FIRST NATIONS INVOLVEMENT IN HEALTH POLICY DECISION-MAKING:

THE PARADOX OF MEANINGFUL INVOLVEMENT

by

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ABSTRACT

Alongside consistent reporting on health inequities affecting Indigenous peoples in Canada, Indigenous people have been routinely excluded from health policy decision-making. This pattern of exclusion perpetuates health policy decisions that are often ineffective at addressing the root causes of persistent health inequities. Despite Indigenous peoples’ repeated calls to be meaningfully involved, and the emergence of health policy initiatives that include Indigenous peoples, the influence of neoliberalism and neocolonialism in the Canadian policy sphere continues to undermine self-determination and limit Indigenous peoples’ involvement in health policy processes. Those advocating for Indigenous health equity are left wrestling with the question: What constitutes, and what can foster, meaningful involvement in the contemporary health policy climate?

This exploratory qualitative research aims to provide a window of insight into this urgent social justice question by exploring the perspectives of twenty leaders and decision-makers in First Nations health and other areas of health policy, with a view to understanding what constitutes meaningful involvement of First Nations peoples in health policy decision-making in BC and Canada. A critical analysis of these data reveals that meaningful involvement is often experienced as a paradox where Indigenous people are excluded via processes of inclusion, and that fostering meaningful involvement requires attuning to the underlying power dynamics inherent in policymaking and taking action to decolonize and transform the policy system itself.

Based on this analysis, I articulate a new conceptualization of and framework for meaningful involvement, which is rooted in seven key elements: Recognizing and Representing Indigenous Peoples; Interrupting and Re-imagining Relationships; Preparing Agreements; Practicing Protocols; Leveraging Power; Exerting Community Authority; and Shifting Social Structures.
This dissertation concludes with a discussion on the significance and implications of these findings and strategic directions and recommendations for meaningfully involving urban First Nations people in health policy decision-making in BC and beyond.
PREFACE

This dissertation is original, unpublished, intellectual work by the author, A. J. Fridkin. The Behavioural Research Ethics Board (BREB) at the University of British Columbia (UBC) approved the research design and implementation reported in Chapter Four. The BREB certificate number was: H11-00980.
TABLE OF CONTENTS

ABSTRACT ................................................................................................................................. ii
PREFACE ..................................................................................................................................... iv
TABLE OF CONTENTS ............................................................................................................... v
LIST OF TABLES ........................................................................................................................ viii
LIST OF FIGURES ......................................................................................................................... ix
ACKNOWLEDGMENTS .............................................................................................................. x
DEDICATION ............................................................................................................................ xi

CHAPTER ONE – INTRODUCTION .............................................................................................. 1
The Act of Witnessing through Research ................................................................................... 1
Will Involvement in Health Policy Lead to Better Outcomes? .................................................... 4
Background to the Research Problem .......................................................................................... 7
The Central Problem: First Nations Exclusion in Canadian Health Policy Decision-Making .... 12
Research Objectives ................................................................................................................... 13
Organization of the Thesis ......................................................................................................... 14

CHAPTER TWO – SYNTHESIS OF LITERATURE ........................................................................ 15
Introduction .................................................................................................................................. 15
Indigenous Involvement in the Canadian Political Sphere .......................................................... 15
Indigenous Quests for Justice: Five Hundred Years of Engagement .......................................... 15
Emerging Perceptions of Government Negotiations .................................................................... 16
Indigenous Political Resistance ................................................................................................... 20
Paradoxical Policies: The Impact of Neoliberalism .................................................................... 28
Neoliberal Underpinnings of First Nations Health Policy: The Case of Health Transfer ... 31
The Influence of Neoliberalism on First Nations Policy Initiatives ............................................. 34
New Approaches to Indigenous Involvement: First Nations Health Policy in BC .................... 37
Urban Indigenous Involvement in Policy .................................................................................... 40
The Need for a Critical Framework for Meaningful Involvement ............................................. 45
Summary ................................................................................................................................... 49

CHAPTER THREE: THEORETICAL FRAMEWORK ..................................................................... 50
Introduction ............................................................................................................................... 50
Assumptions Shaping the Researcher’s Perspective ................................................................. 51
Engaging in Indigenous Health Policy Research as a Non-Indigenous Researcher .................. 53
Guiding Theoretical Perspectives ............................................................................................... 55
Decolonizing and Indigenist Perspectives .................................................................................... 55
Starting with Tokenism ................................................................. 128
Moving Beyond Tokenism .............................................................. 132
Disrupting the Cycle of Exclusion .................................................... 135
Legislating Involvement: The Impact of Formal Agreements ............... 138
  Ensuring Government Accountability ............................................. 139
  Engaging in Decision-Making at the Highest Policy Levels ............... 141
  Laying the Groundwork for New Ways of ‘Doing Business’ .............. 142
Transforming the Policy System: The Need for Structural Change .......... 144
  Re-Imagining Community Engagement ........................................ 146
  Re-Imagining Relationships .......................................................... 150
  Indigenizing Policy ....................................................................... 152
Attuning to Power in Policy Processes: Taking Action Toward Meaningful Involvement... 157
Summary ....................................................................................... 161

CHAPTER SEVEN – RE-CONCEPTUALIZING MEANINGFUL INVOLVEMENT ... 163

Introduction .................................................................................. 163
What Constitutes Meaningful Involvement? ...................................... 164
  The Key Elements of Meaningful Involvement ............................. 166
  The RIPPLES of Meaningful Involvement: A Framework ............... 172
Contributions to the Literature ......................................................... 175
Discussion: Significance and Implications ........................................ 177
  Working Together in a Neocolonial Neoliberal Context .................. 178
  Implications for First Nations Health Policy in BC ....................... 182
  Attention to the Diversity of First Nations People’s Voices .............. 184
  Taking Responsibility for Urban First Nations Health: Opportunities for Fostering Meaningful Involvement ......................... 188
Strategic Directions and Recommendations ...................................... 191
Concluding Comments ................................................................... 194

REFERENCES ................................................................................ 197

APPENDICES ................................................................................ 219

  Appendix A: Study Summary ....................................................... 219
  Appendix B: Interview Guide ....................................................... 220
  Appendix C: Consent Form ......................................................... 222
  Appendix D: Socio-Demographic Form ........................................ 225
LIST OF TABLES

Table 1. Summary of Participants (n=20) .................................................................................. 77
Table 2. Enacting the Key Elements of Meaningful Involvement ........................................ 169
LIST OF FIGURES

Figure 1. The RIPPLES of Meaningful Involvement ................................................................. 173
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\(^1\) I gratefully acknowledge CIHR for providing me with a 3-year Doctoral Research Award to carry out this research.
For blessing me with the values of education and social justice,

this one’s for you, Dad.
CHAPTER ONE – INTRODUCTION

I am a witness
I am inspired by the earth’s response to her
desecration
A tsunami cleanses the earth
A hurricane rearranges rivers
An earthquake is an objection
And we will have to face ourselves,
Face our sense of justice
To include all life

We will need to nourish our imagination
To include a new equality
And summon our souls, our hearts and our minds to a
justice,
which includes all life

- Lee Maracle, Blind Justice (2014, p. 217)

The Act of Witnessing through Research

The impetus for this research emerged from my witnessing the ongoing frequent exclusion of Indigenous² people from health policy decision-making processes. As a public

² The question of ‘who is Indigenous?’ is highly politicized because it has implications for Indigenous peoples’ legal rights, yet such definitions are often necessary in research and policy contexts (Corntassel, 2003). Although LaRocque (2010) asserts, “[t]erminology about [Indigenous] identities is a minefield, given the history of stereotypes and legislative divisions,” considering the focus of this research is on Indigenous peoples’ involvement in policy, I have an imperative to define whom I am referring to by Indigenous peoples. Recognizing Indigenous peoples’ rights to determine and define their own identity (United Nations, 2008) and that there is no internationally adopted definition of Indigenous peoples (United Nations, 2009), I humbly and cautiously draw on existing definitions for the purposes of this research. I draw on Corntassel’s (2003) definition of Indigenous peoples to refer to peoples who: a) identify as the original inhabitants of their ancestral homelands; b) have their own informal and/or formal political, economic and social institutions; c) speak or once spoke an Indigenous language that is distinct from the language of the dominant society; and d) distinguish themselves from the dominant society while maintaining a relationship with their ancestral homelands/sacred sites. Indigenous peoples broadly refers to Indigenous peoples around the globe and internationally, however, in the context of this research, Indigenous people is primarily used synonymously with Aboriginal people to refer collectively to Indigenous people from the geopolitical space that is the current nation-state of Canada. This includes First Nations, Inuit and/or Métis people, whom I respectively refer to in accordance with the definitions in Indian Act and subsequent Canadian policy documents such as the Report of the Royal Commission on Aboriginal people (Royal Commission on Aboriginal Peoples, 1996). Although specific individuals or groups may contest these identities, I use these terms recognizing they have political and social meanings in relation to contemporary legal and political contexts, as well as some individuals’ and communities’ identities. In reference to First Nations people specifically, I refer to people who identify as a First Nations person and who is registered or not registered as a First Nations person with the federal
health graduate student, I witnessed the ways in which First Nations perspectives and interests were routinely left out of key academic public health conversations and debates, despite the numerous reports indicating that First Nations communities and populations experience the greatest health inequities in Canada. As an employee and volunteer worker in a variety of inner city community health settings, I witnessed an absence of First Nations staff and healthcare providers despite the disproportionate numbers of First Nations people seeking urgent access to health and social services. As a civil servant in the federal government and volunteer in a national policy advocacy organization, I witnessed the continued exclusion of First Nations people from core decision-making activities and policy discussions. This research is not a testament to my feelings of sympathy or pity; it is a response to witnessing an ongoing and unresolved issue of social injustice.

In bringing these issues to surface in the academic sphere, this research itself is an act of witnessing; an Indigenous principle used in some First Nations contexts as a way of recognizing or marking historically significant events and legitimizing historical truths that have otherwise gone unrecognized or undocumented. A recent example of this is in the way honorary witnesses were called to publically recognize the historical injustices imposed upon First Nations and Aboriginal people through the residential school system (Truth and Reconciliation Commission of Canada, 2014). Driven by the “fundamental belief in the value of democracy in correcting government policies that are contrary to the public good,” the act of witnessing represents an acknowledgement of public responsibility to redress issues of injustice and inequity towards Indigenous people (Blackstock, 2011, p. 6). Being a witness not only signifies personal government (e.g. both “status” and “non-status”), as well as people who are living in and/or outside of First Nations communities (e.g. both on- and off-reserve) (Browne, McDonald, & Elliott, 2009). I refer to each of these groups respectively where appropriate and as per their explicit use in the literature and in the interviews.
acknowledgement of the legitimacy of injustice, but also a personal commitment to care about the issue and act in support of continued efforts to address the injustice (First Nations Child & Family Caring Society of Canada, 2013).

Witnessing through research can serve to draw attention to Indigenous social justice issues largely invisible in academic areas outside of Indigenous studies (Koptie, 2009b). The participants’ experiences and perspectives are the entry point to understanding the issue of First Nations peoples’ experiences in health policy processes. This research emphasizes the repeated calls in the literature for First Nations peoples and leaders to be meaningfully involved in health policy decision-making in order to address health and social inequities (Cheema, 2007; Coulthard, 2014; Lavoie, Boulton, & Gervais, 2012; Matthews, Pulver, & Ring, 2008; Reading & Nowgesic, 2002), instead of investigating whether First Nations involvement will close the health equity gap. Taking direction from these repeated calls, this research investigates what is needed to foster more meaningful and influential involvement of First Nations people in health policy decision-making. The intent is to deepen an understanding of meaningful involvement to provide insight on how to navigate this complexity. Consequently, this research is not about analyzing whether First Nations people should be involved in health policy decision-making; it is instead about how First Nations people could become more meaningfully and influentially involved.

3 Policy or policy decisions refer specifically to actions taken by governments to achieve certain outcomes, as well as more broadly to processes involving negotiation, contestation or struggles between groups outside of formal policymaking (Ozga, 2000). Health policy is used to refer to a form of public policy, that is actions or inactions chosen by public authorities to address particular problems that are directly related to health or have an impact on health (Bryant, 2009). Policymaking, decision-making and policy decision-making are used interchangeably in reference to the act of making policies or policy decisions, respectively, whereas policy processes refer broadly to processes that are in some way related to, fall within or are part of policymaking or decision-making.

4 While health inequities are defined as systemic social differences in health that are unfair, unjust and modifiable, health equity refers to fairness and social justice in health and access to health care (Pauly, MacKinnon, & Varcoe, 2009; Sen, 2002; Whitehead & Dahlgren, 2007).
Will Involvement in Health Policy Lead to Better Outcomes?

In exploring ways of meaningfully involving First Nations people in health policy, one might question the assumption that involving First Nations people will necessarily lead to better policy decisions or improvements in health outcomes. My reflections on this question are informed by public health and health promotion literature, which widely recognizes that the inclusion of community members in health decision-making is an integral aspect of improving health and addressing health inequities (World Health Organization, 1978, 1986, 2008). Recognition of the importance of community involvement is further evidenced by a plethora of literature on citizen engagement and public participation in various aspects of health and health policy decision-making (see Carman, et al., 2013; Fitzpatrick & White, 1997; Frankish, Kwan, Ratner, Higgins, & Larsen, 2002; Gaventa & Barrett, 2010; Larson, Schlundt, Patel, Goldzweig, & Hargreaves, 2009; Maloff, Bilan, & Thurston, 2000; Rifkin, 2003; Rychetnik, et al., 2013). Despite the recommendations emerging from this literature, it is also acknowledged that community members, and especially those who are most marginalized by health and social policy decisions, are rarely invited to participate in policymaking processes (Beresford, 2007; Kenny & Giacomini, 2005; Lombe & Sherraden, 2008; Rice, 2011). Further studies show that the impact of community engagement is difficult to assess and evaluate, and often results in both positive and negative social and political outcomes5 (Gaventa & Barrett, 2010; Jagosh, et al., 2012). A recent synthesis of literature on participatory research, however, indicates that participatory methods have had an impact on reducing health disparities through the effects of

5 Some positive outcomes of citizen engagement include: a greater sense of empowerment and agency, increased capacities for collective action, new forms of participation, deepening of networks and solidarities, enhanced state responsiveness, inclusion of new actors and issues in public spaces and greater cohesion across groups. Some negative outcomes include disempowerment and reduced sense of agency, tokenistic forms of participation, lack of accountability and representation in networks, violent or coercive state response, reinforcement of social hierarchies and exclusion, and increased conflict and violence (Gaventa & Barrett, 2010).
enhancing programs and through the immediate outcomes of participation, including capacity building, self-empowerment, and infrastructure development, which are sometimes described as having a more profound impact on well-being than the intervention in which participation occurs (Jagosh, et al., 2012). These findings point to the need for further exploration of the issues surrounding meaningful involvement, including what is needed for involvement to be effective, and to what ends.

The question of whether or not including First Nations people in policy will lead to tangible improvements in health outcomes is also difficult to assess, perhaps partly because there is dearth of documented examples of Indigenous people being meaningfully involved in health policy decision-making, and perhaps partly due to limitations in availability of First Nations health population data (see Church, 2015; Loppie Reading & Wien, 2009; Park, Tjepkema, Goedhuis, & Pennock, 2015; Smylie & Anderson, 2006). There appears to be few studies showing that involving Indigenous people in policy has led to better health outcomes. Lavoie et al.’s (2010) study is one exception and shows that First Nations community control of health services has resulted in lower rates of hospitalization. It has also been well-documented that policies co-produced with Aboriginal communities have led to better outcomes because they are developed on communities’ terms (Walker, Moore, & Linklater, 2011), yet not all outcomes from such policies are easily measured or quantified, such as outcomes in social interaction or relationships (Minore & Katt, 2007).

The evidence that including First Nations people in policy will lead to better health outcomes may be overall indeterminate, but there is substantial evidence that policy developed without including First Nations people leads to little improvement in health. To question whether or not including Indigenous people in policy will lead to better outcomes would undermine the
repeated calls for meaningful involvement made by First Nations people and communities, whose voices have largely been excluded in academia and research (Battiste, 2009; Pete, 2015). In addition to the health promoting benefits of community involvement described at length in the health promotion literature, the aims of this research are also grounded in the wide-spread acknowledgement of the need to include Indigenous people as recognized by Indigenous scholars, leaders and activists (Alfred, 2005; Coulthard, 2014; Hunter, 1997; Iorns Magallanes, 2011; Matthews, et al., 2008; Reading & Nowgesic, 2002; The Kino-nda-niimi Collective, 2014; Turner, 2006).

In exploring this research topic, I also recognize the value and significance of First Nations people’s refusal to engage in health policy decision-making processes. For example, in justifying her reasons for not voting in federal elections, Palmater (2015a) argues that Indigenous peoples’ success in resisting oppressive policies has not resulted from voting in federal elections, but from Indigenous peoples’ resistance on the ground. She further argues that self-determination includes recognizing Indigenous peoples’ rights to freely choose how to relate to the Canadian state (Palmater, 2015a). Existing literature on Indigenous peoples’ right to refuse suggests that refusing to engage in particular policy or political processes such as voting does not mean that Indigenous people are not actively participating in policy processes. Tuck and Yang (2014a) argue that Indigenous people’s refusal to participate in research “need not be thought of as a subtractive methodology” (p. 241), and instead can be seen as a resistance effort to actively critique settler colonialism and its “regimes of representation” (Tuck & Yang, 2014b, p. 811). The authors argue that the act of refusal “shifts the gaze from the violated body to the violating instruments,” such as policy processes in this case, which may contribute to “accumulating land and wealth through the extermination and subordination” of Indigenous peoples (Tuck & Yang,
2014a, p. 241). Drawing on these perspectives, I recognize that Indigenous people’s active refusal to participate in health policy decision-making processes could be seen as a form of meaningful involvement.

**Background to the Research Problem**

Health and social inequities affecting First Nations peoples in Canada have been consistently documented in key public health reports over the last several decades. Disparities between Indigenous and non-Indigenous people in Canada exist across virtually every health indicator, including chronic disease, HIV, injuries, disabilities, mental health, problematic substance use\(^6\), suicide, as well as social determinants of health such as housing, poverty, and employment (British Columbia & Provincial Health Officer, 2009b; Brownridge, 2008; Health Canada, 2009; Health Council of Canada, 2005).

The literature suggests the consistency of these health inequities is hardly coincidental; it is the result of a history of colonial policies imposed on First Nations people from the moment of “contact” with European settlers. Wien (1999) argues that the history of Aboriginal policy in Canada “is full of misguided policy choices,” which have contributed to key factors affecting Indigenous peoples’ health, including the erosion of Indigenous economies and subsequent widespread poverty and starvation (p. 102). The Indian Act created a situation where First Nations communities who experienced devastating health effects due to colonization, were legally confined to reserves, which were thriving settings for infectious disease due to isolation and poor living conditions (Kelm, 1999). In spite of First Nations peoples’ resistance and resilience, colonial policies outlawing traditional practices impeded First Nations peoples’ access to cultural practices including traditional medicine (Waldram, Herring, & Young, 2006). The

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\(^6\) The replacement of the term “addiction” with “substance use” in the Diagnostic and Statistical Manual for Mental Health Disorders (DSM-5) (American Psychiatric Association, 2013) may reflect a shifting medical discourse that acknowledges the stigmatizing consequences associated with addiction.
creation of reserves and the Indian Act simultaneously created geographic and policy barriers to First Nations peoples’ access to western health care services (Young, 1984). The residential school system played an equally traumatic role on the health of First Nations people, where high rates of tuberculosis and untreated illness in residential schools resulted in the death of many children, and the overall neglect, abuse, malnutrition, and detachment from their families, language and culture additionally contributed to the poor health of children who attended. The separation of children from their families also had a devastating impact on First Nations communities (Ing, 2006), and the trauma experienced by First Nations people continues to exert intergenerational effects identified as historical trauma (Brave Heart & DeBruyn, 1998). As argued in Chapter Two, current health and social inequities are sustained by the continued implementation of neocolonial policies that uphold historical colonial and oppressive views of Indigenous people (Adelson, 2005; Bourassa, McKay-McNabb, & Hampton, 2004; Brave Heart & DeBruyn, 1998; Browne, Smye, & Varcoe, 2005; Coulthard, 2014; Ing, 2006; Irlbacher-Fox, 2009; Loppie Reading & Wien, 2009; Smye & Browne, 2002; Waldram, et al., 2006; Warry, 2007; Wesley-Esquimaux & Smolewski, 2004).

Despite a history of colonial oppression in Canada, including land degradation, systemic discrimination and racism, Indigenous communities have continued to survive and thrive (Dion Stout, 2012; Kelm, 1999; Reading, 2009). Indigenous communities in Canada are actively involved in promoting health and social equity through education, employment, and economic development, and many communities continue to maintain a renaissance of tradition and pride (Reading, 2009).

The history of First Nations health in Canada illustrates the profound impact of health policies in shaping health inequities and the important role of First Nations people in improving
the health of their communities. It has been well documented that health policies play a key role in determining health inequities (Anand, 2002; Baum, Begin, Houweling, & Taylor, 2009; Canadian Institutes of Health Research, 2009; Collins & Hayes, 2007; Fafard, 2008; Pauly, et al., 2009; Petticrew, Whitehead, Macintyre, Graham, & Egan, 2004; Sen, 2002; Whitehead, 1991; Whitehead & Dahlgren, 2007). Scholars argue that Indigenous peoples’ health and quality of life can only be improved if addressed on Indigenous peoples’ own terms, and there is a body of evidence showing that policies co-produced with Indigenous communities have better outcomes for Indigenous people (Walker, et al., 2011). Indigenous peoples’ involvement in health policy has been additionally shown to improve Indigenous peoples’ health (Matthews, et al., 2008; Reading & Nowgesic, 2002) as well as policy-making processes (Quanz & Thurston, 2006).

Despite this, First Nations people in Canada, and First Nations women in particular (Dion Stout & Kipling, 1998), are still frequently excluded from policy decisions that impact First Nations people’s health (Fiske & Browne, 2008; Loppie Reading & Wien, 2009).

Against this backdrop, there have also been significant efforts and initiatives to involve Indigenous people in health policy decision-making in Canada, including the Indian Health Transfer Policy in the 80’s (O'Neil, 1993a), the Royal Commission on Aboriginal Peoples in the 90’s (Royal Commission on Aboriginal Peoples, 1996; Wien, 1999), and the Kelowna Accord in the 2000’s (DiPenta, 2006; Durbin, 2009; Patterson, 2006). ⁷ Each of these policy initiatives involved extensive engagement of Indigenous people, including submissions of writing from scholars, organizations and community members, and each resulted in a set of recommendations for improving Indigenous peoples’ health and well-being, including the need to involve Indigenous people in health policy decisions.

⁷ Each of these initiatives is discussed in the following chapter.
In addition to these initiatives, discourses on the *meaningful involvement* of Indigenous peoples in policy have begun to emerge in the literature (see Centre for Indigenous Environmental Resources, 2009; Marsden, 2005; Public Health Agency of Canada, 2007). The emergence of discourses on meaningful involvement in relation to First Nations policy may be indicative of an increasing desire on the part of institutions and communities to not only advocate for the inclusion First Nations people in decision-making, but for inclusion in a particular way; however, it is neither clear what such inclusion might look like nor how it can be fostered. This research seeks to deepen an understanding of what constitutes meaningful involvement and how it can be fostered in First Nations health policy.

Another key issue with the current conversation in the literature on meaningful involvement of First Nations people is that it predominantly focuses on the inclusion of nation-based or reserve-based communities, and the involvement of First Nations people ‘away from home’ is typically not considered in such discussions. This may in part be due to the jurisdictional “messiness” of the urban Aboriginal policy landscape (Abele, Lapointe, Leech, & McCrossan, 2011) and inconsistencies in policies across the on- and off-reserve divide (National Collaborating Centre for Aboriginal Health, 2011).

The limitation of a discussion on meaningful involvement that only considers First Nations peoples on-reserve is that the implications may not be applicable to over half of First Nations people away from home, who are typically not considered in such discussions. This may in part be due to the jurisdictional “messiness” of the urban Aboriginal policy landscape (Abele, Lapointe, Leech, & McCrossan, 2011) and inconsistencies in policies across the on- and off-reserve divide (National Collaborating Centre for Aboriginal Health, 2011).

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8 First Nations people *away from home* is used synonymously and sometimes preferably by First Nations groups to refer to First Nations people living off-reserve (see First Nations Health Authority, 2014b). In the context of this research, First Nations people away from home or living away from home refers to people who identify as First Nations and who predominantly reside outside their home First Nations community. This research recognizes that many First Nations people move back and forth between reserves, rural areas and urban cities. In this dissertation, First Nations people away from home refers to First Nations people predominantly residing off-reserve in cities or urban areas, and is thus used synonymously with *urban First Nations people*, although it is recognized that some First Nations people live off-reserve in rural areas, some live in urban settings and consider that to be their home, and some First Nations reserves are located in urban areas (Browne, McDonald, et al., 2009). Because the literature often refers to *urban Aboriginal communities* (see Peters, 2011a), which includes First Nations, Inuit and Métis people living off-reserve in urban areas, this research considers urban Aboriginal communities to implicitly include First Nations people away from home. Each of these terms is used throughout in accordance to the literature and the particular context being discussed.
Nations people in the population. The discussion on Indigenous involvement therefore becomes a discussion on the meaningful involvement of less than half of First Nations people, which has the potential to undermine the integrity of what is meant by meaningful involvement. In addition, Indigenous Canadians comprise a substantial proportion of the entire urban population in many municipalities and large cities, a reality to which governments are becoming increasingly attuned. The extent to which Indigenous people have control over municipal policies has great consequences for urban Indigenous residents (Peters, 2011b). As argued in this dissertation, attention to what meaningful involvement means in the urban context is needed. Through exploring issues of involvement in health policy for First Nations people living away from home, this research contributes to filling these knowledge gaps.

Given the recent advancements related to First Nations involvement in health policy decision-making in BC, contextualizing an analysis on meaningful involvement of First Nations people away from home within the BC First Nations health policy landscape may inform further thinking on what constitutes meaningful involvement and how it can be fostered in the BC context. BC First Nations are now involved in health policy decision-making in ways that are unprecedented in the history of Aboriginal health policy in Canada, exemplified by the recent establishment of a First Nations health governance structure in BC, which was enabled through a history of relationship building between BC First Nations and the federal and provincial governments (First Nations Health Authority, 2014b). Not only is the BC First Nations health

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9 Demographic trends indicate that almost half of Indigenous people in Canada live in urban centres, with 60% of First Nations people living off-reserve compared to 40% living on-reserve in 2006 (Browne, McDonald, et al., 2009; Environics Institute, 2010; First Nations Information Governance Centre, 2008/10).

10 In using the term “First Nations health governance structure,” I am primarily referring to the First Nations Health Council, the First Nations Health Authority and its previous iterations including the First Nations Health Society and the interim First Nations Health Authority, however, I recognize that the First Nations health governance structure also includes the First Nations Health Directors Association (First Nations Health Authority, 2014b). In discussing the First Nations health policy structures or processes in BC, I am primarily referring to the processes used by the First Nations health governance structure, such as their processes for engaging BC First Nations communities. Further discussion on the First Nations health governance structure is found in Chapter Two.
context a useful focal point for this investigation given the impending lessons learned from this unprecedented work, the findings from this research may be useful in informing strategic directions in this area, particularly in relation to the involvement of First Nations people away from home.

The Central Problem: First Nations Exclusion in Canadian Health Policy Decision-Making

The central problem addressed in this research is the repeated exclusion of First Nations people from health policy decision-making processes in Canada, which contributes to ongoing health and social inequities. The primary focus of this research is on how to foster meaningful involvement of First Nations people in health policy decision-making in the current neoliberal neocolonial context. To reach a deepened understanding of what constitutes meaningful involvement in relation First Nations health policy, a secondary focus on how First Nations people away from home can be meaningfully involved in First Nations health policy provides a window into exploring the broader questions on meaningful involvement. For example, focusing on First Nations people away from home may provide an opportunity to explore how a diversity of First Nations people can be meaningfully involved in health policy decision-making. This secondary focus is neither intended to inform an urban Aboriginal health strategy nor propose a model for urban Aboriginal health governance, but to inform the central problematic of how First Nations people, including those away from home, could be more meaningfully involved in First Nations health policy decision-making.

The research situates this central problem within the Canadian context, however, the research interviews and much of the analysis focus on First Nations people’s involvement in the health policy decision-making in BC. Exploring the research problem from within the BC landscape provides an opportunity to learn from the unprecedented ways First Nations people
have become involved in health policy decision-making, and contribute to thinking on ways to strengthen the newly emerging processes and structures. The insights gained from the BC context may also shed light on ways of meaningfully involving First Nations people in other Canadian health policy settings. Although the research maintains a focus on BC, the findings are potentially applicable to First Nations health policy decision-making in BC and beyond.

**Research Objectives**

The overarching purpose of this research is twofold: a) to provide insight into the broader issue of how to foster more meaningful involvement of First Nations people in health policy decision-making in the wider Canadian context; and b) to deepen current understandings on how First Nations people living away from home in urban settings can be more meaningfully involved in BC First Nations health policy processes.

The specific objectives of this research are:

1. To explore, from the perspectives of leaders and decision-makers in First Nations health and other areas of health policy, what constitutes meaningful involvement of First Nations peoples in health policy decision-making in BC and more widely in Canada; and

2. To develop strategic directions and recommendations for meaningfully involving First Nations people living away from home in urban settings in health policy decision-making processes.

To address these objectives, twenty in-depth, open-ended interviews with leaders and decision-makers in First Nations health and other health policy areas were conducted and analyzed based on a theoretical framework rooted in critical and decolonizing perspectives. The findings and analysis are used to inform a new conceptualization of meaningful involvement and a framework for fostering meaningful involvement of First Nations people in BC and other
Canadian health policy contexts. The dissertation concludes with strategic directions and recommendations for fostering more meaningful involvement of First Nations people away from home in health policy decision-making, specifically on First Nations health.

**Organization of the Thesis**

Chapter One introduces this research by discussing the impetus of this research, describing the research problem, and articulating the specific aims of the study. Chapter Two contains a synthesis of literature to contextualize the research problem within the contemporary political climate and current debates on meaningful involvement. Chapter Three outlines the theoretical framework informing the analysis and Chapter Four describes the methodology and research design. As the first of two findings chapters, Chapter Five presents an analysis of participants’ lived experiences at policy decision-making tables related to First Nations health. Chapter Six, the second chapter of findings, presents an analysis of participants’ perspectives on meaningful involvement with a view to understanding what constitutes meaningful involvement and how it can be fostered in a First Nations health policy context. Drawing on the analyses in Chapters Five and Six, Chapter Seven articulates a new conceptualization of meaningful involvement and a framework for meaningfully involving First Nations people in health policy decision-making. The chapter concludes with a discussion on the significance and implications of this research, strategic directions and recommendations for meaningfully involving First Nations people away from home in First Nations health policy decision-making, and concluding comments on moving towards more meaningful involvement of First Nations people in BC.
CHAPTER TWO – SYNTHESIS OF LITERATURE

Introduction

This chapter is not intended to provide an exhaustive review of all literature pertaining to First Nations health policy in Canada, rather it is intended to a) provide a background for understanding the context surrounding First Nations involvement in and the inclusion of First Nations people away from home in the BC First Nations health policy context, including existing key issues, challenges and opportunities, and b) position the research problem within the contemporary political climate and in relation to current conversations and debates in the literature on meaningful involvement.

Indigenous Involvement in the Canadian Political Sphere

Indigenous Quests for Justice: Five Hundred Years of Engagement

It is widely acknowledged that injustice towards Indigenous people in Canada began at the moment of contact and the arrival of European settlers on Turtle Island. While the seizure and exploitation of Indigenous territories and genocide against Indigenous peoples often remains unwritten and unmentioned in Canadian versions of history, these accounts of injustice are well known to Indigenous peoples. The erasure of Indigenous peoples’ perspectives on history has fostered ignorance on the part of many Canadians about the ongoing injustices of colonialism, which has contributed to an overall apathy and lack of action in Canadian society on addressing issues of Indigenous injustice (Belcourt, 2014). Although fighting for justice requires action on the part of everyone in Canadian society and a “shift in public consciousness” (Denis, 2014, p. 219), Indigenous people have continued to confront Canadian governments on issues of injustice.

Indigenous activists claim that they have never been silent; they have been engaged in conversation with governments and “have found ways to individually and collectively resist . . .
oppressive policies and practices” (Coulthard, 2014, p. 4). For hundreds of years, Indigenous people in Canada have been actively working to protect their homelands, maintain and revitalize Indigenous languages, traditions and cultures, and attempting to engage with Canadian governments in a fair and just manner, yet such efforts have often remained unnoticed or ignored (The Kino-nda-niimi Collective, 2014). This lack of responsiveness has persisted and continues in today’s political context. A recent exemplar is the previous federal government’s inaction on the inquiry into the hundreds of cases of missing and murdered Indigenous women and girls in light of Indigenous peoples’ demands.11 Political silence such as this condones gendered colonial violence (Gabriel, 2014), and further illustrates how violence towards Indigenous people is created and sustained by Canadian social and political structures.

**Emerging Perceptions of Government Negotiations**

Indigenous-government relationships are situated within this context of systemic violence. Coulthard (2014) describes the relationship between First Nations and governments as *colonial*; a relationship characterized by domination, where power “has been structured into a relatively secure or sedimented set of hierarchal social relations that continue to facilitate the dispossession of Indigenous peoples of their lands and self-determining authority” (pp. 6-7). Coulthard (2014) further argues that in the Canadian context, “colonial domination” has operated “through force, fraud, and more recently, so-called ‘negotiations’” (p. 7), which suggests structural relations of power have permeated engagement efforts. Other Indigenous leaders argue that First Nations negotiations with governments are undermined by inequitable power relationships that restrict and define the terms of engagement. In reference to First Nations

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11 The recent federal election on October 19th 2015 has marked a change in Canadian federal government (Schwartz, 2015), and new promises for a national public inquiry on the missing and murdered Indigenous women and girls. Newly elected Liberal Prime Minister Trudeau has pledged to launch the inquiry immediately and spend $40 million on the study over two years (Kirkup, 2015).
negotiations on the Conservative federal government’s Comprehensive Claims and Self-Government policies, Diabo (2014) writes,

[I]t seems the negotiating First Nations are so compromised by their federal loans and dependent on the negotiations funding stream that they are unable or unwilling to withdraw from the tables en masse and make real on the demand that the Harper government reform its . . . policies to be consistent with the Articles of [the UN Declaration on Rights of Indigenous Peoples]. (p. 62)

This example and others illustrate how First Nations people tend to become caught in a tangled web of historical colonial politics when trying to self-advocate through government negotiations.

Recognizing the overall ineffectiveness of First Nations engagement in such negotiations, which some view as vehicles for advancing government policies that undermine Indigenous rights, Diabo (2014) argues, “First Nations are the proverbial ‘end of the trail’” (p. 64). When it comes to achieving meaningful change and advocating for Indigenous rights, government negotiations often appear to be a ‘dead end.’ The undercurrents of power within policy systems uphold the status quo and erode the dialogue between Indigenous peoples and government. Turner (2014) argues,

[T]his dialogue has deteriorated and is in danger of disintegrating. This is because the federal government’s solution to the Indian problem has not changed: extinguish Aboriginal title, open up Aboriginal homelands to large multinational resource companies, and exploit natural resources for the economic benefit of “all” Canadians. Aboriginal people can either participate in this economic venture or be left behind to gradually, and inevitably, vanish from the world (then conclude that they brought on their disappearance on themselves). (p. 122)
Some argue that the recent federal government’s approach to negotiations with First Nations has devolved to becoming no more than a “take it or leave it” ultimatum (Diabo, 2014, p. 63), which reflects the perception that the government’s economic hold on Indigenous peoples has turned negotiation tables into a mockery. Palameter (2014) writes, “I am optimistic about the power of our peoples and know that in the end, we will be successful in getting this treaty relationship back on track. However, I am less confident about the Conservative government’s willingness to sit down and work this out peacefully any time soon” (p. 40). The skepticism on negotiations in the contemporary political climate is palpable.

Although these authors’ critiques are largely directed at the Conservative government’s approach to negotiations, the skepticism on government policy processes is not bound to the one particular government party. Shortly following the federal election on October 19th 2015 and the shift from a Conservative to a Liberal federal government (Schwartz, 2015), Palmater (2015b) writes that changing the face of government leaders will not “change the racist system itself, which is the underlying problem” (p. 1). Palmater (2015b) further argues that appointing a First Nations person as Minister of Indigenous Affairs will not change an oppressive policy system and can detract from the goal of building nation-to-nation relationships. In light of the history of inequitable First Nations-government relationships where “Canada controls the ‘rules of the game’” in government negotiations (Irlbacher-Fox, 2009, p. 61), perspectives such as Palmater’s point to the need to focus on changing the systems and processes in which First Nations people are engaged with governments.

Repeatedly, Indigenous leaders have acknowledged the government’s failure to address Indigenous people’s social justice concerns through government negotiations. In her discussion on what has led to the Canadian Human Rights Tribunal, where First Nations organizations took
the federal government to Supreme Court on account of their failure to implement proposed solutions to address First Nations child welfare inequities, Blackstock (2011) writes,

First Nations were confronted with a choice; continue to work with government and hope they redress the inequality voluntarily or consider legal options. After ten years of negotiations that failed to achieve results, it was apparent that voluntary strategies aimed at convincing Canada to provide equitable and culturally-based child welfare services to First Nations children were unlikely to succeed. An independent body would be needed to force the Canadian government into providing equitable funding for child welfare on reserves. After exploring all options, the decision was made [to] . . . file a historic complaint pursuant to the Canadian Human Rights Act . . . alleging that the Canadian government was racially discriminating against First Nations on reserves by providing a lesser level of child welfare funding and benefit. (p. 3)

This example illustrates the frequent ineffectiveness of government negotiation processes to address Indigenous social justice issues, and highlights the extreme measures First Nations people and organizations must undertake to be heard and listened to in the Canadian political sphere. In describing what is needed to push governments to address such issues, Blackstock (2011) argues, “there is nothing more threatening to federal politicians and policy makers than a group that operates in moral ways and has nothing to lose. When the ‘nothing to lose’ organization is willing to reach beyond politicians and bureaucrats to the caring public then a social movement begins to take root” (p. 5).

Some Indigenous activists assert the need for fierce resistance as this has brought about change in the past (Palmater, 2014), and Indigenous people’s efforts of activism have tended to only garner attention when “flash-point events, culminations, or times of crisis occur” (The
Kino-nda-niimi Collective, 2014, p. 21). Considering the often ‘dead end’ of government negotiations, Indigenous activists are sometimes left with no option but to resist inaction and pursue agendas of equity from outside the formal policymaking system.

**Indigenous Political Resistance**

Indigenous peoples’ active resistance to imposed government policies is not a new phenomenon. Throughout the past several decades, First Nations people have engaged in hundreds of collective action events to assert their rights on political issues (Wilkes, Corrigall-Brown, & Myers, 2010), including non-institutional tactics such as the road blockades and standoffs used in the Oka and Ipperwash crises of the 1990’s (Wilkes, 2006). In the current era, First Nations people’s voices are emerging in the political sphere in new ways. Increased public access to the Internet and the rise of social media has served to garner attention to Indigenous people speaking out on social justice issues. The emergence of the Idle No More movement, which seeks to bring public awareness to Indigenous social justice issues and oppose a government who is “counting on our apathy and our lack of understanding history” to advance their own agenda (Van Camp, 2014, p. 207), has “give[n] a population asleep at the wheel a chance to wake up and hear what native communities have been saying for hundreds of years: it’s time to withdraw our consent from the dead-end regime, and chart a new course” (Oja Jay, 2014, p. 112). Characterized by its strong presence in online social media (Sweetgrass, 2013) and the most “sustained, coordinated, national effort that we have seen in the last few decades,” (Palmater, 2014, p. 37), the Idle No More movement is illustrative of the new ways Indigenous activists are influencing public political perspectives.

Indigenous activists have not only played a role in influencing public perspectives on policy, they have also served to influence public policy decisions. One example is illustrated by
Indigenous people’s political resistance to the 1969 White Paper, which some Indigenous leaders argue was essentially a federal government assimilation plan designed to strip First Nations people of their rights (Palmater, 2014; Turner, 2014). The policy was “defeated by fierce native opposition” (Palmater, 2014, p. 37) and swift reactions on part of First Nations leaders (Turner, 2014). Indigenous political resistance has not only been reactive in response to current crises but also persistent and proactive in responding to longstanding issues, which is illustrated by the success of Indigenous women lobbyists in bringing about Bill C-31, an amendment to the Indian Act that allowed many First Nations women to regain their status\(^{12}\) (Harvard-Lavell & Lavell, 2006). These examples highlight Indigenous peoples’ effectiveness in achieving policy change throughout history.

More recently, Indigenous activist efforts have resulted in an emergence of government “recognition” of Aboriginal rights as well as attempts at “reconciliation” through state apologies and commissions of inquiry (Coulthard, 2014). A key initiative underscoring the trend towards recognition and apologies was the Royal Commission on Aboriginal Peoples (RCAP), which was established in 1996 with a “mandate to investigate the troubled relationship between Aboriginal peoples and the state” (Coulthard, 2014, p. 19). Following the RCAP Report (1996) – a $58-million, five-volume, four-thousand-page report with 440 recommendations informed by five years of research and public hearings – Canada saw a rise in state-led reconciliation initiatives (Coulthard, 2014), including the official statement of apology made by Prime Minister Stephen Harper in 2008 on behalf of the government of Canada, and the subsequent initiation of the Indian Residential Schools Truth and Reconciliation Commission (Dorrell, 2009; Truth and Reconciliation Commission of Canada, 2015). Participants in the RCAP Roundtable agreed that

\(^{12}\) Status refers to being registered with the federal government as a “status Indian” as per the Indian Act, which implies having access to certain benefits and privileges such as non-insured health benefits (Browne, McDonald, et al., 2009).
“the political will in support of Aboriginal health must originate in the prime minister’s office,”
and that without this federal leadership, “it is unfair to expect that the Aboriginal political
leadership will assume these responsibilities unsupported” (O'Neil, 1993b, p. 19). Although
RCAP resulted in the most comprehensive set of recommendations for Aboriginal policy to date
and a “point of entry” for a conversation on decolonizing Indigenous-government relationships,
this conversation has not yet occurred and the colonial relationship and injustices continue

The 2014 report on the situation of Indigenous peoples in Canada by the United Nations
Special Rapporteur on the rights of Indigenous peoples (Human Rights Council, 2014)
documented no change in human development indicator gaps between Indigenous and non-
Indigenous Canadians over the past ten years, which was supported by “striking” statistics. The
report noted that of the bottom 100 Canadian communities on the Community Wellbeing Index,
96 are First Nations and only one First Nation community ranked in the top 100. Indigenous
people overall lag far behind the general population at every level of education, and the housing
situation in First Nations communities has reached a crisis with endemic overcrowding and a
majority of water systems that pose a medium or high risk to their users (Human Rights Council,
2014). In January 2013, 113 of the 617 First Nations communities were on boil water advisories,
which was not much better than the 117 advisories reported six years earlier, 79% of which were
in effect for a year and 25% for over a year (Dupont, et al., 2014). Indigenous people represent
25% of the prison population despite representing only 4% of the Canadian population, and
Indigenous women are even more overrepresented at 33% of the total female inmate population
(Human Rights Council, 2014). Aboriginal children continue to be overrepresented in the child
welfare system, with apprehension rates eight times higher than non-Indigenous Canadians. The
number of First Nations children in child welfare care today is unsurpassed by any point in history, and with an estimated 27,000 First Nations children in care, First Nations children represent less than 5% of the child population yet comprise 30 to 40% of all children in care (Blackstock, 2011). The disproportionate number of murdered and missing Indigenous women and girls is indicative of the persistent violence towards Indigenous women in Canada, with over 660 documented cases and many more undocumented cases of missing or murdered women in the last 20 years (Human Rights Council, 2014).

Health inequities between Indigenous and non-Indigenous people have persisted, with Indigenous populations consistently fairing worse than non-Indigenous populations in life expectancy, infant mortality, suicides, injuries and communicable and chronic diseases such as diabetes (Human Rights Council, 2014). In some cases, health disparities between Indigenous and non-Indigenous people in Canada are increasing, which is seen in the rising incidence of HIV/AIDS among Indigenous people in BC (British Columbia & Provincial Health Officer, 2009a). Indigenous people are increasingly seen as a hard-to-reach population and have the most difficulty accessing health services, yet remain the greatest users of some health care services to the extent of being often labeled as “frequent flyers” in health care settings (Allan & Smylie, 2015; Browne, Smye, et al., 2011; McCall & Pauly, 2012). Indigenous people experience multiple barriers to accessing care due to racism and discriminatory practices, which results in an overreliance on emergency services for non-urgent issues that would be better addressed through primary care (Browne, Smye, et al., 2011). Additionally, multiple marginalizing social conditions such as poverty, violence, and urbanization intersect to create horizontal inequities among Indigenous people, including inequities between Indigenous women and men (Browne, Varcoe, & Fridkin, 2011; Dion Stout, 2005; Tait, 2013).
In the face of these growing health inequities, the Conservative federal government severely cut back on Aboriginal health spending. The 2012 Federal Budget included $165 million in funding cuts to Aboriginal Affairs and Northern Development Canada, and $200 million in annual cuts to Health Canada and the Public Health Agency of Canada, which contributed to the financial degradation and subsequent closure of several key Indigenous political and health organizations that were operating under federal funding, including the National Aboriginal Health Organization (NAHO), the Native Women’s Association of Canada (NWAC) and Pauktuutit Inuit Women of Canada (Gregory & Harrowing, 2012; National Collaborating Centre for Aboriginal Health, 2012). The funding cuts to these organizations occurred alongside the winding down of the Aboriginal Healing Foundation, another key federally funded Aboriginal health organization, which received no additional government funding after the government’s mandate to fund it expired in 2012 (Aboriginal Healing Foundation, 2014). Not only have these funding cuts impacted Aboriginal health programming (National Collaborating Centre for Aboriginal Health, 2012), the loss of these

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13 The National Aboriginal Health Organization is a non-for-profit organization established in 2000 to promote the health and well-being of all First Nations, Inuit and Métis people through collaborative research, Indigenous Traditional Knowledge, building capacity and community led initiatives. It was the only Aboriginal controlled organization in Canada dedicated to advance and promote the distinct needs of First Nations, Inuit and Métis populations through knowledge-based initiatives. NAHO published the Journal of Aboriginal Health; a national journal dedicated to fostering a community of people concerned with Aboriginal health research. NAHO closed its doors on June 29, 2012 due to the loss of federal funding, however its materials and resources will remain on their website until 2017 (National Aboriginal Health Organization, 2014).

14 The Native Women’s Association of Canada (NWAC) was established in 1974 with the purpose of representing and speaking on behalf of Aboriginal women in Canada at the national level. Its mandate is to achieve equity for all Aboriginal women in Canada. NWAC works to advance the well-being of Aboriginal women and girls and their families and communities through activism, policy analysis and policy advocacy (National Aboriginal Health Organization, 2014).

15 NWAC is still in operation albeit without government funding.

16 The Aboriginal Healing Foundation is an Aboriginal-managed, national not-for-profit private corporation established in 1998 with a federal grant of $350-million dollars as part of Gathering Strength – Canada’s Aboriginal Action Plan. The Foundation was given an eleven-year mandate to encourage and support, through research and funding contributions, community-based Aboriginal directed healing initiatives to address the legacy of abuse and inter-generational effects stemming from the Indian Residential School System. The Foundation received an additional grant for $125 million in 2007 under the Indian Residential School Settlement Agreement, which extended its lifespan to September 30, 2014 (Aboriginal Healing Foundation, 2014).
organizations impede advocacy efforts to influence public policy pertaining to Aboriginal health and may be indicative of dwindling Indigenous representation in the Canadian political sphere. The funding cuts to NWAC and to Pauktuuttit Inuit Women of Canada in particular are illustrative of how such government actions contribute to the further marginalization of Indigenous women, who often experience the greatest inequities and arguably have the greatest need for a political voice (Gregory & Harrowing, 2012), yet continue be underrepresented and excluded from meaningfully participating in policy (Dion Stout & Kipling, 1998; Green, 2007a).

The Conservative federal government not only presented challenges to Indigenous political involvement through the erosion of Aboriginal political organizations, it created challenges for Indigenous political leaders attempting to advocate for addressing Indigenous peoples’ health issues. The government’s refusal to adhere to the demands of Indigenous leaders created an environment where Indigenous leaders have sometimes resorted to extreme approaches in order to influence policy decisions. This is exemplified by Chief Theresa Spence’s six-week hunger strike in response to the refusal of the Prime Minister and Governor General to meet with her over the housing emergency in Attawapiskat First Nation (Barmak, 2013). The refusal to meet with Spence was accompanied mid-way by the government’s release of a financial audit report highlighting questionable spending of public funds by Attawapiskat leaders, which incited public ridicule of Indigenous leaders fostered by media attention (Oja Jay, 2014). Another example of the challenges faced by Indigenous leaders is illustrated by the resignation of Assembly of First Nations National Chief Shawn A-in-chut Atleo, which may have been a response to insurmountable Indigenous opposition to the Conservative government’s proposed policy on First Nations education (Mendelson, 2014). Not only do these examples illustrate the challenges Indigenous leaders have in pushing forward political agendas that do not
align with status quo government approaches, the criticism Spence and Atleo received respectively from First Nations community members in relation to their respective advocacy efforts (CBC News, 2011, 2014) point to the precarious political position of Indigenous leaders who advocate for Indigenous health and social justice issues in the political sphere.

The public criticism of Indigenous leaders advocating for social justice has harsh implications for Indigenous communities as it contributes to misconceptions about Indigenous peoples’ engagement with governments. The media’s representation of Indigenous leaders has contributed to public perceptions of Indigenous people littered with racist assumptions about Indigenous peoples’ demands for justice, which have occurred alongside a regime of austerity measures designed to “trim whatever is left in Aboriginal budgets that cannot be tied down” (Pasternak, 2014, pp. 44-33). The irony is that First Nations communities are impoverished by the extraction of resources from their own territories at the hand of the government’s quest for economic gain (Pasternak, 2014), as Oja Jay (2014) describes:

[Public] ridicule [of Indigenous people] rests on this foundational untruth: that it is hard-earned tax dollars of Canadians that pays for housing, schools, and health services in First Nations. The myth carries a host of racist assumptions on its back. It enables prominent voices [in the media] to liken protestors’ demands to “living in a dream palace” or “horse manure,” respectively. It’s true that Canada’s federal government controls large portions of the cash flow First Nations depend on. Much of the money used by First Nations to provide services does come from the federal budget. But the accuracy of the myth ends there. On the whole, the money that First Nations receive is a small fraction of the value of the resources, and the government revenue, that comes out of their territories. (p. 109)
In addition to creating and maintaining Indigenous peoples’ poverty, Gabriel (2014) argues that the “economic terrorism” against First Nations people has enabled governments to “bully” First Nations leaders into imposed engagements and detract their attention from the needs of their communities (p. 159). Public opinions on Indigenous peoples’ access to resources are compounded by the perception that Indigenous people are involved in policy decisions through consultations and negotiations. Although the theft of Indigenous peoples’ labour and land has shaped Canada’s political economy since its inception (Pasternak, 2014), “the extraction of Indigenous resources goes unfettered under the guise of ‘consultation and consent’” (McAdam, 2014, p. 66).

The current political climate holds significant barriers for First Nations political leaders and organizations attempting to influence government policy agendas in the name of equity and social justice. At the same time, the end of the Conservative government’s 10-year reign at the federal level and the beginning of the Liberal Trudeau government may hold opportunities for addressing inequities and increasing First Nations peoples’ involvement in policy. The record numbers of Indigenous voters and Indigenous Members of Parliament arising from the recent federal election (Foxcroft & Watts, 2015; Talaga, 2015) could possibly indicate the frontier of an era of change in terms of Indigenous participation in policy and political processes.

Still, the sociopolitical factors shaping First Nations involvement in policy have persisted over time and across various government regimes. First Nations health policy is inextricably bound to the forces of colonialism and neocolonialism,¹⁷ which means fostering First Nations involvement will require reckoning with colonial and neocolonial dynamics, regardless of which government is in power. Understanding how to foster meaningful involvement in the current

¹⁷ Neocolonialism refers to forms of control of peoples, such as Indigenous peoples, who continue to live under conditions of colonialism, resulting in a form of colonialism often more difficult to detect and resist than overt colonialism (Browne, et al., 2005).
Canadian policy landscape thus requires a critical examination of the underlying forces shaping this particular policy context, including social and political forces that transcend geopolitical and national boundaries.

**Paradoxical Policies: The Impact of Neoliberalism**

A key driving force underlying the current political climate in Canada, and thus a key factor shaping Indigenous people’s involvement in policy, is the wide-spread influence of neoliberalism; an ideology based on the belief that the marketplace should be the arbiter of the creation and distribution of resources (Bryant, 2009). With its emphasis on efficiency, lean government staffing, cutbacks to social program spending, privatization and a focus on economic growth, neoliberalism is a dominant political ideology driving the global economy and subsequently driving the development of health policy in Canada, including First Nations health policy (Bryant, 2009; Collins & Hayes, 2007). Giroux and Giroux (2008) describe the powerful influence neoliberalism has on the global political sphere:

> Neoliberalism has become one of the most pervasive and dangerous ideologies of the 21st century. Its pervasiveness is evident not only by its unparalleled influence on the global economy but also its power to redefine the very nature of politics and sociality. Free market fundamentalism rather than democratic idealism is now the driving force of economics and politics in most of the world. Its logic, moreover, has insinuated itself into every social relationship, such that the specificity of relations between parents and children, doctors and patients, teachers and students has been reduced to that of supplier and customer. It is a market ideology driven not just by profits but also by an ability to reproduce itself with such success that . . . it is easier to imagine the end of the world than the end of neoliberal capitalism (p. 182).
Neoliberalism has permeated relationships between First Nations people and governments, “from the time of the fur trade to bankrolling industrialization with [Indigenous] lands and resources” (Pasternak, 2014, p. 42). First Nations people have been “on the geographic frontier of capital accumulation for over 500 years,” which has intensified over time with the Canadian government’s increasing compulsion for resources and capital (Pasternak, 2014, p. 42). With economic objectives at the forefront of the colonial project, colonialism has ridden on the coat tails of neoliberalism.

Neoliberalism has become a dominant ideology within policy discourse and a prominent force shaping contemporary public policy. Characterized by economic efficiency and privatization rather than improvements in health and social wellbeing (Baum, et al., 2009; Collins & Hayes, 2007; Rice, 2011), neoliberal policy emphasizes the notion of individualism and individual responsibility. Following suit, neoliberal health policy implicitly conceptualizes health as a problem of individuals abstracted from their socio-historical-political context, resulting in what Orsini (2007) refers to as “the politics of blame” or the “responsibilization paradigm” (p. 354). Neoliberal health policy emphasizes individual responsibility for health, in that policies aimed at health improvement tend to focus on health behaviour change rather than transformative social or structural change. Neoliberal health policies implicitly construct health issues as problems of individuals or communities instead of problems of social, political and economic environments. The policies and practices of neoliberalism act as a powerful barrier to addressing health inequities, which requires predominant attention to social, political and economic determinants of health (Baum, et al., 2009; Collins & Hayes, 2007). The implementation of neoliberal policy pushes public heath issues of inequity out of the public
sector and into the private sphere, where they become privatized and “owned” by the individuals or communities in which they are situated (MacDonald, 2011).

Due to such inherent individualism, neoliberal health policies have the subsequent effect of burdening individuals or communities with the responsibility for addressing their own health issues, while simultaneously deterring from government responsibility. Ironically, such policies are often touted under the guise of empowerment, in that they implore and ostensibly empower individuals or communities to exert their own agency and take control over their own health through making their own decisions. The end result typically includes neither empowerment nor better health outcomes, and individuals or communities are often blamed by society at large for their own failure to address health issues and thus become seen as the authors of their own demise (Anderson, 1996; Murray, 2004; Salmon, 2007). In this sense, neoliberal policies are paradoxical policies.

The paradoxical effect of neoliberal policies has implications in relation to meaningful involvement of First Nations people in policy. On one hand, the notion of meaningful involvement may be touted as an approach to foster First Nations control over policy decisions that impact First Nations health. On the other hand, meaningful involvement may serve the neoliberal aim of First Nations individuals and communities being ultimately held responsible for addressing their own health and social issues. This is not to say that First Nations do not or should not play an integral role in addressing the health and social issues affecting First Nations communities. Rather, the implications of the broader neoliberal climate must be taken into account in an investigation on what constitutes meaningful involvement.
Neoliberal Underpinnings of First Nations Health Policy: The Case of Health Transfer

The 1979 Indian Health Policy and subsequent 1989 Health Transfer Policy (Lavoie, 2011), is one example of neoliberal policy. With the objective of transferring federal funds to First Nations communities, who would respectively assume responsibility for administering and delivering their own health services on reserves, the Health Transfer Policy was a response to the recognition that Indigenous people must have more control over their own health services (Jacklin & Warry, 2004; Lavoie, et al., 2010). O’Neil (1993a) further argues that the publication of the Health Transfer Policy arose from First Nations peoples’ resistance to the current health care system and “dissatisfaction that had been building across the country for nearly a decade before the [Royal Commission on Aboriginal Peoples] was formed” (p. 39). In providing communities with the opportunities to have increased local responsibility in planning and delivering community-based health services, the Health Transfer Policy is still seen as having the most tangible outcome of First Nations health policy at the federal level (National Collaborating Centre for Aboriginal Health, 2011).

Since its establishment, the Health Transfer Policy “has been the subject of a good deal of controversy” for being seen as primarily serving a hidden government agenda to reduce federal spending and abdicate legal and fiduciary responsibility for health service delivery to First Nations (Culhane Speck, 1989). Through transferring funds from the federal government to First Nations, the weight of responsibility for providing health services was transferred from the shoulders of the federal government to the shoulders of First Nations communities, thereby constructing First Nations health as a “First Nations problem” instead of a public problem requiring state intervention. In light of jurisdictional battles between federal and provincial governments over assuming responsibility for First Nations health, pushing the responsibility for
First Nations health onto First Nations communities can be seen as an abdication of both provincial and federal responsibility.

Furthermore, while the Health Transfer Policy was touted as promoting Indigenous self-determination in that First Nations would have increased control over health services, there were many aspects of the transfer arrangements that laid outside First Nations control. For one, the amount of funding was pre-determined and it was often not enough to provide the services necessary to address communities’ health needs. Secondly, there were many restrictions on how health services could be provided and which health services could be purchased. Thirdly, First Nations had no input into the development of the policy, which included a stipulation that the policy could not be changed (Jacklin & Warry, 2004). Although small improvements in First Nations health programs may have resulted from the Health Transfer Policy (Warry, 2007) and First Nations’ control over health services due to transfer has been shown to result in some improvements to health and health service usage (Lavoie, et al., 2010), it has also been argued that the Health Transfer Policy has not significantly reduced health disparities (Jacklin & Warry, 2004).

This example illustrates how on one hand, the Health Transfer Policy granted First Nations control over health decision-making, yet on other hand it excludes First Nations people from participating in the development of the Policy, which is a key policy affecting First Nations health. The Health Transfer Policy exemplifies MacDonald’s (2011) assertion that state-crafted policies promoting Indigenous peoples’ autonomy often “hand off large areas of responsibility to Indigenous peoples without passing on the actual decision-making power necessary to truly transform these policy areas” (p. 257). This illustrates how First Nations health policies such as the Health Transfer Policy are paradoxical policies; although they may be touted as promoting
community empowerment and self-determination, communities ultimately lack control over public policy decisions that largely determine health and health inequities.

Despite the rhetoric of self-determination that often accompanies neoliberal health policies, the Health Transfer Policy arguably made strides towards advancing First Nations self-government. Following the transfer arrangements, some First Nations communities established administrative processes and expanded existing governance structures to deliver health services to their communities (Jacklin & Warry, 2004). In this way, the Health Transfer Policy may have contributed to some First Nations’ increased capacity for health governance. Furthermore, some First Nations community members reported feeling happy that community leaders were making health service decisions and satisfied with the quality of service (Warry, 2007), thus demonstrating that the policy was received positively at least to some extent. These seemingly oppositional critiques and praises depict the conflicts and contradictions of neoliberal and paradoxical policies such as Health Transfer.

These conflicts and contradictions within the Health Transfer Policy suggest neoliberal health policies may be read in two ways; in one way such policies increase First Nations’ accountability for resolving their own health issues, which are ironically shaped by a history of colonial policies created and implemented by governments, yet from another angle such policies may reveal opportunities from which First Nations people may benefit, including opportunities for moving towards self-determination. Given the pervasiveness of neoliberalism in the contemporary political climate (Giroux & Giroux, 2008), exploring opportunities for advancing First Nations’ health agendas within the current neoliberal policy landscape may be worthwhile. In addition to drawing attention to the ways neoliberalism shapes health policy decision-making,
attention must also be paid to the opportunities neoliberalism presents for involving First Nations people in more meaningful ways.

**The Influence of Neoliberalism on First Nations Policy Initiatives**

An arguable opportunity presented by the neoliberal push towards privatization is increased First Nations ownership over policy decisions affecting First Nations people’s health. In some cases, scholars have argued that the neoliberal political context has created opportunities for First Nations to develop business enterprises and partnerships, which Slowey (as cited in MacDonald, 2011) argues can be a strategic effort towards First Nations’ more “meaningful and equitable participation in the marketplace” (p. 260). This suggests that in some ways the neoliberal nature of the current political climate has created new points of entry for First Nations peoples’ participation in policy. With its focus on privatization and increased First Nations ownership over First Nations health issues, neoliberalism has created a fertile environment for the emergence of self-government initiatives (MacDonald, 2011), such as First Nations-led policy organizations and initiatives.

While the emergence of First Nations-led policy initiatives may be illustrative of the opportunities neoliberalism creates for advancing Indigenous self-determination, which is an important element towards improving Indigenous peoples’ health and addressing health and social inequities (Alfred, 2005; Hunter, 1997; Matthews, et al., 2008; Reading & Nowgesic, 2002), such initiatives may be seen as inherently problematic in that they inadvertently perpetuate neoliberal ideologies, which ultimately further inequity and undermine the type of self-determination and social change that many Indigenous social movements strive to achieve. While Indigenous social movements strive to challenge the political status quo that perpetuates Indigenous peoples’ marginalization and dependence on the state, neoliberal government
agendas reproduce policy environments that create and sustain Indigenous peoples’ marginalization and state dependence, thereby inherently opposing decolonizing agendas seeking to transform policy decision-making environments (Ellis, 2005; MacDonald, 2011).

MacDonald (2011) explains how the emergence of self-government initiatives is indicative of a trend towards *neoliberal Aboriginal governance*, which involves the establishment of “specific state-crafted responses to Indigenous demands that are a part of a broader governmental strategy of neoliberalism” (p. 257). While the emergence of Aboriginal-led policy initiatives may be in part about meeting Indigenous peoples’ demands for self-determination, they may also serve to perpetuate the broader governmental shift towards privatization and abdication of government responsibility for Indigenous peoples’ health. In other words, while Aboriginal initiatives may hold opportunities for advancing Indigenous peoples’ involvement in health policy decision-making, they may also hold economic benefits for governments. Since governments have much to gain from neoliberal approaches to policy, emerging Aboriginal-led policy initiatives that are aligned with the broader neoliberal context must be regarded with a critical eye (MacDonald, 2011).

Aboriginal political organizations such as the Native Women’s Association of Canada (NWAC) and the Assembly of First Nations (AFN) are prime examples of Aboriginal-led policy organizations that are subjected to the critiques of neoliberal Aboriginal governance. Although NWAC and the AFN have undoubtedly played a predominant role in increasing Indigenous peoples’ participation in the Canadian political sphere, they have also been critiqued in the literature as having done little to advance Indigenous self-determination or improve Indigenous peoples’ health, while inadvertently promoting neoliberal government agendas (Monture-Angus, 1999; Nepinak & Gazan, 2014). Although Aboriginal health organizations are often critiqued by
community members on account of their failure to address Aboriginal health issues, such critiques often represent critiques of the neoliberal political environment in which Aboriginal organizations are constructed (MacDonald, 2011). This is illustrative of how neoliberalism pushes the blame of failing to address Aboriginal health and health equity issues away from governments and onto Aboriginal organizations.

The neoliberal political context of policymaking thus has inherent implications for First Nations peoples’ involvement in health policy decision-making. First Nations involvement is essential for health policies to make a difference in addressing First Nations peoples’ health (Alfred, 2005; Hunter, 1997; Matthews, et al., 2008; Reading & Nowgesic, 2002), yet the neoliberal ideologies implicit within the policymaking system contribute to decision-making processes that inherently reproduce inequitable policy outcomes. The inescapable pervasiveness of neoliberalism thus begs the question, must First Nations-led policy initiatives align with neoliberal government agendas in order to participate in policy decision-making within the wider policy arena?

To this end, several important questions are raised in relation to First Nations peoples’ involvement in health policy. How can First Nations-led policy initiatives address health inequities when the underlying neoliberal ideologies driving the policymaking system inevitably perpetuate health inequities? What will be the chances of success in advocating for health policy decisions that do not fit within the neoliberal climate? Are First Nations-led health policy initiatives inherently doomed to fail? How can First Nations people be involved in health policy decision-making in ways that work within the neoliberal policy environment and yet challenge it at the same time? New ways of understanding First Nations involvement in the current neoliberal political climate are needed. Given the emergence of new First Nations-led health policy
initiatives in BC, the BC First Nations health policy context provides an interesting site for exploring these questions.

**New Approaches to Indigenous Involvement: First Nations Health Policy in BC**

While the Canadian Aboriginal health policy system has evolved over the past forty years to become a patchwork of diverse policy arrangements with significant ambiguity and legislation subject to interpretation (Lavoie, et al., 2010; National Collaborating Centre for Aboriginal Health, 2011), the past decade marks a dramatic shift in First Nations health policy in BC. Following Ontario, which was the first province to develop a provincial Aboriginal Healing and Wellness Strategy (Ontario Ministry of Community and Social Services, 2012) known as the most comprehensive Aboriginal health policy in Canada, British Columbia took an historic turn in its approach to First Nations health policy. This turn was marked by the establishment of the 2005 Transformative Change Accord and subsequent Tripartite First Nations Health Plan, which outlined a shared commitment between the federal\(^\text{18}\) and provincial governments and BC First Nations to close the gap in health and social disparities between First Nations and other British Columbians (National Collaborating Centre for Aboriginal Health, 2011).

This policy evolution in BC has led to the creation of a new First Nations health governance structure unprecedented in Canadian history. Whereas policies governing health services and programs for First Nations reserve communities have historically fallen under federal jurisdiction, in October 2013 Health Canada transferred funding and decision-making responsibility for First Nations health programs and services, including the Non-Insured Health Benefits program (now First Nation Health Benefits), to a newly established First Nations Health

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\(^{18}\) It should be noted that leaders in the Conservative federal government signed the Tripartite Agreement, and that the subsequent creation of the First Nations health governance structure emerged under the auspices of the Conservative federal government.
Authority (FNHA). Guided by 7 directives\(^{19}\) that articulate its commitment to being community-driven and increasing First Nations decision-making and control, the FNHA aims to plan, fund, manage and deliver health services to BC First Nations with the funding received from Health Canada (First Nations Health Authority, 2014a).

Although the creation of the FNHA marks a new era in First Nations health in BC, its creation stems from a history of relationship building between First Nations and governments. For example, the policy processes and agreements surrounding the Kelowna Accord\(^{20}\) were highly influential in creating the foundation for the current state of First Nations health policy in BC. Although the commitments reached through the Kelowna Accord process were ultimately not funded by the Conservative federal government that was elected into power a few days following the Kelowna Accord agreements, which were signed by the previous Liberal federal government, the provincial and territorial Ministers, and five Aboriginal political organizations (Patterson, 2006; Webster, 2006), the relationships formed during the process and the resulting 10-year Blueprint for Aboriginal Health (First Ministers and Leaders of National Aboriginal Organizations, 2005) contributed to the subsequent relationships and health plans that have

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\(^{19}\) The 7 Directives guiding the FNHA are: 1) Community-driven, nation-based; 2) Increase First Nations decision-making and control; 3) Improve services; 4) Foster meaningful collaboration and partnership; 5) Develop human and economic capacity; 6) Be without prejudice to First Nations interests; and 7) Function at a high operational standard (First Nations Health Council, 2011).

\(^{20}\) The Kelowna Accord is the conclusion of a highly publicized and unprecedented national process of Aboriginal policy negotiations carried out between 2004 and 2005 under the direct authority of then Prime Minister Paul Martin. This 18-month process began with the Canada-Aboriginal Peoples Roundtable in Ottawa on April 19, 2004 and ended with the Kelowna Accord, which refers to the agreements reached at the First Ministers’ Meeting in Kelowna on November 24 and 25, 2005. The series of consultations leading up to the Kelowna accord – open to approximately 1,000 selected representatives from Aboriginal organizations and provincial, territorial and federal governments – resulted in the Blueprint on Aboriginal Health, a 10-year plan to close the inequity gap between Aboriginal and non-Aboriginal people in Canada. In November 2005 the federal government pledged $5.085 billion over five years to raise the standard of living of Aboriginal peoples up to that of other Canadians by 2016. The promised $5.1 billion immediately circulated in the headlines, however, later in the same month the 38\(^{th}\) Parliament was dissolved and before the monies to implement the Kelowna Accord had been approved (Patterson, 2006), the incoming Conservative government refused to agree to the agreements reached in the Kelowna Accord and would not approve the $5.1 billion that had been promised by the previous government. This effectively “cancelled” the 10-year plan for improving Aboriginal peoples’ health and closing the equity gap (Webster, 2006).
shaped the current First Nations health policy context in BC (First Nations Health Authority, 2014b).

Building on this history, the federal government, provincial government and BC First Nations leaders signed a tripartite agreement outlining the parties’ commitment to addressing First Nations health in BC (First Nations Leadership Council, Government of Canada, & Government of British Columbia, 2007). The signing of this agreement led to the subsequent signing of the Transformative Change Accord, a legal agreement that articulates a shared accountability between the federal government, provincial government and BC First Nations\(^{21}\) to improve First Nations health and well-being and close the health equity gap between First Nations and other British Columbians (First Nations Leadership Health Council, Government of Canada, & Province of British Columbia, 2006). Since the signing of the Transformative Change Accord in 2005, the FNHA has continued to build on this history of partnership-making and reciprocal accountability, illustrated by the emergence of new partnership agreements between the FNHA and the five regional health authorities, as well as between the FNHA, the First Nations Health Council (FNHC), and the First Nations Health Directors Association (FNHDA), which together comprise the BC First Nations Health Governance structure. This emergent health governance structure aims to work with its partners, including governments and BC First Nations, in achieving health system transformation (First Nations Health Authority, 2014b).

What arguably makes this new governance structure a unique and unprecedented approach to First Nations health policy is the comprehensive and wide-reaching involvement of stakeholders. For the first time in history, the response to addressing First Nations health issues aims to include the whole of government partners, the whole of the health system, the whole of

\(^{21}\) BC First Nations refers to the 201 First Nations communities in BC (First Nations Health Council, 2014). Each of these communities have their own band and reserve.
First Nations leadership, and the whole of First Nations communities. In this sense, it is a “whole-some” approach. This unique take on First Nations health governance provokes many questions related to First Nations involvement in health policy. What does First Nations involvement in policy look like in this new governance structure? How does it differ from past approaches? Are First Nations people involved in health policy in more meaningful and influential ways? And if so, what are the contributing factors shaping this involvement? What challenges and opportunities for meaningfully involving First Nations people have become apparent in this new approach to governance? What lessons can be gleaned from the way First Nations involvement is emerging that might inform thinking on how to foster meaningful involvement? This research explores these questions in more depth with a view to understanding how more meaningful and influential involvement of First Nations people might be fostered in BC and elsewhere in Canada.

**Urban Indigenous Involvement in Policy**

To further unpack the issues surrounding meaningful involvement in health policy in BC and beyond, this research positions the involvement of First Nations people away from home as an entry point to understanding the complexity of First Nations involvement. Narrowing the point of inquiry to focus on First Nations involvement in the urban context may provide a window into exploring the more subtle nuances of meaningful involvement and thus deepen an understanding of how First Nations people are, and could be, involved in health policy decision-making. Paying attention to the issues surrounding urban First Nations people’s involvement may inform thinking on how to foster the inclusion of First Nations groups who are typically underrepresented in policy and who experience multiple intersecting social and political inequities.
The intersections of colonialism and urbanization create a unique set of health and social issues affecting First Nations people living away from home. Much like First Nations people living in their home communities, those who live off-reserve in urban areas often experience considerable health and social inequities including barriers to accessing culturally safe health services, which are compounded by urbanization and the impact of living outside one’s home community (Browne, McDonald, et al., 2009; Hanselmann, 2001). Although there is a substantial amount of mobility between their home communities and urban settings, First Nations people living off-reserve tend to experience difficulties in maintaining connections with families as well as accessing social supports in communities, including health and social services and programs only available to those living on-reserve (Browne, McDonald, et al., 2009). Despite often having the greatest health needs in comparison to the wider urban population, First Nations people living in urban areas tend to have the least access to health services (Browne, McDonald, et al., 2009), live in poorer social conditions, and often experience greater economic deprivation (Cardinal, 2005; Environics Institute, 2010), homelessness, substance use, gang membership, violence and incarceration compared to the rest of the urban population (Clatworthy & Peters, 2011).

While these multiple intersecting social conditions are key determinants of health for many First Nations people living away from home, not all First Nations people who live in urban areas experience the same level of marginalization. Considering the diversity of the urban First Nations population, analyzing urban First Nations health issues with a sole focus on marginalization may falsely construct the urban First Nations population as a homogenous entity and detract needed attention away from addressing the roots of these health determinants (Peters,
2011a). Addressing health and social issues affecting First Nations people living away from home requires taking the diversity of the urban First Nations population into account.

To effectively address health and social inequities in a way that considers the particularities of urban contexts, First Nations people living away from home need to be involved in policy decisions. Yet, most urban First Nations people do not have political representation and remain predominately invisible in the political sphere (Abele, et al., 2011; Peters, 2011a). Considering that demographic trends indicate the urban Indigenous population is rapidly growing, with approximately 60% of First Nations adults in Canada living in urban centres and away from their home communities22 (Browne, McDonald, et al., 2009; Clatworthy & Peters, 2011; Environics Institute, 2010; First Nations Information Governance Centre, 2008/10; Peters, 2011a) and 62% of First Nations people living off-reserve in BC (Statistics Canada, 2010), the overall lack of urban Aboriginal representation in policy means the majority of First Nations people tend to be excluded from key policy decisions affecting First Nations people’s health. Without attention to the inclusion of urban community members, the policy decisions may be neither relevant nor beneficial to the majority of First Nations people. Meaningfully including urban First Nations people in health policy is important for mitigating this inequity.

Understanding how to meaningfully involve urban First Nations people in health policy decision-making requires examining the key factors shaping urban First Nations peoples’ involvement. The evolution of First Nations health policy in Canada has been a major factor in shaping the political position of urban First Nations people. The federal government has historically been responsible for the funding and delivery of health services to registered First

22 Although available data indicate that the urban Indigenous population in Canada is increasing, it should be noted that these statistics depend on the definition of “urban”, and changing census definitions make it difficult to make exact comparisons between urban Indigenous populations (Peters, 2011a).
Nations people living on-reserve, whereas health services for non-registered and/or First Nations people living off-reserve has fallen under provincial and territorial jurisdiction along with the responsibility for the rest of the non-First Nations population. Due to the lack of clarity on which government has jurisdiction over health services for First Nations people living off-reserve in urban areas, both federal and provincial governments have tended to avoid responsibility (Browne, McDonald, et al., 2009; Peters, 2011a). Combined with the increasing trends towards urbanization, the historical jurisdictional battle and ambivalence over who has responsibility for the health First Nations people off-reserve has led to a diminishing federal responsibility for First Nations health overall and a policy gap in addressing urban First Nations health issues.

The jurisdictional maze of urban First Nations health policy and the relative lack of political visibility has contributed to the complexity of issues surrounding urban First Nations involvement in policy (Abele, et al., 2011). With no one taking full responsibility for urban First Nations health, mechanisms for including urban First Nations people in health policy decision-making remain relatively absent. The impact of regionalization in most Canadian provinces, including BC, has added another layer of complexity, as these regional organizations tend to serve the majority of First Nations people accessing services off reserve, yet First Nations people are not typically included in regional mechanisms for citizen engagement (Lavoie, Browne, Varcoe, Wong, & Fridkin, 2015). Despite the need for urban First Nations people’s involvement in policy, considering no single government is responsible for addressing health issues specifically for First Nations people living off-reserve in urban areas, the question of where and how to include First Nations people away from home remains.

In the absence of mechanisms for including urban Aboriginal communities in policy, Aboriginal organizations have tended to serve as a political voice for First Nations people away
from home (Lavoie, et al., 2015) and have been key influencers in municipal urban Aboriginal policy (Abele, et al., 2011). Governments have also shown to play an important role in urban Aboriginal policy development given their relative extensive reach and access to financial resources (Abele & Graham, 2011). Collaboration across multiple stakeholders is an important condition for the development of good urban Aboriginal policy, yet some collaborations experience challenges working across communities, organizations and governments (Walker, et al., 2011). Urban Indigenous governance is an area wrought with political tensions in multiple directions, including tensions between First Nations governments and urban Indigenous communities asserting their own rights to self-determination. While urban Indigenous self-organizing has been shown to facilitate cohesion among urban community members and with partners, the lack of a defined system of governance over urban Aboriginal policy creates barriers to cohesion (Hanselmann, 2001). These issues pose significant challenges to urban First Nations people’s involvement, as they raise the questions of what constitutes urban Aboriginal communities, who speaks for First Nations people away from home, and on what issues? Considering a key factor in successful development of urban Aboriginal policy is maintaining a balance between representation from community leadership and key political organizations (Abele, et al., 2011), meaningfully involving urban First Nations people in policy requires attention to these dynamics.

Investigating what meaningful involvement might look like in the context of this complex jurisdictional landscape surrounding urban First Nations health policy may expose political intricacies related to involvement and point to issues that could be addressed to foster more meaningful involvement. Canada provides a solid context for exploring these issues considering the emergence of the federal Urban Aboriginal Strategy (see Abele & Graham, 2011) and the
numerous well-developed working relationships between urban Aboriginal organizations and governments, growing presence of well-educated Indigenous professionals working in cities, and increasing recognition by municipal governments to engage First Nations residents and communities (Abele & Graham, 2011). The BC context in particular is an especially interesting site for inquiry, as the emergence of the First Nations health governance structure may provide new entry points for First Nations people away from home to participate in health policy decision-making. In addition, the development of the BC Off-Reserve Aboriginal Action Plan\(^{23}\) (Ministry of Aboriginal Relations and Reconciliation, 2013) and the recent inclusion of data for urban First Nations people in Aboriginal health outcomes reporting in BC (Ministry of Aboriginal Relations and Reconciliation, 2012) may be indicative of a growing interest and commitment to addressing urban Indigenous policy issues at a provincial level. These opportunities may suggest the timing is right for pushing thinking on how to foster meaningful involvement of First Nations people living away from home in BC and elsewhere in Canada.

**The Need for a Critical Framework for Meaningful Involvement**

The literature offers several insights into approaches to involvement that may inform thinking on how First Nations people can be meaningfully involved in health policy decision-making. There is a surge of literature on public participation in policy that focuses on how deliberative process can be improved to foster participation of various groups of people (Abelson, et al., 2003; Aronson, 1993; Bryant, 2002; Cowan, 2003; Mitton, Smith, Peacock, Evoy, & Abelson, 2009; Torjman, 2007), which points to the wide-spread recognition that engaging publics in policy decision-making leads to better policy decisions. The importance of community control over and participation in health decision-making as an essential element for

\(^{23}\) The BC Off-Reserve Aboriginal Action Plan is led by the Ministry of Aboriginal Relations and Reconciliation in partnership with a team of organizations including the BC Association of Friendship Centres (Ministry of Aboriginal Relations and Reconciliation, 2013).
improving health and addressing inequities had been well documented (Bowen, 2008; Frankish, et al., 2002; Maxwell, Rosell, & Forest, 2003; Rifkin, 2003; World Health Organization, 1986, 2008), and the past several decades have seen an emergence of health literature on community and/or citizen engagement (Frankish, et al., 2002).

A range of frameworks and models have been developed to support meaningful involvement of community members in various health policy and research contexts, such as Arnstein’s (1969) Ladder of Citizen Participation, and the Self-Assessment Checklist for the Meaningful Involvement of People living with HIV/AIDS (Global Network of People Living with HIV/AIDS & Asia Pacific Network of People Living with HIV/AIDS, 2008). Although these frameworks may be helpful in some policy areas, like much of the citizen engagement literature they were developed without an Indigenous policy context in mind, and may be less relevant or less likely to address the complexity of issues that arise when First Nations people participate in policy decision-making (see Cheema, 2007).

As the literature shows, First Nations people’s involvement in policy often occurs through processes that further perpetuate First Nations peoples’ marginalization. Community consultations are a common form of inclusion, which tend to paradoxically construct First Nations people as empowered citizens engaged with governments while simultaneously undermining their power to make decisions (Fiske & Browne, 2006, 2008). Government-initiated engagement processes often have harmful effects on First Nations people, including essentialization (McConaghy, 2000) and misrepresentation (Smye & Browne, 2002), misappropriation of Indigenous knowledges (Rains, Archibald, & Deyhle, 2000), and political manipulation of Indigenous peoples’ input (LaRocque, 2001). Even when First Nations people are engaged with governments with the explicit aim of self-determination, such as self-
government negotiations, the end result is often another iteration of colonialism and forced
government dependence (Irlbacher-Fox, 2009). These examples point to the need to explore the
issues surrounding how First Nations people are involved in health policy with a view to
understanding how to foster safer or less harmful, and more meaningful processes of
involvement that enable the advancement of Indigenous peoples’ agendas.

For meaningful involvement frameworks to be relevant for addressing these issues, the
broader historical, social and political contexts surrounding First Nations policy must be taken
into account. Frameworks for meaningful involvement of First Nations people may be more
relevant for addressing inequities if they are rooted in critical perspectives, which are useful in
exposing underlying power relations within policy and orienting policy development to address
issues of inequity affecting Indigenous people (Fiske & Browne, 2008; Giroux & Giroux, 2008;
Smye & Browne, 2002). Given the ways colonialism/neocolonialism, sexism, racism and
neoliberalism intersect to shape the context surrounding Aboriginal health policy (Bourassa, et
al., 2004; Kenny, 2004; Young, 1984), approaches to meaningful involvement relevant to First
Nations people must also consider multiple intersecting social forces and relationships. For
example, Cheema’s (2007) study on the meaningful participation of Aboriginal people in health
planning draws attention to the importance of accountability relationships and reconciliation
between First Nations people and governments. Studies that attune to underlying power
dynamics, such as Cheema’s (2007), may inform thinking on what constitutes meaningful
involvement within the broader contexts surrounding First Nations health policy. Yet, such
studies tend to provide broad-based recommendations or theoretical considerations rather than
proposing specific frameworks or practical tools for fostering meaningful involvement in applied
settings (see Fridkin, 2012b; Lavoie, et al., 2012).
The literature contains a few examples of models or frameworks for meaningfully involving Indigenous people in environmental policy decision-making areas, such as natural resource management (Marsden, 2005) and environmental assessment (Centre for Indigenous Environmental Resources, 2009). These frameworks are useful in informing thinking on how conceptualizations of meaningful involvement can be translated into policy practice. Considering these frameworks in relation to the First Nations health policy context may also point to common principles for meaningful involvement that can be applied to a variety of Indigenous policy contexts. One common principle may be the inclusion of Indigenous knowledge24 (Centre for Indigenous Environmental Resources, 2009), which is noted as an important element for understanding the interrelated social, political and ecological complexities shaping environmental policy (Arquette, et al., 2002). Indigenous knowledges may also be helpful for addressing the complexity of issues surrounding First Nations health policy problems, and thus may be important to include in a framework for meaningful involvement of First Nations people in health policy.

While the frameworks for meaningfully involving Indigenous people in environmental policy decision-making may inform further thought on what meaningful involvement might look like in the context of First Nations health policy, a framework that considers the particular political landscape of First Nations health policy would be most relevant for health policy development. Through a critical analysis of participants’ perspectives and experiences of First Nations involvement in health policy, the findings of this research inform the development of a

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24 Turner (2006) argues that phrases related to Indigenous knowledge, including “traditional knowledge” or “Indigenous ways of knowing” have become commonplace in mainstream and Indigenous contexts, and that we need to be clear about what we mean by these terms, particularly in relation to “the legal and political discourses of the dominant culture” (p. 98). Here, I loosely use the term Indigenous knowledge to refer to Indigenous peoples’ “distinct ways of knowing the world” (Turner, 2006, p. 98), and in Chapter Three I provide a more nuanced definition in relation to contemporary Eurocentric systems as well as the research methodology.
critical framework for meaningfully involving First Nations people in the specific context of First Nations health policy, and thus contribute to filling this gap in the literature.

**Summary**

Although Indigenous people have had a long history of involvement in the Canadian political sphere, First Nations people continue to be excluded from health policy decision-making in the face of persistent and increasing health and social inequities. The neoliberal neocolonial political climate has shaped First Nations people’s involvement in policy, which means that meaningfully involving First Nations people in health policy requires taking this context into account. Considering the pervasiveness of neoliberalism in First Nations health policy, which serves to detract from government responsibility and place the onus on First Nations communities to address the complex issues affecting their communities, further insight is needed on how to meaningfully include First Nations people within the contemporary neoliberal and neocolonial policy context. The existent literature contains a gap on what constitutes meaningful involvement and a lack of frameworks for meaningfully involving First Nations people in ways that consider the social and political factors shaping First Nations people’s involvement. With a particular focus on the BC context and the involvement of First Nations people away from home, exploring the issues surrounding meaningful involvement may deepen an understanding of what constitutes meaningful involvement and inform thinking on how to foster meaningful involvement within the BC context and beyond.
CHAPTER THREE: THEORETICAL FRAMEWORK

Introduction

The purpose of this chapter is to articulate the theoretical framework shaping the research and the implications in relation to the research questions. This chapter begins with a discussion on the significance of theory in research, followed by an articulation of the underlying assumptions shaping the researcher’s perspective, which includes a reflection on the researcher’s social and political positioning as a non-Indigenous researcher engaged in Indigenous health research. Subsequent sections outline the key theoretical perspectives guiding this research and discuss how each informs the analysis.

Theoretical perspectives are manifest throughout research methodology (Grix, 2004) and underpin every aspect of research. Unpacking the underlying assumptions within the theoretical perspectives guiding research methodology is important for understanding the implicit and explicit implications of research (Anfara & Mertz, 2006), since these assumptions shape the research findings and thus may influence various aspects of research and policy.

Paying attention to the underlying assumptions within research is particularly relevant in the context of Indigenous health research, which historically has had unintended and unanticipated consequences for Indigenous people. For example, epidemiological research aimed at exposing health inequities affecting Indigenous people has resulted in pathologizing constructions of Indigenous people as ‘sick’ and ‘vulnerable, which has inadvertently led to the removal of Indigenous children from their families and communities (O'Neil, Reading, & Leader, 1998). Without attention to the underlying assumptions of research and the implications of these assumptions on Indigenous people, well-intended research may result in further harms to Indigenous peoples and communities. Attuning to the assumptions shaping research
methodology can draw awareness to how research designs could play an important role in mitigating unanticipated harmful consequences.

**Assumptions Shaping the Researcher’s Perspective**

Understanding and articulating the underlying assumptions shaping the researcher’s perspective is of utmost importance, since it is ultimately the researcher who defines the research problem, influences the data collection, and interprets the research findings. A researcher’s philosophical stance is based on certain epistemological and ontological assumptions, which respectively refer to assumptions about knowledge and truth and the worldview in which the researcher engages (Jupp, 2006). As the primary researcher conducting this research, I articulate below the key assumptions shaping my own theoretical ‘lens,’ which has inherently and unavoidably shaped the research design and influenced the findings, analysis and discussions throughout.

My perspective has been influenced by the concept of social construction, originally introduced by Berger and Luckmann (1966) in *The Social Construction of Reality*, where reality is seen as not taken-for-granted but instead constructed or made up of particular social meanings; in this sense, reality and knowledge are subjective (Berger & Luckmann, 1966; Thayer-Bacon, 2003). I am also influenced by the related notion of relational epistemology, which views all aspects of social life as constructed in relation to each other and within interrelated contexts (Thayer-Bacon, 2003). As these perspectives foster a consciousness of the assumptions in how knowledge and reality are constructed, I am continuously attuned to the epistemological assumptions within policy and policy processes as well as power inequities created by the dominance of certain epistemologies over others.
My preoccupation with power is also informed by my socio-political positioning. As a Jewish queer woman, my worldview is shaped by personal experiences of historical displacement, intergenerational effects of genocide and anti-Semitism, as well as sexism, homophobia, heterosexism and intersections of these oppressions. These experiences have fostered my own critical consciousness about the implications of structural and interpersonal oppression. I am acutely aware of my own position of power and privilege as an openly out, legally married queer woman and freely practicing Jew living in the Jewish diaspora on contested colonized Indigenous land. My lived experience of consciously navigating these tensions has fueled my academic interest in social justice and equity, which underscore my draw to theoretical perspectives and research problems that focus on social change, liberation and the redress of structural oppression.

In alignment with these interests, I respond to the tension between structure versus agency by adopting a structuralist rather than an individualist lens (see Elder-Vass, 2010). This perspective is grounded in the assumption that people’s experiences are largely shaped by broader social and political structures, and not solely consequences of individual’s behaviours or life choices. Although I recognize individual agency cannot be understood in isolation of structure, and both agency and structure are inherently seen in relation to each other, I am primarily concerned with how to address issues of inequity through attention to social and structural change in relation to what could be changed at the individual or community level. I am thus drawn to theoretical perspectives that locate policy problems within the broader social, historical, political and economic structures that determine health and health inequities experienced by individuals and communities.
Engaging in Indigenous Health Policy Research as a Non-Indigenous Researcher

Influenced by perspectives rooted in power and privilege, including the view that active recognition and interrogation of white-settler privilege is essential for systemic change and collaboration in the name of Indigenous sovereignty and social justice (Denis, 2014; Rebick, 2014), I am attuned to the way my position as a researcher is shaped by own social and political position. I recognize how Indigenous peoples’ voices have often been silenced in universities, and ironically, often contradicted or corrected by non-Indigenous scholars claiming to be experts on Indigenous peoples and/or issues (LaRocque, 2001). Paying attention to these dynamics warrants interrogation of my role as non-Indigenous researcher conducting Indigenous health policy research and the implications of representing Indigenous people’s perspectives and experiences through the research process.

While non-Indigenous researchers have tended to benefit from engaging in Indigenous-related research, including advancing their own careers and social statuses, research has often had harmful implications for Indigenous peoples, including misrepresentation and misappropriation of Indigenous knowledges, which has contributed to continued colonization and oppression (McConaghy, 2000; Rains, et al., 2000). Research has also tended to construct Indigenous people in damaging ways. Historical and literary texts have maintained colonial constructions of Indigenous people based on myths of “savagery” and the diametric opposition of the “colonizer and colonized,” which have served colonial purposes including the ongoing dehumanization of Indigenous people juxtaposed with European championing of Indigenous humanity and rights. The institutionalization of such gross misrepresentations has had devastating repercussions for Indigenous people (LaRocque, 2010).
These views have influenced my belief that non-Indigenous researchers engaged in Indigenous health research have an ethical imperative to pay attention to these issues, including how Indigenous people are represented and who is benefiting from the research. In this research the object of inquiry is policy and decision-making processes and not Indigenous people themselves, however, in the process I am writing about Indigenous people and issues and unavoidably constructing Indigenous people in a certain light. In response to this awareness and in attempt to avoid unintended harmful consequences and promote research in support of Indigenous self-determination and sovereignty, I critically engage with some key perspectives about non-Indigenous people doing research that implicates Indigenous people.

The role of non-Indigenous researchers in research related to Indigenous people has been highly debated in the literature, yet some Indigenous scholars such as LaRocque (1996) articulate concerns with Indigenous peoples representing themselves. For example, institutions will often explicitly invite Indigenous peoples to speak or act on behalf of their own communities as a way of ensuring “community control” or promoting community “empowerment,” which often serves to place the burden of responsibility on communities to address their own issues while removing non-Indigenous people’s responsibility to address the structural issues that shape Indigenous peoples’ health and social lives (LaRocque, 2001). Regan (2005) argues that although non-Indigenous researchers tend to think of decolonization as a project of others, it is the responsibility of non-Indigenous people to proactively engage in decolonizing projects. Drawing on these perspectives, I view my engagement in this research as an assertion of my responsibility to actively participate in decolonization and engage in Indigenous justice issues.

A key question remains: How can I hold myself accountable to researching in an ethical and responsible way? LaRocque (2001) suggests, “[t]he task [of non-Indigenous researchers] is
to create a space and place [for Indigenous people] to be able to enter into the particular
discourse of western thought and format without having to internalize its coloniality or to defy
our personal and cultural selves" (p. 73). In addition, Regan (2005) argues that as non-
Indigenous researchers we need to pay attention to deeply-ingrained colonialism within western
epistemologies, confront ourselves with respect to our own assumptions and consider how we
may be inadvertently undermining Indigenous peoples’ worldviews and ways of knowing.
Informed by these views, I aim to highlight the perspectives of Indigenous people in relation to
dominant perspectives and expose rather than ignore inherent tensions or contradictions, as well
as actively engage in constant reflexivity with respect to the implicit assumptions of the research
and the implications for Indigenous people. Additionally, I draw on Thayer-Bacon’s (2003)
notion of relational epistemology to see myself as being constantly engaged in relationship with
Indigenous people and inherently connected to the same issues of equity and social justice
created by our interrelated contexts.

Guiding Theoretical Perspectives

Given my philosophical orientation described above, this study is informed by a
theoretical framework rooted in multiple perspectives that are attuned to issues of equity and
relations of power within social and political structures. Each of these guiding theoretical
perspectives is described below.

Decolonizing and Indigenist Perspectives

It is widely acknowledged that academic research and scientific models across the
disciplines are predominately grounded in Eurocentric philosophical traditions (O'Neil, 1993a).
As Indigenous leaders and scholars have taken on more prominent roles in universities and
research settings, the literature has begun to reflect an emergence of perspectives that seek to
disrupt the dominance of Eurocentric epistemology in academia and privilege Indigenous peoples’ voices and perspectives (see Hill, 2012; LaRocque, 2001; LaRocque, 1996; Pete, 2015). Recognizing that privileging Indigenous perspectives in literature can serve to resist colonial constructions and misrepresentations by bringing to surface counter-discourses and narratives rooted in Indigenous peoples’ self-representations (LaRocque, 2010), this research is informed by perspectives grounded in Indigenous epistemologies with a view to disrupting the dominance of Eurocentric perspectives on Indigenous health and health policy issues.

I am drawn to Indigenous scholars who approach research from within Indigenist and decolonizing paradigms, which are rooted Indigenous knowledges25 and epistemologies and centrally concerned with foregrounding Indigenous histories and narratives and advancing Indigenous justice agendas (Denizen, Lincoln, & Smith, 2008). In particular, I draw on Rigney’s (1999) Indigenist approach to research, which emphasizes a focus on resistance, political integrity and privileging Indigenous voices, as well as Smith’s (1999) approach to decolonizing methodologies, which focuses on deconstructing and rewriting history to give voice to Indigenous stories and experiences. These authors have informed the research methodology by guiding the researcher to actively seek out Indigenous participants and emphasize their perspectives and experiences in the analysis. Recognizing the need to foreground Indigenous voices and narratives, attempts have been made where possible to feature excerpts from Indigenous participants’ interviews in this dissertation.

25 Drawing on Kincheloe and Steinberg (2008), I refer to Indigenous knowledge as a multidimensional body of understandings rooted in “a lived-world form of reason that informs and sustains people who make their homes in a local area . . . . Such knowledges involve insights into plant and animal life, cultural dynamics, and historical information used to provide acumen in dealing with the challenges of contemporary existence” (p. 136). Battiste (2005) describes Indigenous knowledge as a holistic paradigm revealing “a wealth of Indigenous languages, worldviews, teachings and experiences,” (p. 1) which represents “an extensive and valuable knowledge system” (p. 3) comprising “far more than the binary opposite of western knowledge” (p. 2). Battiste (2005) explains that Indigenous knowledge “has always existed” but has been “systematically excluded” from contemporary Eurocentric education and social systems (p. 1).
This research also aims to foreground Indigenous peoples’ perspectives in the analysis, by reading the data in relation to relevant literature written by Indigenous theorists and thinkers. Being drawn to scholars who make visible epistemologies and their relationship to one another, the analysis is informed by the work of Ermine (1999, 2007) and Battiste (2000, 2009; 2000), who examine the epistemological and ontological tensions in Eurocentric social systems. I draw on these authors to illuminate the tensions between Indigenous and Western epistemologies and worldviews in policy systems and processes, and expose the implications for First Nations involvement in policy.

In addition, I am drawn to Indigenous and non-Indigenous scholars who maintain a focus on decolonization and transforming social structures through paradigms based on intersections of Indigenous and non-Indigenous perspectives. I draw on two scholars in particular; Turner (2006), who introduces the concept of “word warriors” – Indigenous intellectuals who can integrate Indigenous epistemologies within dominant legal and political discourses, and Regan (2005), who theorizes on the role of non-Indigenous people in projects of decolonization through a process of “unsettling the settler within.” These perspectives are used to orient the research objectives on issues that are relevant and of interest to Indigenous peoples, and focus the analysis on areas that shed light on addressing Indigenous issues of social justice and equity through policy decision-making and transforming policy systems and structures with a view to decolonization. In addition to using these perspectives to guide the analysis, this research draws on Indigenous authors where possible and emphasizes the experiences and perspectives of Indigenous participants.
Critical Theoretical Perspectives

The evolution of critical scholarship is rooted in the works of numerous social theorists concerned with the oppression and marginalization of peoples. The origins of critical theory can be traced to a group of theorists known as the “Frankfurt School,” whose core members were Horkheimer, Adorno and Marcuse (Therborn, 1970). Emerging from Marxist thought, the goal of critical theory was to “bring the basic contradictions of capitalist society to consciousness” (Therborn, 1970, p. 67). Since its emergence in the 1930’s, critical theory has influenced a plethora of schools, interdisciplinary studies and camps of theories, including cultural studies, critical race theory, and poststructural feminism (see Denzin & Lincoln, 2008; During, 1993). This research is informed by the work of several prominent critical theorists, as well as scholars and researchers who draw on a range of critical theoretical perspectives. Theorists of particular relevance to this research are Foucault (1980), who examines the complexity of power relations within institutions, discourses and processes of “government,” as well as Said (1978), who introduced the concept of “Orientalism” – a foundational concept in post-colonialism, and Spivak (1988; 2007), who theorizes on the role of subjugated peoples within dominant social systems.

Although there are many theories that fall under the broader camp of critical theory, this research is broadly informed by some crosscutting themes. In an attempt to describe a normative direction of critical theory that is shaping the overall research and methodology, I articulate below some key tenets of critical theory in relation to the aims of this research.

Firstly, critical perspectives are centrally concerned with ideologies and their relation to power (Bryant, 2009), and can be applied to the analysis of data to expose implicit ideologies and implications (Cheek & Gibson, 1997; Luckett, 2005). For example, Salmon (2007) applies a
critical analysis to Fetal Alcohol Spectrum/Effects (FAS/E) policies in relation to the experiences of Indigenous women affected by FAS/E, which exposes ideologies of privatization in that FAS/E is constructed as problem of “mothering and substance use” as opposed to problem of inequitable social and political systems. Similarly, Murray (2004) draws on critical perspectives to expose neoliberal ideologies within discourses of vulnerability in policy texts, which serve to perpetuate vulnerability and state dependency for certain groups.

Critical perspectives can provide a lens to examine research problems with a conscious eye towards the way in which power relations are socially and historically constituted (Baez, 2007). Abu-Laban (2007) illustrates this by arguing that liberal theories within Canadian political science reflect certain “selected histories,” which has significant effects on policy and in particular for Indigenous people, because although liberal theorists have become more concerned with diverse narratives from a range of peoples in Canada, the impact and legacy of colonialism continues to be largely ignored. This is one example of how critical perspectives offer a window into the ideological underpinnings of particular issues or discourses. In the area of Indigenous health policy research this is highly relevant, since critical perspectives can expose the implicit ways policies may be privileging colonial interests over the interests of Indigenous people.

Secondly, critical theoretical perspectives are oriented to critiquing and transforming society (Bryant, 2009) as opposed to approaches that aim to understand or explain, and thus reproduce, social phenomena. With this orientation, critical perspectives are useful for social justice research because they can inform methodologies that lead to insight on social change. Given the focus of this research on transforming policy processes to include First Nations people in more meaningful ways, critical theoretical perspectives may expose opportunities for structural change within dominant policy systems.
Thirdly, since critical theoretical perspectives emphasize relations of power, critical research is ideally suited to address issues related to inequity (Bryant, 2009) and the inclusion and exclusion of particular groups or ideologies within policies or discourses (Duncan & Reutter, 2006). As this central research problem is focused on the inclusion of First Nations people in health policy with a view to addressing health inequities, critical perspectives are useful for exploring the implications of policy processes in relation to inclusion and equity.

Fourthly, critical perspectives draw attention to the ways in which knowledges and epistemologies are legitimized and delegitimized. Research from a critical stance can challenge the theoretical assumptions on which research is founded, and thus can challenge who is doing the research and the knowledges being drawn upon or produced. The question of whose knowledges are seen as legitimate, and therefore included and reproduced, is highly relevant for examining how policy processes serve to legitimize or de-legitimize Indigenous people’s perspectives and Indigenous knowledges. Ermine (1999) asserts that the “categorization and selective validation of knowledge by Western science has inevitably influenced Western ideology as the driving force behind knowing” (p. 102). In challenging the dominant discourses and knowledges that shape health policy and policy processes, critical perspectives may point to opportunities for the inclusion of alternative knowledges and ways of knowing. Critical perspectives are thus useful for guiding an investigation into the issues surrounding the inclusion of Indigenous people and knowledges in policy.

Postcolonial Feminism

While it could be argued that Indigenist and decolonizing perspectives are a form of critical theoretical perspectives (Denizen, et al., 2008), the literature reflects some key concerns with the commensurability of critical and Indigenous paradigms. Recognizing that critical theory
is grounded in non-Indigenous perspectives, conversations between critical and Indigenous discourses must consider the “legacy of the helping Western colonizing Other” (Denzin & Lincoln, 2008, p. 5). In such conversations, critical perspectives tend to lay claim over Indigenous perspectives and construct Indigenous people as “Other,” thus reasserting colonial domination of Indigenous people (Alexander, 2008; Denzin & Lincoln, 2008). This effect is ironically often perpetuated by critical theories such as postcolonialism,26 which aims to re-examine colonialism through incorporating the perspectives of the colonized (Brydon, 2000). Largely marginalized by and excluded in these debates, Indigenous people have often been at the fringe of postcolonial theory (Denizen, et al., 2008).

Postcolonial theory has also been critiqued by feminist scholars in its lack of attention to the gendered nature of colonial oppression and for perpetuating essentialized constructions of race, ethnicity and culture (Gandhi, 2007; Mohanty, 2003; Narayan, 2000). Anderson (2000b) notes that the “dismantling of Aboriginal womanhood” occurred alongside colonization (p. 58). While feminism presents a useful lens for examining issues of gendered inequity, it has tended to exclude Indigenous women and impose colonial constructions of equality (Green, 2007b; Monture-Angus, 1999). In light of the inextricable links between colonialism, racism and sexism, theoretical perspectives rooted in a postcolonial gendered lens have begun to emerge (Anderson, 2000b; Bourassa, et al., 2004; Green, 2007b).

In response to the inadequacy of both postcolonial theory and feminism to separately examine issues of inequity affecting Indigenous women, postcolonial feminism is an attempt to bring these theoretical perspectives together. Influenced by the thinking of Black feminist scholars (Collins, 2009; Crenshaw, 1989; hooks, 2000) and South Asian feminist scholars

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26 Rooted in Said’s (1978) notion of Orientalism, which sought to critique colonial politics and constructions of otherness and difference, postcolonialism emerged from the work of key critical theorists such as Fanon (Alexander, 2008).
(Mohanty, 2003; Narayan, 2000), postcolonial feminism focuses on disrupting “race-thinking” and drawing attention to how constructions of race, ethnicity, culture and gender shape inclusion, exclusion and inequities (Anderson, 2000a; Browne, Smye, & Varcoe, 2007; Browne, et al., 2005). With its emphasis on discourses of inclusion, postcolonial feminism positions multiple marginalized voices at the centre of knowledge production with the aim of disrupting power relations and transforming society (Anderson, 2000a; Browne, et al., 2005). Postcolonial feminist perspectives have been used in health and health policy contexts as a way of interrogating and transforming policy discourses and processes with respect to their manifestations of colonialism and racialization (see Anderson, 2000a; Browne, et al., 2005; Kirkham & Anderson, 2002). For example, Smye and Browne (2002) use a postcolonial feminist lens to expose ‘culturalist’ discourses within mental health policy that perpetuate stereotypes and ‘othering’ of Indigenous peoples, and interrogate dominant policy discourses in relation to colonialism, racialization and sexism with a view to transforming social processes. This research draws on postcolonial feminist perspectives to attune to the ways colonialism, racialization and sexism, for example, shape the health policy landscape and the implications this has for Indigenous people’s inclusion and exclusion in policy processes.

**Cultural Safety**

With its roots in postcolonial feminism, cultural safety is useful for informing equity-oriented research in an Indigenous health context. Cultural safety was originally developed by Ramsden (1993), a Maori nursing scholar, as a response to cultural sensitivity training in New Zealand that largely failed to address health inequities experienced by Maori people as a result of

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27 Culturalism refers to a process of stereotyping based on the narrow construction of culture as the beliefs, practices and values of ethnic groups. This notion of culture focuses on the differences of other people in relation to each other, a process known as “othering” (Smye & Browne, 2002), and is often regarded by healthcare professionals as the primary contributing factor to health and social issues affecting certain groups of people (Browne, et al., in review).
colonial oppression (Ramsden, 1993, 2005). By drawing attention to underlying power inequities within the health care system (Koptie, 2009a), cultural safety aims to address racism and discrimination within health care settings. A key element of cultural safety is attention to the way culture is typically understood and constructed as the values, beliefs, and customs held by a particular group of people. In recognition of the culturalist assumptions underlying this conceptualization of culture and the implications for othering and racialization, from a cultural safety perspective, culture is conceptualized as a complex process enacted relationally between people(s) within interrelated social, political and historical contexts and is thus dynamic and shifting relative to other social processes such as gender and socio-economic positioning (Browne & Varcoe, 2006). As a theoretical concept, cultural safety emphasizes researcher reflexivity and attention to social, historical and political contexts that shape Indigenous peoples’ health, and can be used as an interpretive lens to prompt reflection on the ways health policy, research and practice may be perpetuating neocolonialism (Smye & Browne, 2002).

Although cultural safety is emerging as a perspective to inform Indigenous health policy development (Brascoupé & Waters, 2009), it has primarily emerged in Canada in the context of health care practice. Cultural safety has informed various aspects of the health care system, including practice guidelines, cultural competencies for health professions, training programs, and policy frameworks (Health Council of Canada, 2012). With a goal of providing better and safer care for Indigenous people, including Indigenous people accessing health care in urban contexts, approaches to culturally safe practice recognize that Indigenous people’s experiences of safety in clinical encounters are related to power inequities inherent in the health care system. A key part of a culturally safe approach to practice is thus paying attention to power dynamics in patient-provider relationships (Browne, Varcoe, et al., 2009; Browne, et al., in review; McCall &
Pauly, 2012). Building on this idea, I draw on cultural safety as a concept for attuning the analysis to the underlying power inequities shaping policy processes, with particular attention to Indigenous people’s experiences of safety at the policy decision-making table.

**Intersectionality**

Like postcolonial feminism, intersectionality draws attention to multiple systems of oppression, for example, colonialism, racism, racialization and sexism, among others. Although the concept has been informed by American Black feminism, Indigenous feminism, third world feminism, queer theory and postcolonial theory, the origin of intersectionality is largely attributed to the work of Black feminist legal scholar, Crenshaw (Collins, 2009; 1989; Hankivsky & Cormier, 2009). Intersectionality draws attention to the multiple intersecting social locations of individuals and groups, as well as the intersecting forces or systems of power that differentially shape people’s health and social lives. The indivisibility between categories of social identity such as race, class and gender, as well as systems of oppression such as racism, sexism and colonialism, are emphasized to the extent these categories are viewed as constituting one another; gender produces race, racism produces classism and vice versa amongst a multiplicity of social variables (Crenshaw, 1989; Crenshaw, 1991; Hankivsky & Cormier, 2009; McCall, 2005).

Although intersectionality has been critiqued with respect to its lack of a defined methodology (Nash, 2008), it is emerging as a theoretical concept informing research and policy (Hancock, 2007). Critical researchers have begun to adopt intersectional approaches in their analytical perspectives (see Browne, Varcoe, et al., 2011; Kelly, 2009; Varcoe, Pauly, Laliberté, & MacPherson, 2011) as well as approaches to policy analysis (Hankivsky & Cormier, 2009; Hankivsky, et al., 2012). When used as a lens through which to view policy issues,
Intersectionality illuminates how policy constructs the relative power and privileges of different people and groups (Hankivsky & Cormier, 2009; Hankivsky, et al., 2012). Intersectionality can be useful for analyzing First Nations policy issues as well as policy processes, as it can consider the multiple factors shaping the First Nations policy landscape, as well as the multiple political and social identities that Indigenous people occupy. I provide one example of this in a previously published work (Fridkin, 2012a) where I use an intersectionality-based policy analysis framework to inform an analysis of Indigenous peoples’ involvement in the development of the Kelowna Accord.

In this dissertation, intersectionality is used to draw attention to the intersecting systems of power shaping First Nations people’s involvement in policy, as well as the involvement of diverse First Nations groups. Intersectionality enables a focus on intersections of First Nations political and social identity, such as First Nations living people away from home, and the implications of such identities on being involved in health policy decision-making. I also draw on intersectionality to illuminate how complexities of involvement are shaped by intersections of neoliberalism, neocolonialism, systemic racism and patriarchy.

Summary

Critical research necessitates the researcher’s articulation of the theoretical perspectives that guide the research, and this chapter outlines the assumptions the researcher brings to this research, which is informed by the researcher’s socio-political location. Influenced by these assumptions, the framework guiding this research constitutes multiple theoretical perspectives including: Indigenist and decolonizing perspectives, critical theoretical perspectives, postcolonial feminism, cultural safety and intersectionality. Each of these perspectives is well suited to the
aims of the research and is used to inform various aspects of the methodology, which is described in the following chapter.
CHAPTER FOUR – METHODOLOGY AND RESEARCH DESIGN

Introduction

This chapter describes the overall research methodology and research design, which is informed by the theoretical framework described above. To begin, I describe the key methodological approaches that shape the overall methodology and articulate how each approach informs the research design. The chapter continues with an overview of the research design, including a summary of methods, overview of participants and a detailed description of data collection and analysis. Subsequent sections discuss considerations surrounding ethics, rigour and scientific integrity, and credibility of the analysis. The chapter concludes with a discussion on limitations of the research.

Methodological Approaches

Unlike many qualitative studies, this research is neither informed by a sole methodology nor follows a prescriptive set of procedures associated with particular methodological traditions. Instead, this research draws on an interpretive descriptive approach as a way of intentionally drawing on multiple methodological approaches in relation to each other to inform the research design. Recognizing the limitations of defined methodologies that require researchers to adhere to prescribed methodological traditions, Thorne (2008) proposes interpretive description as an approach to qualitative research where methodological traditions from various disciplines inform the research design while “retaining the coherence and integrity of a theoretically driven approach” (p. 27). An interpretive descriptive approach involves “disentangling methodological strategies from the theoretical assumptions associated with the original social science disciplinary projects,” to arrive at a uniquely tailored methodology for investigating applied interdisciplinary health research problems (Thorne, 2008, p. 27).
Given the interdisciplinary nature of the research problem, multiple theoretical and methodological approaches from various social science disciplines are useful for this particular investigation, including approaches rooted in sociology, policy studies, nursing and public health. Drawing on interpretive description as an approach to qualitative research, the research methodology has been uniquely designed based on a purposeful set of overlapping and complementary methodological approaches useful for answering the particular objectives of this research. I outline these methodological approaches below and explain how each informs the research.

**Studying “Up” and Grounding Research in the “Everyday”**

An exploration into policy decision-making processes through a focus on the experiences and perspectives of people working in health policy contexts lends itself to drawing on approaches from *institutional ethnography*, which is defined by Dorothy Smith (2005) as an alternative sociology seeking to investigate how textually-mediated translocal relations of ruling coordinate people’s everyday lives. Two approaches inherent to institutional ethnographic methodologies are particularly relevant to this research: *studying “up”* and *grounding the research in the “everyday.”*

The concept of *studying up* in social science research can be thought of as a means of “excavating power in its operation,” in that it involves turning the researcher’s gaze upward, away from peoples and cultures as objects of study, and toward an analysis of social systems and institutions in relation to notions of power (Priyadharshini, 2008). While the researcher’s gaze is turned upward toward an inquiry of “relations of ruling” and “coordinating texts,” which become the units of analysis, an emphasis is maintained on the actualities of people’s everyday lived experiences. This illustrates how research becomes *grounded in the everyday* (Smith, 2005).
Historically, health research has focused on Indigenous peoples as the “object of study,” where the researcher’s downward pointed gaze investigates health and social problems at the level of Indigenous peoples’ communities and bodies. This downward focus has dangerous social and political implications for Indigenous peoples, as the problem becomes locally viewed within Indigenous peoples and communities themselves, thereby pathologizing Indigenous peoples as the source of their own demise instead of positioning the problematic within the social, historical and political contexts shaping Indigenous peoples’ health and lives (Kelm, 1999). In contrast, studying up brings social and political relations into focus as the objects of study, and these external translocal relations are viewed as the source of what coordinates and organizes Indigenous peoples’ everyday realities. The point of this upward gaze is not to undermine Indigenous individual and community agency and detract from a focus on the individual and community level, but to veer away from colonial perspectives that typically fault Indigenous peoples for the health issues affecting their communities, and which are used to lessen government influence on and responsibility for Indigenous peoples’ health and social welfare.

By studying up and grounding research in the everyday, this research interrogates the translocal relations within policy systems and processes, with a view to understanding how they coordinate and organize Indigenous peoples’ everyday experiences of inclusion in health policy decisions. These methodological approaches influence the research design in that the interviews are focused on participants’ lived experiences and perspectives in an effort to understand the broader social and political forces shaping Indigenous peoples’ involvement in policy. The implications of this approach are that the findings and recommendations are not focused on what can be transformed or changed at the level of Indigenous individuals or communities, but what
interventions might exist at the level of policy structures and systems. In addition, as grounding research in the actualities of Indigenous peoples’ lives is essential for ethical research (Smylie, 2005), this approach informs a methodology inclined to support an ethical imperative.

Analyzing Policy Discourses

Given the theoretical orientation of this research towards exposing underlying ideologies and epistemological assumptions within policy and policy processes, this research draws on methodological approaches from critical discourse analysis – a methodology that Jennifer Smith (2007) describes as emphasizing discourses, ideologies and power as they relate to social processes. In this research, I critically analyze policy discourses within the participants’ interviews and relevant literature, with the purpose of exposing implications related to inclusion, exclusion and equity in policy decision-making processes.

Rooted in Fairclough’s (1995) conception of “discourse practice,” critically analyzing policy discourses can deepen an understanding of how policy texts are created, governed, distributed and read, and can thus be used to examine how underlying discourses frame particular policy issues and shape public perceptions based on certain assumptions and ideologies (Smith, 2007). A critical analysis of policy discourses can illuminate how power and dominance are reproduced through policy, and illuminate how power and dominance are played out in institutional settings (Van Dijk, 1996), such as institutions where policy decision-making occurs. For example, Jennifer Smith’s (2007) critical analysis of discourses related to nurse practitioner identity exposes how health care institutions create and retain power through the reproduction of discourses. Smith (2007) draws on the findings of her research to develop alternative policy responses, thus illustrating the potential for an analysis of discourses to
identify and build on discursive shifts and inform the development of policy recommendations (Taylor, 2004).

Drawing from this methodology, in this research I analyze policy discourses emerging in the data to expose their implications in relation to power and inclusion in policy processes. This approach of analyzing policy discourses is used to deepen an understanding of what underlies policy decision-making processes, identify where discursive shifts in policy could be made to disrupt the dominant systems of power, and inform the development of policy recommendations for meaningfully including First Nations people in policy. I also draw on existent critical analyses of discourses in the literature related to Indigenous peoples’ involvement in health policy to make meaning of the emergent discourses in relation to broader research and policy contexts.

**Critical Approaches to Policy Analysis**

When applied to policy discourses, a critical analysis of discourses can be a form of *critical policy analysis*, which aims to expose how broader social and political contexts shape how policy problems are defined, how policy agendas are set, and how policy instruments are developed (Duncan & Reutter, 2006). Unlike the context-stripping approach of mainstream policy analysis, critical policy analysis aims to contextualize policy problems within their historical, social and political landscapes (Eppley, 2009). While mainstream policy analysis is primarily concerned with policy outcomes and how well policy solutions respond to policy problems, I refer to *critical approaches to policy analysis* as methodological approaches concerned with how policy problems are defined and the implications for different groups of people in relation to social justice and equity, and can thus inform policy recommendations or
understandings of policy that are attuned towards transformative social change (Hankivsky, et al., 2012).

Informed by critical approaches to policy analysis, the research extends beyond an analysis of particular policies, and further examines how policy processes reflect certain epistemological and ontological assumptions (Cheek & Gibson, 1997). The analysis pays particular attention to discourses and ideologies of power within policy decision-making processes related to First Nations health, and how such discourses and ideologies implicate First Nations people in relation to involvement in policy. By focusing on a critical analysis of policy decision-making processes, this research informs the development of new ways of understanding meaningful involvement in policy and recommendations for transforming policy decision-making processes and systems in ways that foster Indigenous peoples’ meaningful and influential involvement.

**Research Design**

Drawing on the methodological approaches outlined above, this research involved collecting and analyzing twenty (n=20) in-depth, open-ended interviews with leaders and decision-makers in Indigenous health and health policy. Based on a research proposal developed in consultation with my supervisory committee, the research method was designed to solicit and analyze participants’ experiences in health policy decision-making related to Indigenous people’s health as well as their perspectives on what constitutes meaningful involvement. A detailed account of the data collection and analysis is described below.

**Research Setting**

Considering the significant differences between provinces in terms of First Nations’ historical relationships with governments and provincial health policy systems, this research
maintains an analytical focus on BC as opposed to a multi-provincial focus in order to arrive at more relevant and applicable strategic directions. Since First Nations health policy in BC is interrelated to the broader First Nations health policy landscape, I interviewed participants working in various geographic locations in BC and Canada to provide insight into the broader research problem focused on meaningful involvement. The interviews from all participants informed the broader analysis as well as the analysis focused specifically on BC and urban Indigenous peoples’ involvement in First Nations health policy.

To capture a range of perspectives and insights on meaningful involvement in various policy contexts, I interviewed participants working in a variety of health, public health and health policy-related settings, including regional, provincial and federal government settings as well as non-government organizations and university or research institutions. Each of these governments, organizations and institutions play a role in developing or informing policy related to First Nations people’s health. Interviewing participants from each of these settings was intended to capture a broader view of First Nations health policy decision-making processes and systems, rather than deeply explore the policy decision-making culture within any one individual organization or a particular level of policy decision-making. To arrive at an understanding of the broader systems and structures shaping First Nations peoples’ involvement in policy decision-making, I placed an emphasis on interviewing people who were working at or who had previously worked at senior government or organizational levels and who had experience being involved in health policy decision-making related to First Nations health.

**Recruitment and Sampling**

Considering the research focus is on exploring policy decision-making related to First Nations health, I purposefully sought to interview people who were or who had been directly
involved with policy, and who were therefore working in high-level positions. Recognizing that is relatively challenging to access high-level leaders in policy and that relationships can play a role in establishing trust between researchers and research participants and allaying suspicions or doubts participants may have had about the motivation of the research (Ryan, Kofman, & Aaron, 2010), the recruitment strategy was primarily based on existing relationships with potential participants held by myself, my supervisory committee members and/or other colleagues. Considering I sought to interview participants working at high levels of policy who were often busy and inaccessible, drawing on this existing network of professional relationships was essential in establishing connections with potential participants. The sampling strategy thus involved a combination of purposive and convenience sampling, which are sampling methods commonly used in qualitative research. The sampling strategy was purposive in that it involved pre-selecting individuals who were thought to have good insight into the research topic and who in some ways reflected the diversity of the population involved in First Nations health policy decision-making, and it was convenient in that the selection of individuals were based on pre-existing social networks that were accessible to the researcher and supervisory committee members (see Barbour, 2001; Thorne, 2008).

Recognizing that the concept of representation in qualitative research can be a “messy and complex business,” Thorne (2008) argues that representation in qualitative studies may be more appropriately conceptualized as a broad social ideal, where the intent of sampling is to “reflect a certain kind of perspective built from an auditable set of angles of vision whose nature and boundaries we can acknowledge and address” (pp. 88-89). I draw on Thorne’s (2008) discussion of how sampling strategies are used in qualitative research to articulate the nature of the sampling and recruitment methods used and to be transparent about the sampling logic. In
identifying the main conditions to consider for recruiting participants, such as including people who worked in variety of policy contexts and at higher levels, the sampling strategy resulted in a complement of participants with varied angles of direct and indirect experience related to decision-making on First Nations health. Similar to how key informants are often sought to participate in ethnographic studies, these sampling methods were chosen based on the recognition that there were individuals close at hand who were an excellent source of insight on the topic and who were well equipped to provide insight on “what is happening and why it is happening” in the context of First Nations health policy (see Thorne, 2008, pp. 89-91).

In consultation with my supervisory committee, I developed a list of potential participants working in positions across a range of governmental, organizational and policy levels, paying attention to gender diversity and to the inclusion of Indigenous and non-Indigenous participants. I sought to interview both Indigenous and non-Indigenous participants for two reasons: 1) to explore a range of perspectives and experiences related to First Nations involvement in policy, based on the recognition that socio-political positioning influences a person’s experiences and perspectives; and 2) to include a sample that was somewhat reflective of the population of people working in First Nations health policy settings, which includes both Indigenous and non-Indigenous people. Taking into account existing relationships and the desired diversity of participants, I developed a list of people to invite to a research interview with input from my committee. Initial contact was made in person when opportunities arose, or through an introductory email initiated by a committee member or colleague to introduce me and to explore their interest in learning more about the study. Following initial contact, if the person expressed interest I sent a follow up email with a brief overview of the study and an invitation to participate in an interview. For those who expressed interest in participating, I responded with a
more detailed summary of the study (see Appendix A) and made arrangements to interview them by phone or in person, where possible. At the end of each interview, I asked participants for recommendations as to other relevant people who might be interested in doing an interview. In most cases, the people recommended were already identified as potential research participants.

Recognizing that sample size is a particularly ambiguous aspect of qualitative research that is arguably best determined based on what knowledge is needed to answer the research questions and what available options there are for tapping into that knowledge (Thorne, 2008), a sample size of approximately twenty people was estimated by the researcher and supervisory committee to be appropriate to gain an in-depth understanding of the research problem. Most qualitative studies include a sample size between five and thirty participants, since an in-depth exploration of data that is experiential in nature can be conducted with a small data set (Thorne, 2008). The specific number of interviews to conduct was re-assessed at the mid-way point during data collection and also toward the end, where following a the initial analysis of the data, the researcher and the committee determined if additional insights were needed to adequately explore the research questions or if sufficiently in-depth data had been gathered.

**Overview of Participants**

The twenty (n=20) participants interviewed were leaders, decision-makers or experts who had significant experience working in fields related to Indigenous peoples’ health or other areas of public health policy impacting Indigenous people. Participants were affiliated with a variety of health organizations and institutions, including: government departments and ministries at federal, provincial and regional levels; non-government organizations including political, policy advocacy and community-based organizations; and research institutions including universities or government-funded centres. Participants were located and working in various geographic
locations across Canada, however the majority of participants (13) were working in BC. At the time of the interviews, participants were working in a range of leadership positions including: directors (11), senior leaders (6), managers or team leads (2), or professors (1). These numbers reflect the primary position noted at the time of the interview, however some participants held more than one professional position. Participants had been in their current position for a range of less than 1 to over 10 years; working in Indigenous peoples’ health for a range of 0 to 39 years and mean of 17.4 years; and working in health policy for a range of 4-37 years and a mean of 18.4 years. Efforts were made to include Indigenous participants where possible, and in the end half of the participants (10) self-identified as Indigenous people and half identified as white, Euro-Canadian, European or having mixed ancestry. Approximately half of participants self-identified as women (11) and half were men (9). The age range of participants was between 47 and 76 years, with a mean age of 57 years. Participants were highly educated with 15 participants who completed a graduate degree at the time of the interview and approximately half (9) who had professional designations in nursing, medicine, dentistry or law. Participants verbally self-identified or described their ancestry, gender, education level and relevant work experience to the researcher at the end of the interview, when participants were invited to complete the socio-demographic form (Appendix D). A summary of participants’ socio-demographic and professional information is provided in Table 1 below.

Table 1. Summary of Participants (n=20)

<table>
<thead>
<tr>
<th>Gender</th>
<th>Self-Identified Ancestry</th>
<th>Age (in years)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Indigenous</td>
<td>45-50 51-55 56-60 61-65 66-70 70+ n/a</td>
</tr>
<tr>
<td>Women</td>
<td>Euro-Canadian/ European or Mixed</td>
<td>4 3 5 4 1 1 2</td>
</tr>
<tr>
<td>Men</td>
<td></td>
<td>10 10 10 10 10 10 10</td>
</tr>
</tbody>
</table>
While the researcher maintained a conscious awareness of each participant’s gender and self-identified ancestry, for the most part this information about participants is intentionally not included alongside the data excerpts in this dissertation. Although social positioning such as gender and ancestry are highly relevant for the analysis, this is done for two reasons: 1) to avoid identifying participants based on their perspective and one or more aspects of their identity; and 2) to position the perspectives of participants with non-dominant gender and racial identities on a more “equal footing” as those with dominant identities, in the reader’s eyes. The attuning of the analysis towards gender, race and their intersections is reflected in the broader discussions where relevant.

*Interview Process*

I conducted twenty in-depth, open-ended interviews using an interview guide (Appendix B) designed to solicit participants’ experiences being involved in policy decision-making related to Indigenous peoples’ health, as well as their perspectives on meaningful involvement. The interview guide was developed in consultation with members of my supervisory committee and was further clarified and refined as the interviews proceeded, in response to emerging themes and insights gained from conducting the interviews. For example, the questions were refined and clarified with a view to helping participants describe their perspectives and experiences in as

*28* By referring to participants with *non-dominant gender and racial identities* I am referring specifically to participants who may be marginalized or oppressed due to their gender and/or racial identity, namely participants who identify as women and/or Indigenous.
much depth as possible, however, the key concepts and intentions underlying each of the questions were consistent with the original interview guide. The questions were open-ended and exploratory in nature, and sequenced with the intent of evolving from an information-based conversation to an in-depth discussion (see Appendix B). The initial questions focused on the participant’s current role with a view to contextualizing the interview and establishing a level of comfort, safety and trust in the participant-researcher relationship. The next set of questions solicited participants’ lived experiences being at policy decision-making tables, exploring tensions and challenges of these processes as well as aspects that worked well. Subsequent questions explored participants’ perspectives on what could be done to improve such processes, as well as what is needed for and what constitutes meaningful involvement.

Interviews were conducted in person where possible or otherwise over the phone using Skype. Interviews were conducted at a time and place decided by the participant and during their work hours. At the start of each interview, I provided a verbal overview of the study, including the research objectives and methods as well as a written summary, which was included on the consent form. To promote participants’ level of comfort in speaking freely and sharing their perspectives, I explained that I would be analyzing the data with a view to investigating the broader structural and policy environment, as that is the object of study, and that I would not be analyzing their interview with a view to critiquing their individual perspectives. The consent form (Appendix C) was reviewed and signed by all participants, and each participant was given a copy for their own information and reference. Participants were asked for permission to have their interview audio-recorded, and in cases where consent was given (18), the audio recorder was turned on. For those who did not consent to having their interview recorded (2), I took field notes during the interview highlighting key points in the conversation.
I began each interview by following the interview guide, and then proceeded by responding to participants’ discussions and asking probing questions in relation to the points being raised by participants. I maintained a focus on participants’ experiences, soliciting examples where possible to illustrate what was being described. Throughout the interview I referred to the interview guide, making sure I was covering the key questions at some point in the process. I made efforts to summarize key points being raised and repeat them back to the participants during the interview so as to check if I had understood them correctly and to stimulate further discussion. Each interview lasted approximately 40 minutes to 2 hours. Following the interview, I collected socio-demographic information on the participants and asked for recommendations for others to interview, which was documented on a socio-demographic data form (Appendix D). To close, I thanked the participants and informed them that I would be donating $20 to a related charity in honour of their time. After data collection was complete, I made a $400 donation to an Indigenous health organization with charitable status in honour of the participants’ time.

Following each interview, I recorded field notes that included my overall impressions of the interview, key ideas that stood out, details not captured in the transcript such as participants’ emotions, tone or body language and noted methodological considerations requiring follow up. The interviews and field notes were transcribed by a professional research transcriptionist and subsequently cleaned by the researcher for accuracy and to remove identifiable information such as names of people or organizations, which were replaced with categorical codes.

**Data Analysis**

The interview and field note transcripts were organized using NVivo qualitative data analysis software, which included coding each transcript based on a codebook of topic-based
codes developed from an analysis of initial reflections on the data and further refined after subsequent readings. I undertook a thematic analysis, which involved an inductive process of systematically reading and re-reading the data alongside the development of an evolving coding structure, which supported a more in-depth thematic analysis. The purpose of the coding was to break up the data into purposeful categories in order to see the data in new ways, make new linkages and identify any patterns or relationships that may not have otherwise been seen (Richards & Morse, 2007).

The first level of coding was more descriptive and included an initial reflective reading of the data, which captured my reaction to ideas or concepts that stood out or grabbed my attention (Thorne, 2008). This descriptive coding involved an analysis of the data at a textual level with minimal interpretation. The second level of coding was more interpretive and involved abstracting key concepts from the data to make broader conceptualizations by identifying new themes or concepts, developing new coding categories, and contrasting and comparing the data in relation to emergent themes and concepts.

The thematic analysis continued with a review of the coded data excerpts with a view to identifying significant discourses, processes, and phenomena that shed light on the broader and central research problem. Throughout the process I wrote analytical memos documenting linkages to the literature and between the data, as well as other relevant thoughts or insights, which were used to develop new coding categories, further refine the interview questions, and inform the later stages of analysis (see Richards & Morse, 2007; Thorne, 2008). Subsequent levels of coding involved articulating new conceptualizations arising from the data, which were informed by the guiding theoretical perspectives and research questions (Richards & Morse, 2007). Writing the dissertation was also an analytical process involving continual reflection on
the evolving organization of the findings and the repeated process of reading and re-reading the findings in relation to existent literature. The analysis was also informed by the perspectives of the Supervisory Committee members, including the Indigenous supervisory committee member, who read significant sections of the data and who provided analytical guidance on the interpretation of the emerging themes.

**Ethical Considerations**

In light of the historical colonial context and the harms inflicted on Indigenous communities, ethical considerations were especially important in this research and were addressed in several ways. Firstly, guided by theoretical perspectives inherently oriented towards ethical issues, the data collection and analysis was designed with a consciousness towards mitigating the dominance of western epistemologies and non-Indigenous people’s perspectives and centering Indigenous peoples’ perspectives and knowledges. This was done by taking efforts to recruit Indigenous participants, emphasizing Indigenous participants’ perspectives in the analysis and drawing on Indigenous authors in the literature.

Secondly, the research design was informed by, and adhered to where possible, ethical guidelines for Indigenous health research. In particular, the research was informed by the Canadian Institutes of Health Research (CIHR) Guidelines for Health Research Involving Aboriginal People (Canadian Institutes of Health Research, 2007) and Chapter 9 of the Tri-council Policy Statement (Interagency Advisory Panel on Research Ethics, 2009). As per these guidelines’ articulated imperative to involve Indigenous people in research related to Indigenous people, an Indigenous faculty member on my supervisory committee was actively involved throughout the research process and provided guidance on the development of the research objectives, research proposal, data collection and analysis.
Thirdly, a detailed account of ethical considerations, including risks and benefits to participants and assurance of participant privacy and confidentiality, were articulated in an application to UBC’s Behavioral Research Ethics Board (BREB), which was subsequently approved. Amendments and updates related to the research were submitted regularly to the BREB and ethics approval was maintained throughout the entire process of research.

**Rigour and Scientific Integrity**

Given the inherent political nature of the research and its explicit social justice aims, it could be argued that the assumptions and political motives I bring to this research will inevitably lead to certain findings. To ensure the quality and credibility of the data and to justify the rigour in the analysis, it is important to wrestle with the question, “if one begins with preconceived notions about inequities in health and health care, might one construct the research questions and interpret findings to support certain conclusions? And, might this undermine scientific integrity” (Reimer-Kirkham & Anderson, 2010, p. 197)? As I do indeed have preconceived notions that health policy *ought* to address issues of equity and that Indigenous peoples *ought* to be involved in health policy decisions impacting Indigenous communities, it is important to articulate how the findings of this research will be rigorously extracted from the data, and how the interpretations of the data will emerge from applying a rigorous method of inquiry, and not based on my own “opinion.”

Although traditional scientific research typically aims to eliminate researcher bias and ideologies are not overtly brought into the discussion, this does not mean that ideologies are not present and driving the research. Drawing from Lather’s (1986) assertion that “research which is openly value[-]based is neither more nor less ideological than is mainstream positivist research,” (p. 64) it is arguable that ideologies inherently exist in every form of research, and that failure to
articulate them prevents the researcher from engaging in a discussion on how their own ideologies, however implicit, conflates with the research. As Reimer-Kirkham and Anderson (2010) argue, “…scientific integrity is also compromised when our ideologies are not held up to scrutiny, but are instead taken up and used to drive research so as to produce certain outcomes” (p. 201). The question of how we assure rigour in the face of our ideological motivations is thus important in all traditions of research. Given the emphasis on reflexivity and ideologies in critical inquiry, the theoretical orientation of this research maintains a built-in mechanism for assuring rigour. Although those coming from dominant and traditional science disciplines may not be familiar with nor appreciate the evolution of rigorous methodologies within the critical paradigm, it is recognized that critical inquiry is a legitimate approach to research that generates knowledge according to standards of scientific integrity (Reimer-Kirkham & Anderson, 2010).

Since this research is concerned with fostering equity for Indigenous peoples, it could also be argued that I am conflating my role as a researcher with my role as an advocate. In the critical paradigm of research, there are inherent problems with speaking on behalf of others, as this is seen as a colonial act, which critical researchers, especially critical postcolonial feminists, overtly try to avoid and undo. A researcher whose research is oriented towards health equity, however, is typically not trying to act as an advocate on behalf of particular interest groups, but rather, as Reimer-Kirkham and Anderson (2010) pointedly articulate, “…the agenda is to unmask historically embedded, taken-for-granted social structures that support the status quo, that position people in particular ways, and that are major determinants of health and well-being” (p. 204). Likewise, it is important to note that in this research, I am not attempting to advocate for or speak on behalf of Indigenous people nor am I aiming to push forward the interests of Indigenous communities, although I do aim to engage in research that is relevant to and
hopefully useful or of interest to some Indigenous people or communities. Whereas the findings from this study may be used by Indigenous researchers, leaders, activists, or others with the purpose of advancing specific projects or initiatives from which Indigenous people may benefit, the explicit aims of this research are to expand the thinking on ways of involving First Nations people in policy in more meaningful and influential ways. As such, the aims of this research do not impede the integrity or rigour of this research, rather they hold true to the standards of critical inquiry, which promote rigour through careful attention to reflexivity and the role of ideology.

**Credibility of the Analysis**

Based on the understanding that there is no such thing as “neutral research,” Lather (1986) argues qualitative researchers “no longer need to apologize for unabashedly ideological research and its open commitment to using research to criticize and change the status quo” (p. 67). At the same time, Lather (1986) argues there is still a need to establish the trustworthiness of qualitative data and “guard against researcher bias distorting the logic of evidence within openly ideological research” (p. 67). Establishing credibility and trustworthiness of the data and analysis is important for ensuring accuracy of the findings and achieving a sense that the analysis is well-grounded, yet it is widely recognized that traditional means for assessing the “validity” of data and analysis are largely not applicable nor relevant to qualitative research (Feldman, 2003). In response to the recognition that postpostivist constructions of validity are inherently problematic for assessing rigour in qualitative research, an emerging body of literature on qualitative research methodology is indicative of the need for new conceptualizations of validity and mechanisms for ensuring rigour in qualitative research (Cho & Trent, 2006; Feldman, 2003; Golafshani, 2003; Morse, Barrett, Mayan, Olson, & Spiers, 2002; Whittemore, Chase, & Mandle, 2001).
Drawing on emerging approaches to addressing issues of validity and ensuring rigor in qualitative research, the methodology includes several mechanisms for establishing credibility of the data and analysis. Firstly, I draw on Rapley’s (2001) conceptualization of open-ended interviews as “inherently social encounters” in which no single practice can elicit “better data” than others. Considering such data are “highly dependent on and emerge from the specific local interactional context” of the interview, rigour can most closely be assured through maintaining awareness of the “local context of data production” in the analysis (p. 303). Informed by this approach to rigour in open-ended interviewing, I read the interviews in relation to the participants’ socio-demographic data as well as my observations of the research interview dynamics, which were documented in the field notes. My conscious awareness of social and political factors shaping the interview were also informed by the literature I continually reviewed and synthesized, which provided insight into the particular organizational and policy context in which many participants’ experiences were situated. In addition, my constant reflexivity and awareness of the dynamics shaping the socio-political positioning of the researcher in relation to the participants informed my facilitation of the interview with a view to nurturing a participant-researcher relationship from which a rich discussion could emerge.

Secondly, in the research proposal and this dissertation I paid explicit attention to providing clear and detailed descriptions of the process of data collection, the coding process, and how I constructed the representation from data, which Feldman (2003) proposes are ways of attuning to rigour in qualitative research. Guided by a well-articulated methodology rooted in an appropriate theoretical framework, I established rigour by careful adhering to the proposed methodology outlined, which was developed with the particular research objectives in mind.
Thirdly, I engaged in a process of *triangulation* (Lather, 1986) to establish trustworthiness of the data and analysis, whereby I read the data and emerging findings in relation to multiple credible sources on the research topic, including literature from various disciplines and the perspectives of supervisory committee members with respect to their relevant areas of expertise. The Indigenous supervisory committee member was especially helpful in providing guidance on interpreting the data describing Indigenous peoples’ experiences and perspectives, and in pointing out the relevance of the data to current literature and policy initiatives on First Nations health. To further establish credibility through a process of *face validity* (Lather, 1986), I shared and discussed key aspects of the findings with two participants whose interviews significantly informed the analysis and whose interviews were prominently featured in the dissertation. After reading a summary of the findings and some sections of the dissertation featuring excerpts from their interviews, the participants explained that the findings resonated with their perspectives and experiences related to Indigenous people’s involvement in health policy decision-making, as well as their understandings of the issues at the heart of meaningful involvement.

Lastly, drawing on the notion of *catalytic validity*, which refers to the re-orientation of the research process based on the researcher’s emerging knowledge of reality with a view to transforming it (Lather, 1986), I ensured rigour through continual reflection on the interview process and refining of the interview questions, as well as though the iterative process of analysis involving multiple readings of the data, several stages of coding with increasing levels of complexity, and writing the dissertation, each of which resulted in new or refined themes, conceptualizations, and organizations of the findings.
Limits of this Research

Thorne (2008) argues that justifying sample size in qualitative research is best done by generating a rationale that is consistent with the research questions. In this case, the sample size comprised of twenty participants, which was helpful in capturing a range of perspectives and insights into how First Nations people were, and were not, involved in health policy decision-making in BC and Canada, and what could be done to foster more meaningful involvement. However, a limitation of this study is also that it draws on the perspectives of only twenty people who were variously positioned in relation to health policy decision-making contexts. Interviewing twenty participants versus slightly more or less than twenty was both based on my ability to construct a credible analysis and somewhat arbitrary. That is, if more participants had been interviewed, it is possible that different or divergent insights would have been shared, which may have shifted or expanded the analysis in other directions. Thorne (2008) notes that the concepts of saturation and redundancy are often misguided, in that they encompass the notion that all the possible insights into the topic have been gathered based on the observation of repeated themes emerging in the data. However, she cautions that researchers cannot assume that the findings that seem most evident in the data are necessarily the most relevant findings, nor can it be assumed that there are no more data that could be collected that would further inform the findings. Drawing on Thorne’s (2008) assertion that arbitrary limits around sample size may be justified in smaller studies as long as researchers note that there would always be more to study, I am transparent about the potential limitations of the sample size in this study, and acknowledge that a larger sample size may have provided further insight into the research topic. This is not to suggest the findings are not informative; only that there may be other important perspectives that were not captured in the data and thus not included in the analysis.
It should also be noted that a common criticism of purposeful sampling is that the samples are “biased” by virtue of the selection process, and that this in turn leads to a sample comprised of “a certain type of informant with a certain knowledge” (Morse, 1991, p. 138). Drawing on Morse (1991) and others (see Denzin & Lincoln, 2011) who argue that this inherent bias in qualitative research is purposeful, hence the term purposeful or purposive sampling, and that an “unbiased” or randomly selected sampling strategy would undermine the qualitative principle of gathering data from identified experts, the purposive sampling strategy is aligned with this paradigm of research in which all knowledge is considered to be socially constructed. A possible limitation of this sampling strategy, however, is that the participants in this study may share a similar set of experiences or perspectives, which could limit the range of experiences and perspectives that inform the findings.

**Summary**

Shaped by the guiding theoretical perspectives outlined in Chapter Three, the methodology draws on an interpretive description approach in which methodological approaches rooted in several disciplinary traditions are used in combination to inform various aspects of the research design. The specific methodological approaches informing the overall methodology include: studying “up” and grounding research in “the everyday,” analyzing discourses within policy texts and critical approaches to policy analysis. Drawing on these methodological approaches, a process for collecting and analyzing twenty (n=20) in-depth, open-ended interviews with leaders in Indigenous health policy and other health policy areas was undertaken. Explicit efforts were taken to address ethical concerns, maintain rigour and scientific integrity and acknowledge limitations of the research.
CHAPTER FIVE – SHUT DOWN, SHUT UP, AND SHUT OUT: LIVED EXPERIENCES OF INVOLVEMENT

Introduction

This chapter draws on participants’ lived experiences of involvement in health policy decision-making to illustrate the reality of how First Nations people and organizations are currently involved, and conversely not involved, in policy decision-making related to Indigenous peoples’ health. Consistent with interpretive inquiry, linkages to relevant discussions in the literature are made in certain areas to stimulate key points in relation to existent research.

Going Backwards and Pushed to the Side: Experiences of Not Being at the Table

Despite the increased recognition of the importance of First Nations people being involved in policy decisions, the analysis of participants’ interviews resonates with the many claims in the literature that Indigenous people are still often not involved in policy decision-making affecting the health of Indigenous communities. For example, one participant describes how even though the majority of people served by one particular organization are Indigenous women, the key decision-makers are predominantly non-Indigenous people:

[E]ighty percent of the women at [that organization] are Aboriginal women and so I’d say to them . . . if eighty percent of your clientele are Aboriginal and ninety-nine percent of your staff are white and ninety percent of your board is white, shouldn’t we want to be balancing that? . . . [A]nd they didn’t really think there was anything wrong with that for the most part. (P09)

P09’s observation not only provides an example of how Indigenous people are not involved in decision-making affecting Indigenous people, it also illustrates how the value of having Indigenous people at the table is sometimes overlooked. As argued in the first chapters of this
thesis, there are many arguments in the literature about the importance of including Indigenous people in health policy decision-making, first and foremost being that this is essential for developing policies that are relevant to Indigenous people and that will make a difference in improving health and addressing health inequities. In alignment with this argument, several participants vehemently assert that Indigenous peoples’ involvement in policy decisions is a fundamental requirement if any change towards improving Indigenous people’s health is to be expected. One participant argues:

[W]e have to be at the table . . . and when I say we, I mean Aboriginal we. And [without Aboriginal people at the table] the policies are just not going to fit, they’re going to fail. I mean they’ll succeed to some extent, but they really will not achieve what they should achieve without us being at the table. (P13)

As P13 argues, without First Nations participation, policy decisions are “not going to fit” in First Nations communities. Like many of the arguments made in the literature about the importance of Indigenous involvement, participants’ experiences reiterated that without First Nations participation, policies are not effective in improving health in First Nations communities. Participants noted the value of having First Nations people involved in decision-making because First Nations people are the “experts” on First Nations health, and consequently “have to be at the table” (P13).

Yet the interviews revealed it is often the case that non-First Nations people are charged with making decisions affecting First Nations communities whom they know nothing about. One participant describes the nonsensicality of such a case, where a policymaker’s ignorance about First Nations communities impeded a decision-making process from resulting in good policy decisions:
So I would speak to the person from [government] headquarters and say, “. . . I need to find another way to either frame this [issue to the First Nations community] or to re-profile what we’re providing.” And [the response from the policymaker] was, “Well, just go tell them no.” . . [I didn’t understand this response, until later during an annual meeting when the policymaker] said, “Well, by the way I’ve never been to an Indian reserve. Do you think you could hook me up with an Indian reserve and I could go and see a health centre?” So the person making major policy decisions on health for Indians had never been to an Indian reserve. For me that’s like having an ambassador to Russia that doesn’t know the language, has never eaten the food, has never read the history, doesn’t know Tolstoy or Doestoevsky or Moscow or anything. She had never been to a reserve and yet she was giving me direction on how to deliver services to reserves, where I had lived and worked for fifteen years. It was crazy. (P04)

Another participant asserts, “Policies come from Ottawa, yet those people have never lived in our villages. They have no idea” (P16).

These excerpts illustrate a common problem discussed by participants regarding non-Indigenous people making uninformed decisions about Indigenous people’s health. As was mentioned in the introduction of this dissertation, policy decisions are often made by those in the highest positions of power and the people who are directly impacted by the decisions tend to have least involvement in the decision-making process (Kenny & Giacomini, 2005; Whitehead, 1991; Whitehead & Dahlgren, 2007). The participants’ experiences revealed that despite the recognized importance of Indigenous people’s involvement, First Nations people are still commonly excluded from policy decisions that affect First Nations people and communities, which impedes decision-making processes from resulting in good decisions.
Furthermore, the interviews suggest that First Nations people must be at the table not only because this results in good policy decisions, but also because the impact of being involved, and conversely not involved, in policy decisions has a direct impact on First Nations peoples’ overall health and wellbeing. This is illustrated through the comments of one participant:

Most First Nations people are asking for self-determination and some equity in that process. They’re not at this point worried about ultimate outcomes. But what they will repeatedly say is until they have possession of those processes, ultimate outcomes will be impossible to achieve. And I will say that the program that I work in, we can put all the dentists in the world filling all the teeth that First Nations people have, but . . . dental disease is primarily an entirely preventable social condition disease . . . if you don’t pick up a toothbrush and brush your teeth, they’re going to rot. Period. End of discussion. The high rates of dental disease we see in First Nations people is not a reflection of lack of care or lack of payment. It is a reflection of the people themselves who as yet don’t feel like they’re equal partners in their own care . . . . (P07)

This participant makes the connection between Indigenous peoples’ involvement in their own decisions and the health outcomes they experience. P07’s poignant analogy suggests that Indigenous people’s exclusion from the decision-making world and broader civil society has a direct impact on health behaviour, such as brushing your teeth, which in turn impacts health. Another participant explains this in the context of what happens when First Nations people are included in consultations to support the implementation of ideas pre-determined by governments: “[U]nless you can generate your own ideas and implement your own ideas you’re never going to get to the kind of empowerment you need to make a real meaningful change in the lives of others” (P15). These findings point to how the mere act of inclusion itself can have an impact on
Indigenous peoples’ health, which some studies have shown to be a positive outcome of involvement (Gaventa & Barrett, 2010).

The health effects of inclusion can be further illuminated by drawing on Galabuzi’s concept of social exclusion, which in this case would refer to the exclusion of First Nations peoples from civil society through legal or institutional mechanisms, such as policymaking (Galabuzi, 2004). Galabuzi (2004) argues that the exclusion of racialized groups from policy decisions has an impact on health, not only because groups are excluded from decisions that define the social and economic determinants of health, but also because this kind of social exclusion exacerbates inequality and fosters powerlessness, hopelessness, and despair, which contribute to the emotional and physical health of the group and also impede the group’s attempts to be included in structural or social aspects of society. Reading P07’s analogy from a social exclusion perspective suggests that the exclusion of Indigenous peoples from health policymaking contributes to health inequities and Indigenous peoples’ poor health. Inversely, the act of including Indigenous people in policymaking, regardless of the decisions that are made, has the potential for improving health and addressing inequities.

The Shrinkage of First Nations Involvement at the Federal Level

Despite the value of First Nations people’s involvement in policy as a means of improving health outcomes and addressing inequities, the interviews suggest that First Nations involvement in health policy is scarce and in fact shrinking.\textsuperscript{29} The impact of this shrinkage is felt by participants, as reflected in one participant’s interview:

\begin{quote}
So prior to last [year] the [Aboriginal organization] had a fairly active, vibrant, health department. [Later that year] we were advised . . . [by the Federal government] that all
\end{quote}

\textsuperscript{29} The shrinkage of First Nations involvement is discussed in Chapter Two in relation to the recent closure of several key Aboriginal health organizations (Gregory & Harrowing, 2012; National Collaborating Centre for Aboriginal Health, 2012).
funding towards health, towards [our organization] would cease. Now when we were active in the health area through the funding that we received from [the Federal government] . . . [we] would sit at the table at the national level and would have some say into discussion on health issues . . . . So at the moment, in the current time we are not in the same place because we no longer have that funding therefore we are not at the table at all, therefore we are not having any influence on the development of policy. . . . So that’s a big concern of mine and I guess that’s one of the reasons why I agreed to have this interview with you . . . . [T]he more people that know about that the better it is. So as far as I know there is no-one at the national level from any of the [national Aboriginal organizations] that are providing input on the development of policies for Aboriginal health. (P13)

The depth of P13’s concern is illustrated above as she admits it was the main impetus for participating in the interview, however my field notes describe the tone of sadness in her voice that is not captured in the interview transcript: “She talked about how there was really no-one who was advocating for Aboriginal health at a national level and really it seemed like there was a little bit of despair, I think, in her voice as she talked about the loss of funding” (Field notes from interview with P13). The despair in P13’s voice hints at the impact that the funding cuts have had on Indigenous peoples’ morale; it is reminiscent of Galabuzi’s (2004) description of the impact of social exclusion:

Along with the socio-economic and political inequalities, social exclusion is also characterized by processes of a group or individual isolation within and from . . . . key societal institutions . . . . These engender experiences of social and economic
vulnerability, powerlessness, voicelessness, a lack of recognition and sense of belonging, limited options, diminished life chances, [and] despair . . . (2004, p. 238)

The despair expressed by P13 in recounting the recent history of Aboriginal organizations losing their seat at the federal table is an engenderment of the exclusion of Indigenous peoples from the current health policy-decision making system at the highest level. Given the importance of First Nations involvement in policy decisions that impact the health of First Nations communities, the findings suggest the scarcity and shrinkage of involvement is a reality of key concern to participants.

The participants also reiterated that Indigenous peoples were not always excluded in federal health policy decision-making. For example, P13 described a history of Indigenous peoples’ increased involvement in federal decision-making on Indigenous peoples’ health and explains how on previous occasions, the federal government actually reached out to include Aboriginal health organizations in the processes:

Well I’ve been involved in Aboriginal health since 1974 and back then it was top down . . . and we accepted that. And then the eighties and the nineties came and there became more and more health people [involved, like nurses or physicians] and I found the government was reaching out to us. . . . And now . . . it seems to me [we’re] back at square one. Now it’s top down approach again without any input from Aboriginal people . . . So I find we’re going backwards instead of forwards. (P13)

P13 described the fluctuation of Indigenous peoples’ involvement over the past several decades and how the current state of involvement is at the point that it was in the seventies when P13 first began working in Aboriginal health. This history contextualizes the despair in P13’s voice, as it might seem like the previous work of Indigenous health leaders is not being built upon, but
rather undone in the current policy climate. The direction of the current policy climate, which P13 describes as “going backwards instead of forwards,” may represent the undoing of previous advancements in First Nations people’s involvement in health policy decision-making.

Another participant reflected on this trend of shrinking First Nations involvement and suggests that this is indicative of an overall devaluing of the role Aboriginal organizations play in improving the health of First Nations communities: “[Two Aboriginal health organizations have recently closed] . . . and soon Native political organizations we’ll see shrinking too. And that’s because there’s a sense that these are just bureaucracies that don’t serve the community,” (P15). P15 goes on to say that there is value in the way Aboriginal health organizations have contributed to health policy decision-making: “If you ask anyone say after fifteen years of the [closed Aboriginal health organization] and [after] a half a million-dollar investment, are our communities better? People will say, “Absolutely. I can see it, I can feel it.” And we can measure it.” In discussing the shrinkage of “Aboriginal civil society” as a result of funding cuts to non-profit Aboriginal organizations, P15’s interview points to the impact of non-political Aboriginal organizations in influencing decisions that improve First Nations people’s health. This finding suggests there remains a need to include First Nations people who are on the outside of the political sphere as a way of addressing Indigenous peoples’ health and health inequities.

Although this research focuses on improving the way First Nations people are involved in health policy decision-making, the data serve as a reminder that efforts to get First Nations people to the table cannot be overlooked. Reading these findings in relation to the research question of what constitutes meaningful involvement suggests that, while it may go without saying, having First Nations people at the table is a prerequisite for meaningful involvement. Furthermore, reading these findings in relation to the question of how to foster meaningful
involvement suggests that strategies for getting First Nations people to the table be a first step towards fostering meaningful involvement; fostering meaningful involvement thus begins with attention to fostering involvement altogether.

Challenges with the Inclusion of First Nations People Away Home

Despite the “backwards” direction of First Nations people’s involvement in the Canadian policy sphere, the interviews also suggest the First Nations health landscape is progressing forward at the provincial level in BC. Several participants referred to the recent developments in First Nations health in BC as an example of the direction in which First Nations involvement should be heading. Participants described the new ways First Nations people are involved in health policy BC as “unprecedented,” “historic,” and representative of a “profound change” from the way First Nations health decision-making has occurred in the past. One participant articulates this significance:

Well I think what’s happening in B.C. is going to give an opportunity for [better decisions on First Nations health] to occur. I mean this is a[n] historic situation of the federal government . . . to actually turn over all of the current functions in British Columbia performed and funded by [the federal government] . . . [to] the hands of First Nation leaders [and] First Nations communities. That’s a profound change and I think that’s a great change. (P19)

While some participants reflect on the increasing inclusion of First Nations people in health policy decision-making in BC, the data also point to further issues of exclusion within this context, as several participants discussed their experiences related to the lack of urban Aboriginal involvement in the BC First Nations health context. Two participants describe how the new First
Nations health governance structure and surrounding policy processes have largely excluded First Nations people living in urban communities:

In the [BC First Nations] health plan they are mostly talking about politically affiliated health organizations meeting on reserve, it’s leaving the whole urban sector out. It’s about half of the Aboriginal people in B.C. that are being excluded. We keep hearing that the [BC First Nations health organization] will include everybody but I’m not sure how, and I’m waiting for the mechanism but I sure don’t see it in their writing. (P02)

The way [the BC First Nations health organization] is set up, it is not possible to include urban Aboriginal people. . . . I went [to their meetings] and wanted to ask about urban issues. They said we in the urban community are brothers and sisters and that [they] want to include us but the process didn’t allow time, so we were included in the parking lot. That’s how the process was. Urban Aboriginal people have been pushed to the side. And there have been some overtures [about including an urban Aboriginal health group in the work] but it was stalled. (Field notes from interview with P18)

While the excerpts above suggest there may be an existing desire on part of the First Nations health governance structure to include First Nations people away from home, they also suggest urban Aboriginal communities are largely not represented, at least at the time of this writing.

Some participants mention there have been efforts to include urban Aboriginal people in BC, particularly in the Relationship Accord agreements between the First Nations Health Authority and the other regional health authorities, which have “a fair focus on urban Aboriginal initiatives and interests” (P14). However, others indicate a lack of clarity on what this work will look like, as these processes and relationships are at an early stage of development. P06 explains:
The [BC First Nations health organization] has been engaging with the urban population in [a city] to try to figure out what will be that relationship but that is not yet very clear. And I think there’s quite a bit of anxiety around that at the moment about how it will work out. Anxiety is the wrong word, but uncertainty. (P06)

In highlighting the early stages of relationships between urban Aboriginal communities and the BC First Nations health governance structure, P06 draws attention to the anxiety and uncertainty about how urban Aboriginal people will be involved. The interviews further point to underlying tensions surrounding the inclusion of urban Aboriginal people in First Nations health policy decision-making in BC. P06 alludes to these tensions:

I don’t think we know what the right answer is yet [for including urban Aboriginal people]. I think it is a huge challenge and we’re just walking into it now to try to understand it and find the best way forward. I have heard that there is some nervousness on the part of some of the urban Aboriginal organizations about the [new BC First Nations health governance structure], and so they [the urban Aboriginal organizations] may not agree with it and they may want a separate approach. (P06)

In response to probing questions about what might be underlying such tensions, P06 suggests:

Well I think the [small] degree to which the urban community feels it can have an input into the governance of the [First Nations health governance structure] [is] because there is no mechanism for them to do that. The [First Nations health governance structure] is governed by BC First Nations and many urban Aboriginal people are not members of BC First Nations. So the question is how can [the governance structure] represent them when there’s no mechanism for them to be part of the decision-making? . . . [M]y perception is that the problem rests within the ability for them to participate in governance. (P06)
An analysis of these findings suggest the lack of mechanisms for including urban Aboriginal people in the First Nations health governance structure may be a contributing factor to the skepticism it receives on part of those in the urban Aboriginal community.

The interviews also point to several challenges in engaging First Nations people away from home. Some participants explain how the diversity of urban Aboriginal populations creates a unique context for engagement. One participant explains:

[U]rban Aboriginal populations are] less homogenous. So, for example, [in an urban Vancouver area], well we’re dealing with the Nuu-chah-nulth folks and Haida and Nisga’a and Musqueam, we’re dealing with everybody from everywhere. They don’t have single leadership, they don’t have common language, they don’t have common religion, they don’t have common history. What they get when they come [to the inner cities] is common concerns over the common issues right now. It’s a very different situation [than on reserves]. And it’s much more a flow. It’s almost like dealing with an immigrant group, if you were dealing with Ukrainians and Germans and people from Ghana and people from Bangladesh altogether. Different locations, different jobs, different languages, again that same issue of needing time and funding to be able to sort through the common issues and get a thoughtful approach to it. (P04)

P09 further explains how people within the urban Aboriginal community have varying perspectives on culture and connections to their home communities, ranging from those who are “traditionalists” to youth who have never eaten their traditional food or been to their home communities, which means focusing on urban Aboriginal communities requires consideration of “the diversity of culture, the loss of culture and the fluidity of culture in an urban environment.”
In addition to the challenge of dealing with First Nations diversity in an urban context, another participant explains:

Part of the difference and the challenge in urban Aboriginal governance is the fact that you then really need to consider how non-status, Métis and Inuit in some cases individuals are part of also the governance. So it goes beyond [including only First Nations people]. . . . [I]n the urban context you really have to have a broader concept and thus the governance model also needs to be broader based as well. So I think that those are the differences about the urban context. (P14)

The participants explain that urban Aboriginal communities are comprised of a diverse group of people, including First Nations people with diverse backgrounds, perspectives and differences in terms of First Nations status, as well as other Indigenous people such as Métis and Inuit people. Although each of these groups may have a shared interest in First Nations health policy decision-making, the analysis suggests meaningfully representing each diverse group may be a significant challenge.

The participants also drew attention to the fragmentation of urban Aboriginal communities in BC as an additional challenge to involving First Nations people away from home in health policy decision-making. One participant explains how service delivery organizations tend to represent the voice of “the urban Aboriginal community” in regional health policy decision-making, which presents a challenge as decision-making bodies “don’t have any way of knowing the degree to which those service delivery organizations are actually representing the view of the community . . . .” (P06). P06 continues:

The First Nations/Aboriginal community in the urban areas itself needs to become a little bit more cohesive and . . . be clear about . . . who and how it speaks for . . . the Aboriginal
people in the urban area. . . . And we can’t as a [health decision-making body] define that. We don’t want to define that. We can reach out and try to connect with urban Aboriginal organizations, but as I said, there’s a lot of fragmentation within the organizational community in the urban area. And some of it is clearly service provider oriented, others are a little bit more community oriented . . . . [W]hen we asked the First Nations [health governance] organization . . . about how best to get urban Aboriginal input so we can start building a relationship . . . they would, for example, suggest [an urban organization] as a place to have those conversations. . . . And so, you know, it becomes difficult for us as a [health organization to know] how best to engage the community when it appears from where we are to be fragmented. Now that may be just our again, kind of talk down attitude, I don’t know, but it is difficult for us to know the best places of gaining representation. (P06)

Although the literature points to self-organization of urban Aboriginal communities as an important factor in developing urban Aboriginal policy (Abele, et al., 2011), the interviews point to the need to think further about ways to engage urban Aboriginal communities in the face of such diversity and fragmentation. Meaningfully involving First Nations people living away from home in BC may thus require considering how diverse members of the urban Aboriginal population, including urban Aboriginal organizations, are represented in the BC First Nations health governance structure.

**Implications of Urban Aboriginal Exclusion**

The analysis points to the importance of addressing the challenges noted above, as the lack of urban Aboriginal involvement has several implications. For one, a major concern with the lack of involvement of urban Aboriginal people in health policy decision-making is that
considering almost half of Aboriginal people in Canada are living in urban areas, about half of Aboriginal people in BC may be excluded. Even though urban Aboriginal people are typically not represented in political discussions (Abele, et al., 2011; Peters, 2011a), another implication of the lack of urban Aboriginal involvement is that without a representative voice at the BC First Nations health policy tables, decisions may be less likely to address health issues affecting First Nations people living away from home. The interviews highlight several health policy issues specific to First Nations people who live away from home, including difficulty accessing health and social services and programs off-reserve. For example, P07 explains, that although First Nations people tend to move off-reserve in the hopes of better living conditions, “many [First Nations] people will move from reserves to cities to find themselves again at the bottom of the pile because they’re the latest immigrants.” P07 continues:

[T]he only thing that extends to urban Aboriginal people is the non-insured health benefits program . . . . Aside from that they are like anybody else living in an urban environment, they’re taxpayers, homeowners, the guy next door, right? . . . All they have that differentiates them from the rest of the country is a card that says they don’t have to pay federal sales tax and a card that says they get a certain percentage of their pharmacy, dental, medical transportation paid for and that’s it. All other benefits extended to Aboriginal people such as housing, education are all located on reserve. So for a lot of people trying to make that improvement [in their lives] and going from reserve to urban environments, it requires leaving a certain number of things behind. And it is quite often a very frightening experience for them to make that change. There’s cultural changes, language changes and there’s an infrastructure, bad as it is that’s self-perpetuating as you
get comfortable in it. And to leave that requires a certain amount of fortitude on the individual’s part.

The interviews also point to challenges First Nations people experience in accessing care outside of their home communities. P14 discusses the challenge of accessing services in the urban context in BC:

[P]art of what the challenge is [in the urban context] is breaking down the barriers in existing health services. I was talking with an elder yesterday in (an urban city) who when she goes to town, even though their reserve is really part of the town almost if you want to look at it that way, she’s told to go back to the reserve for some of the wellness programs. So there’s those kinds of barriers as well that need to be beat down.

Considering these implications of urban Aboriginal people not being at the BC First Nations health policy tables and the need for new approaches to urban Aboriginal involvement, this research aims to provide insight into new ways of thinking about meaningfully involving First Nations people away from home that considers these noted issues and challenges.

**Playing Dumb, Scanning Faces, and Surviving Policy Spaces: Experiences at the Decision-Making Table**

While the above section highlights a need to find ways of including urban First Nations people in health policy decision-making, the findings also suggest that attempts are being made to include First Nations people in other ways. This was reflected in the findings as the participants recalled their experiences being involved in decision-making related to First Nations peoples’ health. Considering attempts at involving First Nations people have often resulted in harms and misrepresentation, an in-depth investigation into participants’ experiences of involvement can shed light on the impacts and implications of First Nations people’s
involvement. In exploring these implications, Smye and Browne (2002) pose several considerations to keep in mind:

In the context of a consultative process, we are also concerned about whether or not the voices represented are those of Aboriginal people or simply the rhetorical voice of policy makers espousing the benefits of reform, in the absence of real material gains for Aboriginal people. Are Aboriginal people involved and how: at the symbolic level or is their involvement influential and meaningful? (2002, p. 52)

This question begs consideration of the underlying assumptions surrounding the ways in which Indigenous people are included in decision-making. By asking these questions the authors imply that it is not just enough to know that Indigenous peoples are included in the decision-making process, rather the ways involvement occurs may have various implications. With these questions in mind, this section explores participants’ lived experiences of being at health policy decision-making tables in order to learn what First Nations people’s involvement typically looks like and the implications this has for First Nations people.

*Fighting for the Floor*

By drawing on their experiences at decision-making tables, several participants described how it was not uncommon for First Nations people to have to fight for the floor in order to be heard. For example, one Indigenous participant explains:

[T]he way that the meetings are run, . . . you’ve got two hours, you’ve got this much agenda . . . you have to butt in and interrupt if you want to get something said. I’m so uncomfortable doing that. . . . [I]t completely goes against my nature and I think this is a cultural nature that I have. . . . I use that expression “elbows up” . . . [A]nd it so against my nature to be able to do it. So that is really, really difficult. (P09)
Participants described how the structure of meetings and the interpersonal dynamics around the table not only make it difficult for First Nations people to have their voice heard, they actively silence First Nations people who are present. One participant describes how meetings are typically structured in a way that caters towards dominant personalities, where the "aggressive first person in the door with the high elbows gets the most space" (P04). P04 recalls an experience where due to the limited time constraints of the meeting and the dominance of policymakers’ contributions to the discussion, the First Nations person at the table was not afforded an opportunity to speak:

(E)verybody was looking for an opportunity to blow their own horn and tell the rest of the crew, here’s what I’m doing for the [government I’m representing]. . . . [T]hey had gone around the table and they were getting input from people. [A First Nations woman] was sitting at the top of the table and nobody asked her anything. They went through a whole meeting without making sure everybody had their voice listened to. . . . ‘Okay, now it’s two thirty, we better be catching our float planes back to [the city], nice seeing you.’ Not even acknowledging that First Nation people have traveled down from [a remote First Nations community] to be there for a day and . . . [weren’t] even asked [anything]. (P04)

Another participant explains that “[i]n our [government] culture, sometimes if you don’t pipe up right away . . . that’s it,” and further argues that this kind of environment where people must fight to be heard is not conducive to collaborative decision-making with First Nations people (P05). The interviews suggest that the struggle to be heard is reflective of a dominant “meeting culture,” which tends to inhibit First Nations people from participating. One Indigenous
participant illustrates how this meeting culture makes it particularly challenging for Indigenous people like herself to participate:

Those meeting processes generally are set up for two beat people versus eight beat people. Do you know what I mean? Like people who are just like quick on the uptake [snaps fingers], always got to come back, always thinking ahead, you know, really quick, good chess players . . . versus people who have to sit back and reflect and who don’t necessarily want to jump in with a half-baked thought. . . . [I]t’s pretty common in Aboriginal community to find people . . . [who] are reflective. We want time to think about those things. But we’re against the clock. (P09)

These excerpts suggest that decision-making does not occur in a cultural vacuum, rather government-style meetings are a reflection of a culture that caters towards a certain way of being.

The interviews further point to a policymaking culture that caters towards a particular way of knowing. P09 provides several examples of being repeatedly asked to participate in meetings and speak to Aboriginal issues within the context of a particular health area outside of P09’s own expertise. P09 explains:

I have to have a little bit of their knowledge plus Aboriginal knowledge, right? So it’s hard on that level. It’s hard to be an expert in everything, which is their expectation of me. And so it’s easy for them [the people at the table] to shut me down because they have more specific knowledge in their specific area than I do. (P09)

These dynamics create a situation where even though a First Nations person is invited to participate in meetings to provide expertise on First Nations health, the authority of those with Western scientific expertise takes precedence over those with expertise acquired through
Indigenous knowledge systems or through the experiential knowledge of being a First Nations person. As P09 illustrates above, this hierarchy of knowledge systems creates an environment where it is easy for First Nations people to be “shut down” at the table.

It is no coincidence that the structure of most policy decision-making meetings privilege people whose worldviews are rooted in Western ways of being. The interviews illustrate how colonialism is played out at the level of the decision-making table and permeates the interpersonal dynamics that are created around the room. Battiste (2009) argues that the dominance of Western worldviews is manifest throughout Canadian social systems, such as our health policy-making system, which suggests that Western ways of being and knowing are thus manifest in the very structure of decision-making tables created within the dominant policy system. In this typical meeting style, Western worldviews are not only dominant, but they actually govern the entire conversation. This could be described as a form of epistemological colonialism, where one groups’ worldviews dominates another’s.

Colonialism, however, is not the only system of domination that is working to silence First Nations people at the table. An intersectional analysis exposes how intersections between sexism and colonialism come to life in P09’s experiences of being an Aboriginal woman at the decision-making table:

And so I go to those committee meetings. . . and I sit there and I fret about all of the white male input, right? And there are a couple of Aboriginal community members . . . and we’re women and Aboriginal women are a bit more reticent. We’re not always fighting for the floor or to shake the agenda . . . And I notice that’s fairly common for Aboriginal women. So here we are doing this [Aboriginal health work] and it’s set up
structurally so that our input isn’t necessarily [included and] we’re not there shaping the
document. (P09)

An intersectional analysis shows how P09’s experience of being an Aboriginal woman further
compounds the silencing effects of the typical meeting structure. Her example illustrates how the
compounding effects of colonialism and sexism play out at the decision-making table. As argued
in Chapter Two, Indigenous women have historically been excluded from policy and decision-
making processes (Dion Stout & Kipling, 1998). Just as gendered colonial policies have
contributed to the further exclusion of Indigenous people from participating in Canadian society,
an intersectional perspective reveals how multiple systems of domination and oppression
intersect to compound the marginalization of Indigenous women and further exclude them from
participating in the Canadian policymaking system. This type of compounded exclusion is seen
in the lived experiences of Indigenous women participants. P09’s example illustrates this as she
frames her exclusion in relation to the conflict between the ways of being that are accommodated
for in typical meeting structures and her ways of being as an Aboriginal woman. The analysis
shows that what appears on the surface to be an open space for dialogue during meetings,
actually becomes a space for historical gendered colonial relations to be repeated.

The compounding effects of sexism and colonialism underpin the dynamic of decision-
making tables, even when men are not in the room. P09 illustrates this through the experience of
participating in meetings with women decision-makers who come from feminist perspectives.
P09 describes how, “they’d always be arguing from their feminist perspectives,” and that what
were seen as equitable decisions from a feminist perspective still resulted in decisions that were
inequitable for Indigenous women. P09 brings this case to point by describing her work in the
area of marginalized women’s health, and how even though the decisions that were made
primarily affected Indigenous women, issues specific to Indigenous women were not taken into consideration. P09’s critique of the historical construction of feminism explains why a feminist perspective alone is not sufficient to address the compounding effects of inequities caused by a history of gendered colonialism. She asserts, “Aboriginal women aren’t feminists. We don't buy into it just because we’re really an afterthought with feminism and never felt included” (P09).

Intersectional and postcolonial feminist perspectives draw attention to the necessity of thinking about sexism and racism together, as they overlap and perpetuate one another. These structural forces of oppression are not separate, but intersecting. Reading the findings with attention to only colonialism and not other systems of oppression may further ignore the multiple ways Indigenous people are excluded from policy decision-making. The historical exclusion of Indigenous women in feminism is illustrative of how sexism and colonialism have intersected throughout history to compound the marginalization of Indigenous women. The systemic exclusion of Indigenous women via the equitable aims of feminism (Anderson, 2000b; Green, 2007b) is an example of how meeting structures exclude Indigenous people under the guise of inclusion. As we can see through P09’s experience of being excluded among non-Indigenous feminists, an open space for dialogue, even among feminists, enables the history of gendered colonialism to repeatedly silence Indigenous women.

The interviews demonstrate how the “open” space for dialogue that often occurs at the table enables the dominating perspectives to rule. Some participants discuss the challenge of pushing back against dominant perspectives at decision-making tables. One participant explains:

“[W]e had quite a horrible . . . set of . . . meetings last week and we had Indigenous people at the table. But, you know what? The dominant think is so strong that people
couldn’t even see when they weren’t listening. . . . The big number one problem is the
dominant ideas are alive and well and drown out any dissident voices . . . . (P01).
Some participant questions whether it is possible to shift dominant perspectives at all, let alone at
the decision-making table. P09 explains:

[There are some people] who just have their own perspectives and you’re not gonna move
them . . . they’re not going to open their mind to an Aboriginal perspective. And they still
have that sort of all American idea of ‘we all create our own realities, we have this
democratic ability to pull ourselves up by our individual boot straps and Aboriginal
people generally as a whole don’t do that.’ That’s where they come from, so they’re still
blaming the victim . . . they can’t piece the whole picture together. Or they just refuse to
see it. (P09)

These interviews illustrate the pervasiveness of dominant perspectives in the wider social world
and the seemingly impossible challenge of pushing back against neoliberal attitudes that seep
into policy decision-making tables. The participants’ experiences reveal how these dynamics
create a situation where even though a First Nations person is invited to participate in meetings
to provide expertise on First Nations health, the dominance of neoliberal ideologies results in the
continued silencing and dismissal of First Nations people’s perspectives at the table. In this way,
the interviews illustrate how fighting for the floor is not always enough to shift dominant
perspectives, and other strategies are needed to push back against the power dynamics that
silence First Nations people at decision-making tables.

Actively Strategizing

Although I have featured P09’s experiences in this section of the dissertation, the
interviews from the other participants suggested that she is not alone in her experience. The
personal challenge of navigating these tensions was experienced by other participants as well. Both Indigenous and non-Indigenous participants who had personal connections to Indigenous peoples or communities shared common experiences of frustration, dismissal, and personal conflict when trying to advocate for the inclusion of Indigenous peoples and perspectives in their work. However, the interviews suggest that when participating in decision-making and advocating for addressing Indigenous health, Indigenous peoples are uniquely implicated in that they themselves are socially and politically located in the centre of the policy problem. This is illustrated through P09’s description of how she becomes the centre of the problem when she raises the difficult issues among her colleagues in meetings, “[T]hey agreed [with me] theoretically but when we talk about the tough issues of . . . racist policy or racist service providers, they close up and I become the centre or sometimes even the enemy” (P09).

These findings suggest that in typical decision-making processes such as meetings where decisions are being made about Indigenous people, although Indigenous people may be invited to participate as equal members of the group, their relative social, political, and ideological position creates multiple tensions that can be personally challenging to navigate. This is an important consideration when thinking about the quantity and quality of energy that decision-makers from various socio-political locations expend when participating in discussions around a decision-making table. The interviews suggest that Indigenous people must sometimes actively strategize their approach to participation in order to navigate the multiple tensions with which they are faced. P09 provides an example of this strategizing:

[O]ne of my ways of diplomacy is to play dumb. To play dumb, to play stupid, [by saying], I don’t get it, I don’t get it. If we’re focusing on primordial prevention and if we’re focusing on health inequities why are we [not] focusing on [Aboriginal people’s
health?]. . . [I]t’s been very difficult to ask people to start thinking that way . . . and start thinking about, you know, really, if we’re really going to target health inequities why aren’t we going to look at Aboriginal people, for example? Because we have the highest rating in health inequity. And [the people in the meeting] kind of looked at me. I mean it’s very tough to have those conversations. People are very uncomfortable with those conversations. (P09)

P09 implies that her strategy of “playing dumb”, or asking questions to prompt decision-makers reflexivity around their own resistance to focusing on Indigenous peoples’ health, is one way she tries to navigate the multiplicity of tensions she experiences. She strategizes in an attempt to offset the anticipated dismissal and exclusion of her perspective.

P09’s experiences expose how the careful strategizing required to navigate these tensions amounts to an exorbitant expenditure of energy. She describes the exhausting work of trying to speak out in strategic ways that are likely to get her voice heard by her colleagues:

[Y]ou push the agenda to the degree that you think . . . is right. Because you’re constantly sort of feeling with your toes to try to find that edge and keep pushing it and pushing it. . . . [T]here’s so many different levels of acceptance of Aboriginal people and issues so . . . you’re constantly scanning faces and body language and seeing where you’re at and how people are receiving you and trying to figure out how that’s landing on people. And trying to facilitate good relationship at the same time you’re trying to raise really tough issues. So, you know, it just gets exhausting, it really does. (P09)

The challenge of navigating the tensions around raising uncomfortable issues, dismantling dominant ideologies, evading dismissal, and as P09 suggests above, facilitating good relationships amounts to exhausting work, which is then further compounded by Indigenous
people’s personal connections to the issues and their central socio-political location in relation to the problem.

*Withdrawning and Resigning*

The interviews reveal how the task of fighting to be heard becomes exponentially challenging when Indigenous people are directly and personally implicated by the decisions in ways that the non-Indigenous people around the table are not. P09 recounts an experience of being part of a decision-making group, where she is the only one among her colleagues who is personally connected to issue at hand. Her frustration stems from the disparity between her and the others’ personal connections to the issue:

I’m frustrated beyond belief because . . . [I have relatives] coming into that centre . . . who are ducking and diving because they don’t want me to see them and no-one else there is having that experience because they’re all coming from other parts of town, right? They don’t have [relatives] living in the [low income area] . . . And so I’m trying to tell them that and they’re all looking at me like I’m being difficult. And so that was a real struggle for me. . . . So that was my experience there . . . it was far more difficult than anything I’ve ever done here at [this organization]. It was uncomfortable, I felt excluded, I felt like I didn’t have any friends there, I would go in and rush out. Everybody would sort of stay and chat afterwards but I would leave just because I didn’t feel like I was part of that gang. (P09)

As P09 describes, her personal connection to the issue and to the population being discussed was unique among the group of decision-makers. Her colleagues’ distance from the issue and lack of empathy resulted in her feeling frustrated and excluded. P09 was alone in her experience and was excluded from the social group dynamics. The combined tension of being personally connected
to the issues and being the only person amongst the group required to navigate that conflict resulted in her withdrawal from the group. P09’s lived experiences of decision-making reveal how socio-political inequities among a decision-making group can foster the withdrawal of Indigenous people who hold a unique social, political and ideological position.

Given these complexities, the findings suggest that for some Indigenous people, participating in meetings is an emotionally trying experience. This is illustrated in the powerful way P12 expresses her frustration with the ways Indigenous people are often included in policy decisions:

It really bothers me when I hear Aboriginal people included [in issues that are not important], talking about sophisticated nuances of policy, challenges and barriers. And I’m like, give me a fucking break. Could you just not fucking kill us in emergency room here? . . . I read this stuff every single day [because of the work I do] and I’m horrified and I’m thinking how come the world doesn’t know about these things, right? . . . Let’s get real about [how] we’re trying to survive some of these spaces. (P12)

The emotion in P12’s words are exemplary of the kind of frustration, stress and emotional pain that some Indigenous people may experience through participating in policy discussions, especially when the topic of discussion is perceived as relatively unimportant. P09 describes one experience in a particular set of meetings that were so stressful her subconscious mind attempts to prevent her from participating:

I used to actually just dread going to those [committee] meetings. I’d sit there in my office and work late before I had to go down. Oh god, I feel a headache coming on. Is that a sniffle I feel? Oh my stomach really hurts. And I’d realize [I’m] trying to get sick instead of having to go to this meeting today. (P09)
P09’s description of “trying to get sick” in order to avoid meetings illustrates how the stress from the meetings can be so great that it inhibits one’s participation. Later on in the interview, P09 reveals that she finally resigned from the group, as the personal stress from navigating the multiple tensions became overwhelming. The above findings suggest that the multiple intersecting experiences of oppression faced by Indigenous peoples’ throughout decision-making processes contributes to an internalized, emotional stress, which subsequently leads to withdrawal and resignation from the decision-making process altogether.

The interviews also reveal how the stress and isolation that inhibit Indigenous peoples’ participation is often unacknowledged or misinterpreted by decision-makers who are not faced with the same challenges. For example, while describing a work experience where involving Indigenous people was a challenge, one participant notes, “And this is a completely an aside, Alycia, neither of those [Indigenous people] have been present at all the meetings so it’s not like I have a really good relationship [with them] . . . . For whatever reason they haven’t been able to be in attendance all the time (P03). P03 further reflects, "I think it’s just that they’re too busy. But there is a role in policy making through relationships. And perhaps they didn’t realize the significance of this issue” (P03).

P09 also speaks to the issue of Indigenous peoples’ absence in meetings:

I find a lot of Aboriginal people that I’ve talked to will stop going to meetings and people will ask, ‘Oh well, we invite them and they don’t come, so therefore we’ve done our part. We’ve invited them, they don’t come, so we’re just going to have to carry on without them.’ And there’s never any reflection on why don’t they come. Maybe they don’t come because it’s so uncomfortable for them to be here and maybe [they know] the message
that they’ve got . . . is so uncomfortable. And maybe they’re just not feeling strong enough to be the conveyer of that message today. (P09)

P09 articulates how Indigenous peoples’ unexplained absence in meetings is a common occurrence, and she draws on her own lived experiences to suggest that the experience of participating may be so uncomfortable and the strength required to operate within that environment is so much that Indigenous people are deterred from participating. Furthermore, P09 points out the lack of reflection on part of other decision-makers in relation to why Indigenous people stop attending meetings. These findings may point to the need for increased awareness on how decision-making processes exclude First Nations people, even when they are seemingly included in the process.

The Paradoxical Nature of Involvement

An analysis of the findings above suggests that even when it appears that Indigenous people are involved in decision-making, a closer examination may show that involvement is not always what it seems. The findings reveal how decision-making processes that include Indigenous people can ironically foster Indigenous peoples’ exclusion from the very processes in which they were invited to participate. The ways that Indigenous people fight for the floor, actively strategize and eventually withdraw and resign from decision-making tables is indicative of the silencing, dismissal and ultimate exclusion that can occur by virtue of the process of involvement. In this way, processes of involvement can be paradoxical in that Indigenous people are excluded via processes of inclusion.

Regan’s (2005) writing on unsettling the settler within sheds light on this paradoxical involvement. Regan (2005) discusses the “deep chasm” that opens when non-Indigenous and Indigenous people engage with one another other:
It is the gap between what we (as non-indigenous people) think we are doing – which is engaging with good intentions in an intercultural dialogue, and how Indigenous peoples experience that same event as a manifestation of deeply engrained institutional colonialism and attitudes. In these situations what we are really doing, whether unconsciously or not, is asking Indigenous peoples to fit within our cultural paradigm – to have the intercultural dialogue on our terms, not theirs. And when this is pointed out to us we get uncomfortable. (p. 2)

Regan (2005) argues that conflict emerges from intercultural dialogues where Indigenous people are asked to engage on terms implicitly determined by the dominant cultural paradigm. In this sense, Regan’s point illuminates how intercultural dialogues are often not intercultural at all; rather they are deceptively rooted in the dominant culture to the extent that upholders of the dominant culture are unable to see the underlying paradigmatic conflict.

This perspective helps to explain participants’ numerous descriptions of the “uncomfortable environment” inherently created when First Nations and non-First Nations people come together around the policy table. Reading the findings in light of Regan’s argument illuminates how when Indigenous people are invited to participate at policy tables, they are being invited to participate in a dialogue on the colonizers’ terms, which privileges the voices of those whose ways of being and knowing are rooted Western traditions. The resulting effect is a Eurocentric system that delegitimizes and subjugates Indigenous people’s ways of being and knowing, thereby enabling the silencing and dismissal of Indigenous people even when they are “included” at the table. This notion sheds light on how decision-making processes can serve to “shut down, shut up and shut out” Indigenous people from the system altogether; a feeling
commonly experienced by Indigenous people when participating in various aspects of Canadian society (Department of Justice Canada, 2002, p. 17).

A critical analysis of the silencing, dismissal and exclusion – or shutting up, shutting down and shutting out – that occurs through policy decision-making points to how these effects are created and sustained through colonial structures such as the policymaking system. Kurtz et al. (2008) argue that colonial structures have worked to silence Indigenous people, and Indigenous women in particular, and that this silencing can be understood as an impact of colonization and an act of structural violence. The authors argue that unequal power relations within the health care system can lead to oppressive interactions that silence Indigenous women in health care settings, which ultimately impedes their access to health care and endangers women’s health (Kurtz, et al., 2008). Although Kurtz et al. (2008) describe how this occurs in clinical encounters between Indigenous women and health care providers in urban health care settings, this notion may also help explain the silencing and dismissal that occurs around decision-making tables. Kurtz et al. (2008) argue that the acts of structural violence experienced by Indigenous women in health care settings causes many women to refuse or delay their access to health care services or accept the status quo in attempt to avoid anticipated racist interactions. Likewise, participants’ experiences of resignation and withdrawal may be indicative of Indigenous peoples’ attempts to avoid anticipated encounters of silencing and dismissal, which often occur around the decision-making table.

A critical examination of the forces that contribute to these acts of structural violence can help to further understand the effects of silencing and dismissal that occurs at health policy decision-making tables. An intersectional perspective draws attention to the ways that multiple systems of oppression intersect to differentially impact experiences of people across a spectrum
of social and political identities (Hankivsky & Cormier, 2009). Reflecting on the multiple intersecting forces that differentially shape people’s experiences of participating in decision-making can help to more deeply understand the participants’ lived experiences of being at and not being at the decision-making table. While Kurtz et al. (2008) point to the silencing of Indigenous women in health care encounters as acts of structural violence due to colonialism, an intersectional analysis may reveal, for example, how colonialism, sexism and neoliberalism intersect to create different experiences and implications of participating for different people around the decision-making table. Power operates at multiple levels, such as relationships between Indigenous peoples and governments, women and men, funders and recipients of funding, and those who experience relative social or economic gain or loss from participating in decision-making or from the outcomes of decisions. Thayer-Bacon’s (2003) notion of relational epistemology, in which all beings are seen as constructed in constant relation to each other as well as in relation to broader interrelated contexts, can help to view the dynamics around the table as relational, whereby each person’s social position is relative to the social position of others’ around the table as well as in relation to the broader systems of power that underpin the entire decision-making process.

An intersectional analysis of the findings thus reveals how multiple forces of power intersect to shape the relational dynamics of those around the decision-making table, which differently shape people’s participation and pose challenges for people in various relational positions of power to come together as “equals” around the decision-making table. Drawing on critical perspectives such as intersectionality can provide insight into how to improve health policy decision-making processes given the inherent power inequities that emerge when Indigenous and non-Indigenous people come together to make decisions. An intersectional
analysis of the findings can generate knowledge about how processes such as decision-making could be more responsive to those who are differentially implicated by multiple systems of power and provide direction for more effective and equitable approaches (Browne, Varcoe, et al., 2011). In the following chapters I critically examine the data to glean insights into how decision-making processes could be improved to foster more meaningful and influential participation of Indigenous people, which in turn may lead to better outcomes for First Nations people who are both involved in and implicated by such decisions.

**Summary**

This chapter illustrates how despite the recognized importance of First Nations people’s involvement in policy decision-making related to First Nations peoples’ health, First Nations people are still often not involved at health policy decision-making tables and involvement in policy decision-making overall is shrinking. Furthermore, the participants’ lived experiences reveal how decision-making processes are structured in ways that shut down, shut up and ultimately shut out Indigenous people from decision-making processes. A critical analysis of these findings helps to understand these effects of silencing and dismissal as acts of structural violence shaped by multiple intersecting systems of power. Further analysis based on critical perspectives may provide insight into ways of improving processes of involvement so as to foster more meaningful and influential participation of Indigenous people and transform health policy decision-making processes.
CHAPTER SIX – TOKENISM IS A GIANT STEP FORWARD: PRACTICAL INSIGHTS ON FOSTERING INVOLVEMENT

Introduction

I begin this chapter by reflecting on the value of a critical analysis in shedding light on the research problem. As a critical analyst I ask myself, where are we left by critically analyzing? Where does critical analysis leave those who are consistently caught in this paradox of meaningful involvement? What practical insight does it offer to assist those who work everyday in these paradoxical processes so that they can be effective allies, advocates and activists? How can critical analyses offer a ‘rope of hope’ to those whose commitment to social justice, transformative change and health equity loom under the cloud of these inequitable systems of power?

One might argue that a flaw of critical analysis is that it leaves the analyst in a ‘critical conundrum’: As critical researchers, we fine-tune our skills of analyzing social phenomena to reveal the complexities of social life, yet I find that our rigorous attention to exposing problematics often leaves us with more questions than answers at the end of the day. Considering the social justice and equity-oriented aims of critical analyses, we might ask, is it ethical to conclude our projects with only an exposure of a paradoxical problematic? Is it ethical to only offer a critical analysis of the problem? I argue that these questions point to an ethical imperative critical researchers have, at times, to soften our critical gaze and actively attune ourselves to the question of how we can navigate the complexities we have made visible. What insights can we offer the people implicated in our research for navigating the challenges of their lived realities?

In this research, critical perspectives have informed an analysis that makes the paradox of meaningful involvement visible, and yet what is urgently needed is a lens to make visible a path
forward in light of participants’ everyday realities. I am thus compelled to engage in an analysis that extends beyond exposing the paradox of meaningful involvement, and analyze the data with a view to understanding how to foster meaningful involvement of First Nations people in light of the challenges of health policy decision-making in a neoliberal neocolonial context. Recognizing that the existent literature lacks practical insight into this question and that the participants, who live in the everyday reality of policy decision-making, may have valuable insights for navigating this paradoxical problem, this research in part aims to expose the realities of participants’ practical day-to-day challenges and bring their insights and ‘lessons learned’ to the surface. In this chapter, I am shifting the analysis away from critically theorizing about the problems of policy decision-making, and moving towards a reading of data that articulates and describes the practical realities, challenges and strategies of meaningfully involving First Nations people in health policy processes. The purpose of this chapter is therefore to illuminate the perspectives of participants who have experience working in health policy decision-making, with a view to offering a window of insight into navigating the paradox of meaningful involvement.

As the analytical direction in this chapter moves from ‘exposing the paradox’ to ‘exposing the practical,’ a palpable shift in tone can be felt. This shift in tone can be read as a move from ‘theorizing to realizing,’ as it reflects an intentional effort to veer away from critically theorizing on what happens at policy tables and to instead feature participants’ analyses and reflections on their practical challenges and successes. As participants reflected on their practical lessons learned, their interviews became less emotive and more descriptive in nature. Reading the representation of data and analysis in this chapter may consequently feel less ‘dramatic’ or ‘gripping,’ yet these perspectives offer important insights on what might constitute meaningful involvement. This provides an opportunity to ‘hear’ participants’ perspectives on
what has worked, what has not worked, what is needed and what could be done to involve First Nations people in more meaningful and influential ways. The analysis of participants’ practical insights informs a concluding discussion on considerations for navigating the paradoxical policy decision-making climate and taking action towards meaningful involvement.

**Wrestling with Engagement**

Recognizing the need to meaningfully involve First Nations people in health policy decision-making and reflecting on the challenges they had witnessed in such processes, participants wrestled with the question of how to meaningfully involve First Nations people in the face of historical and ongoing colonization. One participant explains:

Well I think that one of the big issues, of course, is the whole issue of [colonization] . . . . How it also shapes the policies that we have in this country . . . . [H]ow do you back away from a colonial sort of attitude . . . in relationships and build a trusting relationship between the Aboriginal and non-Aboriginal communities so that we can be working together on these public health issues? (P08).

In wrestling with questions such as these, the participants echoed LaRocque’s (2010) stated belief, “the majority of non-Native peoples in our country want to be fair and caring, not just replicating a history full of mistakes and some malefaction. . . . Nevertheless, our encounter is informed by colonization” (p. 14). The participants discussed the good intentions on the part of those working in policy to find ways of involving First Nations people in more meaningful ways; yet despite such intentions, the historical and ongoing nature of colonialism is discussed as a significant stumbling block to working together.

Although the participants’ displayed an acute awareness of the impact of colonialism on Indigenous and non-Indigenous encounters in policy decision-making, their interviews reflected
an uncertainty about how to navigate these dynamics. This is illustrated in a debate among a health policy advisory group, which one participant describes:

[W]hen the [group] first formed, one of its goals was to pay special attention to Aboriginal peoples’ health. That was part of their mandate from the beginning and they never did it. There were endless arguments about, how are we going to incorporate that? Would we have Aboriginal representation in the [group]? If we did that do we need it all levels of the [group], not only at the general [group’s] table but at the expert groups as well? Who would you choose? Who’s credible? How would you keep this from being political? This argument went on and on and on and no-one could come to a conclusion. (P19)

P19 continues to share an analysis of what underlies such debates:

[I]n Canada people who work in health who haven’t worked with First Nations people aren’t comfortable working with First Nations people. . . . [They] are very reluctant to make decisions because they want to be very sensitive that they don’t do thing wrong thing. And in being so sensitive to doing the wrong thing, they never do the right thing. Because they feel so timid and cautious. (P19)

Like P19, other participants explained how there is often a hesitancy to include First Nations people in decision-making that arises from a variety of fears, including making the wrong decisions, crossing jurisdictional boundaries, and receiving backlash from First Nations communities. Several participants discussed the tendency for decision-making between First Nations and non-First Nations people to be uncomfortable, and some participants explain that this discomfort stems from the legacy of colonialism and the history of tensions between Indigenous people and governments. These discussions illustrate how the “psychology of
colonialism lingers” in policy settings, (LaRocque, 2010, p. 6), and how policy decision-making environments may be illustrative of what LaRocque (2010) describes as “the contested ground upon which we, the Canadian colonizer-colonialist and Native colonized, have built our troubled discourse” (p. 3).

Reading the participants’ discussions in light of LaRocque’s (2010) assertion that colonization has served to sustain the colonizer/colonized divide and the distancing of Indigenous people from non-Indigenous people, institutions and systems, shows how the legacy of colonialism has created a policy decision-making environment riddled with junctures that serve to keep Indigenous people away from policy processes. This is illustrated in the excerpt above, where P19 explains that because the group could not resolve the issues around how to include Aboriginal people in the process, the end result was that Aboriginal people were never included, despite the fact that it was part of the group’s mandate from the beginning. This example illustrates how the complex jurisdictional landscape of First Nations health policy, which has evolved within a colonial and neocolonial context, has created uncertainties in knowing which First Nations people to include, and how.

Although participants’ wrestled with these uncertainties of knowing how to include Indigenous people given the challenge of the colonial policymaking environment, they also reiterated the need to find ways of working through these challenges and including Indigenous people in policy decision-making. As P17 asserts, “Aboriginal representation . . .[is] extremely difficult to do . . . at a policy meeting table, but it has to be [done].” Drawing from LaRocque’s (2010) assertion that both Indigenous and non-Indigenous people “are challenged to attend to decolonization while keeping with our respective legacies,” and that ending Indigenous peoples’ marginalization in society must be a “collective aspiration” (p. 14), the interviews point to the
need for insight on how to foster Indigenous representation on the contested ground of health policy decision-making, so that Indigenous and non-Indigenous people can work together on policy issues towards a collective goal of health equity.

From Tokenism to Transformation: Perspectives on Meaningful Involvement

In sharing their perspectives on what constitutes meaningful involvement, the participants provided many insights on how to involve First Nations people in meaningful ways. The interviews highlight a range of approaches to involving Indigenous people in health policy processes within the contemporary neocolonial and neoliberal climate, which participants described as problematic in some instances, and as significant strides towards meaningful involvement in others.

Starting with Tokenism

In their discussions on how First Nations people tend to be involved in health policy processes, several participants alluded to the emerging trend in non-Indigenous institutional settings of recognizing Indigenous people through a protocol of acknowledging traditional Indigenous territories and/or the Indigenous people on whose traditional territory policy processes occur (Wilkes, Duong, Kesler, & Ramos, 2015). One participant explains how the protocol of acknowledging First Nations territory is part of a regime of organizational policies being implemented in a health policy organization:

[Y]ou may have a meeting where you’re involving Aboriginal [or] First Nations people and generally there’s a protocol that one would like to see followed where there’s a recognition of traditional territory of Aboriginal people and First Nations people and

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30 By referring to both Indigenous and non-Indigenous people, the intent is not to sustain the diametric oppositional positioning of Indigenous and non-Indigenous people, which LaRocque (2010) argues is problematic in that it distances Indigenous people from non-Indigenous processes institutions and thereby fosters the structural exclusion of Indigenous people from social and political life. Rather, the intent is to articulate the findings in ways that are consistent with participants’ framing of issues.
that’s not done very consistently. . . . So there’s probably about half a dozen of [these policies] that we’re working through our system [in response] to . . . the recognition of the need to create a culturally competent organization. (P06)

This example illustrates how acknowledging Indigenous territory can be conceptualized as an explicit effort taken by health policy organizations to become culturally competent, whereby the organization works to increase its capacity to better meet the needs of Indigenous people and address inequities in health and health care (see Aboriginal Nurses Association of Canada, 2009; Betancourt, Green, & Carrillo, 2003; Brach & Fraserirector, 2000). Another participant reflects how the trend to acknowledge Indigenous territory may be indicative of a shift in attitude towards recognizing and responding to health issues affecting First Nations peoples, and that this has become prominent in BC health policy settings:

[T]he Aboriginal presence is . . . much more obvious in B.C. than in Ontario and it’s much more positive [in BC]. I’ve asked a couple of people about it . . . [because] I don’t think I completely understand it. I mean you don’t go to a major gathering or a conference without somebody acknowledging you’re on [First Nations] territory . . . and I think it’s lovely. It doesn’t mean to say that B.C. has all the answers, but I gather . . . treaties weren’t signed here . . . and there’s a different attitude. And I think there is more of a commitment to doing something [about First Nations issues]. (P03)

These excerpts illustrate how recognizing Indigenous people through acknowledging Indigenous territory may have a significant meaning in policy contexts, and particularly in the BC First Nations health policy domain. By creating the sense of an “Aboriginal presence,” acknowledging Indigenous territory could be seen as invoking a certain consciousness about including
Indigenous people in policy decision-making and connoting a commitment to addressing Indigenous health issues.

Similarly, some participants discussed how the emergence of efforts to incorporate Indigenous ceremony as an organizational practice, such as smudging or inviting elders to give an opening or closing prayer, is often seen as a significant effort to recognize First Nations people and draw attention to First Nations issues in health policy contexts. Some participants explained how, from an Indigenous perspective, including Indigenous people through ceremony can have a particular and powerful meaning. Turner (2006) illustrates this by explaining how an integral proviso of the Condolence Ceremony is “that keeping one’s word in the public sphere is recognized by everyone,” which reflects the Iroquoian philosophy that promises made in the public domain “are elevated to the highest standards of diplomatic protocol” and in certain situations words can “bind a person to keep a promise” (p. 50).

Although participants discussed the significance of including Indigenous people through ceremony, they also critiqued this approach as a way of including Indigenous people in policy processes. Two Indigenous participants explain:

[It’s] appealing to some people, and mainly the white people actually, to have change represented by someone holding a feather or having an elder come to do an opening prayer. And in no way do I disrespect the significance of that, however, change, a revolution, is never going to pivot on an opening prayer. . . . [S]ome of these ideas are superficial. [They have] [d]eep spiritual meaning [for Aboriginal people], but have very superficial effects on white people. (P12)
We don’t start our meetings with prayer because I know that’s what [senior executives are] expecting . . . Aboriginal [people] to be. And to some degree I question whether that’s the place for it or not. . . . I worry that there’s a danger of us [Aboriginal people] tokenizing ourselves by putting [ceremonial practices] as the number one thing that you can do. It’s easy to do, it costs you five minutes at your meeting, you don’t have to spend any money and, ‘Oh there we’re done. We included Aboriginal people. (P09)

Echoing Turner (2006), participants explained that ceremony may have deep spiritual meaning for some First Nations people, yet they further asserted that it can also be experienced as superficial, tokenizing, and may contribute to the misconception that a sufficient level of involvement has occurred. Dion Stout (2008) suggests although Indigenous cultural practices are often important to Indigenous peoples’ identities, constructions of Indigenous peoples as primarily cultural beings can distract from the important role broader social, political and economic factors play in Indigenous peoples’ health. The author asserts that while Indigenous peoples’ identities are often defined through Indigenous culture, “this view becomes too narrow when it suggests that no one has to work hard on the non-cultural (social, political, economic) aspects of our lives” (Dion Stout, 2008, p. 11). Inviting First Nations people to participate solely in ceremonial ways may thus perpetuate a culturalist建设 construction of First Nation people as primarily cultural beings, which may undermine the broad range of perspectives and knowledges First Nations people may contribute to policy development. Reading the findings in relation to this critique suggests ceremony may be a respectful or meaningful way of including First Nations people, however, efforts are needed to ensure First Nations people are involved in not only

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31From a culturalist perspective, Indigenous involvement could be viewed as the inclusion of Indigenous peoples’ cultural practices, as opposed to, for example, the inclusion of Indigenous peoples’ diverse perspectives and knowledges that are rooted in a range of intersecting social, political and historical dimensions.
cultural ways, but also in ways that influence policy decisions and inform how decisions are made.

Despite participants’ criticisms of the tendency for First Nations people to be involved as, in P16’s words, “token Indians” who are “not allowed to do anything,” the interviews also suggest tokenism should not be overlooked. One participant explains:

We cannot become . . . complicit with the appetite for tolerance . . . [But] in some spaces, that tokenism is a giant step forward. However . . . we can’t stop there. . . . [Y]ou’ve got to start where they’re at, but it doesn’t mean you’ve got to expect less. Like prayer today, [but] how about next year we do something really radical, you know, besides a prayer. (P12)

P12’s powerful statement is paradoxical: On the one hand, tokenism may perpetuate the view that First Nations people only need to be included in cultural ways; yet on the other, any inclusion at all can be seen as a step in the right direction. In light of the critical cautions above, and at the same time, considering the overall shrinkage of First Nations involvement, the interviews suggest that even small efforts to recognize First Nations people and traditional territory and ensure First Nations people are represented, even in tokenizing ways, may signify an important starting place in moving towards more meaningful involvement. At the same time, considering the problems with including First Nations people in primarily tokenistic ways, identifying ways of involving First Nations people that move beyond recognition of traditional territory or tokenistic representation are needed.

**Moving Beyond Tokenism**

The interviews provide several insights about issues of representation and how issues related to which First Nations people need to be at the table could be tackled. In addition to the
oft-cited problem at policy tables of designating only one First Nations person to be the representative voice for all First Nations issues, participants drew attention to the importance of paying attention to which First Nations people are involved. This importance of examining who is involved is reflected in Young’s (2002) argued need for inclusive democratic communication, which “alert[s] to the possibility that a public that appears to have shared understandings might exclude some needs which do not find expression within those shared understandings” (p. 37). Young’s (2002) point serves as a reminder that the First Nations people who are included in policy decision-making processes may not represent the diverse range of needs and interests of First Nations people. This idea resonates in some participants’ assertions of the need to pay attention to which groups and whose interests are being represented when a First Nations person sits at the table. For example, this Indigenous participant discusses the tendency of only certain First Nations voices to be represented in policy processes and emphasizes the importance of questioning who is representing community interests:

[T]here has to be a process whereby . . . First Nations and/or Aboriginal communities, however you define Aboriginal communities, have a voice at the table. So . . . how do the people at the table make sure that the voice of small remote First Nations or regular “Joe Indian” . . . just the average Aboriginal person be at the table? Too often we’ve had . . . only experts, government professionals and no representatives of the people. So we would be making policy decisions and each person would have to say, for instance, . . . I represent the province of B.C. I do not represent First Nations interests. Because what would happen before was people would say, ‘Oh well, that face is brown and that face is brown, so we’ve got all our bases covered.’ That was a fundamental error . . . . I question . . . who at the table has their ears to the ground? Who at the tables hold the voice of First
Nations or Aboriginal people? And if that question is not answered satisfactorily at your policymaking table, the policy making table ethically should fold or it will fold because they won’t be able to reach a helpful decision. (P17)

Participants repeatedly emphasized that while First Nations professionals holding government positions are sometimes positioned at policy tables as the experts on First Nations issues, the perspectives of the “average Aboriginal person” who is not a government representative are just as important for making good policy decisions. Participants discussed the importance of including the people who are directly impacted by the decisions; however, the interviews suggest not all First Nations people are equally positioned to represent this perspective at the table. Participants also emphasized that when determining who needs to be at the table, it is important to consider the varying perspectives that First Nations people have.

In several interviews, participants challenged the assumption that all First Nations people have the critical perspective necessary for pushing back against dominant ways of thinking and making better policy decisions for addressing First Nations health and health inequities. For example, while asserting Indigenous people should “absolutely” be included at the table, P01 argues,

[Y]ou can’t just think that in some kind of band aid way you get an Indigenous person to the table and it’s gonna have any kind of influence. Because there’s such a risk of tokenism and such a risk of [thinking], now we’ve included Aboriginal people so therefore this . . . must be a better policy, not necessarily. . . . [J]ust because you’re Aboriginal doesn’t mean that you think outside of the dominant way of thinking. You know you can have somebody at the table that’s just as capable of saying, ‘Oh,
Aboriginal people should just pull up their socks’ as their Euro Canadian counter parts. (P01)

In addition to exposing the false assumption that including just one First Nations person will lead to better decisions, participants highlighted the need to involve First Nations people who view First Nations issues with an analytical lens that challenges dominant neoliberal ways of thinking, and who are attuned to the structural forces that shape health and health inequities. This may be reflective of the need to involve Indigenous people who view policy issues through a particular lens, such as the lens Turner (2006) describes as a *critical indigenous philosophy*, whereby Indigenous people understand Indigenous philosophy, become educated in Western European ideas, and engage in these ideas as “a philosophical and political activity” (p. 9). Yet in light of this need, the interviews expose how the same structural forces that shape health inequities also impede First Nations people from gaining what is necessary to push back against dominant ideas at the policy table.

**Disrupting the Cycle of Exclusion**

While some participants suggested that including First Nations people with a particular analytical lens is important for developing good policy, others were aware of the challenges Indigenous people face in honing a critical lens that disrupts dominant ways of thinking. Turner (2006) suggests there are relatively few Indigenous people “effectively engaging [with] the Western European history of ideas,” which is partly due to the resistance and hostility experienced by Indigenous people in Western educational institutions (p. 10). Battiste (2009) further argues that the systemic erasure of Indigenous knowledges in mainstream education restricts Indigenous peoples’ access to Indigenous worldviews and perspectives, which in turn

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32 Battiste (2009) argues that the exclusion of Indigenous knowledge in Western social structures not only infringes on Indigenous peoples’ rights to exercise their own culture, but that this exclusion undermines the importance of Indigenous knowledge and prohibits Western society from benefitting and advancing from Indigenous knowledge.
deeply influences Indigenous people’s identities and “denies Aboriginal people access to and participation in the formulation of government policy” (p. 194). These ideas are reflected by one Indigenous participant, who explains, “[Indigenous people in Canada] all went to the same public schools and there’s no Aboriginal history or analysis or perspective. We’re all taught to think like white people in school,” and as a result, many Indigenous people “bought into . . . the great Canadian Indigenous stereotype” (P09). P09 continues:

> It’s hard enough trying to . . . recover your own culture, know your own history, or maintain . . . your sense of yourself when you come into a university setting or a mainstream [government] setting. It’s hard enough to do that, never mind for you to develop the analysis that’s required for us [as Indigenous people] to look at mainstream [with a critical lens] or to look at Aboriginal specific issues.

These excerpts illustrate how systemic racism in the education system often inhibits First Nations peoples’ access to perspectives that are helpful in disrupting dominant ways of thinking about First Nations health policy issues, as well as access to the education needed to participate in the policymaking system, let alone participate in ways that disrupt dominant ways of thinking. In this way, the systemic exclusion of Indigenous people from Western social structures perpetuates a cycle of exclusion.

In recounting BC First Nations’ early negotiations with governments in becoming involved in health policy decision-making, one Indigenous participant illustrates the cycle of First Nations peoples’ exclusion from policy:

33 In a previously published work (Fridkin, 2012b), I argue that the structural exclusion of Indigenous worldviews, knowledges and histories has severe implications for Indigenous peoples’ identities, as it “forc[es] Indigenous peoples to engage in policy by taking up colonial discourses as their own – an ultimate form of assimilation” (p. 115).
[W]e literally had people say to our face, ‘We don’t think you have the capacity to make a decision. We don’t think you have the capacity to hold high-level positions. We don’t think you have the capacity to keep up with us at the table.’ . . . Our expertise . . . on our own population was completely unrecognized. So maybe we weren’t senior bureaucrats, maybe we hadn’t worked within government structures as much as their bureaucrats who we were sitting across the table from, but our knowledge of our populations was profound. And their knowledge of our populations was weak. . . . There are still some who question us on [our expertise and capacity to make decisions]. For instance, we’ve never run a health system. I don’t think there are any First Nations who have ever run a health system. And that was used as justification for not including us in decision-making within the health system. But it’s, what’s the word, you know, when the circle . . . chases its own tail. If we’re never allowed to decision-make how will we ever get experience in decision-making?

P17 draws attention to the ways First Nations peoples’ exclusion from policy decision-making is not only structural, but also cyclical; First Nations people are excluded from the policy system due to systemic racism, yet this exclusion impedes First Nations people from gaining what is needed to participate in the policy system. Fiske and Browne (2008) argue that policy discourses tend to “undermine Aboriginal people’s assertions that they are capable of taking on responsibilities of self-government,” and that, “[i]n every day life these constructions emerge as justification for the status quo” (pp. 13-14). This illustrates one of the ways in which First Nations involvement in policy is paradoxical, and how the exclusion of First Nations people from policy operates at a structural level to perpetuate the continued exclusion of First Nations people from policy decision-making. This poses significant challenges to fostering First Nations
peoples’ involvement in policy: How can First Nations people inform policy decisions or transform the way policy decisions are made, if the system itself is preventing First Nations people from being involved? Fostering First Nations peoples’ involvement in policy therefore requires disrupting this cycle of exclusion. As discussed below, participants provide insight into what is needed to mitigate the effects of structural racism in the policy system and disrupt the cycle of exclusion.

**Legislating Involvement: The Impact of Formal Agreements**

Indigenous policy scholars describe how the systemic exclusion of First Nations people from policy has historically occurred through the “unconcealed, unilateral, and coercive nature of colonial rule” (Coulthard, 2014, p. 4), and how the modernization of colonial policy tools and processes has enabled this systemic exclusion to continue in the contemporary neocolonial policy context (Irlbacher-Fox, 2009). Recognizing these systemic ways First Nations people are excluded from policy, several participants discuss the necessity of implementing powerful measures within the policy system to force governments to include First Nations people in decision-making on First Nations health issues. To illustrate, one participant reflects on what has allowed First Nations people to have more influence in the BC health policy scene:

[I]s it that the stars are better aligned now? Is it that people are more open to addressing Aboriginal issues? Is it that there’s been enough Royal Commissions on us that we’re starting to get some traction? Is it that the apology\(^\text{34}\) . . . has pushed these things forward? We think no. We think what’s really worked here in BC is having that external First Nations [health agreement]. . . . [B]efore that maybe . . . it was the failed Kelowna Accord (P09).

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\(^{34}\) This refers to the official statement of apology to Indigenous Canadians for the implementation of the residential school policies on behalf of the government of Canada, which was delivered by Prime Minster Stephen Harper in 2008 (Dorrell, 2009).
Like P09, participants repeatedly explained how formal agreements between First Nations and governments have played a key role in ensuring First Nations people are at BC health policy tables, and have helped to push forward First Nations health agendas, as this participant explains:

> We are attached to the Transformative Change Accord, if we didn't have that we would have flat burnt out, we never would have gone anywhere. . . . [H]aving some kind of MOUs\(^{35}\) [or] something, we need something. . . . I wrestle with [knowing] that [the desire for] change [or] improving [Aboriginal health] isn’t enough on its own . . . never mind it’s the right thing to do. The business case [is] not good enough when it comes to Aboriginal issues. You have to have something really powerful to force people because if we didn’t have that, it wouldn’t happen. (P12)

Here and elsewhere, the data illustrate how the legally-binding nature of these formal agreements in BC have essentially ‘forced’ governments to include First Nations people at policy tables; as one participant asserts, governments are “compelled by legislation” (P20). In alignment with Lavoie et al’s (2012) research and arguments, showing that legislating mechanisms for Indigenous peoples’ participation can create opportunities to be more meaningfully involved in health policy decision-making, the legislation attached to the BC agreements may have impact on fostering more meaningful involvement of First Nations people in health policy decision-making in BC.

**Ensuring Government Accountability**

One Indigenous participant provides an analysis of what makes the BC agreements so effective:

> I guess for me it’s a stick, right? I constantly raise it . . . . I want to use that [Tripartite Agreement] document to move the agenda . . . to the degree that I can . . . in [this

\(^{35}\)The term *MOUs* refers to memorandum of understandings.
organization. To do it otherwise, without that external document, I think would be a much slower process. And so having external accountability is one of the key areas that makes . . . my job even remotely possible, otherwise I would just be completely tokenized. . . . And I constantly remind [the leaders in this organization that] we have external accountability . . . [and] we’re not just accountable to ourselves. (P09)

As illustrated in this excerpt, several participants note that a key aspect of what makes the agreements so impactful in pushing forward First Nations peoples’ agendas is their ability to ensure government accountability, including accountability for including First Nations people in decision-making as well as for addressing First Nations health issues. Another participant explains that the agreements are “not just paper instruments,” but legally binding documents that articulate goals and “accountability provisions,” which will be measured (P14). The participants explained that formal agreements in BC are not merely symbolic gestures of government commitments to including First Nations people and addressing First Nations health issues; they are legal documents that hold governments accountable to fulfilling their commitments. These findings resonate with the findings in Cheema’s (2007) study, which show that “multi-directional accountability relationships” are a key factor in supporting the meaningful participation of Indigenous people in health policy and planning (p. 29).

The significance of accountability in the BC agreements can be further understood in relation to the impact of neoliberalism on First Nations health policy. As discussed in Chapter Two, neoliberalism has contributed to a policy environment where approaches to First Nations policy have tended to increase First Nations peoples’ responsibility for addressing their own health issues while simultaneously lessening government responsibility (Fee, 2006; Murray, 2004; Salmon, 2007; Tait, 2000). Contrary to this typical iteration of neoliberal approaches to
policy, participants explained how the BC agreements serve to hold governments accountable for improving First Nations health while at the same time stipulating that First Nations people be centrally involved in the decisions. In this way, the BC agreements could be seen as a tool that actively works to mitigate the effects of neoliberalism on First Nations health policy decision-making.

*Engaging in Decision-Making at the Highest Policy Levels*

In addition to facilitating the entry of First Nations people at policy tables, participants explained how the BC agreements enable access to high-level decision-making tables that are typically inaccessible, which create situations where First Nations people have the ear of decision-makers. For example, P13 explains how the Kelowna Accord discussions meant First Nations people sat at the table with the highest-level decision-makers, which meant First Nations people “were being listened to” in a way that had not happened before. Another participant suggests, “[I]t’s important for federal leadership to be shown [at policy tables with First Nations] even if it’s just permissive and present. . . . [i]f you can’t meet with the Minister . . . you’re not going to get anywhere” (P14). In discussing what has helped push forward a First Nations health agenda in BC, P06 suggests the influence of “champions” at senior levels of government “can’t be underestimated.”

An analysis of these excerpts suggests that the involvement of high-level decision-makers may not only have an impact on the potential of decision-making processes to effectively change policy, but that this can facilitate First Nations issues getting on the policy agenda. In this way, the interviews reveal how legislating First Nations involvement is a way of *leveraging power*; it compels those in power to take First Nations peoples’ agendas seriously. By increasing the amount of influence First Nations people can have at the table, legislating First Nations
involvement may thus serve to make First Nations people’s involvement more meaningful and influential.

While legislating involvement essentially emphasizes the need to capture government attention at the highest levels and push First Nations peoples’ agendas from the top down, there is a danger in detracting attention away from the importance of involving those in lesser positions of power, namely, First Nations people who are not necessarily in prominent leadership or government positions. Focusing solely on fostering engagement at the highest levels of policy reinforces the power of governments in influencing First Nations health decisions; it reinforces a policy system where First Nations peoples’ agendas ultimately remain at the whim of governments. The data illuminate how the BC agreements have had an impact on shifting the role of First Nations people at the highest levels of policymaking, where First Nations people have begun to take on high-level positions themselves. As this participant explains,

Aboriginal decision-makers at a high enough level will affect decisions. The old structure is to have a few of us [Aboriginal people] in low-level positions . . . and almost without exception you will see only a few Aboriginal people at the lowest level. [Now in BC,] we’ve tried to change that” (P17).

The emergence of Indigenous people in high-level decision-making positions is one example of how the BC agreements have nurtured a policymaking environment where First Nations people are involved in new ways.

*Laying the Groundwork for New Ways of ‘Doing Business’*

Speaking in relation to the BC context, participants described how efforts to legislate involvement and establish formal agreements have incited “a new way of doing business” (P17). This is illustrated in one participant’s discussion of how the Kelowna Accord led to the signing
of the Transformative Change Accord in BC, which “ended up showing a lot of foresight and really laid a lot of the groundwork for where we are today [in having established a First Nations health governance structure]” (P14). P14 continues to explain how the establishment of the BC First Nations health governance structure has created the opportunity to “reset” the way First Nations have historically engaged with governments and “redefine the rules of engagement.”

Participants explained how the BC agreements have enabled First Nations people to establish structures and processes where First Nations are self-determining. As this participant explains:

[T]he Tripartite Agreement [contains] the recognition that First Nations are self-determining. That’s actually a very difficult one for government to stomach, but it's in our agreement. To us, as First Nations, we fundamentally believe that we have the right to decision-make for our own people. We’re not advisors in our own health, we are decision-makers, we are allowed to self-determine. So that's in the principles of the agreement, so whenever someone at the table says something like we’re not allowed to change the form, we’re not allowed to change the policy, [or] we can’t do it like that, the principles of the agreement [allow us]. (P17)

Noting the disparity between visions of self-determination and the limitations of self-government, Irlbacher-Fox (2009) suggests that self-government agreements can be one tool, albeit imperfect, among many possibilities that may assist First Nations communities in achieving self-determination. Although there may be significant differences in the typical self-government agreements between First Nations communities and governments and the agreements between governments and BC First Nations, these agreements share a common function of shaping federal mandates and defining how authority is shared between First Nations
and governments (see Irlbacher-Fox, 2009). In this sense, the BC agreements may be thought of as self-government agreements that serve as a tool for fostering First Nations self-determination in health policy decision-making, and thus new approaches to how First Nations people are involved.

At the same time, Irlbacher-Fox (2009) cautions about government tools such as self-government agreements in that they tend to focus on what Indigenous peoples must do to change, which supports the consistent message that the government’s role is to provide the tools and funds to support this change. Irlbacher-Fox (2009) argues that if the goal is to improve the health and lives of Indigenous people, then what is needed is refocusing on changing the circumstances that foster Indigenous peoples’ oppression, which means “that Aboriginal policy itself should change” (p. 1). While the data indicate that the BC agreements set the groundwork for a new way of health policy decision-making where First Nations people are involved in more meaningful and influential ways, participants also called for a radical transformation of the health policy system to foster inclusion and equity at a structural level.

**Transforming the Policy System: The Need for Structural Change**

Participants emphasized that meaningfully and influentially involving First Nations people in policy requires change at a deep structural level. For example, in discussing meaningful involvement, P12 explains, “really what we’re talking about is change,” and further clarifies, “I’m talking about change that goes to the guts of the organization [in] how they think and how they act, and that requires doing things in a different way.” While some participants discussed the need to disrupt the status quo, they also wrestled with the question of how to achieve transformative structural change in the face of deeply rooted systemic inequities. One
participant reflects on the limited extent to which government decision-making processes can even have on policy change to improve First Nations people’s health:

I guess at the end of the day there are times where I feel as a policymaker that . . . I’m on the wrong side of the fence, that I’m not going to achieve change by doing this. And I think it’s fair to say that government policy usually . . . is not the engine of change; great sweeping social change does not happen because it came from the halls of power. (P07)

This person’s sense of disillusionment about trying to achieve change within the current policy system is reflected elsewhere in others’ interviews, as participants reflected on their ineffectiveness in trying to achieve change from within the government “halls of power.” In many ways, they reflected the critiques of scholars who argue that current policymaking processes perpetuate inequitable power dynamics and “maintain the continuity of the institutional status quo” (Irlbacher-Fox, 2009, p. 3). Some participants critique the hierarchical nature of governments as being inherently ill suited for achieving change, and explain how policymakers are prohibited from and penalized for doing work that could be considered advocacy. One Indigenous participant reflects on the persistent inability of those working in policy settings to go against the will of governments:

[Policy people] are so afraid of doing wrong, [it’s] all they worry about. . . . and when I heard . . . that I thought, “My god, nothing has changed.” [T]hey’re very afraid of getting into trouble . . . that’s their biggest fear. Getting into trouble with their [authorities]. And I guess we can understand that because it’s a job for them, eh? And when the government says you’ve got to do this, [then] you’ve got to do that. Well, yeah, I guess . . . they’re afraid of what will happen. . . . And I get very upset when I hear those things because,
well I’ve said it over and over, why do we still have to follow them, the words of the oppressors? (P16)

P16 continues:

[O]ur people learn very well from the non-Natives how to . . . control our own people, [but] controlling is not gonna change our people. . . . We have to change everything. I mean everything. . . . but how do we do that, right? We have so [many] people controlling our lives, how can we [make change] unless it comes from the top. It has to come from the top . . . we cannot allow the government to continue to rule us because I know we’re not going to get better . . . if we just follow.

Like P16 in the excerpt above, participants repeatedly discussed the need to incite change from the top-down. Although participants emphasized the challenges of trying to achieve this kind of structural change, they also reiterated the necessity for working towards this goal, as P16 asserts, “This change has to come. It really has to come, to include the First Nations people and that for the benefit of them it needs to change. We can no longer say it can’t be done.” These findings emphasize the need to find ways of achieving structural change and disrupting the status quo top-down approach of policymaking as a means of fostering First Nations involvement at a more meaningful and influential level.

**Re-Imagining Community Engagement**

Although some participants spoke about the need for engaging First Nations people at the highest policy levels so that change comes from the top down, others spoke about inherent problems with the top-down approach to policy decision-making on First Nations health issues. They explained how even when First Nations people are at the table, the issues being addressed are not always of value to First Nations people, which is seen in P12’s frustration with
Indigenous people being included in “fluffy” policy decisions such as “which picture to put on the wall,” meanwhile Indigenous people are being “killed” in emergency rooms. Many participants spoke about the need for First Nations community members to be driving the policy decisions, and they emphasized the importance of community engagement and including the perspectives of First Nations people ‘on the ground.’ Their perspectives resonate with Irlbacher Fox’s (2009) assertion that self-government agreements signed by First Nations people in leadership positions are not always aligned with the perspectives of community members.

Although community engagement was described as essential for making effective policy decisions and seen as a way of disrupting the top-down approach of policy decision-making on First Nations health, participants also had many critiques of conventional community engagement processes, which typically occur in the form of community consultations. One participant explains, “consultation is a tricky thing,” because governments often have a duty to consult First Nations communities on the programs they are putting forward, which are already approved and operating under restrictive guidelines, so they are only prepared to consult on how a program is implemented (P15). P15 further discusses the problem with this approach:

[T]he problem is, that devalues what happens at the community. The community then becomes a place where you implement other people’s ideas. And that disempowers, that disempowers, that disempowers. . . . [T]his is more serious than it sounds. I mean, it’s one thing to say, ‘Well, the real problem here is because you didn’t really ask me in advance and now I’m upset.’ That’s not it. The real problem is that unless you can

36 This refers to situations where Indigenous people are misdiagnosed, neglected or denied proper treatment in emergency rooms, resulting in preventable deaths. Although these situations tend to be underrepresented in media, the death of Brian Sinclair is an example of one well-known case of “fatal racism” that circulated the headlines (Allan & Smylie, 2015). In discussing a similar problem that occurs when Indigenous people are in police custody, Razack (2011) argues, “Aboriginal death becomes a timely rather than untimely death” (p. 1).
generate your own ideas and implement your own ideas, you’re never going to get the kind of empowerment you need to make a real meaningful change in the lives of others.

P15 continues:

Now the other problem is . . . the government rarely talks about consultation anymore. . . [T]hey won’t even say the word [consultation] because they know . . . [it] makes the community mad. . . [B]ecause the community is already in a place where they say, ‘Oh you’re not really consulting me, you’ve already got all your ideas anyway.’ . . . [So then government says,] ‘Before we get money, let’s go out and just sort of say, look, we don’t have any program ideas, we don’t have any money, we don’t have any funding for this, but we just thought we would talk to you generally about that piece and what you might like to see.’ The community doesn’t like that either. The community says, ‘Well what are you doing here? Why are we sitting here wasting our time talking about something and you don’t even have any money or a program in mind?’ So it kind of cuts both ways . . . it’s a very frustrating thing to deal with.

These issues with community consultations are aligned with the critiques in the literature on First Nations community engagement processes, including the frequent failure of governments to incorporate community input into policy decisions, which devalues and delegitimizes community perspectives and can foster cynicism about the false promises of inclusion (Fiske & Browne, 2006, 2008; McConaghy, 2000; Smye & Browne, 2002). These perspectives expose the ways in which discourses of involvement can serve as rhetoric to promote the self-interests of governments while failing to address community issues of concern (Davidson, 2008; McWilliams, 2004). Despite the challenges of community consultations, participants emphasized the importance of community-driven processes and provided examples
of certain processes that provide insight into the conditions necessary for strengthening community engagement. Drawing on one example from Ontario, this participant discusses the process used to develop a provincial Aboriginal Healing and Wellness Strategy,\textsuperscript{37} and highlights its significance as the largest and most comprehensive Aboriginal strategy in Canada that “has had the most impact anywhere else in the country” (P20). When asked about the elements of this process that enabled its effectiveness, P20 articulates:

> You had a community-driven population that knew where it wanted to go. It was . . . culturally appropriate in its direction and the way it handled its . . . governance . . . . It had capacity, it obviously had skills, it was based on reciprocity. At that point it had the resource[s], [which is] something you need to have. And it had stability. And it had influence. And it was valued. . . . If you don’t have policy that is valued it doesn’t go anywhere. So it had the impetus, the value, the drive and the power at the time. . . . It knew very much where it was going, it had knowledge. . . . That’s another important factor, the knowledge piece. . . . and the notion of sharing that [knowledge].

The participants’ views highlighted several considerations for re-imagining what community engagement could look like in a First Nations health context, including finding ways of involving First Nations people in designing the process of community engagement itself. These data reflect Turner’s (2006) assertion that engaging Indigenous people in more substantive ways requires more than just including Indigenous people in a process or dialogue, but that Indigenous people “need to determine who ought to participate in those practices” (2006, p. 72).

\textsuperscript{37} The 1990 Ontario Aboriginal Healing and Wellness Strategy led to the development of a provincial Aboriginal Health Policy four years later, which is a governing policy to assist the Ministry of Health in addressing inequities in First Nations and Aboriginal health programming, responding to Aboriginal priorities, adjusting existing programs to more effectively respond to needs, supporting the reallocation of resources to Aboriginal initiatives, and improving provincial government collaboration to support holistic approaches to health. It is described as the “most comprehensive Aboriginal health policy currently in place in Canada” (National Collaborating Centre for Aboriginal Health, 2011, p. 7).
Given that the extensive body of literature on community engagement generally does not consider Indigenous people (Cheema, 2007), the lessons shared by participants on what has worked and what has not worked in community engagement processes can inform thinking on new ways of engaging First Nations people in health policy processes, not only from the top down, but from the ground up.

**Re-Imagining Relationships**

The literature suggests that strengthening processes where First Nations community members are involved also requires re-imagining relationships between First Nations people and governments (Cheema, 2007). Cheema (2007) argues that reconciling First Nations-government relationships, which can be defined as the rebuilding of damaged relationships (Cheema, 2007; Coulthard, 2014), can play a critical role in how First Nations people are involved with health decision-making. Considering an integral aspect of reconciliation is “the redefining of a balance of power between parties” (Cheema, 2007, p. 24), rebuilding relationships between First Nations people and governments may require an active process of disrupting status quo ways of working together and re-defining relationships with a view towards more equitable power dynamics between parties. McLean (2014) argues that decolonization requires “a reimagining of our relationships with each other based on respectful solidarity” (p. 95), which further suggests that paying attention to the ways decision-making processes implicate relationships may provide insight into how to foster more meaningful involvement.

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38 Coulthard (2014) explains that in Canada, the concept of *reconciliation* tends to be invoked in three ways: 1) in reference to a Indigenous peoples’ individual or collective practices to reestablish a positive “relation-to-self” in situations where this relation has been damaged or distorted by structural violence; 2) in reference to restoring damaged social and political relationships, often requiring individuals and groups to work together to overcome pain, anger, and resentment resulting from injustice; and 3) in reference to a process by which “agreement, concord or harmony” is reached and where things are rendered “consistent or compatible” (p. 107). Coulthard (2014) argues that the third definition is how reconciliation tends to be invoked by the Canadian government, and he critiques this approach to reconciliation as it undermines the realizations of reconciliation in the first two definitions. In referring to reconciliation in this dissertation, I am drawing on this second definition.
The participants’ perspectives align with this literature, and point to interrupting and re-imagining relationships between First Nations people and governments as a key part of what is needed for fostering meaningful involvement. This is illustrated in one participant’s description of how the relationship between a First Nations group and a government group evolved through a process of working together to develop an agreement, and how this shift in relationship resulted in the First Nations group moving from an advisory role to becoming partners in decision-making:

[W]e are still developing the relationship and trust among each other, although I think there tends to be a high level of trust in the groups because we’ve worked together for quite a long time. So there’s certainly a sense of partnership, I think, in the room. I think there’s always a little bit of a sense of skepticism on everybody’s part because there has been a long history of . . . a colonial attitude towards First Nations people. And so I think that there’s a certain skepticism on the part of everybody about how well this is going to work in the future. But I think there’s a huge sense of commitment and energy to make it happen. I think there’s a sense that we have an opportunity to change the way things have been in the past. And I think people are motivated to make that change. . . there’s a lot of energy or personal trust that’s there and a certain amount of excitement that we have an opportunity to do something very important. (P06)

As the participants discussed how the relationship is evolving in the BC First Nations health processes, the interviews revealed that the full impact of this shift in relationship is yet to unfold.

These findings point to the attitudes and sense of commitment among those involved as a significant factor to overcoming the stumbling block of historical and ongoing colonialism. They illustrate how the relationship between First Nations and governments can evolve over time.
through a process of working together, but what is important from the outset is a certain attitude and sense of commitment among those involved in the process to work together in ways that are different from the past. P20 articulates similar themes in discussing what is important for Aboriginal people and governments to work together on policy:

[Y]our players also have to be [engaged in] reciprocity [which] is very much . . . about personality. It’s the notion that you are true partners. When I talk about reciprocity . . . I mean very much the notion of having the right attitude, being committed to it, knowing that each are giving something and . . . both [government and Aboriginal] partners are winning in this.

Examining the data in relation to the literature points to how policy decision-making between First Nations people and governments can be reconciling processes; they may contribute to the interruption of old, colonial relationships and a re-imagining of new relationships in ways that are attuned to mitigating the effects of historical relations of power. These data suggest that transforming relationships between First Nations people and governments is an inherent part of decolonizing and transforming the policy system to enable more meaningful and influential involvement of First Nations people.

**Indigenizing Policy**

Although the interviews point to reconciling relationships as a key factor in transforming the policy system, Indigenous scholars challenge the idea Indigenous people can engage in equitable relationships with governments by “participating more intensely” in a “structure of domination like the colonial nation-state” (Coulthard, 2014, pp. 158-159). Authors such as Coulthard argue for the need for *Indigenous resurgence*, a paradigm that responds to the failure

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39 *Indigenous resurgence* is described by Irlbacher-Fox (2009) as a paradigm developed through Indigenous activist scholarship, which “rejects addressing Indigenous social suffering through redemptive programs of the state and
of the policy system to address issues of Indigenous peoples’ injustice, by rejecting the colonial nature of policy systems and advocating for strategies rooted in Indigenous philosophical and cultural ways (Alfred, 2005; Coulthard, 2014; Irlbacher-Fox, 2009). The need for Indigenous resurgence in policy systems is reflected in one participant’s view, who asserts that governments “only recognize their own structures . . . and authority,” and in response, “Aboriginal ways of being and knowing need to be entered into . . . the discourse” (P17). Drawing on an example of health policy decision-making in the area of mental health, P17 further explains:

[F]or instance, with government they will pay some credence to evaluation . . . [whereas] Indigenous people might lean more towards . . . what’s sensible and . . . what we know from our experience will work. So, for example, the province might say, ‘There’s no evidence that elders can play a role in suicide outcomes.’ First Nations might say, ‘We know to include elders in the wellbeing of our people so we’re going to include them in our suicide framework.’ Government might say, . . . ‘You need to spend twenty-five percent of your suicide budget on evaluating your program and reporting to us on whether your suicide intervention is working or not.’ First Nations would say, ‘Your burden of reporting cripples all of us . . . and we spend more time at our desks writing to you than delivering service’. . . . So those are ways that Indigenous ways of being really need to be part of the recognition, not just the government’s way of doing it.

instead proposes un-doing the causes of suffering through Indigenous resurgence as determined by Indigenous peoples, drawing on Indigenous philosophical and cultural ways. It calls for a rejection of colonial mindsets, among both Indigenous and non-Indigenous peoples and settlers, and, instead a regeneration of Indigenous cultures through freedom in thought and action from a colonial relationship between Indigenous peoples and the settler state” (p. 4). The origin of the concept of Indigenous resurgence has been attributed to Taiaiake Alfred, and has further been written about by other Indigenous scholars such as Leanne Simpson (Coulthard, 2014; Irlbacher-Fox, 2009).
Scholars have argued that Indigenous people have distinct ways of knowing that can be helpful in designing policy-making models (Wajuntah, In progress), resolving complex policy issues, arriving at innovative policy solutions and ultimately improving Canadian social and political systems (Battiste, 2009; Cochran, et al., 2008; Smylie, et al., 2009). Others suggest the inclusion of Indigenous knowledges in Western-based systems is an integral part of decolonization, in that it works to ensure Indigenous people are included in the most foundational aspects of research and policy, which has impacts on the way such systems serve to meet Indigenous peoples’ needs and interests (Cochran, et al., 2008; Sium, Desai, & Ritskes, 2012; Smylie, et al., 2009). In a previously published work, (Fridkin, 2012b) I argue the inclusion of Indigenous paradigms in policy can “mitigate epistemological colonialism,” as it incites the reshaping of policy in ways that are more inclusive of Indigenous peoples and knowledges, rather than reproducing policy discourses that legitimize only Western paradigms. This notion of mitigating epistemological colonialism may shed light on P17’s assertion that Indigenous ways of being and knowing need to enter into policy discourse, as it illuminates how the inclusion of Indigenous policy paradigms can serve to legitimate Indigenous peoples’ knowledges and expertise, and create policy environments where First Nations people are involved at the core of policy decision-making, including defining policy problems that affect First Nations people.

Participants further discussed the important role of First Nations people in bringing a specialized knowledge and expertise to the table. P17 argues that policy decision-making processes must include the “recognition of Aboriginal expertise as a skill that Aboriginal decision-makers bring forward, [which] other parties don’t have.” The literature suggests Indigenous people may play a unique role in bringing Indigenous ways of knowing into
mainstream policymaking. Durie (2004), for example, argues, “Indigenous researchers have a crucial role in straddling the divide between science and indigenous knowledge, acting as agents at the interface. Not only do they have access to Indigenous populations . . . but they also have access to two systems of knowledge and subscribe to both” (p. 1142). Similarly, Turner (2006) suggests, “Aboriginal intellectuals must develop a community of practitioners within the existing dominant legal and political intellectual communities,” (p. 90) as this is essential for ensuring Indigenous peoples are included in the most fundamental aspects of social and political life. In drawing attention to the critical role of Indigenous people as “word warriors” who mediate between Indigenous paradigms and imposed legal and political discourses of the state, Turner (2006) argues that Indigenous people may serve to actively disrupt and transform dominant discourses. Reading the findings in relation to these authors’ discussions points to the important role of Indigenous people in disrupting dominant policy discourses and transforming policy decision-making at the most foundational level.

This analysis illustrates how transforming status quo approaches requires the inclusion of Indigenous ways of being and knowing in policy; it requires indigenizing policy discourses and processes. In her discussion on indigenizing the academy to redress how Indigenous ways of knowing have been “marginalized, dismissed and made invisible” in academia, Pete (2015) defines indigenizing as “re-centering Indigenous epistemes, ontologies and methodologies” (p. 65). Drawing on this notion of indigenization, which Pete (2015) argues is about “identifying, resisting and correcting forms of epistemic ignorance . . . and challenging normative views” (p. 71), this notion of indigenizing policy resonates with participants’ discussions on the need to center Indigenous paradigms in policy with a view to redressing the exclusion of Indigenous ways of being and knowing.
Although Indigenizing policy processes may be a goal to work towards, Hill (2012) cautions:

While it is good to be hopeful, and to pay attention to the important impacts that Indigenous peoples and thought are having within universities, it seems wrong to disregard the profoundly colonial nature of even the most "indigenized" of post-secondary institutions. Without an explicit goal of decolonization, engagement with Indigenous thought might simply overlay (or worse, strengthen) processes of colonization. . . . If moves to indigenize overshadow attempts to decolonize, colonial institutions maintain their power -- in fact, these institutions appear to improve: a better kind of university, with knowledge toward a better kind of still colonial Canada. (p. 1)

In suggesting indigenizing institutions “must work harder to always decolonize,” Hill (2012, p. 1) draws attention to the value of indigenizing with a decolonizing lens. Considering these discussions of indigenizing processes within the realm of academia, indigenizing policy must also be seen as project of decolonization.

While attempts to decolonize policy decision-making through incorporating Indigenous knowledge into Western-based processes have often failed due to inherent ideological contradictions (Ellis, 2005), Sium et al. (2012) argue that decolonization is not about the co-existence of knowledges or replacing dominant paradigms with ones that are marginalized, rather it is about imagining, envisioning and constructing new ground. Similarly, Durie (2004) argues that the interface between Indigenous and Western paradigms need not be a site of contest, as it can also provide opportunities for expanding understandings and knowledge. Durie (2004) suggests, “The challenge is to afford each belief system its own integrity, while developing approaches that can incorporate aspects of both and lead to innovation, greater relevance and
additional opportunities for the creation of new knowledge” (2004, p. 1143). In light of these perspectives, indigenizing policy may require exploring what policymaking might look like at the intersections of Indigenous and Western paradigms. Transforming the policy system to include First Nations people in more meaningful and influential ways may not only calls for new approaches to involvement, it may call for the development of new policy paradigms for understanding and addressing First Nations health policy issues.

**Attuning to Power in Policy Processes: Taking Action Toward Meaningful Involvement**

The analysis illuminates how First Nations peoples’ involvement in the health policy system inherently incites a clash of paradigms. Ermine’s (2007) perspective on Indigenous-Western encounters helps to shed light on the paradigmatic conflicts that are reflected in participants’ interviews:

One of the festering irritants for Indigenous peoples, in their encounter with the West, is the brick wall of a deeply embedded belief and practice of Western universality. Central to the issue of universality is the dissemination of a singular world consciousness, a monoculture with a claim to one model of humanity and one model of society. . . . This is an ingrained belief, an enfolded consciousness recreated through systems, institutions and processes in mainstream Canadian society. This mono-cultural existence suggests one public sphere and one conception of justice that triumphs over all others. . . . In the West, this notion of universality remains simmering, unchecked, enfolded as it is, in the subconscious of the masses and recreated from the archives of knowledge and systems, rules and values of colonialism that in turn wills into being the intellectual, political, economic, cultural, and social systems and institutions of this country. (p. 198)
The analysis of participants’ perspectives reveals a dominance of Western ways of thinking in policy processes, which resonates with Ermine’s discussion of encounters between Indigenous and Western paradigms in Canadian social systems. Ermine (2007) draws attention to the deeply rooted dominance of Western ideology as the singular worldview underlying Canadian social systems, which becomes reproduced when such dominance is unquestioned. As reiterated by the participants, the dominance of Western paradigms in the policy system undermines and delegitimizes Indigenous worldviews, thereby excluding Indigenous people from policy decision-making at a deep, ideological level. This also helps to explain why previous attempts to incorporate Indigenous paradigms in policy decision-making often fail on account of conflicting paradigms (Ellis, 2005). Fostering more meaningful and influential involvement of First Nations people thus requires disrupting the dominance of Western paradigms, because without attention to mitigating the effects of these inherent power inequities, the policy system will intrinsically perpetuate First Nations peoples’ exclusion at a structural level. This also serves to illustrate how structural racism\(^{40}\) operates within the policy system.

This analysis highlights a paradoxical situation: transforming the policy system requires the inclusion of Indigenous paradigms, however, the structural exclusion of Indigenous paradigms inhibits Indigenous peoples’ inclusion in ways that are necessary for influencing and transforming the policy system. The question then becomes, how can the policy system be transformed to foster meaningful involvement of First Nations people, when transforming the policy system requires First Nations people to be meaningfully involved? Recognizing that

\(^{40}\) *Structural racism*, also referred to as systemic racism or institutional racism, is defined by Paradies (2006) as “the racist production, control and access to material, informational and symbolic resources within a society,” which can have an impact on the health of racialized groups (p. 153). Structural racism can also be understood as a form of *structural violence*, which Farmer et al. (2007) describe as the way in which social structures inhibit people from reaching their full potential by limiting access to resources in ubiquitous ways that “seem so ordinary in our ways of understanding the world, they almost seem invisible” (p. 1686).
decolonization warrants reckoning with such critical questions, Sium et al. (2012) further question whether or not it is possible to decolonize institutions of colonial power, let alone if it is possible to decolonize through them. In the context of this research, the ultimate question then becomes whether or not it is possible to decolonize First Nations health policy systems through including First Nations people in the very policy system itself?

The participants’ perspectives on meaningful involvement suggest decolonizing the policy system may indeed be possible. This is illustrated through participants’ explanations of the ways First Nations people have become more meaningfully and influentially involved in the BC health policy system. This analysis also exposes how policymaking can serve decolonizing aims; policy decision-making can be a reconciling process that leads to a redistribution of power in First Nations-government relationships. In drawing attention to ways health policy decision-making processes can work towards decolonization, this research suggests it indeed may be possible to not only transform and decolonize the policy system, it may also be possible to decolonize through the policy system by involving First Nations people in more meaningful and influential ways.

This research suggests even small changes to include First Nations people in more meaningful ways can contribute to a broader transformation and decolonization of the policy system. Yet, participants also provided examples of policy initiatives in BC and Ontario that have had a monumental impact on how First Nations people are involved in decision-making. In particular, participants’ discussions on the impact of the Transformative Change Accord and the establishment of a First Nations health governance structure suggest a path towards meaningful and influential involvement is has already emerged in BC.
This analysis suggests a key factor enabling First Nations people to become more meaningfully and influentially involved in BC is the way in which processes of involvement mitigate the effects of underlying power inequities that serve to exclude First Nations people at a structural level. As critical perspectives are attuned to the ways power operates within social and political systems, reading the data with a critical lens points to meaningful involvement as a process that responds to inherent power inequities in the policy system. This finding helps to answer a key question with which participants wrestle: How can meaningful involvement occur in the neocolonial context given the inherent inequitable power imbalance between First Nations peoples and governments?

The research suggests meaningful involvement can occur in the neocolonial context through taking action to mitigate the effects of underlying power inequities impeding First Nations involvement. Anderson (1996) argues that addressing inequities requires more than “listen[ing] to the voices of those who have been marginalized” and “understanding the historical genesis of oppression,” and instead what is required is a collective willingness to deal with systemic discrimination by naming injustice and taking action (p. 704). This call to action signals the need for efforts that move beyond an acknowledgement of colonialism and instead solicit collective action to addresses the structural barriers impeding the meaningful and influential involvement of First Nations people. This is especially significant in processes with explicit decolonizing intentions, as decolonization is increasingly taken up by non-Indigenous people as a discursive practice serving primarily to alleviate “settler guilt” rather than recognizing and advancing Indigenous peoples’ struggles for sovereignty (Tuck & Yang, 2012). Such critiques may imply that transforming and decolonizing the policy system requires more than decolonizing the thinking of those involved in First Nations health policy decision-making, and instead
connotes the necessity of taking explicit action to advance First Nations peoples’ health equity agendas. These authors’ discussions point to the necessity of theorizing with a view to taking action.

**Summary**

This chapter presents an analysis of participants’ perspectives on meaningful involvement in order to shed light on the research question: What constitutes meaningful involvement in the context of First Nations health policy decision-making? While some participants wrestled with how to meaningfully involve First Nations people in light of colonial history, others provided clear visions on what meaningful involvement looks like. The data analysis suggests that meaningful involvement requires a transformation of the policy system in order to disrupt the cycle of First Nations exclusion from policymaking at a structural level, and at the same time, small efforts such as recognition of Indigenous traditional territory or tokenizing representation can be seen as a meaningful step forward. Recognizing the need for efforts that move beyond tokenization, the analysis highlights considerations for thinking about not only *how* First Nations people are involved but also *who* needs to be at the policy table.

The analysis additionally shows that legislating First Nations involvement through efforts such as formal agreements can have a powerful impact on increasing the level of influence First Nations people can have in a policy process. This is primarily illustrated through participants’ discussions on the impact of the First Nations health agreements in BC on changing the way First Nations people are involved in health policy decision-making. While legislating involvement can lead to a transformation of the policy system, it mainly serves to transform the way First Nations people are involved in the policy system as is. The interviews thus point to the need for disrupting the status quo top-down approaches to First Nations policy development and
transforming the way First Nations policy decisions are made. The data suggests that, in some ways, this transformation is already occurring in BC. Drawing largely on participants’ reflections on the BC First Nations health policy context, the analysis points to mitigating the effects of power inequities as a key factor in fostering more meaningful and influential involvement of First Nations people in health policy decision-making processes. The findings from this analysis can inform ways of thinking about how to navigate the paradox of meaningful involvement and actively work towards decolonization.
CHAPTER SEVEN – RE-CONCEPTUALIZING MEANINGFUL INVOLVEMENT

Introduction

In this chapter, I draw on an analysis of the findings presented in Chapters Five and Six to inform a new conceptualization of meaningful involvement. Chapter Five explores participants’ lived experiences at health policy decision-making tables to reveal how Indigenous people are shut down, shut up and shut out of policy processes, and attempts at involvement are often experienced as a paradox whereby Indigenous people are excluded by the very process in which they are included. Chapter Six draws on participants’ perspectives of what has worked and what has not worked in terms of involving First Nations people in more meaningful ways, to reveal how small efforts to include First Nations people can be meaningful in some ways, yet involving First Nations people in ways that are more meaningful and influential requires attuning to the underlying power dynamics inherent in policymaking and taking action to decolonize and transform the policy system itself.

Based on an analysis of these findings, I articulate seven key elements of meaningful involvement: Recognizing and Representing Indigenous Peoples; Interrupting and Re-Imagining Relationships; Preparing Agreements; Practicing Protocols; Leveraging Power; Exerting Community Authority; and Shifting Social Structures. These key elements are further described in a table outlining the specific purpose and objectives, examples of enactment, the role of First Nations people and aspirational outcomes associated with each element of meaningful involvement. The key elements form the foundation of a framework for meaningful involvement, which is conceptualized as an ongoing process and illustrated by a series of ripples moving towards decolonization and health and social equity for Indigenous people. This chapter concludes with a discussion on the significance of the findings and the implications for involving
First Nations people in more meaningful and influential ways, as well as strategic directions and recommendations for meaningfully involving urban First Nations people in health policy decision-making processes.

**What Constitutes Meaningful Involvement?**

The interviews reveal that in the contemporary health policy context, First Nations people are involved in a variety of ways, ranging from not being at the table at all to being centrally included in key decisions as per agreements and protocols developed in collaboration with First Nations people. Considering the reality that “in some spaces . . . tokenism is a giant step forward” (P12), each stride towards involving First Nations people in a deeper and more influential way than before may represent a significant effort towards transforming the way First Nations health policy decisions are made, particularly in relation to how First Nations people are involved. In this sense, although some policy processes may involve First Nations people in more influential ways than others, the analysis suggests that even the smallest attempts at involving First Nations people in a more influential way than in the past may be a significant, and thus meaningful, form of involvement.

The analysis in this research suggests that even though tokenizing forms of involvement can be meaningful, there is a persistent need to articulate ways of involving First Nations people that move beyond tokenization. The interviews draw attention to the importance of finding ways to deepen First Nation peoples’ influence in policy decisions in which they are affected. Although First Nations people may be involved in ways that are meaningful, the process may not make any difference to First Nations peoples’ health if First Nations people are not actually influencing the decisions. The analysis thus draws attention to several dimensions of meaningful involvement: 1) the significance or “meaning” of First Nations involvement; the 2) amount of
influence First Nations people have on decisions; and 3) the impact of the process on addressing the root causes of health and social inequities. Conceptualizing meaningful involvement in a way that considers these dimensions may be helpful in thinking about how to shape policy decision-making towards becoming processes that not only involve First Nations people in ways that are meaningful, but also in ways that are influential and beneficial to First Nations people. This research thus provides insight into how meaningful involvement can be conceptualized in ways that consider Smye and Browne’s (2002) call to pay attention to whether or not Aboriginal people are involved in a process that “espous[es] the benefits of reform, in the absence of real material gains for [A]boriginal people” (p. 52).

In the context of this research, meaningful involvement is conceptualized as a process that extends beyond conventional notions of meaningful; it implies a process that takes into account several key elements that are reflected in the data. For example, the interviews point to the importance of involving First Nations people in ways that are not harmful and damaging or do not subsequently lead to First Nations people’s withdrawal and resignation, but instead in ways that mitigate the multiple and sometimes covert ways racism and inequitable power dynamics play out at decision-making tables. In this way, meaningful involvement implies policy decision-making processes must be culturally safe – they must account for underlying power dynamics in the policy system, which shape First Nations people’s experiences of safety within policy processes. Drawing on cultural safety as a concept informing thinking on how to mitigate racist encounters in health care practice (Browne, Varcoe, et al., 2009; Browne, et al., in review; McCall & Pauly, 2012), the findings suggest meaningful involvement connotes implementation of culturally safe approaches to policy practice that serve to mitigate interpersonal and structural power dynamics inherent in policy processes with a view to fostering First Nations people’s
safety and thus inclusion at the policy table. The data also point to the importance of stipulating that First Nations involvement is mandatory and that measures are in place to foster First Nations people’s influence in the most integral aspects of decision-making. In this sense, meaningful involvement means challenging and disrupting the status quo; it connotes an approach to decision-making that is transformative and decolonizing. These insights gained from the research as a whole inform thinking on what constitutes the key elements of meaningful involvement.

*The Key Elements of Meaningful Involvement*

To articulate a new conceptualization of meaningful involvement that is attuned to underlying power inequities and disrupting the status quo, this research describes seven evidence-informed key elements of meaningful involvement based on a thematic analysis of the data. Each of these key elements is briefly described below:

1. *Recognizing and Representing Indigenous Peoples*\(^41\) - recognizing or acknowledging First Nations people and/or traditional territory and taking efforts to have First Nations people represented at decision-making tables, even if in tokenizing ways;

2. *Interrupting and Re-Imagining Relationships* - actively interrupting the ways First Nations people and governments have historically worked together and re-defining working relationships based on a process of reconciliation;

3. *Preparing Agreements* - establishing formal, written agreements between parties that articulate the nature of working relationships, mandate First Nations involvement in the process, commit both parties to sharing responsibility for addressing First Nations health issues, and hold parties jointly accountable for the decisions made in process;

\(^41\) I refer to Indigenous Peoples rather than First Nations peoples here in recognition that this conceptualization of meaningful involvement may apply to other Indigenous groups in Canada.
4. *Practicing Protocols* - developing and implementing rules for First Nations people’s engagement in the process, as well as protocols to guide how the parties will work together and enact the relationships set out in formal agreements;

5. *Leveraging power* - taking efforts to foster a process that has the necessary power and sufficient capacity to make and implement health policy decisions, such as engaging the highest level decision-makers in the process;

6. *Exerting Community Authority* - taking explicit efforts to foster a process that is being driven by First Nations community members, namely, First Nations people who are most connected to and familiar with the issues being addressed and who solely represent a community perspective; and

7. *Shifting Social Structures* - taking efforts towards addressing the systemic barriers impeding First Nations peoples involvement in policy, such as explicit efforts to incorporate Indigenous paradigms and/or include First Nations people in high-level positions in the mainstream policy system.

Each of these elements may be understood as existing along a continuum, where each element builds on the previous one so that Indigenous people are increasingly influential in the decision-making process. Conceptualizing meaningful involvement as a continuum of multiple elements may help draw attention to the ways in which First Nations people are and could be more meaningfully and influentially involved in a health policy decision-making process. These elements are not intended to represent a prescriptive list of criteria for what meaningful involvement will look like at every stage of every decision-making process, rather they are intended to inform thinking on how decision-making processes could involve First Nations people in more meaningful and influential ways. To further articulate what each element entails
and to illustrate how each could be enacted in a policy decision-making process, a more detailed articulation of these elements is provided in Table 2 below.
### Table 2. Enacting the Key Elements of Meaningful Involvement

<table>
<thead>
<tr>
<th>Purpose</th>
<th>Recognizing and Representing Indigenous Peoples</th>
<th>Interrupting and Re-Imagining Relationships</th>
<th>Preparing Agreements</th>
<th>Practicing Protocols</th>
<th>Leveraging Power</th>
<th>Exerting Community Authority</th>
<th>Shifting Social Structures</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Recognize First Nations people and/or territory and represent First Nations people in the decision-making process</td>
<td>• Critically examine the historical relationship between First Nations people and governments</td>
<td>• Articulate and agree on the nature of the working relationship between parties</td>
<td>• Articulate specifically how parties will work together in a way that honours the agreed upon relationship between parties and other commitments outlined in agreements</td>
<td>• Foster a process that has the power and capacity to make policy decisions</td>
<td>• Foster a process that has the capacity to develop good decisions and is effective in improving First Nations health</td>
<td>• Foster a process that is driven by First Nations community members who are impacted by decisions</td>
<td>• Address systemic barriers impeding First Nations involvement in the mainstream policy system</td>
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<tr>
<td>• Include First Nations people in the process, even if representation is tokenistic or symbolic</td>
<td>• Establish a new process for First Nations and government groups to work together based on reconciled relationships</td>
<td>• Establish formal, legal agreements between parties that mandate First Nations involvement in decision-making and hold both parties jointly accountable to the process and to decisions reached</td>
<td>• Establish rules of engagement or protocols to guide how the parties will work together</td>
<td>• Include high-level decision-makers who have the power to make decisions in the same process/at the same tables in which First Nations people are involved</td>
<td>• Involve First Nations people at the outset and throughout the entire process</td>
<td>• Incorporate Indigenous paradigms into First Nations policy decision-making</td>
<td>• Include First Nations people in high-level policy positions in the mainstream policy system</td>
</tr>
<tr>
<td>• Include or incorporate aspects of First Nations ceremony or culture</td>
<td>• Establish a new process for First Nations and government groups to work together based on reconciled relationships</td>
<td>• Articulate or define the nature of relationships between parties</td>
<td>• Establish rules of engagement or protocols to guide how the parties will work together</td>
<td>• Include high-level decision-makers who have the power to make decisions in the same process/at the same tables in which First Nations people are involved</td>
<td>• Involve First Nations people at the outset and throughout the entire process</td>
<td>• Incorporate Indigenous paradigms into First Nations policy decision-making</td>
<td>• Include First Nations people in high-level policy positions in the mainstream policy system</td>
</tr>
<tr>
<td>Examples of Enacting Meaningful Involvement</td>
<td>Recognizing and Representing Indigenous Peoples</td>
<td>Interrupting and Re-Imagining Relationships</td>
<td>Preparing Agreements</td>
<td>Practicing Protocols</td>
<td>Leveraging Power</td>
<td>Exerting Community Authority</td>
<td>Shifting Social Structures</td>
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<tr>
<td>• Recognize or acknowledge First Nations peoples or traditional territory</td>
<td>• Each party meets on their own prior to discussions</td>
<td>• Both parties work together to develop written agreements that articulate relationships between parties and outline mutual commitments</td>
<td>• Develop and implement protocols for communication with media or external groups</td>
<td>• Sign agreements between parties by the highest levels of all parties, such as Ministers, CEOs or Chiefs</td>
<td>• Allocate sufficient resources for a full community engagement process</td>
<td>• Take efforts to build First Nations policy decision-making capacity and experience (e.g. internships/mentorships)</td>
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<td>• Include opening or closing prayers or other traditional practices</td>
<td>• Designate a bridge person to facilitate communication between parties</td>
<td>• Develop and implement ground rules to guide meetings or discussions in ways that mitigate silencing and dismissal of First Nations people, such as designating a leader to identify and address racism and/or racialized sexism at the table</td>
<td>• Include the highest level decision-makers at the same tables as First Nations people and/or leaders</td>
<td>• Include community members at every stage of the decision-making process and at the highest levels of decision-making</td>
<td>• Establish and implement a rigorous process for using community input to set priorities and drive the process</td>
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<td>• Involve First Nations Elders to participate in decision-making or to lead traditional practices</td>
<td>• Openly discuss each party’s interests, roles, and decision-making capacities</td>
<td>• Formalize or legalize agreements to mandate or legislate First Nations involvement and hold all parties accountable to the process and to decisions made through the process</td>
<td>• Include the highest level decision-makers from governments or policy institutions that have access to a large pool of resources</td>
<td>• Create high-level policy positions for First Nations people</td>
<td>• Take efforts to build government capacity and experience in working with First Nations people and paradigms (e.g. cultural safety training)</td>
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<td>• Include at least one First Nations person at decision-making tables to represent broad perspectives of First Nations people or perspectives of a specific First Nations group</td>
<td>• Work together on developing a process for First Nations engagement</td>
<td>• Allocate sufficient resources for a full community engagement process</td>
<td>• Recognize First Nations peoples’ knowledge, experience and expertise in hiring criteria</td>
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</table>

42 Although both Elders and elderly people are key in Indigenous societies, *Elders* distinctly refers to Indigenous people “who have shown wisdom and leadership in cultural, spiritual, and historical matters within their communities, and might not necessarily be old. Elders represent an essential connection with the past; they are keepers of the community knowledge and supporters of its collective spirit” (King, Smith, & Gracey, 2009, p. 82).
<table>
<thead>
<tr>
<th>Role of First Nations People</th>
<th>Recognizing and Representing Indigenous Peoples</th>
<th>Interrupting and Re-Imagining Relationships</th>
<th>Preparing Agreements</th>
<th>Practicing Protocols</th>
<th>Leveraging Power</th>
<th>Exerting Community Authority</th>
<th>Shifting Social Structures</th>
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<tbody>
<tr>
<td>• Bring First Nations traditional or cultural perspectives to the process • Advise, provide input or inform the discussion even if not participating in the actual decision-making (e.g. advisory committee member)</td>
<td>• Provide input into developing new relationships and processes for working in partnership with governments • Develop protocols in partnership with governments • Share responsibility for decision-making as per agreements</td>
<td>• Develop agreements in partnership with governments • Share responsibility for decision-making as per agreements</td>
<td>• Develop protocols in partnership with governments • Fully participate in discussions and processes as per agreements and protocols</td>
<td>• Influence and participate in decision-making at the highest levels of government, including decisions on spending or resource allocation</td>
<td>• Drive the process, including setting the agenda and determining who is involved in the process • Determine the policy issues and decide on policy solutions</td>
<td>• Integrate Indigenous paradigms into policy discourses • Influence policy through taking on high-level positions in the mainstream policy system</td>
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</tr>
<tr>
<td>Aspirational Outcomes</td>
<td>First Nations people are present and involved in the process and have some input into decision-making</td>
<td>First Nations people are seen as partners in decision-making and recognized as respected, legitimate leaders and contributors to the process</td>
<td>First Nations people’s rights to be included in the process are recognized, protected and upheld by all those involved in decision-making</td>
<td>First Nations people feel safe, heard, and “empowered” through participating in decision-making; and harmful, stressful or painful experiences associated with participating are reduced</td>
<td>First Nations people have increased influence and control over policy decisions impacting First Nations peoples’ health</td>
<td>First Nations community members are valorized as experts in their own health and wellness • First Nations people’s experiential knowledge is valued and seen as integral to the decision-making process</td>
<td>First Nations people are seen as integral and respected leaders and have increased access to health policy decision-making positions • Indigenous knowledge is recognized as a legitimate form of knowledge and valued as an integral part of health policy decision-making</td>
</tr>
</tbody>
</table>
The RIPPLES of Meaningful Involvement: A Framework

To facilitate an understanding of how enacting these elements of meaningful involvement may contribute to the transformation and decolonization of First Nations health policy decision-making processes, I illustrate these elements in relation to each other in Figure 1 below. I refer to this visual representation as the RIPPLES of Meaningful Involvement, with RIPPLES being an acronym for the seven key elements described above: Recognizing and Representing Indigenous Peoples; Interrupting and Re-Imagining Relationships; Preparing Agreements; Practicing Protocols; Leveraging Power; Exerting Community Authority; and Shifting Social Structures. The RIPPLES of Meaningful involvement is offered as framework to inform policy decision-making processes with respect to how First Nations people could be more meaningfully and influentially involved. This framework is not intended to be a “one-size-fits-all” model or approach for how First Nations people should ideally be involved. Instead, it is intended to be a heuristic device to stimulate further thinking and discussion on ways of meaningfully involving First Nations people in policy decision-making processes.

In articulating the framework there is a risk of constructing meaningful involvement in a way that is over simplified, unclear as to how it could be implemented, and neither innovative nor considerably different from past approaches. In some aspects, the key elements of meaningful involvement described in Table 2 above could be seen as recasting previous approaches that may have led to current iterations of involvement that are neither meaningful nor influential. There is also a risk that in articulating and illustrating the RIPPLES framework, it could become a dominant, normative or hegemonic discourse or conceptualization of meaningful involvement, which could undermine the goal of this framework in interrogating and transforming dominant policy discourses and processes. To guard against this, I explicitly note
that the intention of the RIPPLES framework is not to introduce a new dominant discourse or way of thinking about meaningful involvement that should remain unchallenged, unmodified, or withheld from further refinement, but to offer a starting place, or perhaps in some contexts a continuing place, for thinking about how more meaningful involvement could be fostered. The hope in bringing this framework forward is to advance the discussion on meaningful involvement based on insights gained from the lived experiences and perspectives of First Nations health leaders and decision-makers, which may push forward thinking on how current and future decision-making processes could be strengthened and improved.

Figure 1. The RIPPLES of Meaningful Involvement
This framework illustrates the key elements of meaningful involvement along a continuum, which is represented by a series of concentric ripples. Each “ripple” radiating outwards from Recognizing and Representing Indigenous Peoples to Shifting Social Structures represents the enactment of a key element of meaningful involvement in which First Nations people are increasingly more influential. This illustrates how achieving meaningful involvement requires the enactment of several related elements that stem from and build on one another.

The progression of ripples further illustrates how a single effort to recognize First Nations territory or include a “token” First Nations person in a process may represent an important first step towards more influential involvement; including a First Nations person to represent a “First Nations perspective,” even in a tokenizing way, may be the first drop in creating a series of ripples towards transforming the policy system to one that includes First Nations people at the most fundamental level and addresses rather than perpetuates exclusion and inequity. This illustrates the ripple effect of meaningful involvement; as First Nations people become increasingly influential in policy decision-making, the policy system itself becomes increasingly effective in improving First Nations peoples’ health and addressing health and social inequities.

The ripples are set against a backdrop of decolonization to illustrate how the enactment of each element from one ripple to the next may represent a transformative shift towards decolonization of the wider policy system. This conceptualization of meaningful involvement illustrates how meaningful involvement can be a decolonizing process, as each effort to include First Nations people in increasingly influential ways may work towards mitigating the dominance of Western peoples and ideologies in the policy system, as well as contribute to the advancement of First Nations peoples’ agendas and efforts towards sovereignty and/or self-
determination. Drawing on Ritskes’ (2012) construction of decolonization as a goal rather an endpoint, conceptualizing meaningful involvement as a decolonizing process implies meaningful involvement may be a goal to work towards rather than an endpoint to be achieved. Meaningful involvement is conceptualized as a process of ongoing reflection and taking action to deepen the ways in which First Nations people are involved, thereby deepening the extent to which decision-making can improve health and address inequities.

Although the RIPPLES framework may inform policy processes in ways that ultimately lead to better policy decisions for improving First Nations health and addressing health inequities, the anticipated outcomes of the RIPPLES framework are largely social and political outcomes related to health as opposed to direct health outcomes. Considering the identified outcomes of citizen engagement described in the literature (Gaventa & Barrett, 2010; Jagosh, et al., 2012), this framework may inform processes that result in outcomes from increased First Nations involvement, such as the development of more responsive or effective policy options and decisions, new and strengthened relationships or networks, development of new initiatives or processes, increased self-determination and First Nations control over health policy decisions, increased capacity of policy decision-makers to work effectively with First Nations people, increased capacity of First Nations people to work with governments, and/or increased capacity of the policy system to make informed decisions on First Nations health issues.

**Contributions to the Literature**

Considering the well-documented need for Indigenous people to be meaningfully involved in policy decisions on Indigenous peoples’ health and the scarcity of existing approaches or frameworks for how to meaningfully involve Indigenous people in health policy, the RIPPLES framework and overall findings on what constitutes meaningful involvement of
First Nations people in health policy decision-making fills a significant gap in the literature. Only a few studies have resulted in the development of frameworks or principles for meaningfully involving First Nations people in policy (see Centre for Indigenous Environmental Resources, 2009; Marsden, 2005). The principles for meaningful involvement described in this existent literature were developed in the context of Canadian environmental policy, and yet the themes of these principles are closely aligned with the key elements of meaningful involvement described in this research. The consistency of themes across these frameworks points to their potential and relevance informing policy decision-making in policy areas beyond health.

This dissertation research conceptualizes meaningful involvement as an evolving process relational to the context in which involvement occurs, rather than as a goal that could be achieved through the implementation of a defined set of principles or actions in a particular policy decision-making process. Understanding meaningful involvement as a continuum enables a range of efforts to be viewed as significant steps towards involving First Nations people in more meaningful and influential ways. Considering the existing challenges and overall lack of involvement of First Nations people in policy decision-making, constructing meaningful involvement in a way that assumes even seemingly small efforts to include First Nations people can be significant, may help the process of working towards meaningful involvement seem more attainable, and thus serve as a motivating force for taking action to deepen the level of involvement. This re-conceptualization of meaningful involvement as both a process and continuum thus contributes a unique perspective to the literature on meaningful involvement.

One of the unique contributions of this dissertation results from the explicit critical orientation of this research, which enables a way of thinking about meaningful involvement with a view to transform and decolonize the wider First Nations health policy decision-making
system. This research provides insight into how Indigenous people could be involved in ways that are not only more meaningful and influential in particular health policy processes, but also centrally involved in the social structures that determine how First Nations health policies are made. The findings may thus inform discussions in the literature on decolonizing approaches and ways of thinking about transformative social change.

To continue moving towards decolonization and more meaningful and influential involvement of First Nations people, efforts are needed to ensure attention is paid to assessing and improving processes of involvement. This research may also inform directions for future research, including investigating ways of evaluating and monitoring how First Nations people are involved in health policy decision-making and measuring the transformation towards meaningful involvement, particularly from the perspectives of First Nations people including First Nations people who are involved in the process and impacted by the decisions. This research may inform future studies that aim to build on the findings, such as studies to explore rules for engagement and protocols that effectively counter racism, sexism, and silencing and dismissal of First Nations people at the decision-making table. Outcomes from future studies could result in the development of indicators for meaningful involvement based on this framework or applied tools for guiding health policy leaders in designing decision-making processes that foster more meaningful and influential involvement of First Nations people.

Discussion: Significance and Implications

The overarching purpose of this research is to provide insight on how health policy decision-making processes can meaningfully involve First Nations people, as this is essential for addressing the persistent and increasing health inequities affecting First Nations people. The research suggests that if processes of involvement are to be effective in addressing health
inequities, which are systemic in nature, meaningful involvement must lead to a transformation of the very policymaking system that created such inequities in the first place. Indeed, the participants’ experiences of policymaking depict a policy system that largely perpetuates the exclusion of First Nations people from policymaking, even when attempts to include First Nations people are made; the end result is a policy system that repeatedly fails to include First Nations people in meaningful ways and subsequently fails to make a difference in improving First Nations health. This research thus calls attention to the necessity of transforming this paradoxical policymaking system to address health inequities at their root.

**Working Together in a Neocolonial Neoliberal Context**

In light of hundreds of years of colonization, systemic transformation at the level of policymaking is no easy task. Transformative structural change may take decades to accomplish; a disillusioning reality for those engaged in projects of change. Critical theorizing enables one to imagine ways of dismantling a deeply rooted system, brick by brick. Turner’s (2006) notion of word warriors is an exemplar of such theoretical imagining. Turner argues that word warriors – Indigenous mediators who take up dominant legal and political discourses of the state while remaining connected to an Indigenous intellectual community – have a unique role in navigating the “philosophical battleground” generated by the history of colonialism through engaging in dialogue with non-Indigenous people and discourses (2006, p. 101). The deep dialogical engagement that Turner describes may have transformative potential, as word warriors can bring Indigenous paradigms into the dialogue and work to transform dominant legal and political discourses. Reflecting on the concept of word warriors in relation to a health policymaking context speaks to the critical role of Indigenous policymakers in transforming and decolonizing the policy system.
Turner’s (2006) notion of word warriors provides a helpful framework for conceptualizing the transformative potential of First Nations peoples’ involvement in policymaking processes. Yet, in this approach, the onus of responsibility for decolonizing the policy system falls to Indigenous people. Turner’s call to Indigenous people to take up dominant discourses might be problematic in light of the research findings, which illustrate how the neoliberal policy climate contributes to an inequitable burden of responsibility being placed on Indigenous people to address their own health issues, while simultaneously lessening government responsibility. Focusing solely on what Indigenous people can do to insert themselves into the policy sphere detracts from government responsibility to take action on addressing the systemic issues that inhibit Indigenous people from participating in policy. The question then remains: Who is responsible for decolonizing the policy system and taking action to foster meaningful involvement?

While asserting the need for non-Indigenous people to centre and honour Indigenous voices and leadership, Waila (2015) argues, “the obligation for decolonization rests on all of us” (p. 50). Waila (2015) calls into question the typical non-Indigenous person’s approach to look to Indigenous leaders for direction on how to take action on decolonization: “Respecting Indigenous leadership is not the same as doing nothing while waiting around to be told what to do. ‘I am waiting to be told exactly what to do’ should not be an excuse for inaction, and seeking guidance must be weighed against the possibility of further burdening Indigenous people with questions” (p. 46). This perspective resonates with Audre Lorde’s (1984) discussion on the implications of repeatedly burdening the oppressed with the responsibility to educate the oppressor:
It is the members of oppressed, objectified groups who are expected to stretch out and bridge the gap between the actualities of our lives and the consciousness of our oppressor. . . . Whenever the need for some pretense of communication arises, those who profit from our oppression call upon us to share our knowledge with them. In other words, it is the responsibility of the oppressed to teach the oppressors their mistakes. . . . The oppressors maintain their position and evade responsibility for their own actions. There is a constant drain of energy which might be better used in redefining ourselves and devising realistic scenarios for altering the present and constructing the future. (p. 114)

Regan (2005) further explains how decolonization cannot be a project for Indigenous people alone, as this inherently asks Indigenous people to heal themselves from the impacts of colonialism through participating in “a process of nation-building that is ultimately defined by dominant cultural values and priorities” (p. 6), which draws attention to the paradox of expecting Indigenous people to address their own issues of sovereignty through a system defined by the very values and priorities that create and sustain colonization. These authors’ perspectives draw attention to the critical role of non-Indigenous people in assuming responsibility for and taking action towards decolonization.

The need for non-Indigenous people to take responsibility for decolonizing policy systems acutely resonates with the perspectives of the research participants. The participants explicitly discussed the integral role of non-Indigenous researchers in educating themselves and re-examining their own roles in relation to power in First Nations health policy processes. Regan (2005) argues non-Indigenous people must assume responsibility for “decolonizing themselves” by engaging in deep reflexive work to challenge their own assumptions and acknowledge the underlying power relations that shape the intercultural dialogues:
To get ‘unstuck’ the non-indigenous – not just in government and legal circles, must focus not, as we have done so often with disastrous results, on the problem of the “other” (that is, Indigenous peoples) but turn our gaze, mirror-like, back upon ourselves . . . . As members of the dominant culture, we have to be willing to be uncomfortable, to be disquieted at a deep and disturbing level – and to understand our own history, if we are to transform our colonial relationship with Indigenous peoples. (pp. 6-7)

Regan (2005) calls on settlers to engage in an “active process of struggle” that transforms one’s perspective “from unconsciousness, racism, denial, and guilt about our history to critical inquiry, reflection and social action” (p. 7). In light of this perspective, the uncomfortable task of confronting colonialism may be a necessary part of the active work non-Indigenous people must undertake to decolonize and transform the policy system in ways that enable more meaningful dialogue between Indigenous and non-Indigenous people.

The data in this dissertation continue to point to the ways in which colonialism gets in the way of meaningful dialogue between Indigenous and non-Indigenous people at health policy decision-making tables. Despite participants’ evident desire to sit together at the policy decision-making table, participants repeatedly explained how Canada’s historical and ongoing oppression of Indigenous people creates an “uncomfortable” situation impeding the most earnest attempts at engagement. I sensed this discomfort in the interviewing process as participants reflected on their struggles trying to navigate such exchanges, as they exuded emotions of frustration, anger, disillusionment and despair. While Indigenous and non-Indigenous people may come to the table from inequitably unequal places, Ermine (2007) suggests what is required for moving towards a more ethical way of engaging, is not an investigation into what separates Indigenous and non-Indigenous people or processes, but rather a deep exploration into defining the space in between:
We are now so badly entangled in our political and social lives that the principles of our existences as autonomous human communities have become blurred in that intercultural confusion. We no longer know what informs each of our identities and what should guide the association with each other. The ideas from our knowledge bases are so entangled and enmeshed with the other that we now find it compelling to decipher Indigenous thought from European thought. . . . The anguished pattern in the history of Indigenous-West relations tells us that we have continued to do the same thing over and over again even as we pursued co-existence. So we continue the posturing and the status quo remains as it always has because we lack clear rules of engagement between human communities and have not paid attention to the electrifying space that would tell us what the other entity is thinking across the park bench. (p. 197)

I draw on Ermine’s (2007) perspective to shed light on the inherent tensions that surface when Indigenous and non-Indigenous people sit together at policy tables, and to provide direction on navigating through these tensions. Ermine (2007) draws attention to the need for inquiry on finding common ground and insight for how to nurture a space for ethical engagement, as this is necessary for disrupting the dominant structures of power that often “rupture” relations between Indigenous and non-Indigenous peoples. Ermine’s perspective provides a context for understanding the significance of the perspectives shared by the research participants, and offers direction on bringing Indigenous and non-Indigenous people closer together in an inherently inequitable policy system.

**Implications for First Nations Health Policy in BC**

To illustrate the significance of this research and the points articulated in the RIPPLES framework, I look to the BC First Nations health policy landscape as a case in point to highlight
implications of the ways First Nations people are currently involved, and the insights gained in relation to the central problematic in this research. As participants in this study discussed, in the last decade BC First Nations have come together to establish themselves as cohesive group and identify a representative leadership body to negotiate with governments on First Nations health policy issues, which illustrates how First Nations people are recognized and represented in First Nations health policy decision-making. First Nations leaders have continued to work in partnership with governments to establish new relationships, which is indicative of the enactment of interrupting past and re-imagining new relationships between First Nations and governments. In drawing attention to multiple agreements in BC, participants explained how efforts to include First Nations people in decision-making have included the establishment of formal agreements, which hold both parties jointly accountable to agreed upon processes, as well as protocols that articulate how the parties will work together. The establishment of policy tables between First Nations people and the highest-level policy decision-makers is indicative of First Nations peoples’ increasing involvement in processes that have leveraged the power to develop and implement policy decisions. Participants explain how work is underway to establish a process for ongoing community engagement in First Nations health policy decision-making, which suggests an increase in exerting community authority. In addition to these significant changes to the way First Nations policy decisions are being made, the increasing recognition of First Nations peoples’ expertise and emergence of First Nations leaders in the mainstream policy system illustrates how social structures are shifting.

Viewing First Nations involvement in health policy in BC through the RIPPLES framework can illuminate how each of the key elements of meaningful involvement are enacted to some extent; First Nations involvement in the BC health policy sphere can thus be seen in part
as meaningful and influential. At the same time, the goal of the RIPPLES framework is not to determine that meaningful involvement has been achieved and then rest in knowing there is nothing else to be done. Instead, it connotes continual inquiry on what actions can be taken to foster First Nations peoples’ involvement at an even deeper, more influential level. This means that even though First Nations people are more meaningfully and influentially involved in BC health policy than ever before, ongoing critical reflection on what can be done to strengthen the existing processes is necessary to disrupt the status quo and transform the First Nations health policy system to include First Nations people at a more intrinsic, structural level.

**Attention to the Diversity of First Nations People’s Voices**

While the analysis and re-conceptualization of meaningful involvement illuminates some of the ways First Nations people are more meaningful and influentially involved in BC health policy decision-making than in the past, it also illuminates other ways First Nations people might be excluded. The critical nature of this research emphasizes the need to examine what power inequities may be implicitly playing out even when involvement appears to be meaningful and influential in a certain light. It highlights the need to examine, for example, what involvement might look like if the focus is on how First Nations people are involved as a whole versus a particular group of First Nations people. In this way, the research findings point to the importance of paying attention to not only *how* involvement occurs, but also to the assumptions around *who* is involved.

This research draws attention to the diversity of First Nations people and the diverse ways First Nations people are involved in health policy decision-making. Paying attention to how diverse First Nations people are differentially involved may reveal that some First Nations groups are marginally included despite the meaningful involvement of First Nations people as a
whole. The research participants discussed the importance of paying attention to First Nations peoples’ diversity, particularly in their discussions related to the urban context and the need to consider ways of involving diverse members of the urban Indigenous community. In addition, by alluding to multiple tensions shaping Indigenous women’s involvement at policy tables, including the lack of Indigenous women’s voices and organizations in the broader Canadian policy sphere, participants illuminated the need to consider ways of meaningfully involving Indigenous women in policy. Although the interview questions did not explicitly explore participants’ perspectives on the involvement of Indigenous women, the data suggest there is a need to consider the gender diversity of First Nations people involved in policy and factors that may be impeding First Nations women from participating.

Cancel’s (2013) analysis of Inuit political involvement in Canada provides one example of how processes of involvement can work to perpetuate gendered power inequities within Indigenous groups. Cancel argues that although Inuit people as a whole have been increasingly involved in policy decision-making structures, Inuit women have been relatively excluded. Cancel (2013) describes the presence of unresolved tensions between Inuit men and women, which stem from a history of colonial patriarchy, as a “silent crisis in Canadian Inuit politics” that is masked by the rhetoric of inclusion (p. 153). Cancel further explains that such tensions have been silenced because internal disputes within Inuit communities “would have marred the impression of cohesion which the Inuit have been trying to reinforce for decades in their dealings with the Canadian political system” (p. 149). Consequently, efforts to include Inuit people in policy have resulted in the relative exclusion of Indigenous women from the Inuit political sphere and the subsequent creation of an Inuit political “elite” that is dominated by Inuit men.
This perspective of Inuit involvement in politics has relevance to the current First Nations health policy infrastructure emerging in BC, in that the creation of a political elite that excludes First Nations women, for example, may erode the integrity of the First Nations governance health structure in representing all of BC First Nations people and interest groups. Drawing on his experiences in a First Nations leadership position, Grand Chief Derek Nepinak (Nepinak & Gazan, 2014) discusses the implications of a political elite for First Nations advancing First Nations people’s agendas on the ground:

There is sometimes a general disconnect between the political elite and what’s happening on the ground in our communities and urban environments. When that disconnect becomes apparent, the legitimacy of any political infrastructure is compromised. . . . [W]e need to see fundamental and transformational change in leadership, governance, and the processes we live within during our lifetime. If we are ever going to break out of this colonial mindset of dependency and deferring responsibility to non-indigenous governments, we need to turn to people most grounded in our communities, the grassroots people. It can’t be the political elite because the political elite are comfortable. (p. 86)

Nepinak (Nepinak & Gazan, 2014) draws attention to the dangers of a First Nations policy system where the decisions are based on the direction of a political elite instead of First Nations communities and people on the ground. This point signals the need for diversifying and transforming First Nations political leadership if First Nations peoples’ agendas are to advance and achieve the change they seek to accomplish.

From an intersectional perspective, diversifying leadership may require more than an open call to participate in health policy decision-making, but also attention to the intersecting
social, historical, political, and economic factors that shape participation in policy for diverse First Nations groups. For example, Cancel (2013) demonstrates that the reasons for the political underrepresentation of Inuit women are tied to household stability and historically constructed gender roles, and that an open invitation for Inuit women to participate in politics does not address the underlying issues that prevent women from participating. Green (2007a) argues that the imposition of colonial patriarchy has differentially shaped experiences of colonialism across the gender spectrum, and that Indigenous political elites and governments must be accountable for sexism and guarantee women’s rights to political participation as Indigenous women are also entitled to benefit from decolonization. Diversifying First Nations policy decision-making leadership thus requires attention to addressing colonial gender inequities and other forms of structural discrimination that impede some First Nations groups from participating in policy decision-making, such as First Nations women or First Nations people living in urban areas.

The above discussion and the findings from this research, draw attention to several questions for consideration in the BC First Nations health policy context. For one, it invites inquiry into the potential underlying tensions within the First Nations community that may be perpetuated or fueled by the current iteration of governance. Is there unresolved dissention among First Nations groups that is masked by discourses of inclusion surrounding the new First Nations health governance structure? Will focusing on how the BC First Nations governance structure is unprecedented and historic detract from internal tensions or the exclusion of some First Nations voices or perspectives, such as those of First Nations women or First Nations people away from home? Will drawing attention to internal tensions undermine First Nations political cohesion and/or jeopardize or impede opportunities for more meaningful and influential involvement? Are the current processes of involvement perpetuating a dominance of some First
Nations voices over others and thus at risk for creating a First Nations political elite? And if so, how can First Nations people be meaningfully involved in ways that mitigate this risk? Is there a need to diversify First Nations leadership, and if so, how and in what ways?

The intent in posing these questions is not to critique the significant strides of BC First Nations in establishing a First Nations health governance structure and the efforts towards achieving more meaningful and influential involvement, but instead to illustrate how a framework for meaningful involvement rooted in critical perspectives can expose areas of the current structure that may be strengthened. Using the RIPPLES of Meaningful Involvement as a framework for attuning to how diverse First Nations people are and could be more meaningfully involved in the First Nations health governance structure may provide insight into ways of further transforming processes of involvement so that the current structure may better advance First Nations people’s agendas and address health issues affecting a diversity of First Nations people.

**Taking Responsibility for Urban First Nations Health: Opportunities for Fostering Meaningful Involvement**

Despite the unprecedented and historic ways First Nations people are involved in BC, a different construction of involvement emerges when the RIPPLES of Meaningful Involvement is used as a framework for exploring how First Nations people living away from home are involved. Participants discuss the lack of mechanisms for including urban Aboriginal people in the First Nations health governance structure, which focuses predominately on First Nations people living at home on reserves, as well as a lack of including urban Aboriginal community members in regional health authority decision-making, which is where decisions on urban Aboriginal health tend to be made. Although the data suggests there is some recognition of the
importance of including First Nations people living away from home and a desire to include urban Aboriginal communities, the interviews point to an overall lack of representation of urban Aboriginal people in the current BC First Nations health policy processes.

Given the necessity of First Nations involvement in developing relevant and effective policies, if urban Aboriginal communities are not providing input, the decisions made by the current structure may be neither relevant nor effective for addressing issues of concern for First Nations people living away from home. Although urban Aboriginal people are typically not represented in political discussions (Abele, et al., 2011; Peters, 2011a), without a representative voice at the BC First Nations health policy tables, a large proportion of the BC First Nations population may not benefit from the current decision-making arrangements.

The lack of involvement of urban Aboriginal people not only has implications for First Nations people living away from home, it also has implications for the BC First Nations health governance structure itself. The lack of mechanisms to include urban Aboriginal people in both regional and provincial First Nations health policy processes may be a reflection of the historical jurisdictional battles between the federal and provincial governments and the tendency of neither government to take responsibility for the health of First Nations people living off-reserve (Browne, McDonald, et al., 2009; Peters, 2011a). If the BC First Nations health governance structure neither includes urban Aboriginal people nor asserts responsibility for the health of First Nations people living away from home, it may be seen as an extension of historical colonial politics and as perpetuating an abdication of responsibility for addressing First Nations health. It could thus be subject to the critiques of neoliberal Aboriginal governance structures, including the privatization of Indigenous health issues and the detraction of government responsibility to address them (2011).
Considering the tendency of First Nations-led organizations to be critiqued by community members on account of their tendency to advance neoliberal goals that undermine community interests (MacDonald, 2011), a key implication for the BC First Nations health governance structure is the risk of losing credibility among First Nations people, and particularly those living in urban areas away from home. Considering this crucial moment in history where First Nations are at an unprecedented level of political involvement in BC, such skepticism may impede strategic partnerships or contribute to political fracturing among First Nations groups. Involving First Nations people away from home in the BC First Nations health governance structure may not only be important for addressing health issues affecting urban Aboriginal communities, but also for assuring credibility, and thus success and sustainability, of the BC First Nations health governance structure. A critical framework for meaningful involvement in the BC First Nations health policy context points to the inclusion of First Nations people living away from home as a significant and urgent priority.

Although the data suggest urban Aboriginal communities have largely been excluded from the BC First Nations health policy processes, reading the data in relation to the RIPPLES framework constructs the First Nations health governance structure’s recognition of First Nations people living away from home as an important first step towards including First Nations people in more meaningful and influential ways. This research illuminates how the creation of the First Nations health governance structure may serve as groundwork for fostering more meaningful and influential involvement of First Nations people away from home, and thus can contribute to further transforming and decolonizing the First Nations health policy system in BC.
Strategic Directions and Recommendations

Using the RIPPLES of Meaningful Involvement as a framework for understanding First Nations health policy decision-making in BC, I arrive at the following strategic directions and recommendations for fostering more meaningful and influential involvement of First Nations people away from home in First Nations health policy decision-making:

Action Calls for Recognizing and Representing Indigenous Peoples

1. Efforts should be taken to include at least one First Nations person living away from home in an urban setting is represented at key First Nations health policy tables.

Action Calls for Interrupting and Re-Imagining Relationships

2. Urban Aboriginal communities and/or community members should be financially and socially supported in coming together on their own to self-organize, develop a common agenda, and establish internal processes including identifying representative leadership.

3. All members of those involved in policy decision-making processes affecting urban Aboriginal people and/or communities should be supported in learning about First Nations/colonial history, including the historical on-/off-reserve divide in First Nations policy and the subsequent implications for First Nations people living away from home.

4. Forums should be established for urban Aboriginal communities to come together with First Nations health policymaking bodies to build trust amongst each other, reconcile relationships, and articulate new relationships for working together.

Action Calls for Preparing Agreements

5. Formal agreements such as legal documents should be established between urban Aboriginal communities and key organizations that make policy decisions affecting First Nations people and/or urban Aboriginal communities, including health authorities,
municipal governments and local First Nations. Such agreements should be based on reconciled relationships between parties and these relationships should be articulated in the agreements.

6. Agreements between urban Aboriginal communities and key First Nations health policy decision-makers should articulate a shared responsibility among all signing parties to improve urban Aboriginal people’s health, address urban Aboriginal health issues, and include urban Aboriginal people in policy decisions affecting their health. Such agreements should hold all parties legally accountable to their responsibilities and commitments outlined in the agreements and articulate how each party is accountable to the process and to the decisions reached, such as detailing measures or provisions for ensuring accountability.

**Action Calls for Practicing Protocols**

7. Rules for engagement between urban Aboriginal communities and all partners involved in urban Aboriginal health decision-making should be established and agreed upon by all parties. This includes articulating specific processes and protocols for working together, such as protocols for communication, rules for guiding discussions at the decision-making table, and detailed processes on how the actual decision-making will occur.

**Action Calls for Leveraging Power**

8. The highest-level decision-makers from key First Nations health policy decision-making bodies should be involved and/or on board with the process. Such decision-makers should include, the identified representative leadership of urban Aboriginal communities, CEO or senior executives in the First Nations health governance structures and regional
health authorities, the Mayor or senior executives in municipal governments, and Chiefs or political leaders from local First Nations communities.

9. Sufficient resources should be provided to support a full engagement process as well as implementation of decisions that are reached.

Action Calls for Exerting Community Authority

10. Policy processes to address urban Aboriginal health issues should include experts in urban Aboriginal health policy, including policy and technical experts, researchers, and most importantly, members of urban Aboriginal communities who represent community perspectives and not the interests of organizations or governments.

11. Policy processes should include a comprehensive community engagement strategy to include diverse members of urban Aboriginal communities, for example, status and non-status First Nations people, Métis and Inuit people, First Nations and Aboriginal women, and Two-Spirited people and other Indigenous members of LGBTIQQ2SA communities, who are part of the urban Aboriginal community.

12. Rigorous methodologies for incorporating input from community members into policy decisions and using community input to drive policy processes, including who is representing urban Aboriginal communities at decision-making tables, should be developed and implemented.

13. Efforts should be made to include a diversity of First Nations people who represent urban Aboriginal communities, including First Nations women, are driving policy decisions affecting urban Aboriginal communities.

43 LGBTIQQ2SA is an acronym used in contemporary queer contexts to identify and make visible the diversity of the queer community. Recognizing this acronym has changed over time and continues to change in relation to the current contexts, and that it does not explicitly include the full range of diverse sex and gender identities, including asexual and pansexual people, LGBTIQQ2SA refers to people who identify as lesbian, gay, bisexual, transsexual, transgender, intersex, queer, questioning, 2-Spirit, and allies (Armstrong, 2014).
Action Calls for Shifting Social Structures

14. Efforts or initiatives in the following areas should be financially and socially supported by parties responsible for addressing First Nations and/or urban Aboriginal health:

a. Fostering urban Aboriginal people’s connections to their home communities and cultures, as well as access to traditional and/or Indigenous knowledge systems (e.g. cultural exchange programs);

b. Building urban Aboriginal people’s capacity and experience in policy decision-making (e.g. policy mentorship or internship programs for people living away from their home communities);

c. Creation of high-level policy positions for First Nations people living away from home who have expertise in urban Aboriginal health and/or communities, including First Nations people who are typically excluded from policy decision-making such as First Nations women;

d. Development of policy paradigms and/or policy methodologies based on Indigenous and Western knowledge systems (e.g. Indigenous-Western policy frameworks or policy analysis methodologies) to guide First Nations health policy development in ways that challenge dominant policy discourses that foster the exclusion of urban First Nations people, such as the on-/off-reserve policy divide.

Concluding Comments

This research suggests that First Nations people are often still excluded from health policy decision-making in Canada, and when they are included, the processes of involvement are far from perfect. A critical analysis of the data suggests striving towards meaningful involvement requires ongoing inquiry into the underlying power inequities shaping First Nations involvement.
The impact of past neoliberal, paradoxical policies on First Nations health such as the health transfer policies of the eighties, which gave First Nations more control over decision-making on one hand while lessening government responsibility on the other, may serve as a reminder that even when touted as policies of empowerment, efforts to increase First Nations involvement may not in itself be sufficient for addressing health inequities, and may further lay the blame on communities themselves. Meaningfully and influentially involving First Nations people in health policy decision-making requires attuning to the factors that contribute to these dynamics, and enacting a process of continuous reflection on how First Nations people are and could be involved in ways that are responsive to these power dynamics.

Viewing the BC First Nations health policy context with this analysis in mind illuminates how First Nations people are more meaningfully and influentially involved in health policy decision-making than ever before in BC. At the same time, the findings suggest that the current processes of involving First Nations people still have room for improvement. Attention to the ways First Nations people living away from home can be more meaningfully included in processes such as the BC First Nations health governance structure may provide a window of insight into understanding how First Nations health policy decision-making can be further strengthened and improved in BC and beyond. This includes taking action to mitigate the risk of meaningful involvement becoming a means for fostering a First Nations health policy decision-making elite, thereby perpetuating the dominance of some First Nations people’s voices in the political arena and the subsequent exclusion and marginalization of others. Taking action to involve First Nations people living away from home in health policy decision-making may represent a strategic effort to avoid repeated patterns of dominance and exclusion and thus
disrupt the paradoxical ways First Nations people are involved in policy on one hand and simultaneously excluded on the other.

To foster more meaningful involvement of First Nations people in health policy decision-making and thus work towards developing policy that has the potential to improve First Nations health and address issues of health inequity, processes of involvement must actively mitigate the effects of inequitable power dynamics that play out at policy decision-making tables. Decolonizing the health policy system through mitigating the effects of structural inequities and centrally including First Nations people, however, is not a process that can occur all at once. With transformative structural change always lingering on the horizon, there remains a need to start somewhere. This research emphasizes how even the smallest actions to involve First Nations people in a policy process can be significant steps towards meaningful involvement, especially considering how rarely First Nations people are included at health policy decision-making tables. At the same time, when First Nations people are included at the table or elsewhere in the process, the remaining need is to continue reflecting on who is involved and how involvement occurs, as this ongoing reflection is what may enable transformative shifts towards deeper, more influential, and more meaningful involvement.
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APPENDICES

Appendix A: Study Summary

Exploring the Meaningful Involvement of Urban Indigenous People in Health Policy

Study Summary

I would like to inform you of a study entitled, *Fostering health equity through the meaningful involvement of urban Indigenous people in health policy and decision-making*. This is a doctoral research project being conducted at the University of British Columbia by myself, Alycia Fridkin, under the supervision of Annette Browne, Madeleine Dion Stout and Jim Frankish.

The purpose of this study is to learn more about how health policy and decision-making processes can better address issues related to health and health inequities for Indigenous people living in urban areas of Vancouver and British Columbia. It is my hope that this study will inform new ways of thinking about how urban Indigenous people can be meaningfully included in health policy and decision-making, and how issues related to health equity can be addressed through policy and decision-making.

This study will involve interviewing leaders in Indigenous health and leaders in health policy about their perspectives and experiences related to Indigenous health and health policy in Vancouver, British Columbia and Canada. I am interested in hearing the perspectives of leaders and experts who are currently or have previously been working in the area of a) Indigenous health, and b) other areas of health policy.

If you have experience in policy or decision-making around Indigenous peoples’ health, you may be interested in participating in a research interview for this study. During the interview, I would be asking specifically about your experiences participating in policy and decision-making on issues related to Indigenous peoples’ health.

*If you are interested in hearing more about this study or would like to find out how you can participate, please contact Alycia Fridkin at afridkin@interchange.ubc.ca or by phone at [phone number].*

Researcher Contact Information:

<table>
<thead>
<tr>
<th>Alycia Fridkin, PhD Candidate</th>
<th>Annette Browne, PhD, RN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctoral Researcher</td>
<td>Alycia’s Research Supervisor</td>
</tr>
<tr>
<td>Interdisciplinary Studies, UBC</td>
<td>Professor, UBC School of Nursing</td>
</tr>
<tr>
<td><a href="mailto:afridkin@interchange.ubc.ca">afridkin@interchange.ubc.ca</a></td>
<td><a href="mailto:annette.browne@nursing.ubc.ca">annette.browne@nursing.ubc.ca</a></td>
</tr>
</tbody>
</table>
Appendix B: Interview Guide

Preamble

The purpose of this study is to learn more about how health policy and decision-making processes can be improved so they will lead to policy decisions that better meet the needs of Indigenous people and improve Indigenous peoples’ health. I am interested in learning about decision-making between Indigenous peoples and policy makers, and I am especially interested in learning about policy decisions that are related to urban Indigenous peoples’ health.

I will be asking you about your experiences being involved in decision-making related to Aboriginal health or other policy issues that concern Aboriginal peoples.

To begin, I would like to hear about your role in the organization you are currently working for.

Interview questions

Role in the organization and policy experience

1. Tell me a little bit about your current role or position at this organization/with this community.

2. What kind of policy work or decision-making do you do in relation to Aboriginal peoples’ health? What kind of decision-making have you been involved with?

Aboriginal peoples’ involvement in decision-making

3. In your experiences with policy and decision-making, have Aboriginal people or communities been involved? Please explain and provide examples if possible.
   a. What did the process of involvement look like?
   b. What worked well?
   c. What were challenges? How should these be addressed?

Experiences in decision-making on Aboriginal issues

4. Tell me about your experiences being involved with policy decisions related to Aboriginal issues. Can you provide examples?

Probing questions:
   a. What did the decision-making process look like?
   b. What worked well?
   c. What were challenges? How should these be addressed?
Recommendations for decision-making that involves Indigenous people

5. Based on your experiences, how could policy and decision-making processes on Aboriginal peoples’ health be improved?

Meaningful involvement

6. What should meaningful involvement of Aboriginal people in health policy look like? What is needed to foster meaningful involvement?

Recommendations for involving urban Indigenous people or communities

7. What should meaningful involvement of Aboriginal people in health policy look like?

Urban Indigenous involvement

8. In your experiences, how have Indigenous people living in urban settings been involved in health policy or decision-making? Please provide examples.

   a. What did the process of involvement look like?
   b. What worked well? What were challenges?

9. What is needed to foster meaningful involvement of urban Indigenous people or communities in health policy and decision-making? What recommendations would you have?

Additional comments

10. Is there anything else you would like to tell me that you think is relevant and that we have not discussed today? If so, please feel free to tell me now.

Follow up

Those are all the questions I have for now. Thank you so much for your time, this has been so helpful. If you wouldn’t mind, I now just have a quick form that I would like to complete with you. It will only take about 5 more minutes of your time.

[Complete socio-demographic form].

Thank you again for your time and for the valuable information you shared. In honour of the time you contributed to this interview, I will be making a donation to a local charity using the combined honouraria for this research. [Give thank you card].

If you have any questions or if you wish to get a hold of me in the future for anything related to this research, please contact me at the contact information provided on the consent form, which you may take with you.
Appendix C: Consent Form

Consent Form for Research Participants

To participate in the study,

“Fostering health equity through the meaningful involvement of urban Indigenous people in health policy and decision-making”

Doctoral Researcher: Alycia Fridkin, PhD Candidate
Interdisciplinary Studies Graduate Program, UBC
Tel: 778-318-4475

Research Supervisor: Annette Browne, PhD, RN
School of Nursing, UBC
Tel: 604-822-7558

Dear Research Participant,

You are invited to participate in the research study, *Fostering health equity through the meaningful involvement of urban Indigenous people in health policy and decision-making*. This is a doctoral research project and the results will be published in a doctoral dissertation and made available to the public. This research is funded through a Doctoral Research Award from the Canadian Institutes of Health Research.

Purpose:
The purpose of this study is to learn more about how health policy and decision-making processes can better address issues related to health and health inequities for Indigenous people living in urban areas of Vancouver and British Columbia. You are being invited to take part in this research study because of your involvement and expertise in the area of Indigenous Peoples’ health and/or health policy and decision-making.

What this Study Involves:
This study involves interviewing leaders and experts in Indigenous health and/or health policy and health decision-making in Vancouver, British Columbia, and Canada. As a research participant, you are being asked to participate in a research interview. The research interview will last approximately 1 – 1.5 hours and it will take place at a time and location of your choice. Where possible, the interview will be conducted in person, however if an in-person interview cannot be arranged, the researcher will arrange to interview you on the phone or online via Skype. You are being asked for your permission to have your interview audio-recorded, however you may request to be interviewed without being recorded and you may also ask for the recorder to be turned off at any time during the interview. At any time during or after the interview, you may ask for any part of the recording to be erased or to not be used in the research.
Risks and Benefits:
There are minimal risks to participating in this research, however you may feel as if you are not able to share your personal views during the interview. Please remember that any identifiable information you provide will be removed in the transcripts and the final dissertation, and the goal of this research is not to evaluate your perspectives, but rather to learn about the broader health policy context from the perspectives you choose to share with the researcher.

You may benefit from participating in this research by having the opportunity to share your insights and personal reflections on larger policy issues that you otherwise may not have the opportunity to do in your daily work. Thinking about these broader issues may inform your own personal approach to your policy work or professional practice. Your participation in this research will also contribute towards new ways of thinking about how to improve policymaking so that it benefits Indigenous people living in urban settings. It is the researchers’ hope that your participation in this research will have a larger benefit to Indigenous people living in urban settings in Vancouver and British Columbia.

After this research is completed, you will receive a summary of the research findings and information on how to request an electronic copy of the full doctoral dissertation.

Protecting Privacy and Confidentiality:
If you participate in this research your identity will be kept strictly confidential and all identifiable information such as names of people and organizations that are disclosed during your interview will be removed from written transcripts and the final dissertation. A participant number will be used in place of your name on all transcripts and in the published dissertation. All materials from your interview including this signed consent form, the socio-demographic form and the audio-recording of your interview will be stored in a locked filing cabinet and/or on a secure password-protected shared network located at UBC’s School of Nursing. The only people who will see your information are the two researchers on this study.

This research is voluntary and you can choose to end this interview at any time. At any time you can also decide to withdraw from this research and ask for your interview not to be used.

Remuneration/Compensation:
In honour of your participation, at the completion of this research a donation will be made to a local charity related to the topic of this research.

Contact for information about the study:
If you have any questions or desire further information with respect to this study, you may contact Alycia Fridkin (Doctoral Student Researcher) by email at afridkin@interchange.ubc.ca or by phone at [redacted]. You may also contact Annette Browne (Alycia Fridkin’s Supervisor) by email at annette.browne@nursing.ubc.ca or by phone at [redacted].
Contact for concerns about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

Consent:
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your [for example, employment, class standing, access to further services from the community centre, day care, etc.]. Your signature below indicates that you have received a copy of this consent form for your own records and that you agree to participate in this study.

Do you give permission to the researcher to audio-record this interview? Yes ❏ No ❏

Signature of Participant __________________________ Date __________________________

Please print your name
Appendix D: Socio-Demographic Form

Socio-Demographic Form

Personal Information

Participant # _____________________________

Gender: _________________________________

Date of birth: _____________________________

Cultural background or ethnicity: ________________________________

First Nations, Inuit or Métis: ________________________________

Education and Work/Employment

Highest level of education completed: ________________________________

Professional credentials/designations: (i.e. RN, MD) ________________________________

Current Position: ________________________________________________________

Organization: ____________________________________________________________

Number of years in this position: ________________________________

Number of years working in Aboriginal health: ________________________________

Number of years working in health policy: ________________________________

Follow up

Do you have any recommendations of relevant people to interview? Yes ❑ No ❑

If yes, please provide contact info/details:

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________
Would you be willing to be contacted for a follow-up interview? Yes ❑ Yes ❑ No ❑ No ❑

If yes, what is the best way to get in touch with you? (Please provide phone number, email, etc.)

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

Would you like to receive a summary of the findings of this research and information on how to request a copy of the final dissertation? Yes ❑ Yes ❑ No ❑ No ❑

If yes, what is the best way to send it to you? (Please provide email or mailing address)

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________