STAGING RELATIONSHIPS: USING DEvised THEATRE TO EXPLORE FIRST NATIONS YOUTHS' EXPERIENCES AND PERCEPTIONS OF THEIR RELATIONSHIPS WITH HEALTHCARE PROVIDERS

by

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ABSTRACT

In Canada, vast inequities exist between Aboriginal and non-Aboriginal youth, especially in northern, rural communities. Research has shown positive relationships with physicians greatly impacts on health, yet, to date, research on relationships between healthcare providers and Aboriginal peoples has not widely consulted or involved the younger population. The goal of this research was to explore relationships between Nisga’a First Nations youth (ages 19-25) and their healthcare providers by identifying cultural and social factors that encourage or hinder meaningful access to healthcare.

Using a social determinants of health framework, this research employed community-based participatory approaches and decolonizing methodologies as well as arts-based methods (devised theatre). Four key themes emerged exemplifying two Nisga’a First Nations youths’ experiences of relationships with healthcare providers. The most important finding was that Nisga’a youth participants identified ‘relationships’ as a determinant of their interactions with healthcare providers. Furthermore, using theatre proved to be a successful way to engage youth in research.
6.2 Conclusions and Future Directions ................................................................. 112

APPENDIX I. NORTHERN HEALTH AUTHORITY SERVICE REGION ........ 116

APPENDIX II. LOCATION OF NASS VALLEY IN BRITISH COLUMBIA ...... 117

APPENDIX III. LETTER OF CONSENT FROM NASS VALLEY ...................... 118

APPENDIX IV. OPEN DIALOGUE QUESTIONS ................................................. 119
LIST OF TABLES

Table 1. Research stages 51

Table 2. Research questions explored during drama workshop 57
**LIST OF FIGURES**

*Figure 1.* Screenshot of HARC art worksheets. 57

*Figure 2.* What makes me healthy? 62

*Figure 3.* Experiences with healthcare providers. 65

*Figure 4.* First frozen tableau representing ‘disconnect.’ 70

*Figure 5.* Second frozen tableau representing ‘control.’ 71

*Figure 6.* Final frozen tableau representing ‘empowerment.’ 72

*Figure 7.* Words taken from transcript representing youths’ experiences. 78
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ALL THE MATERIALS USED, AND RESULTS OF THE RESEARCH REMAIN THE SOLE PROPERTY OF THE WILP WILXO'OSKWHL NISGA’A
CHAPTER 1: INTRODUCTION

1.1 Study Objectives and Rationale

Aboriginal (i.e. the descendants of the original inhabitants of Canada) youth across Canada experience vast health inequalities and significant health disparities, however measured, compared to non-Aboriginal youth (Adelson, 2005; Peiris, Brown, & Cass, 2008; Reading & Wien, 2009). Aboriginal youth, in particular, are significantly vulnerable to a variety of socially-determined and biomedical health risks, such as increased rates of teen pregnancy, HIV/AIDS, violence, malnutrition and unemployment (Ning & Wilson, 2012). One factor in enhancing health outcomes for this population, as well as more generally for Aboriginal peoples, is the strengthening of relationships between a patient and their physician. To date, research has not substantially explored Aboriginal youths' use of healthcare services or their interactions with healthcare providers (Ning & Wilson, 2012). This is surprising given the numbers of studies that have investigated Aboriginal peoples' experiences with the healthcare system, given that Aboriginal youth suffer from poorer health than non-Aboriginal youth, and given well-documented knowledge about the link between positive health outcomes and one's use of health services and interaction with healthcare providers (Browne, 2007; Ning & Wilson, 2012). The purpose of this Masters thesis research project was to address this gap in knowledge and explore two Nisga’a First Nations youths’ perceptions and lived experiences of their relationships with healthcare providers in a Nisga’a First Nation community in Northern British Columbia. The categorization of healthcare providers was purposefully left open so as to allow participants to voice their interpretation of what constituted a healthcare provider in their life - such an open ended orientation to
healthcare providers allows participants to orient to the healthcare provider they perceive having the greatest impact in their life. It is important to note that for participants’, the term ‘healthcare provider’ translated as doctor or nurse. This could be read as the power invested in doctors and nurses, particularly in the imagination and minds of these young Aboriginal people in northern BC.

The main objectives of this work were thus to:

1. document the Aboriginal youths’ understandings of ‘health’,
2. explore youth perceptions of, and lived experiences with their healthcare providers,
3. ask Aboriginal youth what they want to say to those who provide health services,
4. devise strategies with youth for the healthcare system and providers that are consistent with Aboriginal youth perspectives and needs around health, and
5. pilot the use of devised theatre as a youth-led-data-gathering-method to narrate the lived experiences of Aboriginal youth with current & future healthcare providers.

To meet these objectives, a cross-cultural, community-based participatory action research project informed by decolonizing methodologies was designed and undertaken in a Nisga’a First Nations community in the Nass Valley region of Northern British Columbia. The project used devised theatre methods, complemented by an open dialogue, to gather data with Aboriginal youth participants. As defined by the United Nations Education, Scientific and Cultural Organization (2016), ‘youth’ refers to a person “between the age where he/she may leave compulsory education, and the age at which he/she finds his/her first employment” (para. 2) and is thus defined as people between the
ages of 19 and 24: youth can also, however, include persons up to the age of 35 years (United Nations Education, Scientific and Cultural Organization, 2016). For the purposes of this project, ‘youth’ was defined as those between the ages of 19 and 25.

The relationship between the Canadian state and the first peoples of Canada is complex and entrenched in a colonial history of oppression of Aboriginal peoples. While this will be discussed in more detail in Chapter 2, along with how this history shapes, or impacts this research project, it is important to mention it at the onset of the thesis, especially with respect to the impact this has on terminology used throughout this thesis. It is important to note that, “terminology can represent something more than just a word. It can represent certain colonial histories and power dynamics” (University of British Columbia, n.d., para. 3). Furthermore, terminology around Indigenous peoples can ‘clump’ together these peoples and, disregard the diversity between each Indigenous group around the world. With this in mind, I try to use the most appropriate term when discussing Indigenous peoples. Throughout this thesis, the term ‘Aboriginal’ refers to the descendants of the original inhabitants of Canada, including First Nations, Inuit and Métis peoples. The term ‘First Nations’ is specifically in reference to this Aboriginal group, and if available, the specific First Nation band will be named. The use of the term ‘Indigenous’ will refer to Indigenous peoples globally.

Furthermore, throughout this thesis I use the term ‘Nisga’a youth’ to represent the Nisga’a youth who participated in this project. It is important to note that in using this term, I am in no way shape or form generalizing at a community, or even nation level, the feeling of young Nisga’a citizens. However, having said that, much can be learned from
listening deeply and listening with focused attention to stories of people and their experiences. There is always room to learn from the stories of even one or two people.

Based on extensive background and literature searches, this research is, to my knowledge, the first of its kind in Canada, using as it does an arts-based method to explore patient-physician relationships between Aboriginal youth and their healthcare providers. It is my hope that this work will contribute to documenting Aboriginal youth perspectives and experiences about health care systems and contribute to the development of meaningful, culturally-appropriate, youth-relevant strategies to improve health and wellbeing for Aboriginal youth in Canada—this, may in turn, address disparities in health.

1.2 Motivation for pursuing this research.

As an individual with interdisciplinary interests, including cross-cultural work, the social determinants of health, and theatre, I sought a Masters program and a research project in which I could combine these diverse interests. I chose to pursue a Masters of Community Health that explored First Nations youths' experiences with their healthcare providers, using devised theatre techniques. Having participated in a health-focused cross-cultural youth exchange with Canada World Youth (CWY) in the third year of my undergraduate degree, I learned the value and importance in working respectfully with people from various backgrounds and perspectives. In this experience I engaged in conversations around the differences in access to healthcare resources based on race and power of certain racialized groups. These discussions were had with people who brought different perspectives than my own. By the end of the program I had become very
interested in the topic of healthcare inequities from a cross-cultural perspective, and I recognized the richness of having multiple perspectives to health care discussions.

While it was through my experience with the CWY that I began to learn and appreciate the impact of social factors on health, it was through a course on the Social Determinants of Health in my fourth year of my Bachelor degree when I delved into and began to learn about the complex factors that contribute to the health and wellbeing of humans, especially those that go beyond biomedical definitions of health. Collectively these past experiences and studies brought me to an interest in the intersection of health inequities, social determinants of health, and cross-cultural work. It is important to note that while the first time I delved into issues of health inequities was in a developing country, known globally for health disparities, I was aware that health inequities also exist in my own country, and are especially prominent within Aboriginal contexts and communities. Indeed, more recently and in a time of Canada’s Truth and Reconciliation Commission and resulting report, it is increasingly understood that non-Aboriginal settlers Canadians MUST take a more active role in understanding the places of privilege from which we operate and the important role we play in the current landscape of inequalities lived by so many Aboriginal peoples today (see Truth and Reconciliation Commission of Canada, 2015).

My interest in using an arts-based method came from my lifelong passion for theatre. In 2013, I joined the Kitchener-Waterloo Youth Theatre (KWYT) group, a theatre company that uses “Devised Theatre” or “Collective Creation” rather than traditional theatre methods or approaches. This type of theatre includes actors collectively creating a piece or story and conveying their story through physical movements.
Furthermore, each actor brings his or her own lived experiences to the story. I found this process inspiring, the method profoundly moving, and it resonated strongly with me as a way to tell a story without (or even beyond) words. Based on my involvement with the KWYT and my experience with devised theatre, when it came to designing a research project with arts-based methods, it was a natural fit to bring in this type of theatre to my research. I felt devised theatre would provide a creative and powerful way for First Nations youth to tell their stories of experiences with healthcare providers—without the pressure and constraints of using only words.

It was a pleasure to unite diverse interests into one project and, perhaps more fulfilling and encouraging, was the discovery of how these seemingly different areas could be powerfully combined and complement one another to create a unique environment in which I could explore First Nations youths’ experiences of relationships with their healthcare providers, in Northern British Columbia.

1.3 Northern British Columbia

Northern British Columbia is a unique geography spanning approximately 600,000 square kilometers of the province, and approximately 64% of British Columbia’s land base (First Nations Health Authority, 2015). Northern B.C. is sub-divided into three regions, including the Northeast, Northwest and Northern Interior regions (Northern Health, n.d.; University of Victoria, 2011). For the purpose of this research, the Northern Health Authority’s definition of Northern British Columbia is used, which, broadly speaking, is defined as reaching north to the B.C.-Yukon border, west to the BC-Alaska border, east to the BC-Alberta border, and south, stretching just past Quesnel and Valemount (Northern Health, n.d.) (see Appendix I).
The population of Northern British Columbia is approximately 300,000, or 6.5% of B.C.’s population, with the majority of the population clustering in the Northern Interior region in the city of Prince George (approx. 70,000 people) (University of Victoria, 2011). According to the First Nations Health Authority, Northern B.C. is home to 35.6% of First Nations peoples in the province, with approximately 34% of First Nations living on-reserve and 54% living off-reserve (First Nations Health Authority, 2015).

1.4 The Nass Valley and the Nisga’a First Nation

The Nass Valley, situated in Northwestern British Columbia, is home to the Nisga’a First Nation, people of the Nass River (see Appendix II). There are four Nisga’a communities located along the Nass River: Gitlaxt’aamiks, Gitwinksihlkw, Laxgalts’ap and Gingolx. This project took place in the community of Gitlaxt’aamiks, formerly known as New Aiyansh, and home to 1,800 people. The community of Gitlaxt’aamiks is located 100km northwest from the city of Terrace, BC. All members of the Nisga’a First Nation belong to one of four Pdeek (i.e. tribes): The Gana Clan whose crest is represented by a Raven/Frog; Laxgibuu Clan whose crest is represented by a Wolf/Bear; Gisk’aast Clan whose crest is represented by the Killer Whale/Owl; and the Laxsgiik Clan whose crest is an Eagle/Beaver (Nisga’a Lisims Government, n.d.). The Nisga’a First Nation is matriarchal, and therefore, men and women hold memberships in their mother’s clan. The official language of the Nisga’a First Nation is Nisga’a (Nisga’a Lisims Government, n.d.).

Covered with lava beds from a volcanic eruption that occurred over 200 years ago, the Nass Valley is a unique landscape in British Columbia (Nisga’a Lisims
Government, n.d.). The Nisga’á First Nation describes the story of the erupting volcano through their oral traditions:

Two children were playing by the river, catching salmon and slitting open their backs. One child slit a salmon’s back, stuck a stick into the wound and lit the stick on fire. The other child slit a salmon’s back and stuck a piece of shale into the wound. As the children placed the salmon back in the water they were amused by the panic and struggle of the fish. An elder saw what the children were doing and warned them of their actions saying, “Take care what you do. The salmon will curse you and the creator will respond kind” (Nisga’a Lisims Government: Volcano, n.d., para. 3). Shortly after, the ground began to tremble and the volcano began erupting with lava that covered two communities and killed more than two thousand people.

This story and the lava beds that cover the Nass Valley to this day serve as a reminder to the Nisga’a people of those who lost their lives to the volcano, as well as the importance of respecting the earth and wisdom of the Elders (Nisga’a Lisims Government, n.d.).

Having signed the first modern day treaty in British Columbia’s history, the Nisga’a First Nation are self-governing and hold control over their population and their land. This makes the Nisga’a a unique First Nation in British Columbia. On May 11, 2000, the Nisga’a Final Agreement was finalized between the Canadian Government and the Nisga’a First Nations, marking British Columbia’s first modern treaty (Nisga’a Lisims Government, n.d.). Therefore, the Indian Act no longer applies to the Nisga’a First Nation. The Nisga’a First Nation is governed by the Nisga’a Lisims Government (NLG), and each community has a local government. The vision of the NLG is Sayt-K’il’im-Goot: one heart, one path, one nation (Nisga’a Lisims Government, n.d.).

1.5 Outline of Chapters

This thesis details the journey of the research and unfolds in five chapters. Throughout all of these chapters it is important to note that any generalization of
Aboriginal peoples is unintentional, and this thesis is based on the recognition of the diversity and uniqueness of all First Nations, Inuit and Métis.

Following from this first chapter, Chapter Two provides an overview of the literature and includes in-depth discussions on social determinants and Aboriginal peoples’ health, focusing specifically on Aboriginal youth, and also outlines existing scholarship on Aboriginal peoples’ experiences and encounters with healthcare systems and personnel in Canada. This discussion ends with a piece on the emergence of storytelling and theatre methods in qualitative research. The background literature included in this chapter demonstrates that Aboriginal peoples, both globally and in Canada, continue to experience an overwhelming burden of health inequities. Furthermore, Aboriginal peoples continue to be targets of racism and discrimination in healthcare settings, where Aboriginal peoples have experienced negative and positive encounters with their healthcare providers.

Chapter Three provides a discussion on my research methodologies, which lay the philosophical foundation for this research and for the methods chosen to undertake the work. The methodologies chosen for this work were based around a social determinants of health framework and included a community-based participatory research approach and decolonizing methodologies. The methods chosen for the project were informed by the choice of methodologies, and as such are participatory, arts-based methods. The primary method of data collection was devised theatre, complemented by an ‘open dialogue.’

Chapter Four covers the results from this research. Four themes emerged from the data and include: disconnect, when the body speaks- incomplete care, empathy, and
empowerment. Following the results, Chapter Five discusses the findings of this work at length while engaging with existing literature. To conclude, Chapter Six outlines the limitations of this project and highlights overall findings. The conclusion ends with considerations and recommendations for further research.
CHAPTER 2: OVERVIEW OF LITERATURE

In Canada vast health inequities and significant health disparities exist between Aboriginal peoples compared to non-Aboriginal peoples (Adelson, 2005; Peiris, Brown & Cass, 2008). Specifically, research has shown that Indigenous youth in Canada and around the world are significantly vulnerable to a variety of socially-determined and biomedical health risks, such as increased rates of teen pregnancy, HIV/AIDS, violence, malnutrition and unemployment (Gracey & King, 2009; Ning & Wilson, 2012; Worthington et al., 2010). These risks are particularly heightened by lack of access to and use of health clinics, in addition to feelings of distrust with healthcare professions (Browne, 2007; Gracey & King, 2009). Much of the literature cites Indigenous health disparities as primarily stemming from social, political, cultural and economic inequities that are rooted in a history of colonialism (Adelson, 2005).

Common to many groups of Indigenous peoples around the world are the effects of colonization, which can be defined as "the implanting of settlements on distant territory" (Said, 1993, p. 8). In Canada, Euro-colonial groups claimed lands now known as Canada as 'empty,' literally 'creating the grounds' to forcefully marginalize and remove Aboriginal peoples from their traditional lands and territories (Castleden, Morgan & Lamb, 2012). Furthermore, colonial policies and practices were forced upon Aboriginal peoples in an attempt to assimilate Aboriginal peoples into European society. These included removal of traditional lands and foods, forced relocation to reserves, the involuntary attendance of children in residential schools, banning of traditional ceremonies, and laws that put into place discriminatory and oppressive practices towards Aboriginal Canadians (Adelson, 2005). The effects of colonialism (those larger set of
laws, policies and discursive structures that buttressed the more material act of colonization, or forced removal of territory) on Aboriginal peoples in Canada, and Indigenous peoples globally, continues to be profound, impacting their physical, social, mental, and emotional health and wellbeing (Gracey & King, 2009).

Northern British Columbia is a unique geography in which Aboriginal peoples have been affected by colonial governments who “literally mapped Indigenous peoples out of British Columbia and onto Indian reserves” (de Leeuw, Maurice, Holyk, Greenwood & Adam, 2012, p. 905). This has resulted in First Nations across Northern British Columbia facing many health disparities that are further affected by lack of access to health services (de Leeuw et al., 2012). In responding to current health disparities, and working to enhance health outcomes, it is important to privilege understanding of this colonial history and how it has influenced Aboriginal perceptions of and relationships with Western health care practitioners. Indeed, research shows that an important factor in enhancing health outcomes for Indigenous youth is confident, empowered, culturally-appropriate clinical encounters that increase willingness to access a healthcare professional and promote positive relationships between patients and their physician (Browne & Fiske, 2001). Furthermore, as Chandler and Lalonde (1998) found, First Nations communities with high levels of safe and culturally relevant services experience lessened risks for youth suicidal ideations. Yet, to date, research on relationships between healthcare providers and Indigenous peoples has not widely consulted or involved younger populations.

Gathering youth perspectives and experiences, from a First Nations community in Northern British Columbia, about health care systems may thus contribute to
conversations about the development of meaningful, culturally-appropriate, youth-relevant strategies to improve health and wellbeing for Aboriginal youth and address disparities in health. Indeed, because this project will be returned to the Nisga’a Nation in which it was conducted, my hope is that the people who participated in and supported the work might be able to use this research to extend their calls for equitable and culturally appropriate health services.

The background to this goal is explored in this chapter, which unfolds in three sections. Section one is a comprehensive discussion of existing literature examining health inequities between Aboriginal and non-Aboriginal peoples and the social determinants of Aboriginal peoples health. Section two discusses Aboriginal encounters with healthcare systems and section three explores the use of storytelling and theatre as emerging methods in research with Aboriginal peoples. Together, these three sections situate this project within an extensive body of literature, all of which informed and contextualized this project. For the purpose of this thesis, the term ‘health disparities’ is referring to “those indicators of a relative disproportionate burden of disease on a particular population” while the term ‘health inequity’ refers to “underlying causes of the disparities, many if not most of which sit largely outside the typically constituted domain of ‘health’” (Adelson, 2005, p. S45).

Part I: The Social Determinants of Aboriginal Peoples Health

2.1 Health Disparities and the Aboriginal Population of Canada.

Over the past few years, health research globally has consistently reported Indigenous peoples suffering from higher rates of infection and disease, and dying much younger than their non-Indigenous counterparts (Allard et al., 2004; Gracey & King
Indeed, Indigenous populations worldwide experience a broad range of health and social challenges such as high infant and child mortality, malnutrition, obesity and diabetes, HIV/AIDS, low educational attainment and unemployment (Gracey & King, 2009). For example, the increasing rates of Type II Diabetes in Australian Indigenous populations has reached an epidemic proportion where nearly 60% of Indigenous peoples over 35 years old living in the remote northwest have the disorder (Gracey & King, 2009). In addition, rates of HIV/AIDS are quickly increasing in numerous Indigenous groups including American Indians, Alaskan Natives, Indigenous African populations, inhabitants of the Asia-Pacific region (which includes Asia, and countries in the Pacific Rim) and Aboriginal Canadians (Gracey & King, 2009).

In 2011, the National Household Survey reported more than one million people in Canada who identify as Aboriginal (4.4% of the Canadian population), including 851 560 identifying as First Nations, 451 795 Métis and 59 445 Inuit (NHS, 2011). Collectively this population suffers from disproportionate burdens of illness and disease compared to their non-Aboriginal counterparts and experience 'third world conditions of health' (Adelson, 2005; de Leeuw, Greenwood & Cameron, 2010). Such conditions include low educational attainment, poor living conditions including overcrowding and underserviced homes, unemployment, poverty and increased rates of disease and illness (Adelson, 2005). Research about health inequities among Aboriginal groups provides unshakable evidence that health disparities existing between Aboriginal and non-Aboriginal peoples are embedded in a history of colonization and poor relations between Aboriginal peoples and the nation state (Adelson, 2005; de Leeuw et al., 2012). The forced relocation to reserves, removal of children from their families to residential
schools and racist attitudes towards Aboriginal peoples are only a few factors that underlie the poor health experienced by Aboriginal Canadians (Adelson, 2005). Among other pressures and stresses, poor socioeconomic conditions and lack of access to resources continue to cause additional and significant challenges for the Aboriginal population (Adelson, 2005).

Furthermore, approximately half of the Aboriginal population in Canada lives on-reserve, in the territories or in rural communities (NHS, 2011). Northern, rural and remote communities in Canada are unique geographies where health inequities are especially prominent. These communities experience a broad range of health inequities including decreased life expectancy, higher rates of chronic illness such as diabetes and obesity and decreased access to health services due to shortage and turnover of health professionals (Pulla, 2012). Lack of access to resources, in particular access to healthcare, is especially a barrier for Aboriginal peoples living in more northern, remote geographies. de Leeuw, Maurice, Holyk, Greenwood & Adam (2012) argued that when examining and working towards improving Aboriginal peoples' health, we must consider geographical location. The authors noted that “First Nations' poor health can only be ameliorated if understood as geographically and historically determined, linked to colonial practices, and associated with dominant systems of social power that spatially and socially (re)produce Indigenous peoples as perpetually othered” (de Leeuw et al., 2012, p.905). Indeed, the implementation of colonial legislation that forced the relocation of Aboriginal peoples from their land on to government issued land (i.e. reservations) has had a tremendous impact on the health of Indigenous peoples (de Leeuw et al., 2012). For First Nations peoples living on-reserves in Northern British Columbia, factors such as
having to travel long distances to get to a healthcare clinic, experiencing racism due to being from a reserve, and differences in Aboriginal perspectives of health and biomedical models of health have negatively impacted First Nations peoples health and experiences with healthcare (de Leeuw et al., 2012). When thinking about Aboriginal peoples health, then, it is imperative that we as researchers and healthcare practitioners include in our discussions the impact of physical geographies, such as the impact of being from a northern, rural, remote community, and socio-imaginative geographies “that racialize people precisely based on being from an Indian reserve” (de Leeuw et al., 2012, p. 909).

Although there exists tremendous health disparities in the Aboriginal population, First Nations, Métis and Inuit communities have developed strategies that have enabled Aboriginal peoples to ‘do well’ despite the horrific trauma and impacts colonialism has had, and continues to have, on the Aboriginal population of Canada. To be resilient is to “do well despite severe hardships, trauma and deprivation” (Kirmayer, Dandeneau, Marshall, Phillips & Williamson, 2011, p. 84). Examples from Mi’kmaq, Mohawk, Métis and Inuit communities have illustrated factors and strategies that have enabled Aboriginal peoples to ‘do well’ (Kirmayer et al., 2011). For the Mi’kmaq peoples who come from Atlantic Canada, some resilience stems from the treaties made with British colonizers, which have stood as symbols of sharing knowledge and living in peace with European settlers (Kirmayer et al., 2011). For some Mohawk communities in Canada, resilience can take the form of resisting colonial systems and reasserting control of Mohawk communities through governing their land and systems (i.e. health services, education, economic development) throughout Mohawk territories (Kirmayer et al., 2011). Much like Mohawk communities, resilience in Métis communities comes from being self-
reliant, autonomous and independent by asserting control over their lives and doing things 'their own way.' For Inuit peoples of Canada, being able to adapt to social environments influenced by southern practices and policies, responding to the shift in Arctic climate, and maintaining a connection with the land and mother earth have all contributed to resilience of the Inuit (Kirmayer et al., 2011). Importantly, all groups mentioned above are similar in that resilience, broadly speaking, is rooted in the continuation of traditional knowledge, practices and values (Kirmayer et al., 2011).

2.2 Aboriginal Youth

Among the demographics most vulnerable to poor health and socioeconomic conditions, including increased rates of HIV/AIDS and low educational attainment, are Aboriginal youth in Canada (Ning & Wilson, 2012). According to Statistics Canada's 2011 National Household Survey, youth make up a substantial proportion and fastest growing group of the Canadian Aboriginal population with almost 50% of the Aboriginal population under the age of 24 (NHS, 2011). Research has shown this young population faces higher rates of disease and illness compared to non-Aboriginal youth (Ning & Wilson, 2012). Although health research with Aboriginal peoples continues to stress the importance of understanding health and well-being from a social determinants of health perspective, literature pertaining to the health of Aboriginal youth fails to address many of the 12 key determinants outlined by the Public Health Agency of Canada (Ning & Wilson, 2012). These 12 key determinants include: income and social status, social support networks, education and literacy, employment/working conditions, social environments, physical environments, personal health practices and coping skills, healthy

However, recent research has begun to turn to Aboriginal youth voices to understand how this demographic understands and experiences health. A study done by Isaak and Marchessault (2008) with First Nations adults and youth in a Northern First Nations community in Manitoba collected information on the perspectives of what ‘health’ means to Aboriginal youth. The authors noted that although health statistics of Aboriginal youth are documented, First Nations peoples, specifically youths’ understanding of these diseases, has been overlooked (Isaak and Marchessault, 2008). Isaak and Marchessault (2008) explained that Aboriginal youth have showed interest in being part of conversations around the implementation and effectiveness of programs aimed at health promotion. Using a qualitative methods approach, the authors conducted in-depth interviews with First Nations adults and focus groups with First Nations youth to explore both the old and young’s understandings of health. Interestingly, both adult and youth participants described health as having emotional, spiritual, physical and mental components, reflecting the teachings of the Medicine Wheel. Although some youth did not directly reference the Medicine Wheel, it was clear that Aboriginal youths’ understandings and perspectives of health include the interconnectedness of mental, spiritual, physical and emotional (Isaak and Marchessault, 2008).

Although research has begun to include the younger Aboriginal population in discussions around health, to date, research has not substantially explored Aboriginal youths’ use of healthcare services or their interactions with healthcare providers (Ning & Wilson, 2012). This is surprising given the numbers of studies that have investigated
Aboriginal peoples experiences with the healthcare system more generally, given that Aboriginal youth suffer from poorer health outcomes than non-Aboriginal youth, and given that the link between use of health services/interaction with healthcare providers and positive health outcomes has been well-documented (Allan & Smiley, 2015; Browne, 2007; Browne & Fiske, 2001; de Leuw et al., 2012; Ning & Wilson, 2012; Gracey & King, 2009).

2.3 Social Determinants of Aboriginal Peoples Health

Over recent years, attention has been given to the important role the social determinants of health (SDoH) play in understanding health inequities (Marmot et al., 2008; Raphael, 2009). Social determinants of health include, but are not limited to: income, education, unemployment, housing, and early childhood development. Indeed, the SDoH allow one to understand how systems and structures can influence health, by acknowledging the link between health and the social context in which one lives (Marmot et al., 2008). In 2008, Marmot and his colleagues summarized key findings and recommendations in a report for the Commission on Social Determinants of Health, in which they called for urgent action by governments, civil society, communities, businesses, and international agencies to address the wide gap in health that exists around the globe. The authors explained how health inequities primarily stem from unequal allocation of power, income, resources and services within countries. Indeed, research has shown that people in a lower SES bracket have poorer health than those with a higher socioeconomic status (Marmot et al., 2008). The social determinants of health take into account the wider social, political and economic conditions that people live in, and how these circumstances affect people’s health: “Social determinants foci move away from
genetic or biomedical inquiries and instead examine why some people and communities are more prone to health deficits, or suffer more severely from their outcomes, as a function of social contexts” (de Leeuw, Greenwood & Cameron, 2010, p. 285).

Recently, literature pertaining to Aboriginal people’s health has stressed the importance of using social determinants of health to understand inequities experienced by Indigenous peoples that underlie their health (de Leeuw, Greenwood & Cameron, 2010; Marmot et al., 2008; Nelson, 2012; Reading & Wien, 2009). Although understanding health from a SDoH perspective has been widely accepted by Indigenous peoples and communities, in part because it reflects values of a holistic understanding of health and wellbeing, the academic SDoH framework requires critical examination as it also risks representing a ‘Western’ model of understanding how health is determined. The SDoH model may not necessarily encompass Indigenous approaches and perspectives of health and could further perpetuate inequalities and the dominance of white, European settler systems (Czyzewski, 2011). Many Indigenous authors have thus identified ‘distal’ determinants of Indigenous peoples health, such as the impacts and roles of colonialism, a process that has played a significant part in shaping the circumstances leading to poor health outcomes of Aboriginal peoples past and present (Reading & Wien, 2009; Richmond & Ross, 2009; Smylie, 2009). Czyzewski (2011) offered a comprehensive discussion about the importance of including colonialism as a distal determinant of Indigenous peoples health, using examples of how discourses around mental health perpetuate and reinforce colonialism. For example, Czyzewski (2011) explained how literature on mental health of Aboriginal peoples does not take into account the role that culture plays in mental wellness. Rather, the majority of literature blames mental illness
on the “disordered Aboriginal,” a concept that comes from anthropologists’, psychologists’ and psychiatrists’ idea that Indigenous people are unable to “deal with their problems.” This further perpetuates othering and racialized stereotypes, according to Czyzewski. In addition, intergenerational trauma, caused by colonial processes such as residential schools, continues to impact the mental health and wellness of Aboriginal peoples. Indeed, scholarship has explored the ways in which colonialism acts as a distal determinant of health that continues to produce poor socio-economic conditions. In addition, and as mentioned above, colonialism elicits a discourse around mental health that blames Indigenous individuals rather than understanding their wellness as being affected by social, economic and political contexts, which have been shaped by a history of colonial practices (Czyzewski, 2011). Colonialism is addressed in this research through use of community-based participatory methods, decolonizing methodology, and methods informed by these approaches, which are discussed in Chapter three.

Other authors have also explored determinants of health specific to Aboriginal peoples. Richmond and Ross (2009) explored determinants of First Nation and Inuit health in rural and remote communities, and discussed ways in which environmental dispossession has affected these determinants. The authors argued that environmental dispossession (i.e. processes such as colonialism that removed Aboriginal peoples from their traditional land) has negatively affected Indigenous peoples wellbeing and is essentially at the heart of social and health inequalities between Aboriginal and non-Aboriginal peoples (Richmond & Ross, 2009). Through interviews with 26 Community Health Representatives, six determinants of health were uncovered: balance, life control, education, material resources, social resources and environmental/cultural connections.
Interestingly, all health determinants except environmental/cultural connections aligned closely with the Canadian model of health determinants. Participants defined environmental/cultural connections “less categorically than other determinants and more so as a process defining people’s abilities to draw resources from the environment in the maintenance of culture and way of life” (Richmond & Ross, 2009, p. 407). These authors found that environmental/cultural connections impact the other health determinants listed. For example, the reduced consumption of traditional foods and decrease in activities such as gardening and cutting wood have negatively impacted Aboriginal peoples physical and spiritual health, which are part of the health determinant ‘balance’ and encompasses the four aspects of the medicine wheel (Richmond & Ross, 2009). With this in mind, the foundation of this research drew from a social determinants of health approach, to acknowledge and encompass broader determinants that impact Aboriginal peoples health, such as environment/cultural connections, and colonialism. This will be further discussed in the methodologies chapter of this thesis.

**Part II: Aboriginal Encounters with Health Care Systems**

The importance to well-being of the patient and healthcare provider relationship has been consistently discussed in social science and medical literature, especially over the past 50 years (Roter, 2000). As Hellin (2002) noted, “the physician-patient relationship is as old as medicine itself” (p.450). The ruling principle of medicine, since the time of Hippocrates, has been to ‘do no harm.’ This criterion has been the guiding principle of the patient-physician relationship, and influenced a ‘paternalistic’ nature of this relationship, with physicians representing a ‘father’ like figure that stands above his children, and the children obeying his orders (Hellin, 2002). In the past 40 years, the
patient-physician relationship has evolved from a paternalistic model to a more patient-centered model. This includes the patient and physician in relationship as equals, both making decisions, and the patient taking ownership over their health (Kaba & Sooriakumaran, 2007). As Shaw, Ibrahim, Reid, Ussher & Rowlands (2009) noted, “the quality of the doctor-patient relationship can affect diagnosis, treatment and recovery” (p.114). Having a good relationship with one’s physician is especially important in maintaining one’s health and wellbeing. Indeed, a positive relationship with one’s physicians leads to improved health outcomes (Shaw et al., 2009).

In Canada, there exists a history of “discriminatory practices, unjust laws and economic or political disadvantage” (Adelson, 2005, p. S46) towards Aboriginal peoples, taking the form of forced relocation of Aboriginal peoples to unfamiliar land, the implementation of the residential school system, cultural and linguistic assimilation of Aboriginal peoples into Canadian settler society, and the implementation of the Indian Act in 1876 (University of British Columbia, 2009). Indeed, Aboriginal Canadians are still affected by the trauma caused from historical relations with the nation state, including loss of traditional lands, forced relocation to reserves, the involuntary attendance of children in residential schools, and discriminatory and oppressive attitudes towards Aboriginal Canadians (see Truth and Reconciliation Commission of Canada, 2015). Furthermore, racism and discriminatory attitudes continue to manifest in relations with Aboriginal peoples, particularly in the context of healthcare settings (Allan & Smiley, 2015) where medical institutions continue to represent a colonial past and present. The term ‘colonial present’ is used to recognize that the effects and ‘actions’ of colonizers are still prominent and occurring today (O’Neil, 1989). Racism takes the form
of longer wait times, fewer referrals and disrespectful treatment (Browne & Fiske, 2001). What’s more, racism directly impacts health; research has shown that reactions to racism cause “racial battle fatigue”, a stress response to cope with continuing discrimination (Allan & Smylie, 2015).

The Non-Insured Health Benefits (NIBH) program is an example of how racism manifests towards Aboriginal peoples within the Canadian healthcare system. This race-based legislation is a health insurance program offered only to those First Nations and Inuit who hold “Indian Status” cards. Non-status and Métis people are excluded from this insurance program, even though they face the same health inequities as those First Nations and Inuit who have access to the program (Allan & Smylie, 2015). What’s more, access and funding for some services provided by the NIBH require on-reserve residency, with a constant shifting of funded medications and services (Allan & Smylie, 2015).

Cass et al. (2002) explored factors that affect communication between Australian Aboriginal patients with end-stage renal disease and their healthcare providers. The authors described how there is a gap in research about the degree of miscommunication present in clinical situations and the consequences that arise from this miscommunication (Cass et al., 2002). The goal of their research was to observe communication between Aboriginal patients and non-Aboriginal staff in a dialysis unit to understand dynamics of intercultural communication. The authors found many factors influencing communication between staff and patients. Interestingly, many factors are common to aspects influencing miscommunication in Canadian healthcare contexts. One aspect that has been cited in literature about communication with Aboriginal peoples in Canada and their healthcare providers is how discourse in healthcare settings is dominated by a western biomedical
model. For example, Cass et al. (2002) explained how healthcare providers left no opportunities for Aboriginal patients to discuss their own understandings and approaches to health.

Research has shown that development of effective cross-cultural communication is a long process. Physicians' changes in understanding of Aboriginal culture do, however, lead to better communication and relationships between physicians and Aboriginal patients, information important for physicians working with Aboriginal communities (Kelly & Brown, 2002). Achieving cultural understanding and a good level of communication requires a long-term process and constant interaction with Aboriginal patients that brings many opportunities for learning experiences. Physicians have noted that the journey towards a better understanding of Aboriginal patients, despite being time-consuming and complex, is rewarding and transformative (Kelly & Brown, 2002).

The term 'cultural competence' has garnered attention in recent years, and has become important in reducing healthcare disparities experienced by Aboriginal peoples (Kirmayer, 2012). Cultural competence is defined by Betancourt et al. (2003) as "the ability of systems to provide care to patients with diverse values, beliefs and behaviours, including tailoring delivery to meet patients' social, cultural, and linguistic needs" (p. v). Cultural competence seems to be optimally developed through "experiential and reflective learning- both in the context of [medical] students’ clinical training and personal life experiences" (Sinclair et al., 2016, p. 12). This was seen in a cultural immersion experience of two medical students in Northern British Columbia. In a reflective article by medical students Klopp and Nakanishi (2012), the students discussed their experience of being immersed in the First Nations community of Nak’azdli in
Northern BC and the “merit” of having knowledge and understanding of other cultures that these kinds of experiences offer. Through this experience, medical students reflected on their own assumptions and perceptions of First Nations peoples, and realized that “cultural immersion is not only meaningful, but that the experiential learning that cultural immersion provides results in heightened attainment of cultural competence” (p. 128)

Similarly, nursing practices have begun to include cultural immersion as part of the nursing curricula, with the objectives of developing a higher degree of cultural competence. Morgan and Reel (2003) discussed their successes in immersing nursing students in rural cultures in the United States through community collaboration. The authors discussed the value of community participation and collaboration when doing community assessments to identify needs of a rural community. Designing medical school curriculum that includes experiential and reflective learning is one way to foster and develop medical practitioners who bring understanding of the role culture plays, and with that, cultural competence. Indeed, having deeper knowledge and understanding of culture, bearing in mind that cultural competence “engenders the belief that certain groups of people have the same, shared cultural meanings” (Klopp and Nakanishi, 2012, p. 128), is important for healthcare providers to develop a compassionate and empathetic relationship with patients, and communities.

Additionally, patient-provider relationships have been situated within wider sociopolitical contexts, shaped by social and historical relations. For instance, Browne’s (2007) discussion engages with the sociopolitical context of nurses’ encounters with First Nations women in a Western Canadian hospital. These encounters, Browne (2007) argued, are shaped by a historical past of colonialism, oppression and power imbalances
between Aboriginal Canadians and the nation state. Other recent research in Australia has
documented clinical encounters between Aboriginal peoples and their non-Aboriginal
healthcare providers and has found many factors, such as poor communication,
stereotyping, and othering as contributing to negative interactions and relationships
between Aboriginal patients and their healthcare providers (Cass et al., 2002). In
addition, research has shown that many Aboriginal patients feel dismissed by nurses and
doctors, as well as feeling their concerns are not heard or acknowledged by healthcare
providers (Browne & Fiske, 2001). The result of these negative encounters is ongoing
marginalization and discrimination towards Aboriginal peoples, perpetuating distrust
towards the healthcare system (Allan and Smiley, 2015; Browne & Fiske, 2001;
Galloway 2014).

Although research has evidenced primarily negative encounters of Aboriginal
peoples with health systems, affirming encounters have also been documented. Much can
be learned from these. Research involving First Nations women has shown that affirming
encounters include Indigenous patients being actively involved in making decisions
around their health and explaining feelings of being accepted and cared for by physicians
and healthcare workers respecting culture, and identity and having a good long standing
relationship with a health care provider (Browne & Fiske, 2001). Documenting positive
encounters with healthcare providers is important. It will inform healthcare practitioners
about understanding what kinds of processes and patient-physician relationships are
meaningful to Indigenous peoples in healthcare systems and delivery. Still, while many
researchers have shifted their focus to working with communities to identify strategies
and solutions in hopes of improving these encounters, there has been no significant or
positive change that I am aware of. Considerable challenges remain (Allan & Smiley, 2015). Furthermore, research may benefit from new methods, anchored in arts-based approaches, such as storytelling and theatre, to enable in-depth narration of lived experience. This is especially the case for young people, whose voices are so lacking in the research.

**Part III: Storytelling and Theatre as Emerging Methods**

### 2.4 Storytelling

Arts-based methods are increasingly being used by researchers who work with Indigenous populations and who intentionally seek to decolonize their research process (see Willox, Harper & Edge, 2012; Goulet et al., 2011). Creativity and art have been cited as promising tools to address persistent health inequities that exist between Aboriginal and non-Aboriginal peoples. Practitioners (i.e. researchers, physicians) moving away from solely ‘biomedical’ models of understanding health and turning towards more comprehensive approaches, such as the social determinants of health, may be one means of deploying arts based methods (Muirhead & de Leeuw, 2012). Included in these alternative approaches/ways of thinking about health is an idea about the connection between art and wellness. In Canada, the inclusion of art in healing and health may be particularly significant to Aboriginal peoples, especially because before European settlers arrived in Canada and attempted to diminish Aboriginal peoples of their sociocultural practices, traditional cultural activities included many creative and artistic expressions (i.e. drumming, dancing, basket making, carving) (Muirhead & de Leeuw, 2012).

Storytelling, specifically, has been cited as a form of identity and resilience for Indigenous peoples. It is a way of passing on stories from their culture, and acts as a
source of "knowledge, wisdom, and affirmation of identity" (Kirmayer et al., 2011, p. 86). Bird et al. (2009) noted however, that there is a gap in literature representing Indigenous voices, especially in research around healthcare and health promotion, as well as "a lack of methodological exploration of the ways in which qualitative research strategies include Indigenous peoples" (p. 18). The authors explored the use of storytelling and narratives as qualitative methods to understand Inuit people's experiences living with diabetes (Bird et al., 2009). Participants were encouraged to tell their story of living with diabetes. One storyteller's experience was used to demonstrate various methodological issues that arise when using qualitative research to explore people's personal experiences (i.e. in this case with diabetes). The authors present four methodological considerations about using storytelling: 1) using participatory research methods, ensuring equity through all stages of the research 2) presenting narratives rather than solely interpreting narratives 3) including aspects of culture, language and place when interpreting narratives as these aspects are not separate from peoples experiences and, 4) using multiple methods of analyses (i.e. including participants in the data analysis process to ensure the data has been presented accurately) (Bird et al., 2009). Bird et al. (2009) argued that addressing the four points above will increase rigor and trustworthiness, thus improving qualitative narrative analyses. There are important factors to consider when conducting qualitative research. They are especially pertinent to storytelling with Indigenous peoples using a participatory approach and suggest including narratives verbatim rather than just through interpretation. Bird et al.'s. (2009) suggestion also enforces taking into account wider contexts in which Indigenous peoples live and using multiple methods of analyses. This was informative to my own thesis work, as the
main data-gathering method employed was a form of storytelling, through theatrical means.

Other research has shown links between storytelling and personal empowerment. Storytelling can provide a means of healing and transformation, confidence building, reconnecting with one's identity, group building, promoting a sense of belonging, and drawing courage and inspiration from other stories (Williams, Labonte & O'Brien, 2003). In addition, storytelling within a group or community has the capacity for people to reconnect with their cultural identity as well as “strengthen new communal narratives that challenge dominant narratives, and to (re)construct communities as empowered rather than disempowered collectives.” (Williams, Labonte & O'Brien, 2003, p. 36).

Furthermore, the use of art has increasingly been called into the education of physicians, which has been noted to have the potential to “enhance empathy, perspective-taking, and openness to different viewpoints, and to prompt reflection on self, others, and the world” (Kumagai & Wear, 2014, p. 973). Given this research explores patient-healthcare provider relationships, arts-based methods anchored in creativity make good sense. Theatre was chosen as the main data gathering method, and is discussed in the next section.

2.5 Theatre

Building from the use of storytelling in scholarship, recent research has begun to use other creative arts-based methods, such as theatre, which has proved to have great potential as a tool to create a space for Indigenous peoples to address health issues in their communities (Goulet et al., 2011). The dramatic arts, more specifically acting and theatrical creations, are one such arts-based method. Indeed, theatre has long had a
history of being used in a political context. In his book, *Theatre of the Oppressed*, Augusto Boal (1979) argued that theatre was used, and is still used today, as a function to increase social awareness of structural oppression in many societies. Specifically, Boal (1979) draws on examples from Aristotelian theatre and Greek tragedy to illustrate how theatre was a tool for elite classes to assert power and control over the public by excluding those in lower social classes from the arts. While oppressive forms of theatre still exist, there has been movement towards theatre as a tool for personal empowerment and social change (Boal, 1979). Such a movement was started by Boal himself, among others. Through his development of *Theatre of the Oppressed*, Boal introduced “forum” and “image theatre” as instruments to evoke liberation. This participatory and interactive form of theatre enables the actors and audience members to produce a theatrical space and time in which to fight against representations of oppressive forces that are present in their everyday lives (Mienczakowski, 1995). Boal’s work is still very relevant today. His theatre methods are used in research to engage and empower people, especially youth, and to produce spaces to tell stories of their lived realities and work through social and personal issues and to devise strategies and solutions (Conrad, 2004; Day, 2002; Rutten et al., 2010). For instance, Goulet et al. (2011) developed a series of theatre workshops, based on Boal’s *Theatre of the Oppressed*, working with Aboriginal youth so they could tell their stories about the socio-cultural aspects of health. These workshops were aimed at creating a safe space “where youth are asked to think for themselves, to use their bodies and to exercise their imaginations in making decisions for action” (Goulet et al., 2011, p. 89). The stories developed by Aboriginal youth revealed that various factors, including forces of social control in and outside of communities, continue to constrain
youth, and, more significantly, that youth do not believe they are able to be agents to effect change (Goulet et al., 2011).

Not only does theatre provide an active, participatory approach to research (see Conrad 2004), it also ensures that participants have the opportunity to contribute their own voices and stories of lived experience. In this way, participants have a chance to create a story that narrates the social, health-related, educational, cultural, political, economic, and personal confinements or strains that impact their lives and engage in honest discussion around these issues in search of a solution. Thus, models of theatre (such as Theatre of the Oppressed) break out of the conventional limits of ‘traditional theatre’ by opening the process of play building and having participants create a story. This challenges the colonial roots embedded in society and enabling self-empowerment and agency. Devised theatre, a similar form of theatre to Theatre of the Oppressed, was chosen as the main data gathering method, and will be further discussed in Chapter three.

**Conclusion**

Research over the years has consistently shown that Indigenous peoples suffer from lowered health status as compared with non-Indigenous peoples (Adelson, 2005, Gracey and King, 2009). In Canada, Aboriginal peoples living in northern, remote geographies are especially affected by health inequities, such as lack of access to and use of healthcare services (de Leeuw et al., 2012). These health inequities have been, and continue to be, rooted in a history of colonialism that continues to affect the health and wellbeing of Aboriginal peoples. Due to this history, now more than ever, research methodologies and methods about Indigenous realities must address the profound impact that colonialism has had, and continues to have, on Indigenous peoples and communities.
(L.T. Smith, 1999). In the past, research around the health of Indigenous peoples has been misrepresentative and results have not reflected Indigenous perspectives or experiences (Castleden et al., 2012). Research with Aboriginal peoples must use approaches, such as community-based participatory research, which seek to address the colonial legacy embedded in research practices, and thus address the power imbalances present between researchers and their subjects (de Leeuw, Greenwood & Cameron, 2012). There are increasingly many ways of doing this. Community-Based Participatory Research tries to ensure community ownership and involvement in all stages of the research process and recognizes Indigenous peoples' knowledge and insight. It acknowledges them as equal partners in the research process (Castleden et al., 2012).

As mentioned above, when working toward understanding Indigenous health, it is imperative that researchers acknowledge how colonialism has shaped, and continues to shape, the overall wellbeing of Indigenous communities. Decolonizing research moves away from ‘Western’ models/approaches to research, and privileges Indigenous “perspectives, processes and ways of knowing and learning” (Bartlett, Iwasaki, Gottlieb, Hall & Mannell, 2007, p. 2376). It is important to note that, while Boal’s method of theatre was influenced by “Western” approaches (i.e. Greek Tragedy and Aristotelian Theatre), the creative element of theatre makes it holistic, not favouring rational modes of being, but rather making room for spiritual, imaginative, and relational modes of being that coincide with Indigenous perspectives. Research processes must honor Aboriginal knowledge development. Research processes must also privilege narratives of lived experience rather than collection of facts/data that are translated into ‘non-personalized’ knowledge. Indeed, when doing research with Indigenous peoples, it is Indigenous
experiences, perspectives, and insights about research questions and objectives that are at
the core of research processes and part of the driving force when partnering with
Indigenous peoples and communities around research activities. As such, all
methodologies and data gathering methods employed in this project have been chosen
with a decolonizing methodology in mind, and will be discussed in the next chapter.
CHAPTER 3: METHODOLOGY AND METHODS

Part 1: Methodology and Approaches

In this research, the term ‘methodology’ refers to the theoretical and philosophical foundations on which this research is built. Three main philosophical tenants, or methodologies, frame the way this research was undertaken. I discuss these below, interweaving the discussion with thoughts about the ways these methodologies inform and are actualized in my own research project.

3.1 Social Determinants of Health Framework

As mentioned in previous chapters, a social determinants of health framework informs this work. The social determinants of health are “the economic and social conditions that shape the health of individuals, communities and jurisdictions as a whole” (Raphael, 2009, p. 2). The social determinants of health, as a way of understanding health outcomes, have a long history despite its more recent ascendance in mainstream conversations about human well-being. In the mid-1800’s, Friedrich Engels examined how poor housing, clothing, diet, and lack of sanitation was directly related to infections and diseases, causing premature death in the working class (Raphael, 2009). Since then, research has begun to develop around health inequities and the impacts social, economic, political and cultural factors play in these inequities (Raphael, 2009). It is no longer a normative, unquestioned practice to consider health as purely biomedical and behaviourally based (Marmot et al., 2008). Rather it has become widely accepted as imperative that health be understood broadly and holistically, as not just the absence of illness, but encompassing social and economic factors including but not limited to: living conditions, income, availability and quality of education, and access to healthcare.
services (Raphael, 2009). The social determinants of health seek to address inequities in allocation and distribution of economic and social resources, and as such, attention is given to economic and social policies as a way of addressing inequities (Raphael, 2009).

When considering the poor health realities of Aboriginal peoples in Canada, and Indigenous peoples worldwide, historical and contemporary realities that have shaped Aboriginal peoples health and wellbeing should be accounted for. Indeed, in order to fully understand the interconnected web of factors associated with health, and how the past and current social standing of Aboriginal peoples connects to health, we must expand the very ‘definition’ of health (Smylie, 2009). The National Aboriginal Health Organization (2007) outlined a list of broader determinants of health specific to Aboriginal peoples including colonization, globalization, migration, cultural continuity, access, territory, poverty, and self-determination. Specifically and notably, the ongoing effects of colonization, including forced relocation from traditional lands, cultural and linguistic assimilation, and impacts of interpersonal and institutional racism, continue to negatively affect Aboriginal peoples’ health. Indeed, the impacts of colonization have been identified as “important determinants of Indigenous peoples health” (Smylie, 2009, p. 282).

My own exploration of First Nations youths’ experiences and perspectives on health and their relationships with healthcare providers makes an effort to include and consider the traditional social determinants of health (see Marmot 2009 and Raphael, 2009). This research also goes further by being cognizant of other determinants specific to Aboriginal peoples health (Smylie, 2009; Reading and Wien, 2009). A social determinants of Aboriginal peoples health ‘framework’ further complements other
methodologies chosen to inform this work, including community-based participatory research and decolonizing methodologies, which are explained in the following paragraphs.

3.2 Community-Based Participatory Research

A community-based participatory research (CBPR) approach was important for this work. CBPR enables researchers to build a level of communication and trust with participants, creating a research-participant relationship that can facilitate a dialogue to bring forward first person stories that may identify determinants of health specific to patient-healthcare provider relationships. As such, CBPR approaches compliment the SDoH framework also chosen as a methodology for this research. Literature has characterized community-based participatory research as:

A collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities (as cited in Minkler, 2005, p. ii3-ii4).

Many researchers favour CBPR methodologies in their work as it provides an ethical means of conducting research and promotes co-learning and bi-directional research (Minkler, 2004; Wallerstein & Duran, 2006; Castleden et al., 2012; de Leeuw, Greenwood & Cameron, 2012). Community-based participatory research does not focus on a specific set of research methods or techniques, but rather places emphasis on the researcher-community relationship and reaching goals of social change (Wallerstein & Duran, 2006).

There are many values in using a community-based participatory approach in health research, especially with marginalized or oppressed populations (Castleden et al.,
First and foremost, a CBPR approach is committed to developing a research question that "reflects...issues of real concern to community members" (Minkler, 2005, pg. ii5). This means that, ideally, the research question comes from the community involved, and the community then seeks partnerships with outside researchers. In addition, CBPR examines costs and benefits of the research project on the community. For example, in keeping with CBPR's value towards equitable partnerships and capacity building within communities, it is important to consider factors such as method appropriateness to communities and opportunities for training and capacity building for the partner communities (Minkler, 2005). Although my own research did not begin with a research question from a First Nations community, partnerships were only made with communities interested in the research topic and chosen methods (i.e. devised theatre), ensuring the research was meaningful to the participating community.

Another strength of CBPR is its opportunity to uncover local knowledge critical to better understanding of questions being asked. For example, using a CBPR approach in conducting a study in India investigating high rates of HIV/AIDS among men in the industrial area of Nandesari, researchers began to understand through local partnerships and 'insider knowledge' that causes of high rates of HIV/AIDS were associated with unprotected sex due to false information believed by men in this region (Shah, 2004). Due to 'insider' knowledge and guidance of local partners, which included male village health workers, the research was strengthened and led to subsequent meaningful interventions to provide correct information to men in the region (Shah, 2004).

Other values and strengths of a CBPR approach include increasing community trust and ownership through gaining approval of the project from community leaders (de
Leeuw, Greenwood & Cameron, 2012). This leads to better recruitment and retention of participants and higher quality of data due to participant and community involvement in the project. Furthermore, CBPR improves accuracy when analyzing data and findings through participant and community involvement in data analysis stages of the research. Including participants and community partners in data analysis ensures that the knowledge provided by the community is represented accurately and truthfully, leading to better-developed and richer themes. This research aimed to explore stories of First Nations youths’ experiences with their healthcare providers, a question that could only be answered through meaningful, collaborative and active participation by the youth participants and community involved. Based on the strengths of a CBPR approach discussed above, my research sought to include as many aspects of CBPR as possible, keeping in mind the challenges in using such an approach. With that in mind, a discussion about the challenges and pitfalls of CBPR follows, highlighting the challenges faced in my own research.

While community-based participatory research can be a valuable and ethical approach to conducting research, there are also challenges in using this methodology. Wallerstein and Duran (2006) have written extensively on the pitfalls of using CBPR. A summary of their critiques follows throughout this next section.

As mentioned above, one value in using a CBPR approach is having a research question driven by the community. However, this can become a challenge as most research projects are driven by those in privileged positions (i.e. academia), who have extensive resources and time to produce their work (Wallerstein & Duran, 2006). In the case of my own research, the research question did not come from the community
involved. Partnerships were, however, sought with communities who found the question meaningful and important for their community. Furthermore, it is important to be mindful of the various stakeholders participating in the research process (i.e. researcher and community members) as participants hold different expertise and knowledge (Minkler, 2005). Challenges can arise when researchers’ and community interests in knowledge production differ; therefore, it is important to maintain open communication throughout the research process to address these challenges as they may arise. This was not a challenge in my own work, as I entered the community first and foremost as a learner, and the participants and community as the experts in this research.

One significant challenge of CPBR is that of ‘insider-outsider’ dynamics, especially with regards to benefits and rewards. ‘Insider-outsider’ dynamics are those between the outside researcher and the partner community (Minkler, 2005). Although an important aspect of CBPR is to ensure the community involved is benefited in some way, the ‘outside’ researcher usually has the most to gain from these collaborations taking the form of grants and publications. One challenge of taking on a community-based participatory approach then, is to address the roles that power and privilege play in the community-researcher relationship. For university researchers, power and privilege take the form of expertise in scientific knowledge and ability to access resources, among others (Wallerstein & Duran, 2006). It was especially important that my own work addressed the power imbalances present in the community-researcher relationship. This was done by first and foremost acknowledging such a power imbalance in research exists, and then challenging the dominance of a ‘single scientific discourse’ by placing value on various types of knowledge, through inclusion of methodologies such as CBPR.
Although CBPR approaches ostensibly commit the researchers who use them to inclusive participation by communities, there can be some constraints on community involvement, such as projects involving marginalized and vulnerable populations. For example, authors Diaz and Simmons (1999) conducted a Reproductive Health Project in Brazil and found that despite their efforts to include marginalized and vulnerable women in the research process, these women were not a position to provide their time and/or energy towards involvement in the project (Diaz and Simmons, 1999). In other words, CBPR can be challenging in so far as it demands from peoples’ already overcommitted and often under valued and under-resourced time. It becomes important, then, for authentic relationships to be built so conversations can be had with community partners to discuss these kinds of challenges, and strategies for these to be overcome.

Other challenges of community involvement include disagreements between researcher and community on methods chosen for projects (Minkler, 2005). Often such disagreements can privilege a researcher, who in relationship with community – even despite all good intentions – can hold greater access to power, making authentic partnership or disagreement difficult. However, through open, respectful communication, collaborations can foster a space in which both the community and researchers’ knowledge are valued for what they can contribute. This certainly takes work, but the very concept of CBPR opens up spaces for such contemplation of relationship and partnership, and a more equitable dialogue between research participant and researcher may open such spaces. Certainly that is one hope and effort of this research.

Research has shown that community-based participatory research is a positive tool when addressing health inequities, and especially when working with Indigenous
populations (Wallerstein & Duran, 2006; Castleden et al., 2012; de Leeuw, Greenwood & Cameron, 2012). Studies with Indigenous peoples have been, and are, rooted in colonial practices (L.T. Smith, 1999). This must be rectified if persistent health inequalities can ever authentically be addressed. Research, then, has to change form and intent exactly because it has been part of the problem of inequality for so long. For example, in the past (and to some extent into the present day), research around the health of Indigenous peoples has been misrepresentative, focusing on pathologizing the “Indian” (Kelm, 2005, see also Willie Ermine, 2007) and results have not reflected Indigenous perspectives or experiences of health and wellbeing. Furthermore, health research has focused on pathology and dysfunction rather than recognizing Indigenous perspectives or experiences and has thus perpetuated stereotypes of Indigenous peoples (Castleden et al., 2012). A community-based participatory research approach seeks to address the colonial legacy embedded in research practices, through honoring Indigenous knowledge and research practices, and thus addresses the power imbalances present between researchers and their subjects (de Leeuw, Greenwood & Cameron, 2012; Ermine, 2007). It aims for community ownership and involvement in all stages of the research process, recognizes Indigenous peoples knowledge and insight, and acknowledges them as partners in the research process (Castleden et al., 2012). Therefore, my choice of CBPR as a primary methodology in this work informed my choice of methods used (i.e. devised theatre), which opens a space for decolonizing the research process, community involvement, and ownership.

Indeed, “community-based participatory research has been identified as a research philosophy and methodology that has the potential to contribute to efforts to decolonize
the university researcher-Indigenous community relationship" (Castleden et al., 2012, p. 3). While this may be overly ambitious, and indeed substantive power imbalances seem to persist despite the best intentions of researchers (de Leeuw, Greenwood & Lindsay, 2013) community-based participatory approaches lay a philosophical foundation for this research. In particular for my research, CBPR further supports my choice of using devised theatre as a method, as devised theatre is a strategy that allows researchers to enter into a first person narrative on lived experience. This was done through facilitating a devised theatre workshop where youth participants were the scriptwriters of what was to be performed. While this research may not have fully adhered to all aspects and guidelines of a CBPR approach, all efforts within the confines of a Masters degree, were made to build equitable partnerships between a Northern, rural First Nations community and the primary researcher. This relational understanding of research, the very heart of the philosophy of CBPR, is thus arguably the central and guiding force of this project – even if some of the stricter mandates of CBPR were adapted to ensure a living and flexible framework that ultimately allowed the project to be completed in the community. Furthermore, community approval, participation and ownership was sought in every stage of the research process, and power imbalances recognized, keeping in line with the parameters of a CBPR approach. A decolonizing methodology complements a CBPR approach, further addressing the colonial legacy and power differentials embedded in the research process, especially when collaborating in research with Indigenous communities, and is discussed in the next section.
3.3 Decolonizing Methodologies

Along with a CBPR approach, a decolonizing methodology offers further philosophical foundation for this research. As previously mentioned, when understanding Indigenous health, it is imperative to acknowledge how colonialism has shaped, and continues to shape, the overall wellbeing of Indigenous communities. Furthermore, constant reflection throughout the research process on how the research activities are perpetuating or dismantling colonial practices is essential. As discussed in Smith's (1999) important work *Decolonizing Methodologies: Research and Indigenous Peoples*, Western research paradigms are viewed as scientific and objective processes; knowledge is "to be discovered, extracted, appropriated and distributed" (L.T. Smith, 1999, p. 58).

Furthermore, Western culture has "frequently identified itself as the ethnocentric centre of legitimate knowledge" (Wilson, 2001, p. 215) and has disregarded Indigenous belief systems and knowledge. Research 'done on' Indigenous peoples by colonizers, travellers and observers has been misrepresentative of Indigenous peoples: it has created stories that have become accepted as "universal truths, marginalizing the stories of the Other" (Wilson, 2001, p. 215). Research, then, that seeks to move away from pathologizing constructions of Indigenous subjects has to carefully account for the long and damaging history of research itself as a violent and pejorative force in the lives and communities of Indigenous peoples. Researchers ourselves are implicated in the very positioning and conceptualizing of Indigenous peoples today – accounting for this, even if we do not reach absolute answers, is part of the work done by decolonizing methodologies.

Decolonizing research moves away from Western models' approaches to research, by acknowledging, focusing, and emphasizing Indigenous ways of knowing and being.
Indeed, “the development and implementation of Indigenous Methodologies have become a near necessity for the implementation of research in indigenous communities” (Evans, Hole, Berg, Hutchinson & Sookraj, 2009, p. 1). Indigenous Methodologies (IM) encompasses alternative ways of thinking about, and doing research. As noted by Louis (2006), Indigenous Methodologies are “fluid and dynamic...[and] emphasize circular and cyclical perspective...[and] aim to ensure that research on Indigenous issues is accomplished in a more sympathetic, respectful and ethically correct fashion” (Louis, 2007, p. 133). Literature has outlined four principles important to Indigenous research agendas including: relational accountability; respectful representation; reciprocal appropriation; and rights and regulation. Relational accountability means approaching research with an understanding that all parts of the process are related, and ensuring that the researcher recognizes their responsibility to maintain this holistic view (Louis, 2007). Respectful (re)presentation involves the researcher being mindful of how they are representing the research and the people involved in the research; it is about leaving space for others to collaborate and contribute ideas. As Louis (2007) notes, “It’s about displaying characteristics of humility, generosity, and patience with the process and accepting decisions of the Indigenous people in regard to the treatment of any knowledge shared” (p.133). The principle reciprocal appropriation requires that there be mutual benefits to both the Indigenous people and the researcher (Louis, 2007). Finally, rights and regulation refers to research that is collaborative and determined by Indigenous practices. This principle protects against the exploitation of Indigenous knowledge, and allows Indigenous peoples to maintain access to and control over dissemination of research findings (i.e. publications). Given these overarching claims, and because the
basis of this research was exploring *relationships*, it was important to build a relationship with the community to enter into this partnership in an equitable, authentic and respectful way. By having worked to achieve community support and relationship from the onset of the project, the research process in this project honors these principles mentioned above.

Furthermore, and in deference to other modes of decolonizing research, Aboriginal knowledge development that favors narratives of lived experience rather than ‘collection of facts or data translated into ‘non-personalized’ knowledge’ (Bartlett et al., 2007) have been used in all aspects of data collection and analysis. In addition, efforts to include Aboriginal peoples in all aspects of the research process were made, acknowledging Aboriginal peoples as the experts in this research. For example, and as explored in the methods section, this research was heavily reliant upon a community partner who was very interested in having this research project done in his community. The community partner was vital in the research process as he helped organize logistics around the devised theatre workshop, and was the main point of contact throughout the entire research process. Indeed, the experiences, perspectives, and insights of Indigenous peoples on research questions and objectives are at the core of the research process and were part of the driving force when partnering with Indigenous peoples and communities around research activities, especially for this project. This collaboration was initiated through pre-established relationships with individuals in the Nass Valley. In keeping with a CBPR and decolonizing approach, the results of this project are acknowledged as the property of the youth participants and their community, and this work is clearly identified as Nisga’a First Nation knowledge. Including a decolonizing approach to health research was especially important because, as Goulet et al. (2011) note, “the process of
decolonization is central in addressing health issues in Indigenous communities” (p. 90). In this project, a decolonizing approach informed the methods chosen (i.e. devised theatre), which allowed for conversation of experiences of First Nations youth with their healthcare providers.

Data gathering methods employed in this project have been chosen with a decolonizing methodology in mind. As a non-Indigenous researcher I was continuously reflecting on how colonialism has, and continues to impact research agendas, norms, values and standards, and thus seeks research methods that challenge ‘Western’ ways of doing research. This was put into practice in this research through receiving approval of the project from the Nisga’a First Nation, having a community partner to learn from and work with during the fieldwork process, and results validation from the participants. Indeed, decolonization “…is concerned with having a more critical understanding of the underlying assumptions, motivations and values which inform research practices” (L.T. Smith, 1999, p. 7). The methods chosen for this project are further described in the following section.

**Part II: Methods**

As introduced in the methodologies section, the combination of a social determinants of health framework, community-based participatory research (CBPR), and decolonizing methodologies, informed the choice of using devised theatre, a qualitative method, for this study. When I use the term ‘method’ I am talking about the ways in which knowledge and ideas were gathered. It is important to note that along with devised theatre, field notes and observations, a community interview, and an open dialogue were done as complementing tools to collect information. For a list of questions asked during...
the open dialogue refer to Appendix IV. Furthermore, a snowball sampling technique was used to recruit participants, which will be discussed later in this section.

Given the imperative of undertaking decolonizing research, which requires participatory methods, this project used such methods to create a space for youth to tell their lived experiences about relationships with healthcare providers in their community. In keeping with the goals and efforts of CBPR and decolonizing methodologies, devised theatre does not favor ‘one’ single way of producing knowledge (in this case of creating a play); rather, devised theater as a research method encompasses multiple ways of telling a story through various modalities, such as movement, sound, and visual technologies (Perry, 2010). At its core, devised theatre is an active, participatory form of theatre - and thus a research tool for gathering knowledge and ideas – that emphasizes collaborative creation and involves “processes of experimentation and sets of creative strategies–rather than a single methodology” (Govan, Nicholson & Normington, 2007, p. 7). Participants in this research were “script-makers” in their creation of a drama piece that told the story of their lived experiences of relationships with healthcare providers. The participants engaged in a process that brought together their lived experiences, with each story being important to the creation of the final product.

The methods section of this chapter will discuss how the research was done. First an overview of devised theatre will be presented, followed by a discussion on the research steps taken for this project including community relationships and collaboration building, the devised theatre workshop and open dialogue, and will finish with a discussion on the approval of completed thesis by the community partner, and results dissemination.
3.4 Devised Theatre: A participatory research method and approach

The main data gathering method for this project was devised theatre. Devised theatre is a genre of theatre that uses performers, participants, and/or artists' real-life circumstances to build an original non-fictional theatre piece (Oddey, 1994; Govan, Nicholson & Normington, 2007; Perry, 2010). The "activity of devising" itself can be described as,

[A] process of making theatre that enables a group of performers to be physically and practically creative in the sharing and shaping of an original product...There is a freedom of possibilities for all those involved to discover; an emphasis on a way of working that supports intuition, spontaneity, and an accumulation of ideas. The process of devising is about the fragmentary experience of understanding ourselves, our culture, and the world we inhabit. The process reflects a multivision made up of each group member's individual perception of the world...Participants make sense of themselves within their own cultural and social context, investigating, integrating and transforming their personal experiences (Oddey, 1994, p. 1).

Much like the drive behind Boal's (1979) *Theatre of the Oppressed*, devised theatre emerged as a response from those engaging in artistic creations wanting to work in an "artistically democratic way" (Oddey, 1994, p. 8). Devised theatre gained increased recognition in the 1970's due to the evolution of socio-political awareness and emphasis on democracy that emerged in the 1960's; innovations in media technologies; significant advancement of the feminist movement; and, most importantly, a response to conventional art forms, these were all driving forces in the ascendance of the practice (Perry, 2010). Unlike traditional literary theatre, which is dominated by "the often patriarchal, hierarchical relationship of playwright and director," (Oddey, 1994; p. 4) devised theatre is created and directed by the participants involved, and the process of play-building is continuously changing and morphing as the devising process unfolds. In
this research project, youth participants took on the roles of playwrights and directors, choosing how best to convey their stories and lived experiences with healthcare providers. Indeed, devised theatre challenges the dominant ideology of “one person’s text under another person’s direction” (Oddcy, 1994, p. 4). It is precisely the flexible, responsive, and inherently anti-colonial nature of devised theatre that made it appealing as a method to apply within a research project focused on trying to understand power-laden relationships between Aboriginal and non-Aboriginal peoples in the settler-dominated lands of British Columbia.

Over the past sixty years, many devised theatre companies have emerged, and continue to emerge, gaining a strong presence in theatre industries across the globe (Perry, 2010). Notable companies include: The People Show (London, UK, est. 1966), Theatre de Complicité (London, UK, est. 1983), Sidetrack Theatre (Sydney, Australia, est. 1979), and Radix (Vancouver, Canada, est. 1988). With this history in mind, it is interesting to note that very little in the way of devised theatre projects have unfolded in British Columbia. Theatre projects have been deployed, with success, in at least one research project similar to this one (see Streigler, 2014) but the application of it within Nisga’a Territory is, to my knowledge, almost entirely novel.

One significant component of devised theatre is the incorporation of multiple lived realities and perspectives. Rather than relying solely on the single vision of a playwright, devised theater privileges multiplicities and complex overlaying of voice (Perry, 2010). The component of incorporating multiple lived realities and perspectives was important for this project, as the participants all came from diverse backgrounds, bringing their own stories and lived experiences. Furthermore, devised theatre was an
ideal method to use for this research project as it provides a participatory and inclusive approach to theatre, and challenges power structures (i.e. playwrights/directors) present in traditional theatre. Through multiple discussions and theatre-based activities, participants collaborated with each other to build an original theatre piece, with each youth’s ideas, input and stories being favoured. Devised theatre provided a physical space and means through which Nisga’a First Nations youth had the psychosocial space to share narratives about their lived experiences of encounters with healthcare providers.

3.5 Research Steps

This community-based research project unfolded in three stages, all being integral to the success and completion of this project. The stages of the research project are summarized in the table below and further explained in this chapter.

Table 1

<table>
<thead>
<tr>
<th>Research Stages</th>
<th>Prince George, BC</th>
<th>June-August 2015</th>
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</thead>
<tbody>
<tr>
<td>Stage One: Community Relationships and Collaboration Building</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage Two: Devised Theatre Workshop and Open Dialogue</td>
<td>New Aiyansh, BC</td>
<td>September 2015</td>
</tr>
<tr>
<td>Stage Three: Approval of final draft of thesis from WWNI and results sharing</td>
<td>Prince George/New Aiyansh, BC</td>
<td>April 2016</td>
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</tbody>
</table>

Stage one: community relationships and collaboration building.

Respectful, ethical, sympathetic and useful. As discussed in the methodological chapter of this thesis, the foundation of this research is anchored in a community-based participatory approach and decolonizing approach to research. As such, it was important that the research process included being respectful, ethical, sympathetic and useful (L.T.
Smith, 1999). For me, then, it was imperative that the research process be done in a respectful manner with the community; that it be ethical and receive approval from the community; that consideration and value be given to all voices involved; and that the research be useful and something of interest to the community involved. However, to achieve a research process anchored in CBPR and decolonizing approaches, time is essential to build relationships and trust with communities. This can become a challenge when researchers are working with a strict timeline. As a Masters student with limited resources and a strict timeline, I was unable to build a substantial relationship with the community before I began my fieldwork. Although this was an initial challenge, the research process remained respectful to the community, received community approval and continues to involve the participants and community throughout the duration of the research.

A critical component of the project was finding interest and receiving approval from a First Nations community to undertake this research. After my thesis proposal received approval (on April 30th, 2015) I began making connections with First Nations communities in Northern BC who might be interested in pursuing this project with me. A snowball sampling strategy was used (Patton, 1990). A snowball sampling strategy enables the researcher to identify information rich cases through asking “well-situated people” (Patton, 1990, p. 176) to refer the researcher to those who could be interested or key informants for the research study in question.

In May 2015, a contact in the Nass Valley was made through my supervisor’s connection to a graduate student, who herself is from the Nass Valley. This contact directed me to the Wilp Wilxo’oskwil Nisga’a Institute (WWNI), the main contact to
receive approval for this research. Following the protocols laid out by the Wilp Wilxo'oskwhl Nisga'a Institute (WWNI), I sent a formal letter and proposal of the research to the President and CEO of the Wilp Wilxo'oskwhl Nisga'a Institute in early May 2015. The proposal was forwarded to the Board of Governors at WWNI for their review on May 25th, 2015. The Board of Governors is made up of six individuals from the Nisga’a First Nation. It was important that I submitted a proposal to the board by May 25th, as the board did not meet in the summer months (July and August). A short time after, I received a letter of conditional approval from the Board of Governors on June 10th, 2015, two and a half weeks after submitting the proposal. ‘Conditional approval’ was based on receiving approval by the Research Ethics Board at UNBC. On July 16th, 2015, I received approval from the UNBC Research Ethics Board for my research project in the Nass Valley and received subsequent full approval of the project by the WWNI Board of Governors. In line with a decolonizing approach, receiving approval from the WWNI had to be given before the research process began.

Immediately after receiving approval from the WWNI for the project, I began to seek collaborations in one of the four Nisga’a First Nations communities in the Nass Valley: Gitlaxt'aamiks, Gitwinksihlkw, Laxgalts'ap and Gingolx (Nisga’a Lisims Government, N.D). Throughout the month of July 2015, I sent e-mails to various people who work for the Nisga’a Lisims Government, to make connections with various people who were able to direct me to community members in the four communities. Initially I did not receive many responses, but at the end of July 2015, I received an e-mail from an individual in the Nisga’a Lisims Government who referred me to PC (name changed for anonymity purposes), a well connected individual. PC described his role in this research
and in the community as: engaging youth and “keep[ing]...youth active and pretty much hav[ing] them utilize all the tools that they already have in the rec centre here and just keep on building on their leadership” (T3, lines 2-4). A research proposal was sent to PC by e-mail, who immediately responded with his support for this project to be held in his community. PC was the main point of contact during the fieldwork portion of the research, and was essential in helping organize the weeklong drama workshop. In August 2015, contact was maintained with PC by e-mail to discuss the logistics of the workshop, and to decide upon a date to hold the workshop. Keeping in line with CBPR and decolonizing approaches, PC was asked to choose a date that best worked for his community to hold the workshop. This was a challenge, as the workshop was initially scheduled for the last week of August 2015, but had to change to the third week in September 2015 due to unavailability of many youth during the month of August. This was a pivotal moment for me as I realized the incredible flexibility needed for community-based research. It is to be the community driving the project.

As a principle community partner, PC led the way in organizing a space to hold the workshop and ensuring a catered dinner was provided for participants. Food was considered an important part of this youth-based project. In planning the workshop, I wanted to provide a meal to participants. This was primarily due to the workshop extending over dinnertime, but also to have time to socialize with participants, and get to know them personally. In conversations over dinnertime, I learned that participants, both women, considered the workshop a chance to have “me time”, and to chat with other adults about issues important to them in their community.
PC also organized my accommodation. Most importantly, PC helped recruit youth from the community to partake in the weeklong drama workshop. PC delivered posters I made, and, included the workshop in their calendar of events at the Rec Centre. It is important to note that PC ‘paved the way’ for this research to be done in the community of Gitlaxt'aamiks. He organized the logistics of the workshop, and informed community members of this project. Without the constant support of PC, I would have entered the community a complete stranger, without the ability to do such a project. Through building a purposeful and meaningful relationship with a community member, this research came alive.

As mentioned in the methodologies chapter, CPBR generally works around a research question that comes from the community. Although the community of New Aiyansh did not create the research question for this project, the topic was of interest to PC and youth participants. The research was reflective of issues and concerns in the community. For example, at the end of the weeklong drama workshop I interviewed PC to ask questions related to the workshop. One of the central questions PC wanted to see answered, or wanted the research to address, was ability for information from the workshop to be used in his community. PC noted, “I kinda hope [the information from the workshop] can turn [the healthcare services] around, and somewhat help because you [can] only write so many letters to do so many things right?” (T3, lines 53-54). Indeed, while not following any ridged or prescriptive template for CBPR, this project followed what might be understood as the ‘spirit of CBPR’ – namely that the research, in line with decolonizing methodologies, is supported by community partners, that it is committed to
utility, and that it is ultimately endorsed as being relevant. To this end, the research, along with an “easy to read” version, will be returned to the Nisga’a Nation.

Stage two: devised theatre workshop and open dialogue.

Drama workshop and discussions. The principal fieldwork for this project was carried out over four days (September 14th-17th, 2015) and involved a 4-day devised theatre workshop, with an open dialogue at the end of the fourth day. The drama workshop initially involved three female participants (which later became only two participants) between the ages of 19 and 25, took place in September 2015, and was organized over the course of four days for 4-5 hours each day. Using techniques, such as Image Theatre from Boal’s (1979) Theatre of the Oppressed, discussions were had about issues and experiences that Nisga’a First Nations youth face when interacting with healthcare professionals and services. Methods anchored in Image Theater encouraged participants to, using nonverbal communication, “sculpt” each other into physical images (for examples see Figure 3, 4, and, 5, on p. 69-70). The basis of Image Theatre is to explore issues of oppression by creating concrete or abstract “images” to depict a thought, feeling, issue, or moment. Participants are asked to reshape the image to show different perspectives. For this research, activities such as Image Theatre provided a non-threatening context to speak about lived experiences in a deep cultural context. A decolonizing methodology demands the incorporation of more Indigenous ways of doing research. The drama workshop provided a research strategy more resonant with Indigenous ways of doing research, and as explored further on, this resonated with community.
Each day of the workshop focused on a different question about health and experiences of relationships with healthcare providers. Activities, games and discussions also focused around the specific questions (See Table 2).

Table 2

<table>
<thead>
<tr>
<th>Day</th>
<th>Question Explored</th>
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<tbody>
<tr>
<td>Day 1</td>
<td>How do First Nations youth understand 'health'?</td>
</tr>
<tr>
<td>Day 2</td>
<td>What are youth perceptions of and lived experiences with their healthcare providers?</td>
</tr>
<tr>
<td>Day 3</td>
<td>What do Nisga’a First Nations youth want to say to those who provide health services?</td>
</tr>
<tr>
<td>Day 4</td>
<td>Devise strategies with Nisga’a First Nations youth for the healthcare system and providers that are consistent with youth’s perspectives and needs around health</td>
</tr>
</tbody>
</table>

Theatre activities and games were taken from: The Health Arts Research Centre Art Worksheets (see Figure 1) (Ward & de Leeuw, 2015); Games for Actors and Non-Actors (Boal, 1992); Improvisation for the Theatre, 3rd Ed (Spolin, 1999); and, Theatre Games for Young Performers. Improvisations and Exercises for Developing Acting Skills (Novelly, 1993).

Figure 1. Screenshot of HARC art worksheets.
Specifically, activities took the form of various theatre games and discussions, involving all participants, with each game/discussion ranging from 10-30 minutes with two short breaks and one long break for dinner. It is important to note that for the first two days of the workshop there were three female participants, however on the third and fourth day one of the participants did not return. The original schedule and outline of activities for the drama workshop changed due to participant interest and comfort in doing theatre activities. This too, arguably, is part of the spirit of decolonizing CBPR — that the very nature of the 'data gathering' is fluid and responsive, not dictatorial or driven from an omniscient power-centered researcher. For example, after the first day, I asked for feedback from participants with regards to what they wanted to get out of the theatre workshop. One participant (who was present during the entire duration of the workshop) was not comfortable participating in all the activities and, as such, activities were modified/chosen based on the comfort levels of the participants. Indeed, researchers “...dedicated to facilitating a process that is representative of all participants will accept that the research...might completely change” (MacDonald, Ford, Willox, Mitchell, Productions, & Storytelling, 2015, p. 490). Building from discussions and theatre activities, a short scene was created to represent the lived experiences of Nisga’a youth, through 3 frozen tableaus. A tableau is a frozen image depicting a scene. An in-depth description of the creation of the short scene and tableaus is discussed in the section that follows.

Field notes and observations. Field notes and observations were documented in a journal throughout the weeklong workshop. On the first day of the workshop, participants did not sign the consent form and noted they did not want to be voice recorded. This was due to
miscommunication on what the recordings were to be used for. On the first day of the workshop, two of the three participants had concerns that voice-recordings would be shared with people other than myself. At first, I did not fully understand this concern, as I thought I had made it clear to participants that voice-recordings were for my own personal use. On the third day of the workshop only two of the three female participants returned to partake in the workshop. I clearly articulated to both participants that voice-recordings would not be heard by anyone other than myself. After clarifying this on the third day, both participants agreed to be recorded. As such, the first and second day did not have any audio recordings of the discussions and instead I relied on written field notes, reflections and observations of discussions that took place over those two days.

Day one. The workshop began on Monday, September 14th, 2015 at the Recreation Centre in New Aiyansh. PC contacted five youth who he encouraged to participate in the workshop. Of the five expected to come, only three attended, all young women. It is important to note that the young women are all mothers, and each day of the drama workshop, participants brought their children, who played at the Rec Centre while their mothers partook in the drama workshop, with some children occasionally joining their mothers in the workshop. The workshop, which was held in the youth room at the Rec Centre, was scheduled to start at 15:00. PC remained present throughout the four days of the workshop, as he was running other youth programs at the Rec Centre during the same time as the workshop. As participants trickled in, they were given information and consent forms. They read over their forms quietly. I moved around the room to ask participants if they had any questions or concerns about the consent forms, but no big concerns were voiced. Only one participant fully signed the consent form, as the other
participants did not want to sign consent for being recorded. This, as mentioned above, was a miscommunication as the participants thought the voice-recordings of the discussions were going to be shown to others outside the workshop. Once this was clarified (on the third day) participants consented to have discussions audio recorded and the final scene video-recorded. After participants were given consent forms, Gary Davis Sr., an Elder and priest in the community, opened the drama workshop with a prayer.

The purpose of the first day of the workshop was to ask youth how they understand 'health.' Each day of the workshop started with a 'check-in': two words that described how youth were feeling that day. Participants enjoyed this exercise as it helped to break the ice and open up a space of dialogue. The check-in was followed by physical stretching and vocal warm up. Vocal exercises were taken from Novelly’s (1993) *Theatre Games for Young Performers, Improvisations and Exercises for Developing Acting Skills.* The vocal exercises included participants’ working on breathing techniques, breathing in slowly, and out slowly. Participants were asked to breathe in counting from one to ten, with their voice starting off quiet, and getting louder as they reached ten. Participants were then asked to count in different voices. For example, participants were asked to count in a happy, sad, and angry voice. After the vocal warm up, I could feel tension and nervousness from the participants.

The participants are very timid/shy about participating- except for one of them. At first I felt hopeless- how was I going to engage them? They were saying, "oh theatre isn’t what I was expecting..." But they all ended up staying and after introducing everything and doing the check-in they got a little more comfortable with the activities (Field Notes 1, lines 1-6).
In the next theatre activity, participants walked around the room and I would give them a scenario, which they had to ‘act.’ For example, I would say, “walk like you are in a muddy swamp.” The participants’ movements began to slow down and they physically acted out the movements they imagined that ‘walking in a muddy swamp’ would be like.

After the warm-up and theatre games, a break for dinner was scheduled. Each day a meal was brought to the Recreation Centre for participants, as the workshop was held during dinnertime. During dinner the three women and myself had conversation, and I asked them questions to get to know them. After the dinner break, participants were introduced to devised theatre exercises, such as ‘Posed Theatre.’ Participants were asked to come up with three random poses – one high up (i.e. standing), one medium (i.e. bending over), and one low down (i.e. close to the ground). Each pose was done in a different part of the room and participants were asked to find a way to move between the three poses they came up with. Posed Theatre was used to help youth “move away from simply moving and to think about creating strong visual images through physical theatre” (Ward & de Leeuw, 2015, Posed Theatre Worksheet). Participants were asked to create images that represented ‘health.’ After the Posed Theatre exercise, a discussion was facilitated on how youth understand health— or more simply put, youth were asked “What is important for you to be healthy?” and “What comes to your mind when you think about the word ‘health’?” A game was facilitated to help encourage discussion, in which participants got in a circle and took turns finishing the sentence: “In my backpack of health is _______. “ After this activity, participants were given sticky notes and asked to write down things that make them ‘healthy.’ These sticky notes were then stuck to
bristol board to show a ‘collage’ of their ideas (See Figure 1). PC participated in this
discussion, as he had come by the room to see how we were all doing.

![Image of a collage project]

*Figure 2. What makes me healthy? Photo by author.*

After the final activity, the session concluded with a ‘check-out.’ Much like the
‘check-in’ participants had the opportunity to express how they were feeling after the
workshop and provide feedback, concerns and ask any questions. I asked participants
what they wanted to see happen in the drama workshop, and reminded them that this
workshop was “theirs.” I wanted to open a space for them to be able to provide me with
feedback so that I could tailor the workshop to their interests, and expectations. The
session concluded early at 7:30 pm. At the end of each day I met with PC to ‘debrief’ how
the workshop sessions went. Due to the low number of youth that participated on the first
day, I asked PC to let others in his community, old and young, know that the workshop
was opened up to whoever was interested in hopes that more people would come the next
day. PC assured me he would let the community know the workshop was opened up to
anyone, however, it ended up being too late of notice for other community members to
participate.
Day two. The purpose of the second day was to facilitate activities and discussions around youth’s perceptions of and lived experiences with their healthcare providers. The same three women participated in the second day. This indicated to me that there was some interest in and acceptance of the research work. I arrived at the Rec Centre at 3:00pm to meet with PC who opened the youth room for me to set up. The second day, which began at 3:30pm, consisted of the same format as the first day: two word check-in, physical and vocal warm-up and theatre games from Boal’s (1992) Games for Actors and Non-Actors, followed by a break for dinner. The vocal warm up was the same format as the first day. The theatre games from Boal’s (1992) Games for Actors and Non-Actors included:

- “Tell your own story”: one participant is asked to recount an experience, and the other participants then illustrate that story with their bodies. The storyteller is not allowed to intervene or make corrections during the illustration given by the other participants. At the end of the activity, participants discuss differences.

- “The plain mirror”: participants get into pairs, and face each other. One participant is the ‘subject’ and the other is the ‘image.’ The subject begins to move, and the ‘image’ must copy what the ‘subject’ is doing. The purpose of this activity is not for the ‘subject’ to move fast and make sharp movements, but rather for the ‘subject’ and ‘image’ to become synchronistic in their movements, so that someone on the outside would not know who is leading the movements.

After dinner, an ‘Image Theatre’ (Ward & de Leeuw, 2015) exercise was organized. Image Theatre exercises encourage participants to use their bodies and body positions to “express their feelings, share ideas or suggest solutions through movement
and interaction with other participants” (Ward & de Leeuw, 2015, Image Theatre Worksheet). Participants were given a physical space (that in turn, opened up a *psychosocial space*) to *share their stories of lived experiences with healthcare providers* through the use of Image Theatre. This activity begins with two participants paired up and the third participant as a ‘spectator.’ The pair starts by shaking hands and freezing in that position. The ‘spectator’ is asked to describe what they see in the image of the two participants shaking hands. One of the participants leaves the frozen image, and the spectator comes in to complete the image, making a different ‘story.’

Participants voiced that they were hesitant and unsure how to act out their experiences using their bodies. This hesitancy could be explained by having a new person (i.e. the researcher) present, and without a lot of time to get to know one another. This was expected, as theatre often asks people to be vulnerable and can be uncomfortable in the presence of strangers. Therefore, it was important to ‘break the ice’ and begin the process with a discussion, and verbal participation, before asking for physical participation. This gave participants a chance to get to know me, and for the participants to put more thought into the physical movements they would create. This led to a discussion with participants about what kinds of experiences they have had with healthcare providers and systems in their community and elsewhere.

The women are a little unsure about how to use their bodies to ‘tell a story’ so I suggested having a discussion instead. The themes that came up today about experiences with healthcare providers were positive and negative. They talked about this one nurse who is back in the community and they really like her. She is approachable and listens to their concerns and they trust her. This was a positive experience that they talked about. When I put the board up that said relationships with healthcare providers, one participant commented, “that board will fill up” (Field Notes 2, lines 9-14).
Given that participants enjoyed the activity on the first day of using sticky notes to express their thoughts, a Bristol board was put up and named “Experiences with Healthcare Providers.” Participants, again, used sticky notes to write words that described their experiences, both positive and negative (See Figure 3). One participant commented, “that board will fill up!” (FN 2, line 12-13). This was in reference to the fact that participants were excited to contribute their stories and thoughts to a shared space, and further emphasized, for myself, the importance of discussion around participants’ experiences, prior to asking for physical expression. This was a pivotal moment, in which the participants took ownership and control over the process, by redirecting the way the drama workshop unfolded. This reminded me of the need for flexibility, and continual awareness of the principles of CBPR.

The second day concluded at 7:30pm after the ‘check-out’ activity, in which participants expressed feeling good about being able to talk about their experiences with others, and excitement for the next day. I spoke with PC briefly to let him know how the second day went, and went home to prepare for the third day.
Today went well. I had the same 3 participants— all female, all mothers. Today we started with some fun activities and did a lot about storytelling. We had a discussion about experiences with healthcare providers and I tried to see if the women were open to creating images to represent their experiences. They are still a little timid and shy. Two of the women still haven’t signed the consent form because they aren’t sure they want to be filmed or recorded. I tried to explain to them that even if they signed the consent form they could still back out at any time (Field Notes 2, lines 1-8).

Day three. The purpose of the third day of the workshop was to ask participants “What they want to say to those who provide health services?” On the third day, only two women attended, as one was unavailable due to prior commitments. Therefore, the workshop on the third day was shorter than the other days. The workshop started at 3:30 pm and began with a check-in, physical and vocal warm-up (similar to that of the first and second day), followed by theatre activities focusing on storytelling (Ward & de Leeuw, 2015).

Although the discussions and activities have been going really well, I am still caught up in the fact that I only have 3 participants. I wish I would have gotten more. After being in the community for 2 days I feel a little more comfortable. I really enjoy going into the workshop and meeting with the women and talking about their experiences and doing theatre activities with them. They are all so interesting and bright and just really amazing women. I don’t know how to describe this feeling but I like hanging out with them and being in the community. I feel honored that they are opening up to me and telling me about their experiences (Field Notes 3, lines 27-34).

The first activity was a one-word story. The participants and myself sat in a circle, and decided on a topic for the story. Each of us contributed one word at a time, to create a story about healthcare experiences with healthcare providers. The next activity involved ‘contentless dialogue’ (Novelly, 1993). This activity included a ‘bare’ script, giving no
clues of what the dialogue was about. Both participants were given a script with ‘bare’ dialogue. The participants took turns speaking their lines, and were asked to speak the lines without any emotion. This exercise was repeated with participants adding ‘colour’ to their dialogue. For example, I asked the women to say their lines in a ‘cold,’ ‘relaxed,’ and ‘crunchy’ way. These exercises helped engage participants in techniques useful to build their final scene.

After finishing these theatre activities, participants took a break for dinner. During dinner, some young kids playing at the Rec Centre joined the participants and myself. It was nice to get to know other youth in the community, and share a meal with others, as there was always an abundance of food left over. After dinner, youth wanted to continue discussions around their experiences with healthcare providers. I asked the women if it was alright if I recorded their discussion, and explained it would be for my own use, so that I could remember what was said in the discussion. The women consented to be voice recorded.

I went over the consent form and told the participants that the recordings are just for me to remember what they said. The participants have now agreed to be voice recorded and do an ‘open-dialogue’ because that is a little bit less intimidating for them than a one-on-one interview. They were joking around about how doing an interview is a little intimidating because you are in the spotlight and if you say something you can’t go back and ‘erase’ it (Field Notes 3, lines 34-38).

By the third day, participants were more open and comfortable discussing their experiences. Youth spoke about negative and positive experiences, as well as what they believe to be an ‘ideal’ relationship with healthcare providers. Participants were asked to come up with words that described experiences they were discussing, as these words
would be used the following day in the final scene created by participants. At the end of the day, the women shared why they had decided to participate in the workshop. Some of their responses were because they wanted to try something new and were interested in the combination of health and drama. The third day finished with a check-out activity at 7:00pm.

Day four. The final day began at 3:30pm and finished at 8:00pm. Only two participants attended, as the third participant who missed the previous day did not return. The final day consisted of: 1) wrapping up the drama workshop with the creation of a short scene expressing lived experiences of participants and, 2) facilitating an open dialogue to ask participants about the scene created, their experience participating in the drama workshop and discuss youth-devised strategies for the healthcare system and providers in the youths' community that are consistent with participants perspectives and needs around health. On the fourth day, the women expressed their sadness that the workshop was coming to a close, and how they really enjoyed participating in something meaningful to them. I too felt sad that the workshop was coming to a close, as by the end of the week, I felt as though the women continued to open up to me, and were comfortable telling me their stories. The final day was exciting, as it included the women creating a physical scene to convey their lived experiences, which had been discussed throughout the week.

(1) Creation of short scene. The aim of the drama workshop was for participants to work towards creating a scene depicting relationships of experiences with their healthcare providers. Participants were encouraged to utilize tools and techniques of devised theatre (i.e. image theater/posed theatre) that were discussed and practiced
throughout the week. There were no expectations or limits of what had to be included in this scene, or how long it had to be. The participants, as ‘directors’ and ‘scriptwriters’ decided how they were going to present their lived experiences. On the final day of the workshop, participants decided the best way to portray their experiences was through choosing words that represent their relationships and experiences, and acting these out in tableaus, which are frozen pictures. The youth sat together and discussed amongst themselves which words they wanted to use. The final scene is described below:

The scene was broken into three “tableaus” (i.e. a frozen image) moving from one to the next. The scene began with the first tableau depicting a negative experience represented by the words ‘disconnected’ and ‘unapproachable.’ This tableau was done on the ground. In silence, two female participants sat on the floor across from each other, one participant curled in the fetal position and the other kneeling over that participant, with a pen and paper in hand. The participant curled in the fetal position was representing a ‘patient’ and the participant kneeling was representing a ‘doctor’ (see Figure 4). The youth froze in this position for 10 seconds. The participants then slowly, and silently, moved into the second tableau (see Figure 5). It is important to note that photos are included to show a visual representation of the participants’ ‘tableaus’, however for respect of privacy and anonymity, the participants’ faces have been blurred out.
During the second tableau, participants moved up, off the floor, into a standing position. The participants stood with their feet wide apart and their arms out beside them, as if they were trying to get their balance. This tableau illustrated moving from a negative experience to a neutral, more positive experience, and represented the words ‘control’ and ‘stability.’ Again, the participant who had been in the fetal position represented the ‘patient’ and the participant who had been kneeling represented the ‘doctor.’ The participants froze in this tableau for another 10 seconds, and slowly and silently moved into the third and final tableau (see Figure 6).
The final tableau depicted both youth standing up tall, reaching up and touching each other's hands. This tableau symbolized positive experiences, representing the words 'empowerment' and 'connection.' Participants explained this frozen image as the doctor and patient making a connection, and finally touching base. Participants stood frozen in this tableau for 10 seconds, and completed the devised short scene representing participants’ lived experiences of relationships with healthcare providers (see Figure 6).
The workshop had the option to finish with a live performance of the short scene created, inviting community members and healthcare service providers to attend. However, youth participants did not feel comfortable presenting their short scene, and alternatively, the final dramatic creation was video-recorded.

(2) Open dialogue. An open dialogue concluded the weeklong workshop. Initially, in-depth interviews were organized to conclude the workshop, but participants voiced concerns of doing one-on-one interviews and were not comfortable with doing that kind...
Participants explained that they were not comfortable speaking one on one, as they felt this placed a great amount of pressure on them to answer the interview questions. As part of a decolonizing methodology, it was my role to shift the direction of the research based on the feedback I received from participants around doing a one-on-one interview. This too, is part of the spirit of decolonizing CBPR— to allow for flexibility in the research process and for participants to take ownership and a leading role in how the research unfolds.

An open dialogue ‘interview’ was suggested as an alternative, which the participants approved of due to the “group” nature. The open dialogue consisted of 9 open-ended questions grouped into two sections: 1) scene creation and, 2) participation in theatre workshop. The questions were used to guide the discussion giving the open dialogue facilitator “the flexibility to keep the [open dialogue] conversational, to go off-script, and to choose questions in the order best suited to the direction of the conversation” (MacDonald et al., 2015, p. 490). Examples of the questions asked included: “Tell me about the scenes you made. What was it about?” “Do you think the scenes accurately portrayed experiences you have had with physicians/healthcare services in your community?” “What is the main message you wanted the scenes to convey? What is the main message you think the scenes actually conveyed?” and, “Would you use theatre to share your experiences and ideas again if you had never participated in this process?” As mentioned earlier, both women spoke of their participation in the workshop as having “me time”. This was brought up again in the open dialogue. When I asked the women about their feelings towards being involved in the drama workshop, one participant noted,

[Participating in the workshop] felt good to get out and be around more adults and just... have ‘adult’ time and ‘me’ time... cause I tend to not have any ‘me’ time, I
always put everybody ahead of myself and there's maybe like that one rare moment where I get 5 minutes of quiet (FG, lines 260-261, 263-264).

This feeling was echoed by another participant who said “I felt like I got to be silly and it didn’t feel like work at all and it just felt like you know games, but it was leading up to something” (FG, lines 269-271). This feedback speaks to the strengths of using arts-based methods in research with young, Indigenous women, and will be discussed further in Chapter 6 (Recommendations for Future Research).

Although the findings will be discussed in much greater detail in the next chapter, it is important to note that two participants conversed in the open dialogue, with both participants voicing positive and negative experiences of relationships with their healthcare providers. This is inductive of the importance of offering flexible kinds of data gathering approaches, as some may not be conducive to participants, as was the experience in the data gathering process of my research.

I’m really sad the workshop is over. I had such a wonderful time getting to know the women and spending time in New Aiyansh. Although I only spent 4 days with the women, I feel like I’ve known them for a while, and really enjoyed chatting with them. They have such amazing stories, and I feel so honored to have heard them, and learned from all of them. (Field Notes 4, lines 1-5).

Stage three: approval of final draft of thesis from WWNI and results sharing.

The third and final stage of the research included ‘member checking’ with participants to ensure the results were accurately representing their stories; seeking approval from the WWNI of the final draft of the thesis and; results sharing with the community of New Aiyansh and the WWNI board of directors. Member checking is “a quality control process by which a researcher seeks to improve the accuracy, credibility and validity of what has been recorded during a research interview” (Harper & Cole,
In CBPR, member checking is an important part of the research process as the findings of the research are shared with participants to ensure that what is written in the results reflects the views, feelings, and experiences of the participants. In February 2016, both participants were contacted via e-mail to ask if they could verify that the findings reflected their experiences. Neither of the participants responded to the e-mail, however, continuous efforts remain to contact them for results verification. In April 2016 a final draft of this thesis [was] sent to the WWNI Board of Directors for their review and approval. After the completion of my thesis defense, a formal presentation on this research will be made to the WWNI Board and the community of New Aiyansh. It is important to note that this process will continue to be an ongoing “living” process wherein I will maintain contact with the community.

3.6 Data Analysis

Narrative analysis was used to interpret data and identify themes (Reissman, 2008). Narrative analysis focuses on stories told by individuals, groups, societies or cultures in order to understand lived experience, and to “follow participants down their trail” (Reissman, 2008, p. 24). Narrative analysis was chosen as the primary analyzing technique due to its focus on preserving each individual’s ‘story’ or ‘account’ to maintain integrity of stories (Shutt, 2011). According to Reissman (2008), narrative analysis does not contain any specific procedures or guidelines to carry out analysis, compared to many other forms of qualitative analysis. There are four analytic approaches of narrative analysis including: thematic analysis, structural analysis, dialogic/performance analysis, and visual analysis (Reissman, 2008). For the purposes of this research, a thematic analysis was used to categorize stories/experiences of First Nations youth, into themes.
Thematic analysis is used in qualitative research to identify themes or patterns in data (Joffe and Yardley, 2004). Themes can be directly observable through repetitive mention of specific phrases or words, or can be implied indirectly through discussions and discourse (Joffe and Yardley, 2004). Thematic analysis allows the data to ‘speak for itself’ because direct quotations are used in the findings. Due to the decolonizing nature of this research, I wanted to use a data analysis technique that would not alter what was said in the transcriptions, and thematic analysis enabled me to keep as much raw data as possible. Furthermore, the work was represented visually, through screenshots from the video recording of participants’ final ‘scene.’

To start analyzing data, transcripts from discussions, the open dialogue and personal field notes were read and re-read, making note of similar themes between stories and quotes. Codes were developed to group common quotes, words, ideas and stories into categories. In addition, concept maps were created to further compare relationships and overlap between themes. Stories and quotes were further condensed and grouped, until four key themes emerged representing negative and positive experiences of stories First Nations youth told during the drama workshop.

Conclusion

In total, three data sets were collected. These included 1) transcripts from group discussions during the weeklong devised theatre workshop and visual recordings (i.e. photos), 2) transcripts from an open dialogue post-workshop, and, 3) personal field notes and observations. Furthermore, visual data (i.e. photos) were included in the representation of data. Drawing and analyzing in an in-depth fashion, the next chapter will discuss the findings of this research project. Specifically, I will “make sense” of the
various data collected and then “put to use” these results with reference both to answering my research questions and gesturing toward where such work might go in the future.
CHAPTER 4: FINDINGS

Upon analyzing and reflecting on multiple data sources, including transcripts from group discussions during a weeklong devised theatre workshop, transcripts from an open dialogue post-workshop, and personal field notes and observations, four key themes emerged that exemplify First Nations youths’ experiences of relationships with healthcare providers in a Northern British Columbia Nisga’a First Nations community. The following themes will be presented in a fashion linear to the way they evolved in the dramatic scene (i.e. negative experiences to positive experiences). It is important to note that participants’ stories shared below are based on lived experiences, individually and with one’s family, and may not represent all Nisga’a youths’ experiences of relationships with their healthcare providers.

4.1 Disconnect

A feeling of disconnect between participants and their healthcare providers was one theme repeatedly emphasized within multiple data sources, most notably from discussions during the weeklong drama workshop, the final scene created, and open dialogue discussion. When describing negative encounters within the healthcare system,
participants used words and shared experiences that described healthcare professionals as unapproachable and distant. For example, in explaining an experience, one participant said, “[The healthcare providers] just seem very disconnected.” (T2, line 24). Participants used powerful metaphors to describe their feelings of disconnection from their healthcare practitioner. As one participant put it,

I don’t want them to have a personal relationship with me, and like invite me over to dinner, but they don’t have to be so disconnected to where you know, there may as well be a big glass pane between us. (T2, lines 18-21)

This idea of a glass pane separating a patient from a doctor points to the feeling that despite being able to see one another, there remains a barrier to any physical touch or interaction.

Experiences in which participants felt inferior to their physician were identified as the root cause behind feelings of disconnect. As one youth noted, “...that’s why we switched from her [to another doctor]...cause she was so ignorant and nose in the air all the time” (T2, lines 10-11). In this sense, participants are describing themselves feeling positioned as ‘not as good as’ or ‘lower than’ in the sense of status. While perspectives about “status” were identified as the place from which disconnect stems, miscommunication was noted as that to which disconnect leads. The comments from participants could allude to their position as a minority (Aboriginal, women, youth), thereby positioning them behind a glass wall, leading to miscommunication. This arose in further discussion, where participants noted how disconnect can be cause for lack of mutual understanding and not being heard by healthcare providers, with one participant noting, “[Miscommunication is] what really bothers me.” (T2, line 22). The idea of a ‘glass pane’ described by participants also speaks to miscommunication. When there is a
glass wall separating you from someone, you see them, but you do not hear them. This was representative of how participants explained miscommunication: healthcare providers “saw” them, but there is no opportunity to be heard. This sentiment was exemplified by a participant who explained how miscommunication included not being heard by her healthcare provider, stating she wants a healthcare provider who “listens genuinely to actually hear, not reply…cause that’s what most people do, is just listen to reply” (T2, line 119, 121). The act of “genuine listening” does not require response, but requires acknowledgement that the speaker has been heard and understood. This may prove difficult for a healthcare provider who is accustomed to providing solutions and advice as their immediate response to patients.

The theme of disconnect was clearly portrayed in the final frozen tableau thematic scene of experiences designed and delivered by participants in the drama enactment. The scene began with participants sitting down side by side. One participant took the role of the doctor and the other acting as the patient. The two participants then moved into a frozen ‘tableau’ (i.e. freeze frame of the scene in which both participants ‘freeze’ in a position) (See Figure 3), illustrating the doctor looking at the patient with annoyance and the patient curled up in a ball beside the doctor. The actors used the word disconnected to describe this tableau repeating the idea of a ‘glass wall’ separating the patient and physician, and went on to describe the image of the patient as helpless or belittled. The participant who played the patient role noted “the specific action I was taking at the beginning [was being] belittled because I just felt like I was in a small little ball where I felt helpless and when you feel helpless you want to return to the fetal position where you feel safe” (FG, lines 59-62). Participants conceptualized the doctor’s look of annoyance
and body language as the reaction to feeling the burden of having to deal with “just another problem.” As the participant playing the doctor put it, “I was in no way approaching [the patient] to help, I was just sitting there” (FG, line 63). The participant voiced embodying a physician view of thinking, “Can [this patient] solve her own problem?” (FG, line 66) or “Can [the patient] just tell me what medicine [they] want me to prescribe [them] and be done?” (FG, line 67). Furthermore, participants described the doctor’s body language presented in the tableau as indicative of wanting the day to end. During the process of making the tableau, participants also mentioned how the first tableau represented the “reality of [healthcare services in their community]” (FG, line 22) and one youth mentioned, “...in a way it kinda does symbolize our healthcare here...it seems like you get that attitude where they don’t really wanna give you their service” (FG, lines 193-195).

The theme of disconnect not only captures feelings of being ‘separated’ from one’s physician, but also feelings that physicians do not understand, value, or practice healthcare with a holistic perspective. Instead, participants depicted physicians dealing with patient ‘problems’ and health concerns by prescribing medication rather than showing interest in talking to or authentically understanding participants’ health concerns. In this context, a patient may feel positioned as a ‘thing’ to be dealt with through quick fixes. Such feelings or experiences may then translate into disconnect between health concerns and health care received, as well as disconnect between patient and physician perspectives of health. Furthermore, there was direct reference to feeling inadequately serviced specifically because of living in a small, isolated First Nations
community, with participants noting, "...in a way it kinda does symbolize our healthcare here" (FG, line 193).

4.2 When the body speaks - receiving incomplete care

The theme of *incompleteness* came up throughout discussions, during the open dialogue and in personal field notes and observations. This theme connects with experiences of being left with unanswered questions to healthcare providers or with unsatisfying responses, and thus feelings of incomplete service that lead to patients seeking health services outside their community. Participants felt healthcare providers should ask if the information or answer was helpful, and, if not, direct the patient to other healthcare providers who may be better suited to answer the questions. As one participant commented, "I don't want [doctors] to feel that I don't trust their opinion but...when you're left with more questions, [doctors] should ask you...‘Was any of this helpful?...Are you kinda just feeling like where you [were] at, [at] the beginning of the appointment?’" (FG, 155, 129-130, 135-136). Participants explained how they would like their doctors to respond in situations where they are unable to answer questions, noting that they would like doctors to say, "...there are people who can better answer your questions, cause I know you have very specific questions. Would you like me to refer you to someone you feel could help you further?" (FG, lines 155-157, 139).

Participants also mentioned experiences in which their physician’s body language made them feel that as patients they were "dragging out the appointment" (FG, lines 150-151) and there was not a space opened to ask questions. As one participant put it, "...if [the doctor] stare[s] hard enough then [the patient will] just leave." (FG, lines 142-143). In these types of situations, participants said they felt like “a burden rather than a patient”
(FG, line 153). This was fully exemplified in a statement made by one participant when she said,

> I always say no when they say ‘Do you have any questions?’...and then I just leave...and then [my family is] like, ‘Oh, why didn’t you say that?’ when I get home and vent about it...and I’m like, ‘Cause it just seems like I was draggin out the appointment.’ (FG, lines 146-147, 149-151).

Participants also reported having to seek out health services available in Terrace, BC, an hour outside of their community, when they felt that their questions and concerns were not taken seriously by their local healthcare practitioner. One participant commented,

> Most times I’m left just racing to [Terrace]...and then the doctor there will be like, ‘Oh I’m so sorry, you shoulda came sooner, coulda been preventable...you or your child wouldn’t of gotten this worse or this bad, it was preventable’... and it’s like, well why don’t we receive this care at home? Why couldn’t I have been told that at home? (FG, lines 306-310).

Despite this frustration with local health services, participants voiced a desire to support their localized healthcare options so they can be proud of their community rather than having to seek health services elsewhere. As one participant commented, “[Having to seek healthcare services outside community is] sad cause like, we’re trying to have our own health facility in our own community so we don’t have to venture out and go elsewhere for help.” (FG, lines 311-312).

### 4.3 Empathy

A third theme that emerged from the research data was **empathy**. Participants clearly voiced a desire for a **relationship** in which healthcare practitioners authentically demonstrate genuine care and respect for their patients’ health and show a sincere desire and commitment to helping and caring for others. For example, one participant
emphasized the desire for healthcare providers to make evident a commitment to caring, through actions, noting,

It’s not like I want anyone to go above and beyond for me, like to exaggerate…and become close personal friends and stuff… I want them to show why they’re in the profession that they’re in through their actions…I want them to show it. (FG, lines 121-126)

In discussions during the theatre workshop, participants described situations where they felt as though healthcare providers had limited amount of time to spend with them and as though the doctor was rushing them out of the clinic, which connects to the feeling of lacking space to ask questions. Such situations fostered feelings of being unwelcomed to return to the health clinic if they had further concerns. These feelings of being unwelcomed may mean that a hostile environment is established, which could lead to serious implications if patients have serious health problems and feel as though they cannot go to the clinic for help. One participant stated, “it feels like you’re kind of just on the clock and [the doctor’s] like, you know, ‘Make it snappy’…you just kind of feel like a number not a person” (T1, lines 44-47). Participants explained how such feelings of being a number or a bother to the healthcare provider dissuade them from opening up in an appointment. The idea of being ‘a number’ is reminiscent of the residential schooling system, where Aboriginal children were literally identified by a number. While this is no doubt not the intention of the healthcare system, it further demonstrates how Westernized healthcare embodies a colonial system. Participants felt that this could be rectified by simple gestures that demonstrate care on the part of physicians, for example, as one participant explained,

I would like it if, you know, they would ask what I’d prefer to be called…I don’t go by my whole name…just so…I feel more comfortable to open up…I don’t feel
like opening up to someone who is going to treat me like a number... like when it's more personal problems... whereas [I would be feel like opening up] if they...get down on my level, to where they're like... 'I really want to help you' (T1, lines 48-56).

It is important to consider this comment in the context of intergenerational trauma, as Aboriginal youth may continue to feel the repercussions of the residential schooling system that stripped Aboriginal children of their identity, and relationship to their culture. Indeed, interactions in the healthcare system in which one is seen, heard, and recognized as a whole person, and not just a 'number', was identified as very important to youth. This type of interaction characterizes 'empathetic' care, which from a youth perspective, is a concept clearly including a personal dimension.

When considering ideas to act out in the final drama scene that was focused on “expressing lived experiences of relationships with healthcare providers”, participants took seriously and focused on the theme of genuine caring and ‘empathy’. Participants both expressed feelings of positive and negative experiences of relationships with their healthcare providers, and felt it important to focus on both in the final dramatic enactment. Participants offered suggestions of creating a scene in which a healthcare provider is taking into account the patient's specific situation and tailoring the course of action to best fit the patient. This was offered as an alternative scenario to situations where youth perceived a physician to have self-promoting priorities. For example, as one participant explained,

I feel like [doctors] have a quota to fill, so that they can just get a big pay check or something... and in a perfect world I would feel like, you know, [the doctor would say] "There is this new drug, but based on what you're telling me I would say that this is not right for you [rather than prescribing the drug because a doctor gets a profit from it]" (T1, lines 66-67, 69-70).
Another quality of empathetic caring described by participants was expressed through the age-old metaphor of “putting oneself in another’s shoes.” This point around empathy arose from discussions in which youth voiced concerns about feeling judged when approaching healthcare providers and wishing that this were not the case. By having a healthcare provider hypothetically place themselves in their patients’ shoes, participants felt that this would contribute to the provider treating patients as they would want to be treated and this type of practice is what participants seek and desire. In further discussion about ways for healthcare providers to change their approach, one participant suggested reflection questions a doctor could be asking themselves saying, “...Like would you, [the doctor], want to be treated with this service?...Would you want to be talked down to this way or talking as an equal?” (FG, lines 38-39, 41-42).

The type of care desired by youth was exemplified for participants by a particular nurse in the community. Amanda [name changed for confidentiality], with whom participants have had many positive experiences, demonstrated what youth felt was an authentic passion for and commitment to caring for people. This passion and commitment were illustrated by Amanda through gestures and qualities such as; following up with patients, providing a comfortable and safe space during appointments, and demonstrating a genuine concern and care. Words such as “inviting” and “concern” were used to describe Amanda’s qualities of caring. Participants also emphasized Amanda’s authentic care and concern through her continuous desire to provide care beyond the scheduled appointment. As one participant explained, “even after I didn’t call her in a week...she called me and she said, ‘I just wanted to follow up because I was really worried’” (T2, lines 32-33). “...you could feel the genuine concern and it wasn’t uncomfortable to where
she was...trying to have a personal relationship, but you could feel like she cared" (T2, lines 42-43). While participants voiced the desire for personal relationship, they understood there was a professional boundary that must be maintained in a healthcare relationship. However, it was clear the participants want a personal and caring relationship in the context of a patient-physician relationship.

To further explain the kind of empathetic caring that they are looking for, participants used their own positive experiences with Amanda. They felt she consistently put herself in their shoes and took into consideration her patients’ unique situations. This approach was especially observed and experienced when participants had concerns about their children’s health. As one participant noted, “…it’s like she’s thinking of her own child at that moment,” (T2, 44-45). In this sense, participants feel that Amanda exemplifies what it means to treat patients as she would want to be treated by a healthcare professional. Indeed, participants positioned Amanda as an archetype of “good care” explaining that she embodies qualities of an empathetic caregiver by following up with patients out of concern. Through lived experience and interaction with Amanda, participants have formed a vision of a positive and beneficial clinical relationship.

4.4 Empowerment

The theme of feeling empowered in relationships with healthcare providers emerged from discussions during the week-long workshop as well as from the final scene created and delivered by the participants. During discussions, positive experiences with healthcare providers that lead to feeling a sense of empowerment and control over one’s own health and wellbeing were shared. For example, one participant described a situation in which she felt empowered by her physician:
I was seeking counseling from a psychiatrist and I only had to go a few times and I would say that I was really satisfied with it...he just kind of asks me questions and repeats what I am saying back to me till I come full circle...to where I'm like, okay, the world's not ending, and so I don't really need to seek out that specific healthcare because I guess I can do that for myself now and I don't need to sit in a room for an hour with, you know, a licensed professional to basically ask myself these questions until I come full circle. (T1, lines 2-12).

Participants also understood empowerment as resulting from being respected, valued, acknowledged and reassured that they are each doing a “good job” as an individual or as a parent in maintaining good health for yourself and your children. As one participant commented, “It’s good to hear you’re appreciated and the things you’re doing are right and not wrong, cause most people are so quick to tell you ‘That’s wrong, you’re doing that wrong’...” (T1, lines 26-28). This highlights the importance of positive reinforcement and recognition in a clinical relationship, especially for young people, as positively reinforcing one’s efforts to maintain a healthy lifestyle. Thus, one factor that contributes to creating an empowering encounter with healthcare providers is focusing on the positive and what a patient is doing well or ‘right.’ This may be linked to traditional modes of Indigenous teaching, in which children are mentored and raised by their community through positive reinforcement and “doing when [children] are able” (Gerlach, 2008, p. 23). Furthermore, Aboriginal cultures value autonomous behaviours in children, thereby allowing children to learn through doing, rather than disciplining or punishing (Cheah & Chirkov, 2008).

The importance of promoting and creating empowerment in healthcare was highlighted especially for situations in which people may not be able to stand up for themselves in circumstances of inappropriate care, noting, “What if, like, my parents or my grandmother or grandfather get this crappy care and they can’t voice?” (FG, lines
293-294). It is also important to note that participants expressed a sense of empowerment and ownership from being part of this research project. One participant explained their feelings of being involved in the drama workshop as,

[I] felt like I got to do something towards changing something I really care about, because we all have that forward way of thinking, like, "is this how my kids are gonna be treated [and] when they have kids is this how my grandkids are gonna be treated?" (FG, lines 288-290)

In this way, these results not only extend to what participants desire in their relationships with physicians, but it extends to what they want for their family, community, and for others.

To finish the drama scene, the youth chose to represent empowerment in their final tableau. They ended with an illustration of ownership. In this final tableau, participants emphasized feeling how empowerment not only connects to maintaining one’s health, but also extends to being able to access the tools and develop confidence to take an active role in one’s health by accessing healthcare and ensuring a positive experience, which includes recognition and respect. Participants described the emotional transition from the first tableau to the final tableau as one that began with feelings of belittlement to feeling control and stability. The stability participants described was in the sense of feeling confident in their relationships with health providers. Participants explained this transition as going from what is (current healthcare experiences) to what could be (ideal healthcare experiences). The research itself, then, allowed for an embodied experience of transforming orientation to interaction with healthcare providers.

One participant described this transition saying,

I guess going into it I would look very stressed and flustered, you know, I would be maybe slouching because I feel heavy and then I sit there and I talk to [the doctor] and, you know, he’s just asking me these questions to where I’m kind of
sitting more and more upright...and then I leave walking...standing upright, the world’s okay. (T1, lines 15-19).

The final tableau was described with phrases such as “conquering something” (FG, line 17); moving towards breaking through the glass pane and finally being able to touch hands, making a connection with the doctor and being able to “communicate rather than just answering” (FG, line 80). As one participant explained, “I was the doctor...I was the healthcare, she was the patient and finally we’ve touched base” (FG, lines 26-27). Another participant explained the final scene as “…more of a literal translation, there was no glass wall there” (FG, lines 73-74). Youth explained these positive experiences as being ideal situations of receiving healthcare services, noting, “...in a perfect world this is where I’d want my healthcare to be” (FG, lines 22-23).

It is important to note that while participants discussed many negative experiences, all discussions ended on a positive note. Youth expressed positive lived experiences with healthcare providers, such as with Amanda. Through these lived experiences, youth participants hold insight and knowledge that can contribute to a conversation around culturally appropriate, youth focused healthcare for their community.
CHAPTER 5: DISCUSSION

"The importance of an intimate relationship between patient and physician can never be overstated because in most cases an accurate diagnosis, as well as an effective treatment, relies directly on the quality of this relationship." T. Hellin

The goal of this research was to explore relationships between Nisga’a youth and their healthcare providers, particularly physicians, by identifying cultural and/or social factors that encouraged or hindered meaningful access to healthcare. To collect this sensitive information, a Community-Based Participatory Approach and decolonizing methodologies were employed. The data collected was critically read and analyzed to identify recurring themes. The Nisga’a youth participants identified ‘relationships’ as central to their interactions with healthcare providers. Furthermore, participants identified relationships as having ‘multifaceted’ dimensions. These have been identified as: disconnect from providers, when the body speaks, empathy and compassionate care, and empowering encounters. In this Chapter, I place the theme ‘relationships’ in direct dialogue with the social determinants of health. The qualities of relationships expressed by participants will be understood as dimensions of the social determinant ‘relationships.’

This chapter discusses the themes by engaging secondary research relevant to understanding the nature of each. It is important to note that the stories and experiences gathered in this study are based on the words of two Nisga’a First Nations youth, from whom generalizations may not be extracted to other First Nations youth. It may nevertheless be the case that other young First Nations people in Canada share similar experiences of relationships with their healthcare providers.

5.1 Disconnect from providers

"...[healthcare providers] don’t have to be so disconnected to where you know, there may as well be a big glass pane between us" (T2, lines 18-21)
Disconnect, as an aspect of 'relationships,' is itself multifaceted. When the youth participants expressed experiences of disconnect from their healthcare provider, they often and initially chose the word ‘disconnected’ (see results). As noted in the quotation above, disconnect was described as separation from providers by a ‘glass pane’, implying that there were barriers to physical and verbal communication. More significantly, participants expressed their feelings of ‘disconnect’ as feelings of inferiority or being looked down upon by healthcare providers. This was evident when participants noted experiences with physicians who have their “nose in the air all the time” (T2, lines 10-11) and feeling “belittled” and like “a small little ball where I felt helpless and when you feel helpless you want to return to the fetal position where you feel safe” (FG, lines 59-62). While existing research regarding Aboriginal peoples experiences and relationships with mainstream healthcare systems has not directly used the word ‘disconnect’, existing research has used words such as ‘discrimination’ and ‘inferior’ to describe these negative encounters (Kurtz, Nyberg, Van Den Tillaart, Mills & The Okanagan Urban Aboriginal Health Research Collective, 2008; Towle, Godolphin & Alexander, 2006; Browne & Fiske, 2001). The word ‘disconnect’, as used by Nisga’a youth participants, could be a word that carries more meaning for Nisga’a youth to describe negative experiences than words such as ‘inferior’ or ‘discrimination.’ The felt experience of ‘disconnect’ would appear to be caused by the experience of discrimination and feeling of inferiority. Participants did not speak directly to colonialism as a factor to explain their experiences of disconnect. However, it should be noted that the Nisga’a First Nation experienced effects of residential schools, where hundreds of children were taken from their homeland and relocated to schools across BC as part of the Canadian government’s
efforts to assimilate Aboriginal children into the Euro-Canadian culture (CBC, 2011). As mentioned in Chapter Four, participants noted feeling like “just another number”, which could be reminiscent of the intergenerational impacts of the residential schooling system. Towle et al. (2006) found that Aboriginal people’s history, specifically experiences of residential school, negatively affected relationships with healthcare providers. In particular, feeling inferior and helpless was identified as having a negative impact on Aboriginal patients’ relationship to the healthcare system. Furthermore, there is research showing how feelings of inferiority, stemming from dominant colonial structures promoting racism and discrimination, “effectively marginaliz[ing] Aboriginal peoples from the dominant system of care” (Hole et al., 2015 p. 1662). It is possible that ongoing feelings of inferiority and disconnect, as felt by Nisga’a youth, are connected to the ‘shadow’ of the residential school experience. As discussed in Canada’s Residential Schools: the final report of the Truth and Reconciliation Commission of Canada (2015), the residential schooling system legacy has had a profound impact, not only on the survivors of residential schools, but on “their partners, their children, their grandchildren, their extended families, and their communities” (Canada’s Residential Schools: The Legacy, 2015, p. 3). The dehumanizing feelings of being called by a ‘number’, once again, draws attention to the profound impact memories of residential schools continue to have in Aboriginal communities. Indeed, research has shown how “abandonment and anonymity in the past [is] remembered in present day experiences with physicians” (Towle et al., 2006, p. 342).

Although youth participants in this study did not directly cite colonialism as a factor causing them to experience relationships of feeling unsafe and inferior to their
physician, connections between colonialism and negative experiences with healthcare providers have been consistently documented (see Allan & Smiley, 2015). The effects of colonialism and the Indian Residential School (IRS) system are not only felt by those who lived it, but its effects are also felt by children of parents who experienced it first hand, that is ‘collective trauma.’ (Bombay, Matheson & Anisman, 2014). More importantly, as a central methodology in this research was a decolonizing approach, it is necessary to acknowledge Indigenous authors who have argued “information about Indigenous health cannot be understood outside of the context of colonial policies and practices both past and present”, and be taken seriously due to the impact this context has had on Aboriginal engagement with the healthcare system. (i.e. Indian Act, forced relocation, residential schooling system; Allan & Smylie, 2015, p. 2).

A ‘disconnect’ between Aboriginal youth and their healthcare provider, because of feeling belittled or talked down to, becomes a health issue especially if the experience of ‘disconnect’ dissuades Aboriginal youth from trusting their healthcare provider or, more seriously, leads them to refuse to seek treatment at mainstream healthcare services which causes them to “set aside their health concerns or delay seeking health services” (Kurtz et al., 2008, p. 56; Loppie, Reading & de Leeuw, 2014).

The fact that both youth participants were women must also be noted in interpreting this theme. The stories told about experiences of disconnect and belittlement by the Nisga’a women in this work is akin to those of Aboriginal women who access mainstream healthcare centres in Southern BC. Aboriginal women in the Okanagan Valley have noted feeling belittled and inferior with their healthcare providers, and related these actions of healthcare providers to being Aboriginal (Kurtz et al., 2008).
Alternatively, similar stories have been expressed from non-Aboriginal women living with chronic diseases who have experienced relationships with their physicians that included feeling helpless, disconnected and oppressed due to physicians exercising power and control over the patient (i.e. acting 'better than' the patient) (Fox & Chesla, 2008). Furthermore, and as noted by participants in this research, connection to healthcare providers (i.e. feelings of trust, respect and 'being visible') leads women to be more comfortable in sharing information about their health with their providers and to seek medical assistance (Fox & Chesla, 2008; Kurtz et al., 2008). All of these stories suggest that, regardless of identity (but not eliminating the fact that one's identity does play an important role), the experience of 'disconnect' by women seeking healthcare services, in particular, can possibly be a gender issue as well. Furthermore, participants in my research were not only women, but mothers as well. However, it was beyond the scope of this research to explore how motherhood impacted the participants' interactions with their healthcare providers.

Refusing to seek treatment, due to the experience of 'disconnect' arising from feelings and experiences of discrimination and inferiority, contributes to and perpetuates ongoing health inequities experienced by Aboriginal peoples in Canada. Based on findings of this research, supported by existing research, the theme of 'disconnect', when interpreted through the lens of social determinants of health, draws attention to how continued acknowledgement, and presence, of the effects of colonialism (i.e. residential schools, structural discrimination and racism) as a potential determinant in relationships between Aboriginal peoples and their healthcare providers, continues to be an active concern for the health well-being of Aboriginal youth. Furthermore, “we must have
knowledge of history in order to understand the present” (Caron, 2006, p. 22). This could include making available cultural education to healthcare providers, and increasing awareness of Aboriginal youths’ lived experiences with their healthcare providers by supporting and encouraging Aboriginal youth to give ‘voice’ to their experience of healthcare.

5.2 When the body speaks - receiving incomplete care

“I always say no when they say ‘Do you have any questions?’...and then I just leave...and then [my family is] like, ‘Oh, why didn’t you say that?’ when I get home and vent about it...and I’m like, ‘Cause it just seems like I was draggin out the appointment.’” (FG, lines 146-147, 149-151)

In conversation with youth participants regarding a dramatic scene they created, in which youth used their bodies, not their mouths, to “do the talking”, it was revealed that body language from a healthcare provider impacted the way participants interacted with their provider. Participants discussed body language used in their scene to explain how the ‘doctor’ character wanted the day to end, noting, “if I [the doctor] stare hard enough then she [the patient] will just leave” (see results). In addition, participants embodied and spoke about feelings of “dragging out the appointment” (see results), and wanting providers to refer them to other healthcare providers who could answer their questions.

These feelings of ‘dragging’ out an appointment were ‘felt’ through body language expressed by the healthcare providers. Browne, Smye, Rodney, Tang, Mussell and O’Neil (2011) found that Aboriginal peoples were attuned to healthcare providers non-verbal gestures including facial expressions, body posture and “the vibes that providers conveyed” (p. 338). When providers outwardly displayed disinterest or
boredom, it is very possible Aboriginal patients will ‘read’ this in the physicians’ body language. Furthermore, research has also documented how ‘sensitivity’ to healthcare providers’ body language is especially present in patients from racialized groups (Dovidio et al., 2008; O’Neil 1989; Varcoe, Browne, Wong & Smye, 2009).

The findings of this research around the theme ‘when the body speaks’ are also echoed in research by Towle et al. (2006) who found, through their study of doctor-patient communication in Aboriginal communities in Canada, that Aboriginal peoples were “very aware of the amount of time that physicians dedicated to their interaction... Aboriginal peoples were sensitive to signs that they are not being given enough time and related to the physician trying to get rid of them” (p.343). Furthermore, Towle et al. (2006) noted that being given enough time with a physician or healthcare provider is related to a better level of communication between the patient and physician. Similarly, in conversation with the youth participants in my research, youth expressed a desire for a better level of communication with their healthcare provider so they wouldn’t have to feel a sense of dismissal (see results).

The significance of this theme to how Aboriginal youth interact with their healthcare system is seen in research documenting how longer clinic visits allow for increased patient participation and patient education, while shorter visits limit patients’ ability to adequately provide information and ask healthcare providers questions, as well as increase the risk of providers prescribing inappropriate drugs (Towle et al., 2006; Dugdale, Epstein & Pantilat, 1999). In my research, participants spoke of experiences with their healthcare providers in which they felt care from the provider was ‘incomplete.’ The experience of the care being incomplete came from not having the time
to ask the healthcare provider questions during the appointment because the participant did not want to feel as though they were “draggin out the appointment” (see results). This feeling, as already noted, was a result of reading the body language of the healthcare provider. However, time spent with patients is also an important element in the doctor-patient relationship and is an essential aspect of care (Dugdale, Epstein & Pantilat, 1999). Spending more time in a visit with physicians has been linked to increased patient satisfaction, preventative health and decreased malpractice claims by patients (Dugdale, Epstein & Pantilat, 1999).

A further complication to the experience of incomplete care, which may result from body language of the healthcare provider, is a result of the geographical location of the healthcare system. In the community of New Aiyansh, where the research of this thesis took place, there are limited health services due to it being a rural area. When the Nisga’a youth participants spoke about healthcare services outside of their community and traveling into a bigger city, this was due to the reality of New Aiyansh being a rural centre.

The experience of incomplete care, in a rural and Indigenous setting, can result from lack of access to services, scarcity of resources, and inadequate service from providers in communities that are rural, remote and in northern areas. Research has shown that, regardless of race, living in a rural location is a barrier to accessing sufficient healthcare services (Marrone, 2007; Browne, 2010). Barriers to care in rural areas include having less healthcare facilities and facilities that are more dispersed, limited number of staff, and higher turnover rates (Browne, 2010). High turnover and decreased retention rates of healthcare providers in northern and rural regions are in part due to challenging
working conditions including "long working hours, a lack of colleagues to share the workload, the lack of extra education, difficulties obtaining routine continuing education, and a perceived lack of opportunities for spouses and children" (Browne, 2010, para. 4). Given these circumstances, it is imperative that the relationship between the patient and the healthcare provider is communicative and open so that a full conversation can be had regarding healthcare decisions.

In this research discussion, the participants expressed that complete care included physicians referring patients to other healthcare providers if the physician felt as though they couldn’t answer a patients’ questions adequately. This patient expectation is mirrored in a study by Bechtel and Ness (2010) who found that patients want clinicians to actively coordinate care across settings, and include patients and family in the decision-making. Simply put, "[patients] want their doctors and other providers to talk to each other" (p. 916). However, when body language is language that says ‘stop dragging this consultation out,’ and the context of the healthcare system is a rural one, the implications of ‘body language’ for incomplete healthcare becomes a major healthcare concern and has a negative impact on health and well-being.

It should be noted that Indigenous peoples, globally, experience the feeling they are not given an adequate amount of time during an appointment to discuss concerns with their healthcare provider (Shahid, Finn & Thompson, 2009; Simonds, Christopher, Sequist, Colditz & Rudd, 2011). Simonds et al. (2011) found that positive clinical interactions between Native Americans and their healthcare provider included the provider being thorough and ensuring that they covered a range of items including asking the patient if they have any questions, ensuring the patient understands all information
given, and providing patients with educational information and advice. Additionally, healthcare providers noted the positive benefits of spending a little extra time with their patients to ensure patients are not left with questions and increase patients trust in their providers (Simonds et al., 2011).

Body language is an important dimension of ‘relationship’ between a patient and the healthcare provider. When a patient reads a healthcare providers’ body language that appears to be expressing that the provider is not interested in ‘completely’ helping them, this body language becomes a social determinant in the healthcare of the patient. This social determinant of health can lead the patient to feel insecure about asking healthcare provider questions important to their health. In addition, when a patient withdraws from the interaction this can lead to patients being dissuaded from accessing healthcare services. In this situation, a patient is left experiencing ‘incomplete’ care.

5.3 Experiences of empathic and compassionate care

“...you could feel the genuine concern and it wasn’t uncomfortable to where she was...trying to have a personal relationship, but you could feel like she cared” (T2, lines 42-43)

A repeated theme in the data was desire for a relationship with healthcare providers based on empathy and compassionate care. Implicit in participants’ discussion on compassionate and empathetic care was how they were more likely to open up and be comfortable with healthcare providers who showed that they genuinely wanted to provide good care for them.

Components of empathy for healthcare providers include compassionate care and putting oneself in the patients’ shoes. (Hojat, Gonnella, Nasca, Mangione, Vergare, & Magee, 2002). In this discussion, however, empathy and compassionate care are used
interchangeably. As expressed in the quote above, research participants described experiences when healthcare clinicians provided empathetic and compassionate care.

A patient’s desire for empathetic and compassionate care is not trivial. In the opening quotation, the research participant used the expression “genuine concern” when speaking about a positive experience she had with a healthcare provider. It was clear from the conversation with participants that what they desired in interactions with healthcare providers was authentic care. Authentic care is empathetic care; compassionate care.

Research has overwhelmingly shown that patients, regardless of ethnicity, want compassionate care. Compassionate care includes healthcare providers getting to know the patient, feeling the patient’s suffering, identifying with and liking patients, and demonstrating respect (Sinclair et al., 2016). In my research, an understanding of genuine concern also expresses the experience of compassionate care.

Sinclair et al. (2016) found in their review of literature around compassionate care that a common conclusion of many studies is that compassionate relationships are “marked by meaning, a genuine sense of care for the patient, and a willingness to provide support” (p. 8). In my research, participants described compassionate care as health providers “putting themselves in the patients shoes” (see results). Research literature has shown that a common analogy, to illustrate “the relational aspect of compassion” is that of healthcare providers ‘putting themselves in the patients shoes’ (Sinclair et al., 2016, p. 8).

Nisga’a First Nations youth in this study discussed the desire for caring relationships that go beyond simply treating the illness of the patient. Participants
illustrated this ‘care’ as including a personal dimension. Some authors have suggested greater levels of empathy and care are needed when treating minority populations, especially Aboriginal peoples, as this fosters trust in the patient-clinician relationship important to effective healthcare delivery. This finding is echoed in the work of Towle et al. (2006) who found relationships between Aboriginal peoples and their healthcare providers were strengthened when there was a ‘personal’ component, and when the provider spent time investing in the relationship. Youth participants in my research study described a caring relationship as the physician putting aside their own self-promoting priorities (see results) and not just prescribing a drug for their own gains. This finding was also mirrored in the work of Towle et al. (2006) who found Aboriginal peoples interpreted physicians rushing them out of the appointment negatively, extending to the medical profession as a whole and as “how much money doctors make or how quickly doctors prescribe drugs as the solution to the problem” (p. 344) rather than putting the care of the patient first.

A determinant of health important to understanding participants’ experience of their healthcare interactions was the rural nature of their community, as expressed in the previous section. This geographical determinant (see de Leeuw, 2015) impacts the patient’s expectation to establish a caring, ongoing relationship with healthcare practitioners, especially in situations of increased staff turnover. A study in Australia has shown that Aboriginal patients in a Western hospital setting, where there exists high staff turnover, felt a lack of care by physicians. Researchers note that this could have “a particular impact on Aboriginal people because of the importance placed upon relationship within their culture” (Shahid, Finn & Thompson, 2009, p. 567).
Although participants did not explicitly do a cultural critique of their healthcare providers it is known, nevertheless, that healthcare culture that has been “imported” has a different value structure than that of First Nations culture. Lo and Stacey (2008) comment on the fact that healthcare has been standardized to produce professional, skilled and quality healthcare systems, that minimalizes the importance of cultural considerations. Research over the past few years has stressed the importance of culturally competent and safe healthcare, however, Lo and Stacey (2008) argue that cultural competence has been constructed in ‘scientific’ and ‘formulaic’ terms, rendering “medical practice culturally insensitive in the first place” (p. 753). Indeed, this creates “culturally inappropriate and unsatisfactory interactions”, as was revealed in my data of participants stories of being treated like a number, feeling inferior and feeling like they are a burden rather than a person. Recognizing relationships as social determinants of health exposes the cultural and social factors impacting the youth patient-physician interaction, and is undoubtedly important. Empathy has been positioned as a moral concept, and as such, “may have little space within the logical, economically driven, and almost impersonal structure of health systems” (Kendall & Barnett, 2014, p. 448). Furthermore, Cherry (1997) writes interactions that lack empathy are unavoidable given that health-care relationships are temporary encounters based on a clinical need. Cherry (1997) goes further to explain that a lack of empathy is necessary to provide professional, skilled and quality healthcare systems.

5.4 Empowering encounters

“...I would be maybe slouching because I feel heavy and then I sit there and I talk to [the doctor] and, you know, he’s just asking me these questions to where I’m kind of sitting more and more upright...and then I leave walking...standing upright, the world’s okay”. (TI, lines 15-19).
As described in my findings Chapter, the theme ‘empowering encounters’ was acted out and embodied in a short scene created by participants. In the scene, youth participants touched hands, representing a connection with their healthcare providers and a feeling of having “conquered something” (see results). This scene revealed how interactions between young Aboriginal women and the healthcare provider could ‘empower’ them in taking responsibility for their well being.

One aspect of empowering clinical interactions is being visible and acknowledged as a person. This was implicit in the youths’ description of positive experiences of relationships with their providers. The idea of being “visible”, “heard” and, acknowledged resonates with research done with Aboriginal peoples and their experiences with healthcare providers. Urban Aboriginal respondents in British Columbia’s Okanagan Valley described positive experiences with healthcare providers as being visible in care, with visibility being “a metaphor for being seen as Aboriginal, heard, and respected” (Hole et al., 2015, p. 1666). This sense of being visible as an Aboriginal patient transferred to feelings of cultural safety as well as being respected, listened to, and treated like a ‘human being’, all of which lend to positive relationships with the healthcare provider (Hole et al., 2015; Bechtel & Ness, 2010). This stands in stark contrast to the glass wall metaphor explained by participants (see results), where only being ‘seen’ was limiting because participants’ felt like as though they were unheard. Youth participants discussed how positive relationships, built upon being given the tools, developing confidence, being acknowledged and taking ownership of one’s own health, is an expression of an empowering encounter.
The theme of empowering encounters also relates to a body of recent research drawing attention to ‘patient-centered’ care, or ‘whole-person’ care, in which the patient is seen as a partner in the doctor-patient relationship, rather than a “thing” to be dealt with (Bretchetel & Ness, 2010). The work of Chen, Mullins, Novak, and Thomas (2016) draws attention to the importance of using a social determinants of health framework when thinking about determinants in patient-physician relationships because this framework takes into account wider socio-political, and cultural contexts in which people live and experience healthcare. Furthermore, the multidimensional framework, proposed by Chen et al. (2016) places the patient at the center of care, and draws attention to the dynamic in the patient’s healthcare experience that includes roles of the provider, community, and social and physical environments. This research has shown how “healthcare providers, community environment, and the healthcare delivery system can individually or simultaneously influence patients’ knowledge, confidence, or self determination to improve patient activation and empowerment” (Chen et al., 2016, p. 28). This research is important to interpreting my findings to show youth want healthcare providers who empower them to take control of their own health. It was clear in my research how participants expressed their expectation to exercise self-determination and to make autonomous decisions promoting their wellbeing. Current attention in healthcare research focusing on patient engagement and active participation in exercising self-determination and autonomous decision-making has been described as the “blockbuster drug of the century” (Chen et al., 2016). This expression highlights how ‘relationship’ with its multi-faceted dimensions, is a significant social determinant in the culture of patient-physician interaction.
It should be noted that the experience of empowerment with healthcare providers is not something only desired by Aboriginal peoples. Work by Stubbs (2007), showed that when middle-aged people with diabetes experienced a positive working relationship with their healthcare provider, the patient felt more motivated to take control of their health and make lifestyle changes. Furthermore, when physicians prescribed patients’ medications rather than encouraging patients to change their diets and lifestyle, this translated into patients being less compliant with physicians’ recommendations and feeling their “sense of responsibility diminished and motivation decreased” (Stubbs, 2007, p.195).

Conclusion

This research has identified how ‘relationships’, as a social determinant of health, are multifaceted, and central to interactions between young Nisga’a First Nations women, and their healthcare providers. Furthermore, the thematic dimensions of ‘relationships’ discussed in this Chapter (i.e. disconnect, when the body speaks- incomplete care, empathy and, empowerment) are interconnected. In the final Chapter, I will discuss limitations of this project, and include considerations and recommendations for future research.
CHAPTER 6: LIMITATIONS, CONCLUSIONS AND FUTURE DIRECTIONS

6.1 Limitations, Challenges, and Learnings

"Finding an appropriate balance between the requirements of ethical research and the requirements of academic success can be challenging, particularly for novice researchers" Ballamingie and Johnson, 2011, p. 711

When I began this research project, I was excited about the opportunity to be able to come to know First Nations youths' lived experiences about their healthcare system. As I come to the end of this research journey however, I have come to realize that I was naive about how complex my research undertaking, in fact was. The above quotation, taken from Ballamingie and Johnson's (2011) The Vulnerable Researcher: Some Unanticipated Challenges of Doctoral Fieldwork, contextualizes my present reflections on what I believe are significant limitations of this research project. The breadth of the ethical dimension of my research, especially in terms of honoring the realities of power-dynamics between researcher-community/researcher-institution and the culture of a rural First Nations community, is one that has profoundly affected my perspective on the research I have done. Upon reflecting about limitations of this project, and in light of Ballamingie and Johnson's (2011) quotation, I believe there is an imbalance between the requirements of ethical considerations important to non-Indigenous researchers in an Indigenous cultural context, and in my understanding of what was required for academic success in this research project.

The first encounter with my naivety, regarding the ethical dimension of this project, occurred when my participants expressed discomfort with signing the consent form, where audio-recording was already approved by the UNBC Research Ethics Board. I was surprised I had to confront concern with being audio-recorded. It was my
understanding that the consent form clearly stated that audio-recordings would only be used by the researcher, and would not be shown to anyone else. I did not anticipate my participants would have concerns with my research data-collection strategies. As a novice researcher, I did not know how to validate their concerns. When I reflected on my participants concern in light of decolonizing methodologies, I experienced vulnerability concerned with not wanting to appear to be acting deviously in how I was collecting data for this project.

Although this misunderstanding with my participants was addressed, I felt it became a limitation to collecting the most reliable data. By having to handwrite conversations, I could not be an authentic conversation partner. I found myself in a research position of having to ‘probe’ for more information. When I tried to probe, participants expressed, indirectly, impatience with having to repeat what they had said and give further explanation when they felt they had been clear. Given my findings that participants placed great emphasis on relationship and not wanting to feel disconnected from their healthcare provider, I was left wondering if this was an experience I too set up for them. I believe I could have understood better the experiences of participants, had I been able to become even more of an authentic conversation partner.

Even though I have had to confront my sense of vulnerability through this research, this ‘limitation’ has also been a positive learning experience for me as researcher in a First Nations context. I have learned the necessity of engaging First Nations youth participants in all stages of the research process, including the design and wording of giving consent to research done by a non-community member researcher. This, in turn, made me reflect on the use of formal consent forms.
As Miller and Bell (2002) explain: “Whilst ethics committees increasingly require researchers to produce consent forms for them to vet and for research participants to sign, the formality of such procedures will certainly alienate some groups and individuals” (p. 65). Given that this research project employed a community-based, participatory approach, and was based in decolonizing methodologies, I now believe it is necessary to consider alternative approaches to gaining consent to undertake research. In particular, there must be great sensitivity to how research language and perception of research methodology is interpreted by the participants. This underscores the importance of relationship building and discussions with the community involved in the research as to what kinds of communication methods are preferred (i.e. writing, verbal). Furthermore, I have learned the importance of sitting down and going through consent forms WITH participants, to ensure clarity and understanding of the content and implications of consent forms.

Another challenge of this research project was that of employing a community-based participatory research methodology. While the CBPR research methodology is especially needed in the context of research with Indigenous peoples, I have come to question whether this research methodology can be most appropriately and ethically employed, especially in the context of graduate level research. I found one of the biggest limitations of using CBPR was ‘time.’ Community-based participatory research is based on principles of equitable participation and co-learning, and requires an honest and authentic relationship between researcher and community. However, to achieve such a partnership, time is required to build relationships with community members. As an ‘outsider’ and an outsider with limited time and resources, I was not able to commit to a
time allocation to be in the community of New Aiyansh prior to beginning the research. This proved to be a limitation as I was someone unknown to the community, which may have dissuaded people from participating.

Recruiting Nisga’a First Nations youth between the ages of 19-25 was challenging, and I learned that this population is very hard to get in contact with. In conversation with participants and with my community guide PC, after the drama workshop, I was told that there are not a lot of youth ages 19-25 in the community, as most leave to find jobs. This was very important information to know, as the community might have benefited more if the age range was left open, and younger youth and adults could participate. However, including younger people in research (i.e. under the age of 18) is a significant challenge as there are multiple ‘ethical’ guidelines that must be followed (as outlined by the UNBC Research Ethics Board). This could be one reason why youth voices are so lacking in research scholarship. Although I did open up the workshop to anyone interested, it was not until after I got to the community and started the workshop, which ended up being too late of notice for people to participate. Building relationships with communities BEFORE the process, and constantly working with community partners is invaluable, as you gain information about what will best serve the community, and in turn possibly receive more participation. Although this ‘lesson’ has been learnt by many other researchers, and I was aware of it before starting the project and had intentions to spend time in the community before the research began, I felt constrained by the resources and time I had to complete this masters level project. Therefore, I was not able to fulfill this aspect of CBPR.
In addition, the community data collection part of the project was completed in only four days. While participants shared many incredible stories and experiences of relationships with their healthcare providers, I am mindful this project only ‘skimmed’ the surface of collecting data relevant to my research focus. I am well aware how the data from this project, while incredibly valuable, may not tell ‘the whole story.’ More significantly, an incredibly important aspect of CBPR is providing participants the opportunity to review the data and results. This is an important ‘member check’ to ensure what has been recorded and interpreted is accurate and valid. The findings and interpretation of research data in this thesis does not have a member check. Participants were e-mailed on two occasions, twice requesting their review of findings and interpretation. However, participants did not reply to this request. This is another challenge of working with youth, especially youth who reside in a rural community where there is no cellular service, and limited Internet connection. I believe the absence of the member check has real ‘ethical’ implications for this research report, especially in light of the CBPR and decolonizing methodologies that are meant to ensure that research findings honour the culture in which the research was undertaken. This ‘ethical concern’ has weighed on me, as I strongly believe that what I have written is not entirely valid until I receive confirmation of accuracy from my participants.

Finally, an aspect of CBPR is that it be ‘action’ oriented. Although an important aspect of this project was devising strategies with youth for their healthcare providers, a concrete action plan was not developed. However, the themes that emerged from the data do suggest strategies that could be developed to improve youth patient-healthcare provider interactions.
I am well aware that this research project is relying on data from only two participants, however, the lived experience of anyone, even a single person, has value and merit, and should not be dismissed as insignificant. While I did not ask participants to identify the sources of their perceptions and lived experiences with healthcare providers, I do not believe this to be a limitation because this information is not relevant to data collected in this project.

6.2 Conclusions and Future Directions

This thesis project explored the lived experiences of two Nisga’a First Nation youths’ relationships with their healthcare providers. The rationale for this project is that youth voices, observations, and insights are largely absent within published literature on patient-physician relationships with Aboriginal peoples and their non-Aboriginal healthcare providers. This has resulted in an unfortunate and substantial gap in research. A focus on relationships with healthcare providers from a Nisga’a youth perspective was timely and appropriate, as research priorities continue to emphasize youth inclusion and engagement in Indigenous health (Worthington et al., 2010). It is important to note that the stories and experiences gathered in this study are based on the words of two Nisga’a First Nations youth, from whom generalizations may not be extracted to other First Nations youth. It may nevertheless be the case that other young First Nations people in Canada share similar experiences of relationships with their healthcare providers.

Three methodologies built the philosophical foundation of this research. These include a Social Determinants of Health framework, Community-Based Participatory Research, and Decolonizing approaches. These methodologies informed my choice of
using arts-based methods (Muirhead & de Leeuw, 2012), specifically devised theatre.

Other methods chosen, and informed by CBPR and decolonizing approaches, included an open dialogue and personal field notes, and observations.

In analyzing three data sets, including transcripts from group discussions during a weeklong devised theatre workshop, transcripts from an open dialogue post-workshop, and personal field notes and observations, four key themes emerged that exemplify Nisga’a First Nations youths’ experiences of relationships with healthcare providers in a Northern British Columbia Nisga’a First Nations community. These themes include: disconnect, when the body speaks: incomplete care, empathy and, empowerment. It was discovered that Nisga’a youth participants identified ‘relationships’ as a determinant of their interactions with healthcare providers. The discussion has demonstrated that ‘relationship’, as a social determinant of interaction between patient and healthcare provider is multifaceted. The dimensions of relationship identified in this discussion are interconnected. Research put into conversation with these dimensions of relationship in patient-healthcare provider interaction has amplified ‘relationship’ as a social determinant of health needing serious consideration in appreciating the patient-healthcare provider interaction among Nisga’a youth.

This research also makes valuable methodological contributions. One aspect of this research was integrating decolonizing methodologies and a social determinants of health framework into a community-based participatory research approach to facilitate a devised theatre workshop strategy to encourage Nisga’a First Nations youth ‘to tell stories’ about their lived experiences of interactions with health providers. Devised theatre proved to be a successful strategy to engage youth participants in story telling.
about their interactions with healthcare providers. Furthermore, this strategy gave the youth participants' ownership over the research environment. What is notable is participants' description of devised theatre as providing a fun and engaging way to express lived experiences. Participants noted that “[devised theatre] gets things across more, and on a physical level...people are visual learners and they’re more likely to...relate” (FG, lines 322, 333). In addition, and as noted in the results, participants voiced a sense of ownership over the research process, and as one participant put it, “we were contributing to something important” (FG, line 286). Indeed, this project has added the voices of two young Nisga’a First Nations women to the public record.

No research study is complete in and of itself. This research project opens the door for opportunities for research to further understand how relationships, as a social determinant of health, impacts Nisga’a First Nations youths’ interactions with their healthcare providers. In addition, this research can also identify lessons learned in engaging Aboriginal youth— a voice so lacking in existing research scholarship:

• As noted in my findings, participants spoke of feeling like a ‘number’ in their interactions with healthcare providers. This furthers the need to appreciate how the legacy of the residential school system continues to impact First Nations youth, and how they perceive their interactions with their healthcare provider.

• In collection of data from the research, the focus was on participants’ relationships with their healthcare provider. The circumstance of all participants being mothers was noted, but not explored as a factor impacting their relationship...
with healthcare providers. Further research could investigate the “motherhood factor” in patient-healthcare provider relationships between Nisga’a First Nations youth and their providers.

- More arts-based, and participatory methods (especially theatre) are important to use when including Nisga’a First Nations youth in research. In this research, feedback from participants on the drama workshop was very positive, with one participant noting, “I very much enjoyed [the drama workshop]...cause I felt like I got to be silly and it didn’t feel like work at all and it just felt like, you know, games, but it was leading up to something” (FG, lines 269-271). Furthermore, participants spoke of their involvement in the drama workshop as having ‘me time’ and ‘adult time’ away from their children and partners. This is important to note because I believe there would have been less participation if this project used a survey or questionnaire to collect stories of youths’ experiences with their healthcare providers. Therefore, my recommendations for future research including Nisga’a youth voices include using arts-based, participatory methods.
Map of Northern British Columbia Health Service Distribution Areas (Northern Health, N.D.)
APPENDIX II. LOCATION OF NASS VALLEY IN BRITISH COLUMBIA

Screenshot of Map Indicating Location of the Nisga’a Nation Nass Valley in British Columbia (Nisga’a Lisims Government, n.d.)
APPENDIX III. LETTER OF CONSENT FROM NASS VALLEY

WILP WILXO'O'SKWHL NISGA'A INSTITUTE

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June 4, 2015

Julia Petrasek MacDonald
MSc (Community Health) Candidate
Health Arts Research Centre
Northern Medical Program

Dear Julia Petrasek MacDonald,

The Wilp Wilxo’skwhl Nisga’a (WWNI) Board of Governors met May 25, 2015 and I am pleased to inform you that your research proposal “Staging Relationships: Using Devised Theatre to Explore Indigenous Youths’ Experiences and Perceptions of their Relationships with Physicians” had been approved pending approval from UNBC Research Ethics Board. You will be expected as a condition of your research to work closely with WWNI, as well as provide the findings from your research.

Please see attached motion:

MSC #4
The Wilp Wilxo’skwhl Nisga’a Institute Board of Directors approves Julia Petrasek MacDonald’s research proposal “Staging Relationships: Using Devised Theatre to Explore Indigenous Youths’ Experiences and Perceptions of their Relationships with Physicians” pending approval of UNBC Research Ethics Board.

MSC #4 Stephen Azak / Noah Guno

Congratulations!

Sincerely,

[Signature]

Diana L. E. Nyce, PhD Candidate
Chief Executive Officer

Letter of approval from the WWNI Board of Governors
APPENDIX IV. OPEN DIALOGUE QUESTIONS

1. Tell me about the scenes you made.
   a. What was it about?

2. Do you think the scenes accurately portrayed experiences you have had with physicians/healthcare services in your community?
   b. How does your personal experience differ from the experience/meaning portrayed in the scenes?

3. What is the main message you wanted the scenes to convey?
   a. What is the main message you think the scenes actually conveyed?

4. Did you enjoy the drama workshops?
   a. What part did you like the best? Why?
   b. What part did you like the least? Why?

5. How would you describe the experience of creating the scenes?

6. Were there any aspects of making the scenes that you found difficult?
   a. If so, what were they?
   b. If so, how did you overcome these challenges?

7. Were there any aspects of making the scenes that you found easy?
   a. If so, what were they?
   b. If so, why?

8. How did you feel about being involved in this project before the process began?
   c. During the process?
   d. After the process?

9. Would you use theatre to share your experiences and ideas again if you had never participated in this process?
REFERENCES


Kirmayer, L. (2012). Rethinking cultural competence. Transcultural Psychiatry, 49(2), 149. DOI: 10.1177/1363461512444673


