A Foucauldian engagement with the “problem of ethics” in the Canadian HIV community-based research movement

by

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A thesis submitted in conformity with the requirements for the degree of Doctor of Philosophy in Social and Behavioural Health Sciences
Dalla Lana School of Public Health, Collaborative Program in Bioethics
University of Toronto

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Abstract

This dissertation examines the Canadian HIV community-based research (CBR) movement, with an attention to how research ethics is understood and practiced. HIV CBR brings together health researchers, clinicians, service providers, and people living with HIV (PHAs) to undertake collaborative research and evaluation. HIV CBR is characterized by inclusive and community-driven research processes, a commitment to partnership building, and the involvement of relevant stakeholders. However, HIV CBR practitioners claim the formal research ethics review process is unresponsive and alienating, and fails to address the ethical issues present in their work. For these reasons, research ethics review has been identified as a major barrier to HIV CBR. Towards examining these claims, interview data were collected from recipients of Canadian Institutes of Health Research (CIHR) HIV CBR operating grants from across Canada. The analysis offered here departs from the majority of the literature by using Michel Foucault’s approach to ethics. Foucault’s work considers the role of power, discourse, and how conceptions
of morality emerge within particular systems of governance. This dissertation includes an introductory chapter, three core chapters written in a manuscript format and a concluding chapter. In Chapter 1, I situate my dissertation at the intersections of HIV CBR, empirical bioethics, and critical public health. Chapter 2 examines the confessional dimensions of interviewing participants about their ethical transgressions. Chapter 3 offers an analysis of the relationship between actors in the CBR movement, related funding programs, and the state. Chapter 4 examines the relationship between actors in the CBR movement and prescriptive research ethics. In Chapter 5, I conclude by exploring the implications for advancing greater critical reflexivity in HIV CBR. Overall, this dissertation theorizes the so called “problem of ethics” in HIV CBR and uses it as opportunity to ask different kinds of questions about community engagement in collaborative research.
Acknowledgments

I would like to thank my mother Eva Guta for making countless sacrifices on my behalf and for her tireless and unwavering support. I want to thank my dear friend Ryan O’Connor for convincing me to finish my first year of undergraduate studies despite my reticence. I want to thank Dennis Magill for teaching me the importance of “planting seeds.” I want to thank Sarah Flicker for her endless generosity and infectious enthusiasm. I want to thank my partner Ryan Nunn for his patience, love, and support.

I will be forever grateful to my supervisor Carol Strike for her mentorship, guidance, and support over these past 6 years, and for taking a big chance on me. I want to thank my committee members Sarah Flicker, Stuart Murray, Ross Upshur, and Ted Myers for each challenging me in different ways, and for coming together as a supportive unit. If I had to start over from the beginning, I would ask each of them again.

I would like to thank my friends and colleagues who provided support and laughter. First, I want to thank my cohort mates Jenevieve Mannell, Erica Di Ruggiero, and Franziska Satzinger. I would also like to thank Paul Gorczynski, Carmen Logie, Anna van der Meulen, Melisa Dickie, Alex McClelland, Gillian Kolla, Marilou Gagnon, Elizabeth Manning, Stephanie Nixon, Michael G. Wilson, Robb Travers, Jennifer Pool, Oliver Mauthner, Kimberly Gray, and Brenda Roche.

I have benefited immensely from the generosity of the faculty and staff at the Dalla Lana School of Public Health and the Joint Centre for Bioethics. I would like to thank Joan Eakin, Barbara Secker, Diane Tang and Vanessa Anievas. I would also like to thank Denise Gastaldo and Jan Angus for sharing their Nursing perspective. Finally, I would like to thank Ann Robertson for giving me a nudge in the right direction.

I would especially like to thank the participants who shared hours of rich insights with me, and the members of my research team for letting me make dual use of our data.

My research was supported by funding from the Ontario HIV Treatment Network and the Canadian Institutes of Health Research.
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Chapter 1
Introduction and overview

Interest in research ethics review and its impact on knowledge production has been increasing amongst scholars in recent years. Various aspects of the ethics review process have been debated in bioethics (Schücklenk & Ashcroft, 2000; Woods & McCormack, 2012), medicine and the biomedical sciences (Chalmers, 2011; Heilig et al., 2011; Lamas et al., 2010), and increasingly in the social sciences and humanities (de Jong, van Zwieten, & Willems, 2012; Dyer & Demeritt, 2009; K. Hoeyer, Dahlager, & Lynoe, 2005). The history of research ethics review has been examined in detail in recent full length monographs that chart its evolution and impact (Schrag, 2010; Stark, 2011; van den Hoonaard, 2011). Detailing these complex histories and accounting for the range of perspectives therein exceeds the scope of this dissertation. However, in this introduction I identify key issues in the relevant literature and provide context for the subsequent chapters. I start by introducing why formal research ethics review exists and identifying areas where this requirement comes into conflict with other scientific and institutional norms. Next, I delve into the substantive focus of this dissertation, community-based HIV research, where a number of debates, tensions, and contradictions in research ethics converge. This convergence, and the “problem” that emerges, invites alternative ways of thinking about research ethics. Towards making sense of these, I turn to the transdisciplinary writings of Michel Foucault.
1.1 Background

The need for formalized ethics review and oversight was established in response to egregious acts committed against human research subjects in the name of advancing “science” (Chadwick, 1997; Elshtain, 2008; Rothman, 1982). Most notable were the Nazi eugenics and racial hygiene experiments, and the Tuskegee syphilis experiment. The Nazi experiments were carried out on Jewish concentration camp inmates, prisoners of war, and individuals targeted because of perceived physical or psychological “abnormalities.” These experiments consisted of involuntary procedures ranging from exposure to extreme environmental conditions to surgery without anesthesia, and often resulted in death (Annas & Grodin, 1995; Schmidt, 2004). Running concurrently in the United States, but lasting until 1972, the Tuskegee syphilis experiment involved the recruitment of 600 impoverished African American sharecroppers with syphilis infection (Jones, 1993; Reverby, 2009). These men were monitored without treatment until they died long after penicillin had been proven effective for treating syphilis. These disturbing episodes provided the impetus for the development of formal protections for patients and human research subjects (Belmont Report 1979; The Nuremburg Code 1949; Declaration of Helsinki 1964). Collectively, these protections recognized the dignity of human life, required consent from human research subjects or “participants,” and permitted them to withdraw their consent. These protections have evolved into “over 1,000 laws, regulations, and guidelines on human subjects protections” (International Compilation of Human Research Protections, 2012).
In Canada, the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2nd edition* (TCSP-2 2010) serves as the governing research ethics framework. The TCPS-2 was developed through collaboration between Canada’s three federal funders: the Canadian Institutes of Health research (CIHR), the Natural Sciences and Engineering Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC). In the TCPS-2 research is described as “a step into the unknown” that “often entails risks to participants and others.” The document is meant to enable researchers to identify the ethical dimensions of their research and reduce or mitigate research related harms. The TCPS-2 promotes respect for human dignity through the three core principles of respect for persons, concern for welfare, and justice. These principles are said to “transcend disciplinary boundaries and, therefore, are relevant to the full range of research covered” (TCPS-2, B. Core Principles 2010). This framework, like similar ones in the United States, United Kingdom, and Australia, governs both research practice and procedures for obtaining formal ethics review.

Most research ethics guidelines require the independent review of research by Research Ethics Boards or Institutional Review Boards (REB/IRBs) located at universities and research-intensive settings (e.g., hospitals, clinics, etc.). The ethics review process usually requires the completion of an ethics protocol (comparable to a grant proposal) and its submission to the REB/IRB located at the researcher’s home institution and/or an institution where the research will be conducted. The ethics review process is similar to many other requirements in the academy (e.g., peer review for grants and manuscripts), but has received considerably more attention and criticism in recent years (for a balanced comparison see Upshur, 2011). A number of critics have raised
concerns about REB/IRBs being suspiciously secretive and overly focused on “checking off boxes” (Allen, 2008; Ashcroft & Pfeffer, 2001; O'Reilly, Dixon-Woods, Angell, Ashcroft, & Bryman, 2009). Others have questioned whether REB/IRBs are effective and accountable (Coleman & Bouesseau, 2008; Savulescu, Chalmers, & Blunt, 1996). The growing infrastructure needed to support ethics review within and across institutions has been likened to a “research ethics industry” (Allen, 2008; Ashcroft, 1999). However, the major critique has charged ethics review with restricting research and constituting a serious threat to academic freedom (Dingwall, 2008; Haggerty, 2004; Lewis, 2008). The term “ethics creep,” coined by Haggerty (2004), has been used to describe a process where ethics review is expanding and colonizing aspects of research previously outside of its purview. This process paradoxically entails an expansion of research ethics review and a restriction of the types of research being allowed to proceed.

Those working in the social sciences (sociology, anthropology, criminology, etc.) have been especially resistant to the standardized approaches imposed by formal research ethics requirements (for a historical analysis see Schrag, 2011). The popular claim is that REB/IRBs impose a biomedical conception of harm, vulnerability, and autonomy that does not reflect social science research norms and practices (Klaus Hoeyer, 2006; K. Hoeyer et al., 2005). Within this biomedical orientation, research related risks are framed as something researchers should control. For quality and accuracy, biomedical research replicates the same conditions and procedures each time, maintaining the level of risk. However, this is difficult, if not impossible, for social science research conducted in naturalistic settings. In the “field,” conditions are neither predictable nor controllable and may require context-dependent responses and strategies to
addressing risk and harm (Ellis, 2007; Hopkins, 2007; Sultana, 2007). Researchers using qualitative methods have been especially vocal about the challenges they encountered trying to explain their flexible procedures to unsympathetic review boards (Lincoln & Tierney, 2004; van den Hoonnaard, 2002). However, Hedgecoe (2008) has challenged claims that REB/IRBs are hostile to qualitative research with examples of deference to reviewers with relevant expertise.

The social science critique of ethics review has been, in part, a reaction to the perceived loss of disciplinary independence and autonomy. Before the establishment of centralized ethics review, the social sciences had their own approaches to self-governance through disciplinary and professional standards (Haggerty, 2004; Schrag, 2010). What constituted ethical practice was determined within the discipline and promoted through professional codes (e.g. the American Anthropological Association Code of Ethics 2009) and imparted through mentoring of graduate students. However, proponents of a return to this supposed “golden era” in the social sciences usually overlooked the number of problematic research studies conducted during the period of self-governance. These included two notable studies in psychology: Stanley Milgram’s (1974) “obedience study” and Philip Zimbardo’s (1973) “Stanford prison experiment.” In sociology, Laud Humphreys’ (1970) infamous “tearoom trade” covert study of sex in public settings caused concern and ongoing debate (Babbie, 2004; Lenza, 2004). Finally, a number of anthropological studies have been criticized for exploiting indigenous peoples (see the in-depth examination by Tierney, 2000) and for cultivating questionable relationships between researchers and military sponsors (Lucas, 2009). These examples are ones that “made the headlines,” often because of whistle-blowers, but there are likely more which went unreported.
Proponents of a return to disciplinary governance have further overlooked the changing realities of academic life that have occurred since the introduction of centralized research ethics. These include the commodification of knowledge production and the introduction of corporate managerialism and accountability in academic institutions (Dominelli & Hoogvelt, 1996; Owram, 2004; Smith, 2005). Guta et al. (2012) have questioned whether the conflict created by ethics review is not the problem but rather a symptom of neoliberal restructuring of universities and growing competition therein. According to Ylijoki (2005) allusions to the “academic freedom” of the past have served to sentimentalize a period that never really was. These debates about the “good old days” have detracted from much needed discussions about what it means to be an ethical researcher in the current epoch. This dissertation shifts the emphasis from the ethics review process to the researchers themselves and examines the process of adapting, modifying, and resisting prescribed research ethics. Before proceeding with a description of the substantive focus of this desertion, I will introduce a form of research that blurs traditional boundaries in research and has become a new focus of criticisms about research ethics.

1.2 Community-based research: An alternative research paradigm and ethical terrain

In an attempt to better understand the needs of those immediately affected by health issues, community-based participatory research (CBPR) has emerged as an alternative research and evaluation paradigm for public health (Israel, Schulz, Parker, & Becker, 1998; Lantz, Viruell-Fuentes, Isreal, Softley, & Guzman, 2001; Wallerstein & Duran, 2006). This approach has actively engaged researchers, clinicians, and communities in the development of public health
research, program evaluations, and social and clinical intervention design (Green, Daniel, & Novick, 2001; Kone et al., 2000; Minkler, 2005). The W.K. Kellogg Foundation’s Community Health Scholar’s program has provided an oft-cited definition of CBPR as:

…a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health (cited in Minkler & Wallerstein, 2008, p. 6)

Starting with a research question of importance to the community has been said to promote a shared understanding about the purpose and benefits of research. Definitions of “community” include those directly affected by a health issue, but also allies working in service provision or advocacy roles (Green & Mercer, 2001). To engage these different groups, CBPR projects have adopted a range of research designs and methodological techniques to promote inclusion and generate data (Israel, Eng, Schulz, & Parker, 2005). Engaging marginalized communities through research has been credited with producing more useful research results than would have been possible through traditional investigator driven research approaches (Higgins & Metzler, 2001; Minkler, 2005; Minkler & Wallerstein, 2008; Quigley, 2006). The CBPR approach has gained popularity in schools of public health and community medicine programs moving it from the “margins to the mainstream” (Horowitz, Robinson, & Seifer, 2009). Participatory approaches, including CBPR, have become central to public health and health promotion research (Mantoura & Potvin, 2013). In Canada, the term community-based research (CBR) is more commonly used than CBPR and will be the standard throughout this dissertation.
1.2.1 CBR and ethics

The techniques that make CBR effective at mobilizing communities in health research have also brought it into conflict with formal ethics review requirements. Reflective of criticism from the social sciences, a number of CBR scholars have also identified a paradigmatic clash between formalized ethics review and participatory frameworks. The resulting literature has framed REB/IRBs as overly bureaucratic and oppressive in contrast to the emancipatory goals of CBR (Blake, 2007; Susan Boser, 2006; S. Boser, 2007; Martin, 2007; Rolfe, 2005; Shore, 2006). In early work by Downie and Cottrell (2001, pp. 9-10), they identified the key issues as follows: REB/IRBs are not equipped to deal with the kinds of “non-traditional” methods CBR uses; the review process offers little to CBR; the process is “frustrating and demoralizing,” takes too long, and fails to address ongoing ethical issues. As a result, there have been documented examples of REB/IRBs creating barriers to CBR (Bradley, 2007; Malone, Yerger, & McGruder, 2006). Although similar complaints have come from researchers working in other fields, the defining element of relationships between researchers, community-organizations, and community members involved in roles other than as participants, has made reviewing CBR a unique challenge for ethics boards.

The absence of mechanisms to support researchers after the initial ethics review remains an important issue. Current review processes require researchers to report any “adverse events,” but this expectation comes from biomedical research where drug reactions or death may occur. This has been expanded by some REB/IRBs to account for “unanticipated events” like breaches in
confidentiality which are more reflective of social science research (see the University of Toronto Adverse/Unanticipated Event Report Form). However, ethical issues in CBR often emerge slowly throughout the “life of a project” and are easily overlooked within current conceptions of research ethics. These include tensions arising from: the problematic notion of a singular “community” with delegated representatives (Flicker, 2005; Jewkes & Murcott, 1998; MacQueen et al., 2001); questions over who has the authority to provide community consent (Macaulay et al., 1998; Marshall & Rotimi, 2001; Serrano-Garcia, 1990); CBR teams inadvertently causing conflict between community members (Brugge & Kole, 2003; Grossman, Agarwal, Biggs, & Brenneman, 2004; Marshall & Rotimi, 2001); CBR projects raising false expectations of change (Close & Hollis, 2003); and researchers feeling pressured to compromise their objectivity to promote community needs (Ogden, 1999; Padgett, 2008). At any point throughout the research process, one or all of these issues could manifest and require resolutions few research teams are able to anticipate in advance. Interest in these kinds of ethical issues is evident in the growing documentation of ethical challenges experienced within CBR projects (see the special issues of the Journal of Empirical Research on Human Research Ethics 3.2, 2008 and the International E-Journal for Critical Geographies, 6.3, 2007). While the growth of interest in CBR ethics is promising, this literature has primarily focused on single case examples and failed to theorize outwards to other research and practice contexts.

1.2.2 Towards theorizing CBR ethics

Wallwork (2008, p. 57) has offered a promising exception to the lack of theorizing on ethics and CBR by locating these issues within larger debates about the “social nature of persons”
influencing bioethics. He has identified areas of convergence between CBR and ethics review and opportunities for improvement: first, despite claims to the contrary, ethics review already encourages researchers to attend to communal interests; second, however, current review structures could benefit from expanding existing notions of harm, consent, and social justice to the communal level; and, third, ethics review needs to better engage with new moral perspectives including “postmodern sensibilities” (Ibid). This last point has important implications for the bioethics enterprise which has relied on normative conceptions of ethics. Citing the seminal work of Israel et al. (1998), Wallwork (2008, p. 74) has observed that:

Increasingly, postmodern sensibilities are beginning to appear in the literature on community-research partnerships, mostly in connection with acknowledging the value and validity of ‘local knowledge’ and claims regarding the social construction of all knowledge, including universal ethical principles and ‘objective’ scientific ‘truths.’

This led him to further posit that CBR exhibits a Foucauldian “hermeneutics of suspicion with respect to the covert power, hidden ambitions, and cultural biases that infuse supposedly ‘impartial’ scientific research” (Wallwork, 2008, p. 74). I disagree with this reading of Israel’s work which is better located within a modernist or realist perspective. CBR does acknowledge multiple “truths,” but these are investigated and classified, translated into interventions, and used to promote behaviour change for improved public health outcomes. This approach to “truth” stands in opposition to Foucault’s project, and he would have likely questioned the kinds of situated truth claims made on behalf of community. However, this linking of CBR, ethics, and Foucault, invites rethinking aspects of this research movement and the nature of practices characterized as benefiting the “community.” Before examining the implications of Foucault’s theoretical oeuvre, I will introduce the substantive focus of this dissertation.
1.3 Examining the Canadian HIV CBR movement

This dissertation examines the Canadian HIV community-based research (CBR) movement which has been credited with promoting inclusive and community-driven research protocols (Allman, Myers, & Cockerill, 1997, p. 22). The Canadian HIV CBR movement has provided a testing ground for collaborative research designs and methodological and analytic innovation (Bauer et al., 2009; Flicker, Smilie-Adjarkwa, et al., 2007; Trussler, Perchal, & Barker, 2000). The movement has promoted a particular approach to research partnerships that involve interdisciplinary teams of researchers working with community and policy stakeholders. This has resulted in social scientists, clinicians, epidemiologists, and public health officials and policy makers coming to the same “table” as people living with and/or affected by HIV. This convergence of actors has created unique dynamic and resulting tensions that need to be investigated. I consider myself to be part of this research movement having made contributions in the form of research (see for example Flicker et al., 2010; Flicker et al., 2009; Guta, Nixon, Gahagan, & Fielden, 2012; Guta et al., 2010; Travers et al., 2008), conference session organizing, and ongoing participation in consultations and dialogues. This dissertation does not address a specific public health issue, like increasing rates of HIV infection amongst a particular population. Rather, my aim here is to examine techniques and processes that are said to improve public health research. I draw heavily on critical writings about the “new public health” (Bunton & Petersen, 1997; Petersen & Lupton, 1996) and consider their implications for understanding HIV CBR as it is currently practiced.
1.4 Dissertation format and research questions

This dissertation is comprised of three core chapters that each examines theoretical and methodological issues relevant to HIV CBR: the first chapter describes the process of conducting interviews about the ethical implications of HIV CBR and the methodological challenges that emerged for the interviewer; the second paper examines practices within the HIV CBR movement to demonstrate how actors are governed through neoliberal ideology; and the final manuscript examines how actors within the movement resist dominant discourses about science and ethics. Each core chapter is written as a journal manuscript with a slightly different style intended for audiences at target bioethics, social science, and research methods journals.

Drawing on Michel Foucault’s writings on power, discourse, and ethical self-formation, this study sought to answer the following overarching research question: How are the prevailing discourses that inform research and ethics taking shape in the Canadian HIV CBR movement, and what are the implications for research and practice? Towards addressing this primary question, the following sub-questions are addressed respectively in the following chapters:

1) How do HIV CBR practitioners respond when asked to talk about the ethical and methodological issues in their work?
   a. What is required from the interviewer to create a space to disuse these issues?
2) How are HIV CBR practitioners impacted by governmental strategies that determine the conditions of research and community-engagement?
   a. How are they implicated in reproducing this system?

3) How do HIV CBR practitioners make sense of formalized research ethics guidelines and institutional requirements?
   a. What techniques do they draw upon to construct their “ethical subjectivities”?

The unifying theme of this dissertation is an attempt to work across the social sciences, public health, and the field of bioethics to examine ethical and methodological issues in HIV CBR. This analytical work problematizes and disrupts taken-for-granted assumptions and practices in HIV CBR contributing to a resurgence of critical debate in the broader HIV movement. This dissertation further aims to contribute to imperial bioethics inquiry by offering new theoretical and methodological avenues. Critical and reflexive writings in the participatory action research literature (Fine, 2006c; Healy, 2001) and international development literature (Cooke & Kothari, 2001) influenced my analytics. These writings have inspired me to take the personal and professional risks associated with offering an insider’s critique of HIV CBR.

1.5 Theoretical overview

All my books...are little tool boxes...if people want to open them, to use this sentence or that idea as a screwdriver or spanner to short-circuit, discredit or smash systems of power, including eventually those from which my books have emerged...so much better! (Interview with Foucault and Roger-Pol Droit, cited in McLaren, pp. 1-2)
This dissertation draws on Foucault’s writings to examine various aspects of HIV community-based research and how ethics is understood and performed. Foucault characterized much of what constitutes modern health care (including biotechnologies and public health interventions) as regulatory and disciplinary technologies acting upon individuals and collectives (Rabinow & Rose, 2006). Foucault (1994m) offered his writings as a “tool-box” to be used in whatever ways readers deemed useful. Whereas his contemporaries like Bourdieu (1977) offered formulas for making sense of social phenomenon, Foucault resisted telling other how to think (Oksala, 2005, p. 8). Aspects of Foucault’s theoretical “tool-box” have been used in HIV studies to explore public health prevention and surveillance, and the discipline and regulation of people living with HIV (Elbe, 2005, 2008; Geary, 2007; Keogh, 2008; Liesch & Patton, 2010; Mykhalovskiy, McCoy, & Bresalier, 2004; R. Parker & Aggleton, 2003; Wojcicki & Malala, 2001). This dissertation uses Foucault’s writings on “confessional practices” (see chapter 2), “governmentality” (see chapter 3), and “ethical subjectivation” (see chapter 4), to identify different threads within the data that tell different stories about HIV CBR.

While Foucault (1985, pp. 25-26) was not concerned with research ethics, he was interested in the “margins of variation or transgression individuals or groups conduct themselves in reference to a prescriptive system” as a method for examining ethics. Foucault’s writings are useful for challenging the ways power is exercised to produce certain kinds of knowledge and practices within research. The “problem of ethics” provides an empirical and discursive space to explore the intersections of complex social and bio-political processes. Normative conceptions of ethics do not emerge in isolation, but are part of the social context in which they originate. My intent is
to situate debates in CBR and research ethics within what Foucault (1980, p. 194) described as a social “apparatus” (dispositive), “a thoroughly heterogeneous ensemble consisting of discourses, institutions, architectural forms, regulatory decisions, laws, administrative measures, scientific statements.” This analytic orientation made it possible to identify and examine the various systems that make certain forms of research and action possible.

My approach especially builds on recent scholarship in bioethics that has considered the implications of Foucault’s work for examining how researchers and healthcare providers resist and transcend prescriptive ethics (Chambon & Irving, 2003; Frank & Jones, 2003; Koro-Ljungberg, Gemignani, Winton Brodeur, & Kmiec, 2007; Murray, 2007). These authors have collectively recognized the role of social, political and contextual factors that produce an ethical milieu, be it the university, hospital, or community-based organization. The merging of Foucault’s interest in “care of the self” and bioethics provides an opportunity to re-think and theorize CBR and explore community engagement as both an ethical and political issue. Failure to reflect on issues of power in HIV research has led to poor outcomes despite otherwise participatory processes (Khanlou & Peter, 2005). My goal is to bring power to the surface throughout this dissertation and highlight, in the Foucauldian sense, its relational and productive qualities.

1.6 Methodological overview
All research is situated within a *paradigm* consisting of a particular set of beliefs, values, and methods to attain knowledge (Guba, 1990; M. Patton, 2002). Paradigms are reflective of the researcher, their relationship to the *other*, what they consider to be knowledge, and how they negotiate value conflicts encountered in the research process (Lincoln, 2010). Guba and Lincoln (2005) have famously classified these paradigms as positivism, post-positivist, critical, constructivist, and, more recently, participatory. This popular distinction between the paradigms may not reflect the realities of all research approaches. Researchers working in the health sciences are often required to work across paradigms to reconcile their scholarly interests and disciplinary expectations. Gastaldo (2006) has reinterpreted these paradigms for researchers in the health sciences as: 1) positivist/post-positivist; 2) the critical-social paradigm (encompassing the emancipatory/liberationist and postmodernist/poststructural); and 3) and the interpretivist or constructivist. This framework considers the position of the researcher within their particular paradigm (their relationship to knowledge production) while situating those in the critical-social paradigm as ranging from the organic intellectual (“researcher is involved in empowerment, advocacy or committed towards social justice”) to the transgressive intellectual (“aware that the researcher benefits from current power arrangements and has multiple subjectivities”). This framing reflects my own understanding of the research paradigm.

In keeping with Gastaldo’s (2006) framework, my research can be situated within the critical paradigm and straddles the organic and transgressive. Ontologically, my approach recognizes a reality mediated by power relations. Epistemologically, it rejects grand theories and sees truth as a dominant discourse thereby turning to qualitative methods and discourse analysis as preferred
methodological approaches. Kincheloe and McLaren (2005, p. 304) have described scholars working within the critical tradition as having an awareness of the “ideological imperatives and epistemological presuppositions that inform their research as well as their own subjective, intersubjective, and normative reference claims.” They are not afraid to produce work which is “political” and action oriented (Ibid, p. 304). Agger (1991, p. 111) has asserted that “the most lasting methodological contribution of critical theory to social science is the way it attunes empirical social researchers to the assumptions underlying their own busy empiricism.” This introspective challenge is visible in the way “critical theory aims to promote self-reflexive exploration of the experiences we have and the ways in which we make sense of ourselves, our cultures and the world” (Malpas & Wake, 2006, p. ix). This should not be read as promoting a solely individualistic pursuit or “critique for the sake of critique,” but that critical research should be deployed to affect social change (Kress, 2011).

Critical theory has been attributed to the western Marxist influenced writings of the Frankfurt School which promoted using “cultural reflexivity” to examine how conceptions of the “self” are produced by capitalism (Daly, 2006). Foucault and the Frankfurt School shared similarities in their critique of reason and socio-historical analysis and interest into how beliefs and practices shape individual lives (McCarthy, 1990). In his 1982-1983 lecture series, Foucault (2010c, p. 21) situated himself within this tradition, saying:

It seems to me that the philosophical choice confronting us today is the following. We have to opt either for a critical philosophy which appears as an analytical philosophy of truth in general, or for a critical thought which takes the form of an ontology of ourselves, of present reality. It is this latter form of philosophy which,
from Hegel to the Frankfurt school, passing through Nietzsche, Max Weber and so on, has founded a form of reflection to which of course, I link myself insofar as I can.

This association between Foucault and the founders of modern sociology helps bridge the supposed disciplinary gap between sociological methods and Foucauldian theory. Merging the two has produced seminal works in the sociology of health and illness tradition about the changing nature of medicine and public health (see Annandale, 1998; Armstrong, 1997).

Despite having personally derided the label, Foucault’s work has been aligned with a poststructural tradition in the critical paradigm (Kappeler, 2008; Schaff, 2002; Sinnerbrink, Deranty, & Smith, 2005). Comprised of a range of theoretical positions, poststructuralism “interrogate[s] language, meaning, and subjectivity” towards disrupting and problematizing accepted “truths” about the nature of reality (Cheek, 2000, p. 40). Poststructuralism has been used to investigate the role linguistic and other signifying practices in mediating individual’s understandings of their experiences (Burman & Parker, 1993; I. Parker, 1992). This approach has been useful for examining the influence of social institutions such as medicine, law, and economics, have on shaping knowledge (Ashenden, 2005; Belsey, 2006; Newman, 2005). Poststructural theories and techniques challenge Enlightenment dichotomies (on which the modernist positivist sciences are based) such as “rational/irrational, subject/object, science/nature” (Francis, 2000, p. 22). Rather, poststructuralist writers have argued against notions of an essential and universal truth, and the privileging of any one tradition over another (Koro-Ljungberg, 2008, p. 222).
Newman (2005, p. 1) has likened the poststructuralist approach to an “anti-authoritarian ethos—an implicit commitment to question the truth claims of any form of political, social, and even textual authority.” For this reason, a number of scholars have questioned whether poststructuralism can be a tool for producing change (for a discussion of these critiques see Francis, 2000). This assertion has been based on a misreading or conflation of all the diverse perspective lumped together as poststructuralism. In respect to Foucault’s approach, Sikka (2008, p. 239) has argued his “philosophies are not irredeemably bleak and nihilistic; rather they can be seen as dynamic, political, and ethical.” Newman (2005, p. 144) has posited that “far from rejecting the Enlightenment out of hand, poststructuralist thinkers…are actually committed to a rethinking of the Enlightenment’s discursive limits and, through this, a renewal of its critical and emancipative project.” I concur with Sikka and Newman and recognize the potential of poststructuralism as a tool to promote critical dialogue.

Poststructural theories and approaches have been used to guide or support empirical qualitative studies (Baxter, 2002; Cheek, 2000; Frost et al., 2010; Llewellyn, 2009; Ryan, 2009). Søndergaard (2002) has argued that “poststructuralist discourse extends the possibility for empirical researchers to focus on the constitution of social practices and cultural patterns and on processes of subjectivation.” However, Miller and Brewer (2003, p. 4) have pointed to a number of tensions between poststructuralism and qualitative research:
The post-structuralist/postmodern critique of the practice of qualitative research is wide ranging and concerns the theories of knowledge (epistemology) used in social research, theories of the nature of social reality (ontology) underlying research practice, and the status of the claims made in research, such as the status of the written text and the rhetorical skills used to give the author's account validity (its representational claims).

In writing about the poststructural qualitative turn in public health research, Krug and Hepworth (1997) have warned that the power relations poststructuralism challenges can be reaffirmed by research which fails to explore the role of the researcher. What makes an analysis poststructural is not the method, but an understanding of the limitations of representation and meaning afforded by the method. I am conscious of these critiques and the importance of maintaining theoretical and methodological congruence (Caelli, Ray, & Mill, 2008; Carter & Little, 2007).

My approach is in keeping with Guba and Lincoln’s (2005, p. 4) description of the qualitative researcher “as bricoleur, or maker of quilts, [who] uses the aesthetic and material tools of his or her craft, deploying whatever strategies, methods, and empirical materials are at hand.” This approach encourages the blurring of boundaries between disciplinary traditions and forms of representation. In this case it means drawing on data collected for another purpose and considering its theoretical implications. I will now describe the empirical data being used for this dissertation and my relationship to it.
1.7 Dissertation project

1.7.1 Data source

Data were collected as part of the multi-stage Canadian Institutes of Health Research (CIHR) funded study “Improving the Accessibility of Research Ethics Boards for Community-Based Research in Canada”, which included: a content analysis of existing REB/IRB forms and guidelines, 24 key informant interviews with REB/IRB staff and board members, and 50 interviews with experienced HIV CBR practitioners. I conducted the majority of the interviews for both phases with the exception of 4 French language interviews and one English language interview for phase 3. Data for my dissertation were drawn from the final stage comprised of in-depth interviews with recipients of the CIHR HIV CBR operating grants funded between 2005 and 2010 (see appendix A for interview questions). The process of conducting these interviews is detailed in chapter 2, but a few important issues are discussed here about producing a nested dissertation.

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<th>Table 1. Participant Demographics</th>
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1.7.2 Nested dissertation

My dissertation was “nested” in a larger project comprised of an interdisciplinary research team working in HIV and using CBR approaches, as well as a community member and a partnering HIV research funding organization. Graduate students conducting secondary analysis for their dissertations have experienced both benefits and drawbacks when their analysis was “nested” in a larger study. Heaton (2004c) has identified benefits in the form of project resources and access to data and drawbacks associated with the relatively low status of graduate students and their work in teams, and blurred boundaries between the main research topic and the secondary analysis. I experienced a number of benefits from having my dissertation nested in the larger project: access to research funding which would have been unavailable to a graduate student (salary support, supplies, travel expenses, transcription, etc.), and the status of the team which helped gain access to participants who may not have otherwise been willing to speak to a graduate student. However, there were drawbacks in the form of administrative delays; the pressures for simultaneous data collection and analysis for two phases of the project; conflict between my competing roles as a co-investigator, project coordinator, and graduate student; and confusion over boundaries between my dissertation and the larger research study. The research team established terms of reference to address some of these issues including that my project was distinct from the research team’s work and the objectives identified in the catalyst grant proposal for which funds were secured. All parties agreed the research team would not have any input into my dissertation process, but should be named in the acknowledgment section in any published
manuscripts subject to their approval. The only exception is the nominated principal investigator Dr. Sarah Flicker who served as one of my dissertation committee members.

1.7.2.1 Secondary Analysis

The secondary use of data is common in quantitative research – with large data sets being shared, compared over time, and re-analyzed through new techniques – but it less often done in qualitative research. While there is no standard definition of secondary qualitative analysis, Heaton (2008, p. 34) has described it as “the re-use of pre-existing qualitative data derived from previous research studies” including “material[s] such as semi-structured interviews, responses to open-ended questions in questionnaires, field notes and research diaries.” Secondary analysis may take a number of forms including the sharing of previously collected data sets between researchers, and also revisiting one’s own previously collected data (Heaton, 2008).

The reluctance of qualitative researchers to conduct secondary analysis relates to epistemological, methodological, and ethical concerns about using data for other purposes than it was originally collected for (Heaton, 2004a). Firstly, there may be a mismatch between the original project’s research questions, interview style, transcription, and analysis (Dargentas & Le Roux, 2005; Notz, 2005). As well, secondary analysis does not offer important contextual information about the interview (sights, sounds, smells, etc.) (van den Berg, 2005). Finally, secondary analysis raises ethical questions about whether participants would have agreed to their transcripts being viewed for reasons other than were originally described. However, few qualitative studies state their theoretical stance to participants as part of negotiating consent.
These issues identified with secondary qualitative analysis are important, but overlook that qualitative data can always be interpreted through different lenses (Bornat, 2005). These critiques have not accounted for the growing reality of large research teams who may have little contact with the data and the common use of paid interviewers and transcriptionists (Bishop, 2007). Qualitative researchers often adopt different theoretical explanations after they have collected their data to explain themes they had not expected. Historically, many seemingly benign studies about factories, hospitals, and educational institutions have turned into seminal studies of racism, sexism, classism, and homophobia (Carrington, 1999; Hochschild, 1983; Leidner, 1993). Overall, the lack of secondary analysis in qualitative research is unfortunate considering qualitative data lends itself to answering different research questions and revisiting it avoids unnecessarily replication and burdening of research participants (Kelder, 2005).

Returning to the previous discussion of poststructuralism and qualitative research, Kaufman (2011) has touted the benefits of using poststructural analysis to find new meaning in previously collected data suggesting it actually adds an ethical dimension to the work. Payne and Nicholls (2010) have discussed the benefits of revisiting previously collected interview data where they were able to identify and analyze discursive positions and disciplinary practices. Finally, Frost et al. (2010) have promoted the possibility of analytic pluralism within qualitative research through a Foucauldian reading of empirical data. Seale (2011, p. 358) has claimed that any approach to qualitative research has pros and cons and the only way to know if it will work in any particular
context is to “just do it!” In summary, I chose to conduct a secondary analysis within a larger qualitative study, by engaging with the interview data through a Foucauldian framework.

1.8 Summary

This dissertation investigates how interactions within HIV CBR teams serve to *shape* and *constrain* possibilities for ethical community engagement by exploring the effects of power on the personal and relational aspects of ethical decision-making. In the following chapters I will examine how HIV CBR practitioners understand the ethical aspects of their practice, how they navigate uncharted ethical terrain, and what discursive resources they draw upon. The following chapters each provide a unique contribution. In chapter 2, I discuss the methodological and ethical tensions of interviewing HIV CBR practitioners about their work. In chapter 3, I re-articulate normative aspects of HIV CBR within the logic of governmentality to challenge emancipatory claims about this research movement. In Chapter 4, I moved beyond disciplinary governance to account for modes of resistance and practices that challenge what it means to be an ethical health researcher. In the concluding chapter, I discuss the overall contribution of this dissertation and locate it within a revival in critical social science and humanities perspectives in HIV studies (Mykhalovskiy & Rosengarten, 2009a, 2009c). My overall goal is to use this dissertation as an opportunity to theorize aspects HIV CBR practice and advance a critical approach to the ethics of community-engagement.
Chapter 2
Discourse, confession, and performing the ethical subject:
Reflections on interviewing researchers about the ethical implications of their work

2 Abstract:

This paper builds on calls for greater reflexivity in empirical bioethics by critically examining my experience of interviewing fellow Canadian HIV researchers about ethical issues in their work. Drawing on Ives and Dunn (2010), I use the “confessional tale” as a reflexive tool to make sense of the process of collecting qualitative data and the “confusion, uncertainty, and dilemmas” that arose. I revisit Foucault’s seminal writings on confessional practices to frame the inducement to confess as a product of discourse and power relations. I begin by describing my attempts to stylize myself as a worthy and virtuous confessor to account for my relational interviewing style and strategic use of self-disclosure. I then draw on recent work about confessional practices to consider the ways confession functions as; a disciplinary practice of the self, an ethical relation with the other, and as offering the possibilities of domination and freedom. This theoretical engagement with my interviewing process exposes the complexity of capturing ethics talk and how power circulates in the interview. The paper ends with a discussion of the relational aspects of ethics talk and the possibility of moving from confession to more authentic forms of dialogue.
2.1 Introduction

Increasingly, the discipline of bioethics has been asked to produce and make better use of empirical research (Streich, 2008; Strech, Synofzik, & Marckmann, 2008; Sugarman, 2004). Empirical investigations in bioethics are a departure from its normative roots, but may offer important insights into how moral reasoning takes place in the real world (Alvarez, 2001; Kon, 2009). This so called “empirical turn” in bioethics has been influenced by social science critiques asserting that traditional bioethics inquiry has failed to consider the social and contextual dimensions of ethical issues (De Vries, Turner, Orfali, & Bosk, 2006; Frank, 2000; Solomon, 2005; Turner, 2003; Weston, 1991). While empirical bioethics work has been increasing, the methods used have remained largely quantitative, and the studies have focused on examining biomedical issues (Borry, Schotsmans, & Dierickx, 2006). These studies endorse positivistic conventions about science as objective and value free, and promote clear boundaries between researcher and researched (Guba & Lincoln, 2005; Krauss, 2005). Often missing in the empirical bioethics literature is an attention to the social and relational aspects of the research process.

Only a few bioethicists have openly reflected on their experience of conducting empirical research and their influence on the research process (for a notable example see Panikkar, Smith, & Brown, 2012). However, the growing interest in the potential for qualitative approaches to advance bioethics invites the use of related tools for locating and interrogating the role of the researcher (Dunn & Ives, 2009; Ives, 2008; Ives & Draper, 2009). As an early proponent of social science informed empirical bioethics, Hedgecoe (2004, 2007) emphasised the importance
of “reflexivity” and an attention to the role of the researcher in shaping knowledge production. Sandelowski and Barroso (2002, p. 216) have described reflexivity as “the ability to reflect inward toward oneself as an inquirer; outward to the cultural, historical, linguistic, political, and other forces that shape everything about inquiry; and, in between researcher and participant to the social interaction they share.” In qualitative research, there have been rich debates about the nature and purpose of reflexivity for decades (Alvesson & Sköldberg, 2009). These debates eventually resulted in what Denzin and Lincoln (2005, p. 3) described as a “crisis of representation” where “researchers struggled with how to locate themselves and their subjects in reflexive texts.” This “crisis” sent many social scientists to the humanities to learn about poststructural writing and analysis techniques to find new insights into their work.

Dunn and Ives (2009, p. 94) have argued this “crisis of representation” has implications for informing empirical bioethics about the importance of thinking “imaginatively about how data [are] produced, developed, and presented through our interactions with our participants at all stages of the research process.” Elsewhere Ives and Dunn (2010, p. 261) proposed a reflexive approach to bioethics that “demands a critical interrogation of the relationship between the researcher, the world she is studying, and her experience and awareness of that world.” They have proposed a corresponding reflexive methodology based on ‘autoethnography’ and the ‘confessional tale’ to provide “the tools for a more accountable philosophical bioethics” (Ibid p. 262). These confessional tales are “personalised statement[s] that expos[e] confusion, uncertainty, and dilemmas within, and about, the process of analysing a particular problem” (Ibid
Ives and Dunn’s approach has important implications for promoting a “reflexive turn” in bioethics. Following in this tradition, I critically reflect on the experience of conducting interviews with researchers about the ethical implications of their work. Here the “confessional tale” is used as a reflexive tool to make sense of collecting qualitative data and the “confusion, uncertainty, and dilemmas” arising throughout the research process (Ives & Dunn, 2010, p. 262). My analysis also problematizes the inducement to confess by engaging in a dialogue with Michel Foucault’s writings on confessionary practices. While many bioethicists are weary, if not hostile, to Foucault’s theories, others would argue that he has much to offer bioethics (Deutscher, 2010; Frank & Jones, 2003; Murray, 2007; Tremain, 2008). What follows is an attempt to engage in a reflexive remembering and reinterpreting of experiential, theoretical, methodological, and ethical issues in the practice of empirical bioethics.

2.2 Confession as theoretical lens

Foucault is known for writings on power that challenged the supposed binary between rulers (with power) and ruled (lacking power). Instead, he posited that power is central to all social encounters making it both productive and relational (Foucault, 1978, p. 93). This does not deny the propensity for power to be used oppressively, but makes room to discuss the ways power “traverses and produces things…induces pleasure, forms knowledge, [and] produces discourse”
(Foucault, 1980, p. 119). Foucault (1980, p. 156) identified a cyclical relationship between power and knowledge; through exchanges of power we create forms of knowledge that in turn make power operable (Foucault, 1980, p. 52). This brings into question dominant notions of truth and how it is produced in any particular historical period. In *The History of Sexuality: Volume 1*, Foucault (1978, p. 59) examined how the Christian sacrament of confession spreads out to form a “singularly confessing society,” saying:

The confession has spread its effects far and wide. It plays a part in justice, medicine, education, family relationships, and love relations, in the most ordinary affairs of everyday life, and in the most solemn rites; one confesses one's crimes, one's sins, one's thoughts and desires, one's illnesses and troubles; one goes about telling, with the greatest precision, whatever is most difficult to tell. One confesses in public and in private, to one's parents, one's educators, one's doctor, to those one loves; one admits to oneself, in pleasure and in pain, things it would be impossible to tell to anyone else, the things people write books about. One confesses -- or is forced to confess....Western man has become a confessing animal.

For Foucault (1978, p. 61), the confession has become a secular and scientific “ritual of discourse” that “unfolds within a power relationship.” The practice of qualitative interviewing, despite its claims of “giving voice” to participants, is a powerful means through which to elicit individual confessions and shape societal understandings of experience (Gubrium & Holstein, 2003). Winch (2005, p. 182) has described qualitative methods as a mechanism by which the “subject” can confess and have “their personal experiences…collated to instigate new categories and regimes.” Fejes (2008) has made a similar argument about the requirement for reflexive writing in the training of health professionals, where confessions are solicited and evaluated in a process of producing a desirable subjectivity in them. If confessions are a product of discourse,
and do not offer an objective truth, what does this say about the credibility of empirical data and reflexive accounts? In response, Bastalich (2009, p. 4.1) has argued “the ethical dilemma of researchers is not how to provide an authentic account of persons or of social events that are not obscured by power” but instead to resist making such claims and account for its influence. While Ives and Dunn (2010) have convincingly presented the “confessional tale” as a tool for bioethics, it needs to be recognized as part of a larger socio-political and historical inducement to confess. With this in mind, I now examine my role as an interviewer in this recent study.

2.3 The study

I draw on my experience of collecting data for a multi-phase, Canada-wide, study examining the impact of research ethics review on community-based research (CBR). The impetus for this study was the recognition that ethics review may unfairly burden researchers working in a CBR framework (Flicker, Travers, Guta, McDonald, & Meagher, 2007). The study empirically examined various aspects of this “problem,” from what issues are taken up in research ethics and institutional review board (REB/IRB) forms (Guta et al., 2010) to what REB/IRB members identify as the issues (Flicker & Worthington, 2012; Guta, Nixon, Gahagan, et al., 2012; Guta, Nixon, & Wilson, 2012). In this manuscript, I focus on interviews conducted with grant recipients from a funding program that supports HIV CBR. In total, 50 interviews were conducted with university-based researchers, researchers housed in community settings, service providers, clinicians, and graduate students. Participants differed in terms of their disciplinary and applied training, lived experience, and history of involvement in the HIV movement; but all
were involved in HIV CBR. Being responsible for primary data collection, I conducted all but five of the interviews.

The interview guide was semi-structured with open-ended questions. The first section asked about the participant’s training, current role, and what brought them to the HIV sector. Subsequent sections explored the development stage of their project, navigating ethics review, and the ethical and methodological issues that emerged in the field. The final section asked for reflections on the boundaries between research, advocacy, intervention, and community development characteristic of this work. These interviews were in-depth (or, ‘focused’) and required me to take an active role in the discussion (Holstein & Gubrium, 2003; Liamputtong & Ezzy, 2005). They were conducted in-person or over the telephone depending on the participant’s location and preference. While telephone interviewing has been criticized for the loss of contextual cues (Novick, 2008), the quality may be comparable to in-person interviews (Sturges & Hanrahan, 2004). Both types of interviews provide rich data and some minor differences to be examined later.

The larger study for which data were collected used a grounded theory design and an iterative and inductive approach to coding and analyzing the data (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The data and analysis presented here is part of independent doctoral work and focuses on instances in the data when the interviews became discernibly about the participant and interviewer interacting in ways that were methodologically significant. These
methodological moments were captured in a methods code and through analytic memos (chapters 3 and 4 present participant’s self-described experiences about their CBR practice).

The analysis offered below blends standard qualitative analyses with confessionary self-writing and autoethnography. A number of qualitative scholars have used the confession as a tool to make sense of their qualitative journey (Conti & O’Neil, 2007; Kluge, 2001) or have problematized the confessional nature of qualitative interviewing (Paechter, 1996; Pillow, 2003). Others have used autoethnography to reflect on the ethical dimensions of their field work (Ellis, 2007; Goodwin, Pope, Mort, & Smith, 2003; Wong, 1998). This analysis avoids the truth claims expected in traditional grounded theory (a position challenged even by its proponents, see Charmaz, 2006; Clarke, 2005). Instead, I use the criteria for establishing quality in autobiographical self-study research advanced by Bullough and Pinnegar (2001, pp. 16-18). They called for research to: ring true and enable connection, promote insight and interpretation, seek to improve the learning situation for the self and others, and attend carefully to persons in context or settings. When using recorded conversations, analysts should “interrogate the relationships, contradictions, and limits of the views presented” (Ibid, pp. 19-20). Feldman (2003, pp. 27-28) has added that self-studies should provide clear descriptions of data collection, how representations from the data are constructed, and offer multiple explorations of same self-study. When data are presented “I” refers to the interviewer and “P” for the participant. Participants are further described as “A” (academic) or “C” (community-based researcher).
2.4 Struggling to speak and other methodological “moments”

During interviews for other studies, I have discussed such sensitive issues as sexuality, illicit drug use, homelessness, living with HIV, and mental illness. Those interviews could be described as falling within a traditional model where the interviewer asks pre-determined questions followed by the participant responding. Reviewing old transcripts, I am visible in the text through short interruptions of participant’s long narratives. I began this project anticipating it would be easier than projects that came before it. In this case, I would be speaking to “professionals” about ethical issues in their work. This distinction was naïve as these interviews proved more challenging than anticipated. I quickly realized that evoking “ethics,” especially formal research ethics, brought participant’s practices into question. For researchers and clinicians working with vulnerable populations, there are few admonishments as grave as to be deemed *unethical*. This is evident in the growing body of research interested in examining and even quantifying knowledge and uptake of academic and clinical ethics (for some recent examples see Jordan & Hill, 2012; Lozano, 2012; Saini, 2013; Vertrees, Shuman, & Fins, 2012). My questions to participants about their relationship to ethical boundaries subjected them to an investigative gaze that caused discomfort. In turn, this caused me anxiety and disrupted my usual interviewing style leaving me feeling unsure of how to broach sensitive topics. What follows is an interrogation of key issues that surfaced during these interviews and possible interpretations.
2.5 Confessional practices

2.5.1 Becoming a worthy confessor

In his 1974-1975 lecture series Foucault (2003a, pp. 178-180) discussed the social function of the confession, specifically the training and self-discipline required by the confessor (the priest who witnesses the confession). The qualified confessor must be ordained and possess a number of specific virtues; he must be *zealous* (have a benevolent love of others), *holy* (able to insulate himself against the sins being transmitted), *learned* (able to function as a judge and doctor and able to guide and govern), and *prudent* (able to apply these other characteristics to particular circumstances). In qualitative research, novice researchers (not yet “ordained”) are sent out to hear confessions as part of their methodological training or employment. I realized early that asking high profile researchers with decades of experience to confess their ethical transgressions to me was not an appropriate task for a novice. Those in positions of authority do not confess to just anyone. I responded to their concerns by offering an account of myself, which I hoped would build rapport. Below is an excerpt from one of the earliest interviews. Here, I located myself as part of a larger team of experts while also describing my interests and experience:

I: Do you have any questions for me?

P: No. They probably will come as we start talking. I guess we'll see where it's going…it sounds like really interesting project and I'm curious sort of what the scope of it is?

I: Well, there's several phases…[discussion of first two phases of the project]…now, we're looking at how recipients of [these grants] experience ethics
review and the kinds of things we don't get an opportunity to think about or work through during an ethics review but end up having to deal with at a later time. To get that conversation going, and everyone on the team is enmeshed in CBR, so it's very much a conversation amongst friends perhaps, or colleagues. So it's certainly not a critique of this kind of work, but, getting a chance to just talk about some of these issues. I conduct community based research and I also sit on a REB, so I wear both hats.

P: Right, great. That gives it, sort of, perspective. It's a very different perspective.

I: Yeah, you know, sometimes I find myself being in a very strong advocacy role. And then sometimes perhaps, I end up even being a bit more critical than some of my colleagues (laugh).

P: That's okay though. When we talk about my experience, you'll understand why that's the case, yeah, anyway.

I: I'd love to hear about your work and how you became involved in CBR.

(Interview 5, A)

In this case, positioning myself as learned and prudent, able to judge ethics and CBR, piqued the participant’s interest and increased her comfort. This, I believe, helped create a space where she felt comfortable opening up about issues at the intersections of methods, ethics, and the larger goals of CBR. Our discussion produced one of the richer accounts shared during these interviews. The success of this early interview encouraged me to continue to use this strategy, and the above script (or with some variation) became my standard introduction. I attempted to be conscious of the participant’s experience and interests. If they worked on sensitive research topics in which I had experience, I emphasized my insider knowledge. Many had worked in social service provision, in which case I would mention being a social worker. When I lacked a
comparable experience, I expressed my general interest in their topic and attempted to make connections with my own work. This served to position me as a practitioner and scholar who wanted to understand the experiences of others, and not just a graduate student. Many participants told me these self-disclosures clarified the project for them, and assuaged any concerns they had about participating, or as one particularly assured participant put it: “that’s great, that’s super great, thank you” (Interview 8, A).

The need to position myself as worthy of their confession was especially important for interviews conducted over the telephone where there was an absence of reassuring body language. Over the phone, words needed to be chosen carefully to prevent confusion. Traditionally, confessions were conducted with the confessor and confessant separated through a lattice that provided privacy and a sense of anonymity to the confessant. Spatial arrangements influenced the research process, especially when interviews were conducted in-person. Foucault (1984c) remarked that “space is fundamental in any form of communal life; space is fundamental in any exercise of power.” I observed that while telephone interviews often started with unease on both ends, those participants ultimately proved more candid than in-person interviews. This may have been influenced by their chosen surroundings. For example, one participant described feeling particularly comfortable and relaxed: “I’m actually sitting here in my housecoat. I’m on a semi-vacation day, so this was a perfect day to do this” (Interview 12, A). In contrast, the in-person interviews and spatial arrangements (separated by a desk and a visible tape-recorder) resembled an interrogation. Many experienced researchers seemed unnerved by the recorder’s
presence. The spatial arrangement of the interview influenced participant’s disclosures by making some aspects of the confessionary encounter visible while concealing others.

When participants expressed frustration or confusion with an REB/IRB encounter, I shared my insider knowledge gained from six years as an REB member. My goal was to provide examples as points for comparison. For instance, if the participant expressed concerns about their REB/IRB being overly protective, I responded with an insider’s perspective, to which they might counter with a description of the protections they put in place to avoid research related harms. In the example discussed below, the participant alluded to his REB/IRB requiring certain questions be removed from a survey despite his appeals that “fell on deaf ears.” He initially shared few details about the process and appeared uncomfortable discussing the details. I changed tactics by sharing one of my own experiences then returning to the issue:

I: Would it surprise you to hear that with my REB we were able to administer [a sexual health] survey, actually it was administered by youth to youth as young as 13, without parental consent?

P: Yeah, I guess it’s just the REB that you get, you get very progressive ones, and you get ones that are still back in the days of old.

I: In that case, someone on the board said, I would not want you to give this to my kid, but you made a strong argument, and I’m not going to stand in your way [P: ok, ok, ok] which sounds like a different REB culture [P: yeah] than the one that you had. [P: yes, yeah] I’m sorry, how did you resolve…

P: Well it was resolved, miraculously, through advocacy… [followed by long in-depth discussion of the process]…(Interview 16, A).
This participant had initially been reluctant to describe his experience or provide any details, but my sharing an example made talking about these issues see acceptable. He reframed his experience in different terms and provided more detail about who was involved and how the experience unfolded. Ultimately, the story was more interesting than a simple refusal from the REB/IRB. It involved numerous interested parties and changed the review culture at the REB/IRB in question. In this case, my selective use of self-disclosures likely earned me the participant’s trust. However, such disclosures may have put others on the defensive when talking to me. It was only following data collection that I reflected on how positioning myself as both researcher and reviewer influenced the interview dynamic.

Foucault (1978) explained the confessor’s power entails the authority to prescribe a penance to the penitent; historically these ranged from prayers to excommunication and even death. In these interviews, participants could certainly refuse to answer questions or end the interview at any point. However, my taking the position of ethics expert provided me with what Bourdieu (1991) called “symbolic power.” Participants knew I sat on an REB, in some case their REB, which may have positioned me as some kind of “ethics police.” Thus, my disclosures were not neutral statements of facts, but served to shape a particular interview dynamic. This participant admitted to having fretted in anticipation of our interview which he envisioned as interrogation about ethics forms:

P: This is a much nicer discussion [than I expected]! I got to my office at 9 and I’m thinking, ‘I don’t know what this is about, and I hope it’s not asking like the nitty-gritties of like when ethics returned this what did you do?’ And I’m like ‘I
don’t remember, I’ll have to go look through all my ethics…” You know what, thank you, because you raised a lot of very important topic areas that I don’t think I’ve spent that much time recently reflecting upon. I want to thank you for raising a lot of these issues so I think they’re really thoughtful (Interview 48, A).

Ultimately, this participant enjoyed our conversation, but this was in contrast to the interrogation or audit he expected. Positioning myself as a researcher and reviewer may have affirmed assumptions that circulate in both domains about my “inherent right to investigate” and extract confessions (Ibanez, 1997, p. 119). Researchers interested in ethics need to reflect on how they present themselves and the impact it can have on participants. While my self-positioning may have influenced my interviews, I do not mean to suggest participants were dazzled into submission by my credentials. Rather, I suspect it facilitated access and gave me temporary credibility, but at a cost discussed in the following sections. I further complicate my role by considering aspects of these interviews through new interpretations of Foucault’s work.

2.5.2 Confession as a disciplinary practice of the self

Returning to Foucault’s assertion we have become a “confessing animal,” confessional practices need to be understood as central to the formation of modern subjectivities. However, Taylor (2009, p. 78) has argued that for Foucault all confessions involved “a particular form of truth production, constructing the truths of selves in its quest to ‘reveal’ them.” Thus, by confessing, we create truths that are the product of particular power relations. Confession then may not reveal the subject’s authentic experience, but simply reproduces discourses on the topics being discussed – in this case, research ethics. This realization has important implications for thinking
through the limitations of qualitative interviewing. Instead of viewing interviews as windows into “truth,” they ought to be looked at as a “game” (or, strategy) subject to particular rules. During an interview where he reflected on polemics, Foucault (1984a, p. 381) remarked:

In the serious play of questions and answers, in the work of reciprocal elucidation, the rights of each person are in some sense immanent in the discussion. They depend only on the dialogue situation. The person asking the questions is merely exercising the right that has been given him: to remain unconvinced, to perceive a contradiction, to require more information, to emphasize different postulates, to point out faulty reasoning, and so on. As for the person answering the questions, he too exercises a right that does not go beyond the discussion itself; by the logic of his own discourse, he is tied to what he has said earlier, and by the acceptance of dialogue he is tied to the questioning of other. Questions and answers depend on a game—a game that is at once pleasant and difficult—in which each of the two partners takes pains to use only the rights given him by the other and by the accepted form of dialogue.

What then is meant by the logic of one’s own discourse? Foucault (1994a, pp. 11-13) described discursive practices as the “demarcation of a field of objects, by the definition of a legitimate perspective for a subject of knowledge, by the setting of norms for elaborating concepts and theories”. Scientific and institutional discourses are rich with such “games of truth,” that function to establish officially sanctioned knowledge (Foucault, 1988d, p. 16). I will demonstrate how the interaction produced during these interviews was influenced by the discursive practices and resources available to both parties, and served to discipline us in different ways.

2.5.2.1 An inducement to shame and pleasure
Taylor (2009, p. 82) has added to Foucault’s writings by considering whether confessions “may tend towards untruth by [their] very nature as pleasurable, as shameful, as excusatory, and as coercive.” The participant who was reluctant to speak earlier told me: “I’m not sure if I am supposed to talk to you about that, but I will talk to you about it” (Interview 16, A). He said this as he suspiciously scanned the room, a public venue of his choosing, as if looking to see if anyone was listening. Taylor (2009, p. 88) has argued “the claim that one is overcoming resistance and shame in order to tell the truth, makes the confession an act of bravery…and thus pleasurable in virtue of its very claims about pain and shame.” I often responded to such displays of reticence, by encouraging participants in ways that could be considered leading. A colleague described me as “very complimentary,” as seen in my telling participants their experiences were “very interesting” and their reflections “fascinating.” This could be read as a strategy to depersonalize their experience, making their stories “data” (the shared language between us) thus putting them at ease. Yet, this also served to bring out their ego. Many told stories of “fighting the system,” and took pride in having resisted their REB/IRB. More than a few constructed themselves as having an outsider ethos. Did they find pleasure from constructing themselves as victim, hero, or benevolent researcher? This participant described the pleasure she experienced from our conversation, and simultaneously positioning herself as highly reflexive:

I: Is there anything that we haven’t talked about that you…
P: I can’t imagine…it’s very weird for me to talk for this long, but it’s also very exciting to talk about this because it’s obviously something that I’ve given a lot of thought to, and spent a lot of time dealing with…and we don’t get to spend this much time just getting to think about it or putting it into words or talking about it so that’s actually been kind of cool (Interview 27, A).
Taylor (2009, pp. 104-105) has also considered the way confession leads to displeasure when it fails to achieve the therapeutic benefit of catharsis and leaves the speaker feeling betrayed. A participant who lamented her lack of opportunities to confess reflected this sentiment: “I desperately need to talk to somebody! Who? And I think, I don’t know anybody, so I talk to myself like some kind of lunatic” (Interview 11, C). Here, presenting myself as a worthy confessor allowed me to fill this participant’s personal need to confess as a means of ridding herself of the guilt and confusion that can accompany research with marginalized communities. Elsewhere, this role could have been served by professional supervision as is common in health and therapeutic professions. This raised questions for me about my interviews being exploitive when participants had no other outlet.

In other interviews, I may have unintentionally made participants feel ashamed about their practices. Some participants were unfamiliar with the version of CBR suggested by my interview questions and could not speak to popular practices (especially questions about developing terms of reference and emerging community-engagement approaches), or had not previously reflected on the ethical dimensions in their work. This led to occasional awkward silences and a few sheepishly apologized for not being CBR “enough.” This participant acknowledged her discomfort and her perception of the interview being an examination:

P: I just have this hesitation about whole-heartedly adopting this identity as being a CBR person, because I might answer one of your questions, like, incorrectly and then fail the test of being a CBR researcher.
I: [name], it’s not a test.
P: (laughs) (Interview 37, A)
Another participant, who just reflected on her choice to exclude some stakeholders in a CBR project (a stance rarely discussed in the literature), paused to say:

P: …you’ve been a very good interviewer and you haven’t imposed any of your own perspectives on me, so that’s good [laughs]. But of course now I’m going to leave the interview thinking, ‘Oh God what does Adrian think of me now, holy crap!’ anyway… (Interview 39, A).

My reliance on the discourse of CBR (what is “good practice”), served to position some participants as on the outside of this work (marginalized within the margins) and may have silenced some. One participant openly questioned whether some community-based organizations feel pressured to participate in research, an issue rarely discussed in the literature. Excited by this quandary, possibly a bit too excited, I asked her to elaborate, but she was unwilling or unable to continue. Perhaps this participant was not ready to confess these thoughts and my zeal caused her to become guarded. Or, she had said only as much as she was willing to.

### 2.5.2.2 Making room for false confessions

Despite the reliance on confessions in medicine and law for unearthing “truth,” the very nature of confession as pleasurable and shameful creates the propensity for false confessions (C. Taylor, 2009, p. 82). Interestingly, a number of participants described giving false confessions in their ethics protocols. These were not lies per se, but provided the REB/IRBs with only as much information as the researcher deemed necessary. This next participant valued the ethics review process as an opportunity to identify potential risks, but withheld her knowledge about the more sensitive issues:
P: I would propose that a lot of the pre-work that we did, again this was mostly a guess, but we could’ve gotten through ethics without having done it. There were probably lots of places [where] I don’t think we talked about that [risk reduction approach] in ethics. I: Yeah?
P: Because there weren’t boxes for it, and that’s fine, the ethics approval process forced us to consider this range of issues, and then there were these other issues that we knew were also ethical in nature that we need to attend to…and there will always be nuances and complexities that aren’t captured in the core set of concerns that you might find on an REB/IRB form (Interview 44, A).

This participant was aware of the kinds of issues that could emerge in the field and was prepared to address them, but she did not want to raise these issues with the reviewing REB/IRB. Such examples gave me pause. If participants offered false or partial confessions in one context, could they be doing the same during our interview?

I believe participants offered false or partial accounts for a number of reasons. First, whenever possible, I recruited more than one member of a research team and there were often discrepancies in their accounts. Some of these came from their respective positioning in the project, and being privy to some information and not others. But, there were also intentional omissions as in not wanting to name names (be they research team members or institutions involved), despite these being of public record. Secondly, some of the participants were known to me. They were colleagues and friends with whom I compared “war stories” from the field. However, what was shared over coffee between friends was not necessarily shared on the record. I listened, occasionally perturbed, as they told partial or incomplete stories, often omitting
aspects that I was privy to “off the record.” This academic participant, a friend, became surprisingly guarded about basic information that was well known to me:

I: So what was this project about?
P: I said I don’t want to give away what it is.
I: Okay.
P: It’s about HIV positive people.
I: Okay, umm…
P: If I tell you the title, you’ll be able to tell what it is (Interview 37, A).

I was reluctant to push in these instances, instead letting participants disclose as much or as little as they felt comfortable. I appreciated why asking participants to describe their research projects and implicate their partners in a discussion about ethics was threatening and resulted in selective sharing. This complicated interview dynamic has not adequately examined in empirical bioethics, despite the many challenges it poses to positivist conceptions of quality and rigour.

Flicker (2004) has reflected on false confessions from participants, or what she described as “implausible narratives,” and questioned the researcher’s role as “arbiter of truth.” Rather, all confessions are simultaneously true and false. The following participant discussed the dual function of the confession:

P: But there are two things about that, one is: things are not that way in practice. The second is the storytelling about it is important, it’s important that we embellish and glorify, the analogy is to the lives of gay men. We do a lot of storytelling and a lot of identity seeking through telling each other embellished stories, but the reality is, whether you’re a liar or not there’s a point. There is a need to embellish the story, there is a need to do that kind of narrative, so we’re in a business in which we need a little bit of that.

I: But do we create false expectations…?
P: Absolutely, and you know what, we take risks with the narratives we tell. Even when I’m talking to you, I take a risk that you might misunderstand certain things, or others who read what you and I talked about. Do I want to live my life without taking those, those are minor risks, I’ve taken bigger risks than that (Interview 17, C).

This participant was responding to a question about the way community-based research is discussed in forums like conferences and workshops and the tendency to overstate the positives. However, his response to my concern about these “public confessions” is equally useful here. These false, or “embellished,” confessions serve an important function in shaping, maintaining, and reproducing a discourse. They cannot be celebrated as true or dismissed as false, but are simultaneously both. Interview data needs to be analyzed with this in mind, that data is true, false, partial, embellished, and at risk of being misunderstood.

2.5.3 Confessing the other

Foucault (2003a, p. 186) explained that the confessor must avoid teaching the penitent something they do not know (a specific sin) and only ask them what they know and what they have done. This has important parallels with notions of objectivity and bias in research, where the researcher should avoid leading the interview in ways that impose or implant their own ideas onto the participant’s narrative. As discussed previously, I drew on the CBR literature and my own experiences to guide participants. I framed examples as “some people have said” or “in the literature you’ll find…,” but also through examples from my own work. These provided a quid pro quo, with the currency being uncomfortable or troubling stories. My stories, or self-
disclosures, often facilitated the discussion by giving participants something against which to react or respond. This often led to their spontaneous recalling of a relevant experience: “oh, that reminds me!” or they would say “nothing like that has happened, but that reminds me of….” There were of course instances where participants did not relate to my experiences, but these were fortunately few. The concern here from a methodological standpoint is that my narrative took over and participants responded to my story as opposed to telling their own. I justified my approach as being within a postmodern orientation to qualitative interviewing. Ellis and Berger (2003) have termed this “reflexive dyadic interviewing” in which “the researcher’s disclosures are more than tactics to encourage the respondent to open up; rather, the researcher often feels a reciprocal desire to disclose” (Ibid 2003, p. 162).

Diverging from Foucault, Taylor (2009, p. 167) has drawn on other theorists to consider “the ethics of the relation between confessant and confessor, and on the pressure exerted on the listening other to respond.” Here the attention shifts to “the one who listens, as in the case of the scrupulous priest or the counter-confessing analyst, [and that they] may become the one who speaks, internalizing the desire to confess which he aims to inculcate in the other” (Ibid p. 167). In addition to needing to position myself as a worthy confessor for methodological reasons, my need to offer an account of myself was rooted in a more general need to do so when encountering the other. I shared stories not just as “illustrative examples,” but as confessions to be validated. I also wanted to hear that they were “very interesting”, or even “fascinating.” I experienced pleasure when participants wanted to hear more about my experiences and shame when they
seemed unimpressed. I experienced a desire to confess to these participants as much as they with me. This is part of being a confessing animal, which is not put aside when conducting research.

Taylor (2009, p. 174) has argued that “manipulation” of the confessional other is common, making the confession “a dialogue in which both parties try to extract an echo from the other...” When asked about their training and how they became involved with community-based research, many participants used this as an opportunity to resist their academic label and emphasized being part of the communities they research. This was especially true of participants who identified as members of sexual minority or ethnic communities. This participant offered an elegant description of herself as an Aboriginal researcher:

P: Well it’s partly rooted in an Indigenous way thinking about the world, which is my cultural background and we were taught, and I continue to be taught by my elders, that you don’t force yourself onto people, that whatever career or profession or work you engage in, you do it in a humble and respectful way, and that you do it in service to your community (Interview 12, A).

While I tried to convince participants of being worthy confessor they simultaneously wanted to convince me their narrative was authentic. This reflects positional claims in CBR about who gets to speak about the community. As we discussed the details of their projects we simultaneously tested each other’s boundaries and performed the discourse of CBR and research ethics. In doing so, we co-created an evolving script of what it means to be ethical when doing this kind of work. Yet, not all participants offered such rich descriptions of their motivations or were interested in having in-depth conversations. Taylor (2009, p. 178) has invoked Butler’s warning “that
although we might ethically pose the question, ‘who are you’,” we should not expect our desire to know to be fulfilled.” There were some participants who resisted the inducement to confess.

2.5.4 Alternatives to confession

Foucault (1982) identified a notable example of confessional silence in the case of Pierre Riviere, who having slaughtered his entire family refused to offer an explanation and remained silent during his trial. However, as the case showed, remaining silent and refusing to speak does not remove one from discourse. Foucault (1978, p. 27) rejected the supposed binary between what one says and what one does not say, and argued there are “many silences, and they are an integral part of the strategies that underlie and permeate discourses.” Taylor (2009, p. 197) has added that “silence can be a position which reflects one’s oppression or which demonstrates one’s freedom, or it can be a means of oppressing the other....” In an interview, which stands out from the others, the participant, an experienced academic researcher, seemed to enjoy deflecting my questions instead probing me for examples:

I: [was it] for you, in terms of where you were at, and your colleagues, that [CBR] just seemed like the way to do things?
P: Mmm-hmm.
I: Was there a perception though that perhaps others might not see it that way?
P: Who do you mean by others?
I: External stakeholders?
P: Might not see CBR or?
I: Yeah.


P: Yeah. Um, that was the experience (laugh). You want a story? (laugh)
I: I'd love a story.
P: (laugh) I know how this works (laugh).
I: Whatever you're comfortable with (Interview 4, A).

This interview is memorable not just because of the participant’s refusal to speak and the discomfort it caused me, but because the silences were contrasted with the participant’s rich description of his self-reflexive process:

P: I keep a journal. I don’t often read it, but I do keep one. I just come home and blurb out my frustrations, or my joy, or whatever. And maybe reflect a bit about why that is. And then forget I ever said it. But it's [there] (Interview 4, A).

Why did this participant, who clearly took time to reflect on his work, agree to participate but refuse to tell his story? My initial reaction was to dismiss this participant as intentionally difficult and the interview data as “thin.” In contrast, the majority of the other interviews were full of “juicy quotes” surfacing a range of controversial issues. However, I later read this “thin” data as representing an act of resistance, a refusal to confess, and a rejection of my “right to know.” This participant’s private reflections, or “self-writing,” fits within Foucault’s interest in forms of subjectivity that provide alternatives to confession (C. Taylor, 2009, pp. 197-198). This participant’s refusal to speak also foreshadowed my subsequent dilemmas with the analytic task of making sense of these confessions and why some silences were needed.

2.5.4.1 Confessing the collective and the ethics of representation
In reflecting on the richness of these interviews, I became aware that some of these confessions might be dangerous to share. Not necessarily for the anonymous participants, but for an entire community of researchers with shared practices who become implicated in their confessions. Whose stories, or confessions, were these to share? May one person confess on behalf of another, let alone an entire research team or organization? Ellis (2007) has questioned if one’s story is ever their own to tell, inviting researchers to consider how they implicate others. Participants in this study seemed particularly sensitive to these issues and offered certain kinds of confessions to protect others, whether known or imagined. What then is the responsibility of the researcher when transforming confession into knowledge? Fine, Weis, Weseen, and Wong (2003) have written about the important relationship between qualitative research, representation, and social responsibility. The problem they faced when describing “community,” was “how best to represent the stories that may do more damage than good, depending on who consumes/exploits them” (pp. 182-183). This is especially important in community-based research, which is premised on redressing the legacy of researchers who took information from communities and then portrayed them in stigmatizing ways. Within these interviews were stories of researchers engaged in practices that could be understood as “problematic” by many REB/IRBs. These examples are discussed in detail elsewhere (see chapter 4), but include acts like giving honoraria before a data collection session to someone who needs to use drugs. These stories could be interpreted as compassionate or as extremely unethical depending on who reads them. What would the participants who shared their stories think once they have been decontextualized and exposed? Regardless of their intention, whether to submit to the logic of the confession, or to manipulate it bending the confessor, their stories take on new meaning outside of the confession.
The question becomes whether such stories can be combined and re-shaped to highlight their essence without exploiting them?

2.6 From confession to shared experience of *imagining*

Foucault (2003a, p. 181) remarked that a good confession is characterized by the “investment of pain, pleasure, and solace on the part of both the penitent and confessor....” I was surprised at how many people thanked me following these interviews for the opportunity to reflect on their own projects. The sentiment expressed was that these were difficult issues to talk about, but it was liberating to do so. One participant elatedly exclaimed: “I’m so glad. I’m so glad [making the time] was worth it. It was really neat to be able to talk about some of these things. You know they just chase around the dust ball of your own mind for so long” (Interview 7, A). Following another interview a participant asked “can I call you sometime to talk about these issues some more?” There were many such examples, all surprising to me, because I had not heard this from interview participants in other studies. I was affected by many of these interviews and the emotional impact of the stories they told. These were their stories, but aspects mirrored my own. Facilitating and participating in these interviews was at times exhausting. Dickson-Swift et al. (2009) have considered the toll of “emotion work” in qualitative interviewing and the potential for burnout. Continuing to reflect on what was said, how it was said, and what it meant can become burdensome for the interviewer. Thus “confessional tales” have their personal costs.
In writing this account, I have become troubled by my problematic claim to that early participant that our interview would be “a conversation amongst friends.” Reviewing later interviews I only made this claim once, likely a result of my nervousness, and it was not part of the subsequent script. Kvale (2006) has rightfully questioned the claim that interviewers are warm and caring, reminding us that supposed dialogues include numerous asymmetries of power. Mauthner, Birch, Jessop, and Miller (2002) have warned that notions of friendship can become instrumentalized by researchers to achieve particular ends, which raises many questions about personal and professional ethics. However, many of these interviews, despite having the specter of a confession looming, also had elements of engaged dialogue. In reflecting on the possibilities of moving from confession to dialogue, Ibanez (1997) has argued that if we are unable to deploy power in truly democratic ways, we should at least be “capable of reflexivity and reciprocity with respect to the impact they have on those we ‘study’.” These interviews addressed a need and provided a forum for myself and the participants to engage in discussions about shared practices and to imagine an ethics of “authentic practice” for HIV community-based research (Murray, Holmes, Perron, & Rail, 2008). Authenticity in this case should not be understood as fixed or stable, but rather as an aspirational, subjective, and evolving process. One works to become authentic as understood in a particular place and time.

Ironically, I have kept in touch with that early participant and we have developed a friendship based on our shared interest in these issues. This is not unusual for those working in the AIDS movement, where friendships are often formed through shared estrangement that bring us together in unconventional ways (Roach, 2012). This forming of friendships is likely problematic
from the perspective of an empirical bioethics rooted in notions of objectivity that separate the researcher and participant, as are many of the reflections and arguments made in this chapter, but this will be true of much of the knowledge gained from confessional tales.

2.7 Conclusion

This chapter has offered a theoretically informed account of interviewing researchers about their experiences investigating sensitive topics and the ethical tensions that emerged. This task of interviewing proved more difficult than expected and resulted in a complex negotiation that at times resembled a confession, but which required me to shift between confessor and confessant. Foucault’s work offered important insights into the process of taking on the researcher role and served to frame the interviews as discursive productions mediated by power and pleasure. Taylor’s (2009) work on confessional practices further helped to identify the relational aspects of these interviews and the way confessor/confessant are disciplined through their interaction with each other. This chapter has contributed to surfacing the central role of power in empirical bioethics research with consideration for the ways research is socially and contextually mediated. The goal has not been to offer a guide or specific tools but to problematize taken-for-granted aspects of the interview encounter and the potential for reflexive confessions. López (2004) has asserted that social science techniques, informed by Foucault’s concept of discursive formations, will advance a more reflexive bioethics. Such a critical approach is needed to prevent qualitative research from losing its transformative potential as a result of being caught up in the empirical turn in bioethics (Ashcroft, 2003). The task then is to imagine an empirical bioethics informed by
poststructural theories of language and power with attention to reflexivity to resist the pressures to systematize methods and analysis. This chapter has advanced Fry’s (2009) vision of empirical bioethics as “…an interdisciplinary project...[with]...diverse philosophical and empirical traditions and approaches to describing and interpreting the world.” The hope is that this analysis will stimulate more discussion about *ethics talk* and the role of empirical bioethics.
Chapter 3
Governing through community engagement: Lessons from the Canadian HIV community-based research movement

3 Abstract

Increasingly, the “general public” and specific “communities” of interest are being integrated into the scientific process. This shift emphasizes “scientific citizenship” and collaboration between interdisciplinary scientists, lay people, and multi-sector stakeholders (universities, healthcare, and government). The objective of this chapter is to problematize these developments through a theoretically informed reading of empirical data that describes the consequences of bringing together diverse actors to produce evidence. Specifically, the Canadian HIV community-based research (CBR) movement is examined using qualitative interview data collected as part of a national study. Drawing on the Foucauldian concept “governmentality” the complex inner workings of the impetus to conduct collaborative research are surfaced. Participants’ talk of the “need” for research is contrasted with community “suspicion” of research and also their accounts of feeling constrained by the requirement to collaborate. This analysis surfaces the ways in which a formalized approach to CBR, as promoted through state funding mechanisms, determines the structure and limits of engagement while simultaneously encouraging the production of a finer grained knowledge about marginalized communities. Here, discourses about risk merge with notions of “scientific citizenship” to implicate both researchers and communities in a process of governance.
3.1 Introduction

The traditional model of science has been challenged by calls for greater public participation and involvement in decision-making processes (Bäckstrand, 2003; Elam & Bertilsson, 2003; Jackson, Barbagallo, & Haste, 2005). Proponents of this new relationship between science and society have advanced an idealized vision of the “scientific citizen” who actively participates in scientific forums (Bickerstaff, Lorenzoni, Jones, & Pidgeon, 2010; Irwin, 2001). This shift has been partially attributed to the public’s loss of confidence in science following high profile controversies, and a general lack of transparency from the scientific community (Mayer, 2003; Wynne, 2006). Subsequently, new dialogue processes have been established to increase inclusion in decision making about issues like clinical guidelines (Boivin et al., 2010), healthcare priority setting (Mitton, Smith, Peacock, Evoy, & Abelson, 2009), and even genetics research (Hails & Kinderlerer, 2003; O’Doherty & Burgess, 2009). However, concerns have been raised that these strategies pre-empt criticism and actively shape popular attitudes about scientific advancements. Braun and Schultz (2010) have argued they construct and differentiate the “public,” enabling certain kinds of dialogues while precluding others. These initiatives have relied on the pretext that engagement is necessary, regardless of actual public interest, and used primarily instrumental techniques (Barnett, Burningham, Walker, & Cass, 2012). Gregory and Lock (2008, p. 1261) have observed current forms of public dialogue effectively screen out more opinionated individuals and have replaced “spontaneous democratic activity such as street protests or mass-media debate.” As a result, more radical elements have become irreconcilable with the bureaucratized and sanitized version of public dialogue promoted today.
In their discussion of “scientific citizenship,” Elam and Betilsson (2003, p. 245) identified early AIDS activism as a classic example of the public confronting the “established moral and epistemic authority” of scientists. This unprecedented clash began when people living with HIV (PHAs) challenged established conventions by demanding a say in decisions about their health (Denver Principles, 1983). AIDS activists protested the closed door culture of public scientific institutions, private pharmaceutical companies, and government regulatory bodies to demand greater transparency and accountability (Epstein, 1996). The activism that marked this period was credited with disrupting scientific hegemony and creating a template for other social movements (Altman, 1994; Silversides, 2003). However, the resulting “partnerships” between the public, science, and government have been charged with producing a bureaucratic structure that undermines the AIDS movement’s original goals (Comaroff, 2007; Guta, Murray, & McClelland, 2011). The objective of this chapter is to examine the consequences of bringing stakeholders together in the shared pursuit of science. This analysis examines participation further along the “ladder of engagement” (Abelson et al., 2003) in the form of lay representation on scientific advisory boards and as members of research teams.

The Canadian HIV community-based research (CBR) movement provides an empirical site to examine the ways different discourses, programs, and technologies operate to promote a particular version of “scientific citizenship.” This chapter starts with an overview of the movement, an introduction to the theoretical framework, the methods and data used, and a theoretically guided presentation of the results.
3.2 The Canadian HIV community-based research movement

Communities affected by HIV were amongst the first to demand community input into the research process (Schensul, 1999). This led to the growing popularity of partnerships between HIV stakeholders and university-based researchers to conduct community-based research (CBR) (Harris, 2006). Allman et al. (1997) defined HIV CBR as involving the participation of community members as partners and co-learners in the research process. The movement has since taken important steps towards “democratizing” research (Ogden, 1999) and promoting the involvement of people living with HIV (Travers et al., 2008). In Canada, HIV CBR is characterized by frequent encounters between academic researchers, community-based organizations, and people living with HIV, and relevant policy and funding stakeholders. This research movement developed in parallel with the growth of community-based participatory research (CBPR), as advanced by Israel et al. (2010; 2005; 1998) and Minkler (2005; 2008). The acronym CBR is more commonly used in Canada, and CBPR in the United States, but the two are often synonymous.

While there is no specific research method associated with CBR, these projects have involved community members in research design and data collection (Flicker et al., 2010; Logie, James, Tharao, & Loutfy, 2012b; Markus, 2012). With respect to HIV, this community-based approach has made it possible to study marginalized and “at risk” populations (Bauer, Travers, Scanlon, & Coleman, 2012; George et al., 2012; Greene et al., 2010; McClelland et al., 2012; O'Brien, Davis, Strike, Young, & Bayoumi, 2009; Strike et al., 2010). The growth of CBR is evident in a
dramatic increase from one publication in 1987 to nearly four-hundred in 2010. Proponents of CBR have systematically document evidence of its success (Jagosh et al., 2012; Viswanathan et al., 2004). This has led some to claim CBR has gone from the margins to the mainstream (Horowitz et al., 2009). Consequently, government, funders, policy makers, universities, and a host of non-profit and community-based organizations are now interested in HIV CBR (see for example this multi-stakeholder government sponsored partnerships, CIHR 2012e).

In Canada, this work has been supported by the Canadian Institutes of Health Research (CIHR) through a unique “HIV/AIDS Community-based Research Program.” The CIHR enables much of the health research infrastructure across the country. The HIV CBR funding program has recognized the historical legacy of community involvement in HIV research and now “supports research that engages communities in all stages of research, from the definition of the research question, to capacity building and integration of community members in conducting research, to active participation in disseminating research results” (CIHR 2012a). The CIHR (2012a) has defined CBR as:

…a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities. CBR brings researchers together with members of the community to: identify the issues; collect, analyze and interpret the data; and decide how to use the results to inform policy, change practice and improve conditions in the community.
This program was designed to assist community-based and non-governmental organizations “in developing the knowledge they need to carry out their work in the most effective manner and in creating research expertise within these organizations” (CIHR 2012). In recognition of the disproportionate burden of HIV infection amongst Aboriginal peoples in Canada, the program has both a “general” and “Aboriginal stream.” Finally, the program has established a unique governance model organized by a steering committee comprised of “equal representation of HIV/AIDS CBR researchers and broader community organizations” (CIHR 2012). Each grant proposal is evaluated with “equal weight” for the “potential impact and scientific merit” (CIHR 2012). In all, the CIHR HIV CBR funding program is a sophisticated example of integration between academics, communities, and government funders.

The CBR program is emblematic of the CIHR’s (2009, pp. 12-14) commitment to “citizen engagement” through “the meaningful involvement of individual citizens in policy or program development.” Within the CIHR (2009, p. 15) typology, “the term ‘citizen’ includes interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations.” In their “framework for citizen engagement,” the CIHR (2009, p. 29) has identified CBR as an important tool and recommended more funding opportunities to encourage these collaborations. Funders in other jurisdictions have also recognized CBR, most notably the Centres for Diseases Control (see the National Community Committee 2011) and the National Institutes of Health Research (see CBR funding opportunities with the Office of Behavioural and Social Science Research) in the United States. The importance of public engagement has been emphasized in all
of these programs, and requires additional theorizing. The Canadian HIV CBR movement offers an important site to investigate these issues by way of an established research movement and funding program.

### 3.3 Theoretical framework

This analysis draws on Michel Foucault’s (1980) writings on the complex relationship between power and knowledge. Foucault (1988a, p. 16) was interested in the “ensemble of rules for the production of the truth” found in scientific and institutional discourses and their general deployment in the shaping of social order. Foucault (2003d, p. 138) used the concept “governmentality” (or, the “conduct of conducts”) to account for the ways power inserts itself into actions, attitudes, and discourses, and determines individual conduct. In his 1977-1978 lecture series, Foucault (2007f, pp. 108-109) defined “governmentality” as:

[T]he ensemble formed by institutions, procedures, analysis and reflections, calculations, and tactics that allow the exercise of this very specific, albeit very complex, power that has the population as its target, political economy as its major form of knowledge, and apparatuses of security as its essential technical instrument...it is the tactics of government that allow the continual definition of what should or should not fall within the state’s domain, what is public and what is private, what is and what is not within the state’s competence, and so on.

The specifics of political economy, conceptualizations of population, and forms of securitization are historically and contextually mediated. In the modern epoch, governmentality has been orchestrated through neoliberalism, a political economic rationality that merged economic
analysis with a theory of human capital (Foucault, 2010a, pp. 218-219). Through “bio-politics,” governance took up the regulation of “biological processes: propagations, births and mortality…” (Foucault, 1978, p. 139). Previously “natural” processes were re-conceptualized through economic rationalities and made calculable, predictable, and governable. Foucault (1980, p. 171) explained this form of governance turned the population it into “an object of surveillance, analysis, intervention, modification, etc.” This is the government “of children, of souls, of communities, of families, [and] of the sick” (Foucault, 2003d, p. 138). The productive potential of the population has been managed through a process of direct and indirect control deployed through social structures and institutions (e.g., the law, education, public hygiene, statistics, etc.) that form an “apparatus of security” (Foucault, 2007f). Whereas issues like crime and diseases were previously addressed through confinement and exclusion, a securitization framework necessitated techniques for classifying, quantifying, and monitoring threats with consideration for the economic well-being of the population (Foucault, 2007f, pp. 6-10).

In Foucault’s (2010c, p. 3) terms, HIV provides an important “focal point of experience” in “which forms of possible knowledge (savoir), normative frameworks of behaviour for individuals, and potential modes of existence for possible subjects are linked together.” Governmentality is used to examine the claims that HIV CBR is an alternative research paradigm as espoused in the CBR literature and policy documents. This analysis draws heavily on Miller and Rose’s (2008, p. 89) writings which framed the “birth of the community” as part of neoliberal re-organizing of society into sites of difference that can be “investigated, mapped, classified, documented, [and] interpreted.” They identified early AIDS organizing as an example
of the ways “‘governing through community’ involves a variety of strategies for inventing and instrumentalizing [the] dimensions of allegiance between individuals and communities in the service of projects of regulation, reform, or mobilization” (Ibid p. 92). This theoretical framework links governmentality to community and provides a critical lens through which to examine HIV CBR.

### 3.4 Data collection procedures

The interviews conducted between May of 2010 and July of 2011 were semi-structured and lasted between one-to-three hours. Interview questions were drawn from the literature and personal experience with HIV CBR. The interview questions contained four sections asking questions: about the participants training and experience; how they became involved in their respective project(s); how the ethics review process unfolded; and what kinds of issues emerged over the “life” of the project. Due to the geographic distribution of participants, half of the interviews were conducted by telephone. Participants were asked for, and provided, consent to be interviewed and digitally recorded. Ethics review for this study was received from the seven institutions of the research team (York University, Wilfrid Laurier University, St. Michael’s Hospital, the University of Toronto, McGill University, the University of Calgary, and Dalhousie University) and standard informed consent procedures were followed with all participants. Participants were thanked with a $25 bookstore gift card.
3.4.1 Data management and analysis

Interviews were transcribed verbatim and data imported into NVivo 9 qualitative data management software. The analytic strategy for this chapter was informed by Clarke’s (2005) “situational analysis” (SA) approach, developed to complement grounded theory with “postmodern” theoretical and methodological insights. Clarke (2005, p. 55) has blended Strauss’s interest in “negotiation” and Foucault’s interest in the “conditions of possibility” to consider actions, discourses, and practices that make up a “situation.” Clarke (2005, p. 72) has advanced the use of “situational maps” to identify the human and nonhuman (e.g., material infrastructure and resources) actors as well as relevant discourses, conflicts, symbols, organizations, and institutions to visualize all the elements influencing a situation. Clarke (2005, pp. 74-75) has rejected the popular sentiment of “letting the data speak for themselves” arguing instead that many relevant aspects of a situation remain unsaid during interviews because of social and cultural conventions related to the topic. This analytic strategy was useful for identifying dominant themes in the data but also less obvious relationships.

Clarke (2005, p. 86) has established three kinds of analytical maps: situational maps, “as strategies for articulating the elements in the situation and examining relations among them;” social worlds/arenas maps, “as cartographies of collective commitments, relations, and sites of action;” and positional maps, “as simplification strategies for plotting positions articulated and not articulated in discourses.” The mapping of discourses has proven useful for identifying how they emerge in social relationships, how they produce identities and subjectivities, and how they
are implicated in power/knowledge (Clarke, 2005, p. 155). The strategy used in this chapter involved analyzing interview data in relation to techniques of governmentality, discourses that circulate within the CBR literature broadly (empowerment, capacity-building, partnership building, etc.), and some specific to the Canadian HIV CBR movement (e.g., policy relevance). The purpose of this analysis is not to provide a definitive explanation of the data, but to surface tensions and inconsistencies in the dominant discourses that circulate within this movement. This is appropriate considering Clarke (2005, p. 28) has rejected the modernist goal of developing formalized theory.

In respect to quality, Walters (2012a, pp. 141-143) has identified strengths and limitations with using governmentality to map power relations: mapping can take an infinite number of routes and reveal landscapes of power, but maps are not neutral and can conceal as much as they reveal. Dean (2010, p. 33) has argued that an analytics of government is “perspectival” and “there is no absolute standard of truth by which this analytics can be judged.” Rather, its intelligibility is determined by comparing it to other accounts of the same phenomenon. Clarke (2005, pp. 12-14) has called for an approach to rigor that involves reflexivity and an acknowledgement of the role of the analyst in shaping the analysis. Below, I offer one possible analysis amongst many. The findings are presented in two sections. First, I illustrate how a funding mechanism designed to promote community engagement makes certain kinds of research and relationships possible. Following this, I demonstrate the consequences of bringing together various stakeholders with divergent interests and the limits of community engagement.
3.5 Governing through citizenship, community, and the logic of evidence

Since the 1980s, neoliberal policy reform has impacted Canada in multiple waves (Luxton & Braedley, 2010). These reforms have been especially evident in the education (Giroux, 2002), health and mental health (McGregor, 2001; Teghtsoonian, 2009), and public service sectors (Baines, 2004; Woolford & Curran, 2013). The public sector has been redefined from its welfare state roots to meet market ideology and the logic of competition and accountability. The most recent wave has encouraged “evidence-based” decision-making frameworks that require public services to use “the best available research evidence” in program and policy development (Hammersley, 2005; Howlett, 2009; D. Taylor, 2005). The “best evidence” has been established through consultation with a variety of stakeholders and decision-makers, including researchers, through the kinds of participatory dialogues discussed earlier (O’Brien-Pallas & Baumann, 2000; Walshe & Rundall, 2001). In response to this evidential demand, some Canadian voluntary and non-profit sector organizations have generated their own data to maintain and/or obtain new sources of funding (Grundy & Smith, 2007; Laforest & Orsini, 2005). While this has resulted in the greater uptake of research methods by community-based organizations, a potential tool to identify deficits and improve conditions, these methods have also enhanced the state’s ability to strategically manage policy decisions (Parsons, 2002). The shift to “evidence” as ideology, and the growing requirement to participate, provides a backdrop to the following discussion of findings from interviews with HIV CBR practitioners.
3.5.1 Managing need and suspicion

Participants were asked to describe how they became involved in their respective CBR projects and the planning and organizing phases. Many participants, but especially the academics, invoked the dominant discourse in CBR: that research should be community-initiated, address relevant needs, and have an action-centred social change agenda (see the previously cited definition from the W.K. Kellogg Foundation’s Community Health Scholar’s program):

My approach has always been to respond to community needs and so rather than pursuing my own research agenda, I respond to community invitations to be involved in different projects…[It] was, grounded [in] the community need, and their articulated need for the research, and they basically said ‘we want this done’ (Interview 12, A).

My first question in a meeting would be ‘Ok, this might be something I’m interested in but what are you interested in? Where do you see the needs kind of right now? Or ‘what do you see as critical right now?’ (Interview 47, A).

This popular sentiment serves to position the academic as benign and lacking personal motivations except to, as some participants put it, “serve” community. This reflects Miller and Rose’s (2008, p. 68) claim that experts in community have changed their tactics to better “embod[y] neutrality, authority and skill in a wise figure operating according to an ethical code ‘beyond good and evil.’” However, the historical legacy of earlier research that failed to meet community needs left some communities “suspicious” and resistant to research:

Communities out there are very…suspicious of researchers…they [community members] are like ‘So…after that, what next? You are here just like any other ones that we have seen come and take all these things and go. Someone else
coming in, take all these things and go.’ And that’s why these particular communities, they feel they are just too over-researched and they don’t want you to take anymore (Interview 10, C).

Community “buy-in” was necessary for these kinds of research initiatives to be successful, providing those involved with a “moral voice” and the authority to enter community spaces (Nikolas Rose, 2000, p. 1403). This suspicion was often overcome through complex negotiations where community-based organizations were eventually convinced of the benefits of research and assured their interests would be protected:

We [academics] saw the value of community-based research in terms of its potential to be informing program and policies at the community level but this is the first [time that] the community we [were] dealing with had engaged in research to this extent. I wouldn’t say necessarily mistrust but due to those cultural differences there were a lot of reservation on the side of the organization to be getting involved…they wanted to ensure that in signing up for the study….that they have a say in all the decision-making and of course that is what defines community based research but again that’s just something that needed a lot of back and forth discussion to be able to clarify the roles and responsibilities..[and]…that everyone felt that this was indeed something that was going to be beneficial and useful to them… (Interview 34, A).

Peterson and Lupton (1996, pp. 146-147) have observed that “community participation” has become a duty imbued with regulatory effects. When there is resistance to participation, in this case framed as suspicion towards the motivations of researchers, it is constructed as a knowledge deficit that “needs” to be overcome (Ibid p. 154). This tension between community “need” and “suspicion” brings into question the claims made by proponents of CBR (Israel, Schulz, Parker, & Becker, 2001) who have failed to reflect on where this inducement to research comes from and the potential consequences. For Rose (2000, p. 1401) community has “become the object
and target for the exercise of political power while remaining, somehow, external to politics and
a counterweight to it.” The subsequent analysis seeks to politicize CBR and show that when
democratic modes of governance merge with “social scientific ways of knowing,” they work to
“(re)produce citizens who are capable of governing themselves, of acting in their own interests
and in solidarity with others” (Cruikshank, 1999, p. 3).

3.5.1.1 Funding and the conditions of possibility

With increasing “opportunities” for community-based organizations to participate in evidence
production, their participation has signaled its own evidence of change in the service sector.
Participating has come to demonstrate that resources are being used efficiently and organizations
are accountable to their client stakeholders. However, what has been framed as addressing the
community’s ‘need’ for research is actually fulfilling the requirement to demonstrate knowledge
of the community:

I think community is invested in these projects because they need to see these end
results, and a lot of these results help them figure out how many people a year are
visiting [them] and what their needs are, and helps them argue for more funding
in the provincial government as well or from the health authorities (Interview 31, A).

While these funds were targeted for research, they were sometimes used to maintain existing
programs, staff, and service levels. This participant who worked in community but moved to
academia, offered a more candid explanation for partnering than is usually documented in the
literature:
Money! I need money! I mean really, that’s the honest truth. It’s so hard to get core funding for service organizations if you don’t have statistics to back it up. And this is a community that we identified that needed help but there was no research around it. So that was one reason. The other is it’s easier to get research dollars than it is to get core funding, so we could actually, again, as a community-based research project, we’re actually, I think providing a service at the same time (Interview 9, A).

This relationship between government and community-based organizations was rarely problematized in the interviews, and many participants took the availability of funding as the solution to many of their problems. The availability of funds was often framed as “serendipitous”:

Well it was a combination of things, it was the opportunity, [and] it was the need. We needed the information, we had to have something to come back with to the government, then the opportunity came to apply for funding, and we had a group of [community] people who were beginning to see they had a role…the thing for funding would come across my desk and I’d fire it off to the [executive director] of one of the different organizations and say, ‘you know we should apply for this…’ [to] support their other project proposals that they were putting in, it was serendipity…it was just a matter of being in the right place at the right time...

(Interview 7, A).

Miller and Rose (2008, pp. 65-68) have argued such forms of inscription and the collection of evidence are central aspects of modern governance and serves to enrol these organizations in social, economic, and political processes without being seen to encroach on their “freedom.” While they are not being forced to participate in this process, failing to do so marks any organization as uncompetitive in the eyes of funders. The availability of strategic research funding opportunities targeted to particular “risk communities” represents a re-orientation of the public sector away from addressing broad social issues to focusing on the most “abjected” within
society (Ibid, pp. 104-106). These community-based organizations remain competitive to the extent that they can claim to attract groups targeted by the state for intervention.

3.5.1.2 Authentic or instrumental partnerships?

Challenging the claim that communities intrinsically want leadership roles in research, and that research is a “tool” for community-based organizations, this academic questioned whether communities are even interested in knowledge production:

I’m generalizing, and I’m sure there are agencies who do, but some of them have gotten into wanting to be the primary holder of [research] funds because the project money has dried up somewhat so they’re, they’re looking to research as a way to sustain them, not because they’re really that interested in being the primary researchers. That’s my personal opinion (Interview 13, A).

This quote challenged the claim that community-based organizations want leadership roles on research projects, but also highlighted a tension over who holds the funds. This next participant described the possibility of exploitation as a result of the pressure to obtain funding. First, he recounted an experience of being engaged by community solely for his credentials:

In one grant, they signed me up, you know, used me as the research expert, to shake loose the funds. I think they invited me to one meeting in the summertime, when I was away on my summer holidays and I never heard from them again. That was a grant that was rated [highly] in the competition, and I think it produced very little (Interview 2, A).

Later, he reflected on researchers exploiting community, possibly a symptom of the pressure to obtain funding within the academy, saying:
I think that it fosters abuse, and there [are] too many examples of researchers saying all the right things to get community groups to endorse their so-called community-based research. Then they get the money and they bugger off and community never sees them again, and they have little control or influence over the actual research. Researchers just see it as a funding pot to get money…

(Interview 2, A).

In an attempt to prevent such abuses, and demonstrate authenticity, many partnerships adopt a formal “memorandum of understanding” signed by each of the partners (see Chau, Islam, Tandon, Ho-Asjoe, & Rey, 2007). This participant described the usefulness of this approach:

After we all came to the decision [to] move forward together, one of the first things we did was to start fleshing out a memorandum of understanding that helped to clarify the roles and responsibilities of each co-applicant, and it also acted as an important discussion piece and decision-making piece for us to refer back to anytime there is any type of confusion or in order really just to try and hammer out the logistics of management (Interview, 34 A).

However, another participant questioned whether these kinds of documents just contribute to the bureaucracy of grants:

You have to do that. It bores me to tears…If you don’t have a good relationship with your partner…no memorandum of understanding, no prenuptial, will make it better, nothing. So, yes I do it because it’s part of a bureaucracy, some of the tools we use… (Interview 17, C).

These results highlight the ways in which funding processes drive a supposed “need” and codify it as a research “partnership.” This orientation to partnership and engagement can be understood as part of neoliberal “competitive contractualism” that has been affecting community organizations for some time (Larner & Craig, 2005, p. 409). The approaches discussed here are further evaluated through granting review processes where the “quality” of individual research
partnerships is scrutinized and compared against others. As will be shown, those who promised the “greatest return on investment” were often rewarded.

3.5.1.3 Growing expectations

The participants in this study were all recipients of CIHR HIV CBR operating grant program which required they “engag[e] communities in all stages of research” (CIHR 2012a). This next academic participant described this as an unrealistic expectation:

…and you must be working with people through the whole process of design, analysis, interpretation, dissemination, which is great, it’s just not that practical. I think you can engage people [in] certain aspects of the processes, but to be 100% engaged from the beginning to the end, I don’t know many people in communities are interested in that. But I think there is this huge gold standard of a CBR approach that I think it’s like, you either do all of these and you’re CBR or you don’t do all of them and you’re not CBR (Interview 37, A).

This sentiment was echoed by another participant who worked with extremely marginalized individuals, and argued this approach to research assumes a certain interest and ability that may not reflect the realities of community member’s lives:

I think there’s a presumption that there’s a particular CBR model that works right? I think it comes from research based or with ASOs right? I don’t think that every kind of community member comes with a particular level of education, or expecting every researcher to emulate or be able to perform in that manner, ignores the kinds of issues that people in other populations face [and assumes] that everybody has the time, the inclination and the ability to participate as an equal partner, I think it is wrong, and
sometimes you get comments [from reviewers] like that, that there’s an expectation that you can do that and that’s not true, you can push the envelope… (Interview 38, A).

This next participant explained how funding proposals, despite having come from otherwise strong community partnerships, are ranked poorly if they do not demonstrate the Greater Involvement of People Living with AIDS (GIPA) principle in particular ways:

They’ve got people from universities working with ASOs and they have ASOs working with communities, and they have tight connections working with a lot of those organizations. They are pretty much admired in the community but then when you send these [proposals] to a committee to review, and if you haven’t totally dotted the ‘I’’s and crossed the ‘T’’s, then you don’t get the money because you ‘don’t have enough GIPA in there.’ Well for me a lot of that GIPA is understood at the grassroots level because that’s where we have been for the last 10 years (Interview 49, A).

Unfortunately, this expectation to demonstrate increasing levels of community engagement is rarely supported with the necessary resources:

I think there’s still an expectation that community-based research can be done on the cheap. While I think it is far more expensive than, or just as expensive as clinical research, or epidemiological research, kind of just pure and simple. I’m happy to do all [that engagement] as long as there’s money (Interview 17, C).

This next participant was also critical of the lack of funding, but recommended promising less and leveraging other resources to fill the gaps:

We had no choice, CIHR caps you at like $120,000, so you have to promise less, but I’m getting much better at budget writing. I think you got to be creative at leveraging other kinds of resources. I’ve come to depend heavily on having grad students who engage with my research projects and see them as learning opportunities (Interview 33, A)
However, the responsibility for making up funding shortfalls often fell onto the community partners who had to take on extra work:

I think it’s important here to note the way the project was funded on quite a shoestring budget, it required us to be quite creative and for a lot of people to be working in-kind, and I think that at this point it’s been a lot of work for the community partners, they weren’t aware that it was going to be this much work. I think we’ve learned lessons for the future to budget in a bit [of] extra funding for these partners because they are just not able to meet the needs and demands of research all the time (Interview 24, A).

A governmentality analysis was useful here to account for the ways citizens become implicated in systems of governance. These growing requirements while established in funding guidelines, were determined with academic and community representatives and continue to be evaluated by those stakeholders. Successful applicants become the reviewers in subsequent years and reproduce, if not advance, these expectations. Cruikshank (1999, p. 117) has argued that such neoliberal strategies which shift attention from the state to bureaucratic and administrative functions helps to mask power and depoliticize power relationships.

3.5.1.4 From quality data to ‘real world’ impact

An additional requirement to obtain funding is the need to demonstrate not only community engagement, but that the data collected will inform program policy change (CIHR 2012a). For many participants this made sense as part of the research/practice cycle:

My whole intention of getting the information that I was looking to essentially turn it into programming and because of my role, co-existing as [an investigator] in this project and
also a program coordinator, I did have the ability to do that, where any information that I got I would be able to turn directly into programming (Interview 1, C).

This next participant observed a trend towards more intervention style research, and away from simply documenting conditions in communities. This shift is also said to reflect changing community “needs”:

I’ve seen [as] someone who’s been in this system for a while, that the level of complexity has been notching up rapidly…Again as long as it’s what the community wants, right? And what kind of information the community needs. So the noise I’m hearing now in the research community is that more and more people are talking about the need to do intervention studies, ‘we’ve got to have intervention studies we need to know what works’ (Interview 39, A).

Having evidence to prove what programs work is understood as a precondition for “real” policy change. The “knowledge transfer and exchange” literature that promotes this logic has become an important component of CBR (Lavis, 2006; Lavis, Robertson, Woodside, McLeod, & Abelson, 2003). The premise is that having the “right” kinds of evidence, framed appropriately and delivered to the right audience, will result in policy change. However, this literature has downplayed the highly politicized nature of decision-making and the myriad factors at play. This next participant reflected on the implications for conducting research with policy goals:

The issues that we choose, and where we choose to study them, always reflects that there is some tangible thing in terms of policy, there are programs that [have] to come out of it. I am not saying that there should be no policy or program outcomes, I think that you know we need research to support the decision-making about policy, programs, etc….but in this work we do, people think well if there’s not some policy then you’re wasting your time (Interview 15, C).
Finally, this participant raised questions about where this emphasis on policy came from and whether it was actually community initiated:

I think there’s…a story that has sort of evolved into that collaborative stuff. A few years ago at the [x] conference, somebody from Health Canada stood up and said very authoritatively that ‘the purpose of CBR was to inform policy.’ And I thought ‘it is?’ What? Inform policy? No it isn’t, it’s to do the work of communities. But it all got sort of co-opted you know? (Interview 11, C).

The impetus to produce evidence can be attributed to what Miller & Rose (2008, p. 67) have described as “action at a distance” and the “installing a calculative technology.” Conducting research, defined in certain ways by funders and the state, has made it possible for community-based organizations to come to certain conclusions about “where they are,” calibrate themselves in relation to where they should be, and devise ways of getting from one state to the other” (Ibid, p. 67). This is a form of indirect governance that does not enforce certain practices, and instead relies on organizations to produce evidence about themselves and each other, that will result in the same ends. For Miller and Rose (2008, p. 107) this emphasis on measurements and outcomes manages not only “professional-client relations,” but also the professionals involved.

3.6 Governing through the bonds of allegiance

Miller and Rose (2008, p. 63) have revised Foucault’s definition of governmentality to account for the development of new governmental technologies that operate through “a multitude of connections” and “between the aspirations of authorities and the activities of individuals and groups.” The concept of “community,” and especially in relation to those defined as “risk
groups,” has emerged as a “new territory for the administration of individual and collective existence…” (Ibid 2008, p. 88). The following section presents data that demonstrate the consequences of bringing together different stakeholders in community-based research.

### 3.6.1 The convergence of stakeholders

A defining characteristic of CBR has been the commitment to bring relevant stakeholders together in research partnerships (Israel et al., 1998). Many participants prided themselves on their complement of partners:

> We had the community health centres involved, the [name removed] bureau was involved, Public Health was involved, we might even have had [high profile individual] on, too, I can’t remember. But usually we’d have some provincial person if we could (Interview 14, A).

> Well this is genuinely multidisciplinary, which is another complication, right? I’m actually a [social scientist], and one is an epidemiologist, the other one is a [basic scientist]. So that's real multidisciplinary, right? (Interview 18, A).

However, bringing together partners from different disciplines and sectors, with different goals and objectives, often required a long negotiation process. This participant described a multi-year process to develop and submit a single proposal:

> …it took about three years of pre-application phase...but then in [calendar year] the frequency of our meetings increased, about once a week as we brainstormed what issues needed to be addressed. What could a research project potentially look like? And certainly after the first year of discussions we agreed that we’re a good fit for each other… (Interview 26, A).
Once partnerships are established, there is the ongoing requirement to nurture and develop these relationships:

I mean the challenges to sort of keep up with all of the projects, I think every researcher has that problem, keeping up with them all cause when you have a community-based project there are partnerships to maintain and all the projects that are community based have multiple investigators and multiple partners and multiple students and so there’s a lot of balls to keep in the air that are different… (Interview 35, A).

…the process piece is very consuming….being able to know who the players are, how do we engage individuals to build a consensus. When they’re all together I’m very conscious of what we can discuss and what we can’t discuss. So it’s very complex and I find [it’s a] nuanced processes. Even with my academic partners there are different egos at play, there’s different interests, there’s different agendas, so it’s always kind of around trying to build some form of negotiation and compromise to what are the values that we want to build in this research? (Interview, 48 A).

Peterson and Lupton (citing Minson, 1996, p. 159) have argued these techniques for “maximizing involvement” depend on the individual’s self-discipline to allow them to “work with and negotiate with others, to attend regular meetings, to ‘manage’ ones time, etc.” In CBR, time requirements can be particularly onerous and may be a barrier to conducting actual research (Castleden, Morgan, & Lamb, 2012). Here, the emphasis on working together disciplines individual’s to act in conformity with “the administrative model of decision making” and within hierarchical structures (Petersen & Lupton, 1996, p. 159). However, in the CBR literature there has been little recognition for the way these structures re-enforce dominant power relations and the ‘trade-offs’ made by the respective actors. Rather, the focus has been on facilitating longer
lasting partnerships (Israel et al., 2006). The following section attends to this gap with consideration for the different stakeholders usually involved in CBR.

3.6.1.1 Academic partners

A number of academic participants described feeling constrained by expectations in CBR. One participant questioned whether the relationship model imposed in CBR is an appropriate fit with an academic culture that promotes independence:

I’m an academic so my research team is made up mostly of academics but I’ve also got community-based people on there too, but academics, we’re not pack animals, and there’s now a whole granting structure that wants us to be pack animals, Well, we’re not pack animals! We’re den animals, and so we often, it’s very, very hard for us to work together… (Interview 26, A).

The HIV CBR program at CIHR (2012) has limited the role of researchers to “contribut[ing] their research expertise in methodology, scientific rigour and supervision of future researchers.” This suggests a consultancy role, but researchers often take on more responsibility, as this participant discussed:

Once people know that you’re the one with that education, you’re wanted in charge [of] the project, you’re hiring them. Like it or not, the person who is doing that has the power. You could try to like sugar coat it and say ‘we’re all in this together!’ But, somebody is getting paid more, somebody is supervising. The researcher [is] supposed to be this perfect, powerful, all-knowing person who can predict everything, design the perfect research project. Obviously that’s not true, but with CBR it’s assumed ‘you just have to really engage with communities and [everything] will be all right,’ you know? (Interview 37, A).
This next participant questioned whether these partnerships were actually undermining researchers’ autonomy and the supposed goal of bettering services:

I think sometimes, as they say, the pendulum has swung back to the other end, because it’s very stifling in that way because you feel that you cannot say anything because you’re going to say something against the grain… the community is so powerful that if you say something they won’t allow you to play in the sandbox anymore…and it’s this weird thing where these agencies desperately need a research presence to justify their existence and yet, with your researcher lens you may see some problems, and wouldn’t it be better for everyone if those problems were solved, and yet simply by naming them and suddenly you risk their being able to exist (Interview 16, A).

This participant’s narrative highlights the way research is important and necessary to the extent it is able to obtain information about service users that can bring in more program funding. Should the research bring into question the need for the program or the organizations effectiveness, they become a threat and their work will need to be censored.

3.6.1.2 Community partners

The HIV CBR program at CIHR (2012) has tasked “community leaders” with ensuring “that research will lead to practical and useful outcomes that will directly benefit the community.” Both academic and community participants described the challenges faced by community-based organizations when they become involved in research. The following participant described how once a project starts, there are few mechanisms to actually ensure community involvement:
Yeah there’s always terms of reference but that doesn’t mean I’m gonna have the same amount of influence at a table [as] I want, right? But if you sit there and agree to the terms of reference then you’re pretty much signing on for what you get, right? But I’ll have to be there to make sure that at least they’ve heard what I have to say, whether or not they implement it. I don’t know how to make people accountable when they don’t have to be accountable to me (Interview 50, C).

This next participant described the impact a project can have on a community as a result of conflict between community partners over who controls the process:

The biggest differences of opinion were between community members themselves. It wasn’t so much the academics against the community members it was the community members fighting with other community members about what was needed and wanted. So this notion of this romanticized homogeneous community that really knows what it wants, didn’t so much pan out when you had such a tremendous diversity within community who represents community and what community means and that’s where the biggest battles were fought, literally battles, in terms of the notions of control and decision-making (Interview 33, A).

Dreyfus and Rabinow (1982, p. 186) have commented that in Foucauldian terms, “power is exercised upon the dominant as well as the dominated; there is a process of self-formation or autocolonization involved.” In the Canadian HIV CBR movement, the processes that researchers and communities have advocated for, and helped design, now serve to discipline them through the requirements for ongoing meetings and negotiations. As described earlier, this administrative function serves to depoliticize the issues at stake and shifts the perceived locus of power from the state to the individual partners. The concern becomes who has more or less influence in the project and whose agenda is being pursued?
3.6.1.3 Peer research assistants

The opportunities and challenges that result from involving “peer research assistants” (PRAs) were recurrent themes throughout the interviews. The PRA approach involves the recruitment and training of community members with a lived experience of HIV, and/or members of “at risk” communities (injection drug users, sex workers, etc.) to participate in the research process (for a discussion of challenges and opportunities with this approach see Greene et al., 2009; Logie, James, Tharao, & Loutfy, 2012a). While community members are said to want to be openly involved in CBR through PRA positions, this participant described having encountered a different response:

…it was supposed to be that [peer’s] are empowered enough that they would want to put their name and phone number as a contact on the recruitment flyers, but not one of them did when [it] down to it because of stigma, which is very real, and I’m not saying that they should have if they didn’t feel comfortable, the assumption when I signed on was that these were people that were confident about coming out as being HIV positive. But that was not the reality (Interview 37, A).

In reflecting on what the “peer” label means for community members, this participant discussed the reluctance of these peers to be identified as PRAs:

…it seems to me as though peer has a particular definition that discloses something, that discloses certain kinds of confidential information about the people who are designated as peers…and my fear about peer research assistants is that, I hope it doesn’t end like this, but that people or certain kinds of people become trapped in a particular kind of identity… (Interview 15, C).
These initiatives have been criticized for the ways they require community members to disclose information about themselves and the kinds of managerial techniques used to organize them (Guta, Flicker, & Roche, 2013). This next quotation demonstrates the ways a neoliberal rhetoric of self-improvement has crept into these initiatives:

These people were all of the margins of society, they were all using, they were committing crimes…I mean social violence, social conflict so there's all kinds of things going on…. So what happened was so beautiful…they began to change. They were eating better! They were making some small sum of money every week. They had a sense that they weren’t just taking from society, they were contributing. They got a sense of value – the research data they were collecting nobody else could collect. Skin improved! Hair improved! None of them was using anymore, they were all on methadone. Housing situation improved! Social conflict decreased! Crime decreased! You know the research became something more than the research (Interview 7, A).

The concern here is not whether this researcher’s claims about the transformative potential of the research accurately reflects the peers’ experiences. Indeed, such claims are questionable considering the modest resources and support most CBR projects are able to offer. Rather, the issue is why outcomes related to increased social functioning and productivity are being used to measure success. The concern raised by Guta et al. (2013) was that these initiatives rely on the rhetoric of harnessing lived experience to produce social change, but function as interventions into the lives of marginalized peers seeking to transform them into better functioning citizens. Returning to the earlier discussion of whether CBR can sustain the growth of its engagement strategies, these participants reflected on what happens to PRAs at the end of a project:

[I’ve] been in the situation a couple of times where you hire them, it’s a part-time position right? Like hourly, and it’s not necessarily a lot of hours and it’s not a lot of money… you can’t live on that, okay? And it’s only a short-term and I’ve
actually seen this a few times where the [peer] research assistant gets a lot of hopes up and they have a lot of expectation and anticipation and then the projects finished and they don’t have anything, I’ve struggled with that (Interview 32, A).

We bring people into a study [and when] the study ends…they no longer have a job, it’s a problem right? It’s a big problem, and it gets repeated every time, hopefully by the time that that project ends another [opportunity] has shown up otherwise everybody gets laid off…even though we may have this idea that we’re equal partners and we share decision making, in the end it’s very clear that they’re dependent, it’s very uncomfortable (Interview 38, A).

This dependency can be understood as a form of discipline that acts on the aspirations of community members who may be less likely to resist the requirements of participation for fear of not being offered future opportunities. Through these community engagement initiatives seeking to turn community members into “researchers,” governmental technologies can reach the most marginalized (sex workers, injection drug users, the homeless, etc.), and through techniques of “empowerment” instill in them the logic of active citizenship and entrepreneurialism (Cruikshank, 1999; P. Miller & Rose, 2008).

3.7 Discussion

This analysis has examined claims that “scientific citizenship” and related strategies for engaging “communities” in science represent the democratization of knowledge production. By way of the Canadian HIV CBR movement, a well-established and sophisticated example, this analysis has shown that community engagement through research has significant costs for those involved. The results presented are in keeping with concerns raised in the literature about “inclusion” being
a strategy to create the conditions for more effective uptake of scientific knowledge (Barnett et al., 2012; Braun & Schultz, 2010; Gregory & Lock, 2008). Whereas early AIDS activism ushered in an era of “scientific citizenship” (Elam & Bertilsson, 2003, p. 245), the radicalism has been replaced by a complex bureaucracy. In Canada, a process has emerged through which community “needs” are translated into research projects bringing academic partners and community-based organizations together to produce evidence about communities. To access specialized funding opportunities developed in partnership with the state, these projects adopt prescribed engagement and partnership strategies to be competitive. These requirements are often onerous; however, community-based organizations need to have a research presence to be seen as competitive. Furthermore, these additional research funds help supplement their diminishing operating budgets. While stakeholders are brought together in some productive ways, this coming together also results in inter/intra-stakeholder conflict and competition.

This focus on contracting engagement through formalized grant structures and collaborative agreements, and having all the “right people” at the table, is evidence that the movement has become professionalized and bureaucratic. Through the logic of “community participation,” these participants are sublimating their emancipatory goals to meet neoliberal requirements for greater accountability and productivity (Petersen & Lupton, 1996, p. 173). This work is being intensified with higher expectations and fewer resources turning those with similar interests and mandates into competitors. Finally, and in-keeping with Roy and Cain’s (2001) earlier findings about programmatic restructuring in AIDS service organizations, people living with HIV are unlikely to be meaningfully involved where there are too many competing interests. Further
drawing on Cain (2002), the concern becomes that the CBR movement has lost perspective on the political issues at stake and will begin “devouring” itself.

Miller and Rose (2008, p. 93, 93) have argued that such forms of community governance “even when it works upon pre-existing bonds of allegiance, transform them, invests them with new values, affiliates them to expertise and reconfigures relations of exclusion.” These partnerships constrain both academic and community partners requiring they take on roles and responsibilities that are time consuming and not well supported through existing funding mechanisms. The emphasis on research with “policy impact” restricts the kinds of research being conducted and opportunities for engagement. This privileging of research outcomes over process contradicts the core principles of CBR (Israel et al., 1998) ultimately affirming more traditional forms of inquiry. The popular strategy of involving people living with HIV in these projects temporarily brings them into contact with research and employment and attempts to build their “capacity,” but fails to address their long-term social determinants of health. Yet, it was these “needs” that supposedly necessitated the research in the first place. Drawing on early AIDS activism, Cruikshank (1999, p. 67) has argued that “technologies of citizenship, such as those aimed at empowering ‘the poor,’ link the subjectivity of citizens to their subjection, and link activism to discipline.” Thus, scientific citizenship provides simply another way of packaging discipline, but is especially effective within the logic of HIV CBR because “community” has overshadowed the state as the site of conflict and change (Nikolas Rose, 2000).
The preceding analysis focused on the influence of neoliberalism and material consequences for the actors involved in the HIV CBR movement. While these neoliberal trends have been well-documented, if not previously in regards to CBR, the literature has overlooked Foucault’s (2007f, p. 108) interest in the relationship between economy, population, and “modes of security.” The regulation of academic partners, community-based organizations, and individuals living with HIV requires further consideration. Responses to health issues like HIV do not emerge haphazardly; funding does not “serendipitously” appear as some participants in this study claimed. The HIV CBR program is “a key component of CIHR's commitment through the Government of Canada's Federal Initiative to Address HIV/AIDS in Canada” and “provides leadership and direction for the research portion of the Federal Initiative” (CIHR 2012g). The “Federal Initiative” is part of the Public Health Agency of Canada (PHAC) and “provides funding for prevention and support programs reaching key priority populations, as well as research, surveillance, public awareness, and evaluation” (PHAC 2012). The Federal Initiative provides an organizing hub through which PHAC, Health Canada, the CIHR and Correctional Service Canada are able to “collaborate” with various partners in the HIV response. Combating HIV becomes the central feature in a “milieu” that links actors within an “apparatus of security” (Foucault, 2007f, p. 21). Elbe (2005, 2009, 2010) has identified similar securitization processes operating globally to re-shape the HIV treatment and prevention response.

Through a securitization lens, we see that the HIV CBR program fills an important role in the process of normalizing knowledge about HIV and affected communities, while also determining the multi-stakeholder response. Through partnership building, various actors are made
“stakeholders” and are brought together to construct “communities” for targeted interventions. This process of documenting and classifying “community” practices, beliefs, and shared networks through social scientific methods is part of a bio-political process of demarcating between those who, in Foucault’s (1978, 2003f) terms, the state should “make live and let die.” Building on Foucault, Esposito (2011, p. 9) has described bio-politics as the state’s efforts to “immunize” itself against threats like HIV by constructing divisive notions of community and the other: “immunity constitutes or reconstitutes community precisely by negating it.” The Canadian government’s funding cuts to HIV programs that oppose its policies (Paperny, 2012), and fighting expensive legal battles to close others it deems morally problematic (Fafard, 2012), while actively scaling-up the HIV CBR program (CIHR 2012e) are examples of “immunizing.” Communities are researched not to improve their conditions, but to protect the collective from them. While critics might counter that too much is being made of this small program, it is worth reiterating that the HIV CBR program is identified as a model of citizen engagement (CIHR 2009). This analysis has implications for understanding the deployment of initiatives seeking to engage communities in health research throughout the CIHR and beyond to other comparable research funding institutions with direct ties to the state.

3.8 Conclusion

The conclusion drawn is that the HIV CBR movement serves governmental ends by collecting needed surveillance data through community-engaged processes and by keeping potentially critical voices occupied through increasingly complicated funding and partnership requirements.
The seeming success of HIV CBR, and the trappings that come with it, can be read as symptomatic of its faults. If this analysis errs on the side of domination at the expense of forms of resistance, it stands in opposition to the often uncritical praise accompanying the CBR movement (see for example Brondani, Moniri, & Kerston, 2012). This should not be taken to suggest an absence of critical voices in the movement; many are privileged in this analysis over those who framed CBR in a more positive light. The question raised by this analysis is how should those in the movement respond to the narrowing of opportunities for more authentic forms of engagement? Or, in Foucault’s terms, what are the opportunities for “counter conduct” by those who are governed (Davidson, 2011). Surely we cannot return to the beginnings of the epidemic when scientists worked in isolation and communities were actively excluded. However, as CBR becomes redefined as a tool to promote new biomedical prevention technologies (Wilton, 2012) it may be time to pause and reflect. It is worth asking, as Flicker (2008) has done, who is really benefiting from HIV CBR? If communities are no longer benefiting, could the networks and partnerships established in the name of CBR be deployed in different ways? Researchers and communities need to turn their collective gaze past the constructed borders of “community issues” towards the governmental institutions whose inaction fuels the spread of HIV in Canada and beyond. Risks associated with this confrontational refocusing exist as other researchers who speak out describe (see "Death of evidence," 2012). However, as the early AIDS activism proved, change is possible with the caveat that ongoing hyper-vigilance will be required to obtain and maintain the desired changes.
Chapter 4
Examining the relevance of Foucault’s “ethic” for research ethics:
Lessons from the Canadian HIV community-based research movement

4 Abstract

There has been growing interest in Michel Foucault’s final works on “ethics” and the relationship between governance and self-formation. Recently, scholars have used Foucault’s ethical imperative of “care of the self” to examine power relations in medicine, education, and research. This chapter contributes to this emerging scholarship by examining ethical practice in community-based research (CBR). This approach to research is said to transgress traditional conceptions of research and the boundaries imposed by research ethics. Analyzing data from a national sample of Canadian HIV CBR practitioners, results are framed using Foucault’s “morality of behaviors,” and reveal that many have an ambiguous relationship to research ethics. These researchers understand and use prescribed codes, but adapt them in practice to account for the realities of participants’ lives, the needs of members of their research teams, and the community as a whole. Ethics here becomes a shared responsibility with decisions made between stakeholders in a research partnership. These partnerships provided an ethical terrain in which participants challenge themselves to work differently, and as a result care for themselves and others in ways that resisted the propensity for domination through research.
“...there are different ways to ‘conduct oneself’ morally, different ways for the acting individual to operate, not just as an agent, but as an ethical subject of action” (Foucault, 1985, p. 26).

4.1 Introduction

Three decades into the global HIV/AIDS epidemic, this complex health issue has continued to raise important questions about ethics in research (Heimer; Lazzarini & Altice, 2000; Moser et al., 2002). Investigations of HIV remained closely linked with “risky” practices (unprotected sex, selling sex, injection drug use, etc.) and marginalized identities. These topics have put social science researchers in conflict with research ethics boards and institutional review boards (REB/IRBs) tasked with reducing research related risks and harms. REB/IRBs tend to rely on biomedical conception of risk, harm, and vulnerability (Schrag, 2010; van den Hoonoord, 2011). This orientation to research ethics has promoted positivist objectivity and detachment, drawing clear lines between researcher and researched. Growing calls for HIV research to better engage affected communities has challenged the need for these distinctions (Baldwin et al., 1996; Grinstead, Zack, & Faigeles, 1999; Schensul, 1999). In Canada, this call has evolved into the HIV/AIDS community-based research (CBR) movement and is characterized by the direct involvement of communities in the research process (Allman et al., 1997; Harris, 2006). However, ethics review requirements have been identified as a barrier to HIV CBR and practitioners have described the process as exclusionary and unresponsive to their work (Flicker et al., 2009; Ogden, 1999). The long-term partnership and relationship building promoted in
CBR has conflicted with the detached model expected by research ethics (Blake, 2007; Bradley, 2007; Munoz & Fox, 2011).

In response, a body of literature has emerged that challenges the perceived paradigmatic clash between formalized ethics review and participatory frameworks (Susan Boser, 2006; S. Boser, 2007; Martin, 2007; Rolfe, 2005). Existing ethics review frameworks with their emphasis on autonomy, non-maleficence, beneficence, and justice have been criticized for failing to adequately capture the ethical complexity of research conducted ‘with’ in contrast to solely about communities (Flicker, Travers, et al., 2007; Shore, 2007). Wallwork (2008, p. 74) has identified a postmodern thread in some discussions of CBR that reflect a Foucauldian “hermeneutics of suspicion with respect to the covert power, hidden ambitions, and cultural biases that infuse supposedly ‘impartial’ scientific research.” The possibility of such an approach to CBR ethics is intriguing and will be considered further in this chapter.

The objective of this chapter is to take the “problem” posed by ethics review requirements in HIV CBR and use it as an opportunity to ask different questions about what it means to be an ethical researcher. Fox (2003) has argued that collaborative research is “transgressive” because it dissolves traditional boundaries between researcher/researched and research/practice to produce more “ethically and politically engaged research.” This opening up of transgressive space is intriguing and invites further theorizing. In his final works, Foucault (2005, p. 252) framed his decades long intellectual project as an attempt “to connect together the question of politics and
the question of ethics” through an analysis of power relations, governmentality (the government of self and others), and the relationship of the self to self. Foucault’s approach is useful for responding to Guillemin and Gillam’s (2004) call to close the perceived gulf between “procedural” ethics (REB/IRB requirements) and “practice” ethics (issues emerging in the field). This analysis challenges the distinction between "ethics" as understood in research ethics (an epistemological project) and "ethics" in the Foucauldian sense as the relationship with the self (an ontological project). As will be demonstrated, these projects clash and converge in the “transgressive” space created by collaborative research.

This chapter uses the Canadian HIV CBR movement as a site to read how technologies of the self operate in response to technologies of governance. Whereas previous work aimed to locate community-based research within systems of domination and regulation (see chapter 3 of this dissertation and also Guta et al., 2013), this chapter emphasizes forms of resistance by asking what it means to govern well in research relationships. Using interview data collected from HIV CBR practitioners (academic and community-based researchers), this chapter examines the ways in which they navigate the requirements of research ethics while trying to work equitably with communities. What emerges is a research ethic that resists prescribed modes of behaviour but maintains a dialectical engagement with them. This chapter starts with an introduction to Foucault’s writings on ethics, followed by a description of the methods used for data collection and analysis, and then offers a theoretical engagement with the results.
4.2 Theoretical framework

Foucault (1994a, p. 281) was primarily interested in “how the human subject fits into certain games of truth, whether they were truth games that take the form of a science or refer to a scientific model, or truth games such as those one may encounter in institutions or practices of control.” Foucault (2007f, pp. 108-109) attributed control to “governmentality” (the “conduct of conducts”) which he defined as a complex ensemble of forms of power orchestrated through “institutions, procedures, analysis and reflections, calculations, and tactics...” Dean (2010, p. 18) has added that governmentality “employ[s] a variety of techniques and forms of knowledge, that seek to shape conduct by working through the desires, aspirations, interests and beliefs of various actors, for definite but shifting ends...” Foucault’s writings on governmentality have inspired notable studies of the relationship between economy, medicine, law, politics, and subjectivity in modern systems of governance (Dean, 2010; Higgs, 1998; P. Miller & Rose, 2008; Nikolas Rose, 1999; Walters, 2012c). Recently, governmentality has been used to make sense of formal ethics review requirements in modern academic institutions (Guta, Nixon, & Wilson, 2012; Koro-Ljungberg et al., 2007). Collectively, these contributions to the literature have provided novel ways of thinking about power relations and questioned taken-for-granted practices. However, Foucault’s work has continued to be criticized for presenting a totalizing experience of power at the expense of resistance (for an overview of these critiques see Muckelbauer, 2000). Such claims have ignored Foucault’s (1985, 1990) final writings and lectures on ethical self-formation where he identified historical strategies for resisting governmental operations of power (Faubion, 2011; O’Leary, 2002; Oksala, 2005).
In his unconventional approach to ethics, Foucault (1985, pp. 25-26) examined the historically shifting and conditional nature of morality and the “margins of variation or transgression individuals or groups conduct themselves in reference to a prescriptive system.” Foucault (2005, p. 14) was especially interested in the impact of the Cartesian privileging of *gnôthi seauton* (“know yourself”) over *epimeleia heautou* (“take care of yourself”) on the relationship between self and knowledge. During his investigation, Foucault (1985, pp. 10-11) revisited the lost “arts of existence” in Greek antiquity:

…those intentional and voluntary actions by which men (sic) not only set themselves rules of conduct, but also seek to transform themselves, to change themselves in their singular being, and to make their life into an œuvre that carries certain aesthetic values and meets certain stylistic criteria.

These *arts* guided the process through which individuals questioned their conduct, achieved mastery over their desires, and shaped themselves into “ethical subjects” (Ibid, p. 13). Foucault (1994a, p. 286) admired the Greek approach to ethics for its concern with the problem of “freedom,” an individual’s *ēthos* (“a way of being and behaviours”) and the ongoing work required to cultivate it into something good and beautiful. This work on the self, or “care of the self” was an individualistic pursuit but required cultivating an awareness of one’s desires in order to prevent the domination of others and to ensure proper relationships with them (Ibid 1994a, p. 288). These *others* are encountered in the community, in civic life, and through intimate relationships and friendships. This “care of the self” was thus an ethical and political practice (Infinito, 2003, p. 156). Foucault (1985) acknowledged this was elitist ethic primarily concerned with modes of governing women, children, and slaves, but he remained intrigued by its potential to help rethink contemporary relations.
Perceived as a departure from his earlier writings on mental illness, punishment, and sexuality, Foucault (1994a, p. 177) explained that “…one must take into account not only techniques of domination but also techniques of the self.” This shift in focus finally introduced the “autonomous sphere of conduct” that critics had argued was absent in Foucault’s earlier writings (Davidson, 2011, p. 31). Building on his interest in the “arts of existence,” Foucault (2007a, p. 154) turned his attention to “technologies of the self,” which:

…permit individuals to perform, by their own means, a certain number of operations on their own bodies, on their own souls, on their own thoughts, on their own conduct, and this is in such a way that they transform themselves, modify themselves, and reach a certain state of perfection, of happiness, of purity, of supernatural power, and so on.

Foucault (1988f, p. 18) differentiated between the technologies of power (that serve to conduct and dominate) and technologies of the self (which individuals use to stylize themselves). Foucault (1994a, p. 225) characterized the encounter between the technologies of domination and of the self as governmentality in action. This shift in Foucault’s emphasis should not be taken as a refusal of the “coercive apparatuses of intervention,” but as providing opportunities to discuss the “great variety of informal incitements and incentives that ask or invite human actors to govern themselves” (Faubion, 2011, p. 3). For Davidson (2011), Foucault’s addition of an analysis of “counter-conduct” to governmentality provided an ethical dimension to resistance and linked ethics to politics. However, Frank and Jones (2003, p. 180) have acknowledged that “demonstrating the possibilities of freedom within the constraints of being a subject may have been Foucault’s most difficult, and least completed, task.”
While Foucault was not concerned with ethics review, his conception of “ethics” has implications for thinking about how researchers cultivate their ethical stance. Recent scholarship in critical bioethics has considered Foucault’s work for resisting prescriptive forms of ethics (Chambon & Irving, 2003; Frank & Jones, 2003; Murray, 2007). Frank and Jones (2003, p. 186) have envisioned a “Foucauldian practice of bioethics” framed through “intensified critical self-reflection, which asks how bioethics influences the formation of subjectivities within medical relations of power.” Others have considered Foucault’s work in relation to formalized research ethics (Bastalich, 2009; Guta, Nixon, & Wilson, 2012; Juritzen, Grimen, & Heggen, 2011; Koro-Ljungberg et al., 2007). Bastalich (2009, p. 4.9) has argued a Foucauldian research ethic would not necessarily dismiss standard practices of obtaining consent and disclosure, but would promote an awareness that these practices “do not in themselves remove researchers from the field of power or from questions of correct ethical conduct.”

Koro-Ljungberg et al. (2007) have read “care of the self” as an invitation for researchers to think differently about ethics and their responsibility to participants. Specifically, they have argued that “care of the self” offers a “form of ethical counter discourse” capable of problematizing “the ethical hegemony and governmentally guided ethical decision making (Ibid, p. 1090).”vi Frank and Jones (2003, p. 184) have used that “care of the self” to account for “the process of becoming a subject who is capable of choosing which truth games and technologies to be subjected to.” As discussed earlier, HIV CBR blurs boundaries in research requiring different ways to think about ethics. Foucault’s attention to “care of the self” and “counter conduct” provides a framework for thinking about the ethically murky terrain of “community.” Borrowing
from Frank and Jones (2003, p. 186), the question becomes: how can researchers “offer [their] knowledge and skills to others with the necessary requirement of entering into certain relations of power but still care for [their] own self and the self of the other?” Drawing on empirical data, this chapter applies this question to consider the practice of HIV CBR in Canada.

4.3 Method

The data presented in this chapter were collected as part of a multi-stage Canada-wide research study that examined the relationship between community-based research and research ethics review. Participants were recruited from a publicly available list of recipients of the Canadian Institutes of Health (CIHR) operating grant program that supports HIV CBR. A purposive sampling strategy was developed to reflect both Canadian regional diversity (the provinces and territories) and the priority populations identified in national policy documents (injection drug users, men who have sex with men, etc.). In total, 50 interviews were conducted with a diverse group of university-based academics, researchers housed in community organizations, clinicians, and graduate students. These semi-structured interviews were conducted between May of 2010 and July of 2011. Interview questions were drawn from the literature and research team member’s personal experience with HIV CBR. Half of the interviews were conducted by telephone. Participants were asked and all granted permission for the interview to be recorded. The interviews lasted between one to three hours. Ethics review for this study was obtained from the home institutions of the research team members (York University, Wilfrid Laurier University, St. Michael’s Hospital, the University of Toronto, McGill University, the University
of Calgary, and Dalhousie University), and standard informed consent procedures were followed. Participants were thanked with a $25 bookstore gift card.

4.4 Data analysis

The interviews were transcribed verbatim and the data were imported into NVivo 9 qualitative data management software. The current analysis used Clarke’s (2005, p. 55) “situational analysis,” which complements grounded theory with Foucault’s interest in discourse and practice. Clarke (2005, p. 72) has developed a process of “mapping” the human and nonhuman actors, discourses, conflicts, symbols, organizations, and institutions to represent the situation of interest. This made it possible to identify connections that are not apparent through conventional approaches that focus solely on participant’s narratives. The strategy used in this analysis involved revisiting the coded data pertaining to participant’s self-described motivations for undertaking CBR, attitudes towards research ethics, and how they defined ethical issues in the field. In the excerpts presented below, participants are identified by their status at the time of the interview with an “A” for “academic” (university-based researchers/clinicians, and graduate students) or “C” for “community” (conducting research in some capacity at a community-based organization). In this analysis, the data were read with an attention to Foucault’s writings on ethics and governmentality to identify instances of conflict between participants, key systems (ethics review, universities, etc.), and others (colleagues, community members, etc.). This approach made it possible to connect procedural and practice ethics (Guillemin & Gillam, 2004), and “problematize” (Foucault, 1994a, p. 114) current conceptions of research ethics.
Two limitations to this analysis are noteworthy. First, the themes discussed here only represent a sub-section of the data and were chosen to support a theoretical argument. The process undertaken was not systematic and does not represent the diversity of perspectives within the data. These results cannot be generalized to community-based research in general. As well, the perspectives of academic participants are privileged as they were more likely to be able to contrast formal research ethics requirements and ethics as practiced in communities. Second, the data presented here were collected as part of a research project that did not set out to engage with Foucault’s work. However, using Foucault’s theories as a lens to reinterpret previously collected data has added richness and complexity elsewhere (Frost et al., 2010; Kaufmann, 2011).

4.5 On the aspects of morality

Foucault (1985, p. 25) examined conduct through what he termed the “morality of behaviors,” these being: 1) “the manner in which [individuals] comply more or less fully with a standard of conduct”; “the manner in which they obey or resist an interdiction or prescription”; and “the manner in which they respect or disregard a set of values.” O’Leary (2002, p. 11) has elaborated on the final point, saying it is “the way individuals constitute themselves as moral subjects of the code – that is, the way they ‘conduct themselves’ and ‘bring themselves’ (se conduire) to obey (or disobey) a set of prescriptions.” In the current analysis, Foucault’s approach provided a framework to present and make sense of the data starting with a discussion of participant’s attitudes towards research ethics, followed by how they used research ethics in practice, and finally how they practiced ethics in HIV CBR. Ethics here is understood as emerging within
particular power relations that shape discourse and practice; “the ethical is always political and vice versa” (Infinito, 2003, p. 155). The HIV CBR movement rests at the intersection of various technologies of governance that determine access to material resources as well as shaping knowledge and practice (see chapter 3). The goal here is to understand how individuals stylize themselves, not outside of these relations (as if stepping outside of power were possible), but in response to them. The following analysis offers an engagement between Foucault’s uncompleted project and interview data, and provides insights into how some HIV researchers have stylized themselves in response to increasingly structured community-based research practices.

4.5.1 Relationship to procedural research ethics

The goal of the larger research project for which data were collected was to examine how HIV CBR practitioners navigate research ethics and their dealings with REB/IRBs. Guillemin and Gillam (2004, p. 263) have described these issues as “procedural ethics” and explain that for “many researchers, the completion of the research ethics committee’s protocol form is a formality, a hurdle to surmount to get on and do the research.” Koro-Ljungberg et al. (2007, p. 1078) have equated these requirements with Foucault’s description of the “examination” arguing it “turns researchers and research projects into cases that are then objectified, categorized, and normalized” (Ibid, p. 1078). The result is “a powerful [institutional review board] that gives researchers little to no autonomy and control over their own research” (Ibid, p. 1078). In the current study, participants provided examples of ethics review being a barrier, but not to the extent described by Koro-Ljungberg et al. (2007). The REB/IRB submission process was seen as “daunting” by some participants:
REBs can be daunting…submitting a protocol there is a lot of information that is required, there’s a lot of explanation that you have to do about why you are doing it this way…it can be a fairly daunting process…some of these documents are massive when you go through all the questions and then you append all the documents that ought to be appended, like your questionnaires or your discussion guides and it becomes a piece of work. And you can’t take it lightly because of course you can’t do the research without that approval (Interview 15, A).

Some interviewees also mentioned unfortunate examples of REB/IRBs failing to protect participants by perpetuating discriminatory and stigmatizing views:

I don't think people have any faith in the REB to resolve these things in any informed way because they're so completely disconnected from the community and most members of the REB don't even have content expertise in the area. In fact, we have sufficient evidence from our existing REB reviews, that there's actually a lot of stigma and discrimination towards the community being studied and a great deal of ignorance about it. So I don't think the REB is seen as a helpful tool. It's seen as a bureaucratic hoop to jump through (Interview 2, A).

However, many participants in this study described finding a balance between their needs and their REB/IRB’s requirements. This participant, with years of community and research experience, described having found an appreciation for these protections:

I see some of it as being highly bureaucratic and not really in touch with community-based research specifically and HIV specifically, and then others make perfect sense. I think that's a very necessary step that does need to be required because there have been some unscrupulous researchers in the past that have gone in to the same population that I'm working with and [have] not been upfront or honest, or morally upright, in terms of the research that they’ve done. So I'm glad that those safeguards are in place for the community members, but they do need to be a little bit more relevant to the community research that's done nowadays (Interview 1, C).
For many of the participants, research ethics review was not a barrier to research per se, but the process was described as requiring more from them than researchers using traditional approaches. This participant described being required to jump through “extra hoops”:

I’ve had to fight for it but…I have not yet been turned down. I’ve had to go through that extra hoop, [of] proving the validity, [that] this is grounded, credible, good work. Then I get the approval. I’ve never been turned down. But I have resented the extra hoop to jump through that seems to me comes from not understanding what the real concerns are that an ethics board needs to be addressing when it’s community-based research and that first most big one is that you can actually cause harm, you can unintentionally, and even intentionally I suppose, cause real hurt (Interview 7, A).

However, other participants objected to ethics review being considered “just a hurdle,” and valued the importance of the process:

I get very frustrated with researchers who view ethics approval as an obstacle to their work. I have no patience for that argument…that view of getting through [and] ethics as a hoop. Rather, I think, thank goodness there is at least some milestone here that’s forcing reflection on a range of ethical issues…because it’s also operational issues, like this is what often happens in research; you map out your proposal, what you’re going to do, but then when you actually have to go and do it, there’s like days more of thinking you have to do to figure out how you’re actually going to enact this thing. All those steps have little ethical dimensions to them, so I think thank goodness for ethics approval because it forces you to attend to that (Interview 44, A).

For this participant, “hoops” and extra work were an important, if not always enjoyable, part of the research process:
I don't know, maybe I'm different. I don't see a problem with having to go above and beyond. I think there's value in being forced or being asked to be reflective about what you're doing, in terms of not harming. I mean, yeah, it's a pain. Yes, it's challenging but you are being asked to rethink or think through your processes in a way that, I mean, at least history shows that people haven't always done (Interview 4, A).

The review process may represent an act of normalization as described by Koro-Ljungberg et al. (2007), but this is not a solely objectifying experience. For a number of the participants, the ethics review process was an opportunity for self-examination, an act of inspection that one conducts upon oneself; an opportunity to examine “what one is, what one does, and what one is capable of doing…” (Foucault, 1990, p. 68). Despite claims that ethics review is a threat to the social sciences (Haggerty, 2004), and community-based and participatory research (S. Boser, 2007; Rolfe, 2005), participants were far from rejecting the requirement of ethics review.

### 4.6 Beyond the review: ethics as lived practice and negotiation

A number of qualitative researchers have considered the distinction between procedural research ethics and the ethics of research practice (Cutcliffe & Ramcharan, 2002; Guillemin & Gillam, 2004). Guillemin and Gillam (2004, p. 264) have defined the latter as “the ethical obligations a researcher has toward a research participant in terms of interacting with him or her in a humane, non-exploitative way while at the same time being mindful of one’s role as a researcher.” This framing of research practice ethics recognizes the power researchers have in directing the research process. Power has been overlooked in debates about ethics by critics who simplistically
construct researchers as benevolent and REB/IRBs as oppressive (Dingwall, 2008). This participant characterized procedural ethics as representing the minimum standard and CBR as inviting a higher standard of ethical engagement:

Ethics review was a very minimal standard for us, it establishes the minimum acceptable and the maximum allowable, and in between there’s this whole world of different options that you can choose… You’ve got your minimums and your maximums, but within that nothing tells you ‘what’s the right thing to do?’ You know for us as a team we just kind of said, getting ethics approval, that’s sort of our minimum standard, and we as a team are holding ourselves to a higher standard of accountability and a higher standard of ethics. There’s not a way that you can necessarily highlight all of that to its best advantage within the current forms… aspirational kind of ethic versus the minimum standard… (Interview 27, A).

For this next participant, ethics started long before the filling-out of forms and had much to do with the researcher’s integrity and relationship to others:

So for me ethics doesn’t begin when you start to write your proposal, it starts long before that. You know, it’s really about having integrity…and it’s based on real respect, really respecting people and respecting where they’re coming from…for me that’s where it begins and everything else sort of comes very easy after that, you’re not going to make big mistakes in ethics…I say to students, ‘think about the person in the world that you care most about and, and pretend that that’s the person that you’re undertaking this research with, and you don’t want to harm this person, you don’t want to disrespect this person, you don’t [want] them to feel at all exploited or coerced, so you know just treat these people as though you really care about them’, and by the way maybe you should just really care about them anyway (Interview 12, A)
For Foucault (1994a, p. 287), “care of the self” was the precondition to govern others in the “city, the community, or interpersonal relationships, whether as a magistrate or a friend.” This claim may be disconcerting to those who argue CBR is egalitarian. However, as discussed in chapter 3, CBR is implicated in a process of governing researchers and communities. The hierarchies produced are not inherently exploitive. Foucault (1994a, p. 298) said, “I see nothing wrong in the practice of a person who, knowing more than others in a specific game of truth, tells those others what to do, teaches them and transmits knowledge and techniques to them.” However, ignoring this reality increases the likelihood of these relationship becoming dominating. In the following sections, I demonstrate that the transition from the procedural ethics to practice ethics represents an attempt to govern well.

4.6.1 Encountering risk, harm, and vulnerability

Participants were asked to reflect on the ethical issues that emerged during their projects, some of which spanned years. Participants told stories of encountering what Guillemin and Gillam (2004, p. 265) have described as “ethically important moments,” the “difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research.” These instances provided an opportunity to see the way researchers “govern” as well as how they interpreted and expanded prescriptive research ethics to account for collective issues.

4.6.1.1 With Participants
Most REB/IRBs are primarily interested in the details of how participants will be recruited and consented (Steinke, 2004), and especially the specific language used in the forms. However, this participant used this requirement to reflect on more complicated questions about reproducing power dynamics with potential participants:

Well it was very clear from the outset that, you know, if these young kids are being approached by guys who are driving up in a car rolling down the window and buying their bodies, we weren’t a hell of a lot better. We might have been asking for their minds but we were doing the equivalent of driving up in a car rolling down the window and asking the price and so it took us a long time to figure out ways through that (Interview 7, A).

This next participant described the challenges she experienced reconciling her dual identity as a clinician and a researcher in an interaction with a young injection drug user. Here, she was concerned about harming this participant by introducing routine prevention messaging:

I’ve interviewed a kid who tells me that the only person they share needles with is their mother and I think, okay. At the end I say, ‘Listen, you shouldn’t be sharing needles with anybody.’ And they say, ‘Well it’s my mother, she’s not going to hurt me. She would never hurt me.’ You are in really dangerous water there. I think, ‘Oh fuck’. Well, if I’m going to continue that conversation, the gloves are off - do you know what I mean? I don’t want to damage that relationship, that’s a really important relationship, but the question needs to be asked. Am I going to convince her not to share needles with her mother? No! But what I want to do is plant the idea that she’s probably safer if she doesn’t do it with anybody (Interview 11, C).

The issue of recruitment was often tied to compensation came up in many of the interviews. HIV CBR projects often recruit through small networks and are committed to honouring participant’s contribution through honorariums. REB/IRBs may see these recruitment and compensation
approaches as potentially coercive (Grant & Sugarman, 2004; Head, 2009). This participant reflected on the challenges of recruiting participants who were economically marginalized and managing addiction issues, but are still able to cope with the research:

I struggle with this notion of recruitment, we can’t do a random mailing, these are people who don’t have addresses, we need a particular kind of recruit, we need somebody who is strong enough, not using to a point where they can’t consent or they don’t know what they’re doing, but is still in touch with that side of life, you know? So, recruitment is challenging and it flies in the face of what’s seen as ‘this is what you do to recruit’…it’s different, it’s about people being sure that they’re not going to be hurt and or exploited and that takes time… (Interview 7, A).

For this next participant, the question was not whether compensating someone who is marginalized is coercive, but whether standard approaches to compensation are adequate considering the realities of their lives:

You know ethics boards would say ‘you shouldn’t really appear to be paying people because that’s some kind of coercion or inducement’ or something like that, I say well there are certain kinds of people who maybe in fact I should be paying them, not just giving them an honorarium, an honorarium is like you know merely saying ‘thank you for sharing part of your life story with me’, maybe I should be paying them for being there…is this a community with a high degree of unemployment, low incomes, whatever (Interview 15, C)

4.6.1.2 With Peers

A popular approach in HIV CBR is the use of “peer research assistants” (PRAs), community members trained to conduct research (Greene et al., 2009; Logie et al., 2012a). Many participants
involved community members in their research projects in advisory roles, in data collection, and/or as members of the research team. These kinds of relationships are rarely accounted for in ethics review. This participant described extending protections usually reserved for participants to these peers:

Like I said earlier, they’re so many issues that are ethical for me [but] questions around that aren’t actually there. It’s all about the participants, and I think when you’re working with peer researchers there’s nothing in that ethics application that’s about the support and treatment and ethics around working with peer researchers and they’re experiences. For me that’s central (Interview 19, A).

The involvement of peer researchers required new ways of thinking about ethics. This participant, a graduate student with experience working in community, described needing to accommodate for the realities of these peer’s lives:

I was cognizant of the fact that some of the women that we were training as research assistants were not only sex trade workers but were also drug users and perhaps were going to have a hard time meeting a schedule and showing up on time and not coming to work high, and that they may have crisis outside of that which involved you know, going to court or something to do with their children. So we had to make a commitment to support [the PRAs] no matter what. So we did have a woman who had an issue with her partner and as a result she lost her child, she started using drugs again. She stopped actively working but…I went to court with her a number of times. I think you’re kind of obligated when you put somebody in that position to support them through the process (Interview 8, A).

Another participant echoed the previous sentiment by describing a situation with a peer researcher that challenged for her what it means to be an ethical researcher:
We had somebody who just couldn't sit still, one of our peers. I asked her ‘[name], how are you? What do you need and are you able to be here?’ She said ‘I really need to get paid early.’ I said ‘So are you going to come back? I have no problem doing that. I just need to know if you're going to come back.’ She said ‘I'll be back. I said ‘Will you be present? Or will you just be here?’ We had a really good relationship and she said ‘No, I'll be better.’ I said ‘Okay. We start at this time and if you're back, you're back. Just so you know I get where you're at. And I really am hoping you get to come back but I get it.’ She went and used and came back, and she was fine for the afternoon. But she really needed to use. I'm not going to go buy it for them. I can't do that. But I will support them to do what they need to do. Later, she and I talked about it and she said it was a huge leap of faith and trust on my part, that no one had given her for a really long time, and that is why she came back (Interview 5, A).

These kinds of “ethically important moments” that test researchers’ relationships to established norms as well as to stigmatized and illegal practices were not uncommon. Another participant with similar experiences asked: “Is it humane to let people, you know, stick it out through a project and suffer for four hours?” (Interview 2, A).

4.6.1.3  With the community as a whole

Concern was also raised about the potential for research-related harms to extend beyond the participants and peers to the broader community. This participant described how being an academic in her semi-rural community brought her into direct contact with people who saw her as a resource:
I don’t know if you’ve ever been to [city] but it’s very hard to be a social scientist [here] and not have those connections made for you. People walk into your office and say “Are you a researcher, can you help me?” And I’ve always thought one of the most unethical things we can say is “no”, when we’re asked by marginalized groups to help them (Interview 26, A).

This next participant described wrestling with the socio-historical legacy of research in the community she was working with and feeling a duty to ensure this project would be different:

We knew we were operating in a context of distrust and we felt a certain sense of, accountability isn’t quite right, but we had this certain responsibility and this certain, and it’s not obligation, cause it’s not something that was we felt was a burden, but we definitely had a sense that we had to do this right, and this was our duty, this was just part of who we were and how we were going to approach this. And we wanted this project to be something that built trust that allowed for future research (Interview 27, A).

Furthering this sentiment, this next participant described her feelings of trepidation during a dissemination activity where sensitive findings were being presented back to the community, including many of her participants:

We presented the findings [in a community forum] and I was crying and I said, ‘I feel like I am hurting you again, with your own words, it almost feels like I’m doing you harm by presenting these words back to you, your stories back to you’, and they said ‘No, you’re not hurting us, this is our story and we need to tell our story, and yes, it’s painful to hear it, but it’s something that needs to be told, don’t feel like you’re hurting us, even though you are hurting us.’ Do you know what I mean? That’s a heavy burden for me to carry, to tell a story that is so tragic and to know that some people will read it and they won’t be moved by it (Interview 12, A).
This examples raised important questions about the potential of data, interpretation, and analysis to stigmatize whole communities and the importance of an ethics of representation (Fine et al., 2003). Collectively, these preceding examples of how risk, harm, and vulnerability were conceptualized reflect a shared sense of responsibility conveyed by many of the researchers interviewed. The language of “duty” and “servitude” was common and had the effect of framing CBR as a “calling” more than a research approach. Participants struggled with ethical issues concerning researchers, vulnerable participants, peers, and the community as a whole, all issues existing ethics review structures rarely consider (Flicker, Travers, et al., 2007; Guta et al., 2010).

Towards finding resolutions for these ethical issues and determining how to proceed, many participants turned not to their REB/IRBs, but instead to collective decision-making structures.

4.6.2 Ethics as shared responsibility

Infinito (2003, p. 166) has remarked that Foucault’s ethic “is not practiced in isolation but is a way of being in the world that requires individuals to be in dialogue with the people around them.” A number of participants described building on the relationships they had established with participants and their academic or community partners to negotiate complex ethical issues. This academic researcher described relying on her participants, many of whom she had known for years, to tell her if she had overstepped her boundaries:

I mean there’s always the worry of doing harm rather than good. I also trust the participants so much that if there’s a risk, or if they’re feeling uncomfortable or if there’s the potential of harm, they’re going to let me know, I mean these are really open forthcoming people. I mean this is why I have a lot of respect for people
who use drugs as regularly and who face the challenges of that because there’s no pretense. It doesn’t get more real than that, and I really trust them to know that, to let me know what’s going on in their lives, what’s going on at this particular moment and so I’m not as tormented about the potential risk or harm. I really trust people to help me negotiate through that and to be honest about it (Interview 26, A).

Foucault (1990, p. 51) explained that the cultivation of the self involves “talks that one has with a confidant, with friends, with a guide or director.” This next participant described finding community-relevant solutions through dialogue with his community partners:

We feel our primary responsibility is to the community that's involved, not the institutional REB. So we try and generate solutions at the community level, and try and address those within our ethics applications. But, you know, we feel that it would be, it would be showing a lack of honouring of the community if we simply took every ethical issue to the REB and negotiated a solution with them without first generating solutions within the community that's acceptable to them (Interview 2, A).

These examples reflect what Foucault (2007a, pp. 47-59) described as a “critical attitude” towards the relationship between truth and power or, in other words, “the connections that can be identified between mechanisms of coercion and elements of knowledge.” These participants’ narratives challenge current conceptions of autonomy and risk in research ethics. This does not negate the potential for harm, but these participants are resisting and complementing the definitions of ethics imposed by their REB/IRBs. In doing so they add a new ethical imperative between risk and benefit established in research ethics codes, that of support and care. Foucault admired the Greek’s approach to ethics, in part, because it could “satisfy both the human longing for form and the need to be relatively free in relation to this form” (O’Leary, 2002, p. 162).
Below, the potential for community-based research collaborations to serve as sites of freedom and creativity is examined further.

4.7 Community partnership as an ethical terrain

An often noted difference between CBR and traditional modes of research is a commitment to partnership building with communities (Israel et al., 2001). This includes the expectation that researchers leave the ‘ivory tower’ and enter the community in significant ways. Researchers who spend little time in the community, or who are not upfront about their community-commitments may be seen as inauthentic or opportunistic. This distinction between CBR and other forms of research is questionable considering many social scientists spend considerable periods of time in communities and may produce political work. However, the emphasis on sustained partnerships in CBR invites questions about the limits and boundaries of these partnerships. This section presents data about the boundaries between research and other interventions, the relationships that emerge as a result, and the work required by the self to cultivate and maintain a corresponding ethic.

4.7.1 Boundary work

To examine Fox’s (2003) claim about the transgressive potential of collaborative work, participants were asked to reflect on whether HIV CBR blurs boundaries between research,
advocacy, intervention, and community development. For many participants, this murkiness was described as a positive and defining characteristic of this work:

I’d say that capsulizes my experience. I think for me, whenever possible, there’s nothing wrong with those fuzzy lines. It’s what I’ve been able to learn from the people, communities and agencies that I’ve had the privilege of working for or with. I would argue quite strongly that CBR, our research, is a form of intervention right off the bat. I think it’s hard to draw finite distinctions in terms of research, advocacy, program development, because I think it’s all interrelated. So, yeah, I think that statement capsulizes what I think CBR is all about (Interview 3, A).

This next participant, a graduate student who used CBR and also epidemiological approaches, promoted the potential of boundary blurring to affect change and described herself and her colleagues as “academic activists”:

I’m all for all blurring the boundaries, we like to call ourselves academic activists, we’re not just doing research for research for but we’re doing it for community knowledge development we’re doing it for capacity building, a lot of our results are feeding back into policy being developed in the city. I think it’s a really good thing to blur the lines and sort of step out of the ivory tower as much as possible and work together. The beauty about CBR is that they’re informing us and were informing them. I can understand from funders and ethics boards [why] they don’t like to see things blurred and everything should be quite siloed. I don’t think that’s the direction that research is going to be taking, at least with HIV research… (Interview 34, A).

Participants were asked if there could be problems associated with this blurring of boundaries. Most, like the previous participant, felt that boundary blurring was a positive aspect of their
practice. However, this next participant warned about the importance of not losing oneself in the process:

I think it’s very difficult to separate the different domains when you engage with communities, these communities don’t have these strict borderlines between the personal and professional that we tend to shape in our own professional world. I think that you have to be comfortable with that blurring and you always have to maintain your own personal ethics with that… When you’re sitting around a table thinking you’re going to set up a [protest action] you’ve got to think this through, you’ve got to protect your own morals and ethics. But I think building friendships in a research project are key to developing collaborative and caring spaces (Interview 48, A).

Working outside of the boundaries of the academy was described as “beautiful,” a sentiment that speaks to Foucault’s interest in the aesthetic aspect of ethics and the process of moulding or crafting oneself into a beautiful subject of ethics (O’Leary, 2002, p. 4). The possibility of new or different kinds of relationships was described as “key to developing collaborative and caring spaces,” but this must be considered against the warning to not lose one’s own personal ethic.

4.7.2 Intimacy, friendship, and new possibilities

Infinito (2003, p. 168) has argued ethical self-formation requires “a space within which to tryout alternative modes of being a self.” This space needs to be conducive to experimentation and where “individuals can participate in the ongoing production of themselves with and in front of others.” Sharing time and space often brought teams together in ways they had not expected, but
which were also integral to a project’s success. This participant described the importance of “breaking bread”:

> It sounds flippant but, if you’re asking me what I learned, the core piece for me is just emphasized in a really strong way that, what you do when you work with people - you break bread with them. Most of the projects I’ve designed, the first thing you want to do, or the close to the first you want to do, if people are just starting to work together, you get together and you have a meal and preferably alcoholic beverages if that’s appropriate for the group right (laughs). You get to know each other first, and it makes everything easier. And you know, you can expand that to the notion of community engagement and understanding community, etc. (Interview 39, A).

While participants did not identify making friends as their goal, friendships often developed between team members despite the often-uncomfortable circumstances of research meetings, data collection sessions, and conferences to disseminate project findings. These were the kinds of relationships formed in the basement meeting rooms of community-based organizations or in the waiting rooms of a community health centres. This participant emphasized the relational aspect of this work and the importance of being able to share space:

> I couldn’t tell you how many hotel rooms [name] and I shared, like on the road in the middle of nowhere. You’re in the car with someone for potentially 5 or 6 hours and then when you get there you’re sharing a hotel room and you’re having breakfast, lunch, and supper together. You better freaking like them! So, it has to be someone you want to spend some time with and you think other people will want to spend some time with too, because if not then your whole project is a bust and I mean if half of the job is community development and relationship building and then they have to be people who other people will want to spend time with (Interview 33, A).
Inevitably, spending extended periods of time together resulted in conflict and disappointment for some participants. Unfortunately, research ethics does not account for the kinds of relationships that might develop or may already exist in participatory forms of research (Blake, 2007). This participant offered her approach, one based on humility, for managing these conflicts when they occur:

> It can be extremely volatile, and that is the nature of relationships. I mean, it's not always a good thing, but if you care about somebody, really care about them, I mean more than you care about your pride or your way, you find a way to make it work. You have some humility when you've made a mistake...it's been my experience, if you're honest with people and you are humble, it goes a long way...but you know anything that’s going to be useful is going to be complicated... it’s worth taking the time to do it well and to establish trust, and it’s not about getting it and then being finished with it (Interview 12, A).

While not all research relationships become friendships per se, many participants stressed the importance of contributing to the community outside of research related activities:

> We've had a long-standing, very close, relationship. I can speak for myself and [academic collaborator], we've dedicated hundreds of hours of volunteer time with that organization, but also helping them write funding applications and the like. And we've been there a long time, so they know we're not just parachuting in and out, and I think that's what really makes it work, is the long-standing trust and relationship, and doing more than just research with them, has been really huge as well (Interview 2, A).

Another participant characterized this giving of oneself as a precondition for “be[ing] seen as authentic and for people to actually come to you” (Interview 37, A). Roach (2012) has considered the implications of Foucault’s work on ethics and friendship to account for the relationships that emerged during the early days of AIDS organizing. These friendships were
made possible by a shared sense of estrangement to difficult circumstances that allowed “new subjective, communal, and political forms [to] be imagined” (Ibid 2012, p. 8). However, these relationships should not be understood as the antidote to domination, for relationships can devolve and become an exercise in controlling another’s conduct (Foucault, 1994a, p. 301.). This returns us to the need for “care of the self” to understand one’s propensity for domination.

4.7.3 Work on the self

For Foucault, ethics relied on “a certain attitude towards the self; an attitude which facilitates continuous critical self-transformation and which manifests in practices as diverse as [sadomasochism] or genealogical critique” (O'Leary, 2002, p. 140). HIV CBR is another site to examine practices of self-transformation. This self-work often came in the form of refusing the expectations placed on researchers to conduct research in particular ways as well as rejecting the prescriptive relationship between truth and knowledge production in the academy. This next participant compared the traditional approach to research with CBR:

You get trained to be the expert; you’re the expert in the room. We’re going to teach you, particularly in epidemiology, how to present your case, how to defend your case and to ward off opposition. So, you get trained to be the expert, you don’t get trained to be the listener, it’s a different position right (Interview 38, A).

Another participant, with decades of research and practice experience, described inverting the privilege assumed within the traditional model to be able to practice in community:
But you have to understand the nature of that privilege. So what you need to do is, when you're working with individuals in these communities, you're got to flip it around where they become your teacher. And you're the student, and you have to listen. You have to be patient (Interview 3, A).

Infinito (2003, p. 160) has likened “care of the self” to a performance: “we are continually involved in assessing our ‘performance’ as a subject in the world -- a world inhabited by other subjects.” This is reflected in the next participant’s description of having to “perform” repeatedly and prove himself in community settings to earn and re-earn trust:

You have to prove yourself to people many times, and I used to hate that, and I used to blame people for that. I don’t anymore. I understand it, we all have issues of trust. So, [the] fact that I walked through the door meant shit, nothing, so I walked through the door ten times, until they received me with a hug and we talked about; ‘hey we have a new idea, or how can we write this proposal.’ I was very lucky, but I’m also very forceful that way. I wanted to serve, and I did, so I was pretty much a politician that way. In [AIDS service organization] they’re not stupid, they’re like ‘Okay sure, you have a PhD, now show us what you do with that, you’ve got to dance, do the dance’ (Interview 17, C).

This level of engagement and commitment did not come easily to everyone. Indeed, it was a personal challenge for this next participant:

No, I'm a total control freak. So I had to do a lot of self-talk and really work on my own desire to control this and make it productive and come out with a usable deliverable at the end of this. I constantly had to fight that through the entire thing, and constantly had to remind myself that the process of what we were doing was just as valuable as what I was trying to get at. And I think that's what helped me, ultimately, to leave my own, the preconception of what I wanted to get from this, at the outset, and then allow the process to happen and basically throw
my hands up and say ‘Okay, I'm going to record what happens and then I'll analyze it later and decide what it is that we have’ (Interview 1, C).

Finally, a participant who coordinated a large CBR study emphasized the need for flexibility: “I looked at the entire project as it had to be flexible; my job was trying to be the flexible piece (laughs) you know?” (Interview 42, C). This commitment to relationship building and the simultaneous challenging of oneself created the possibility of altogether different kinds of intellectual and practice spaces. Foucault (1985, p. 75) was interested in such attempts at self-mastery: “since one was expected to govern oneself in the same manner as one governed one’s household and played one’s role in the city.” The participants featured in this analysis challenged themselves to govern well not only in their research projects, but as part of a process of self-mastery that made their professional ventures personal. Their resistance included rejecting the expectation to produce certain kinds of research. In refusing to make CBR “productive and come out with a usable deliverable,” the imperative to govern through the logic of community was challenged.

4.7.4 Critical reflexivity

Faubian (2011, p. 116), an anthropologist and Foucauldian scholar, has called for greater attention to the “reflexive” technologies exercised “in becoming and continuing to be an ethical subject of a qualitatively distinguishable sort.” This is in keeping with Guillemin and Gillam’s (2004, p. 3) linking of reflexivity and ethics in qualitative methods. In ending our interview, this
participant emphasized the importance of the relationship between self and the “messy” boundaries of this work:

In my perspective and my experience, CBR, because of all the different stakeholders and commitment and emotions and feelings and everything that’s involved, is something that we can’t get comfortable with. That we need to always say ‘I wish I could have done that better’ or ‘How am I going to do it differently next time?’ …and we need to take the time to reflect, critically reflect, ‘Oh, I fucked up but how can we move forward to develop this further?’ Don’t get me wrong, I love doing community-based research, I love the process of it, even all the challenges, the length of time, the second guessing myself, the messiness, the discomfort, the questioning all of that stuff, that’s what is so amazing about it, it makes you have to think about these sort of things that not all researchers do, and I love that part of it… (Interview 19, A).

Imagining the possibilities of an “ethic of discomfort,” Foucault (2007a, p. 144) encouraged others to “never consent to be completely comfortable with your own certainties…[and] remember that, in order to give them an indispensable mobility, one must see far, but also close-up and right around oneself.” Murray et al. (2008, pp. 686-687) have related this type of discomfort with the “care of the self” and the necessity to develop more authentic forms of practice in healthcare. The need for many of the participants in this study to wrestle with the ethical issues in HIV CBR transcended any specific code or value and is reflective of this discomfort. This is the work of becoming an ethical and authentic practitioner.

4.8 Conclusion
The challenge posed to me by another scholar was to disentangle "ethics" as understood in research ethics (an epistemological project) and Foucauldian "ethics" as a relationship with the self (an ontological project). However, what became apparent through undertaking this analysis is that these two orientations to ethics are intertwined in HIV CBR. Complex and competing interests circulating within the HIV CBR movement simultaneously re-produce and resist dominant ways of researching, questioning what it means to be ethical, and re-shaping social relations. Participants in this study described a sense of responsibility to others and a commitment to fostering relationships through research. In keeping with Koro-Ljungberg et al. (2007), researchers respond to the requirements of formal research ethics in ways that showed an understanding of, but resistance to, dominant discourses within research and ethics. Decisions to not research when it might reproduce exploitation and decisions about how to relate to a peer researcher struggling with withdrawal reflect this approach to ethics. In addition, researchers wrestled with and questioned the potential of research to re-traumatize whole communities through the dissemination of their own experiences. These decisions were often made collaboratively and with a sense of shared accountability. Despite Koro-Ljungberg et al.’s (2007, p. 1088) assertion that ethics review “removes autonomy and decreases individual responsibility[y],” findings from this study show HIV CBR practitioners are actively engaging with research ethics in creative and dynamic ways.

The actual “ethical work” of HIV CBR only became apparent through examining how researchers govern themselves and others within their relationships. These relationships emerged at the intersections of blurred and “messy” boundaries and occasionally produced something
more than either party imagined – friendship. In keeping with Foucault’s (1985, 1990) own approach, this examination has not made claims about what should be considered ethical (what is right or wrong), but has simply shown the range of creative and dynamic conceptions of ethics emerging despite the supposed stranglehold of formal research ethics. The forms of “counter-conduct” described here, especially in relation to issues like drug use, will not be acceptable to all researchers – nor should they be. Bernauer and Mahon (2003, p. 162) have pointed out that transgressing “power-knowledge-subjectivity relations” will differ between actors, but “an ethics of stylization invites one to engage in struggle according to one’s unique rootedness in the world and history.” This rooted ethics can be extended to a researcher’s individual relationship to collaborative inquiry and pushing the boundaries of the researcher/researched relationship.

While Foucault resisted telling others how to live, he modeled a unique intellectual, political, and personal ethos that inspired others to think and act differently (Cooper & Blair, 2002). The researchers who participated in this study demonstrated unique ways of reconciling their passions, fears, and discomfort. Fine (2007) has argued that by theorizing about researchers’ subjectivities, individual researchers may become more aware of their effects on the research process and develop alternative ways of thinking about methodologies, analysis, and collaboration. But more than this, by theorizing and reflecting on these issues they may imagine new roles for the academic in society. While openly discussing strategies for counter-conduct puts some researchers at risk of “subjection by illumination” (Foucault, 1980, p. 154) this is outweighed by the possible benefit of others being inspired to rethink their own practices and imagine a different research ethics.
Chapter 5
Discussion and Concluding Remarks

“There are times in life when the question of knowing if one can think differently than one thinks, and perceive differently than one sees, is absolutely necessary if one is to go on looking and reflecting at all” (Foucault, 1985, p. 8).

5 Introduction

In the preceding three chapters, I used the Canadian HIV community-based research (CBR) movement as a site to examine the implications of recent developments in science and the changing relationship between communities and knowledge production. The HIV CBR movement has fostered practices that blur the lines between research, advocacy, intervention, and community development raising important questions about what constitutes ethical research practice. Proponents have argued collaborative research is more ethical and better attends to issues of power, process, and justice. However, the literature is full of examples of practitioners encountering resistance during the ethics review process. The resulting conflict is often framed as a clash between participatory and biomedical research frameworks. I responded to this supposed clash and the perceived “problem of ethics” in HIV CBR by asking different kinds of questions than are examined in the CBR literature. Using elements of Michel Foucault’s theoretical “toolbox,” I brought together seemingly disparate elements (institutions, policies, actors, practices, etc.) that together create the conditions of possibility for particular forms of knowledge production and community engagement. Specifically, Foucault’s “confessional,” “governmentality” and his novel approach to “ethics” provided a framework to challenge the
popular claim that community-based research somehow operates outside of the power dynamics characteristic of mainstream research. Instead, I located this research movement at the intersections of various strategies and technologies governing both researchers and communities. Establishing these Foucauldian concepts made it possible to then identify and theorize related forms of resistance and modes of ethical self-formation. In this final chapter, I review the preceding chapters and consider their individual and collective contributions.

5.1 Theoretical contribution: Connecting together questions of ethics and politics

Together these chapters offered an unconventional, but much needed, examination of theoretical, methodological, and ethical issues at the intersections in collaborative forms of public health research. Marsh (2010) has emphasized the theoretical and analytic possibilities of examining points in the power/knowledge articulation that render dominant discourses problematic, causing disruptions to established ways of knowing and acting. My interest in the substantive topic of HIV CBR and the so-called “problem of ethics,” represents such an engagement with a disruption and made it possible to enter into larger debates about knowledge production.

In keeping with Foucault’s (2005, p. 252) self-described project, this dissertation has connected “together the question of politics and the question of ethics” through an analysis of power relations, governmentality (the government of self and others), and the relationship of the self to self. When applied to the HIV CBR movement, this framework has made it possible to link
seemingly disparate discourses about CBR – the “need” to involve people living with HIV in research, the changing research funding landscape, and emerging conception of research ethics – in one analysis. Foucault’s (1978) well known problematization of the “repressive hypothesis,” which claimed sex had been censored and prohibited during the Victorian era, initially informed my interest in the “problem of ethics.” Foucault (1978, p. 7) rejected the claim sex had been repressed, pointing instead to the explosion of ways of describing and categorizing sex that emerged during this period, and argued that what sustained the repressive hypothesis was the:

…opportunity to speak out against the powers that be, to utter truths and promise bliss, to link together enlightenment, liberation and manifold pleasures, to pronounce a discourse that combines the fervour of knowledge, the determination to change the laws, and the longing for the garden of earthly delights.

This was helpful for problematizing aspects of HIV CBR, which conjures similar emancipatory themes as it purports to be an “alternative” form of knowledge production. Foucault (1978) encouraged questioning such claims and that a reliance on counter-discourses may unintentionally reaffirm and legitimate dominant discourses through their oppositional reliance on them. This problematic logic is evident in the idea that obtaining research funding to support the production of finer grained surveillance data on communities provides the tools to secure their liberation. The issues of poverty, marginalization, and stigma fuelling the HIV epidemic in Canada and the rest of the world have been well-documented since the beginning of the epidemic (Epstein, 1996; Farmer, 2001; R. Parker & Aggleton, 2003; C. Patton, 1990). The focus on the “communities” most affected and what they understand to be the issues represents the continuation of a decades-long project transferring responsibility for health from the state to individuals and groups (P. Miller & Rose, 2008; Petersen & Lupton, 1996). My theoretical and
methodological contribution has come primarily from linking the supposedly neutral practice of CBR to these larger social and political forces by way of an engagement with ethics.

In chapter 1, I introduced a number of issues and bodies of literature that provided the basis of this dissertation. First, I offered an overview of the historical emergence of bioethics and the development of research ethics review and governance. Here, I introduced key debates and criticisms of research ethics, most notably that it threatens social science inquiry through a process of “ethics creep” (Haggerty, 2004). I then introduced community-based research, a popular approach in public health and health promotion research, which has raised many questions about the effectiveness of existing ethics review frameworks (Flicker, Travers, et al., 2007). CBR and related forms of community-engaged research are a “hot topic” in the research ethics literature with claims that ethics review is a barrier to CBR (Flicker et al., 2009) and that it fails to adequately prepare researchers for the actual kinds of ethical issues they may encounter in communities (Reid & Brief, 2009). These contributions to the literature have raised important questions about the compatibility of ethics review and CBR, but this literature has not effectively theorized what it means to be ethical in CBR. In response, I examined the Canadian HIV CBR research movement as a site to theorize debates in research ethics asking questions that complicate the role of researchers, communities, and funders, while problematizing the inducement to research collaboratively.
In chapter 2, I offered my methodological reflections on conducting interviews with HIV CBR practitioners from across Canada. This chapter addressed the lack of reflexivity in empirical bioethics by using the “confessional tale,” as promoted by Ives and Dunn (2010), to surface the “confusion, uncertainty, and dilemmas” experienced when interviewing colleagues and strangers about the ethical issues in their work. The method in this chapter blended the “confessional tale” with autoethnographic self-writing techniques along with excerpts of interview data to provide a critical lens for reflecting on methodological and reflexive issues. My argument was that empirical investigations of ethical issues are more complicated than is acknowledged in the empirical bioethics literature; ethics talk is laden with symbolism that obscures meaning and “truth.” Asking participants to confess their ethical transgressions is neither easy nor straightforward. I problematized the inducement to confess by drawing on Foucault’s seminal writing on confessional practices. I described my attempts to stylize myself as a worthy confessor and how this self-moulding shaped my interview style. Drawing on Taylor’s (2009) elaboration of confessionary practices, I considered the ways these confessions were partial and mediated by pain and pleasure while also contemplating alternatives to confession.

Through a theoretical and reflexive engagement with my data collection process, I challenged a number of taken-for-granted assumptions about the truth function of storytelling in empirical bioethics. Specifically, confessions are discursively mediated and can be understood as “games” played between confessor and penitent (or interviewer and participant). In my interviews, this dynamic greatly influenced the kinds of information solicited and exchanged with participants. While research seeks to obtain objective facts and accounts of a phenomenon, in these
interviews, participants often gave partial accounts in an understandable attempt to protect their institutions, research teams, and the communities with whom they worked. With empirical investigations becoming more common in bioethics and calls for greater reflexivity, this is the first paper of its kind to document and examine the relationship between the researcher and participant in a process of meaning making. Offering an important critical and reflexive contribution to the field of empirical bioethics, this paper bridges the gap between empirical bioethics and decades of debates in the social sciences about qualitative research.

In chapter 3, I offered the first of two chapters that attend to practices within the HIV CBR movement. The first of these chapters considers HIV CBR alongside larger trends that are changing the relationship between science and society. The rhetoric of “scientific citizenship” has been deployed to engage the “general public” and specific “communities” in debates about scientific advancement. Whereas CBR is framed as a “bottom-up” response to health inequity, I located it within a broad shift orchestrated by the state. Foucault’s “governmentality” provided an overarching theoretical framework for this chapter and a lens through which to read and interrogate the data. The method used in this chapter was based on Clarke’s (2005) “situational analysis” (SA) approach. SA has complemented grounded theory with theoretical and methodological insights from Foucault that made it possible to step outside the data to identify relevant elements that are absent in the interviews. In this approach, text from funding guidelines and theoretical insights from the governmentality and critical public health literature informed my reading of the data. My analysis examined the consequences for diverse actors with access to different material resources, brought together in research to partner and produce evidence. This
approach identified the way CBR is becoming more formalized and restricted as a condition of state funding mechanisms and served to highlight the impact this process is having on research and related forms of community engagement.

Specifically, the unique funding mechanism developed through consultations with researchers and communities, and managed by the CIHR, serves to constrain the kinds of research that gets funded. Despite the claim that CBR is “community-initiated,” this research perpetuates neoliberal strategies for governing the public sector and managing marginalized groups. Community-based organizations are initiating research, but often to fill the gap left by programming budget shortfalls. The subsequent research partnerships discipline both community and academic partners through complex obligations requiring considerable investments of time and resources. People living with or at risk of HIV who work on these projects in various capacities often slip between the cracks of budget shortfalls. This analysis centred the workings of power in CBR and challenged the naïve, but popular, notion that power can be “addressed” by attending to process (Israel et al., 1998). Rather, the process of CBR is where power is most operable and calculable – the time spent meeting, writing, and debating within teams – all served to detract from the changing funding and research landscape. The concern I raised is that CBR has become less about addressing public health inequities through research than about keeping actors in the HIV movement occupied. While this could be said to reflect a growing “administrative burden” faced by all academics (Wimsatt, Trice, & Langley, 2009) the requirements in HIV CBR take a markedly different form. Researchers are not just being presented with more administrative duties and requirements, they are being asked to have
“meaningful” relationships. These relationships are premised on the need to obtain continued material support from the state to conduct research, which makes it difficult to then challenge the state’s retreat from its commitments to funding HIV programming and services.

Finally, in chapter 4 I considered the implications of Foucault’s latter works on “ethics” and “care of the self” as a framework for interpreting ethics in HIV CBR. This approach made it possible to recognize HIV CBR as part of a governmental “apparatus,” but still remain open to seeing the ways practitioners actively participate and resist domination by cultivating their sense of self and understanding of the other. They are challenging dominating systems and structures by forming relationships that blur the boundaries between research, intervention, activism, and community development. The method guiding this analysis was again informed by Clarke’s (2005) SA approach. In this case, the SA approach was helpful for examining the transgressive aspects of HIV CBR and the blurring of traditional boundaries in research. I complemented this approach with Foucault’s framework for analyzing the “morality of behaviors,” and presented the data in three sections: what participants think about formal research ethics; how they actually use it in their work; and how they stylize themselves as ethical researchers. My interest in the stylistic elements of ethics is a departure from much of the research ethics literature especially the literature on CBR ethics. The latter often portrays a binary opposition between a supposedly oppressive research ethics review process and the emancipatory goals of CBR. In this case, the data does not support the claim that ethics review is a significant barrier to HIV CBR. But rather that ethics review is one “space” for ethical engagement to which CBR researchers commit.
Despite some complaints about the ethics review process, most participants appreciated why it is needed and used it as an opportunity to reflect on their methods, motivations, and impact. However, ethics review was described as the minimum standard of ethics. The real ethics work occurs in the doing of CBR. Positioning ethics review as the baseline for ethical practice, CBR practitioners re-interpret established notions of research ethics in ways that attend to broader and collective issues of context and community relevance. Here, conceptions of harm, risk, and vulnerability were reimagined not only to include research participants, but also research team members (including peers) and the community as a whole. This approach made ethics a shared responsibility within research teams and with the community. Particularly interesting in the data were reports of unconventional relationships that resembled friendships more than working relationships. These partnerships and friendships offered an ethical terrain in which practitioners could experiment with and perform ethics. This is a very different orientation to ethics than is promoted by bioethics as it rests on a critical reflexivity over normative values and standardized rules and obligations. This is promising, but raises new questions about the limits of the boundaries being challenged, crossed, and disrupted. What is the role of research ethics in this transgressive space, if any, and what are the risks in making these practices visible when the tendency is to govern and control them?

In all, this project has offered an analytics of power attuned to a broad range of issues from micro interactions to macro interventions. I anticipate that aspects of this analysis will be unwelcome by some. Foucault’s relational approach to analyzing power can be unsettling, especially for those who claim to be helping. His approach requires implicating oneself within
power relations in a way that many would prefer to disavow. Many critics have misread Foucault’s writings as being nihilistic, relativistic, amoral, and even promoting an acceptance of the status quo (for example see Sayer, 2009). Foucault (1994a, p. 292) responded by saying “if there are relations of power in every social field that is because there is freedom everywhere.” In other words, power and resistance are synonymous, always present, and in competition. Muckelbauer (2000, p. 73) has explained that such criticisms were often directed by those proposing a programmatic version of resistance that relied too heavily on “a space outside of power, a unified subject, and normative foundations.” I have encountered such criticisms from colleagues within the HIV CBR movement who respond to my concerns by reiterating the importance of getting back to “what really matters” and focusing on “real world problems.” I can appreciate why they responded in these ways. The alternative can be very unsettling. Foucault’s work was blamed for having an “anesthetizing” effect on French social workers confronted with the disciplinary logic of their practice. In response, Foucault (1991, p. 83) argued that their “not knowing where to turn” was a sign they were ready to start looking and thinking in new ways. Contrary to dismissals of theorizing as unproductive, the work of unsettling and disturbing represents a readiness and commitment to transformation (Chambon, 1999, p. 53). I now consider the broad implications of the chapters comprising this dissertation.

5.2 Implications for the field: Imagining CBR as critical boundless resistance
My goal with this dissertation was to offer a critical analysis and reflection on the HIV CBR movement without claiming to know a better way of doing things. In doing so, I have actively resisted the inducement to produce the kinds of “policy actionable” research and “best practice” guidelines that have overtaken HIV CBR. Foucault (1988a, p. 51) cautioned that when the state asks intellectuals to provide better ways, it is inevitably a “trap” that should be avoided. I cannot possibly prescribe alternatives for working with the numerous communities affected by HIV across Canada. Rather, my goal has been to respond to a call for the revival of critical social science perspectives in HIV studies (Mykhalovskiy & Rosengarten, 2009a, 2009c).

To examine my contribution to this call, I first turn my interest to Foucault’s (2010c, p. 42) final lectures in which he explored the historical relationship between “truth-telling (dire-vrai), [and] the obligation and possibility of telling the truth in procedures of government.” That is, I will reflect on the process and implications of taking a critical stance within an apparatus of power. Central to this is the concept of parrhesia, which Foucault (2005, p. 366) traced etymologically as “the act of telling all (frankness, open-heartedness, plain speaking, speaking openly, speaking freely.” Foucault (1988a, p. 51) understood truth telling as an obligatory form of resistance to being governed, saying:

…we can demand of those who govern us a certain truth as to their ultimate aims, the general choices of their tactics, and a number of particular points in their programs: this is the parrhesia (free speech) of the governed, who can and must question those who govern them, in the name of the knowledge, the experience they have, by virtue of being citizens, of what those who govern do, of the meaning of their action, of the decisions they have taken.
I have practiced Foucault’s free speech in this dissertation. Specifically, I have spoken out against systems and process that trouble and concern me. I do not claim this is a parrhesiastic act in the historical sense; my life has never been in jeopardy. Rather, I have felt an obligation to respond to diminishing opportunities for critical debate and dissent as echoed by participants in this study who felt they risked being excluded from the CBR “sandbox” by speaking out. These diminishing opportunities for what Foucault described as “counter-conduct” (Davidson, 2011) have not limited to HIV CBR, but are part of a broader shift in HIV towards promoting a singular integrated bio-medical vision of the public health response (see Adam, 2011; Guta et al., 2011; C. Patton, 2011). While the issues discussed in this dissertation may seem insignificant compared the global scale-up of “high impact treatment and prevention” technologies (Nguyen, Bajos, Dubois-Arber, O'Malley, & Pirkle, 2011), these initiatives also increasingly drawn on the rhetoric of community (see Gagnon & Guta, 2012a; Gagnon & Guta, 2012c).

I often reflect on a participant in this study who refused to be characterized as a community-based researcher despite modeling idealized practice with communities. She said she did not like what came with that label and the potential of being called not “CBR enough.” Her rejection of this title is an example of resisting the increasingly regimented approach to CBR that is being promoted. For me, this is reminiscent of a lecture Foucault (2007a, pp. 46-47) gave in which he discussed critique as an act of insubordination and desubjugation. Critique is the process of resisting governance, or “the art of not being governed quite so much” (Ibid p. 45). This simultaneous commitment to working with communities while refusing the CBR label allowed this participant to work in ways that, while still constrained by the logic of science and funding,
were more acceptable to her. In my own practice, as a member of various research teams, I have started *speaking freely* and asking questions about assumptions in our funding proposals, namely, that there is an active group of community members who want to participate. I have challenged this assumption in a number of public talks arguing that the current model privileges the least marginalized and most capable of benefiting from neoliberal capacity-building. In doing so, I have tried to care for myself and others and to better consider the ethical implications of this work. I envision CBR that does more than identify barriers to services and programming gaps. This is important, but should be considered the ethical *minimum*. My stance reflects Rail, Murray, and Holmes (2010, p. 219) invitation to employ *parrhesia* “to disrupt the epistemological status quo and to unpack the play of power in health research.” I imagine CBR as *critical boundless resistance* using localized problems as a starting point to make global connections and disrupt definitions of “problem, policy, and need,” while simultaneously looking inwards and outwards. This is a CBR that promotes above all else, a critical reflexivity.

### 5.3 Future research directions

A number of theoretical and methodological implications embedded in chapters 2 to 4 offer guides for future research. First, chapter 2 invites greater methodological debate and reflexivity in empirical bioethics. The goal of this chapter was to bring well-established debates from the qualitative methods literature to bioethics. Chapter 2 raised important questions about what it means to participate in *ethics-talk* and how framing interviews this way is bound to produce tension, fear, and reluctance on the part of participants. The “confessional tale” offered an
important lens through which to read the data, but could be complemented by other approaches more attuned to the gendered, racialized, classed, and sexualized self (Harding, 2004). The auto-ethnographic and self-writing approach was useful here, but could be complemented by other forms of discourse analysis. If the confession is discursive, and therefore a product of power relations, then empirical bioethics would benefit in general from accounting for not just what people say, but how they say it and linking their narratives back to social structures and systems. For example, while it is important to know people’s attitudes to sensitive issues like euthanasia, these narratives must be examined as examples of a discursive formation that emerges at the intersections of law, medicine, religion, etc.

Chapter 3 presented findings about how HIV CBR is orchestrated by government, revealing that power is actualized through the relationship between funding review, researchers, and communities. There is still considerable data to be analysed from this project and I have committed to writing papers about how informed consent is understood and practiced, and a more in-depth analysis of the peer researcher role. For a future project, I am interested in an issue that was under explored in these interviews. There were allusions in a number of interviews to CBR advancing by using more traditional research approaches including biomedical approaches (e.g., tissue sample collection and analysis). I am interested in the implications of this for community engagement and the relationship with new “high impact treatment and prevention technologies” (see Wilton, 2012 for a discussion of the role of CBR in advancing these interventions). Finally, future research could look beyond the HIV sector and the Canadian context. Similar work could be conducted outside of health with research funded by the Social
Science and Humanities Research Council of Canada (SSHRC) where scholars would be working from different disciplinary and theoretical stances possibly envisioning other forms of collaboration. As well, a comparative study between Canada, the United States, United Kingdom, or Australia could be helpful in determining whether this a larger trend.

Finally, chapter 4 looked past claims in the literature about how ethics review is a barrier to CBR, a claim that ignores the growth of the sector, to see how ethics is imagined and performed within this movement. Future research would benefit from this shift in focus along with greater debate about the ways researchers deviate, re-imagine, or transgress established ethics norms. When done in private, this kind of transgression could easily become dangerous, but when part of a system of debate it is more likely to improve research practice. My goal here was to link ethics and politics through Foucault, but he is by no means the theoretical end-point. I intend to revisit this data through the complementary writings of Delueze and Guattari (2003), Agamben (1998), and Esposito (2011) who each take up Foucault’s work in different ways. Finally, while many ethics scholars argue that the existing review structure does little to improve ethical research practice, they rarely offer an alternative. Doing away with REB/IRBs could be more dangerous than keeping them. In a few months’ time the investigators from the larger research project in which my dissertation was nested will meet with other CBR practitioners, representatives of funding agencies, and ethics review stakeholders. The goal of this meeting is to create a space to dialogue about our findings and develop tools to address especially sensitive issues in CBR. This meeting has the potential to be generative and contribute to the long-term development of more responsive review mechanisms.
I am optimistic there are others in the HIV CBR movement who are interested in opportunities for more critical debate. I was part of a group who, with funds from the CIHR, organized a one-day workshop in the spring of 2012 to discuss critical social science and humanities perspectives in HIV. The number of attendees who were graduate students, working in community-based organizations, and even clinicians, surprised me. They were interested in discussing the potential of critical perspectives while clearly remaining committed to working with communities. The provision of funds from CIHR showed there are sympathetic reviewers who want these kinds of discussions to continue. I believe there is room within the HIV CBR movement to work across the critical and applied and that this dissertation will be of interest to others working in this way. However, I do not want to perpetuate the growing conflation of critical social science research and CBR (for a thoughtful discussion see Mykhalovskiy & Cain, 2008). I do, however, personally welcome opportunities to engage in critical CBR and independent investigator driven critical social science research.

5.4 Strengths and limitations

The dissertation has a number of limitations related to its design. First, this dissertation is nested in the larger CIHR funded study entitled “Improving the Accessibility of Research Ethics Boards for Community-Based Research in Canada,” which has a large Canada-wide research team. There are a number of limitations associated with the larger project’s design including: a Canadian focus, an initial focus limited in scope to the ethics review submission process, and a sample comprised of researchers funded through one granting program. The focus on the experience of Canadian HIV researchers does not necessarily reflect the experiences of their
counterparts working in other jurisdictions. For example, in the United States, university-based researchers have to obtain external salary support, but there are many more potential funding sources than in Canada. The focus of the study was initially limited to examining CBR practitioners’ experiences navigating the ethics review process, and not systemic and structural issues like neoliberal restructuring of the academy and grants programs. Much of the data pertaining to these issues emerged as a result of the interview dynamic and my intentional probing during interviews, but was not planned for in advance. If these concerns had been identified and anticipated in advance, there could have been greater depth to these discussions. However, had the focus of the study been explicitly critical of the HIV CBR movement and its relationship to funding structures, there would likely have been far fewer participants. Finally, the sample is comprised primarily of researchers funded through the CIHR HIV CBR operating grant program and may not be reflective of the experiences of researchers using community-based and collaborative approaches in other areas (e.g., diabetes and cardiovascular health) or those working outside of health (e.g., poverty, education, global development).

In spite of these minor limitations, this dissertation has a number of noteworthy strengths. The dissertation offers a novel theoretically informed examination of the HIV CBR movement using data from a national sample of researchers. These researchers offered perspectives from various disciplinary backgrounds and experience working with diverse communities affected by HIV. Most of the literature about CBR is limited to describing the trajectory of an individual project focusing on practice issues (what did and did not work in the project) and has not used social theory to inform the analysis. My approach was to take this increasingly popular, but under-
theorized, approach to research and interrogate it using Foucauldian governmentality and insights from critical public health studies (Bunton & Petersen, 1997; Labonte & Green, 2007; Lupton, 1999; Petersen & Lupton, 1996). This dissertation has implications for other jurisdictions where similar neoliberal restructuring has taken place and where community-based research is increasing in popularity (e.g., United States, United Kingdom, and Australia). The findings presented here are not generalizable in the sense of having a representative sample that can be extrapolated to an entire population. However, the analysis offered has provocative and theoretical generalizability (Fine, 2006a, p. 98), which may encourage readers to think differently about their own work and develop other ways of researching.

5.5 Concluding remarks: Does community matter?

I would like to conclude by addressing and reflecting on an important tension in my work. On the one hand, I characterized community-based research as a governmental technology that disciplines and regulates those within its gaze. On the other hand, I characterized community as an ethical terrain, which provides opportunities for the governed to cultivate themselves as particular kinds of subjects. While the preference is to take a firm stand, I do not see these as mutually exclusive. They are ubiquitous and in a constant state of flux; they represent the relationship between power and resistance that Foucault described. Ultimately, this tension has kept me interested in community-based research for nearly a decade. I continuously revisit the basic tenet that research should be community-initiated and driven from multiple perspectives. This tension represents a methodological issue, a theoretical issue, and an ethical issue. If HIV CBR offered nothing more than a site to read totalizing forms of discipline or the banality of
ethics review administration, my interest would have turned elsewhere long ago. The rhetoric of community and shared struggle continue to sway me as it does the researchers interviewed. In “The Coming Community,” Agamben (1993, p. xix) imagined the potential of communal relations “mediated not by any condition of belonging…nor the absence of conditions…but by belonging itself.” Paradoxically, in Agamben’s account, by renouncing claims for shared identity and conditions of marginalization (as is done in HIV CBR), a new form of belonging emerges that is more threatening the state because of its singularity. Returning to Foucault (1994a, p. 256), my goal in identifying the dangers inherent in the formalized practice of HIV CBR has been to advance a “hyper and pessimistic activism” in response to the limited and divisive notions of community promoted. I hope this dissertation provides a starting point for developing a new form of HIV CBR that is better connected to its radical roots in the AIDS movement.
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There are also community-based REBs and independent for profit REB/IRBs.
While the critical feminist PAR literature has informed CBR there are number of reasons for treating these as separate bodies of scholarship and practice: 1) CBR come much more from a medical and public health framework, and 2) it is often constructed as being superior to PAR because research questions are said to be community initiated, and 3) because of the significant uptake of the CBR approach by funders and academic institutions.

Other scholars have treated critical approaches in the Marxist tradition and poststructural approaches in the Foucauldian tradition as distinct and even antithetical projects. Some scholars [see (Heslop, 1997)] have argued Foucault’s work cannot be considered critical and should not be placed within a critical paradigm. I take the position that Foucault’s work was a critical project at the margins of a Marxist dominated paradigm.

Others, like Frost et al. (2010) have located Foucault within a constructivist paradigm. This reading is questionable considering Foucault’s interest in the material and discursive and his ongoing engagement with Marx.

Based on unpublished Scopus review by Doug Brugge, Tufts U., 2011

Foucault’s ethic shares important similarities with feminists and communitarian ethics, but problematizes the supposed goal of achieving a shared morality (Koro-Ljungberg, Gemignani, Winton Brodeur, & Kmiec, 2007, p. 1089).
Appendices

Appendix A: Improving the Accessibility of Research Ethics Boards for Community-Based Research in Canada – Interview Questions

Intro:

Can you tell us a little bit about you and your research work? How much of your research would you say is CBR-related?

Today we want to focus on your CIHR HIV CBR application. In the following questions; it would be helpful for you to reflect on the period when you were pulling together your proposal.

Assessing Level of Community Involvement:
What was the “issue/problem” you investigated? Whose idea was it to research this topic?

Which communities did you work with, and how was “community” defined in your project? Is this community represented by other groups (were they involved)?

How was this relationship formalized? Was there a memorandum of understanding? Where was the project/funds housed?

Was there existing expertise within the community and had community members been involved in previous research on this topic? How was that incorporated into this new project?

Please describe ways in which community participants were involved in planning, implementation and evaluation?

Were community participants involved in analytic issues: interpretation, synthesis and the verification of conclusions?

- did you have an explicit agreement for acknowledging and resolving in a fair and open way any differences between researchers and community participants in the interpretation of the results?

Was there an agreement between researchers and community participants with respect to ownership of the research data?

Please describe ways in which capacity was built within the community through this project? Please describe the project’s outcomes, and how these benefited the community.

Was there an agreement between researchers and community participants with respect to the dissemination of the research results?
Preliminary Work (pre-funding):

What was the original intent of the project, as it was funded by CIHR?

How did you become involved in this project?

Tell us about your previous experience with this community? What ethical issues were you aware of with this community? What ethical issues did your partner(s) bring to light?

How did you reconcile ethical issues, if there were any?

Scientific Review:

How were these issues addressed in your CIHR grant proposal?

Did the grant reviewers pose any ethical concerns in their feedback? Can you describe them?
How did you incorporate these suggestions into your work?

Ethical Review:
How did you write the ethics protocol (single author, group collaboration, etc)? Did the design of your study fit the requirements of the REB’s forms/documents? Did you apply for expedited or full review?

Did you specifically identify any ethical issues of concern to your community of interest in your ethics protocol? Explain.

Did you seek consultation on the process (e.g., call the REB, consult with community leaders)?

Did you argue your case to the REB in person? If so, what happened?

Did the REB make any recommendations/comments?

- Were these helpful?
- Did they inform the design of your study? If you had revisions, did the REB accept them?

Overall, how did your design change from the funding phase?

How long did the process take from start to finish?

**Project:**

Did your final design match your original concept? If it changed, how?

- How did the project stakeholders react?

Did you submit any amendments over the life of your project?
• Why or why not?

• How were these received?

Were there unexpected ethical issues during the life of your project? Can you please tell us about them?

• Were these flagged by the REB as areas of concern during the initial review?

• How did you deal with these unexpected issues? Overall, how did ethical review affect your project?

**CBR Ethics in general:**

In your experience submitting CBR research proposals to Ethics Review Boards, how have they been received?

(if applicable) Have you noticed any differences in your interactions with your Ethics Review board between submitting CBR and other kinds of research proposals?

How accessible do you think Ethics Review boards are for researchers/communities that wish to do CBR?

Tell me about a positive and/or negative experience you had with an Ethics Review Board on a CBR study in addition to the CIHR grant discussed above.
Are you aware of researchers and/or communities developing their own informal ethical guidelines for the purpose of collaborating on a study? Can you tell us about them? Have you ever used one?

Can you reflect on the relationship between REBs and CBR?

Can you think of any ways to improve Ethical Review for CBR?

- What do you think of setting up a special CBR ethics review model (with special guidelines for CBR)?

- Can you think of any examples, models, or best practices which could be adapted?

Thank you for your time – is there anything else you want to add?