom or Habit of Gender." *Theory, Culture and Society* 20: 21-42.
- AIDS Bureau, Ontario Ministry of Health and Long-Term Care, Public Health Agency of Canada (PHAC), Ontario and Nunavut Regional Office, and Ontario HIV Treatment Network (OHTN). 2012. *View from the Frontlines: Annual Summary & Analysis of Data Provided by Community-Based HIV/AIDS Services in Ontario 2012*. Toronto, ON: AIDS Bureau, Ontario Ministry of Health and Long-Term Care and Public Health Agency of Canada, Ontario and Nunavut Regional Office. Retrieved August 16, 2013 (<https://www.ochart.ca/documents/2013/VFTFL-2012-WEB.pdf>).
- Albert, Mathieu and Daniel Lee Kleinman. 2011. "Bringing Pierre Bourdieu to Science and Technology Studies." *Minerva* 49(3):263-73.
- Albert, Mathieu, Suzanne Laberge, and Brian D. Hodges. 2009. "Boundary-Work in the Health Research Field: Biomedical and Clinician Scientists' Perceptions of Social Science Research." *Minerva* 47(2):171-94.
- Alexander, Jeffrey C. 1995. *Fin de Siècle Social Theory: Relativism, Reduction, and the Problem of Reason*. New York: Verso.
- Altman, Dennis. 1994. *Power and Community: Organizational and Cultural Responses to AIDS*. London: Taylor & Francis.
- Archibald, Matthew E. and Charity Crabtree. 2010. "Health Social Movements in the United States: An Overview." *Sociology Compass* 4(5):334-43.
- Arno, Peter S. and Karyn Feiden. 1992. *Against the Odds: The Story of AIDS Drug Development, Politics And Profits*. New York: HarperCollins.
- Auerbach, Judith D., Justin O. Parkhurst, and Carlos F. Cáceres. 2011. "Addressing Social Drivers of HIV/AIDS for the Long-Term Response: Conceptual and Methodological Considerations." *Global Public Health* 6(Suppl 3):S293-309.

- Bannerji, Himani. 2000. *The Dark Side of the Nation: Essays on Multiculturalism, Nationalism and Gender*. Toronto, ON: Canadian Scholars Press.
- Barbot, Janine. 2006. "How to Build an 'Active' Patient? The Work of AIDS Associations in France." *Social Science & Medicine* 62(3):538–51.
- Barbot, Janine and Nicolas Dodier. 2002. "Multiplicity in Scientific Medicine: The Experience of HIV-Positive Patients." *Science, Technology, & Human Values* 27(3):404–40.
- Barnard, Matt. 2010. "What is Framework?" 2010 ESRC Research Methods Festival, July 2010, St Catherine's College, University of Oxford, UK. Retrieved April 20, 2012 (http://onlineqda.hud.ac.uk/movies/ESRC_RMF_2010/#Part2).
- Benton, Ted and Ian Craib. 2001. *Philosophy of Social Science: The Philosophical Foundations of Social Thought*. New York: Palgrave.
- Berridge, Virginia. 2002. "AIDS and the Rise of the Patient? Activist Organisations and HIV/AIDS in the UK in the 1980s and 1990s." *Medizin* 21:109–24.
- Bhopal, Kalwant. 1995. "Women and Feminism as Subjects of Black Study: The Difficulties and Dilemmas of Carrying Out Re-search." *Journal of Gender Studies* 4(2):153–68.
- Bischoping, Katherine. 2005. "Quote, Unquote: From Transcript to Text in Ethnographic Research." Pp. 141–54 in *Doing Ethnography: Studying Everyday Life*. Toronto: Canadian Scholars' Press.
- Bishop, Robert. 2007. *The Philosophy of the Social Sciences: An Introduction*. London: Continuum.
- Bolton, Ralph. 1992. "AIDS and Promiscuity: Muddles in the Models of HIV Prevention." *Medical Anthropology* 14(2-4):145–223.
- Bourdieu, Pierre. 1975. "The Specificity of the Scientific Field and the Social Conditions of the Progress of Reason." *Social Science Information* 14(6):19–47.
- Bourdieu, Pierre. 1977. *Outline of a Theory of Practice*. New York: Cambridge University Press.
- Bourdieu, Pierre. 1984. *Distinction: A Social Critique of the Judgement of Taste*. Cambridge, Mass.: Harvard University Press.
- Bourdieu, Pierre. 1986. "The Forms of Capital." Pp. 241–58 in *Handbook of Theory and Research for the Sociology of Education*. Westport, Conn.: Greenwood Press.
- Bourdieu, Pierre. 1988. *Homo Academicus*. Cambridge, UK: Polity Press.
- Bourdieu, Pierre. 1989. "Social Space and Symbolic Power." *Sociological Theory* 7(1):14–25.
- Bourdieu, Pierre. 1993. *The Field of Cultural Production: Essays on Art and Literature*. Cambridge, UK: Polity Press.
- Bourdieu, Pierre. 2000. *Pascalian Meditations*. Cambridge, UK: Polity Press.

- Bourdieu, Pierre. 2001. *Masculine Domination*. Stanford, Calif.: Stanford University Press.
- Bourdieu, Pierre. 2004. *Science of Science and Reflexivity*. Chicago: University of Chicago Press.
- Bourdieu, Pierre and Loïc J. D. Wacquant. 1992. *An Invitation to Reflexive Sociology*. University of Chicago Press.
- Bourdieu, Pierre and Loïc Wacquant. 1999. "On the Cunning of Imperialist Reason." *Theory, Culture & Society* 16(1):41–58.
- Boyer, Ernest L. 1996. "The Scholarship of Engagement." *Bulletin of the American Academy of Arts and Sciences* 49(7):18–33.
- Brown, Phil and Stephen Zavestoski. 2004. "Social Movements in Health: An Introduction." *Sociology of Health & Illness* 26(6):679–94.
- Brown, Phil, Stephen Zavestoski, Sabrina McCormick, Brian Mayer, Rachel Morello-Frosch, and Rebecca Gasior Altman. 2004. "Embodied Health Movements: New Approaches to Social Movements in Health." *Sociology of Health & Illness* 26(1):50–80.
- Bryman, Alan. 2004. *Social Research Methods*. Oxford: Oxford University Press.
- Butler, Judith. 1999. "Performativity's Social Magic." Pp. 113–28 in *Bourdieu: A Critical Reader*, edited by Richard Shusterman. Malden, Mass.: Blackwell Publishers.
- Calhoun, Craig and Joseph Karaganis. 2001. "Critical Theory." Pp. 179–201 in *Handbook of Social Theory*, edited by Barry Smart and George Ritzer. Thousand Oaks, CA: SAGE Publications, Inc.
- Camic, Charles. 2011. "Bourdieu's Cleft Sociology of Science." *Minerva* 49(3):275–93.
- Canadian Treatment Action Council (CTAC). 1999. *CTAC Newsletter*. Toronto, ON: Canadian Treatment Action Council.
- Canadian Treatment Action Council (CTAC). 2014. "History." *ctac.ca*. Retrieved July 17, 2014 (<http://www.ctac.ca/about-us/history>).
- Centre for Disease Control. 2014. *HIV Among African Americans*. Centre for Disease Control. Retrieved June 11, 2014 (http://www.cdc.gov/hiv/pdf/risk_HIV_AfricanAmericans.pdf).
- Clapp, Richard W. 2002. "Popular Epidemiology in Three Contaminated Communities." *The ANNALS of the American Academy of Political and Social Science* 584:35–46.
- Cohen, Cathy. 1999. *The Boundaries of Blackness: AIDS and the Breakdown of Black Politics*. Chicago: University Of Chicago Press.
- Collins, Patricia Hill. 1989. "The Social Construction of Black Feminist Thought." *Signs* 14(4):745–73.
- Collins, Patricia Hill. 1990. *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. Boston, Mass.: Unwin Hyman.

- Collins, Patricia Hill. 1997. "Comment on Hekman's 'Truth and Method: Feminist Standpoint Theory Revisited': Where's the Power?" *Signs* 22(2):375–81.
- Collins, Patricia Hill. 1998. *Fighting Words: Black Women and the Search for Justice*. Minneapolis: University of Minnesota Press.
- Corea, Gena. 1992. *The Invisible Epidemic: The Story of Women and AIDS*. New York: HarperCollins.
- Crenshaw, Kimberle Williams. 2002. "The First Decade: Critical Reflections, or a 'Foot in the Closing Door.'" Pp. 9–31 in *Crossroads, Directions and A New Critical Race Theory*, edited by Francisco Valdes, Jerome Mccristal Culp, and Angela Harris. Philadelphia, PA: Temple University Press.
- Creswell, John W. 2007. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Thousand Oaks, CA: SAGE Publications, Inc.
- Crossley, Nick. 2001. "The Phenomenological Habitus and Its Construction." *Theory and Society* 30(1):81–120.
- Crossley, Nick. 2003. "From Reproduction to Transformation." *Theory, Culture & Society* 20(6):43–68.
- Crossley, Nick. 2006. "The Field of Psychiatric Contention in the UK, 1960-2000." *Social Science & Medicine* 62(3):552–63.
- Deer, Cécile. 2008. "Doxa." Pp. 119–30 in *Pierre Bourdieu: Key Concepts*, edited by Michael Grenfell. Stocksfield, UK: Acumen.
- Dei, George J. Sefa. 2003. "Why Write 'Black'?": Reclaiming African Culture Resource Knowledges in Diasporic Contexts." Pp. 211–30 in *Afrocentricity and the Academy: Essays on Theory and Practice*, edited by James L Conyers. Jefferson, N.C.: McFarland.
- Dei, George J. Sefa, Leeno Luke Karumanchery, and Nisha Karumanchery Luik. 2004. *Playing the Race Card: Exposing White Power and Privilege*. New York: Peter Lang.
- Delgado, Richard. and Jean Stefancic. 2012. *Critical Race Theory: An Introduction*. New York: New York University Press.
- Denzin, Norman K. 1989. *Interpretive Interactionism*. Newbury Park, Calif.: Sage Publications.
- Deresiewicz, William. 1991. "Against All Odds: Grass-Roots Minority Groups Fight AIDS." Pp. 534–42 in *The AIDS Reader: Social, Political, and Ethical Issues*, edited by Nancy F. McKenzie. New York, N.Y.: Meridian.
- Emirbayer, Mustafa and Victoria Johnson. 2008. "Bourdieu and Organizational Analysis." *Theory and Society* 37(1):1–44.

- Emirbayer, Mustafa and Erik Schneiderhan. 2012. "Dewey and Bourdieu on Democracy." Pp. 131–57 in *Bourdieu and Historical Analysis*, edited by Philip S Gorski. Durham, NC, USA: Duke University Press. Retrieved October 10, 2014 (<http://site.ebrary.com/lib/alltitles/docDetail.action?docID=10641611>).
- Emirbayer, Mustafa and Eva M. Williams. 2005. "Bourdieu and Social Work." *The Social Service Review* 79(4):689.
- Epstein, Steven. 1995. "The Construction of Lay Expertise - AIDS Activism and the Forging of Credibility in the Reform of Clinical Trials." *Science, Technology, & Human Values* 20(4):408–37.
- Epstein, Steven. 1996. *Impure Science: AIDS, Activism, and the Politics of Knowledge*. Berkeley: University of California Press.
- Epstein, Steven. 2000. "Democracy, Expertise and AIDS Treatment Activism." Pp. 15–32 in *Science, Technology and Democracy*, edited by Daniel Lee Kleinman. State University of New York Press.
- Epstein, Steven. 2007. *Inclusion: The Politics of Difference in Medical Research*. Chicago: University of Chicago Press.
- Epstein, Steven. 2008. "Culture and Science/Technology: Rethinking Knowledge, Power, Materiality, and Nature." *The ANNALS of the American Academy of Political and Social Science* 619(1):165–82.
- Feagin, Joe R. and Eileen O'Brien. 2010. "Studying 'Race' and Ethnicity: Dominant and Marginalized Discourses in the Critical North American Case." in *The SAGE Handbook of Race and Ethnic Studies*, edited by Patricia Hill Collins and John Solomos. London: SAGE Publications Ltd.
- Ford, Chandra L. and Collins O. Airhihenbuwa. 2010. "Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis." *American Journal of Public Health* 100(S1):S30–S35.
- Frazier, John W., Joe T. Darden, and Norah F. Henry. 2009. *The African Diaspora in the United States and Canada at the Dawn of the 21st Century*. Binghamton, NY: Global Academic Pub. Binghamton University.
- French, John D. 2000. "The Missteps Of Anti-Imperialist Reason: Bourdieu, Wacquant and Hanchard's Orpheus and Power." *Theory, Culture & Society* 17(1):107–28.
- Frickel, Scott, Sahra Gibbon, Jeff Howard, Joanna Kempner, Gwen Ottinger, and David J. Hess. 2010. "Undone Science: Charting Social Movement and Civil Society Challenges to Research Agenda Setting." *Science, Technology, & Human Values* 35(4):444–73.
- Frickel, Scott and Kelly. Moore. 2006. *The New Political Sociology of Science: Institutions, Networks, and Power*. Madison, Wis.: University of Wisconsin Press.

- Gamson, Josh. 1989. "Silence, Death, and the Invisible Enemy: AIDS Activism and Social Movement Newness." *Social Problems* 36:351.
- Gibbs, Graham R. 2010. "Bryman's 4 Stages of Qualitative Analysis." Online QDA. Retrieved April 20, 2012 (<http://onlineqda.hud.ac.uk/movies/Coding/>).
- Gieryn, Thomas F. 1983. "Boundary-Work and the Demarcation of Science from Non-Science: Strains and Interests in Professional Ideologies of Scientists." *American Sociological Review* 48(6):781–95.
- Gieryn, Thomas F. 1999. *Cultural Boundaries of Science: Credibility on the Line*. Chicago: University of Chicago Press.
- Gillett, James. 2003. "The Challenges of Institutionalization for AIDS Media Activism." *Media, Culture & Society* 25(5):607–24.
- Gould, Deborah B. 2009. *Moving Politics: Emotion and ACT UP's Fight Against AIDS*. Chicago: The University of Chicago Press.
- Grenfell, Michael. 2008a. "Interest." Pp. 153–70 in *Pierre Bourdieu: Key Concepts*, edited by Michael Grenfell. Stocksfield, UK: Acumen.
- Grenfell, Michael. 2008b. "Methodological Principles." Pp. 219–27 in *Pierre Bourdieu: Key Concepts*, edited by Michael Grenfell. Stocksfield, UK: Acumen.
- Guba, Egon G. and Yvonna S. Lincoln. 2005. "Paradigmatic Controversies, Contradictions, and Emerging Confluences." Pp. 191–215 in *The SAGE Handbook of Qualitative Research*, 3rd ed., edited by Norman K. Denzin and Yvonna S. Lincoln. SAGE Publications, Inc.
- Guillemin, Marilys and Lynn Gillam. 2004. "Ethics, Reflexivity, and 'Ethically Important Moments' in Research." *Qualitative Inquiry* 10(2):261–80.
- Guta, Adrian, Sarah Flicker, and Brenda Roche. 2013. "Governing through Community Allegiance: A Qualitative Examination of Peer Research in Community-Based Participatory Research." *Critical Public Health* 23(4):432–51.
- Halfpenny, Peter. 2001. "Positivism in the Twentieth Century." Pp. 371–86 in *Handbook of Social Theory*. Thousand Oaks, CA: SAGE Publications, Inc.
- Hall, Budd. 1993. "Introduction." Pp. xiii–xxii in *Voices of Change: Participatory Research in the United States and Canada*, edited by Peter. Park, Mary Brydon-Miller, Budd Hall, and Ted Jackson. Westport, Conn.: Bergin & Garvey.
- Hammersley, Martyn and Paul Atkinson. 2007. *Ethnography: Principles in Practice*. 3rd ed. London: Routledge.
- Hanchard, Michael. 2003. "Acts of Misrecognition: Transnational Black Politics, Anti-Imperialism and the Ethnocentrism of Pierre Bourdieu and Loïc Wacquant." *Theory, Culture & Society* 20(4):5–29.

- Haraway, Donna. 1988. "Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective." *Feminist Studies* 14(3):575–99.
- Harding, Sandra. 1992. "After the Neutrality Ideal: Science, Politics, and 'Strong Objectivity.'" *Social Research* 59(3):567.
- Harding, Sandra. 2004. "How Standpoint Methodology Informs Philosophy of Social Science." Pp. 62–80 in *Approaches to Qualitative Research: A Reader on Theory and Practice*. New York: Oxford University Press.
- Harding, Sandra. 2008. *Sciences from Below: Feminisms, Postcolonialities, and Modernities*. Durham: Duke University Press.
- Hartsock, Nancy C. M. 1983. *Money, Sex, and Power: Toward a Feminist Historical Materialism*. New York: Longman.
- Healey, Mark Alan. 2003. "Powers of Misrecognition: Bourdieu and Wacquant on Race in Brazil." *Nepantla: Views from South* 4(2):391–402.
- Hess, David J. 2004. "Medical Modernisation, Scientific Research Fields and the Epistemic Politics of Health Social Movements." *Sociology of Health & Illness* 26(6):695–709.
- Hess, David J., Steve Breyman, Nancy Campbell, and Brian Martin. 2008. "Science, Technology, and Social Movements." Pp. 473–98 in *The Handbook of Science and Technology Studies*, edited by Edward J Hackett, Olga Amsterdamska, Michael Lynch, and Judy Wajcman. Cambridge, Mass.: MIT Press.
- Hinote, Brian P. and Kenneth L. Wilson. 2006. "Sustaining AIDS Mobilization: The Problem of Late-Stage Mobilization among High-Risk HIV/AIDS Subpopulations." *Social Theory & Health* 4(1):25–42.
- HIV Endemic Task Force. 2003. *Strategy to Address Issues Related to HIV Faced by People in Ontario From Countries Where HIV Is Endemic*. Ontario: African and Caribbean Council on HIV/AIDS in Ontario. Retrieved November 28, 2009 (http://www.accho.ca/pdf/ACCHO_strategy_ENGLISH_Dec2003.pdf).
- Hoffman, Lily M. 1989. *The Politics of Knowledge: Activist Movements in Medicine and Planning*. Albany, N.Y.: State University of New York Press.
- hooks, bell and Cornel West. 1991. *Breaking Bread: Insurgent Black Intellectual Life*. Toronto: Between the Lines.
- Hunter, Margaret. 2002. "Rethinking Epistemology, Methodology, and Racism: Or, Is White Sociology Really Dead?" *Race and Society* 5(2):119–38.
- Husbands, Winston. 2009. "Resisting Against the System: Research with African, Caribbean, and Black Communities in Canada." Presented at the OHTN Summer Learning Institute, July 16, Toronto, ON. Retrieved June 13, 2014 (<http://www.ohtnweb.ca/sli/frmResources.aspx>).

- Indyk, Debbie and David A. Rier. 1993. "Grassroots AIDS Knowledge." *Science Communication* 15(1):3–43.
- International AIDS Society. 2014. "Conferences." *iasociety.org*. Retrieved July 17, 2014 (<http://www.iasociety.org/Default.aspx?pageId=3>).
- International Conference on Primary Health Care. 1978. "Declaration of Alma-Ata." USSR: World Health Organization. Retrieved July 14, 2014 (http://www.who.int/publications/almaata_declaration_en.pdf).
- James, Llana. 2009. *African, Caribbean and Black Canadian HIV/AIDS 2009 Think Tank Report*. Toronto, ON: African and Caribbean Council on HIV/AIDS in Ontario. Retrieved September 12, 2013 (http://www.accho.ca/pdf/2009_ACCHO_Think_Tank_Report_Final.pdf).
- James, Carl, David Este, and Wanda Thomas Bernard. 2010. *Race & Well-Being: The Lives, Hopes, and Activism of African Canadians*. Black Point, N.S.: Fernwood Pub.
- Jamison, Andrew. 2006. "Social Movements and Science: Cultural Appropriations of Cognitive Praxis." *Science as Culture* 15(1):45–59.
- Jenkins, Richard. 1992. *Pierre Bourdieu*. London: Routledge.
- Jasanoff, Sheila S. 1987. "Contested Boundaries in Policy-Relevant Science." *Social Studies of Science* 17(2):195–230.
- Keefe, Robert H., Sandra D. Lane, and Heidi J. Swarts. 2006. "From the Bottom Up: Tracing the Impact of Four Health-Based Social Movements on Health and Social Policies." *Journal of Health* 21(3):55–69.
- Kincheloe, Joe L. and Peter McLaren. 2005. "Rethinking Critical Theory and Qualitative Research." Pp. 303–342 in *The SAGE Handbook of Qualitative Research*, 3rd ed., edited by Norman K. Denzin and Yvonna S. Lincoln. Thousand Oaks, CA: SAGE Publications, Inc.
- King, Anthony. 2000. "Thinking with Bourdieu against Bourdieu: A 'Practical' Critique of the Habitus." *Sociological Theory* 18: 417-433.
- Klawiter, Maren. 2004. "Breast Cancer in Two Regimes: The Impact of Social Movements on Illness Experience." *Sociology of Health & Illness* 26(6):845.
- Kleinman, Arthur. 1981. *Patients and Healers in the Context of Culture: An Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry*. Berkeley: University of California Press.
- Kleinman, Daniel Lee and Abby J. Kinchy. 2003. "Boundaries in Science Policy Making: Bovine Growth Hormone in the European Union." 44(4):577–95.
- Krimsky, Sheldon. 2000. *Hormonal Chaos: The Scientific and Social Origins of the Environmental Endocrine Hypothesis*. Baltimore, MD: Johns Hopkins University Press.

- Kvale, Steinar. 1996. *InterViews: An Introduction to Qualitative Research Interviewing*. Thousand Oaks, Calif.: Sage Publications.
- Lareau, Annette and Erin McNamara Horvat. 1999. "Moments of Social Inclusion and Exclusion: Race, Class, and Cultural Capital in Family-School Relationships." *Sociology of Education* 72(1):37–53.
- Latour, Bruno. 1993. *The Pasteurization of France*. Cambridge, Mass.: Harvard University Press.
- Lee, Jo-Anne, and John S. Lutz. 2005. "Toward a Critical Literacy of Racism, Anti-Racisms, and Racialization." Pp. 3–29 in *Situating "Race" and Racisms in Time, Space, and Theory: Critical Essays for Activists and Scholars*. Montréal: McGill-Queen's University Press.
- Lemelle, Anthony J. 2002. "Racialized Social System and HIV Infection: The Case of African Americans." *International Journal of Sociology and Social Policy* 22(4/5/6):133–58.
- Lemelle, Anthony J. and Barbara M. Scott. 2006. "African American HIV/AIDS and Social Institutions: New Realities Calling for New Policies." in *Free at Last? Black America in the Twenty-first Century*, edited by Juan Battle, Michael Bennet, and Anthony J. Lemelle. New Brunswick, NJ: Transaction Publishers.
- Lieberman, Evan S. 2009. *Boundaries of Contagion: How Ethnic Politics Have Shaped Government Responses to AIDS*. Princeton, N.J.: Princeton University Press.
- Lincoln, Yvonna. 1995. "Emerging Criteria for Quality in Qualitative and Interpretive Research." *Qualitative Inquiry* 1(3):275–89.
- MacLean, L. M., M. Meyer and A. Estable. 2004. "Improving Accuracy of Transcripts in Qualitative Research." *Qualitative Health Research* 14(1):113–23.
- Maguire, Steve, Cynthia Hardy, and Thomas Lawrence. 2004. "Institutional Entrepreneurship in Emerging Fields: HIV/AIDS Treatment Advocacy in Canada." *Academy of Management Journal* 47(5):657–79.
- Mason, Tina L., Daniel G. Oliver, and Julianne M. Serovich. 2005. "Constraints and Opportunities with Interview Transcription: Towards Reflection in Qualitative Research." *Social Forces* 84(2):1273–89.
- Massaquoi, Notisha. 2007. "An Unsettled Feminist Discourse." Pp. 75–94 in *Theorizing Empowerment: Canadian Perspective on Black Feminist Thought*, edited by Notisha Massaquoi and Njoki Nathani Wane. Toronto, ON: Inanna Publications and Education Inc.
- McAdam, Doug, John D. McCarthy, and Mayer N. Zald. 1988. "Social Movements." Pp. 695–737 in *Handbook of Sociology*, edited by Neil J. Smelser. Newbury Park, Calif.: Sage Publications.
- McCaskell, Tim. 2012a. "A Brief History of AIDS Activism in Canada." *socialist.ca*. Retrieved July 17, 2014 (<http://www.socialist.ca/node/1453>).

- McCaskell, Tim. 2012b. "How AIDS Activists Changed Canadian Health Policy." *Dailyxtra.com*. Retrieved July 17, 2014 (<http://dailyxtra.com/canada/news/aids-activists-changed-canadian-health-policy>).
- McCormick, Sabrina, Phil Brown, and Stephen Zavestoski. 2003. "The Personal Is Scientific, the Scientific Is Political: The Public Paradigm of the Environmental Breast Cancer Movement." *Sociological Forum* 18(4):545–76.
- McLellan, Eleanor. 2003. "Beyond the Qualitative Interview: Data Preparation and Transcription." *Field Methods* 15(1):63–84.
- McLeod, Julie. 2005. "Feminists Re-reading Bourdieu." *Theory and Research in Education* 3(1):11–30.
- Meyer, David S. and Nancy Whittier. 1994. "Social Movement Spillover." *Social Problems* 41(2):277–98.
- Miles, Matthew B. and Michael Huberman. 1994. *Qualitative Data Analysis: An Expanded Sourcebook*. Thousand Oaks: Sage Publications.
- Moore, Kelly. 2006. "Powered by the People: Scientific Authority in Participatory Science." Pp. 229–323 in *The New Political Sociology of Science: Institutions, Networks, and Power*, edited by Scott. Frickel and Kelly. Moore. Madison, Wis.: University of Wisconsin Press.
- Moore, Kelly and Nicole Hala. 2002. "Organizing Identity: The Creation of Science for the People." *Research in the Sociology of Organizations* 19:309–35.
- Mukherjea, Ananya and Salvador Vidal-Ortiz. 2006. "Studying HIV Risk in Vulnerable Communities: Methodological and Reporting Shortcomings in the Young Men's Study in New York City." *Qualitative Report* 11(2):393–416.
- Murphy, E., R. Dingwall, D. Greatbatch, S. Parker, and P. Watson. 1998. "Qualitative Research Methods in Health Technology Assessment: A Review of the Literature." *Health Technol Assessment* 2(16).
- Mykhalovskiy, Eric and Marsha Rosengarten. 2009. "Commentaries on the Nature of Social and Cultural Research: Interviews on HIV/AIDS with Judy Auerbach, Susan Kippax, Steven Epstein, Didier Fassin, Barry Adam and Dennis Altman." *Social Theory & Health* 7(3):284–304.
- Nelson, Alondra. 2011. *Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination*. Minneapolis: University of Minnesota Press.
- Nussbaum, Bruce. 1990. *Good Intentions: How Big Business and the Medical Establishment are Corrupting the Fight Against AIDS*. New York: Atlantic Monthly Press.
- Ontario AIDS Network (OAN). 2011. "The Ontario Accord: Statement of Solidarity with GIPA/MIPA." *Ontario AIDS Network*. Retrieved July 17, 2014 (<http://ontarioaidsnetwork.on.ca/ontario-accord/>).

- Ontario HIV Treatment Network (OHTN). 2009a. "OHTN Use of Grants Guidelines." *ohtn.on.ca*. Retrieved August 30, 2013 (<http://www.ohtn.on.ca/pages/funding/guidelines.aspx>).
- Ontario HIV Treatment Network (OHTN). 2009b. "What Is the Research Conference?" *ohtn.on.ca*. Retrieved July 17, 2014 (<http://www.ohtn.on.ca/pages/about-us/FAQs.aspx#general01>).
- Ontario HIV Treatment Network (OHTN). 2011. "OHTN Research Conferences." Retrieved November 1, 2011 (<http://conference.ohtn.on.ca/Conference/index.php>).
- Ontario HIV Treatment Network (OHTN). 2014. "Funding." *ohtn.on.ca*. Retrieved July 17, 2014 (<http://www.ohtn.on.ca/Pages/About-Us/Who-We-Are.aspx>).
- Panofsky, Aaron. 2011. "Field Analysis and Interdisciplinary Science: Scientific Capital Exchange in Behavior Genetics." *Minerva* 49(3):295–316.
- Parker, Richard G. 2009. "Civil Society, Political Mobilization, and the Impact of HIV Scale-Up on Health Systems in Brazil." *Journal of Acquired Immune Deficiency Syndromes* 52(Suppl. 1):S49–S51.
- Patton, Cindy. 1990. *Inventing AIDS*. New York: Routledge.
- Patton, Michael Quinn. 1999. "Enhancing the Quality and Credibility of Qualitative Analysis." *Health Services Research* 34.5 Pt 2:1189–1208.
- Patton, Michael Quinn. 2002. *Qualitative Research & Evaluation Methods*. 3rd ed. Thousand Oaks, CA: SAGE Publications, Inc.
- Philip, M. Nourbese. 1997. *A Genealogy of Resistance: And Other Essays*. Toronto, ON: Mercury Press.
- Poland, Blake D. 1995. "Transcription Quality as an Aspect of Rigor in Qualitative Research." *Qualitative Inquiry* 1(3):290–310.
- Psathas, George and Timothy Anderson. 1990. "The 'Practices' of Transcription in Conversation Analysis." *Semiotica: Journal of the International Association for Semiotic Studies* 78(1/2):75–99.
- Public Health Agency of Canada. 1982. "Pneumocystis Carinii Pneumonia in a Homosexual Male-Ontario." *Canada Diseases Weekly Report* 8(13):65–67.
- Public Health Agency of Canada. 2009. *Population-Specific HIV/AIDS Status Report-People from Countries Where HIV is Endemic*. Ottawa, ON: Public Health Agency of Canada.
- Quimby, Ernest and Samuel R. Friedman. 1989. "Dynamics of Black Mobilization against AIDS in New York City." *Social Problems* 36(4):403–15.
- Reay, Diane. 1995. "'They Employ Cleaners to Do That': Habitus in the Primary Classroom." *British Journal of Sociology of Education* 16(3):353–71.

- Remis, Robert S., Carol Swantee, Lorraine Schiedel, and Juan Liu. 2007. *Report on HIV/AIDS in Ontario 2005*. Toronto, ON: Ontario Ministry of Health and Long-Term Care. Retrieved June 14, 2014 (http://www.ohemu.utoronto.ca/doc/PHERO2005_report.pdf).
- Remis, Robert S., Carol Swantee, Lorraine Schiedel, and Juan Liu. 2008. *Report on HIV/AIDS in Ontario 2006*. Toronto, ON: Ontario Ministry of Health and Long-Term Care. Retrieved June 14, 2014 (http://www.ohemu.utoronto.ca/doc/PHERO2006_report_final.pdf).
- Remis, Robert S. and Elaine P. Whittingham. 1999. *The HIV/AIDS Epidemic Among Persons from HIV-Endemic Countries in Ontario, 1981-98: Situation Report*. Toronto, ON: Department of Public Health Sciences, University of Toronto. Retrieved June 13, 2014 (<http://www.ohemu.utoronto.ca/doc/technical%20reports/Endemic+tables+figs.pdf>).
- Reynolds, Tracey. 2002. "On Relations Between Black Female Researchers and Participants." Pp. 300–309 in *Qualitative Research in Action*, edited by Tim May. Thousand Oaks, CA: SAGE Publications, Inc.
- Ritchie, Jane and Jane Lewis. 2003. *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Thousand Oaks, Calif.: SAGE Publications, Inc.
- Rodney, Patricia, and Esker Copeland. 2009. "The Health Status of Black Canadians: Do Aggregated Racial and Ethnic Variables Hide Health Disparities?" *Journal of Health Care for the Poor and Underserved* 20(3):817–23.
- Royles, Dan. 2014. "Don't We Die Too?": The Political Culture of African American AIDS Activism." PhD Dissertation, Department of History, Temple University, Philadelphia, PA. Retrieved July 17, 2014 (<http://gradworks.umi.com/36/11/3611169.html>).
- Said, Edward W. 1978. *Orientalism*. New York: Pantheon Books.
- Schoepf, Brooke G. 2001. "International AIDS Research in Anthropology: Taking a Critical Perspective on the Crisis." *Annual Review of Anthropology* 30:335–61.
- Shapin, Steven. 1995. "Cordelia's Love: Credibility and the Social Studies of Science." *Perspectives on Science* 3(3):255–75.
- Shilts, Randy. 1988. *And the Band Played on: Politics, People, and the AIDS Epidemic*. New York: St Martin's Press.
- Shim, Janet K. 2000. "Bio-Power and Racial, Class, and Gender Formation in Biomedical Knowledge Production." *Research in the Sociology of Health Care* 17:173–95.
- Silverman, David. 2005. *Doing Qualitative Research: A Practical Handbook*. Thousand Oaks, CA: SAGE Publications, Inc.
- Smith, Dorothy E. 1990. *The Conceptual Practices of Power: A Feminist Sociology of Knowledge*. Boston, Mass.: Northeastern University Press.
- Smith, Linda Tuhiwai. 2012. *Decolonizing Methodologies: Research and Indigenous Peoples*. London: Zed Books.

- Stanley, Liz. 1990. "Feminist Praxis and the Academic Mode of Production: An Editorial Introduction." Pp. 3–19 in *Feminist Praxis and the Academic Mode of Production: An Editorial Introduction*, edited by Liz Stanley. New York: Routledge.
- Statistics Canada. 2008. *Canada's Ethnocultural Mosaic, 2006 Census: National Picture*. Ottawa, ON: Statistics Canada. Retrieved June 13, 2014 (<https://www12.statcan.gc.ca/census-recensement/2006/as-sa/97-562/p2-eng.cfm>).
- Stockdill, Brett C. 2003. *Activism Against AIDS: At the Intersection of Sexuality, Race, Gender, and Class*. Boulder, Colo: Lynne Rienner Publishers.
- Stoller, Nancy E. 1998. *Lessons from the Damned: Queers, Whores, And Junkies Respond to AIDS*. New York: Taylor & Francis Group.
- Swartz, David L. 2012. "Metaprinciples for Sociological Research in a Bourdieusian Perspective." Pp. 19–35 in *Bourdieu and Historical Analysis*, edited by Philip S Gorski. Durham, NC, USA: Duke University Press. Retrieved October 10, 2014 (<http://site.ebrary.com/lib/alltitles/docDetail.action?docID=10641611>).
- Swedberg, Richard. 2005. "Can There Be a Sociological Concept of Interest?" *Theory and Society* 34(4):359–90.
- Taylor, Verta, Nancy Whittier, Alan D. Morris, and Carol McClurg Mueller. 1992. "Collective Identity in Social Movement Communities: Lesbian Feminist Mobilization." Pp. 104–29 in *Frontiers in Social Movement Theory*. New Haven, Conn: Yale University Press.
- Tharao, Esther and Robert S. Remis. 2002. "History of the HIV Endemic Task Force (HETF) and Its Activities: Retracing the Footsteps." Presentation to the Federal-Provincial-Territorial Advisory Committee on AIDS, February 2, Victoria, BC. Retrieved June 13, 2014 (<http://www.ohemu.utoronto.ca/Presentations.html#1998>).
- Tierney, William G. 1993. *Building Communities of Difference: Higher Education in the Twenty-First Century*. Westport, Conn.: Bergin & Garvey.
- Travers, R., M.G. Wilson, S. Flicker, A. Guta, T. Bereket, C. McKay, A. van der Meulen, S. Cleverly, M. Dickie, J. Globerman, and S.B. Rourke. 2008. "The Greater Involvement of People Living with AIDS Principle: Theory Versus Practice in Ontario's HIV/AIDS Community-Based Research Sector." *AIDS Care* 20(6):615–24.
- Treichler, Paula A. 1999. *How to Have Theory in an Epidemic: Cultural Chronicles of AIDS*. Durham: Duke University Press.
- UNAIDS. 1999. *From Principle to Practice: Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA). Best Practice Key Material*. Switzerland: UNAIDS. Retrieved October 28, 2014 (http://data.unaids.org/publications/IRC-pub01/jc252-gipa-i_en.pdf).

- UNAIDS. 2007. *Financial Resources Required to Achieve Universal Access to HIV Prevention, Treatment, Care and Support*. Geneva: The Joint United Nations Programme on HIV/AIDS (UNAIDS). Retrieved June 2, 2010 (http://data.unaids.org/pub/Report/2007/jc1678_fin_res_req_en.pdf).
- UNAIDS. 2013. *Global Report: UNAIDS Report on the Global AIDS Epidemic*. Geneva: Joint United Nations Program on HIV/AIDS (UNAIDS) and World Health Organization (WHO). Retrieved (http://www.unaids.org/sites/default/files/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf).
- Vandormael, A. 2007. "The TAC's 'Intellectual Campaign' (2000-2004): Social Movements and Epistemic Communities." *POLITIKON* 34(2):217–33.
- Vincent, Robin and Lucy Stackpool-Moore. 2009. "Moved to Act: Communication Supporting HIV Social Movements to Achieve Inclusive Social Change." *Development in Practice* 19(4-5):630–42.
- Wacquant, Loïc J. D. 1992. "Toward a Social Praxeology: The Structure and Logic of Bourdieu's Sociology." in *An Invitation to Reflexive Sociology*, edited by Pierre. Bourdieu and Loïc J. D. Wacquant. Chicago: University of Chicago Press.
- Wacquant, Loïc J. D. 1997. "For an Analytic of Racial Domination." *Political Power and Social Theory* 11:221–34.
- Wacquant, Loïc J. D. 1998. "Pierre Bourdieu." Pp. 215–29 in *Key Sociological Thinkers*. Houndmills, Basingstoke, Hampshire: Macmillan Press.
- Wacquant, Loïc J. D. 2001. "Deadly Symbiosis: When Ghetto and Prison Meet and Mesh." *Punishment & Society* 3(1):95–133.
- Wacquant, Loïc. 2004. "Pointers on Pierre Bourdieu and Democratic Politics." *Constellations* 11(1):3–15.
- Wacquant, Loïc. 2005. "Race as Civic Felony." *International Social Science Journal* 57(183):127–42.
- Wacquant, Loïc. 2009. "The Body, the Ghetto and the Penal State." *Qualitative Sociology* 32(1):101–29.
- Wacquant, Loïc. 2010. "Class, Race & Hyperincarceration in Revanchist America." *Daedalus* 139(3):74.
- Walcott, Rinaldo. 2003. *Black Like Who?: Writing Black Canada*. Insomniac Press.
- Women's Health in Women's Hands. 2014. "Women's Health in Women's Hands." Retrieved May 2, 2014 (<http://www.whiwh.com>).
- Wolcott, Harry F. 1994. *Transforming Qualitative Data: Description, Analysis, and Interpretation*. Thousand Oaks, Calif.: Sage Publications.

- World Health Organization (WHO). 2014. *The Top 10 Causes of Death*. Geneva: World Health Organization. Retrieved November 10, 2014 (<http://www.who.int/mediacentre/factsheets/fs310/en/>).
- Yosso, Tara J. 2005. "Whose Culture Has Capital? A Critical Race Theory Discussion of Community Cultural Wealth." *Race Ethnicity and Education* 8:69–91.
- Yosso, Tara J. and Daniel G. Solórzano. 2005. "Conceptualizing a Critical Race Theory in Sociology." Pp. 118–45 in *The Blackwell Companion to Social Inequalities*, edited by Mary Romero and Eric Margolis. Malden, MA: Blackwell.
- Zavestoski, Stephen, Rachel Morell-Frosch, Phil Brown, Brian Mayer, Sabrina McCormick, and Rebecca Gasior Altman. 2004. "Embodied Health Movements and Challenges to the Dominant Epidemiological Paradigm." *Research in Social Movements, Conflicts and Change* 25:253–78.

Appendices

Appendix A – Funding Databases

Canadian Foundation for AIDS Research (CANFAR)

http://www.canfar.com/en_CA/p/canfar-research-grants-recipients

Years: 2002-2010

Canadian Institutes for Health Research (CIHR)

<http://www.cihr-irsc.gc.ca/e/38021.html>

Years: 2003-2010 (included up until June 2011)

Ontario HIV Treatment Network (OHTN)

<http://www.ohtn.on.ca/Pages/Funding/Results-All.aspx>

Years: 2002-2010

Social Sciences and Humanities Research Council (SSHRC)

<http://www.outil.ost.uqam.ca/CRSH/RechProj.aspx?vLangue=Anglais>

2002-2010



Appendix B – Information Letter

Knowledge Production and Power in HIV Research: African, Caribbean and Black Community Engagement with Science

I am a PhD candidate at the University of Toronto, Dalla Lana School of Public Health, under the supervision of Professor Peggy McDonough. This research project is being conducted as part of my PhD requirements. The following are the main questions that inform this study:

1. What does the field of African, Caribbean, and Black HIV research in Ontario look like and what informs the setting of research priorities?
2. How do African, Caribbean and Black organizations and actors in the Ontario HIV sector use and produce scientific research in their attempt to define a community response to HIV?

The purpose of this letter is to request your participation in this study as a voluntary participant.

What is this study about?

This purpose of this study is to learn more about how HIV-related scientific knowledge is produced by, for, and about Ontario's African, Caribbean, and Black community. This will involve an examination of community research priorities and how these priorities affect the field of HIV research generally. It will also involve an exploration of the ideologies that inform HIV research about the African, Caribbean, and Black community and differences in community and academic perspectives.

Why is this study important?

This study will provide insight into how scientific research about HIV is produced by, for, and about Ontario's African, Caribbean, and Black community. Because of the significant role research plays in defining practical responses to HIV, understanding how research is shaped and produced will be useful for community activists, service providers, policy makers, and researchers.

This study may also contribute to the broader goal of understanding how the interaction between community advocacy and science informs the overall response to public health issues.

How will this study be conducted?

This research project is qualitative in design and consists of two stages of data collection. The objective of stage one will be to understand the range and nature of HIV research being conducted about the African, Caribbean, and Black community through the analysis of key documents. Stage two will entail interviews with key researchers involved with African, Caribbean, and Black HIV-related research, both in community and academic settings, to understand their opinions about how research about these communities is, and should be, conducted.

Who is being approached to participate in this study?

I will be approaching approximately 20-25 key researchers who have, or have had, research projects about HIV in African, Caribbean, and Black communities in Ontario. Participants will represent a range of scientific disciplines and community organizations.

What would you be asked to do as a participant?

You would be asked to take part in an hour-long interview in a location of your choice or over the telephone if you are located outside of Toronto. The interview will be recorded (with your permission) and transcribed. The interview will focus on your research, your professional background, and your opinions concerning HIV research about the African, Caribbean, and Black community in Ontario.

If you choose to participate in this study, you may withdraw at any time. If you choose to stop participating during an interview, you may decide whether you want your interview data destroyed.

How will your confidentiality be protected?

I will aim to keep your participation anonymous; however, I can not guarantee your anonymity. Please keep this in mind if you decide to participate in the interview. At no time will your name be used when the study results are presented or published. When the results are presented, only broad terms will be used to describe your location in HIV research (e.g., community or university). Also, your professional identity will be masked and your organization will not be named. However, you also have the option of being identified, if you wish. In this case, your name may be used in relation to direct quotes in the study results.

All collected data will be kept in a locked cabinet and a password-protected computer. Access to the primary data will be limited to me and members of my thesis committee (Peggy McDonough, Erica Lawson, and Mathieu Albert).

Thank you for taking the time to consider participating in this study. Please contact me at kimberly.gray@utoronto.ca or **416-830-6034** if you have any questions or wish to take part in the study.

Sincerely,



Kimberly Gray



Appendix C – Consent Form

Knowledge Production and Power in HIV Research: African, Caribbean and Black Community Engagement with Science

You are invited to take part in a qualitative study about HIV-related research in Ontario's African, Caribbean, and Black community. This study is being conducted by Kimberly Gray as part of her PhD requirements at the University of Toronto, Dalla Lana School of Public Health under the supervision of Professor Peggy McDonough.

You have been asked to participate because you are a researcher in the area of HIV. You are under no obligation to participate.

Why is this study being done?

This purpose of this study is to learn more about how HIV-related scientific knowledge is produced by, for, and about Ontario's African, Caribbean, and Black community. This will involve an examination of community research priorities and how these priorities affect the field of HIV research generally. It will also involve an exploration of the ideologies that inform HIV research about the African, Caribbean, and Black community and differences in community and academic perspectives.

Because of the significant role research plays in defining practical responses to HIV, understanding how research is shaped and produced will be useful for community activists, service providers, policy makers, and researchers.

What will the interview involve?

The interview will be approximately one hour in length and conducted at a location of your choice or over the telephone if you are located outside of Toronto. With your permission, the interview will be recorded. With your consent, you may also be contacted again by Kimberly Gray if clarification or elaboration is needed about certain comments you make during the interview.

By participating, you may be answering questions about:

- the research that you undertake regarding HIV and Ontario's African, Caribbean, and Black communities,
- your professional background in relation to your work in HIV research, and
- your experience and opinions concerning HIV research about the African, Caribbean, and Black community in Ontario.

Who is being approached to participate in this study?

Approximately 20-25 key researchers who have, or have had, research projects about HIV and Ontario's African, Caribbean, and Black community will be approached to participate. Participants will represent a range of scientific disciplines and community organizations.

How will your confidentiality be protected?

The researchers will aim to keep your participation anonymous; however, your anonymity can not be guaranteed. Please keep this in mind if you decide to participate in the interview. At no time will your name or organization's name be used in relation to the study results. When the results are presented or published, only broad terms will be used to describe your location in HIV research (e.g., community or university) and your professional identity. However, you also have the option of being identified, if you wish. In this case, your name may be used in relation to direct quotes in the study results.

All collected data will be kept in a locked cabinet and a password-protected computer. Access to the primary data is limited to the researchers involved in this study.

What if you change your mind?

You may withdraw from the study at any time. If you choose to stop during an interview, you may decide whether you want your interview data destroyed. There are no negative consequences to you if you choose to stop the interview or withdraw from the study.

Are there any risks to participating?

There are thought to be few risks to participating because you are already involved in research about HIV in African, Caribbean, and Black communities.

Are there any benefits to participating?

Participation may offer no direct personal benefits to you. However, your participation in the study may contribute to the broader goal of understanding how the interaction between community advocacy and science informs the overall response to public health issues.

Will the results be published?

The results from this study may be published in scholarly journals and community publications and presented at research conferences and community venues. You can contact Kimberly Gray if you wish to receive a copy of a published report or presentation.

Who do I contact if I have questions?

If you have any questions about your participation in the study, please contact Kimberly Gray, the principal investigator and interviewer, at kimberly.gray@utoronto.ca or 416-830-6034.

You can also contact her supervisor Peggy McDonough at peggy.mcdonough@utoronto.ca or 416-946-7936.

If you have any concerns about your rights as a participant, you can contact the Office of Research Ethics at ethics.review@utoronto.ca or 416-946-3273.

Consent and signatures

I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to taking part in the study with the understanding that I may withdraw at any time without any consequences. I have received a signed copy of this consent form.

I consent to a follow-up interview in the event that clarification or elaboration is

necessary: Yes No

I am willing to have this interview recorded: Yes No

I consent to having my name used in the study results: Yes No

I voluntarily consent to participate in this study and continue with the interview.

Signature of participant

Date

I believe the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of investigator/interviewer

Date

Name of investigator/interviewer

Appendix D – Interview Guide

A. Background

First I will ask you some questions about your professional background. This will help me understand your answers in relation to your professional training, work experience, and current work environment.

Question	Probe
1. What is your current position and organizational affiliation?	<ul style="list-style-type: none"> ○ How long at this position and organization ○ History at organization
2. How did you come to do HIV research?	<ul style="list-style-type: none"> ○ Highest degree obtained ○ Other relevant training ○ Involvement with community activism? (either HIV or other social causes)
3. How long have you been working in HIV research?	<ul style="list-style-type: none"> ○ Working or volunteering ○ Other HIV-related work besides research
4. Can you tell me a bit about the research you have been involved in (in relation to HIV and the ACB community)?	<ul style="list-style-type: none"> ○ How did you become interested in this research? ○ Who have you worked with? ○ How has your organization worked with ACB community in relation to HIV research? ○ In what capacity have you been involved in research? ○ Current projects

B. Research in the African, Caribbean, and Black Community

Now I would like to ask you about your opinions in relation to HIV research about Ontario's African, Caribbean and Black community.

Question	Probe
1. What kind of HIV research do you think should be prioritised for the ACB community? <i>Leave open before probing.</i>	<ul style="list-style-type: none"> ○ e.g., scientific disciplines, substantive areas, sub-groups to be addressed, community or academic ○ What does research mean to you/why is research important?

<p>2. What do you think is currently missing from the HIV research agenda concerning the ACB community? <i>Leave open before probing.</i></p>	<ul style="list-style-type: none"> ○ Why do you think this? ○ Do you think this will change (i.e., that this gap will be filled)? <ul style="list-style-type: none"> ○ Why or why not?
<p>3. How you think ACB community members should be involved in HIV research?</p>	<ul style="list-style-type: none"> ○ Why? ○ What should the relationship look like between community and academic researchers? ○ What is your experience working with community/academic researchers?
<p>4. Can you reflect on what challenges the ACB community has faced as it tries to put forward a community research agenda? <i>Leave open before probing.</i></p>	<ul style="list-style-type: none"> ○ Do you think their position as a racialized community has affected this process? ○ Do you think race is a factor? ○ Personal experiences as Black researcher in HIV research
<p>5. What do you think researchers have to do in order to get funded (to do HIV research about/with the ACB community)?</p>	<ul style="list-style-type: none"> ○ Why do you think it is this way? ○ Do you agree with this? ○ How have <i>you</i> managed to secure funding?
<p>6. Can you share with me any situations where you have not been successful obtaining funding?</p>	<ul style="list-style-type: none"> ○ How did you overcome these?
<p>7. Is there anything else you would like to be done differently in HIV research about the ACB community?</p>	<ul style="list-style-type: none"> ○ Why?

Thank you very much for participating in this research. As we discussed earlier, I will contact if I have any further clarifications.

Appendix E – Guidelines for Transcription of Interviews

The following principles underlie the guidelines:

1. *Preserve the morphologic naturalness of transcription.* Keep word forms, the form of commentaries, and the use of punctuation as close as possible to speech presentation and consistent with what is typically acceptable in written text; every utterance should be transcribed. Transcripts should include elisions, mispronunciations, slang, grammatical errors, and nonverbal sounds.
2. *Preserve the naturalness of the transcript structure.* Keep text clearly structured by speech markers
3. *The transcript should be an exact reproduction.* Generate a verbatim account. Do not prematurely reduce text.

FORMATTING

1. Arial 10-point font
2. One inch top, bottom, right and left margins.
3. No indents and all text left justified
4. In the transcript, refer to participant by their id (e.g., P013) and interviewer as “I”.
5. To save transcripts, use the file name “KG Transcript P(ID e.g., 013) [transcriber’s initials]”.
6. Include page number in footnote (e.g., 1 of 24) and participant ID.

Information to include at the top of the first page of each transcript:

1. Participant ID
2. Date of interview
3. Location
4. Transcriber’s initials
5. Date transcribed

CONTENT

Audio recordings shall be transcribed verbatim (i.e., recorded word for word) including nonverbal sounds (e.g., laughter, sighs, coughs).

- Nonverbal noises and sounds that are not words should be typed in angled brackets, for example <laughs> <telephone rings>.
- If words are mispronounced they should be transcribed just as the individual said them (e.g., slang, misuse of words, grammatical errors).
- Filler words (e.g., hm, huh, mmm, uh huh, yeah, ahah) should also be transcribed.
- Word or phrase repetitions shall be transcribed. If a word is cut off a hyphen shall be inserted at the end of the last letter or audible sound (e.g., he wen- he went and did what I told him to).
- Use capitals to denote strong emphasis or raised voice and italics for distinct change in tone.

Pauses

If a substantial speech delay occurs at either beginning or during a statement (more than two or three seconds), the transcriber shall use “long pause” in brackets.

Example:

Sometimes the individual may require additional time to construct a response. (Long pause) other times, he or she is waiting for additional instructions or probes.

Overlapping speech and interviewer's interruptions

If the interviewer uses encouraging words/noises (e.g., um, mmm, hmm, ah), try to phonetically spell the words and start a new line .

Example:

P099: Um, say not being from the community, I don't have the innate ability to sort of *get it*

I: Right

P099: Um, but I, I think the workers are get, overwhelmed um with the bigger, um, societal issues, the point that I think people get almost paralyzed

I: mmm

If there is overlapping speech, use a dash to indicate when one of the speakers starts to speak before the first speaker is finished.

Example:

P099: (big sigh) So it's a bit frustrating. Umm so that would be-e-e like, the biggest, struggle. I don't know if you know what I'm (laughing) talking about -

I: (laughing) I know what you're talking about. (both laughing)

Questionable Text

If words are inaudible or difficult to decipher, type the word inaudible in brackets, for example (inaudible).

If the transcriber understands the word but is unsure of the accuracy, place the word(s) inside two question marks.

Example:

P099: I went over to the club on ?Avalon? to meet with the street outreach team.

Sensitive Information

If an individual uses his or her own name during the discussion, the transcriber shall replace this information with the appropriate interviewee identification label/naming convention.

Example:

P099: My family always reminds me, "P99, think about things before you open your mouth."

If an individual provides others' names, locations, organizations, and so on, the transcriber shall enter an equal sign immediately before and after the named information. The analyst will use this labeling information to easily identify sensitive information that may require substitution.

Example:

P099: We went over to =John Doe's= house last night and we ended up going to = O'Malley's Bar= over on =22nd Street= and spending the entire night talking about the very same thing.

Making the text more readable

The analyst will use square brackets to add text that will help make the text more understandable, particularly when presenting results.

Example:

P099: But also, so we've talked a bit about the community, what about the, how, how can the community [be] successful at getting funding -

References

- Eleanor McLellan, Kathleen M. MacQueen and Judith L. Neidig (2003) Beyond the Qualitative Interview: Data Preparation and Transcription *Field Methods* 15: 63
- Poland, Blake (1995) Research Transcription Quality as an Aspect of Rigor in Qualitative Research *Qualitative Inquiry* 1: 290

Appendix F – Glossary for Transcription of Interviews

Acronym/term	Explanation
A/C track	African and Caribbean HIV surveillance track – study run by the Public Health Agency of Canada
ACB	African, Caribbean and Black community(ies) – an inclusive term used to describe the Black community in Ontario
ACCHO (pronounced Ah-cho)	African and Caribbean Council on HIV/AIDS in Ontario
ACT (pronounced Act)	AIDS Committee of Toronto
APAA (pronounced Apa)	Africans in Partnership Against AIDS
BlackCap (pronounced as written)	Black Coalition for AIDS Prevention
CAAN (pronounced Can)	Canadian Aboriginal AIDS Network
CAB (pronounced Cab)	Community Advisory Board
CAC	Community Advisory Committee
CBO	Community-based organization
CBR	Community based research
CIHR	Canadian Institutes of Health Research
DEBI (pronounced as written)	Diffusion of Effective Behavioural Interventions – a database in the US of effective HIV interventions
Epi (pronounced Epi)	Epidemiology
IDUs	Intravenous drug users – another community affected by HIV
KTA	Knowledge, Translation to Action
KTE	Knowledge, Translation and Exchange
LGBTQ	Lesbian, gay, bi-sexual, trans-sexual, queer community – an inclusive term to describe various groups in the gay community
MSM	Men who have sex with men – an inclusive term for the gay community (i.e., includes men who have sex with men who do not identify as gay)
OHTN	Ontario HIV Treatment Network
PHA (pronounced P-H-A)	Person living with HIV or AIDS
PHAC (pronounced either Fac or P-hac)	Public Health Agency of Canada
PI	Principal Investigator
RA or RC	Research Assistant or Research Coordinator
SSHRC (pronounced Shirc)	Social Sciences and Humanities Research Council
U of T	University of Toronto
Women's Health	Women's Health in Women's Hands – a community health clinic for Black women often referred to as 'Women's Health'

Appendix G – Key for Participant Acronyms in Results Chapters

Acronym Breakdown	Description	Participant Label
AN	Non-ACB academic researchers	
--B	Basic/clinical sciences	ANB14; ANB15
--H	Health sciences	ANH3
-- S	Social sciences	ANS34
AA	ACB academic researchers	
--B	Basic/clinical sciences	AAB30
--H	Health sciences	AAH9; AAH28; AAH36
-- S	Social sciences	AAS6; AAS21; AAS29
CBR	Community-based researchers	CBR1; CBR23; CBR25; CBR38
CA	Community advocates	CA13; CA20; CA26; CA32; CA37
GO	Government official	GO11